UTS UNIVERSITY OF TECHNOLOGY SYDNEY

More Than a Meal: Building an Evidence-Based Framework of Mealtime-Related Quality of Life, Participation, and Inclusion for People with Swallowing Disability

Doctor of Philosophy: Speech Pathology (C02066)

Rebecca Jane Smith

Supervisors: Professor Bronwyn Hemsley and Doctor Lucy Bryant

Graduate School of Health

14th October 2022

Certificate of Original Authorship

I, Rebecca Smith declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy in Speech Pathology, in the Graduate School of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

Signature: Production Note:
Signature removed prior to publication.

Date: 14/10/2022

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First, I would like to acknowledge all of the participants who took part in this research. Whether that was by engaging in the interviews, focus groups, or survey, I would like to say thank you. Your experiences and views of dysphagia, quality of life, and 3D food printing, informed this thesis and without your input, this research could not have been completed. I hope that this research can help shape positive mealtime experiences for people with dysphagia into the future.

Second, I would also like to thank my supervisors, Professor Bronwyn Hemsley and Doctor Lucy Bryant. With your encouragement from the beginning, I had the confidence to apply for the PhD program. You have both been an immense support over the last three and a half years and have helped me become a better researcher to help shape the future of the speech pathology profession. Finally, thank you for your advice and feedback on many drafts, this thesis certainly would not have the same impact without it.

I was grateful to receive financial support throughout my PhD candidature. Firstly, this project was funded by a University of Technology Sydney Doctoral Scholarship (April 2019 –December 2019). I would also like to thank the National Health and Medical Research Council (NHMRC) for a Post Graduate Scholarship (APP1191359) from January 2020 to March 2022. I was also supported by the Australian Government Research Training Program for the length of my candidature. This funding allowed me to dedicate the time to answer the questions of this project in a sufficient manner for all people with dysphagia. I would also like to acknowledge that a late version of this thesis was proofread by Matthew Sidebotham from Workwisewords.

To my family, you showed me the importance of hard work and exactly how personal dysphagia was to me. To my grandfather, Ronald Smith (1932–2020), your fighting spirit lives on in this PhD. You never remembered if I was Rebecca or Sarah, but your support was always there to the end, and when I see your meal from the aged-care facility used as part of this PhD project, I think of you. To my grandmother, Eva Dawson, your influence shaped me more than you know, you did everything you could for all of us grandchildren, including talking about your swallowing difficulties with me. To my grandfather, Russell Dawson, your voice of reason and logic was constantly with me in all decisions of this PhD and I hope I have done you proud. To my parents Sue and Tony, you always wanted the best for me and pulled me up when I was down, thank you for everything. To my sister, Sarah, for living with me throughout this PhD and all the COVID-19 lockdowns, we made it. To Alison, Adam, and little Harriet, you gave us all hope during the lockdowns and Harriet your cuddles mean the world. Lastly to Basil the dog, you are THE PhD Pup, enough said.

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Note on Thesis Format and Style

This thesis follows the Publication Manual of the American Psychological Association (APA) Seventh Edition (APA7) for both referencing and style guidelines (American Psychological Association, 2020). Australian English spelling is used throughout; apart from published articles requiring American English spelling. The Australian term ‘speech pathologist’ is also used throughout this thesis apart from articles published in journals where the publisher required the term ‘speech-language pathologist’ to be used. Person-first language is also used in this thesis to describe people with dysphagia.

Following APA guidelines (American Psychological Association, 2020) this thesis is double spaced except for tables and figures which are single spaced. Tables and figures are placed within the body of the text after they are first referenced. References from the thesis, including the published chapters, are formatted according to APA 7 (American Psychological Association, 2020) and are consolidated in the reference list at the end of the thesis.

Chapters 2, 3, and 11 appear in this thesis in the full published form including tables, figures and reference lists as in the published version and following the formatting and referencing guidelines required by the publishing journal. These papers are included with permission.

Throughout this thesis a number of terms are used specific to this research. A glossary of definitions can be found in Appendix A.

Ethical Approval

This project received ethical approval from the University of Technology Sydney Human Research Ethics Committee in 2019 [ETH19-3708]. The ethics application was then amended in 2021 to include a survey and was approved by University of Technology Sydney Human Research Ethics Committee in 2021 [ETH21-6568 and ETH21-6781].

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- National Health and Medical Research Council (NHMRC) Post Graduate Scholarship (e.g., participant vouchers)
- Provision of a laptop (University of Technology Sydney)
- Funding to complete Dysphagia Disorder Survey Training Course (Graduate School of Health, University of Technology Sydney)
- Open access publication fee for one research paper published in a Q1 journal (Graduate School of Health, University of Technology Sydney)

Publications and Presentations

International peer-reviewed publications are presented below in order of appearance in the thesis. Presentations are presented here in reverse chronological order within each category. Conference abstracts and poster presentations are in Appendix B.

International Peer-Reviewed Journal Articles

Smith, R., Hemsley, B., & Bryant, L. (2019). Systematic review of dysphagia and quality of life, participation, and inclusion experiences or outcomes for adults and children with dysphagia. PROSPERO 2019. CRD42019140246. https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019140246

Smith, R., Bryant, L., Hemsley, B. (2022c). Dysphagia and quality of life, participation, and inclusion experiences and outcomes for adults and children with dysphagia: A scoping review. *Perspectives of the ASHA Special Interest Groups, 7(1),* 181-196. https://doi.org/10.1044/2021_PERSP-21-00162

Smith, R., Bryant, L., Reddacliff, C., Hemsley, B. (2022). A review of the impact of food design on the mealtimes of people with swallowing disability who require texture-modified food. *International Journal of Food Design, 7*(1), 7–28. https://doi.org/10.1386/ijfd_00034_1

Smith, R., Bryant, L., & Hemsley, B. (in press-b). The true cost of dysphagia on quality of life: The views of adults with swallowing disability. *International Journal of Language & Communication Disorders.*

Smith, R., Bryant, L., & Hemsley, B. (in press-a). "Know the risks but balance that with their enjoyment": Impacts of dysphagia on quality of life from the perspective of allied health professionals. *Advances in Communication and Swallowing.*

Smith, R., Bryant, L., & Hemsley, B. (2022d). *"I only eat to because I have to, to live": An online survey examining the impacts of dysphagia on quality of life* [Manuscript submitted for publication in Disability and Rehabilitation]. Graduate School of Health, University of Technology Sydney.

Smith, R., Bryant, L., & Hemsley, B. (2022a). *3D food printing to improve mealtime quality of life: The perspective of people with dysphagia and their supporters* [Manuscript submitted for publication in Disability and Rehabilitation: Assistive Technology]. Graduate School of Health, University of Technology Sydney.

Smith, R., Bryant, L., Hemsley, B. (2022b) Allied health professionals' views on the use of 3D food printing to improve the mealtime quality of life for people with dysphagia: Impact, cost, practicality, and potential. *American Journal of Speech-Language Pathology*, *31*(4), 1868–1877. https://doi.org/https://doi.org/10.1044/2022_AJSLP-21-00391

Smith, R., Bryant, L., & Hemsley, B. (2022e). *"It looks better than a bowl of mush": Views on food design and 3D food printing to improve the mealtime experience for people with dysphagia* [Manuscript submitted for publication in American Journal of Speech-Language Pathology]. Graduate School of Health, The University of Technology Sydney.

International Peer-Reviewed Conference Presentations

Smith, R., Bryant, L., Hemsley, B. (2022, November 17–19). *The Cost of Dysphagia: Impacts of Dysphagia on Quality of Life for People with Dysphagia*. [Technical presentation]. 2022 ASHA Convention, New Orleans, Louisiana. https://convention.asha.org/

Smith, R., Bryant, L., Hemsley, B. (2022, March 15–18). *"All the food is like wet dog food": Could 3D food printing improve mealtime management and quality of life for people with dysphagia who need pureed food?* [Poster presentation]. Thirtieth Annual Dysphagia Research Society Meeting, San Juan Puerto Rico. https://www.dysphagiaresearch.org/page/30th_Annual_Meeting_Attendee_Information

Smith, R., Bryant, L., Hemsley, B. (2022, February 3–4). *Printing our way to improved mealtimes for people with dysphagia: Views of key stakeholders on the use of 3D food printers* [Poster presentation]. Ninth United Kingdom Swallow Research Group Conference, Online virtual conference. http://www.uksrg.org.uk/conferences/uksrg-2022/

Smith, R., Bryant, L., Hemsley, B. (2021, November 4–6). *Can the personal cost of dysphagia on quality of life, participation, and inclusion be reduced through improved food design and 3D food printing? Views of adults with swallowing disability.* [Poster presentation]. Eleventh annual congress of the European Society for Swallowing Disorders, Online virtual conference. https://essd2021.org/

Smith, R., Bryant, L., Hemsley, B. (2021, November 4–6). *Mealtimes are a balancing act: Health professionals' views on the quality of life impacts of dysphagia and potential for improvements through 3D food printing.* [Poster presentation]. Eleventh annual congress of the European Society for Swallowing Disorders, Online virtual conference. https://essd2021.org/

National Conference Presentations

Smith, R., Bryant, L., Hemsley, B. (2021, May 31- June 2). *The impacts of dysphagia on quality of life, participation, and inclusion for adults and children with dysphagia: A* *systematic review* [Poster presentation]. Speech Pathology Australia National Conference 2021, online virtual conference.

Smith, R., Bryant, L., Hemsley, B. (2021, May 31- June 2). *A review of food design for people on texture-modified diets: The shape of things to come* [Conference presentation]. Speech Pathology Australia National Conference 2021, online virtual conference.

Smith, R., Bryant, L., Hemsley, B. (2020, May 24–27). *The impacts of dysphagia on quality of life, participation, and inclusion experiences or outcomes for adults and children with dysphagia: A systematic review* [Accepted Conference presentation]. Speech Pathology Australia National Conference 2020, Darwin, NT, Australia.

Local Conference Presentations

Smith, R., Bryant, L., Hemsley, B. (2020, December 2). *The impacts of food design on the quality of life, participation and inclusion of people with swallowing disability.* The Inaugural Speech Pathology Symposium (SEER) Showcasing Emerging and Established Researchers.

Smith, R., Bryant, L., Hemsley, B. (2020, July 30). *More than a meal? 3D food printing for safe and enjoyable meals*. Paper presented at the University of Technology Sydney Faculty of Health Three Minute Thesis Challenge. Online virtual event.

Smith, R., Bryant, L., Hemsley, B. (2020, July 3). *More than a meal? 3D food printing for safe and enjoyable meals.* Paper presented at the University of Technology Sydney Graduate School of Health Three Minute Thesis Challenge. Online virtual event.

Smith, R., Bryant, L., Hemsley, B. (2019, November 29). *More than a meal: A constructivist grounded theory of a mealtime related quality of life and inclusion for people with* *swallowing disability.* Paper presented at the University of Technology Sydney Graduate School of Health Student Seminar.

Invitations to Speak

Smith, R., Bryant, L., Hemsley, B. (2022, February 8). *The impacts of dysphagia on quality of life: Can it be improved with 3D food printing?* [Conference Presentation]. The Myositis Association Australia National Zoom Meeting, online virtual event.

Smith R. (2020, 2021, 2022). Dysphagia disorders in developmental disability [PowerPoint slides]. Lecture delivered in the Master of Speech Pathology course, Subject 96124 Swallowing Disorders. The University of Technology Sydney.

Research Translation through Online Publications

I developed an online blog to share updates and new information related to dysphagia and quality of life (see https://rebeccasmithsp.wordpress.com/). Along with this blog I also used my Twitter account (@beccysmith7) to increase research translation to the wider international community.

Awards

Awards are presented in reverse chronological order:

- The University of Technology Sydney, Vice Chancellor Conference Fund (2021): $290
- The University of Technology Sydney, Faculty of Health, 3 Minute Thesis Competition Runner Up (2020): $500 (combined for Runner Up and People’s Choice)
- The University of Technology Sydney, Faculty of Health, 3 Minute Thesis Competition People’s Choice Award (2020): $500 (combined for runner up and People’s Choice)
- The University of Technology Sydney, Graduate School of Health, 3 Minute Thesis Competition Winner for Best Presentation (2020): $200
- The University of Technology Sydney, Graduate School of Health. 3 Minute Thesis Competition People’s Choice Award (2020): $100

Appendix C includes copies of the awards received by the researcher during this PhD candidature.

Author Attribution Statement

I am the lead author for all published papers included in this thesis and a description of my role for each study is presented here in Chapter order.

Smith, R., Hemsley, B., & Bryant, L. (2019). Systematic review of dysphagia and quality of life, participation, and inclusion experiences or outcomes for adults and children with dysphagia. PROSPERO 2019. CRD42019140246. https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019140246

Smith, R., Bryant, L., Hemsley, B. (2022c). Dysphagia and quality of life, participation, and inclusion experiences and outcomes for adults and children with dysphagia: A scoping review. *Perspectives of the ASHA Special Interest Groups.* https://doi.org/10.1044/2021_PERSP-21-00162

I led the design of the above scoping review, then completed the database searches, determined inclusion status of studies, extracted data, analysed data, and wrote the manuscript with feedback from co-authors within their supervisory roles.

Smith, R., Bryant, L., Reddacliff, C., Hemsley, B. (2022). A review of the impact of food design on the mealtimes of people with swallowing disability who require texture-modified food. *International Journal of Food Design, 7*(1), 7-28. https://doi.org/10.1386/ijfd_00034_1

I led the design of this narrative review, then completed the database searches, determined inclusion status of studies, extracted data, analysed data, and wrote the manuscript with feedback from co-authors within their supervisory roles.

Smith, R., Bryant, L., & Hemsley, B. (in press-b). The true cost of dysphagia on quality of life: The views of adults with swallowing disability. *International Journal of Language & Communication Disorders.*

I led and completed the design of this study, data collection, transcription, data analysis and coding, and writing of this paper; with input from co-authors in their supervisory roles.

Smith, R., Bryant, L., & Hemsley, B. (in press-a). "Know the risks but balance that with their enjoyment": Impacts of dysphagia on quality of life from the perspective of allied health professionals. *Advances in Communication and Swallowing.*

I led and completed the design of this study, data collection, transcription, data analysis and coding, and writing of this paper; with input from co-authors in their supervisory roles.

Smith, R., Bryant, L., & Hemsley, B. (2022d). *"I only eat to because I have to, to live": An online survey examining the impacts of dysphagia on quality of life* [Manuscript submitted for publication]. Graduate School of Health, University of Technology Sydney.

I led and completed the design of this study, data collection, data analysis and coding, and writing of this paper; with input from co-authors in their supervisory roles.

Smith, R., Bryant, L., & Hemsley, B. (2022a). *3D food printing to improve mealtime quality of life: The perspective of people with dysphagia and their supporters* [Manuscript submitted for publication]. Graduate School of Health, University of Technology Sydney.

I led and completed the design of this study, data collection, transcription, data analysis and coding, and writing of this paper; with input from co-authors in their supervisory roles.

Smith, R., Bryant, L., Hemsley, B. (2022) Allied health professionals' views on the use of 3D food printing to improve the mealtime quality of life for people with dysphagia: Impact, cost, practicality, and potential. *American Journal of Speech-Language Pathology*, *31*(4), 1868–1877. https://doi.org/https://doi.org/10.1044/2022_AJSLP-21-00391

I led and completed the design of this study, data collection, transcription, data analysis and coding, and writing of this paper; with input from co-authors in their supervisory roles.

Smith, R., Bryant, L., & Hemsley, B. (2022e). *"It looks better than a bowl of mush": Views on food design and 3D food printing to improve the mealtime experience for people with dysphagia* [Manuscript submitted for publication]. Graduate School of Health, The University of Technology Sydney.

I led and completed the design of this study, data collection, transcription, data analysis and coding, and writing of this paper; with input from co-authors in their supervisory roles.

Further publications arising from my research during the course of this thesis can be found in Appendix D.

Table of Contents

List of Tables

List of Figures

List of Appendices

Abstract

Dysphagia (difficulty swallowing) affects an estimated 8% of the world's population and can result from a number of lifelong health conditions (e.g., cerebral palsy) or acquired health conditions (e.g., stroke). Dysphagia can lead to poor respiratory health, poor nutritional health, and death. Dysphagia can also reduce a person's quality of life by leading to social isolation around meals and a fear of choking. A common intervention for dysphagia, the provision of a texture-modified diet, may also impact on a person's quality of life if the foods are unappealing and lead to reduced oral intake. To add to previous food shaping techniques of using piping bags or food moulds, 3D food printing has been proposed as a way to improve quality of life by making texture-modified foods more visually appealing.

The overall aim of this study was to gain an in-depth understanding of the impacts of dysphagia on a person's mealtime quality of life and, within that, the influence of food shaping techniques including 3D food printing on mealtime experiences, participation and inclusion. This study involved applying constructivist grounded theory techniques to build an evidence-based framework explaining (a) the impacts of dysphagia and dysphagia interventions on mealtime quality of life, participation, and inclusion for adults with dysphagia; (b) barriers and facilitators to mealtime quality of life for adults with dysphagia; (c) the impact of food design strategies on the mealtime experience of people with dysphagia; and (d) the feasibility of using 3D food printing as food shaping technique to improve the visual appeal of texture-modified foods and mealtime experiences for people with dysphagia.

Constructivist grounded theory techniques and a mixed methods approach guided data collection, analysis, and reporting across component studies. First, a scoping review of the literature revealed widespread impacts of dysphagia on mealtime quality of life. This was followed by a narrative review of food design strategies to improve the mealtime experience for people with dysphagia. The reviews informed the design of the research instruments of this research. Then, nine people with dysphagia and four of their supporters engaged in in-depth interviews, a mealtime observation, and an immersive 3D food printing experience and interview to understand their views and experiences of both dysphagia and mealtime quality of life and 3D food printing. Following this, fifteen allied health professionals engaged in one of four focus groups about their views on mealtime quality of life associated with dysphagia, and the feasibility of 3D food printing. Finally, to verify and expand upon these studies, an online survey was completed by people with dysphagia, supporters of people with dysphagia, and allied health professionals. These methods provided the best and most feasible strategy for answering the research questions during the COVID-19 pandemic. These original, integrated studies enabled the triangulation of findings and the development of an evidence-based framework, developed through meta-synthesis of the two literature reviews and the findings of the original research.

Overall, dysphagia and its interventions negatively impacted on mealtime quality of life, particularly through limited choice and control related to food and mealtimes, reduced physical safety, reduced social engagement, and poor mealtime experiences. Several factors were identified as barriers and/or facilitators to quality of life. These factors included the person with dysphagia’s ability to engage in designing their own meal, ownership of swallowing difficulties, the opinions of others supporting the person, the provision of education, the person’s adaptability or resistance to change, and the provision of interventions to improve swallowing. Participants considered that 3D food printing could improve mealtime experiences; however there were barriers to use that would need to be overcome for this to be possible. These included the practicality of the device, the suitability for different populations, cost of the device, and the acceptability of printed foods. The final stage of the research, a meta-synthesis across studies, integrated results to build an evidence-based

framework to guide clinicians working in the field of dysphagia towards holistic and person-centred management of dysphagia, designed to sustain and improve a person's mealtime quality of life, participation, and inclusion.

Thesis Synopsis and Chapter Outline

This thesis provides new information about the impacts of dysphagia on quality of life and the potential to improve the mealtime experience using food shaping techniques, including 3D food printing. Each section includes individual studies, culminating in a meta-synthesis chapter presenting the overarching evidence-based framework on dysphagia, quality of life, and food shaping including 3D food printing. Each section builds on the prior section and the understanding of the concepts being examined. Section 1 provides the context of what is already known on the topic of dysphagia, quality of life, and 3D food printing. This contextual information shaped the methodological approach taken and the methods used throughout the remainder of the thesis, described in Section 2. Sections 3a and 3b describe the exploration on the impacts of dysphagia on quality of life (Section 3a) and the feasibility of 3D food printing to improve the mealtime experience for people with dysphagia (Section 3b). In Section 3c, data described in the literature reviews (Section 1) and original research (Section 3a and 3b) are triangulated and synthesised through qualitative research synthesis to build an evidence-based framework. Lastly Section 4, describes areas for future research, and identifies implications of this research for clinical practice.

Section One: Introduction

Chapter 1 provides an introduction to the background and aims of this research regarding the impacts of dysphagia on mealtime quality of life and the feasibility of using 3D food printing to improve mealtime quality of life, participation, and inclusion of people with dysphagia. It also describes current research regarding the use of food design strategies for people with dysphagia to improve the mealtime experience, in particular 3D food printing. To clearly outline prior knowledge on dysphagia and mealtime quality of life, and to identify gaps in the research, Chapter 2 provides a scoping literature review examining the impacts of dysphagia on mealtime quality of life, participation, and inclusion. The PROSPERO Protocol for this review is included in Appendix E (Smith et al., 2019). One of the key issues identified in the scoping review was that dysphagia affected mealtime quality of life around food and meals, particularly impacting on the visual appeal of texture-modified food. Chapter 3 explores these issues further through a narrative literature review on the impact of food design on mealtime enjoyment and engagement for people with dysphagia. The literature reviews presented in Section One identified that dysphagia, mealtimes, and quality of life are intricately related in ways that are not yet well understood. There was a paucity of research on dysphagia and mealtime quality of life using qualitative research approaches.

Section Two: Methodology

Chapter 4 describes the methodology of the present doctoral research to address the gap identified in Section One. It outlines the ontological, epistemological, and theoretical standpoints taken by the researcher in the course of this research. It also outlines the ethical considerations of the project.

A number of methods were put in place to follow the methodological approach outlined in Chapter 4. These methods were used to examine the impacts of dysphagia on mealtime quality of life and the feasibility of 3D food printing and are described in Chapter 5. This chapter outlines the use of interviews, mealtime observations, mealtime document analysis, surveys, and focus groups. As this project was completed from 2019 to 2022, it was impacted by COVID-19 and the associated social distancing and travel rules enacted. Chapter 6 describes the impacts of COVID-19 on this PhD project. This chapter is also expanded upon through an article co-authored by three speech pathology higher degree research students at UTS, including this HDR candidate. This article was published in Speech

Pathology Australia’s ‘Speak Out’ in 2020. A copy of this non-peer-reviewed article can be found in Appendix D.

Section Three: Results

Based on the methods described in Section 2, three studies were completed to gain an in-depth understanding of the impacts of dysphagia on quality of life, food design strategies implemented by people with dysphagia, and the feasibility of 3D food printing to improve the mealtime experience. These studies included people with dysphagia, supporters of people with dysphagia, and allied health professionals.

Part A: The Impacts of Dysphagia on Quality of Life, Participation, and Inclusion

Chapters 7, 8, and 9 report the on the results relating to the impacts of dysphagia on quality of life. In Chapter 7, the perspectives of people with dysphagia are explored. This chapter describes the results and analysis of results from Study 1a, interviews with people with dysphagia, mealtime observations, and examination of mealtime documents to determine the impact of dysphagia on quality of life. However, this chapter also acknowledges that management of dysphagia involves both the people with dysphagia and their supporters, and allied health professionals. Chapter 7 outlines the perspectives of people with dysphagia and their supporters, and Chapter 8 discusses the views of allied health professionals on the impacts of dysphagia on quality of life (Study 2).

Due to low participant numbers and COVID-19 restrictions, a further study was conducted to gain the perspectives of a wider group of people with dysphagia, supporters of people with dysphagia, and allied health professionals who work with people with dysphagia to verify and expand on the findings of the other studies, and so to inform creation of an evidence-based framework using constructivist grounded theory methods. Thus, Chapter 9 describes an online survey completed by people with dysphagia, supporters of people with dysphagia, and allied health professionals to examine the impacts of dysphagia on mealtime quality of life, participation, and inclusion. This survey was used for data triangulation with the results of prior qualitative research described in Chapters 7 and 8.

Part B: The Feasibility of 3D Food Printing to Improve the Mealtime Experience for People with Dysphagia

As the improvement of food design was identified as an important factor influencing mealtime quality of life for people with dysphagia in Chapter 3, Part B of this section investigates the use 3D food printing, proposed to improve the visual appeal of texture-modified foods, in greater detail.

Chapters 10–12 report on results across interviews, focus groups and survey data related to the feasibility of using 3D food printing as a strategy to improve mealtime experiences for people with dysphagia. Chapter 10 describes the 3D printed food experiences of people with dysphagia and their supporters (Study 1b). In this study, participants provided their views on the use of 3D food printing to improve mealtime quality of life. As health professionals, including speech pathologists, occupational therapists, and dietitians, have significant input into prescribing and supporting mealtimes for people with dysphagia, their perspectives were also considered important to explore. Chapter 11 presents the views of allied health professionals obtained during the focus groups on the feasibility of using 3D food printing to create more visually appealing meals (Study 2). Due to the low participant numbers across studies and COVID-19 restrictions impacting on the research, an online survey (Study 3) was conducted with people with dysphagia, supporters of people with dysphagia, and allied health professionals. This is presented in Chapter 12. This was done to inform development of an evidence-based framework using constructivist grounded theory methods.

Part C: Establishing an Evidence-Based Framework

In Part C, the results of each individual study in Section 3a and 3b were synthesised to construct an evidence-based framework of the impacts of dysphagia on quality of life and the feasibility of 3D food printing to improve the mealtime experience. Chapter 13 provides a qualitative meta-synthesis of the research findings of Chapters 2, 3, and 7–12 and presents an evidence-based framework to guide clinical practice and further research.

Section Four: Discussion

Chapter 14 provides an overarching discussion and conclusion to the research. This includes a discussion on the implications of the research, the limitations of this study, and directions for future research.

Section One: Introduction

Chapter 1: Background to the Research

Dysphagia

Dysphagia (swallowing difficulties) can have a wide range of implications that limit a person's quality of life, participation, and inclusion in mealtime activities (O'Halloran & Larkins, 2008; Threats, 2007). To date, dysphagia research has predominantly examined the impacts of dysphagia on a person's respiratory and nutritional health (Threats, 2007) and risk of choking (Hemsley, Steel et al., 2019). There has been less attention to the wider social, emotional, behavioural, or psychological impacts, and to the impact on quality of life or participation for the person with dysphagia or their family members, support workers, or others.

Dysphagia can occur at any stage of the swallowing process, putting the person's respiratory and nutritional heath at risk (Hemsley et al., 2019). Oral stage dysphagia may include difficulty chewing food or keeping the bolus (mass of chewed food) in the mouth. Pharyngeal dysphagia may be associated with symptoms of coughing or choking on foods or a wet-sounding voice after drinking. Oesophageal dysphagia may include symptoms of food getting 'stuck' in the throat at the level of the chest bone, reflux, or regurgitation of food (Groher & Crary, 2016). Although these symptoms might occur in specific stages of the swallow, other symptoms of dysphagia may occur as a result of difficulties at any stage of the swallow, including poor respiratory health and weight loss (Broz & Hammond, 2014). People with dysphagia also have an increased risk of malnutrition and dehydration, which can negatively impact on their long-term care requirements (Foley et al., 2009; Rowat, 2011; Sura et al., 2012).

It is estimated that 8% of the world's population are affected by dysphagia, which impacts on their overall health, wellbeing and quality of life (Cichero et al., 2017). Dysphagia can result from a number of acquired or lifelong conditions, including but not limited to: stroke, Parkinson's, cerebral palsy, dementia, intellectual disability, motor neurone disease, or forms of head and neck cancer (Groher & Crary, 2016; Kumar, 2010). Furthermore, approximately 52.7% of older people in nursing homes present with dysphagia symptoms (Engh & Speyer, 2022). It is also widely recognised that dysphagia can be a normal part of the aging process as physiological changes occur in the human body that reduce the person's ability to swallow safely (Cichero et al., 2013). As people are living longer, there will likely be an increase in the overall number of people living with swallowing difficulties in the community and in aged-care settings. This will impact on the resources required for aged-care facilities (e.g., the time and equipment needed to provide appropriate meals to those that need them), and on the staff, who need to ensure residents with dysphagia are not put at risk of conditions related to their dysphagia including aspiration, dehydration, malnutrition, and pneumonia (Broz & Hammond, 2014).

Diet Modifications as a Dysphagia Intervention

One of the frontline interventions for dysphagia is food texture-modification, whereby foods are processed or cooked so as to be soft and easier to eat (Groher & Crary, 2016). Foods provided to a person on a texture-modified diet may be made softer to accommodate chewing difficulties, and fluids may be thickened to slow the rate of flow through the oral-pharyngeal phase of the swallow (Cichero et al., 2017). The International Dysphagia Diet Standardisation Initiative (IDDSI) Framework was designed to provide standardised terminology for texture-modified foods and their testing methods to make texture-modified foods across countries comparable and consistent (Cichero et al., 2013). According to the IDDSI Framework (IDDSI, 2019), texture-modified foods are classified using specific terms for each of the food textures. Fluids range from Level 0 Thin (normal fluid) to Level 4 Extremely Thick (honey or pudding consistency) and foods range from Level 3 Liquidised to

Level 7 Regular (IDDSI, 2019). The IDDSI framework also provides methods for testing the texture of foods, involving the *Flow Test*, *Fork Drip Test*, *Spoon Tilt Test*, *Fork or Spoon Pressure Test*, *Chopstick Test,* and *Finger Test* (IDDSI, 2017). As the IDDSI Framework is relatively new, it is not yet known how use of the IDDSI Framework might impact on mealtime quality of life studies.

Although texture-modified food is recommended to reduce a person's risk of aspiration and choking, there can be negative consequences for a person with dysphagia. For example, people with dysphagia may have reduced fluid intake, which, if the person is already medically unwell, may lead to kidney dysfunction or delirium (Swan et al., 2015). Thickened fluids, which are used to reduce the swallowing rate of fluids, can also negatively impact on the person as it can lead to pooling of fluids in either the mouth or vallecular space, which may become a choking hazard (Johnson et al., 2014). Consequently, the implementation of a texture-modified diet needs to be monitored to ensure it does not put further strain on the person's health.

Raheem et al. (2021) suggested that the structure of texture-modified food for people with dysphagia is dependent not only on the ingredients used but also on the processing methods used to create the food. Their literature review discussed how processing methods used to create texture-modified food need to produce food that follows texture specifications, as well as nutritional and visual acceptability requirements. Some common processing methods include the use of thickeners, thermal processing, and non-thermal processing (Raheem et al., 2021). Although each of these processing methods can produce foods of the correct consistency, they may not meet a person's nutritional needs. For example, fruit and vegetables that are softened through thermal processing (i.e., cooking in hot water) may lose much of their essential nutrients. To resolve this issue, further micronutrients may be added to the food to account for those lost. The authors recommended that people who prepare texture-modified meals need to improve their knowledge of methods to prepare foods in a way that maintains the nutritional value and sensory appeal of the food (Raheem et al., 2021). This should include methods to prepare meat, fish, carbohydrates, fruit, and vegetables, in a way that both meets the person's food texture and nutritional needs and maintains good health.

Impacts of Dysphagia on Mealtime Quality of Life

A biomedical approach to dysphagia is necessary to understand its effects on human health and the threats that dysphagia poses to respiratory and nutritional health with potentially fatal consequences (Howells et al., 2019b). As such, it is perhaps not surprising that there has been less of a focus on the nature or impact of swallowing difficulties in relation to mealtime quality of life, and indeed on the wider cultural impacts of dysphagia (Howells et al., 2019b). Quality of life is a complex concept, defined as a person's view of their standing in life, and is based on their cultural values, goals, expectations of themselves and their concerns (World Health Organization (WHO), 1998). Recent research also suggests that mealtime quality of life is reduced for people who have numerous medical conditions and for those who's partner works outside of the home (Namasivayam-MacDonald et al., 2022). Given its wide impacts on health and the need for modification of food textures, dysphagia might affect not only the quality of life for the person with dysphagia, but also that of their support person providing assistance with meals (i.e., a family member or direct support worker). Mealtime difficulties associated with dysphagia may change a person's mealtime culture and inclusion, and that of their families (Howells et al., 2021b, Namasivayam-MacDonald et al., 2022). For example, family members who support the person with dysphagia may need to adapt their own food and mealtimes to meet the needs of the person with dysphagia, and often need training and support to know how best to manage dysphagia and its impacts.

Aside from the associated or secondary health concerns people with dysphagia may have (e.g., respiratory or nutritional difficulties), they also experience social impacts relating to their ability to engage in mealtime activities or cultural events. The International Classification of Functioning Disability and Health (ICF) (WHO, 2001) provides a system for considering a person's activity and participation. The ICF codes have been used to highlight how dysphagia can impact on an individual's quality of life, with Threats (2007) particularly highlighting the codes d550 eating, d560 drinking, d6300 preparing meals, d9205 socialising, and d930 religion and spirituality.

Balandin et al. (2009) reported on the mealtime experiences of adults with cerebral palsy and noted that both dysphagia and associated mealtime management strategies can lead to activity limitations and secondary impacts on participation and inclusion. In the study, participants reported greatly reduced enjoyment of meals, which led to social isolation as they avoided situations involving food. They also reported that texture modification was sometimes implemented without their involvement. For example, one participant in the study said, "Well, [I] used to pick what I like, I can't do that anymore, I just get given what they think is best" (Balandin et al., 2009, p. 201). Other participants reported they could not talk and eat concurrently due to the risk of coughing or choking and described having to choose between eating and socialising. As a result, they preferred to avoid social events involving food. When they did eat food with others, coughing or choking events led them to isolate themselves from a group out of embarrassment and fear (Balandin et al., 2009). In some situations, this isolation exposed them to greater danger, as they did not have supervision or access to assistance. Balandin et al. (2009) maintained that despite eating and drinking being core aspects of work and social gatherings, adults with cerebral palsy and dysphagia do not have the same level of participation as others due to their fear of coughing and choking. Similar findings were reported by Westergren et al. (2016), who examined the effects of dysphagia on people with Parkinson’s. Westergren et al. (2016) reported that people with Parkinson’s-related dysphagia often found a place out of sight to eat at social events, particularly if there were new acquaintances at the event, to reduce the risk of embarrassment over coughing or choking on food.

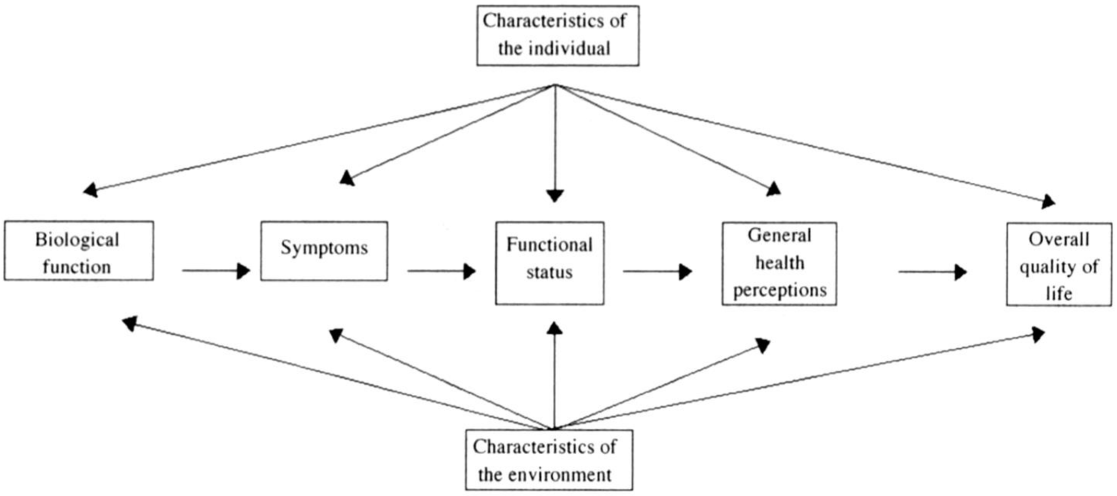
A systematic review of health-related quality of life and oropharyngeal dysphagia studies demonstrated that as the severity of a person’s dysphagia increases, their quality of life decreases (Jones et al., 2018). This suggests that the increased limitations faced by those with severe dysphagia greatly impact their mealtime experience in comparison to those with mild dysphagia symptoms (Jones et al., 2018). Extending on this, a recent cross-sectional observational study of adults over the age of 65 with a neurological disease and in hospital found that dysphagia-specific quality of life was related to gender, diagnosis, educational level, level of modified diet, and affectional social support received by others (Jung et al., 2022). This further highlighted the array of factors influencing quality of life for people with dysphagia; however, it does not explain these in an in-depth manner to show how and why these factors are so important. Thus, further in-depth qualitative research is needed.

Similarly, dysphagia interventions may impact on a person’s mealtime quality of life, participation, or inclusion. The introduction of dysphagia interventions (e.g., texture-modified food) may result in the person, or their close family members, having limited participation in cultural aspects of meals (e.g., a person may choose not to attend a Christmas party because the food poses a choking risk) (Balandin et al., 2009). These barriers need to be considered and supports put in place to reduce the impact of dysphagia on the person’s participation and inclusion (Balandin et al., 2009). Many health conditions associated with dysphagia also carry a high risk of communication disability or cognitive impairment (e.g., stroke, cerebral palsy, Parkinson’s, motor neurone disease), and determining the person’s own views on their quality of life when making treatment decisions may be difficult (Hemsley et al., 2015; McGinnis et al., 2019).

Due to the medical and health-related impacts of dysphagia, it is important to consider prior conceptualisations of 'health-related' quality of life (HRQOL) when considering quality of life outcomes (Ferrans et al., 2005). Ferrans et al. (2005) described how an individual's personal characteristics and environment can impact on their HRQOL (see Figure 1). Characteristics of the individual that impact on their HRQOL include demographic factors, psychological factors, and biological factors (e.g., disease risk, or body mass index). Environmental factors are also considered in the model of HRQOL as both social and physical environment can impact on a person's quality of life (Ferrans et al., 2005). Theoretically, treating a health condition like dysphagia could potentially impact both positively and negatively on HRQOL, depending on the person's views.

Figure 1

Revised Wilson and Cleary Model for Health Related Quality of Life



Note. Revised Wilson and Cleary Model for Health Related Quality of Life. From "Conceptual Model of Health Related Quality of Life" by C. E. Ferrans, J. J. Zerwic, J. E. Wilbur, and J. L. Larson, 2005, Journal of Nursing Scholarship, p. 338. Used with permission. Adapted from "Linking Clinical Variables with Health-Related

Quality of Life: A Conceptual Model of Patient Outcomes," by I. B. Wilson and P. D. Clearly, 1995. Copyright by JAMA.

In the conceptual model of HRQOL (see Figure 1), the arrows between the five measures of patient outcomes (biological function, symptoms, functional status, general health perceptions, and overall quality of life) represent the relationships and interactions between each of these outcomes in the model (Ferrans et al., 2005). 'Biological function' refers to the functions of organs and body systems; and 'symptoms' refers to any physical, emotional, or cognitive effect the person may perceive. Functional status, the third conceptual outcome, is comprised of the physical and social functions that an individual fulfils. General health perception is a subjective concept that examines all elements of health outcomes described above in the model. Lastly, overall health-related quality of life reflects how satisfied an individual is with their life (Ferrans et al., 2005). The HRQOL model illustrates that social and environmental factors are ever-present and may impact the person at any level. Furthermore, the individual's social environment can be influenced by their family, friends, cultural heritage, and the opinion of their health care providers (Ferrans et al., 2005).

Recent studies have examined the level of care provided to people living with dysphagia in the community by speech pathologists to support their HRQOL (Howells et al., 2019a). In a 2019 survey, only 28.5% of speech pathologists reported the routine collection of information on the functional impacts of dysphagia on quality of life (Howells et al., 2019b). Furthermore only 43.8% of speech pathologists encouraged social engagement in social groups as part of their dysphagia management. These results indicate the limited support provided to people with dysphagia regarding quality of life and social engagement (Howells et al., 2019b). Based on individual semi-structured interviews on the topic with 15 speech pathologists, Howells et al. (2019a) found that speech pathologists placed an emphasis on client autonomy in dysphagia management as a way to maintain mealtime enjoyment and their quality of life. The importance of carer engagement was also discussed in terms of supporting the person’s informed choice and decisions regarding quality of life (Howells et al., 2019a).

Further research has also examined the lived experience of dysphagia from the perspective of the person with dysphagia and their caregiver (Howells et al., 2021a; Howells et al., 2021b). Researchers conducted interviews with 15 people with dysphagia who live in the community and found that a dysphagia diagnosis led to a journey of loss and change through changes in food, lifestyle choices, and social experiences (Howells et al., 2021a). Participants also described having to find solutions for continued success in mealtimes (e.g., cooking meat differently) and strategies they could use to engage in meals outside of the home. These strategies included ordering a soft cake rather than a main meal, or sitting at a table where they could not be observed by others (Howells et al., 2021a). However, in this study quality of life was measured using a quantitative questionnaire, the Assessment of Quality of Life (AQOL-8D), rather than through in-depth qualitative analysis examining quality of life. Furthermore, the majority of participants in the study were over 70 years of age and appeared to present with mild dysphagia; hence, the perspectives of people with more severe dysphagia, and younger people with acquired dysphagia, were not included.

Howells et al. (2021b) also reported that supporters of people with dysphagia describe their role as assisting the person with dysphagia to reduce the risk of choking or aspiration. This included cooking food differently, cutting food up smaller, and observing the person eat to ensure they swallow each mouthful (Howells et al., 2021b). The caregivers also discussed dysphagia-related challenges they faced when going out for a meal; numerous participants described only going out for coffee and cake rather than a whole meal as it was easier for the person with dysphagia to swallow (Howells et al., 2021b). This demonstrates the impacts dysphagia can have not only on the lifestyle of the person with dysphagia but on that of their caregiver as well. However, the 15 participants with dysphagia presented with dysphagia related to an arteriovenous malformation, progressive neurological condition, multi-system atrophy, general aging, head and neck cancer, or a jaw fracture (Howells et al., 2021b). There were a number of conditions associated with dysphagia that were not included in this sample; for example, dysphagia related to a developmental disability. Hence, further research is needed to gain an in-depth understanding of the impacts of dysphagia on the quality of life and lifestyle of people with dysphagia associated with a wide range of lifelong and acquired aetiologies.

Assessing Swallowing-Related Quality of Life

To date, there has been very little research exploring either the philosophical underpinnings of swallowing-related quality of life, or its measurement. Nonetheless, some effort has been made to measure swallowing-related quality of life for people after a stroke. The Swallowing Quality of Life Questionnaire (SWAL-QOL) is a quantitative assessment tool designed to assess swallowing-related quality of life and it is some time now since its validation (McHorney et al., 2002). In the absence of other validated tools, the SWAL-QOL is frequently used to measure swallowing-related quality of life in various populations (Kim, 2018; Youssof et al., 2017). It provides measures of negative impacts of dysphagia on the person's social functioning, fatigue levels, and duration of mealtimes. Indeed, tools that have been developed for measuring overall quality of life yield quite different results when applied to individuals with dysphagia compared to individuals without dysphagia. For example, Maclean et al. (2009), using the World Health Organization Quality of Life (WHOQOL) assessment with adults following a total laryngectomy, reported no significant differences in overall quality of life scores between participants with and those without dysphagia. However, in the same study, using the University of Washington Quality of Life Questionnaire (UW-QOL) the authors reported that participants with dysphagia had significantly lower scores than people without dysphagia for the social scale, which indicated problems with anxiety, pain, mood, and participation in activities (Maclean et al., 2009). These findings indicate a need for more robust qualitative research, identifying the parameters (or factors) that need to be measured and conceptualised in a theoretically robust model explaining the impacts of both dysphagia *and* its treatment on the person with dysphagia's mealtime quality of life, inclusion, and participation. An in-depth understanding of these impacts is needed to develop valid instruments that might also be used in tandem with standard measures of dysphagia.

Food Design

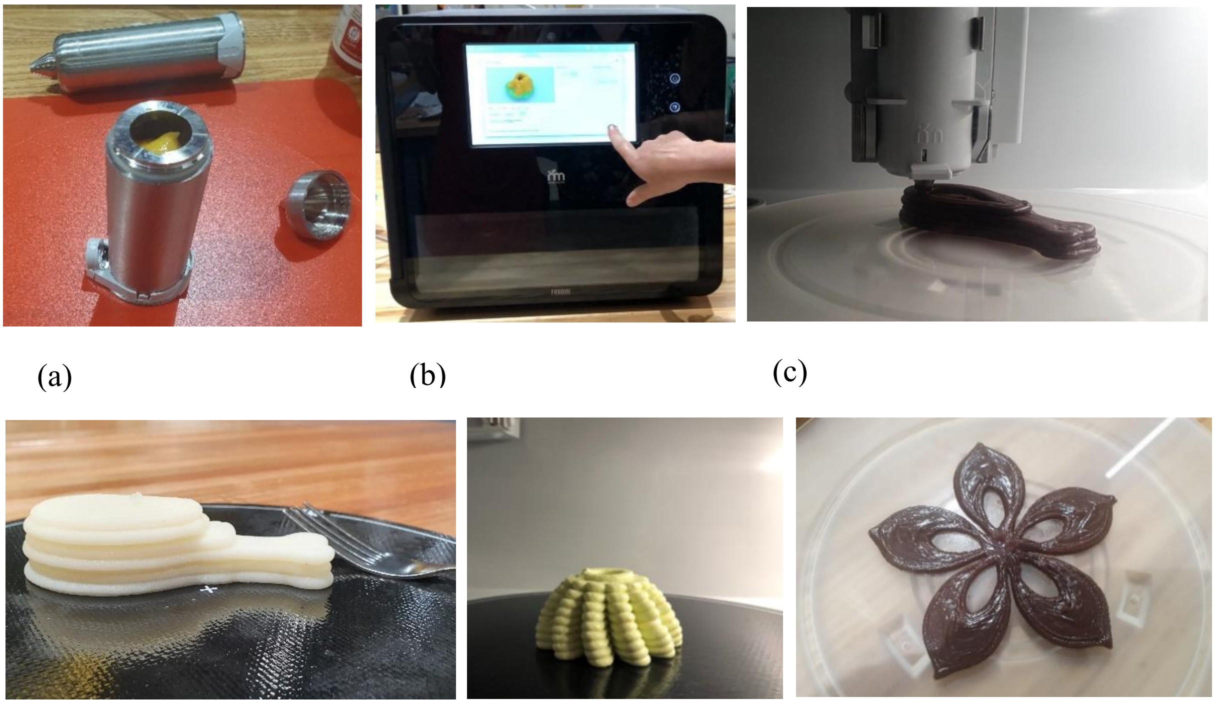
Dysphagia and the provision of texture-modified foods can have numerous impacts on the mealtime experience that shape the person's quality of life (Balandin et al., 2009). Elements of a meal may be modified to improve the mealtime experience for people with dysphagia (e.g., modifying the taste of the food or the mealtime environment). Food design is a broad, multidisciplinary field that encompasses a range of concepts, including "design with food, design for food, food space design or interior design for food, food product design, design about food, and finally, eating design" (Zampollo, 2016, p.4). Food design encompasses more than the design of the food itself; it also includes cutlery and tools used to eat the meal, the mealtime environment, and the social behaviours involved in a meal (Zampollo, 2016). For people with dysphagia who require a texture-modified diet, the creation of their meals is linked to the 'design with food' process as they make decisions relating the texture, shape, colour, temperature, and aroma of the food. The views of the person with dysphagia need to be considered when designing the visual appeal or structure of a texture-modified meal to improve its acceptability to the person. However, for many people with dysphagia, this process can be problematic. For example, pureed foods may be plated in scoops, with each ingredient being plated separately to prevent them from mixing (Milte et al., 2017); or, in some situations, foods are pureed together, which could significantly impact on a person's enjoyment of the food and their mealtime interactions (Cichero, 2015). Food moulds are one strategy used to improve the visual appeal of pureed meals; however, there is conflicting evidence regarding the acceptance of food moulds, as some people have reported moulded foods are harder to swallow than pureed meals scooped onto the plate (Stahlman et al., 2001).

3D Food Printing

In recent years, 3D food printing (notably first used with chocolate and sugar) has been suggested as a method to improve food design for people with dysphagia (Sun, Peng, Yan et al., 2015; Sun, Peng, Zhou et al., 2015; Sun, Zhou et al., 2015). 3D food printing is an additive manufacturing process that involves food being pushed through a food-grade nozzle from a capsule or syringe in layers to create a shape (Hemsley et al., 2019). This is achieved through extrusion-based printing methods. For this project, the Foodini 3D food printer (Natural Machines, 2022a), which currently only prints foods with a puree consistency, was used. The Foodini is approximately 45cm wide, 43cm tall, and 43cm deep and as a result could fit on a domestic kitchen bench (Natural Machines, 2022a). Prior to printing, all food products must be of a puree consistency that can then be spooned or piped into the printer capsule (see Figure 2 below for pictures and associated note regarding the Foodini 3D food printer and some of the items printed with the machine). Once the printer capsule is filled, it is placed inside the printer and the design for the print can be selected on the 25cm display screen (Natural Machines, 2022a). The Foodini printer can maintain the temperature of the puree within the capsules; however, it cannot cook the food. Therefore, cooking must be done before food is placed in the capsule; alternatively, the printed shape may be reheated after the print is finished (Natural Machines, 2022a). The time required for each print depends on the size of the design; for example, printing a single chicken leg would take significantly less time than printing a complete dinner of meat and vegetables. The ‘Twisted Star’ shown below (Figure 2) can be printed in three to four minutes.

Figure 2

The Process of 3D Food Printing



(a) (b) (c)

(d) (e) (f)

Note. (a) Metal capsule with lid off filled with pumpkin puree, (b) Hand pointing to touch-screen of Foodini printer, (c) Partially printed chicken leg made out of chocolate ganache, (d) Complete chicken leg printed out of mashed potato, (e) Pureed avocado printed into a shape called ‘Twisted Star’, and (f) Flower printed using chocolate ganache.

3D Food Printing for People with Dysphagia

Various engineering research teams have postulated that 3D food printing could improve the mealtime safety (through improved food standardisation), quality of life (through improved visual appeal of the foods), and participation and inclusion in meals (through being involved in the food design using 3D food printing processes) (Godoi et al., 2016).

Hemsley, Palmer et al. (2019) reviewed the published literature on 3D printed foods. In total, the review included 16 papers, with only three original studies and the remainder reviews or commentary papers. Ultimately, the authors concluded that there is little evidence confirming the claim that 3D printing of food enables people with dysphagia to enjoy pureed foods and improves their quality of life. Research is needed in this area with a focus on engaging the person with dysphagia in the 3D printing process (Hemsley, Palmer et al., 2019). The review also demonstrated that evidence of 3D food printing comes primarily from engineering disciplines and is mainly focused on the technological factors impacting on the success of printing food products; it does not look directly at the inclusion of people with dysphagia or health professionals working with them in this process, nor does it consider the person's personal factors (e.g., physical capabilities in using a 3D food printer) that may influence their choices of 3D printed food design. There is also currently limited information on the safety of 3D printed foods for people with and without dysphagia (Costa et al., 2017; European Food Safety Authority, 2015).

In a more recent literature review on 3D food printing, Pereira et al. (2021) described the steady increase of literature discussing 3D food printing since 2015 but noted a number of limitations, including the high cost of 3D printers, printing speed, food safety concerns, consumers' perceptions of printed food and limitations in printing accuracy (Pereira et al., 2021). In relation to 3D printing for people with dysphagia, the authors suggested that there are still gaps in the literature regarding the formulation of food for printing and the post-processing methods required after a shape is printed, particularly for printing of meat products (e.g., heating) (Pereira et al., 2021).

Pilot studies have trialled 3D food printing to create texture-modified nutritious foods. Kouzani et al. (2016) successfully printed a pavlova out of egg white, and in 2017 Kouzani et al. printed a tuna fish with a 3D food printer, using natural ingredients without added thickeners. The 3D printed tuna fish consisted of tuna, beetroot, and pumpkin (Kouzani et al., 2017). In both of these studies, specific printer settings were required for the print to be successful, including the texture of the print surface and the pressure on the printing barrel. Kouzani et al. (2017) concluded that 3D food printing is not straightforward and further research is needed as to the ways that different foods ‘behave’ when pureed and printed.

Dick et al. (2020) reported on the innovative 3D printing of a number of food products including vegetables, pork, bread, and chicken. The authors trialled printing pork paste when mixed with different combinations of xanthan gum and guar gum as a hydrocolloid. Dick et al. (2020) found that heating the pork and the addition of the hydrocolloids meant the samples showed less hardness, cohesiveness, and chewiness than the sample with no hydrocolloids, suggesting additional water retention. Pant et al. (2021) similarly tested the properties of vegetable food inks when hydrocolloids were added. Different amounts of hydrocolloids were needed depending on the water content of the vegetable; for example, peas required less stabilisation than carrots, and both required less stabilisation than bok choy, which had a high water content of approximately 96% (Pant et al., 2021). Wendin et al. (2020) found that different amounts and types of hydrocolloids were needed when printing broccoli, chicken, and bread pastes, demonstrating the complex processes required for successful 3D food printing. However, none of these studies included participants with dysphagia to trial the printed food to determine whether it was suitable or acceptable for their consumption.

Researchers have also compared the effectiveness of shaping texture-modified food through 3D food printing to shaping using food moulds. Strother et al. (2020) shaped pureed carrot using 3D food printing and food moulds and found that there was no significant difference between shaping methods on the food’s sensory and textural properties. There was also no significant difference in the taste of moulded or 3D printed foods (Strother et al., 2020). Significant difference in textural or taste properties only occurred with changes to the type of gum used to create the shape (e.g., gelatine, guar gum) (Strother et al., 2020).

However, samples were not trialled by people with dysphagia, who may have rated the moulded and 3D printed foods differently. Instead, the foods were trialled by 12 trained panellists. As a result, further research is needed to test these methods with people with dysphagia. This is particularly important as prior research has found that people with dysphagia rate the visual appeal of texture-modified foods differently to people without dysphagia (Ettinger et al., 2014). This means that the opinions of people without dysphagia should not be used in place of the opinions of people with dysphagia, and people with dysphagia need to be consulted on their food choices and preferences.

The potential nutritional benefits of 3D food printing were also considered in a qualitative study comprising of interviews with ten 3D food printing and nutritional experts (Burke-Shyne et al., 2021). The interview participants expressed the view that 3D food printing could be beneficial for people who require texture-modified diets and could also be used to create personalised nutrition and to create novelty products (Burke-Shyne et al., 2021). However, a number of technical issues were identified as potential barriers to 3D food printing, including cost, food safety issues, and the speed of printing (Burke-Shyne et al., 2021). Burke-Shyne et al.'s research provided further insight into the use of 3D food printing for people with dysphagia, however further research is needed to demonstrate its feasibility from the perspective of people with dysphagia and speech pathologists who are involved in the provision of texture-modified diets, as neither of these groups were included in Burke-Shyne et al.'s expert panel.

Research Aims

There is a demonstrated need for greater qualitative in-depth examination of the impacts of dysphagia and its interventions on mealtime quality of life. In addition, further research is required to determine the feasibility of 3D food printing as a food design strategy to improve the mealtime experience and quality of life for people with dysphagia. Thus, the aim of this research is to develop an evidence-based framework to examine (a) the impacts of dysphagia and its interventions on mealtime quality of life, participation, and inclusion of adults with dysphagia; (b) facilitators and barriers to mealtime quality of life for adults with dysphagia; (c) the impacts of food design strategies on the mealtime experience of people with dysphagia; and (d) the feasibility of 3D food printing to improve the mealtime experience for adults with dysphagia. These aims will be examined from the perspective of adults with dysphagia, supporters of people with dysphagia, and allied health professionals who work with people with dysphagia to inform development of a framework of factors influencing quality of life outcomes for people with dysphagia.

Overview of Methodology

For this study, a relativist ontological stance was adopted to allow for multiple viewpoints shaped by the person's environment and experiences to be examined (Gardner et al., 2012). A constructivist epistemological position was adopted in which knowledge of the research topic was generated through the perspectives of the researchers and participants. An interpretivist theoretical standpoint (symbolic interactionism) was also adopted, with meaningful understanding of an event established through a person's experiences and environment (Gardner et al., 2012).

Based on this philosophical standpoint, a constructivist grounded theory approach was selected as the most appropriate methodology for this study as it allowed for consideration of both the interpretations of the researcher and the participants being acknowledged, while honouring the multiple data sources and perspectives that can be combined to understand a phenomenon. The constructivist approach is subjective and takes into account the researcher's own stance, interpretations, and values (Mills et al., 2006). Constructivist grounded theory techniques are suitable in areas where little is known and multiple factors impact the human experience (Charmaz, 2017). These techniques allow for the use of reflexive strategies to assist researchers in creating novel theories from empirical evidence (Charmaz, 2017). The concept of 'quality of life' is, by its very nature, qualitative. The constructivist grounded theory approach supports exploring all of the issues from the 'ground up', without the lens of 'mealtime safety' and respiratory health being prioritised and potentially overshadowing the more conceptual and neglected questions relating to quality of life. The philosophical approach for this study is described further in Chapter 4.

Ethical Considerations

Ethical approval was first received from the UTS Human Research Ethics Committee (ETH19-3708) with two amendments made at later times (ETH21-6568 and ETH21-6781).

Chapter 2: Scoping Review of Dysphagia and Quality of Life, Participation, and Inclusion Experiences and Outcomes for Adults and Children with Dysphagia

Chapter 1 of this thesis provided an introduction to the topic of this research: the impact of dysphagia on a person's quality of life, participation and inclusion, and the feasibility of using 3D food printing to improve mealtime engagement of people with dysphagia. Following Chapter 1, the theoretical effects of dysphagia on quality of life were evident; however, the scope and nature of the literature was unclear. To fully understand the nature and scope of quality of life in dysphagia research, a scoping review was completed. Chapter 2 provides this scoping review on the impacts of dysphagia and its interventions on quality of life, participation, and inclusion for children and adults with dysphagia. The studies reviewed could include any research measuring mealtime quality of life using any instrument. As such, the findings are limited to measuring aspects of mealtime quality of life defined within those tools and with the populations in the included studies.

The systematic methods used in completing this review can be seen in the published PROSPERO Protocol (see pages 377-384 of this thesis):

Smith, R., Hemsley, B., & Bryant, L. (2019). Systematic review of dysphagia and quality of life, participation, and inclusion experiences or outcomes for adults and children with dysphagia. PROSPERO 2019. CRD42019140246. https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019140246

The findings of this review were accepted for an oral presentation at the 2020 Speech Pathology Australia National Conference; however this conference was cancelled due to the COVID-19 pandemic. The findings were then presented at the 2021 Speech Pathology Australia Virtual National Conference as a poster. The review was published in *Perspectives of the ASHA Special Interest Groups*. Material is copyrighted by the American Speech-

Language-Hearing Association (ASHA) and is used with permission as part of a thesis (CC BY-NC-ND). This article can be found online at: https://perspectives.pubs.asha.org/. The reference for this article is:

Smith, R., Bryant, L., Hemsley, B. (2022c). Dysphagia and quality of life, participation, and inclusion experiences and outcomes for adults and children with dysphagia: A scoping review. *Perspectives of the ASHA Special Interest Groups, 7(1),* 181–196. https://doi.org/10.1044/2021_PERSP-21-00162

ASHA American Speech-Language-Hearing Association

PERSPECTIVES

SIG 13

Review Article

Dysphagia and Quality of Life, Participation, and Inclusion Experiences and Outcomes for Adults and Children With Dysphagia: A Scoping Review

Rebecca Smith,[a] Lucy Bryant,[a] and Bronwyn Hemsley[a,b]

[a] Graduate School of Health, University of Technology Sydney, New South Wales, Australia [b] Faculty of Education and Arts, The University of Newcastle, New South Wales, Australia

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ABSTRACT

Purpose: Research shows that dysphagia impacts quality of life negatively, but the nature of these impacts is not well understood. This review article aims to examine the impacts of dysphagia and its interventions on mealtime-related quality of life, participation, and inclusion for people with dysphagia.
Method: The protocol for this scoping review was published in July 2019 and involved a search of five scientific databases using dysphagia and quality of life–related terms.
Results: In total, 106 studies were included in this review article. A qualitative metasynthesis demonstrated that dysphagia had various negative impacts on quality of life, particularly in populations with severe dysphagia. Dysphagia interventions had a range of positive impacts on quality of life; however, modifying food texture also had negative impacts. Most studies (n = 95) included adults with acquired dysphagia. Only seven studies included people with lifelong conditions, including cerebral palsy or intellectual disability, and only four studies included children. Almost half of the studies (n = 44) used quantitative instruments, including the Swallowing Quality of Life questionnaire or the Eating Assessment Tool, to measure the impact of dysphagia on quality of life, and few studies used qualitative approaches.
Conclusions: There are both positive and negative impacts of dysphagia and dysphagia-related interventions on quality of life, participation, and inclusion. Most research is quantitative and limited to adults with acquired dysphagia. Qualitative and longitudinal studies that include populations with lifelong disability and children are needed to determine how dysphagia and its interventions impact quality of life across conditions and over the life span.
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Dysphagia (difficulty swallowing) is highly prevalent, estimated to affect approximately 8% of the world's population (Cichero et al., 2017). Dysphagia is associated with a wide range of lifelong conditions (e.g., cerebral palsy, intellectual disability, Down syndrome, and autism; Sheppard et al., 2014) and acquired conditions (e.g., cerebrovascular accident [CVA], traumatic brain injury, dementia, Parkinson's disease, multiple sclerosis, motor neuron disease [MND] or amyotrophic lateral sclerosis [ALS], and head and neck cancer; Groher & Crary, 2016). The prevalence of dysphagia varies widely across conditions. For example, it is estimated that dysphagia affects as many as 45.06% of people with stroke (Rofes et al., 2018) and 85% of children with cerebral palsy (Benfer et al., 2013). Older people also have an increased risk for swallowing difficulties; an estimated 40%–60% of older people in nursing homes have dysphagia (Eisenstadt, 2010; Shanley & O'Loughlin, 2000). Dysphagia broadly impacts health and well-being, as health is defined

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Correspondence to Rebecca Smith: rebecca.j.smith@student.uts.edu.au. *Disclosure: The authors have declared that no competing financial or nonfinancial interests existed at the time of publication.*

as a position of total well-being related to physical, psychological, and social health (World Health Organization [WHO], 1946, 2001). Dysphagia can cause multiple psychosocial and physical impacts, including reduced quality of life, poor respiratory or nutritional health, and premature death from choking or aspiration pneumonia (Hemsley, Steel, et al., 2019).

Food or fluid texture modification, one of the main compensatory interventions for dysphagia (United Kingdom National Health Service, 2021), aims to sustain or increase oral food intake and nutrition while maintaining the person's respiratory health (Groher & Crary, 2016; Wu et al., 2020). The need for texture-modified food is based on clinical and instrumental swallowing assessments, with food textures commonly classed according to the International Dysphagia Diet Standardisation Initiative categories of Regular/Easy to Chew (Level 7), Soft and Bite-Sized (Level 6), Minced and Moist (Level 5), Pureed (Level 4), or Liquidized (Level 3; Cichero et al., 2017). Fluid textures are further classified as Extremely Thick (Level 4), Moderately Thick (Level 3), Mildly Thick (Level 2), Slightly Thick (Level 1), and Thin (Level 0). Extensive evidence supports the view that appropriately modified food and fluid increases a person's physical health and safety through reduced aspiration or choking risk (see Steele et al., 2015). However, texture modification may also cause health-related complications. For example, decreased fluid intake may occur if the person dislikes thickened fluids (Swan et al., 2015). This can have severe consequences on the person's physical health, including kidney dysfunction and delirium for medically unwell people (Swan et al., 2015). In addition, thickening of fluids increases viscosity and reduces flow rate during the swallow but can cause adverse effects, including pooling of fluids in the mouth or the vallecular space (Johnson et al., 2014). Although texture modification ensures that food is of the correct consistency, it can change the food's temperature or taste, thus reducing the person's mealtime enjoyment (Reissig, 2017).

Thus, it is apparent that dysphagia and a texture-modified diet can negatively impact a person's quality of life, particularly as the severity of dysphagia increases (Jones et al., 2018). The WHO defines quality of life as a person's awareness and judgment of their position in life regarding cultural beliefs and values as well as concerns (WHO, 1998). Quality of life is a broad concept that incorporates physical and mental health, beliefs, personal relationships, and the environment (WHO, 1998). Mealtime participation considers how a person engages in mealtime-related activities (e.g., choosing foods or food preparation) and extends to social or workplace situations and cultural events (Balandin et al., 2009).

In this review article, the health-related quality of life (HRQOL) model was used to conceptualize mealtime-related quality of life, which is quality of life driven by events surrounding mealtimes (Ferrans et al., 2005). HRQOL refers to the impact of a person's health on quality of life (Karimi & Brazier, 2016). As such, the HRQOL model demonstrates the impacts of the health condition and its treatments on quality of life (Ferrans et al., 2005). HRQOL is affected by a person's swallowing function, dysphagia symptoms, treatments, and general health, as well as personal and environmental characteristics. Thus, both dysphagia symptoms and treatments could positively or negatively impact quality of life (Ferrans et al., 2005). An improved understanding of how dysphagia and its interventions might affect a person's mealtime quality of life, participation, and inclusion could guide policy and practice to improve or maintain health-related quality of life in people with dysphagia. Dodrill and Estrem (2020) also related the outcomes of swallowing difficulties in children to HRQOL and reported that children with dysphagia face many of the same difficulties faced by adults with dysphagia. Negative outcomes may be driven by fatigue from eating, reduced enjoyment of meals, or reduced participation in events due to the compensatory strategies required (Dodrill & Estrem, 2020).

Reviewing the evidence from different populations with dysphagia could provide important insights into balancing the impact of dysphagia and its interventions on both health and quality of life. In a recent review of choking, both a symptom and a sequela of dysphagia, Hemsley, Steel, et al. (2019) outlined the value of considering evidence across populations and identified common risk factors and management strategies to reduce the choking risk for people with or without dysphagia. Examining studies about swallowing-related quality of life across populations may provide further insights into the impacts of dysphagia and its interventions and yield important insights and comparisons to guide overarching policies and practices. Examining literature across populations necessarily increases the requirement to expand the inclusion criteria to ensure consideration for smaller and more diverse populations. In systematically reviewing the impact of oropharyngeal dysphagia on a person's quality of life, Jones et al. (2018) excluded studies with less than 15 participants, potentially excluding important smaller scale, in-depth qualitative research on highly heterogeneous populations (e.g., people with lifelong disability), which could provide important insights into the lived experience of dysphagia and impacts on quality of life through in-depth qualitative analysis. Furthermore, many of the articles included in Jones et al. focus on people with acquired rather than lifelong developmental conditions. Therefore, the aim of this review article was to conduct a scoping review of research on the impacts of dysphagia *and* its interventions on quality of life, participation, and inclusion for children and adults across populations with either lifelong developmental dysphagia or acquired dysphagia.

Method

The review protocol was registered with PROSPERO (International Prospective Register of Systematic Reviews; Smith et al., 2019). In July 2019, five scientific databases were searched by the first author. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009) was followed, and an adapted PRISMA statement was established. The PRISMA extension for scoping reviews checklist was also implemented as part of this scoping review (Tricco et al., 2018). No time limitations for publication year were imposed. Boolean phrases "OR" and "AND" combined the search terms (see Supplemental Material S1).

Inclusion and Exclusion Criteria

This review article included articles that were (a) peer-reviewed full articles in English outlining original research and (b) related to dysphagia *and* its impact on quality of life, participation, or inclusion. Original research, including qualitative, quantitative, and mixed-methods studies or systematic reviews relating to children over 2 years of age and adults, was included. Any study that did not meet the above criteria was excluded. Furthermore, the authors of this review article made a consensus decision to exclude 13 studies relating to patients with head and neck cancer, whose primary interventions were for cancer and not dysphagia, and whose quality-of-life impacts were primarily related to the impacts of cancer treatment. As the studies using the Eating Assessment Tool (EAT-10) in this review article had used the tool specifically to measure quality of life, not only symptom outcomes, a consensus decision was made by the authors of this review article to include studies using symptom measures such as the EAT-10 (Belafsky et al., 2008). It was considered that studies using the EAT-10 as a measure of quality of life could yield important information on how researchers to date have defined and measured quality of life in relation to dysphagia.

References were imported into EndNote (Clarivate Analytics, 2019) before applying the inclusion or exclusion criteria. The first author screened titles and abstracts, and the second author checked all decisions. The remaining full texts were then rated by the first and third authors, reaching a consensus decision on inclusion. A third rater (the second author) was brought in to make a decision if consensus could not be reached between the two raters. Ancestry searches and forward citations of the included studies were retrieved for consideration against the inclusion criteria using the same method to arrive at the final list of included studies.

Quality Assessment

The Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh et al., 2012) was used to assess the quality and potential bias of the included studies. The QATSDD is a 16-item quality assessment tool used to evaluate quantitative, qualitative, and mixed-methods research designs (Sirriyeh et al., 2012). Reasonable sample size judgments were based on findings of Peduzzi et al. (1996), who discussed that at least 10 participants are required per variable or that a sample size of 150 participants is needed. In the QATSDD, qualitative and quantitative studies are scored from 0 to 3 on 14 items (maximum score of 42), and mixed-methods studies are scored on 16 items (maximum score of 48; Sirriyeh et al., 2012). This assessment was completed separately by the first and second authors. Where consensus was not reached, the third author assisted to reach a majority decision.

Data Analysis

Data extracted from the studies included the type of study; the number of participants; and relevant results on the relationship between dysphagia and quality of life, inclusion, and participation. An integrative review method (Whittemore & Knafl, 2005) allowed for relevant results from all study types to be combined and analyzed in a qualitative metasynthesis. Extracted data were read and reread by the authors and converted into units of meaning, discussed, and formed into categories using NVivo (QSR International, 2018). In the metasynthesis, data were analyzed across studies to identify themes and subthemes. Data were also examined to identify common and unusual patterns, determine relationships, and make contrasts and comparisons between the categories of meaning (Whittemore & Knafl, 2005).

Results

Characteristics of the Included Studies

The initial search identified 15,448 articles, 80 of which met the inclusion criteria. Ancestry search and forward citation checks allocated a further 26 studies, resulting in a total of 106 studies being included in this review article (see the full list of studies in Supplemental Materials S3 and S4 and the PRISMA statement in Supplemental Material S2). The interrater reliability of decisions during the full-text review was 87%, demonstrating high agreement (McHugh, 2012).

The average QATSDD score was 73%, with a minimum of 50% (Aruga et al., 2018; Farri et al., 2007) and a maximum of 93% (J. S. Kim et al., 2005). Reflecting on the inclusion of smaller scale qualitative studies, two reports had a single-case study design (Malandraki et al., 2014; Sanchez-Kuhn et al., 2019), and 14 reports had two to 10 participants (Aruga et al., 2018; Athukorala et al., 2014; Ayres et al., 2016; Carlsson et al., 2004; Frost et al., 2018; Hellden et al., 2018; Johansson & Johansson, 2009; Klinke et al., 2014; LaDonna et al., 2016; Luchesi & Silveira, 2018; Malandraki et al., 2016; Martino et al., 2010; Moloney & Walshe, 2018; Remijn et al., 2019). Reporting of recruitment was relatively poor: 22 studies provided either no or minimal recruitment data, scoring 0 or 1 on the QATSDD rating for that item. Furthermore, only five studies explicitly described stakeholder involvement in the study design with clients or steering groups (Ang et al., 2019; Carlozzi et al., 2016; Diniz et al., 2018; Karagiannis & Karagiannis, 2014; Remijn et al., 2019), indicating there was little input from people with dysphagia in research to date on dysphagia-related quality of life (see Supplemental Material S3 for overall QATSDD scores). Almost all of the included studies (*n* = 95, 90%) related to dysphagia in populations with acquired conditions. Only seven of the 106 studies (7%) related to populations with dysphagia associated with lifelong developmental health conditions.

Systematic Reviews Included in This Review Article

Eight reviews examined the impacts of dysphagia and dysphagia-related interventions on quality of life for populations with specific health conditions (Carneiro et al., 2013; Katzberg & Benatar, 2011; Klinke et al., 2013; Langmore et al., 2006; Li & Deng, 2019) or focused on people with oropharyngeal dysphagia (Jones et al., 2018; Swan et al., 2015; Verdonschot et al., 2017). The impacts of percutaneous endoscopic gastrostomy feeding for people with MND/ALS were examined in two reviews (Katzberg & Benatar, 2011; Langmore et al., 2006). Similarly, Carneiro et al. (2013) focused on dysphagia-related quality-of-life impacts for people with Parkinson's disease, whereas Li and Deng (2019) and Klinke et al. (2013) focused on people with dysphagia after a CVA. None of the included reviews provided a holistic view of the impacts of lifelong or acquired dysphagia and their interventions on the individual. Details of prior systematic reviews are presented in Supplemental Material S4.

Studies Examining the Impacts of Dysphagia on Adults

Overall, 63 (61%) original studies examined the impacts of dysphagia on the quality of life, participation, and inclusion of adults. There were 40 quantitative, 17 qualitative, and six mixed-methods studies representing various populations with dysphagia (see Supplemental Material S3). Table 1 details the impacts of dysphagia on participants and relates these to the HRQOL model. All included studies found that dysphagia impacted negatively on participants' quality of life, particularly reducing their emotional and biopsychosocial well-being. Furthermore, greater severity of dysphagia significantly correlated with reductions in quality of life (Arslan et al., 2019; Carneiro et al., 2014; da Costa Franceschini & Mourao, 2015; Hong & Yoo, 2017; Luchesi & Silveira, 2018; Pierce et al., 2016; Song et al., 2020; Turley & Cohen, 2009; Vogel et al., 2014). However, the duration of dysphagia did not always make a difference; in six studies where dysphagia symptoms were stable, there was no correlation between the duration of dysphagia and quality-of-life impacts (Carneiro et al., 2014; J. S. Kim et al., 2005; Leow et al., 2010; Plowman-Prine et al., 2009; Pontes et al., 2017; van Hooren et al., 2016; see Table 1).

Measurement of Quality of Life

In total, 20 quantitative assessment tools were used in the studies to measure quality of life (see Supplemental Material S5). Three of the studies outlined the development of the Swallowing Quality of Life (SWAL-QOL) questionnaire (McHorney, Bricker, Kramer, et al., 2000; McHorney, Bricker, Robbins, et al., 2000; McHorney et al., 2002). McHorney, Bricker, Kramer, et al. (2000) conducted focus groups with people with dysphagia to develop a conceptual foundation and established the SWAL-QOL and Quality of Care in Swallowing Disorders surveys (McHorney, Bricker, Robbins, et al., 2000). The SWAL-QOL questionnaire was then validated with participants with and without dysphagia, and results showed significant differences in scores between groups, highlighting the impact of dysphagia on quality of life (McHorney et al., 2002).

Overall, the SWAL-QOL questionnaire and/or the EAT-10 was used in 44 of the studies. In studies using the SWAL-QOL questionnaire, participants with dysphagia had significantly reduced quality of life across all domains (McHorney et al., 2002): burden, food selection, frequency of symptoms, eating, fear, fatigue, sleep, communication, mental health, social role, information, and quality of services (Carneiro et al., 2014; Diniz et al., 2018; Vogel et al., 2017).

Another four studies used condition-specific assessments, including assessments specific to Huntington's disease or Parkinson's disease (Carlozzi et al., 2016; Plowman-Prine et al., 2009). Other assessment items that were used less frequently included the Communicative Participation Item Bank (McAuliffe et al., 2017) and the

Table 1. Themes identified regarding quality of life and their relationship to the health-related quality of life (HRQOL) model (Ferrans et al., 2005).

Theme and subthemes	Component of the HRQOL model addressed by theme	References
Attempts to maintain quality of life (a) Personal attempts to maintain quality of life (b) Eating regular food	(1) Characteristics of the individual and (2) overall quality of life	(a) Klinke et al. (2013), Klugman & Ross (2002), Luchesi & Silveira (2018), Milte et al. (2017), Moloney & Walshe (2018), Nyberg et al. (2018), Perry & McLaren (2003), Pontes et al. (2017), Seshadri et al. (2018), Shune & Linville (2019), and Tarlarini et al. (2019) (b) Hellden et al. (2018), Johansson & Johansson (2009), Klinke et al. (2013), LaDonna et al. (2016), Martino et al. (2010), Milte et al. (2017), Moloney & Walshe (2018), Perry & McLaren (2003), Seshadri et al. (2018), and Shune & Linville (2019)
Biopsychosocial impacts (a) Fatigue and sleep effects (b) Increased time to eat (c) Negative mental health impacts (d) Reduced desire to eat (e) Associated risk factors to dysphagia	(1) Characteristics of the individual, (2) biological function, (3) symptoms, (4) functional health status, and (5) general health perceptions	(a) Arslan et al. (2019); Balandin et al. (2009); de Faria Gaspar et al. (2015); Gustafsson & Theorell (1995); Klinke et al. (2013); Medin, Larson, et al. (2010); Medin, Windahl, et al. (2010); Miller et al. (2006); Paris et al. (2013); Printza et al. (2020); Wegner et al. (2018); and Yi et al. (2019) (b) Balandin et al. (2009), de Faria Gaspar et al. (2015), Martino et al. (2010), Printza et al. (2020), Remijn et al. (2019), Song et al. (2020), Wegner et al. (2018), and Yi et al. (2019) (c) Balandin et al. (2009), Carneiro et al. (2013), de Faria Gaspar et al. (2015), Ekberg et al. (2002), Farri et al. (2007), Gustafsson & Theorell (1995), Hewett et al. (2016), Johansson & Johansson (2009), Klinke et al. (2013), Klugman & Ross (2002), Manor et al. (2018), Martino et al. (2010), Moloney & Walshe (2018), Morisaki (2017), Pierce et al. (2016), Plowman-Prine et al. (2009), Printza et al. (2020), Roy et al. (2007), Tibbling & Gustafsson (1991), Turley & Cohen (2009), and Verdonschot et al. (2013, 2016, 2017) (d) Alali et al. (2018); Balandin et al. (2009); da Costa Franceschini & Mourao (2015); Ekberg et al. (2002); Farri et al. (2007); Klinke et al. (2013); Leow et al. (2010); Medin, Larson, et al. (2010); Miller et al. (2006); Moloney & Walshe (2018); Paris et al. (2013); Pitts et al. (2019); and Remijn et al. (2019) (e) Balandin et al. (2009), Byeon (2019), Klinke et al. (2013), Leow et al. (2010), McAuliffe et al. (2017), Pierce et al. (2016), and Yi et al. (2019)
Emotional response (a) Fear of choking (b) Frustration (c) Humiliation (d) Incompetency (e) Loss	(1) Characteristics of the individual, (2) biological function, (3) symptoms, (4) functional health status, and (5) overall quality of life	(a) Balandin et al. (2009); Carlsson et al. (2004); Ekberg et al. (2002); Jacobsson et al. (2000); Klinke et al. (2013); Manor et al. (2018); Martino et al. (2010); Medin, Larson, et al. (2010); and Moloney & Walshe (2018) (b) Alali et al. (2018), Balandin et al. (2009), Klinke et al. (2013), Martino et al. (2010), and Moloney & Walshe (2018) (c) Ang et al. (2019); Balandin et al. (2009); Jacobsson et al. (2000); Klinke et al. (2013, 2014); Luchesi & Silveira (2018); Martino et al. (2010); Medin, Larson, et al. (2010); Medin, Windahl, et al. (2010); Moloney & Walshe (2018); Remijn et al. (2019); and Shune & Linville (2019) (d) Balandin et al. (2009), Klinke et al. (2013), Perry & McLaren (2003), and Roy et al. (2007) (e) Balandin et al. (2009); Carlsson et al. (2004); Gustafsson & Theorell (1995); Jacobsson et al. (2000); Johansson & Johansson (2009); Klinke et al. (2013); Klugman & Ross (2002); Luchesi & Silveira (2018); Martino et al. (2010); Medin, Larson, et al. (2010); Medin, Windahl, et al. (2010); Miller et al. (2006); Moloney & Walshe (2018); and Perry & McLaren (2003)
Impact on family/carers (a) Emotional impact on family (b) More support required (c) New role in mealtime support/responsibility	(1) Characteristics of the environment, (2) functional status, (3) general health perceptions, and (4) overall quality of life	(a) Balandin et al. (2009), Johansson & Johansson (2009), Mahant et al. (2011), Miller et al. (2006), and Moloney & Walshe (2018) (b) Balandin et al. (2009), Mahant et al. (2011), Moloney & Walshe (2019), and Shune & Linville (2019) (c) Balandin et al. (2009), Mahant et al. (2011), Malandraki et al. (2014), Miller et al. (2006), and Moloney & Walshe (2018)

(*table continues*)

Table 1. *(Continued).*

Theme and subthemes	Component of the HRQOL model addressed by theme	References
Social isolation (a) Avoiding eating in social situations (b) Communication difficulties (c) Loss of independence (d) Reduced participation (e) Saving face around others (f) Treatment by others	(1) Characteristics of the individual, (2) characteristics of the environment, (3) symptoms, (4) functional status, and (5) overall quality of life	(a) Alali et al. (2018); Balandin et al. (2009); da Costa Franceschini & Mourao (2015); Diniz et al. (2018); Ekberg et al. (2002); Farri et al. (2007); Hellden et al. (2018); Klinke et al. (2013, 2014); Martino et al. (2010); Medin, Larson, et al. (2010); Miller et al. (2006); Moloney & Walshe (2019); Nyberg et al. (2018); Remijn et al. (2019); Roy et al. (2007); and Tibbling & Gustafsson (1991) (b) Balandin et al. (2009), Klinke et al. (2013), McAuliffe et al. (2017), and Yi et al. (2019) (c) Alali et al. (2018); Balandin et al. (2009); Gustafsson & Theorell (1995); Jacobsson et al. (2000); Klinke et al. (2013); Mahant et al. (2011); Medin, Windahl, et al. (2010); and Moloney & Walshe (2018) (d) Ang et al. (2019); Arslan et al. (2019); Carlsson et al. (2004); de Faria Gaspar et al. (2015); Diniz et al. (2018); Mahant et al. (2011); Manor et al. (2018); Medin, Larson, et al. (2010); Milte et al. (2017); Nyberg et al. (2018); Paris et al. (2013); Perry & McLaren (2003); Plowman-Prine et al. (2009); Remijn et al. (2019); Roy et al. (2007); Shune & Linville (2019); and Stavroulakis et al. (2016) (e) Ang et al. (2019); Balandin et al. (2009); Hellden et al. (2018); Klinke et al. (2013, 2014); Klugman & Ross (2002); Medin, Windahl, et al. (2010); Milte et al. (2017); Perry & McLaren (2003); and Seshadri et al. (2018) (f) Alali et al. (2018), Carlsson et al. (2004), Johansson & Johansson (2009), Klinke et al. (2013), Mahant et al. (2011), Miller et al. (2006), Moloney & Walshe (2018), and Shune & Linville (2019)
Measurement of impacts (a) Assessment use and development to measure quality of life (b) Correlation between severity of dysphagia and the impact on quality of life (c) Correlation between time with dysphagia and quality of life (d) Confirmation of the impacts of dysphagia on quality of life	(1) Biological function, (2) symptoms, (3) functional status, (4) general health perceptions, and (5) overall quality of life	(a) Aruga et al. (2018), Carlozzi et al. (2016), and Jones et al. (2018) (b) Arslan et al. (2019), Carneiro et al. (2013, 2014), da Costa Franceschini & Mourao (2015), Hewett et al. (2016), Hong & Yoo (2017), Jones et al. (2018), J. S. Kim et al. (2005), Leow et al. (2010), McAuliffe et al. (2017), Pierce et al. (2016), Song et al. (2020), Tabor et al. (2016), Turley & Cohen (2009), van Hooren et al. (2016), and Vogel et al. (2014) (c) Carneiro et al. (2013, 2014), J. S. Kim et al. (2005), Leow et al. (2010), Plowman-Prine et al. (2009), Pontes et al. (2017), and van Hooren et al. (2016) [38, 58, 67, 73–76] (d) Carneiro et al. (2013), P. H. Chen et al. (2009), Colpaert et al. (2017), Diniz et al. (2018), Eslick & Talley (2008), Finger et al. (2019), Hellden et al. (2018), Jones et al. (2018), Klugman & Ross (2002), LaDonna et al. (2016), Leow et al. (2010), Luchesi & Silveira (2018), Mahant et al. (2011), Manor et al. (2018), Moloney & Walshe (2019), Morisaki (2017), Paris et al. (2013), Pierce et al. (2016), Pitts et al. (2019), Pontes et al. (2017), Printza et al. (2020), Roy et al. (2007, 2018), and Vogel et al. (2017)
Dysphagia therapy effects on quality of life (a) No difference between different therapies on quality of life (b) Therapy had no impact on quality of life (c) Therapy improved quality of life (d) Therapy had a negative impact on quality of life (e) Self-taught methods to improve quality of life (f) Therapy recommendations	(1) Biological function, (2) symptoms, (3) functional status, (4) general health perceptions, and (5) overall quality of life	(a) Heijnen et al. (2012), Kelly et al. (2013), J.-H. Moon et al. (2018), Reyes et al. (2015), Sundstedt et al. (2016), and Ünluer et al. (2019) (b) Balandin et al. (2009), Hagglund et al. (2019), Milte et al. (2017), Reyes et al. (2015), and Sundstedt et al. (2016) (c) Argolo et al. (2013), Athukorala et al. (2014), Ayres et al. (2016, 2017), Bahceci et al. (2017), S.-C. Chen et al. (2018), Colpaert et al. (2017), Frost et al. (2018), Heijnen et al. (2012), Jin et al. (2020), Kang et al. (2012), Karagiannis & Karagiannis (2014), Liu et al. (2018, 2019), Malandraki et al. (2016), Manor et al. (2013), D. H. Moon et al. (2019), Rogus-Pulia et al. (2016), Sanchez-Kuhn et al. (2019), Tarlarini et al. (2019), Ünluer et al. (2019), Verin et al. (2011), Vieira et al. (2018), Xia et al. (2016), and Zhang et al. (2016) (d) Ang et al. (2019), Mahant et al. (2011), Moloney & Walshe (2018), Shune & Linville (2019), Stavroulakis et al. (2016), Swan et al. (2015), and Tarlarini et al. (2019) (e) Balandin et al. (2009), Moloney & Walshe (2018), Seshadri et al. (2018), and Shune & Linville (2019) (f) Balandin et al. (2009), Malandraki et al. (2014), Moloney & Walshe (2018), Shune & Linville (2019), and Tarlarini et al. (2019)

M. D. Anderson Dysphagia Inventory (P. H. Chen et al., 2009; Roy et al., 2007, 2018). One study conducted multiple regression analysis to account for the impact of dysphagia on quality of life and other independent variables (Morisaki, 2017). The author reported that mental health, activities of daily living, and general health significantly differed in community-dwelling elderly people with dysphagia and that these factors were associated with their quality of life (Morisaki, 2017). Across all of the included studies, quantitative measures provided little in-depth exploration of the experience of dysphagia or dysphagia-related interventions on quality of life, participation, or inclusion.

Qualitative and Mixed-Methods Studies Examining Quality of Life and Dysphagia

The mixed-methods and qualitative studies included in this review article made up just over one third of the original research and utilized interviews ($n = 22$), observations ($n = 3$), focus groups ($n = 2$), open-ended questionnaires ($n = 2$), and autobiographies ($n = 1$; see Supplemental Material S3). Content themes in the qualitative elements of the studies are presented in Table 1, with illustrative quotes in Table 2.

Participants described emotional responses to dysphagia and its interventions, including frustration, humiliation, loss, and fear of choking. Miller et al. (2006) described

Table 2. Participant quotes regarding dysphagia and quality of life themes.

Theme	Subtheme	Quotes
Attempts to maintain quality of life	Eating regular food	"When the sacrifice became too burdensome, they abandoned the recommended diet modification and reverted to regular softer foods with his wife 'watching him like a hawk.'" (Seshadri et al., 2018, p. 754)
Biopsychosocial response	Fatigue	Miles said: "Last year I noticed there was a slight change in how I feed myself, my movement in my wrist and my shoulder and my elbow, I'm getting more stiffer." (Balandin et al., 2009, p. 201)
	Increased time to eat	"Almost everyone finishes before me and there is no time left for leisure." (Remijn et al., 2019, p. 1901)
	Reduced desire to eat	"I sometimes think, 'Oh, I feel like an apple,' but it takes so long to eat. So, leave it." (Remijn et al., 2019, p. 1901)
Emotional response to dysphagia	Frustration	"It's harder, when you gotta watch other people eat what you'd like." (Balandin et al., 2009, p. 202)
	Humiliation	"It's embarrassing if you go out to a meal. . . .Yes, I mean, people look at you." (Medin, Windahl, et al., 2010, p. 1350)
	Loss	"I used to love cooking. For my husband and the grandchildren. Now I can't do it. Nanny's body's just cracking up on her." (Perry & McLaren, 2003, p. 190)
	Feelings of incompetence	Fearing loss of ability to feed self "while you can feed yourself you can gauge what you, how much you put on the spoon, but when you are being fed by somebody else they gauge it for you." (Balandin et al., 2009, p. 201)
Impact on families and carers	New role for family member	"Siblings had roles in caregiving, such as with tube feeding. The needs of their disabled sibling were seen to limit other activities (e.g., recreation, time with parents)." (Mahant et al., 2011, p. e399)
	Avoidance of eating at social situations	"I do not want people to be bothered by having me for a visit." (Klinke et al., 2013, p. 255)
	Treatment by others	"...you get the sarcastic looks, they see you. . .walking with this tube hanging around [your child]." (Mahant et al., 2011, p. e398)
Social and work isolation	Comorbid communication difficulties	"None of the six participants who used communication boards had access to their boards during meals." (Balandin et al., 2009, p. 203)
	Loss of independence	"Not only would Emma (wife) have to feed me, which was undignified enough, but I would be eating with my mouth open and also, no doubt, be coughing on my food." (Moloney & Walshe, 2018, p. 1528)
	Reduced participation	"Residents desired to eat in good company and be among friends, rather than be restricted to sitting by 'diagnosis.'" (Shune & Linville, 2019, p. 149)
	Saving face	"Some participants pretended to drink coffee, lifted their cups to their mouths and took sips without swallowing. This was an attempt to maintain normal cadence in socialising." (Klinke et al., 2014, p. 6)
Dysphagia therapy effects	Therapy had a negative impact on quality of life	"[Modified food] makes them feel less normal. Like they're different or they're...almost like childish." (Shune & Linville, 2019, p. 149)
	Self-taught methods	Participants could eat regular food that was prepared in a specific way. "I would have normal meals, like lamb or chicken, pork, it has to be quite tender, if it's too hard I will choke, cough." (Balandin et al., 2009, p. 200)
	Therapy recommendations	"Successful dining for residents with dysphagia is reliant upon residents being valued as individuals with their own individual needs." (Shune & Linville, 2019, p. 148)

participants' feelings of "guilt and selfishness" (p. 616) as family mealtimes were no longer enjoyable for people with dysphagia. Nyberg et al. (2018) also reported that participants believed their mealtimes were "not performed in a culturally proper way" (p. 93) and that they tried to maintain normality and inclusion by choosing regular foods that they could eat. LaDonna et al. (2016) described similar coping strategies to overcome isolation, for example, by choosing meals that the person with dysphagia could share with friends and family (see further examples in Table 2). Some people with dysphagia described pretending to drink coffee in front of others to maintain the appearance of normality and "proper" mealtime cultural norms (Klinke et al., 2014). Moloney and Walshe (2018) examined the autobiographies of 10 people with dysphagia secondary to a CVA and reported that dysphagia had significant emotional and social impacts for participants.

Across the studies, various psychosocial and mental health impacts were associated with dysphagia, including symptoms of depression or anxiety (Eslick & Talley, 2008; Tibbling & Gustafsson, 1991; Verdonschot et al., 2013, 2017). Verdonschot et al. (2016) found that the relationship between anxiety, "piecemeal deglutition" (p. E202), and the postswallow vallecular pooling of thickened liquids was significant, as was the relationship between depressive symptoms and dysphagia. However, Verdonschot et al. (2016) also found that the probability of having anxiety decreased as dysphagia severity increased, suggesting that this was because people with more severe dysphagia had a longer disease history, no longer causing them increased anxiety.

The Impact of Dysphagia Interventions on Quality of Life in Adults With Dysphagia

In total, 32 (30%) of the included studies examined the impacts of dysphagia interventions on quality of life for adults (see Supplemental Material S3). Of these, the majority (n = 25) reported that a wide variety of dysphagia interventions positively impacted quality of life (see Table 1). However, there was much variation between studies regarding study design, with samples ranging from one to 124 participants (Ünluer et al., 2019; Xia et al., 2016), as well as variation in therapy intensity, which reduced confidence in the findings. Two studies revealed that enteral tube feeding had positive and negative impacts on quality of life (Ang et al., 2019; Stavroulakis et al., 2016). Another study reported the negative impacts of texture-modified foods (Seshadri et al., 2018); however, dysphagia severity or progression of the associated health condition may have influenced the outcome. In four studies, there was no significant difference in quality of life after therapy (Hagglund et al., 2019; Kelly et al., 2013; Reyes et al., 2015; Sundstedt et al., 2016). Dysphagia interventions also impacted the person's inclusion and participation (e.g., Ang et al., 2019; Seshadri et al., 2018; Stavroulakis et al., 2016; Ünluer et al., 2019). Stavroulakis et al. (2016) and Ang et al. (2019) reported that gastrostomy feeding was isolating for people as they could not share communal meals, whereas Seshadri et al. (2018) reported that texture-modified diets similarly caused isolation from social gatherings. Ünluer et al. (2019) then found that repetitive transcranial magnetic stimulation used in conjunction with traditional swallowing intervention had greater impacts on social functioning than traditional swallowing therapy alone.

In four of the studies examining the impacts of dysphagia on quality of life in adults, both dysphagia symptoms and texture-modified diets commonly impacted quality of life (Hellden et al., 2018; Milte et al., 2017; Moloney & Walshe, 2018; Shune & Linville, 2019). Shune and Linville (2019) highlighted that it was not just swallowing difficulties that led to a person's reduced participation and a sense of exclusion but also the appearance of the texture-modified food. They reported that texture-modified food made people feel "self-conscious or like, 'Why me? Why do I have to eat this?'" (Shune & Linville, 2019, p. 149). Similarly, Hellden et al. (2018) reported that texture-modified diets made it challenging to eat away from home as it was difficult to find foods of an appropriate texture. Milte et al. (2017) reported that participants weighed up food safety of a meal (i.e., would it increase dysphagia symptoms or did it meet diet recommendations) with the expected enjoyment of the meal when making food choices. This highlighted the impact of food choices on quality of life for people with dysphagia who require texture-modified food.

Studies Examining the Impacts of Dysphagia on Children

Only four studies included children aged over 2 years in their sample, highlighting the limited focus of research on children. Dysphagia led to higher anxiety, lower self-esteem, and negative impacts on social participation for children (Gustafsson & Theorell, 1995). Regarding intervention, Mahant et al. (2011) reported that enteral tube feeding negatively impacted the quality of life for children and their families. In comparison, Malandraki et al. (2014) reported that intensive swallowing telepractice therapy improved EAT-10 scores, indicating that therapy did result in improvements to quality of life.

Discussion

The findings of prior research examining the views and experiences of people with dysphagia are of vital importance for informing interventions that improve their quality of life. In this review article, valuable insights into the lived experience of people with dysphagia reveal the extra effort required for them to be included in mealtime-related activities and underline the significance of mealtime-related participation and inclusion for this group. Nonetheless, the findings of this review article indicate that despite there being several systematic reviews and individual studies examining quality-of-life impacts of dysphagia and its intervention, few studies yield an in-depth understanding of mealtime-related quality of life or mealtime participation and inclusion for people with dysphagia. Most studies used quantitative instruments (e.g., the SWAL-QOL questionnaire or the EAT-10), providing only glimpses into the lived experiences of people with dysphagia from their own perspective or the perspective of their supporters. Furthermore, few studies reported any stakeholder involvement in the study design.

Overreliance on Quantitative Measures and Cross-Sectional Designs

In the studies identified in this review article, the frequent use of the SWAL-QOL questionnaire (McHorney, Bricker, Kramer, et al., 2000; McHorney, Bricker, Robbins, et al., 2000; McHorney et al., 2002), often the sole means of measuring quality of life in these studies, indicates an overreliance on quantitative methods to explore what is essentially a qualitative human experience. To date, there has been an underutilization of rigorous qualitative research methods that would provide important insights into the nature of dysphagia, its interventions, and mealtime experiences. Similarly, common use of the EAT-10 (which is not a quality-of-life measure) to assess mealtime-related quality of life could indicate the absence of more suitable tools and a need for further tool development in this area. Furthermore, our quality appraisal of studies revealed high variability in their quality. Nonetheless, studies with smaller samples provided useful insights into the quality-of-life impacts of dysphagia and its interventions that should inform training for those who provide mealtime assistance to people with dysphagia.

There was a reliance on cross-sectional designs, and there were no longitudinal studies that examined dysphagia-related quality of life across the life span. Such research would allow for the adaptation and development of strategies to increase the participation and inclusion of people with dysphagia on texture-modified diets (e.g., through greater community knowledge of dysphagia and the availability of texture-modified foods in cafés and restaurants). Given the impact of the problematic appearance of puree foods on mealtime enjoyment, further solutions to increase the appeal of texture-modified foods may require technical advancements to make attractive texture-modified foods more widely available (Hemsley, Palmer, et al., 2019).

Clinical Implications

The findings of this review article reveal significant gaps in the literature on the quality-of-life impacts of dysphagia and its interventions for people with lifelong (developmental) disability. The experiences and impacts of dysphagia on quality of life may differ widely for people with lifelong dysphagia when compared with those reported by people with acquired dysphagia. Their lived experiences of dysphagia and its interventions over a lifetime might provide important insights into the impacts of chronic dysphagia. For example, individuals with cerebral palsy or intellectual disability could provide insights into the impact of mealtime assistance, managing texture-modified foods across the life span, and accessing supports to improve mealtime participation and inclusion (Benfer et al., 2015). People with developmental disability may also experience a decline in swallowing function after the third decade of life (Balandin et al., 2009). Their views on dysphagia-related quality of life are likely to be quite different to adults with progressive symptoms associated with acquired conditions, including MND (Stavroulakis et al., 2016) and Parkinson's disease (Carneiro et al., 2014). In comparison, adults with acquired dysphagia secondary to a CVA experience a sudden loss of function, enjoyment, and independence, requiring significant adjustments owing to mealtime assistance or texture-modified foods not previously needed. This may limit their mealtime enjoyment through loss and grief (Hong & Yoo, 2017).

Overall, this review article suggests that dysphagia-related quality of life is under-researched in children with dysphagia, leaving clinicians without detailed evidence-based guidance on management for this group. Examining the experiences of children with dysphagia could identify aspects of dysphagia that should be measured across the life span to determine the lifetime impacts on quality of life. The need for texture-modified foods from childhood is likely to shape personal factors, including attitudes; knowledge; beliefs toward foods; and, potentially, development of understanding of balancing the risks and benefits of various food choices. Further research should examine how family members, health professionals, and peers support children with dysphagia in shaping these personal responses to dysphagia and its interventions. This would enable clinicians to support people with lifelong disability and dysphagia along with their families to enhance mealtime-related quality of life, participation, and inclusion across the life span.

Considering the high prevalence of dysphagia in children and adults with conditions associated with developmental disability, a greater understanding of quality-of-life impacts is needed to demonstrate ways to reduce the incidence of preventable choking deaths in this population (Hemsley, Steel, et al., 2019). If the psychosocial costs of maintaining a texture-modified diet (e.g., decreased quality of life) are greater than the perceived benefits (e.g., reduced choking and improved respiratory health and nutrition), people with dysphagia associated with lifelong disability and their families may abandon dietary modifications designed to reduce the health risks. Thus, a greater understanding of strategies to improve the quality of life of a person on a texture-modified diet may reduce morbidity and mortality in individuals with lifelong disability.

Limitations and Directions for Future Research

This study was limited by only including studies in English and a publication bias by requiring peer-reviewed articles. Although the literature search was conducted in July 2019, to reduce the impact of this limitation, the search was updated in August 2020 to locate any further studies meeting the inclusion criteria that offered further insights into the findings of the review. Overall, 10 additional studies were found, which are summarized in Supplemental Material S6. Only two of these studies included participants with dysphagia associated with lifelong conditions (Padilla et al., 2019; Pilz et al., 2020), and the remainder included participants with acquired dysphagia (Byeon, 2020; Chan et al., 2020; Covello et al., 2020; J.-Y. Kim et al., 2019; Rönnefarth et al., 2020; Shune & Namasivayam-MacDonald, 2020; Swales et al., 2020; Toledo-Rodríguez et al., 2019). All studies used a quantitative measure of quality of life, with seven using the SWAL-QOL questionnaire. Two of the studies involving people with acquired dysphagia also used qualitative, open-ended surveys or interviews (Padilla et al., 2019; Swales et al., 2020). Thus, studies located from July 2019 to August 2020 aligned with findings of this review article and did not change the results.

Future research exploring the theoretical constructs of dysphagia-related quality of life could help guide the design and development of new quality-of-life measures that are relevant across populations. It could also inform factors to be measured in controlled trials of interventions aiming to improve quality of life for people with dysphagia. Future research should also include children with lifelong disability who face a life course trajectory of ongoing impacts of both dysphagia and its interventions and whose experiences could inform planning and preparation for support strategies needed to sustain their quality of life as they get older.

Conclusions

Dysphagia and its interventions can significantly impact a person's quality of life, participation, and inclusion, and as a result, clinicians should take a holistic approach to their assessment and management of dysphagia to promote the person's quality of life. While there is a large body of literature relating to dysphagia-related quality of life across populations with dysphagia, it primarily relates to adults with acquired conditions and uses quantitative assessment measures to understand quality-of-life impacts. This could leave clinicians working with people with dysphagia uncertain about evidence-based strategies for improving dysphagia-related quality of life. The findings of this review article across populations highlight that dysphagia and its interventions can have a negative impact on a person's quality of life, particularly on psychosocial well-being and social isolation. Strategies to provide more enjoyable meals to people who require texture-modified foods are also needed. Future research should include qualitative and longitudinal methods for a rich, in-depth understanding of mealtime-related quality of life across the life span for people with dysphagia.

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Supplementary Files for Published Article

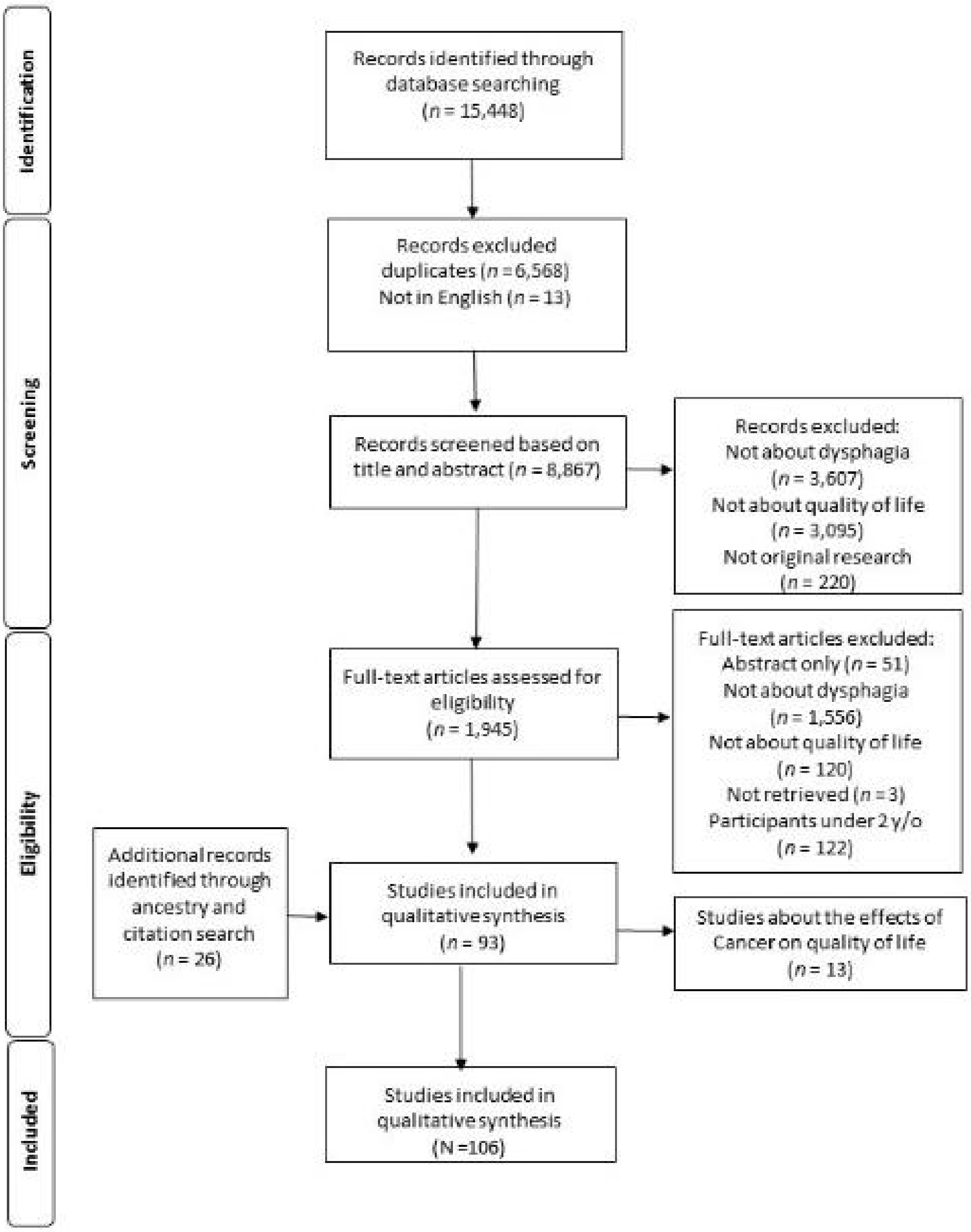
S1 (Supplementary File 1)

Medline Search Strategy for Systematic Review

Search terms
1. dysphagia.mp. or Deglutition Disorders/
2. deglutition disorder.mp.
3. swallowing disorder.mp.
4. choking.mp. or Airway Obstruction/
5. Feeding Methods/ or feeding.mp.
6. eating.mp. or Eating/
7. swallowing impairment.mp.
8. swallowing therapy.mp.
9. quality of life.mp. or "Quality of Life"/
10. enjoyment.mp.
11. participation.mp. or Patient Participation/ or Community Participation/ or Stakeholder Participation/ or Social Participation/
12. inclusion.mp.
13. self-determination.mp. or Personal Autonomy/
14. "Activities of Daily Living"/ or independence.mp.
15. Personal Autonomy/ or autonomy.mp.
16. community participation.mp.
17. patient participation.mp.
18. social inclusion.mp.
19. social participation.mp. or Interpersonal Relations/
20. Mental Health/ or wellbeing.mp.
21. lifestyle.mp. or Life Style/
22. Anxiety/ or avoidance.mp.
23. distress.mp.
24. depression.mp. or Depression/
25. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
26. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
27. 25 and 26

S2 (Supplementary File 2)

PRISMA Flowchart of Inclusion Process (Adapted From Moher et al., 2009).



S3 (Supplementary File 3)

Description of Included Studies

References and type of study	Relevant aim	Number of participants (N), group, age, and cause of dysphagia	QoL assessment used/ data collection tool	Treatment received (treatment group)	QATSDD score (%)
(Gustafsson & Theorell, 1995) QUANT Cross-sectional (Child)	Dysphagia management strategies.	87 people with dysphagia; 16-36 years; cause not specified.	Questionnaire	-	33/42 (79%)
(Mahant et al., 2011) QUAL Case Series (Child)	Impact of GJT or fundoplication.	16 parents of children with GJT or fundoplication and neurological impairment.	Interviews	GJT and fundoplication tube feeding.	34/42 (81%)
(Malandraki et al., 2014) QUANT Case Study (Child)	Effectiveness of therapy via telehealth.	1 child 6 years; Optiz BBB/G Syndrome and Asperger's Syndrome.	EAT-10	Intensive paediatric swallowing telepractice program. One-hour sessions twice a week.	31/42 (74%)
(Remijn et al., 2019) QUAL Cross-sectional (Child)	How dysphagia with CP impacts participation.	10 participants aged 15-23; CP.	Interviews	-	30/42 (71%)
(Alali et al., 2018) QUANT Cross-sectional	Impact of dysphagia on QoL.	103 adults with MS	SWAL-QoL and EAT-10	-	36/42 (86%)
(Arslan et al., 2019) QUANT Cross-sectional	Impact of dysphagia on QoL.	84 adults with a neurological disorder	SWAL-QoL and EAT-10	-	22/42 (52%)
(Aruga et al., 2018) QUANT Case Series	Usefulness of Kuchi-kara Taberu Index Chart	3 adults with dysphagia; mixed causes	Kuchi-kara Taberu Index	-	20/42 (50%)
(Balandin et al., 2009) QUAL Cross-sectional	People's experiences with dysphagia.	32 adults with CP	Interviews	-	29/42 (69%)
(Byeon, 2019) QUANT Cross-sectional	Factors impacting swallowing QoL.	142 adults with age related dysphagia.	SWAL-QoL	-	32/42 (76%)
(Carlozzi et al., 2016) QUANT Diagnostic Accuracy test	Swallowing QoL test for Huntington's Disease.	507 adults with Huntington's disease	HDQLIFE Measure	-	38/42 (90%)

(Carlsson et al., 2004) QUAL Case series	Experiences of dysphagia after a CVA.	3 adults with dysphagia after CVA	Interviews and mealtime observations	-	27/42 (64%)
(Carneiro et al., 2014) QUANT Case-control	Swallowing QoL in PD	62 with PD and 41 controls.	SWAL-QoL	-	32/42 (76%)
(Chen et al., 2009) QUANT Cross-sectional	Dysphagia and QoL in a geriatric population.	107 adults with age related dysphagia	MDADI and SF-12	-	32/42 (76%)
(Da Costa Franceschini & Mourao, 2015) QUANT Cross-sectional	Dysphagia and QoL in ALS.	17 adults with ALS	SWAL-QoL	-	33/42 (79%)
(de Faria Gaspar et al., 2015) QUANT Cross-sectional	QoL and dysphagia after CVA.	35 adults with dysphagia (9 tube fed); CVA	SWAL-QoL	-	31/42 (74%)
(Diniz et al., 2018) QUANT Diagnostic case control	Assessment for swallowing QoL in PD.	140 adults with dysphagia; PD, 47 controls.	SWAL-QoL	-	35/42 (83%)
(Ekberg et al., 2002) Mixed Cross-sectional	Effects of dysphagia on QOL.	360 adults with dysphagia; mixed causes; 28 health professionals.	DGH Scale and interviews	-	25/48 (52%)
(Eslick & Talley, 2008) QUANT Cross- sectional	Impact of dysphagia on the community.	672 adults with dysphagia; mixed causes.	CPQ	-	35/42 (83%)
(Farri et al., 2007) QUANT Cross-sectional	Impact of dysphagia on QoL.	73 adults with dysphagia from surgery.	DGH Scale	-	21/42 (50%)
(Finger et al., 2019) QUANT Cross-sectional	Onset of patient reported dysphagia symptoms.	268 adults with dysphagia; mixed causes.	EAT-10	-	34/42 (81%)
(Hellden et al., 2018) QUAL Cross-sectional	Experiences of dysphagia after CVA.	5 adults with dysphagia; CVA.	Interviews		33/42 (79%)
(Hewett et al., 2016) QUANT Case-control	QoL in people with EOE.	44 adults with dysphagia; EOE; 44 controls.	EOE Adult Quality of Life Questionnaire	-	33/42 (79%)
(Hong & Yoo, 2017) QUANT Cross-sectional	Swallowing QoL in patients with CVA.	79 adults with dysphagia; CVA; (*n*= 35 non-oral intake).	SWAL-QoL	-	25/42 (60%)

(Jacobsson et al., 2000) Mixed Case-control	Experiences of eating after a CVA.	30 adults; CVA; 15 controls.	Interviews and mealtime observations.	-	24/48 (50%)
(Johansson & Johansson, 2009) QUAL Cross-sectional	Experiences of relatives involved with dysphagia.	9 relatives of adults with dysphagia; mixed causes.	Interviews	-	31/42 (74%)
(Kim et al., 2005) QUANT Cohort study	Swallowing of young and older people with CVA.	96 young CVA onset participants, 160 old CVA onset participants.	SS-QoL	-	39/42 (93%)
(Klinke et al., 2014) QUAL Cross-sectional	Experiences of dysphagia after CVA.	7 adults with dysphagia; CVA.	Interviews	-	30/42 (71%)
(Klugman & Ross, 2002) Mixed Cross-sectional	Perceptions of dysphagia and their impact on QoL.	30 adults; MS.	Questionnaire	-	28/48 (67%)
(LaDonna et al., 2016) QUAL Cross-sectional	Experiences of relatives living with people with dysphagia.	6 relatives of adults with dysphagia; DM1.	Interviews	-	32/42 (76%)
(Leow et al., 2010) QUANT Cross-sectional	Impact of dysphagia on QoL for elderly and people with PD.	32 adults with PD, 16 elderly people, 16 young controls.	SWAL-QoL	-	31/42 (74%)
(Luchesi & Silveira, 2018) Mixed Case series	The importance of oral feeding in ALS.	4 adults; ALS.	Interview and SWAL-QoL	-	24/42 (57%)
(Manor et al., 2019) QUANT Case series	The link between FEES results and QoL.	14 adults; Huntington's disease.	SWAL-QoL and SDQ	-	29/42 (69%)
(Martino et al., 2010)QUAL Cross-sectional	Psychological issues in people with acute or chronic dysphagia.	8 adults (3 acute and 5 chronic); dysphagia of mixed causes,	Focus groups	-	31/42 (74%)
(McAuliffe et al., 2017) QUANT Cross-sectional	Variables of participation in PD.	378 adults; PD.	CPIB	-	33/42 (79%)
(Medin, Larson, et al., 2010) QUAL Cross-sectional	Experiences of eating difficulties 3 months post CVA.	14 adults; 3 months post CVA.	Semi-structured interviews	-	33/42 (79%)
(Medin, Windahl, et al., 2010) QUAL Cross-sectional	Management of eating 6 months post CVA.	13 adults; 6 months post CVA.	Semi-structured interviews	-	31/42 (74%)

(Miller et al., 2006) QUAL Case series	How dysphagia impacts on QoL in PD.	37 adults; PD.	Interviews	-	28/42 (67%)
(Milte et al., 2017) QUAL Case series	Dining experiences for participants and carers.	19 adults; Cognitive impairment or dementia.	Interviews and focus groups	-	31/42 (74%)
(Moloney & Walshe, 2018) QUAL Case series	Experiences of dysphagia after a CVA.	10 adults with dysphagia; CVA.	Phenomenological analysis of published autobiographies	-	30/42 (71%)
(Moloney & Walshe, 2019)Mixed Cross-sectional	Speech pathology management QoL in dysphagia.	148 speech pathologists.	Original questionnaire	-	36/48 (75%)
(Morisaki, 2017) QUANT Cross-sectional	Swallow function and QoL.	225 adults with dysphagia; no specific cause.	DRACE and the SF-8	-	38/42 (90%)
(Nyberg et al., 2018) QUAL Cross-sectional	How people with dysphagia perceive mealtimes.	14 adults; mixed dysphagia causes.	Interviews and mealtime observations	-	29/42 (69%)
(Paris et al., 2013) QUANT Cohort study	Impact of dysphagia on QoL with ALS.	14 adults; ALS; 16 controls.	SWAL-QoL	-	28/42 (67%)
(Perry & McLaren, 2003)QUAL Cross-sectional	Perceptions to eating after a CVA.	206 people, includes 10 carers; CVA.	Semi-structured interviews		29/42 (69%)
(Pierce et al., 2016) QUANT Cross-sectional	Social, emotional, and functional impacts of dysphagia.	101 adults; Sjogren's syndrome.	MDADI, SF-36	-	31/42 (74%)
(Pitts et al., 2019) QUANT Cross-sectional	Link between lingual pressure and swallowing QoL in PD.	24 adults; PD; 24 controls.	SWAL-QoL, and the test of interior and tongue strength	-	28/42 (67%)
(Plowman-Prine et al., 2009) QUANT Cross-sectional	Swallowing QoL in IPD.	36 adults; IPD.	SWAL-QoL, and PDQ-39	-	22/42 (52%)
QUANT (Pontes et al., 2017) Cross-sectional	QoL of elderly with dysphagia after a CVA.	35 participants; CVA.	SWAL-QoL	-	24/42 (57%)
(Printza et al., 2020) QUANT Cross-sectional	Dysphagia perceptions, and QoL in MS.	108 adults (*n* = 27 with dysphagia); MS.	SWAL-QoL, EAT-10, and DYMUS	-	32/42 (76%)

(Roy et al., 2007) QUANT Cross-sectional	Socioemotional effects of dysphagia.	117 participants, 44 with dysphagia; mixed causes.	MDADI	-	28/42 (67%)
(Roy et al., 2018) QUANT Cross-sectional	QOL and dysphagia in Rheumatoid Arthritis.	100 participants; Rheumatoid Arthritis.	MDADI and the SF-36		32/42 (76%)
(Shune & Linville, 2019) QUAL Cross-sectional	Mealtime safety and enjoyment in dysphagia.	3 residents with dysphagia; mixed causes; 3 family members, 6 nurses, 3 dietary staff, 3 speech pathologists, 3 occupational therapists.	Interviews	-	36/42 (86%)
(Song et al., 2020) QUANT Case-series	Dysphagia in X linked dystonia parkinsonism and QoL.	34 adults; X linked dystonia parkinsonism.	SWAL-QoL	-	29/42 (69%)
(Tabor et al., 2016) QUANT Case-series	Dysphagia impacts on QoL in ALS.	81 adults; ALS.	SWAL-QoL and ALSFRS-R	-	24/42 (57%)
(Tibbling & Gustafsson, 1991) QUANT Cohort-study	Dysphagia impacts on QoL in the elderly.	796 adults; dysphagia of no specific cause.	Questionnaire	-	28/42 (67%)
(Turley & Cohen, 2009) QUANT Cross-sectional	QoL impacts of dysphagia in the elderly.	248 adults with dysphagia; cause not specified.	VRQOL and CES-D	-	30/42 (71%)
(van Hooren et al., 2016) QUANT Case series	Swallowing related QoL and IPD.	100 adults; IDP.	MDADI, DSS and VHI	-	31/42 (74%)
(Verdonschot et al., 2016) QUANT Cohort-study	Link between dysphagia and affective symptoms.	107 adults; mixed dysphagia causes.	HADS, FEES, and DSS	-	27/42 (64%)
(Verdonschot et al., 2013) QUANT Cohort-study	Severity of anxiety and depression in dysphagia.	96 adults; mixed dysphagia causes.	HADS, FEES, DSS, MDADI, and FOIS	-	30/42 (71%)
(Vogel et al., 2014) QUANT Cohort study	Dysphagia and QoL in Friedreich ataxia.	36 adults; Friedreich ataxia.	AusTOMS	-	31/42 (74%)
(Vogel et al., 2017) Mixed Cohort-study	Dysphagia and QoL in POLG.	14 adults with POLG, 34 controls.	SWAL-QoL	-	29/42 (69%)
(Wegner et al., 2018) QUANT Cross-sectional	Swallowing related QoL and COPD.	17 adults; COPD.	SWAL-QoL	-	31/42 (74%)

(Yi et al., 2019) QUANT Cross-sectional	Impact of dysphagia on QoL in CP.	117 adults with dysphagia; CP; 117 controls.	SWAL-QoL	-	31/42 (74%)
(Ang et al., 2019) QUAL Cross-sectional	Experiences with long-term enteral tube feeding.	9 adults with dysphagia; mixed causes; 9 carers.	Interviews	Enteral tube feeding.	38/42 (90%)
(Argolo et al., 2013) QUANT Case series	Motor swallowing exercises and QoL in PD.	15 adults; PD.	SWAL-QoL (prior to and post intervention)	Motor swallowing exercises.	28/42 (67%)
(Athukorala et al., 2014) QUANT Case series	Swallowing skill training in PD.	10 adults; PD.	SWAL-QoL (prior to and post intervention)	Task specific exercises with sEMG feedback.	34/42 (81%)
(Ayres et al., 2017) QUANT Cohort study	Effectiveness of manoeuvre application in PD.	24 adults (divided into 3 treatment grousp); PD.	SWAL-QoL (prior to and post intervention)	1. Chin tuck manoeuvre 2. Environmental and 3. Postural information vs control.	36/42 (86%)
(Ayres et al., 2016) QUANT Case series	QOL in PD before and after swallowing therapy.	10 adults; PD	SWAL-QoL (prior to and post intervention)	Chin tuck and guidelines on mealtime behaviours.	25/42 (60%)
(Bahceci et al., 2017) QUANT Case series	Relationship between swallowing and QoL after a CVA.	72 adults between 0-30 days post CVA.	SWAL-QoL (prior to and post intervention)	Oral hygiene, head/trunk positioning, oro-motor exercises, galvanic stimulation.	33/42 (79%)
(Chen et al., 2018) QUANT Cohort study	Effects of swallowing exercises on the QoL of oral cancer patients.	76 adults (split equally into control and experimental group); head/neck cancer.	MDADI and SSQ (prior to and post intervention)	1. Swallowing exercise education program. 2. Usual care.	37/42 (88%)
(Colpaert et al., 2017) QUANT Case series	Use SWAL-QoL to examine dysphagia in Zenker's diverticulum.	25 participants (17 had dysphagia); Zenker's diverticulum.	SWAL-QoL (prior to and post intervention)	Surgery to repair diverticulum.	34/42 (81%)
(Frost et al., 2018) QUANT Case series	Improve oral intake with traditional swallowing therapy and NMES.	10 adults with dysphagia; non-specified cause.	SWAL-QoL and EAT-10 Prior to, mid, and post intervention).	NMES and traditional swallowing therapy.	33/42 (79%)
(Hagglund et al., 2019) QUANT RCT	Impact of oral neuromuscular training on swallowing.	116 adults, dysphagia of non-specified cause.	SWAL-QoL (prior to and post intervention)	Neuromuscular training using the IQoro device.	33/42 (79%)
(Heijnen et al., 2012) QUANT Pseudo-RCT	Compare traditional swallowing therapy to NMES therapy and QoL.	88 adults (divided into 3 treatment groups); PD.	SWAL-QoL and MDADI (prior to and post intervention)	1. Traditional logopedic swallowing therapy 2. Traditional logopedic swallowing therapy and NMES at motor level. 3. Traditional logopedic swallowing therapy and NMES at sensory level.	36/42 (86%)
(Jin et al., 2020) QUANT Case series	Impact of CAECPM on swallowing QoL.	19 adults; CVA or lateral skull surgery.	CSWAL-QoL	CAECPM.	29/42 (69%)

(Kang et al., 2012) QUANT Non-RCT	Exercise program to improve swallowing after CVA.	50 adults (split equally into control and experimental group); CVA.	SS-QoL assessment (prior to and post intervention)	1. Traditional swallowing therapy 2. Oral, pharyngeal, laryngeal and respiratory exercises and traditional swallowing therapy.	30/42 (71%)
(Karagiannis & Karagiannis, 2014) QUANT Case series	Relationship between access to water and QoL.	16 adults with dysphagia; mixed causes.	4 question survey using faces rating chart	Fraizier Rehabilitation Centre Free Water Protocol and thickened fluids.	31/42 (74%)
(Kelly et al., 2013) QUANT Case series	QoL after botulinum toxin injections.	49 adults with UES.	EAT-10 (prior to and post intervention)	Cricopharyngeal botulinum toxin injections.	29/42 (69%)
(Liu et al., 2018) QUANT RCT	Compare nape acupuncture and rehabilitative swallowing therapy impacts on QoL.	100 adults (split equally into control and experimental group); pseudobulbar palsy.	SWAL-QoL (prior to and post intervention)	1. Nape acupuncture and rehabilitative swallowing training. 2. Rehabilitative swallowing training.	32/42 (76%)
(Liu et al., 2019) QUANT RCT	Impact of Gao nape acupuncture and swallowing training after a CVA.	100 adults (split equally into control and experimental group); CVA.	SWAL-QoL (prior to and post intervention)	1. Gao's nape acupuncture and rehabilitative swallowing training. 2. Rehabilitative swallowing training.	26/42 (62%)
(Malandraki et al., 2016) QUANT Case series	Impact on intensive dysphagia rehabilitative training on swallowing.	10 adults; neurological disease or injury.	EAT-10 (prior to and post intervention)	Intensive dysphagia rehabilitative training protocol.	32/42 (76%)
(Manor et al., 2013) QUANT RCT	Compare VAST to traditional swallowing therapy.	42 adults, (split equally into control and experimental group); PD.	SWAL-QoL (prior to and post intervention)	1. VAST. 2. Traditional dysphagia therapy.	30/42 (71%)
(Moon et al., 2018) QUANT RCT	Impact of TPSAT on QoL after a CVA.	16 adults (split equally into control and experimental group); CVA.	SWAL-QoL (prior to and post intervention)	1. TPSAT and traditional swallowing therapy. 2. Traditional swallowing therapy.	36/42 (86%)
(Reyes et al., 2015) QUANT RCT	Effects of respiratory muscle training on swallowing.	18 adults (split equally into control and experimental group); Huntington's disease	SWAL-QoL (prior to and post intervention)	Inspiratory and expiratory muscle training against progressive (experimental) or fixed (control) resistance.	32/42 (76%)
(Rogus-Pulia et al., 2016) QUANT Case series	Use of Swallow STRONG to improve swallowing QOL	56 adults; dysphagia of no specified cause.	SWAL-QoL (prior to, mid, and post intervention)	Swallow STRONG using isometric progressive resistance oropharyngeal therapy.	32/42 (76%)
(Sanchez-Kuhn et al., 2019) QUANT Case study	tDCS with swallowing training after CVA.	1 adult; CVA.	SWAL-QoL (prior to and post intervention)	tDCS.	23/42 (55%)

(Seshadri et al., 2018) QUAL Cross-sectional	Texture modified diet with lifestyle.	20 adults; dysphagia of mixed causes.	Interviews and mealtime observations	Texture modified diet.	33/42 (79%)
(Stavroulakis et al., 2016) QUAL Cross-sectional	Gastrostomy experiences of patients and carers.	18 adults, 10 patients and 10 carers; MND	Interview three months post-surgery	Gastrostomy.	37/42 (88%)
(Sundstedt et al., 2016) QUANT Case control	Impact of deep brain stimulation on swallowing.	9 adults with PD; 9 healthy controls.	SWAL-QoL (prior to and post intervention)	Caudal zona incerta deep brain stimulation.	30/42 (71%)
(Tarlarini et al., 2019) QUANT Case-series	Taste changes and QoL in ALS	21 oral fed participants and 10 enteral tube fed participants; ALS.	UW-QOLQ	Device that provides selected flavours to foods.	30/42 (71%)
(Unluer et al., 2019) QUANT RCT	rTMS impacts on swallowing and QoL.	28 adults, 15 in experimental and 13 in control group; CVA.	SWAL-QoL (prior to and post intervention)	1. rTMS and traditional swallow therapy. 2. Traditional swallow therapy.	34/42 (81%)
(Verin et al., 2011) QUANT Case series	Use of SSTES to improve swallowing.	13 adults; neurological disorders.	SWAL-QoL (prior to and post intervention)	SSTES for six weeks.	26/42 (62%)
(Vieira et al., 2018) QUANT Non-RCT	Impact of texture modified diet on QoL.	25 adults, 12 at risk of dysphagia; CVA	SWAL-QoL (prior to and post intervention)	1. Traditional swallow therapy and texture modified food. 2. Traditional swallow therapy.	26/42 (61%)
(Xia et al., 2016) QUANT RCT	Acupuncture and traditional swallowing therapy for dysphagia.	124 adults, (split into control and experimental group); CVA.	SWAL-QoL (prior to and post intervention)	1. Acupuncture and traditional swallowing therapy. 2. Traditional swallowing therapy.	36/42 (86%)
(Zhang et al., 2016) QUANT RCT	NMES motor and sensory impacts on dysphagia.	82 adults (divided into 3 treatment groups); medullary infarction.	SWAL-QoL (prior to and post intervention)	1. Traditional swallow therapy. 2. Traditional swallow therapy and motor NMES. 3. Traditional swallow therapy and sensory NMES.	30/42 (71%)
(McHorney, Bricker, Kramer, et al., 2000) QUAL Cross-sectional	Conceptual foundation for the SWAL-QoL.	52 adults; dysphagia of mixed causes.	Focus groups	-	37/42 (88%)
(McHorney, Bricker, Robbins, et al., 2000) QUANT Diagnostic accuracy	SWAL-QoL reliability and range of skewness.	106 adults with mixed dysphagia causes.	SWAL-QoL	-	35/42 (83%)

(McHorney et al., 2002) QUANT Diagnostic case control	Report on reliability of SWAL-QoL and SWAL-CARE.	386 adults; dysphagia of mixed causes; 40 controls.	SWAL-QoL	-	37/42 (88%)

Note. Amyotrophic lateral sclerosis (ALS), Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R), Australian Therapy Outcome Measures for Speech and Swallowing (AusTOMS), Centre of Epidemiological Studies Depression Scale (CES-D), cerebral palsy (CP), cerebrovascular accident (CVA) Chest Pain Questionnaire (CPQ), Chinese Version of the Swallowing Quality of Life Questionnaire (CSWAL-QoL), chronic obstructive pulmonary disease (COPD), coblation-assisted endoscopic cricopharyngeal myotomy (CAECPM), Communicative Participation Item Bank (CPIB), Disability-Goal-Handicap Scale (DGH Scale), Dysphagia in Multiple Sclerosis (DYMUS), Dysphagia Risk Assessment for Community Dwelling Elderly (DRACE), Dysphagia Severity Scale (DSS), Eating Assessment Tool (EAT-10), eosinophilic oesophagitis (EOE), fibreoptic endoscopic evaluation of swallowing (FEES), Functional Oral Intake Scale (FOIS), gastrojejunostomy tube (GJT), Hospital Anxiety and Depression Scale (HADS), Huntington Disease Health Related Quality of Life Measure (HDQLIFE), idiopathic Parkinson's disease (IPD), M.D. Anderson Dysphagia Inventory (MDADI), mitochondrial DNA polymerase gamma (POLG), motor neuron disease (MND), multiple sclerosis (MS), neuromuscular electrical stimulation (NMES), non-randomised control trial (non-RCT), Parkinson's Disease (PD), Parkinson's Disease Questionnaire-39 (PDQ-39), qualitative study (QUAL), Quality of Care in Swallowing Disorders Survey (SWAL-CARE), quality of life (QOL), quantitative study (QUANT), randomised control trial (RCT), repetitive transcranial magnetic stimulation (rTMS), Short Form Health Survey 8 (SF-8), Short Form Health Survey 12v2 (SF-12), Short Form Health Survey 36 (SF-36), Stoke Specific Quality of Life Assessment (SS-QOL), submental sensitive transcutaneous electrical stimulation (SSTES), surface electromyography (sEMG), Swallow Strengthening Oropharyngeal Program (Swallow STRONG), Swallowing Quality of Life Questionnaire (SWAL-QoL), Sydney Swallowing Questionnaire (SSQ), systematic review (SR), tongue pressure strength and accuracy training (TPSAT), transcortical direct current stimulation (tDCS), University of Washington Quality of Life Questionaire-4 (UW-QOLQ), video-assisted swallowing therapy (VAST), Voice Handicap Index (VHI), Voice Related Quality of Life (VRQOL).

S4 (Supplementary File 4)

Analysis of Review Studies

Reference	Aim	Included studies	Population included	Limitations/ gaps in the review
(Carneiro et al., 2013)	SWAL-QoL and Parkinson's.	2 cohort studies.	People with dysphagia resulting from Parkinson's.	Only included 2 studies, included studies specifically about the SWAL-QoL and dysphagia resulting from Parkinson's.
(Jones et al., 2018)	HRQOL and oropharyngeal dysphagia.	35 studies (31 case series and 4 pseudo randomised).	People with oropharyngeal dysphagia; mixed causes of dysphagia: neck cancer, CVA, Parkinson's.	Papers only included if in English, oesophageal dysphagia was excluded, and authors of included studies were not contacted.
(Katzberg & Benatar, 2011)	PEG and QoL in ALS.	11 non-RCTs and 4 case control studies.	People with ALS or MND.	Did not include dysphagia of other causes, and only looked at the impact of tube feeding.
(Klinke et al., 2013)	Views on eating difficulties after a CVA.	33 case studies and case series studies.	People with dysphagia after CVA.	Quality of results was based on the types of analytical questions asked, and only included participants with dysphagia after CVA.
(Langmore et al., 2006)	PEG and QoL in ALS.	11 case or cohort studies.	People with ALS or MND.	Uncontrolled studies not included, and only included studies where ALS/MND was the cause of dysphagia.
(Li & Deng, 2019)	Acupuncture and traditional swallowing therapy.	17 RCTs.	People with dysphagia post CVA.	Heterogeneity and publication bias observed. The long-term curative effects of acupuncture combined with swallowing training could not be evaluated because all of the studies included reported only short-term effects.
(Swan et al., 2015)	Texture-modified foods and HRQOL.	8 studies (2 RCTs and 6 non-RCTs).	People with oropharyngeal dysphagia; mixed causes.	Small number of studies, the heterogeneity of population, the study design, lack of standardised terminology.
(Verdonschot et al., 2017)	Oropharyngeal dysphagia and depression/ anxiety.	24 studies (15 cross sectional, 5 prospective, 2 retrospective, and 2 case control studies).	People with oropharyngeal dysphagia; mixed causes: CVA, cancer.	Search strategy included mesh terms and limited free-text terms and grey literature was not included.

Note. *Amyotrophic lateral sclerosis (ALS)*, cerebrovascular accident (CVA), health related quality of life (HRQOL), *motor neuron disease (*MND), non- randomised control trial (non-RCT), percutaneous endoscopic gastrostomy (PEG) quality of life (QoL), randomised control trial (RCT) Swallowing Quality of Life Questionnaire (SWAL-QoL).

S5 (Supplementary File 5)

Assessment Items Implemented for Quality of Life

Assessment implemented	Study
Assessment items examining either quality of life or a domain of quality of life	
SWAL-QoL	(Alali et al., 2018; Argolo et al., 2013; Arslan et al., 2019; Athukorala et al., 2014; Ayres et al., 2017; Ayres et al., 2016; Bahceci et al., 2017; Byeon, 2019; Carneiro et al., 2014; Colpaert et al., 2017; Da Costa Franceschini & Mourao, 2015; de Faria Gaspar et al., 2015; Diniz et al., 2018; Frost et al., 2018; Hagglund et al., 2019; Heijnen et al., 2012; Hong & Yoo, 2017; Jin et al., 2020; Leow et al., 2010; Liu et al., 2018; Liu et al., 2019; Luchesi & Silveira, 2018; Manor et al., 2013; Manor et al., 2018; Moon et al., 2018; Paris et al., 2013; Pitts et al., 2019; Plowman-Prine et al., 2009; Pontes et al., 2017; Printza et al., 2020; Reyes et al., 2015; Rogus-Pulia et al., 2016; Sanchez-Kuhn et al., 2019; Song et al., 2020; Sundstedt et al., 2016; Tabor et al., 2016; Unluer et al., 2019; Verin et al., 2011; Vieira et al., 2018; Vogel et al., 2017; Wegner et al., 2018; Xia et al., 2016; Yi et al., 2019; Zhang et al., 2016)
EAT-10	(Alali et al., 2018; Arslan et al., 2019; Finger et al., 2019; Frost et al., 2018; Kelly et al., 2013; Malandraki et al., 2016; Malandraki et al., 2014; Printza et al., 2020)
Kuchi-kara Taberu Index	(Aruga et al., 2018)
Disability-Goal-Handicap Scale	(Ekberg et al., 2002; Farri et al., 2007)
Hospital Anxiety and Depression Scale	(Chen et al., 2018; Verdonschot et al., 2016)
Functional Oral Intake Scale	(Verdonschot et al., 2013)
Chest Pain Questionnaire	(Eslick & Talley, 2008)
Swallowing Disturbance Questionnaire	(Manor et al., 2018)
Sydney Swallowing Questionnaire	(Chen et al., 2018)
Communicative Participation Item Bank	(McAuliffe et al., 2017)
Dysphagia Risk Assessment for Community Dwelling Elderly	(Morisaki, 2017)
Short Form Health Survey (SF-8, SF-12, SF-36)	(Chen et al., 2009; Morisaki, 2017; Roy et al., 2018)
M.D. Anderson Dysphagia Inventory	(Chen et al., 2009; Chen et al., 2018; Roy et al., 2007; Roy et al., 2018)
Australian Therapy Outcome Measures for Speech and Swallowing	(Vogel et al., 2014)
Voice Related Quality of Life	(Turley & Cohen, 2009)
Centre of Epidemiological Studies Depression Scale (CES-D)	(Turley & Cohen, 2009)
Condition specific assessments examining quality of life	
Huntington Disease Health Related Quality of Life (HDQLIFE) Measure	(Carlozzi et al., 2016)
The Eosinophilic esophagitis (EOE) Adult Quality of Life Questionnaire	(Hewett et al., 2016)
Parkinson's Disease Questionnaire-39 (PDQ-39)	(Plowman-Prine et al., 2009)
Stoke Specific Quality of Life assessment (SS-QoL)	(Kang et al., 2012)

S6 (Supplementary File 6)

Studies found in August 2020

Study	Aim	Population	Method	Result
(Byeon, 2020)	Effects of Mendelsohn manoeuvre and NMES on swallowing and QoL.	N = 43, CVA.	Swallow assessed using FDS and QoL assessed using SWAL-QoL.	Participants who had both NMES and Mendelsohn had highest FDS and SWAL-QoL scores than participants who had one therapy.
(Chan et al., 2020)	QoL in patients with PD using the CSWAL-QoL.	N = 67, PD.	The CSWAL-QoL and Geriatric Depression Scale to assess QoL and depression.	Sleep, fatigue, eating duration and communication were the most severely affected by PD. Significant link between swallowing and depression.
(Covello et al., 2020)	Evaluate the oral health status, dysphagia, and QoL of people with MS.	N = 101, MS.	Assessed on DYMUS and the OHIP-14.	15% of people needed to pause when eating, 25% had difficulty swallowing. Dysphagia impacted on QoL "although not more than the disease itself" (p. 7).
(Kim et al., 2019)	Meaning of life impacts on the relationship between depression and QoL in people with dysphagia?	N = 90, CVA, degenerative disease, TBI, or nervous disorder.	SWAL-QoL measured QoL, CES-D measured depression, and PIL measured meaning of life.	Meaning of life had mediating effect on the QoL and depression of people with dysphagia.
(Padilla et al., 2019)	Explore QoL in Hispanic New Mexicans with dysphagia.	N = 7, CVA, muscle weakness, CP, Guillain-Barré syndrome, TBI.	SWAL-QoL, Neuro-QOL, interviews (interviews only with participants with acquired dysphagia).	QoL categorised as an emotional experience (themes: distrust, fear, frustration, acceptance, triggers, and impacts).
(Pilz et al., 2020)	To describe swallowing related QoL in people with DM1 and examine its association with swallowing and disease severity.	*n* = 75 with DM1, *n* = 25 controls; DM1.	SWAL-QoL.	SWAL-QOL scores were significantly lower for those with DM1 than controls.
(Ronnefarth et al., 2020)	Determine impacts of dysphagia in cerebellar ataxia patients on QoL.	N = 119, cerebellar ataxia.	SWAL-QOL.	Participants with dysphagia had significantly reduced QoL over those without dysphagia.
(Shune & Namasivayam-MacDonald, 2020)	Type/extent of burden felt by older adults caring for their spouse with dysphagia.	N = 422 older adults with dysphagia and their spouse.	National Health and Aging Trends Survey (population based survey).	Older adults caring for their partners with dysphagia were more likely to feel emotional burden. They also reported feelings of loneliness, depression, financial difficulties, and physical difficulties.
(Swales et al., 2020)	Participation and psychological impacts of dysphagia and	N = 78, PD.	Mixed-methods survey.	Emotional impacts of swallowing changes: frustration, annoyance, embarrassment, loneliness,

Study	Aim	Population	Method	Result
	communication difficulties in PD.			depression, anxiety, self-consciousness, adjustment/ acceptance. "don't enjoy eating out as much…self-conscious in company" (p. 5).
(Toledo-Rodríguez et al., 2019)	How QoL is perceived in people with neurogenic dysphagia in Chile.	*n* = 27, neurogenic dysphagia (CVA, PD, HD, MS, Encephalo-cranial trauma), *n* = 113 controls.	SWAL-QoL-CH (Chile).	Participants with dysphagia presented with significant differences in all SWAL-QoL-CH domains.

Note. Centre of Epidemiological Studies Depression Scale (CES-D), cerebral palsy (CP), cerebrovascular accident (CVA), Chinese Version of the Swallowing Quality of Life Questionnaire (CSWAL-QoL), Myotonic Dystrophy (DM1), Dysphagia in Multiple Sclerosis (DYMUS), Functional Dysphagia Scale (FDS), Huntington Disease (HD), Oral Health Impacts Profile (OHIP-14), *multiple sclerosis (*MS), neuromuscular electrical stimulation (NMES), Quality of Life in Neurological Disorders (Neuro-QoL), Parkinson's Disease (PD), Purpose in Life Test (PIL), quality of life (QOL), Swallowing Quality of Life Questionnaire (SWAL-QoL), Swallowing Quality of Life Questionnaire- Chile (SWAL-QoL-CH), traumatic brain injury (TBI).

Chapter 3: A Review of the Impact of Food Design on Mealtimes of People with Swallowing Disability

The scoping literature review presented in Chapter 2 examined the impacts of dysphagia and its interventions on the quality of life, participation, and inclusion of people with dysphagia. The review highlighted that dysphagia negatively impacts on quality of life, particularly as the severity of the condition increases. Furthermore, most dysphagia interventions, other than texture-modified foods (one of the most common dysphagia interventions) and enteral tube feeding, had a positive impact on quality of life. Texture-modified foods reduced quality of life as the poor visual appeal reduced mealtime enjoyment and increased isolation. Based on these findings, a narrative review of the literature was conducted in relation to the impact of food design strategies (food structure and visual appeal) on the mealtime experience for people with dysphagia. 3D food printing was examined in this review as a tool that may help to improve the visual appeal of texture-modified food for people with dysphagia. A narrative review method was selected over a systematic review, in the knowledge of there being little controlled research in this area to date and a need to explore, describe, and synthesise relevant research. This narrative review is presented in Chapter 3 of this thesis and has been published as an Open Access article in the *International Journal of Food Design*. Material is copyrighted by the journal and use of this article within a thesis is permitted under the Creative Commons Attribution Non-Commercial No Derivatives Licence (CC BY-NC-ND).

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REBECCA SMITH
The University of Technology Sydney

LUCY BRYANT
The University of Technology Sydney

COURTNEY REDDACLIFF
The University of Technology Sydney

BRONWYN HEMSLEY
The University of Technology Sydney

A review of the impact of food design on the mealtimes of people with swallowing disability who require texture-modified food

ABSTRACT

Texture-modified foods are a common component of interventions provided to people with dysphagia (swallowing disorders) to maintain their respiratory health, nutritional health and to reduce the risk of aspiration-related illness or choking on food. However, the unsightly and unappetizing appearance of texture-modified foods may negatively impact on the mealtime experience and acceptance of texture-modified foods of persons with dysphagia. The aim of this review was to determine

KEYWORDS
dysphagia
food design
texture-modified diet
mealtimes
3D food printing
swallowing

what is known about the impact of specific elements of food design – food structure and visual appeal – on the mealtime experiences of people with dysphagia. This review of 35 studies presents evidence on how the physical characteristics of texture-modified foods for people with dysphagia can be considered during food production, formulation or service to improve their mealtime experience. Overall, the visual appeal, texture, taste, aroma, temperature, mealtime environment and mealtime assistance all impact upon mealtime experiences and should be considered carefully in the design of a person's mealtime plan and food-related dysphagia interventions to improve their mealtime-related quality of life. Further research needs to include the views of people with dysphagia, particularly those with lifelong conditions, who might require texture-modified food for an extended period over their lifespan.

INTRODUCTION

Dysphagia, or difficulty swallowing, affects approximately 8 per cent of the world's population (Cichero et al. 2017) and is highly prevalent in people with lifelong and acquired health conditions (e.g. stroke, Parkinson's, cerebral palsy, intellectual disability) (Kumar 2010). Along with its negative impacts on nutritional health, dysphagia and its interventions can negatively impact the person's quality of life, both by the need for restrictions in food choices and by reduced independence, autonomy and self-determination in reliance on others for mealtime assistance (Balandin et al. 2009; Hall and Wendin 2008).

Modifying the texture of food is one of the most commonly used first-line interventions in dysphagia management (Robbins et al. 2002). The International Dysphagia Diet Standardisation Initiative (IDDSI) classifies food and fluid according to texture into eight categories, with five of these relating to food: Level 7 Regular/Easy to Chew; Level 6 Soft and Bite-Sized; Level 5 Minced and Moist; Level 4 Pureed; and Level 3 Liquidized (Cichero et al. 2017). Recommendations for the IDDSI level of food texture required are based on both observational and instrumental assessments of the person's swallowing (Ricci Maccarini et al. 2007). Texture-modified diets, moving through the different levels from Soft & Bite-Sized to Pureed or Liquidized, understandably involve a substantial modification of the food's structure and appearance, affected by how it is processed (e.g. food processor, blender, cut up) and served (e.g. how it is served on a plate or in a bowl).

According to the IDDSI framework, Pureed or Liquidized foods are the most significantly modified food textures (Cichero et al. 2017). However, modifying a food's texture may not remove all the risks associated with swallowing, as pureed food may still pool in the person's neck (in the vallecular spaces) and increase their risk of choking (Gustafsson 1995). Furthermore, adding liquids to food to achieve the correct consistency may dilute the food's flavour and nutritional value, unless this is accounted for in the preparation (Keller et al. 2012; Cichero 2017). Poor acceptance of unappealing meals can reduce the person's food consumption and increase their risk of malnutrition (Keller et al. 2012). Furthermore, dissatisfaction with texture-modified food often leads to non-compliance with diet recommendations to avoid problematic food textures (Colodny 2005). Colodny (2005) reported that 39.7 per cent of participants with dysphagia rejected diet recommendations due to the food's structure or consistency, or taste. In the interviews, one participant with dysphagia stated, 'take that junk off my tray' (Colodny 2005: 66). Consequently, people with dysphagia may risk eating regular texture foods to maintain their quality of life or mealtime enjoyment, as one participant said: 'I'll take my chances, I don't want that horrible stuff' (Colodny 2005: 66).

Increased acceptance of texture-modified food may be achieved through improved food design (Hemsley et al. 2019). Food design is a broad field that encompasses 'design with food, design for food, food space design or interior design for food, food product design, design about food, and finally, eating design' (Zampollo 2016: 4). Thus, food design – more than the design of the food product – includes the design of tools used in the meal (e.g. cutlery), the mealtime environment (e.g. where the food is consumed) and the design of the social rituals of the meal (Zampollo 2016). The creation of texture-modified food for people with dysphagia relates to a process of design with food where decisions are made about the texture (food structure or consistency), taste, temperature, shape and colour of the food. It is important that the views of the person with dysphagia are considered when designing the food's structure or appearance to improve its acceptability.

Poor acceptability of texture-modified foods by people with dysphagia can be problematic for their mealtime engagement. For example, a person with dysphagia may feel isolated at social gatherings if they cannot eat what others are eating or if they fear choking on food in public (Balandin et al. 2009). In addition, attempts to improve mealtime experiences and inclusion for people with dysphagia should consider several elements of food design beyond the food, including food space design and eating design (Balandin et al. 2009; Reissig 2017). In all of these domains, the needs and preferences of the person with dysphagia must be considered, particularly for those receiving mealtime assistance as it can influence their mealtime pleasure (Reimer and Keller 2009).

The sensory appeal of texture-modified food also influences its acceptance by people with dysphagia (Reissig 2017). Spence et al. (2010) described the importance of a food's colour perceptually matching its intended flavour, as flavours are more likely to be identified correctly if presented in the colour of the original food product (e.g. red, strawberry-flavoured products being more identifiable). The plating of the food also influences the person's perception of the food. For example, if texture-modified food is typically plated in scoops to prevent mixing (Milte et al. 2017), the uniform nature of scoops for each item may disrupt the visual appeal of the meal and reduce interest.

Aguilera and Park (2017) conceptualized *food choice* for people with dysphagia in a model connecting convenience, health and mealtime pleasure (see Figure 1). Through their involvement in making food choices, people with dysphagia can be engaged in the process of designing the menu and selecting foods that are safe and enjoyable to eat. In the model, 'Convenience' refers to accessing food of the correct consistency for safe swallowing; 'Health' refers to food containing adequate nutrients for the consumer's needs, and 'Pleasure' refers to the enjoyment of food's sensory components. The interconnection of these concepts theoretically influences the person's overall mealtime experience.

The model of food choice could help guide an appreciation of literature pertaining to food structure for people with dysphagia on texture-modified diets. Therefore, the aim of this review was to determine what is known about the impact of food structure and composition, including its texture, appearance

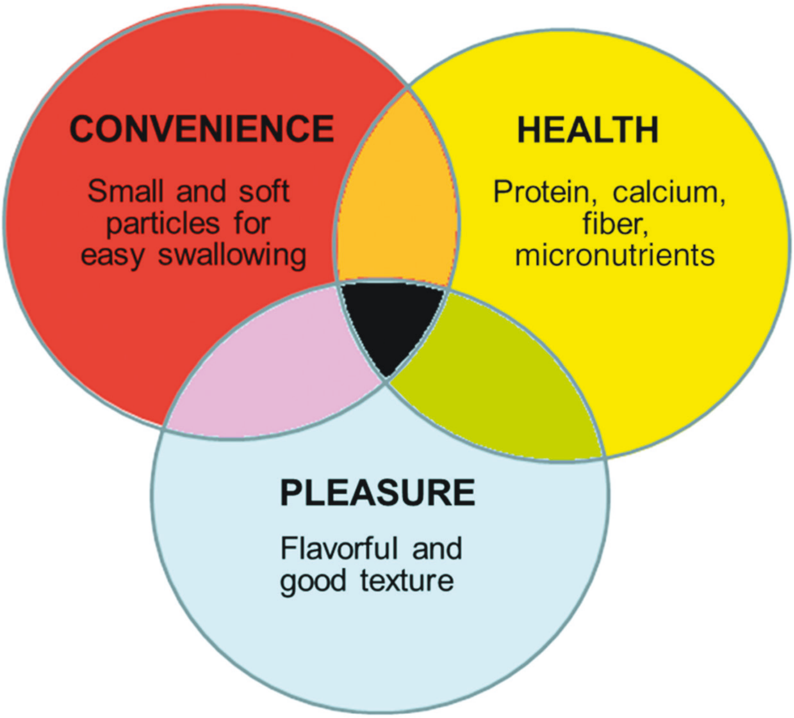

Figure 1: Drivers of Food Choice for People with Dysphagia. *Illustration from bottom-up approaches in the design of soft foods for the elderly (Aguilera and Park 2017: 155). Courtesy of Wiley-VCH Verlag GmbH & Co. KGaA. Reprinted with permission.*

and taste, on the food choices and experiences of people with dysphagia. The theoretical framework for the review recognized the interlinked drivers of food choice conceptualized in the Aguilera and Park (2017) model and how these might impact people with dysphagia. The findings of this review will help identify the gaps in knowledge and strategies for including people with dysphagia in the design of food structure and appearance that support their mealtime-related health and quality of life (Smith et al. 2022).

METHOD

In an emergent area of interdisciplinary research, involving fields of both food design and dysphagia management, a narrative review methodology was used. In July 2020, five databases (EMBASE, Medline, CINAHL, Web of Science and PsycINFO) were searched using combinations and permutations of terms related to dysphagia (e.g. dysphagia, swallowing disorder, deglutition disorder), food texture (e.g. puree, soft, minced and moist) and food structure and appearance (e.g. food shape/shaping, food mould, piping bag, 3D food printer, aesthetics). A copy of the full search strategy is available from the first author. Inclusion criteria were: (1) relates to dysphagia and the design of texture-modified foods, (2) is written in English and (3) is a full paper of original research, a critical review, commentary or editorial. While it is recognized that mealtime experiences are influenced by the emotional, social and cultural contexts of meals more broadly (Ochs and Shohet 2006), these wider concepts were only included in the review as they appeared in studies relating to people with dysphagia and their experiences of texture-modified foods.

Following the initial search, two raters (RS and BH) were involved in selecting studies at the title, abstract and full text stages with a third rater (CR) assisting to resolve disputes on inclusion. On study selection between the two raters, an inter-rater reliability rate of 0.97 was achieved, indicating almost perfect reliability (McHugh 2012). Cited sources and forward citations of included papers were searched for relevant studies, and Google Scholar was searched for relevant authors to locate additional studies. With a wide range of study designs included, narrative synthesis was used (Ryan and Cochrane Consumers and Communication Review Group 2013) to examine the relationships of concepts in the Aguilera and Park (2017) Drivers of Food Choice model.

RESULTS

The initial database search located 276 articles. Another 23 relevant papers were found through cited sources, forward citations and Google Scholar searches. In total, 35 studies were included, and the characteristics of included studies are in Table 1. Figure 2 is a flowchart outlining the steps for study inclusion.

Food preparation

Techniques for creating texture-modified foods

Various technologies can be used to create the desired food texture for people with dysphagia and improve the convenience and pleasure of meals (Aguilera and Park 2017). High-pressure food processing is widely used to create texture-modified foods (Cichero 2017); however, other techniques used include ultrasound, thermal processing and pulsed electric fields (Sungsinchai et al. 2019). The success of texture modification is influenced by the type of food, its size and how it is prepared when raw (Sungsinchai et al. 2019). The most appropriate food and texture modification methods must be used to optimize the safety of texture-modified food.

Gels are also used to create the correct food consistency and to hold the shape of pureed food for people with dysphagia (Hori et al. 2015). Hori et al. (2015) examined the level of tongue pressure required to swallow different gels and reported that as gel consistency increased, so did the amplitude and duration of tongue pressure required and the amount of stress exerted by the tongue. However, the duration of swallow was not impacted (Hori et al. 2015). Hence, gel consistencies must match the tongue strength of an individual to optimize mealtime engagement.

Techniques used to create texture-modified food also impact mealtime experience and mealtime safety. Ilhamto et al. (2014) reported that people did not consistently use standardized recipes or governance documents and instead used experimentation to achieve the correct food consistency or to meet individual preferences. Consequently, food no longer met the standard texture requirements (Ilhamto et al. 2014). This highlighted the difficulties associated with creating food that is aesthetically pleasing, meets the individual's preferences and adheres to texture modification guidelines.

Table 1: Included studies.

First author, year	Aim to determine	Methods and participants	Relevant findings	Further research
Aguilera, 2017	Food choice for the elderly	Edited book section	Food choice driven by convenience, health and pleasure. Changing the food properties can meet needs	Examination of functional/nutritional ingredients
Balandin, 2009	How adults with cerebral palsy experience mealtimes	Qualitative interviews. Adults with cerebral palsy (N = 32)	A good relationship with support staff providing mealtime assistance essential for enjoyable mealtimes	Larger participant group
Burger, 2019	Texture-modified diet best practice accessibility within German aged care homes	Quantitative cross-sectional survey. N = 590 aged care homes	84.2% separated texture-modified food on plates. Only 27.9% reshaped food	Develop a best practice approach for texture-modified food and improve implementation
Cassens, 1996	Amount of pureed food eaten with 3D food presentation	Mixed methods. Aged care residents (N = 18)	15% increase in food intake, 41% increase in caloric intake, 36% increase in protein intake	Long-term impacts of 3D food presentation
Cichero, 2015	Needs of hospitalized patients with dysphagia	Edited book section	Food should be of correct texture, nutrient-dense, flavoursome and appealing	N/A
Cichero, 2017	Impacts of taste and texture on swallowing	Review	Modify textures to meet chewing/swallowing ability. Label food using IDDSI	Novel strategies of food appearance and structure promoting variety and nutrition
Dick, 2019	3D food-printing application with meat	Review	3D-printed meat could help people with dysphagia	Better understanding of meat properties for printing
Ettinger, 2014	How older adults like modified food	Quantitative taste testing. People with dysphagia (n = 12), people without dysphagia (n = 45)	Ratings significantly different between groups. People without dysphagia cannot be used instead of people with dysphagia	Cognitive function assessment to control for cognitive impairments

First author, year	Aim to determine	Methods and participants	Relevant findings	Further research
Farrer, 2016	Food intake changes through food moulds	Quantitative intervention study. Aged care residents (*N* = 65)	Non-statistical difference in food wastage or satisfaction with moulds	Larger cohort studies
Germain, 2006	Nutritional care programme's impact on food intake	Quantitative intervention study. Aged care residents with dysphagia (*N* = 15)	Participants gained weight, increased intake of energy, protein, fats, phosphorus, potassium, calcium, magnesium, vitamin D, zinc, vitamin B12	Larger participant groups. Evaluate overall health status
Hemsley, 2019	Review 3D food-printing studies and its use in dysphagia management	Review	Sixteen papers included. None examined the feasibility of 3D-printed food for dysphagia	Reactions of people with dysphagia to 3D-printed foods. Barriers/facilitators to use
Higashiguchi, 2013	'iEat®' impact on consumption rate, nutritional intake and satisfaction	Quantitative intervention study. Aged care residents (*N* = 57)	'iEat®': Significant higher scores on appearance, joy of eating, satisfaction of shaped food	N/A
Hori, 2015	Gel consistency's impact on tongue pressure during swallow	Quantitative tongue pressure test. Adults without dysphagia (*N* = 15)	Tongue pressure required increased as gel consistency increased. Duration of swallow not impacted	Bolus textures prepared for a natural swallow
Hung, 2011	Understand personhood during mealtimes	Qualitative interviews. Aged care residents with dementia (*n* = 20), carers (*n* = 4)	Dining experience related to pacing, providing assistance, environmental stimulation/utilization, respectfulness, validation of feelings and connecting with others	Include more people with dementia in research. Translate theoretical basis into practical applications
Hung, 2015	Care facility dining room renovation influences residents' experiences	Mixed: focus groups, environmental assessment Care facility staff (*N* = 14)	Renovations improved atmosphere, social interaction, autonomy, independence, lighting. Residents stayed in the dining room longer, 72% gained weight	Environmental changes influence cultural mealtime components

Continued

Table 1: Continued

First author, year	Aim to determine	Methods and participants	Relevant findings	Further research
Ilhamto, 2014	Challenges and practices of pureed food production in care facilities	Qualitative interviews. Nutrition managers (*n* = 27), cooks (*n* = 26)	Standardized recipes/governance documents not consistently followed. Inconsistent terminology between sites	Consistent terminology. Strategies to improve visual appeal of food
Keller, 2014	Perceptions of pureed food: experiences, impacts on quality of life. Strategies to improve texture-modified food	Qualitative interviews. People with dysphagia (*N* = 15)	Food had poor sensory appeal, lacked variety and inconsistent quality. None enjoyed the food but appreciated oral meals and knew food was necessary	N/A
Lepore, 2014	Plating impacts the identification and acceptability of puree	Quantitative food rating. Young adults (*n* = 97), older adults (*n* = 70)	Younger adults identified more pureed food. Scooped purees were more accepted. Older people preferred the taste of scooped food	Pureed food acceptability. Impact of shaping food on food intake
Liu, 2017	Creation of accurate 3D food prints	Review	Printing challenges: accuracy, productivity, creating colourful/flavourful food	Precision, speed and productivity, nutritional benefits of 3D food printing
Liu, 2018	Develop a 3D food printer for fibrous meat	Quantitative experimental testing	Printer developed: addressed storage and food variety concerns	N/A
Milte, 2017	Mealtime experiences of people with cognitive impairment and carers	Qualitative interviews. People with cognitive impairment and carers (*N* = 19)	Barriers faced in receiving appealing and nutritional meals. Participants lost control/choice with dysphagia	Improving mealtime quality of life within budgetary boundaries
Okkels, 2018	Most liked modified snacks based on flavour and sensory properties	Quantitative ratings. Adults with dysphagia (*N* = 30)	Cold and sweet foods were most liked. Flavour and appearance were equally important	Larger participant group, longer trial period
Ott, 2019	Impact of Biozoon® texture-modified, nutritionally enriched and reshaped food	Quantitative intervention study. Aged care residents (*N* = 16)	Significant increase in energy/protein intake and in body weight. Some participants did not like the food	Larger participant groups to confirm effects

First author, year	Aim to determine	Methods and participants	Relevant findings	Further research
Piwnica-Worms, 2010	Flavour processing in semantic dementia using a novel flavour assessment	Quantitative flavour test. People with semantic dementia (n = 3), logopenic primary progressive aphasia (n = 1)	Participants had significant difficulty determining the congruence of flavour combinations and identifying flavour correlating with odour identification	Chemosensory dysfunction correlates with neurodegenerative conditions
Pouyet, 2014	Finger food attractiveness to people with Alzheimer's disease	Quantitative paired comparison testing. People with Alzheimer's disease (N = 114)	Finger foods with sauce chosen more. Food shape did not significantly impact food chosen first or amount eaten. Food with two layers chosen more frequently	Food attractiveness, impact of cognitive and sensory abilities
Reilly, 2013	Molecular gastronomy to improve the texture of dysphagia-safe food	Quantitative sensory testing. University students (N = 60)	Spherification, gelification, emulsification, food moulds and piping bags improved food appeal	Benefits of techniques versus oral supplements
Roberts, 2011	Large versus small dinner settings: impact of care homes on mealtime interactions	Qualitative case study. Observations and interviews. Care staff (N = 2)	Six-person lunch allowed for shared dining experiences, minimal noise/ distraction, choice and resident-led conversation	Therapeutic dining environments for people with dementia
Ruigrok, 2006	Improving mealtimes and dignity in assisted feeding	Quantitative case study. Aged care residents (N = 23)	Residents valued socializing with staff. Background music relaxed them. Mealtime assistance more dignified when staff sat at their level and asked for permission	Examine unappealing minced meals, positioning, dental care plans, social grouping influence
Stahlman, 2000	Views of moulded pureed fruits and their influence of visual appeal	Quantitative taste test. Adults with dysphagia (n = 2), adults without dysphagia (n =12)	Food moulds did not positively influence taste, liking, texture, appearance, ease of chewing or swallowing	Better understanding of food mould impacts

Continued

Table 1: Continued

First author, year	Aim to determine	Methods and participants	Relevant findings	Further research
Stahlman, 2001	Perceptions of pureed food and ease of chewing/swallowing for people with/without dysphagia using thickeners and moulds	Quantitative taste test. Adults with dysphagia (*n* = 15), adults without dysphagia (*n* = 15)	Participants with dysphagia found moulded food significantly more difficult to chew and swallow. Moulded food was not seen favourably	Food moulds with a larger participant group
Sungsinchai, 2019	Use texture modification technologies for different foods	Review	Technologies used: high pressure processing, high hydrodynamic pressure, ultrasound, gamma irradiation and pulsed electric field	Non-traditional texture modification methods and their combined use
Tan, 2018a	Review 3D printing studies, food modification and use of hydrocolloids for printability	Review	Hydrocolloids improved puree printability and fidelity. No single solution for all foods. Each food is different	How hydrocolloids are chosen, optimal hydrocolloid amounts, minimum hydrocolloid content
Tan, 2018b	Food ink formation using texture modifiers	Review	Hydrocolloids improve food printability. Future 3D food printers should be efficient, able to cook, continuously print, easy to maintain	Types of hydrocolloids, optimal hydrocolloid ratios, minimum hydrocolloid amount needed
Ullrich, 2014	Mealtime experiences of older people with dysphagia	Qualitative interviews, observations. Aged care residents and staff (*N* = 35)	Participants with dysphagia separated from others. Non-moulded food viewed negatively. Interactions increased with moulded food	Provide nutritious, socially appropriate, tasty food
de Villiers, 2019	Impacts of production methods on bolus properties	Quantitative experimental testing	Heating food increased viscosity, no longer smooth. Aeration created safe room temperature boluses	Impacts of body temperature and saliva on food consistency

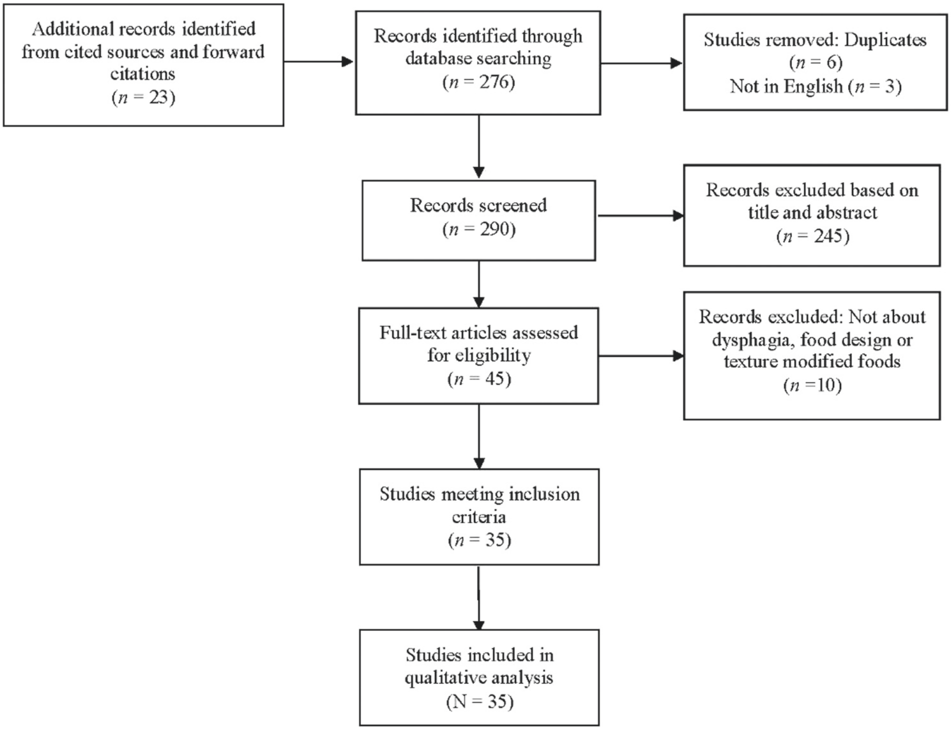

Figure 2: Study inclusion process.

Designing sensory appeal: Taste and aroma

When eating, flavour is determined not only through taste but also through food aromas and the chewing process where aerosols are produced and registered in the frontal cortex of the brain (Cichero 2015). This process may drive mealtime pleasure (Aguilera and Park 2017). Texture-modified foods require less chewing, meaning that fewer aerosols are produced, thereby reducing the sensory experience. Keller and Duizer (2014) reported that reduced aroma and taste led to reduced interest in food, which could be problematic if the food was already diluted with liquid to meet the texture requirements. In a study of aged care residents, one resident with dysphagia descried the food as 'horrible […] tastes just like chalk', and participants added their own condiments to food to increase their interest (Ullrich et al. 2014: 233). Cichero (2017) also reported that using natural flavours, including garlic, black pepper, thyme and ginger, may increase food intake in elderly people by up to 25 per cent. Thus, manipulating food flavours may increase mealtime enjoyment for people with dysphagia, and these strategies should also be promoted within the community (Cichero 2017).

The impact of dementia on flavour perception was discussed by Piwnica-Worms et al. (2010). In their study, three adults with dementia and six age-matched people without dementia tasted individual jellybeans of one flavour and jellybeans of mixed flavours. Participants with dementia showed a significantly reduced ability to identify flavour combination compatibility and a reduced ability to name single flavours when compared to participants without dementia (Piwnica-Worms et al. 2010). Many people with dementia have dysphagia, impaired flavour-processing skills and limited contextual food knowledge; hence texture-modified foods require other markers for food identification (e.g. matching the food's appearance and smell) (Piwnica-Worms et al. 2010).

Flavour preferences may assist in meeting a person's nutritional needs in dysphagia management (Okkels et al. 2018). In a pilot study, Okkels et al. (2018) reported that 55 older adults tasted different texture-modified snack foods and then completed a survey on their preferences. Cold, sweet foods were the most 'well liked' (e.g. vanilla ice cream), while the 'least liked' were pumpkin, carrot and clear soups. There was also a strong correlation between fat content, energy intake and how much the flavour was liked (Okkels et al. 2018). The authors concluded that snack food flavours are important for people with dysphagia and that high-energy sweet snack foods may increase nutritional consumption and mealtime engagement (Okkels et al. 2018).

Designing nutritious food

According to the model of food choice used in this review (see Figure 1), the nutritional value of food can also be modified to maintain health in dysphagia management. Many people with dysphagia fatigue during mealtimes and may require nutritionally dense meals to reduce the risk of malnutrition or dehydration. This can be achieved by adding food enrichers, including protein powder or butter (Cichero 2015). Similarly, microgels or soft gels can be added to carry proteins, fats and fibre in texture-modified food (Aguilera and Park 2017). This shows how the nutrients of texture-modified foods can be increased for the person to receive adequate energy (Aguilera and Park 2017).

Gels were used by Ott et al. (2019) to modify the protein content and shape of texture-modified food. Participants with dysphagia received food that was shaped using food moulds and Biozoon® Smoothfood texturizers (Biozoon 2020) and enriched with protein powder or rapeseed oil for six weeks to determine if it improved their nutritional status (Ott et al. 2019). Participants' energy and protein intake significantly increased during the six-week trial compared to a six-week period of receiving regular texture-modified food (Ott et al. 2019). In regard to enjoyment, five participants enjoyed the trial diet, while one did not like the taste (Ott et al. 2019). As the study examined shape and nutrition modification concurrently, the authors could not determine which factor had a greater impact on mealtime engagement (Ott et al. 2019). They reported that an increased protein intake may have only occurred due to the enriched protein content of the food, not as a result of increased mealtime enjoyment.

Food formulation

Designing the visual appearance of texture-modified food

The visual appeal of texture-modified food and the ability to discern a food based on its appearance are important for the acceptance of food and mealtime enjoyment (Cichero 2015). Keller and Duizer (2014) examined how people on texture-modified diets experienced food presentation in aged care settings. Residents on a pureed diet considered their food plain, and adding sauce and/or coloured spices improved the food's appearance. In interviews with residents who had a cognitive impairment, Milte et al. reported that one participant described the presentation of pureed food as 'pulverized slop […] it was so disgusting' (2017: 55). Furthermore, in a cross-sectional survey of German aged care homes, 84.2 per cent of aged care facilities served pureed food items separately on the plate, but only 27.9 per cent reshaped the food (Burger et al. 2019). Most facilities in the study did not modify the food's structural shape to increase its visual appeal; they simply modified its texture to the correct texture and ensured foods were served separately on the plate. This may have been due to a lack of resources or knowledge, but it likely impacted the mealtime engagement of residents (Burger et al. 2019).

Poor plating of food, or lack of attention to its structure and shape, can also make it difficult for aged care staff providing mealtime assistance to accurately identify texture-modified food, which reduces opportunities for interaction between the person with dysphagia and the staff (Ullrich et al. 2014). Pouyet et al. (2014) examined how the appearance of texture-modified finger food impacted the enjoyment of meals of 114 people with Alzheimer's disease. In the study, foods that were layered and had sauce were more visually appealing than foods presented in one layer or without sauce (Pouyet et al. 2014). Milte et al. (2017) discussed the loss of mealtime choices linked to poor food presentation, noting that adults with cognitive impairment reported little variety in options presented (i.e. all items looked the same) as few people required texture-modified foods at their home. This reduced their mealtime pleasure and their overall opinions of texture-modified foods (Milte et al. 2017).

Cassens et al. (1996) explored the 3D presentation of texture-modified foods with thickeners (i.e. to retain the shape created). In a mixed-methods study with eighteen residents in aged care with swallowing difficulties, 3D food presentation strategies resulted in a 15 per cent increase in food intake, a 41 per cent increase in calorie intake and a 36 per cent increase in protein intake (Cassens et al. 1996). However, results may not have been due to the presentation alone; during the trial, participants also received more attention from the staff who potentially encouraged them to eat more food.

In a study comparing the opinions of twelve people with dysphagia and 45 people without dysphagia, Ettinger et al. (2014) explored the acceptability of pureed turkey and pureed carrot samples, which were rated on visual appearance and flavour. There was no significant difference between the ratings of appearance or flavour for the carrot and turkey samples for the twelve participants with dysphagia. In contrast, there was a significant difference in the ratings from participants without dysphagia for the appearance and flavour of pureed carrot and for the flavour of pureed turkey samples (Ettinger et al. 2014). Participants with dysphagia gave samples a higher rating, indicating they liked the food more than people without dysphagia did. The positive correlation of food appearance and flavour ratings in this larger participant group demonstrates the potential benefits of presenting pureed food in appealing ways to improve flavour perceptions (Ettinger et al. 2014). However, the differences in results between participant groups show that the opinion of people without dysphagia cannot be used in place of the opinion of people with dysphagia, who should be consulted about their preferences (Ettinger et al. 2014).

Several technologies and food preparation techniques that consider the structure and visual appeal of food are featured in literature and are described below.

Food moulds. Food moulds are generally silicon moulds into which puree food is placed to create a desired shape. Despite their commercial availability (see Flavour Creations 2020 for an example), there is limited research evaluating the effectiveness of food moulds for mealtime enjoyment. Stahlman et al. (2000) examined the perceptions of people (*N* = 14) towards moulded puree compared to puree scooped into a bowl. On a rating scale from 'extreme dislike' to 'extreme like', moulded peach puree was liked significantly less than scooped puree by participants without dysphagia. Participants with dysphagia also found moulded puree more difficult to swallow (Stahlman et al. 2000). A second study by Stahlman et al. (2001) compared the acceptability of moulded food for participants with and without dysphagia (*N* = 30). Both groups rated the moulded puree significantly lower on satisfaction than the scooped puree (Stahlman et al. 2001), suggesting that food moulds did not positively influence the perceptions of pureed food.

Other studies have reported mixed results on the effectiveness of food moulds. In a sample of 65 participants, Farrer et al. (2016) found no significant differences in food waste or satisfaction between participants who received moulded food and those who did not. In a larger study of 167 young and old adults without dysphagia, Lepore et al. (2014) found that food moulds helped younger people identify food; however, participants preferred scooped food. In contrast, Higashiguchi (2013) found that moulded meals led to a greater satisfaction with food appearance and the joy of eating. Similarly, Germain et al. (2006) found that participants who received moulded food gained weight and experienced an increased energy and nutrient intake. Ullrich et al. (2014) also reported that moulded food assisted the staff in describing the food to residents. These mixed results demonstrate the need for further studies verifying the benefits of food moulds.

3D-printed foods. 3D food printing is an additive manufacturing process where food is printed in layers to create shapes (Hemsley et al. 2019). The PERFORMANCE Project aimed to develop visually appealing meals using 3D printing for elderly people with dysphagia (Liu et al. 2017; RTDS Group 2015). A literature review by Liu et al. (2017) described the results of a survey conducted with aged care residents who tried 3D-printed food (Lunardo cited it Liu et al. 2017). Results indicated that 79 per cent found the food comparable to scooped food; 43 per cent preferred 3D-printed food over scooped food; and 54 per cent believed the texture was good (Lunardo cited in Liu et al. 2017). However, no results from this project have been published as original data in a peer-reviewed journal (Hemsley et al. 2019); so research is needed to determine the acceptability of 3D-printed foods in people with dysphagia.

There are five literature reviews examining 3D food printing and its impact on mealtime experience for people with dysphagia. The reviews concluded that 3D food printing could benefit people with dysphagia as food could be printed separately on the plate without mixing, and hydrocolloids (e.g. gelatine) could be added to pureed food to assist with the food's printability and visual appeal (Liu et al. 2018; Tan et al. 2018b). However, each food product would require individualized preparation methods, and further research should examine the correct types and amounts of hydrocolloids for successful 3D food printing (Tan et al. 2018a).

The use of meat in 3D food printing and its potential impact on the mealtime engagement of people with dysphagia was reviewed by Dick et al. (2019). Little evidence was found on the printing of pureed fibrous meats and no evidence relating to beef meat, although it could provide an alternative to scooped meat in aged care homes (Dick et al. 2019). Dick et al. (2019)

highlighted that difficulties may arise with printing meat at a safe temperature and recommended further research. Hemsley et al. (2019) further reviewed sixteen papers on the use of 3D food printing and concluded that 3D food printing could provide visually appealing meals for people with dysphagia, but there was little original research to support this claim or the claim that there might be nutritional benefits of 3D-printed food (Hemsley et al. 2019). At the time there were no studies on the usability or feasibility of 3D-printed food for people with swallowing disability; however, the authors recommended that 3D-printed food should be at least the same quality as traditionally prepared food (Hemsley et al. 2019).

Mixed presentation methods. Molecular gastronomy is the study of physical transformations that occur to food while being prepared (Reilly et al. 2013). Some techniques, including piping bag use, spherification, gelification and emulsification, have been tested to improve the visual appeal of texture-modified food. In Reilly et al. (2013), 60 people without swallowing difficulties reported that molecular gastronomy techniques could improve the sensory appeal of pureed food. Participants rated the taste, visual appeal and texture of pureed foods on a five-point Likert scale, where 1 was 'did not like at all', 3 was 'neutral' and 5 was 'much liked'. All five food products ranked between 3 and 5 on the scale (Reilly et al. 2013). Authors suggested that although food created using these techniques may be costly, extra food would be eaten, thus reducing the need for supplements (Reilly et al. 2013). As the research did not include participants with dysphagia and as the sensory elements of food were not examined separately, the effectiveness of these techniques for people with swallowing disability or which component had the greatest impact are unknown.

Designing the food temperature

Serving food at an appropriate temperature can affect the convenience (regarding food safety) and pleasure of mealtimes for people with dysphagia (see Figure 1). The importance of maintaining optimum temperatures for cold and hot foods (under 5 or over 60°C, respectively) is widely recognized (Cichero 2015). If the food is too hot, a person who struggles to transport food within their mouth may suffer thermal burns as the transport time is extended. In comparison, if the food is too cold, food may be less appealing, thus impacting mealtime engagement (Cichero 2015). In a quantitative experimental study, de Villiers et al. (2019) examined the importance of serving texture-modified food at the correct temperature for the food's safety. Specialized nutritious foods were made into IDDSI Level 4 Pureed food when mixed with either room-temperature or heated milk or water. The heated samples became lumpy upon cooling and no longer met the IDDSI requirements (de Villiers et al. 2019). The impact of temperature on the safety of texture-modified food is particularly relevant for residential care facilities and hospitals where food may cool before it is served (de Villiers et al. 2019).

Mealtime service

Designing the mealtime environment

Mealtime locations can be modified to improve engagement and pleasure for people with swallowing disability (Aguilera and Park 2017). Hung et al. (2015)

examined the impact of dining room renovations on mealtime experiences for people with dementia in aged care facilities. By building a small kitchen near the dining room, residents could enjoy the autonomy and choice of having a kitchen nearby. Participants could relax, and they stayed longer and interacted more in the dining area. Consequently, 72 per cent of residents gained weight (Hung et al. 2015). In another study of aged care residents with dementia, a small dining room for six people was more beneficial than a large dining room for 60 people. The smaller group enabled residents to share the dining experience with reduced noise, more choice and resident-led conversation (Roberts 2011). This highlights the importance of the environment on mealtime engagement for people with dementia, who often require texture-modified food (Hung et al. 2015; Roberts 2011).

Designing mealtime assistance

The provision of mealtime assistance may influence a meal's convenience (Aguilera and Park 2017). Hung and Chaudhury (2011) outlined the practices that should be upheld by the staff in aged care assisting at mealtimes, including appropriate pacing of the assistance, respect for the person, validation of beliefs, empowerment and inclusion within mealtime activities. When used, these practices had a greater impact on mealtime experiences than on mealtime environment (Hung and Chaudhury 2011). Similarly, Ruigrok (2006) highlighted how mealtime assistance could be dignified as it allowed the person to eat regular food, which they could not eat without support or supervision.

DISCUSSION

The results of this review demonstrate how the various components of texture-modified food can be designed during several stages of food preparation (food texture, flavour or nutritional value), formulation (visual appeal or temperature of food) or food service (mealtime environment or assistance) to help improve mealtime experiences and engagement of people with dysphagia. Each of these components relates to one or more elements of the Drivers of Food Choice model described by Aguilera and Park (2017) (see Figure 1).

Methodological limitations

The quality of studies included in this review was highly variable. The use of a second rater to determine the inclusion or exclusion of studies was implemented to reduce selection bias. However, within the studies, some sampling bias towards populations with acquired health conditions (e.g. stroke or dementia) was evident. These populations were much more likely to be included in research relating to dysphagia and mealtime experiences. And yet, the voices of people with dysphagia are still only faintly heard in the literature. Only half of the studies in this review included any participants with dysphagia ($n = 17$), and only one of these included participants with dysphagia associated with lifelong disability (e.g. cerebral palsy, intellectual disability) (Balandin et al. 2009). People with dysphagia, and particularly those with lifelong dysphagia, should be included in research on food structure and appeal, as they face ongoing difficulties in accepting texture-modified food, and their needs and perceptions may also change across the lifespan.

There was also some sampling bias within the studies towards populations living in aged care facilities as opposed to community or group home environments. People with dysphagia living independently in the community or in group homes should also be included in research examining the structure and visual appeal of food, as they may be much more likely to engage in food preparation at home. For example, there is a greater chance that they are involved in menu planning, shopping, selecting, preparing and cooking food. These experiences and their engagement may further influence their views on texture-modified foods and acceptability in terms of the food's structure, shape and visual appeal. Furthermore, people with dysphagia who live in the community may also be more likely to be involved in the preparation, production and consumption of meals to share with others (e.g. family or friends), further influencing their food choices. Overall, further research is needed on food structure and appearance in dysphagia management across a broader range of populations and settings.

Impact of findings

In this review, various studies report on the manipulation of the food's visual appeal through the use of food moulds, 3D food printing, piping bags, spherification, gelification and emulsification (Liu et al. 2018; Reilly et al. 2013; Ullrich et al. 2014). The number of strategies identified in the included studies highlights the importance of improving the visual appeal of food for people with dysphagia. However, there are gaps in the research; for example, 3D food printing is promoted as a solution for pureed food presentation, but there is no evidence yet to support this claim (Hemsley et al. 2019; Sungsinchai et al. 2019). Further research should demonstrate how novel technologies, including 3D food printing, can be paired with nutritional fortification strategies to create nutrient-rich meals. This research may also benefit people with other eating problems or disorders where high-nutrient and easy-to-swallow meals are required. For example, 3D food printing could be used in creating highly nutritious, pureed or soft foods for people recovering from a gastric bypass surgery. The benefits of food-printing technologies should also be examined for people with the avoidant-restrictive food intake disorder or for children presenting with food selectivity (e.g. children with autism spectrum disorder) to increase their interest in food and activities surrounding its preparation and consumption (Marí-Bauset et al. 2014).

This review highlights the importance of food temperature and texture on maintaining mealtime pleasure and the safety of people with dysphagia (Milte et al. 2017; Ilhamto et al. 2014). Maintaining appropriate food temperature and texture is essential for the convenience and safety of texture-modified foods and cannot be altered without a potential compromise to meal's safety. Technologies used to modify the food's visual appeal (e.g. 3D food printing) need to be accessible for people with dysphagia who also have cognitive or communication impairments, which may reduce their ability to engage in mealtime activities. Consequently, people with these disabilities should be included in future research examining food temperature and texture (Hung et al. 2015; Roberts 2011).

Finally, this review highlights the importance of the location of meals and the type of mealtime assistance provided to enhance mealtime enjoyment (Hung et al. 2015; Roberts 2011). As environmental changes influence the dignity and inclusion of people with dysphagia, it is likely that manipulating the food's structure and appearance is not sufficient to improve mealtime-related quality of life if the wider mealtime environment is not conducive to an enjoyable meal.

CONCLUSION

This review demonstrates the increased research interest in how the structure and appeal of texture-modified food can impact mealtime experiences and engagement of people with dysphagia. The review also highlights the benefits of concurrently changing multiple elements of the meal. For example, Okkels et al. (2018) modified both the taste and the temperature of texture-modified foods to improve mealtime experience. The lack of attention to the experiences of people with dysphagia, particularly those with lifelong dysphagia, indicates an urgent need to discover more about their views on these common interventions. Technological advances in texture-modified food production should continue to drive improvements in the visual appeal, flavour, texture and nutrition of texture-modified foods, and continued research is required to determine the effectiveness of these technologies. People with dysphagia should be included in future studies examining the appearance and appeal of food, as the opinions of people without dysphagia do not generalize to those with dysphagia (Ettinger et al. 2014). As mealtimes are an essential component of social and cultural events (Balandin et al. 2009), further advances in modifying the food structure and appearance for people with dysphagia are essential for continued dignified community engagement. Future research should also examine the social and emotional influences on mealtime experience for people with dysphagia.

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CONTRIBUTOR DETAILS

Rebecca Smith is a speech pathologist who graduated with first-class honours and the university medal. She is currently completing her Ph.D. at the University of Technology Sydney.

Contact: The University of Technology Sydney, 100 Broadway, Ultimo, NSW 2007, Australia.
E-mail: rebecca.j.smith@student.uts.edu.au

https://orcid.org/0000-0001-9523-785X

Lucy Bryant is a speech pathologist with research and clinical expertise in the use of information technology in speech pathology practice.

Contact: The University of Technology Sydney, 100 Broadway, Ultimo, NSW 2007, Australia.
E-mail: lucy.bryant@uts.edu.au

https://orcid.org/0000-0001-8497-7406

Courtney Reddacliff is a speech pathologist with extensive experience in private practice. She is involved in research and clinical education at the University of Technology Sydney.

Contact: The University of Technology Sydney, 100 Broadway, Ultimo, NSW 2007, Australia.
E-mail: courtney.reddacliff@uts.edu.au

https://orcid.org/0000-0002-7841-3548

Bronwyn Hemsley is head of speech pathology at the University of Technology Sydney and a certified practising speech pathologist with over 34 years' experience working with people with swallowing and communication disabilities in clinical, research, teaching and policy development.

Contact: The University of Technology Sydney, 100 Broadway, Ultimo, NSW 2007, Australia.
E-mail: bronwyn.hemsley@uts.edu.au

https://orcid.org/0000-0002-6255-3140

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Section Two: Methodology

Section 1 of this thesis provided the context and reasoning for the research to occur through a scoping literature review (Chapter 2; Smith, Bryant & Hemsley, 2022c) and a narrative literature review (Chapter 3; Smith, Bryant, Reddacliff et al., 2022). Based on this knowledge, a research plan was established to achieve the overall research aims of examining the impacts of dysphagia on quality of life, the barriers and facilitators to mealtime quality of life, and the feasibility of 3D food printing to improve the mealtime experience.

Section 2 of this thesis describes the research plan by outlining the methodology (Chapter 4), methods (Chapter 5), and the impacts of COVID-19 on this project (Chapter 6). Chapter 4 outlines the ontological and epistemological standpoint of this research before outlining the ethical considerations. Chapter 5 describes the qualitative research methods used as part of this constructivist grounded theory approach including in-depth interviews, focus groups, and mealtime observations. Chapter 6 then outlines how this project was impacted by COVID-19 and the changes that were made to meet COVID-19 restrictions. The information presented in Section 2 is essential in describing the theoretical lens and the corresponding methods chosen by the researcher to answer the research questions.

Chapter 4: Methodology

Methodology: Qualitative Paradigm

The purpose of this chapter is to describe the qualitative research methodology chosen for this project. This project investigates mealtime quality of life for people with dysphagia, an area where there is little previous in-depth qualitative research describing the concept (Hemsley et al., 2019). A qualitative constructivist grounded theory approach was selected as being most suitable, as it enables exploration in an area where little is known and the construction of knowledge that takes into account multiple data sources and also the interpretations of the researcher. This approach allows an in-depth understanding of the human experience from personal perspectives of people with dysphagia to be developed, and for identifying areas of interest that are suitable for future measurement using quantitative methods (Patton, 2014). This chapter provides the theoretical underpinnings for the overall design and implementation methods for this research. It provides an in-depth explanation and rationale for the methodology and outlines the ethical considerations of this project. Throughout this chapter, the PhD candidate is referred to as ‘the researcher’.

Qualitative Research

Qualitative research methods are used to gain an understanding about the human experience, usually from a specific population. Qualitative methods do not align with counting or measuring data that is seen in quantitative research (Hammarberg et al., 2016) and the two paradigms deliver different types of knowledge and understanding. For example, quantitative research methods yield information about who completed a specific action or what they did, while qualitative research yields information on the nature of these behaviours, the contexts in which they occur and why these actions or behaviours may occur (Given, 2008). It is typical for qualitative research methods to explain a new or novel phenomenon as well as peoples' thoughts and feelings towards it (Given, 2008). An individualised perspective is also gained from participants in qualitative research, as each person experiencing an event may have a different interpretation of what happened and the impact upon them. Quantitative research is used when specific facts are required to answer the research question (Hammarberg et al., 2016). Unlike most prior research on swallow-related quality of life, which has taken a quantitative approach to discrete measurements on survey instruments, this research did not aim to quantify elements of quality of life impacted by dysphagia. Instead, it aimed to determine people's perception of events and objects (i.e., texture-modified food). Qualitative research methods were used to determine (a) the impacts of dysphagia and dysphagia interventions on quality of life, participation, and inclusion; (b) the barriers and facilitators to improved mealtime quality of life, participation, and inclusion for adults with dysphagia; (c) the impact of the use of food design on the mealtime experience of people with dysphagia; and (d) the feasibility, usability, and potential impact of using 3D food printing to increase the person's quality of life as well as their participation and inclusion in mealtime processes. The use of qualitative research strategies allowed for complex events and experiences related to dysphagia and quality of life to be examined.

Constructivist Grounded Theory Approach

Qualitative research methods have been described as eminently suitable for use in speech pathology research as they allow for complex disorders to be understood and for examination of topics where there has been little previous research (Skeat & Perry, 2008). A constructivist grounded theory approach is one such qualitative research methodology that allows for the interpretations of the researcher and the participants to be acknowledged. It also utilises multiple data sources that can be combined to understand a phenomenon from a range of perspectives. In this approach, the researcher selects methods that enable in-depth exploration and repeated, close contact with the participant group and the problem; thus, the results of such research are based on real-world, lived experiences (Patton, 2014). In this study, the perspectives of people with dysphagia, supporters of people with dysphagia, and allied health professionals who work with people with dysphagia were honoured as important for informing the aims of the research. The researcher's views are also acknowledged as integral to the research, as the researcher has a background as a Certified Practising Speech Pathologist and has personal lived experience with two family members with dysphagia. Considering the importance of considering mealtime quality of life as a qualitative phenomenon, and inviting the inclusion of multiple perspectives, the constructivist grounded theory approach was selected as the most suitable methodology to address the aims of this research.

Development of Constructivist Grounded Theory

Grounded theory emerged through collaborative work between Barney Glasser and Anselm Strauss on the experience of dying in hospital (Glaser & Strauss, 1967). Through their analysis of the process of dying, they developed systematic methods that social researchers could use to study topics and create conceptual theories in a qualitative manner. They advocated for the development of theories through research grounded in collected data rather than testing a hypothesis from an existing theory (Charmaz, 2017). Grounded theory, a qualitative method, emerged at a time where quantitative research was gaining strength among social scientists and greater weight was placed on replicable studies and the deduction of hypotheses (Charmaz, 2017). In direct contrast to this, Glaser and Strauss aimed to use qualitative research to establish theoretical frameworks that provided a wider understanding of the phenomenon being examined (Glaser & Strauss, 1967). Their work assisted in establishing the reliability of qualitative research in its own right (Charmaz, 2017).

Glaser and Strauss took an objectivist epistemological approach and assumed that an *objective* version of the truth existed for any given phenomenon (Glaser & Strauss, 1967). Although collaborating to release their work on grounded theory in 1967, Glaser and Strauss had differing theoretical viewpoints, with Glaser being influenced by positivism (a person's opinion is driven by facts of society) and Strauss being influenced by pragmatism and symbolic interactionism (a person's perception of an object is shaped by their own knowledge of it, how they interact with the object, and their perception can change over time) (Charmaz, 2017). By the 1990s, this had led to diverging approaches to grounded theory. Strauss collaborated with Juliet Corbin to provide an in-depth description of how to complete a grounded theory, which took a post-positivist view that reality is subjective (Skeat & Perry, 2008). Glaser considered that Strauss and Corbin's interpretation of grounded theory forced data to fit with preconceived ideas on the topic, which went against the original grounded theory (Charmaz, 2017). Glaser criticised the work by Strauss and Corbin, and as a result Glaserian and Straussian versions of grounded theory emerged (Skeat & Perry, 2008).

Second-generation grounded theorists began to emerge in the 1990s to early 2000s, and variants of grounded theory were established, including constructivist grounded theory and situational analysis (Charmaz, 2017). Constructivist grounded theory was developed in 1994 by Kathy Charmaz and was situated between positivism and post-modernism (Gardner et al., 2012). In constructivist grounded theory, Charmaz reported that researchers are part of the society they are studying, thus their past and present interactions influence their current theory (Gardner et al., 2012).

Rationale for a Constructivist Grounded Theory Approach: Ontology and Epistemology

The ontological stance taken in completing this research was a relativist position, which assumes that humans understand truth and reality as it is positioned within a specific place, time, and social environment (Charmaz, 2017). A constructivist grounded theory approach utilises a subjectivist or constructivist epistemological position which acknowledges that researchers cannot be completely objective during data collection and analysis as their perceptions influence their actions (Gardner et al., 2012).

A constructivist grounded theory approach is a systematic approach to constructing a theory or evidence-based framework based on the results of qualitative data collection (Gardner et al., 2012). The constructivist approach denies the *objective* existence of reality, instead suggesting that reality is a social construct of the mind and can be shaped by many standpoints, including time, place, cultural perspectives, and shared meaning of an event (Gardner et al., 2010; Mills et al., 2006). The concept of 'reality' is relative to the types and number of perspectives provided on a topic. The social constructs identified may be held by an individual or a group in society (Mills et al., 2006). The constructivist approach is subjective, and takes the researcher's own stance, interpretations, and values into account in relation to the data and the analysis process implemented (Mills et al., 2006). As such, the researcher must acknowledge their own stance and interpretations of meaning, while also acting as a facilitator to gather and respect the voices and differing perspectives of the participants.

Inductive data analysis methods are used in this research, as the qualitative research methods applied do not involve proving or disproving a predetermined theory or hypothesis (Gardner et al., 2010; Mills et al., 2006). This contrasts with quantitative research, in which a deductive approach is used. A deductive approach was not appropriate for this research as the nature of the impacts of dysphagia on quality of life are not well understood, as shown in the scoping review of the literature (see Chapter 2; Smith, Bryant & Hemsley, 2022c). Constructivist grounded theory methodology is particularly suitable as there is little known about this topic; there are multiple factors influencing the human experience; and interaction between the research participants and the researchers would allow for the examination of important concepts related to quality of life or 3D food printing (Charmaz, 2017; Skeat & Perry, 2008). Data triangulation, which involves data collection from a variety of sources being analysed together in order to confirm and strengthen findings, is also common in qualitative research methods. Data analysis occurs through constant comparison of the data analysed from three of more methods of data collection that assists in strengthening confidence in the results, and rigour of the research. Both constant comparison and triangulation methods are important components increasing the rigour of qualitative research. Studies that only use one data collection method (e.g., interviews) are at higher risk of methodological errors as the data cannot be checked against data collected using a different method (Patton, 2014). Triangulation of data also allows the researcher to see connections or relationships between the themes, and to build a framework based on the participants' experiences (Charmaz, 2017). An inductive reasoning approach was demonstrated through the researcher's observations of people in their regular mealtime environment, conducting interviews in their regular environment, and then conferring with allied health professionals in focus groups.

Multiple research methods were used in this study to build the evidence-based framework through inductive analysis and data triangulation. Interviews, mealtime observations, document analysis of speech pathology reports and mealtime plans, surveys, and focus groups were used across the multiple, integrated studies. These methods are detailed in Chapter 5. Through the constructivist grounded theory methodology, inductive reasoning was used to create new knowledge based on observation leading to the establishment of broad conclusions (Charmaz, 2017). In using the constructivist grounded theory approach, the topic was examined from the 'ground up' from the perspectives of people impacted by or involved in dysphagia management, addressing the more conceptual and neglected questions relating to quality of life for people with dysphagia. It also recognised that the dysphagia-related health issues may impact in complex ways on a person's quality of life, and that these relationships are worthy of in-depth exploration in their own right. For example, a specific physical symptom of dysphagia, such as coughing on foods or fluids, may negatively impact on a person's quality of life and desire to eat with others if they are embarrassed at others seeing them choke (Alali et al., 2018).

A constructivist grounded theory approach is interpretivist in regard to its methodological standpoint, as reality is discovered by the researcher and is based on time, culture, and context (Gardner et al., 2012). This then leads to a theoretical perspective of symbolic interactionism according to which people rely on social interactions to make meaning of objects, events, and behaviours (Gardner et al., 2012). The ontological and epistemological standpoints are further described in Table 1.

Table 1

Philosophical Approach of Study

Framework component	Perspective	Description
Ontology	Relativism	There is no single reality, there are multiple, equally valued views within a broad framework. It is contextually set within time, place, and culture (Gardner et al., 2012).
Epistemology	Constructivism	Reality is socially constructed on the basis of multiple truths (Patton, 2014). Reality has to be interpreted.
Theoretical perspective	Symbolic interactionism (interpretative)	Meaning is derived from a shared reality that is influenced by time, culture, and context (Gardner et al., 2012).
Methodological approach	Constructivist grounded theory	Aims to generate a theory or framework with emphasis on diverse local environments with multiple realities, views, and actions. It is an interpretative approach with flexible guidelines (Charmaz, 2017).
Reasoning approach	Inductive reasoning	Observation is the foundation of knowledge and certain generalisations can be made from specific observations. Broad conclusions can be drawn from what is seen in the observations (Patton, 2014).
Methods	Mixed data generation (mostly qualitative)	Data generation will occur through in-depth interviews, mealtime observations, mealtime document analysis, usability heuristics, surveys, and focus groups. NVivo 12 will be used for analysis of results.

Rigour in the Research

Reflexivity and Truthfulness

It is essential to consider the influence of the participants and the researcher when using a constructivist grounded theory approach (Charmaz, 2017). The researcher of this project has a background in the clinical field as a Certified Practising Speech Pathologist, and in research as a research assistant and through the completion of Graded Honours (First Class) in 2016. The researcher also has personal experience with dysphagia through two family members who had dysphagia of different severities, causes, and duration.

Bias was acknowledged and reduced through the collection of perspectives from multiple parties: people with dysphagia, supporters of people with dysphagia, and allied health professionals. As a result, the views of any one group were not considered the only truth on the topic. Data from all groups were treated equally and constant comparison occurred between the groups during analysis. The researcher was also aware that the allied health professionals recruited for the focus groups may have demonstrated a highly specific policy stance based on their place of employment. To overcome this, research participants were reminded of the purpose of the focus groups and the researcher utilised predetermined questions to ensure conversation remained on topic. Due to the qualitative nature of the study, trustworthiness was judged through four naturalistic criteria: credibility, transferability, dependability, and confirmability (Cypress, 2017; Korstjens et al., 2018).

Credibility

Credibility refers to the accurate description of a person's lived experiences (Cypress, 2017; Korstjens et al., 2018). This was achieved though triangulation of data collected from people with dysphagia, supporters of people with dysphagia, and allied health professionals to gain a greater understanding of the impacts of dysphagia on quality of life and the feasibility of 3D food printing to improve the mealtime experience. The credibility of participants was confirmed by ensuring that sufficient data were collected across the data collection events (Studies 1a, 1b, 2, and 3). The credibility of the data was also confirmed through reflexive discussion and confirmation of interpretations with project supervisors, who were both Certified Practising Speech Pathologists, and data was cross-checked across categories (Cypress, 2017).

Transferability

The transferability of the data collected from research participants to other people with dysphagia, their supporters or allied health professionals was increased through the use of purposeful sampling of people with lived or working experience of the issues arising for people with dysphagia in relation to quality of life and mealtime experiences. The qualitative approach selected also allowed in-depth data on the participant context to be collected, improving transferability. Although the inclusion of this information allowed for transferability of results, these results could not be generalised to all people with dysphagia due to the heterogeneity of the population.

Dependability

Dependability of results within this project was achieved through the analysis of data by second and third raters to achieve consensus (Cypress, 2017; Korstjens et al., 2018). Content themes and component categories of meaning were discussed by the researcher and her supervisors to ensure all themes were adequately covered (Cypress, 2017). If consensus was not initially achieved, further discussion occurred until a consensus was reached. Summaries sent to participants of Studies 1 and 2 after their involvement in those studies were also discussed by the researcher and supervisors to confirm the inductive reasoning and qualitative interpretations of the data. Findings from Study 1 with people with dysphagia and their supporters were also confirmed during the focus groups with allied health professionals in Study 2, which allowed researchers to gain clarity on points of discussion. Similarly, Study 3 survey methods were used to verify the findings from both Studies 1 and 2.

Confirmability

Finally, confirmability was maintained through the use of reflexive journal writing, which involved the researcher recording memos (daily introspections) that may have been relevant to the outcomes of the study. The researcher then reflected on these notes during the data analysis stage, while remaining aware of her role as the primary instrument of the study (Cypress, 2017; Korstjens et al., 2018). Retrospection also occurred after every interview or mealtime observation. The researcher also checked back with participants involved in Studies 1 and 2 to ensure that the qualitative interpretation of the data aligned with the participants' perspectives.

Recruitment and Sampling

Following a constructivist grounded theory approach, non-probability sampling methods were implemented in two stages. This included purposeful sampling followed by theoretical sampling. As this was a qualitative study, researchers aimed to continue data collection until data saturation was reached (Guest et al., 2006; Patton, 2014). However, recruitment was impacted by COVID-19 restrictions and social distancing, and data saturation was not achieved, limiting the extent to which findings could be generalised to other people with dysphagia or their supporters or health professionals (Patton, 2014).

Purposeful Sampling

Purposeful sampling aims to select samples that are rich in information and provide the best information on the research question (Emmel, 2013a). This is one of the strengths of purposeful sampling, as it allows for a greater, in-depth understanding of a concept rather than empirical generalisation (Patton, 2014). This is also in line with the concept of quality of life, which is subjective and relies on the person's state of mind and their relationship with others and the environment around them (WHO, 1998). Purposeful sampling involves the researcher making scientific observations of the participants' experiences and recognises that researchers bring their own theoretical beliefs to the research. The researcher uses their theoretical position and their judgement to select the sample. It is an intentional approach to provide information on the components of the phenomenon being examined. Thus, purposeful sampling is a practical option as the researcher uses their knowledge of the specific area to solve a real-world problem (Emmel, 2013a). This form of sampling also allows the researcher to examine the differences that exist between participants, which increases the sensitivity towards the concepts being examined (Emmel, 2013b).

The current study specifically required participants to be a person with dysphagia, a support person of a person or people with dysphagia (i.e., a family member or direct support worker), an allied health professional, or a residential care manager who provided care to people with dysphagia. Thus, the researcher's knowledge and judgement were required to select suitable participants who could provide the richest data possible (Emmel, 2013a). Because of the highly specific nature of the participants, purposeful sampling was needed for the study to be cost- and time-effective. Purposeful sampling was also used in the recruitment of allied health professionals and residential care managers due to their interest in the phenomenon. Allied health professionals needed to have experience working with people with dysphagia for at least two years.

Intensity sampling and snowball recruitment were implemented to achieve purposeful sampling in this research (Patton, 2014). These strategies included making judgements before, during, and after sampling occurred so the sample effectively met the needs of the research. These judgements were made from the researcher's knowledge of the topic to explore all aspects of the data collected in an in-depth manner (Emmel, 2013a). Participants with dysphagia and supporters of people with dysphagia were recruited using intensity sampling methods which involved collecting information-rich cases where the phenomenon being examined was frequently seen however not in extreme or deviant forms (Patton, 2014). People with extreme cases of dysphagia who could not safely eat pureed foods and who had different perceptions of mealtime participation and inclusion were not included as they could not eat food orally and 3D food printing was therefore not suitable for their needs. Participant eligibility was assessed in a clinical swallowing assessment using the Dysphagia Disorder Survey (Sheppard et al., 2014). Criterion sampling, another type of purposeful sampling, was not used as participants were recruited from different environments and presented with dysphagia symptoms of differing severities and causes. Therefore, participants could not be compared against a single set of criteria (Patton, 2014).

Health professionals were recruited through purposeful and snowballing recruitment techniques (Patton, 2014). These methods were used to recruit professionals who had detailed knowledge of working with people with dysphagia. The process was initiated by contacting organisations who work with people with dysphagia (e.g., non-government organisations) and then speaking to the health care professionals employed within the organisation. These staff members were encouraged to pass the study information on to other potential participants who work in the same field. Snowball recruitment strategies were also implemented with allied health professionals by recruiting through social media networks established within the professions (e.g., the Facebook pages of speech pathologists who work with people with dysphagia). This created some difficulty in quantifying the number of potential participants reached; consequently, the response rate could not be determined (Duffy et al., 2005). Recruitment was also homogeneous, as all health professionals needed experience working with people with dysphagia to be eligible for participation (Patton, 2014).

Theoretical Sampling

Theoretical sampling was used in this study to elaborate on and define the categories of the qualitative framework emerging (Emmel, 2013b). Theoretical sampling was appropriate as it allowed the researcher to complete in-depth examination of behaviour and social interactions to create an evidence-based framework. Theoretical sampling also met the aims of the study as this method of sampling only relates to the development of an evidence-based framework, it does not try to represent an entire population or increase the generalisability of study results (Charmaz, 2017). If theoretical sampling occurred at the beginning of recruitment, categories created may have been closed early without reaching saturation, or the themes established may have been over-reliant on participant statements (Charmaz, 2017). The categories created may also have been of poor quality, in that they were non-specific or were redundant with regards to the framework being established (Charmaz, 2006). Three issues of theoretical sampling need to be addressed to examine all components of the social world: how the researcher controls the influence of the theory or framework emerging, the researcher's theoretical sensitivity, and constant comparison between participants (Emmel, 2013b).

Controlling the Influence of the Framework Emerging. Theoretical sampling requires the researcher to determine what group or subgroup of participants is needed for the next stage of data collection and to define their purpose (Glaser & Strauss, 1967). As previously stated, theoretical sampling was shaped by the emerging framework and the information required to construct and finalise the framework – for example, recruiting specifically for people who had swallowing difficulties from birth if this cohort was not captured in the original sample (Emmel, 2013b). This was appropriate, as the researcher was not attempting to find a true representation of an entire population; instead, the aim was to create categories that could be applied to specific situations (e.g., mealtimes of people with dysphagia in the community) (Glaser & Strauss, 1967). This was particularly important when completing research with people with dysphagia as they are a highly heterogeneous population and experiences cannot be generalised. It was also appropriate when exploring the subjective concept of quality of life as specific components of the person's life (e.g., where they live) could influence their responses.

Theoretical Sensitivity. The theoretical sensitivity of the researcher could influence theoretical sampling (Hoare et al., 2012; Glaser & Strauss, 1967). Initially, when establishing the evidence-based framework, the researcher began with a broad basic outline of the issue to be examined. The researcher did not make decisions about the sample based on preconceived beliefs; instead, they were open to discovering new concepts to refine the concepts examined in the early part of the research (Emmel, 2013b). This was achieved by sampling from groups the researcher did not know personally. This assisted the researcher to remain open and receptive to the development of an emerging framework that could be tested against prior evidence. This also allowed the researcher to predict where and how they might find data to fill categories regarding dysphagia, quality of life, and 3D food printing (Charmaz, 2017).

Constant Comparison. The researcher engaged in constant comparison of concepts identified from different participants. This was required to refine the emerging evidence-based framework and was particularly important as sampling became more selective, focusing on specific concepts that link to the framework (Emmel, 2013b). This comparison occurred between events (to determine any similarities or differences), between concept and events, and between different concepts (Emmel, 2013b). Constant comparison techniques allowed the researcher to increase the precision of categories developed and the relationship between the categories, and to determine whether there was any variation in the analysis compared to the literature (Charmaz, 2017). Overall, constant comparison was used to establish a framework from the emerging evidence and it also allowed the researcher to extend the scope of their findings (Emmel, 2013b).

Sample Size

Sample sizes in this project were based on the notion of data saturation – the point at which collection of additional data collected no longer provided new theoretical insights (Charmaz, 2006). According to Guest et al. (2006), saturation is reached when new information or data does not change the codes and categories that have been created, thus the data set is exhausted. Guest et al. (2006) conducted interviews with 60 participants to determine when saturation was reached. They reported that 93.4% of codes came from the first 12 interviews and there was little information found in the remaining interviews that had not already been coded (Guest et al., 2006). As this study aimed to establish an evidence-based framework using constructivist grounded theory approach, it was important saturation was reached, as the data creates the body of the framework. However, as suggested in previous research (Vasileiou et al., 2018), it was acknowledged that saturation may not always be achieved after 12 interviews due to the variability in the participant groups. For example, the focus groups in Study 2 involved a mixed group of allied health professionals, however the majority of participants were speech pathologists and there were no dietitians involved. Therefore, saturation was not achieved from the focus groups as it could not be assumed that dietitians would have the same perspective on the topic as speech pathologists.

Ethical Considerations

This project involved adults with a swallowing disability (a vulnerable population) discussing the impacts of their swallowing difficulties on their lifestyle and the feasibility of 3D food printing. Participant involvement in the study had the potential for both physical and psychological harm and consequently it was a high-risk study. Ethical approval was sought and granted from the University of Technology Sydney Human Research Ethics Committee (ethics approval number: ETH19-3708). An amendment was made to the ethics application to allow for data collection to occur online to meet COVID-19 restrictions. A COVID-19 Safe Plan was then also approved in October 2020 for face-to-face, in-person data collection to recommence. Further amendments were made to the ethics application in September 2021 to allow for data collection to occur through an online survey (ETH21-6568 and ETH21-6781). Ethical concerns for participants of Studies 1, 2, and 3 are described below in Tables 2 and 3.

Table 2

Ethical Issues for Participants with Dysphagia and Their Supporters

Type of risk	Risk*	Strategies to reduce risk
Physical risks	• Risk of coughing or choking during Study 1a or 1b.	• A Certified Practising Speech Pathologist conducted the swallowing assessment. Only participants who could currently eating puree foods safely were included in the study. If coughing or choking occurred, their usual response strategies were enacted.
	• Fatigue during Study 1a or 1b.	• Any participant showing signs of fatigue were given the opportunity for a break or to cease participation completely.
	• Allergic reactions to food during the swallowing assessment or 3D printed food experience. • Food poisoning during the swallowing assessment or 3D printed food experience.	• Participants ate their own food during the swallowing assessment. Only food materials that the participant usually ate and tolerated well were used in the 3D printed food experience. • The investigators completed a food handling course to ensure all food products are handled and stored appropriately to reduce the risk of food contamination occurring.
Psychological harm	• Feeling self-conscious or emotionally distressed during the interview or survey.	• If the participant felt emotionally distressed, data collection stopped until the person recovered, or else abandoned. If the participant wished to access counselling services as described on their participant information statement, they could.
	• The participant may feel embarrassed when discussing specific events that have occurred in the past (e.g., choking event) in the interview or survey.	• All information about the participant was treated as confidential. • Participants and supporters of people with dysphagia were free to withdraw from the study at any time if they continued to feel uncomfortable.
Confidentiality	• A person's views of their mealtimes can be considered sensitive and private.	• The participant with dysphagia and supporters of people with dysphagia were required to provide consent to take part in the study which informed them that all data was to be de-identified in the analysis process and each participant was be referred to by a code. All data was stored on a secure UTS server called STASH.
Other issues	• The person with dysphagia may have co-occurring communication impairments impacting their ability to give informed consent.	• Only participants who identified as being able to provide informed consent for participation in the study were included in the study.

*The physical risks to participants associated with 3D food printing would have been a concern if the 3D food printing experience occurred face-to-face. Due to COVID-19 restrictions, all 3D printed food experiences were held online.

Table 3

Ethical Issues for Allied Health Professionals

Potential risk	Risk	Strategies to reduce the risk
Psychological harm	• Focus group participants may feel self-conscious about being audio recorded, particularly if their responses are being compared to those provided by other health professionals. • Survey participants may become self-conscious or emotionally distressed during the survey.	• The health professionals were provided with an information sheet of the risks before giving consent. They were free to withdraw from the study at any time. Participants were also provided information on where they could access counselling services if needed.
Social harm	• Focus group participants may feel at risk of damaging their professional reputation by discussing their opinion on policies and procedures.	• Participants were informed that they could withdraw from the study at any time or they could decline to answer a question if they felt uncomfortable.
Confidentiality	• Focus group participants will not be anonymous to the researchers or other participants of the focus group. • Survey participants have the option to remain anonymous or they may provide their contact information at the end of the survey.	• Participants were provided with an information sheet informing them of risks. All data collected from the focus groups was de-identified after data collection was completed and all data was then stored on a secure UTS server (STASH). • Contact information retrieved through the surveys could only be accessed by researchers for the purpose of this research. Information also stored on STASH.

Conclusion

In this chapter, the constructivist grounded theory approach has been described and highlighted as the most appropriate methodological approach for examining how dysphagia impacts on quality of life and how 3D food printing may be implemented to improve the mealtime experience for people with dysphagia. By implementing this approach, the researcher could identify the core concerns of the participants and then create an explanatory theoretical framework that explained the phenomena (Skeat & Perry, 2008). This also suited the relativist ontological standpoint taken in this project. Inductive reasoning was used to form broad conclusions from the results. Reflexivity was also highlighted as a major element in the trustworthiness of this qualitative data. As noted above, the constructivist grounded theory approach involves the collection and triangulation of multiple data sources to assist with verification of results. Chapter 5 will discuss the specific methods used within the methodology.

Chapter 5: Methods

This chapter outlines the methods used across this project, which align with the methodological standpoint described in Chapter 4. Multiple data collection methods were implemented following a constructivist grounded theory approach of data triangulation to establish an evidence-based framework. Data collection methods were also chosen based on the findings of the prior literature reviews (Chapter 2, Smith, Bryant & Hemsley, 2022c; Chapter 3, Smith, Bryant, Reddacliff et al., 2022), particularly regarding the small body of in-depth qualitative research on dysphagia and quality of life and the lack of inclusion of people with dysphagia in 3D food printing research.

The research methods used included interviews, mealtime observations, and mealtime document analysis (Study 1a), a virtual 3D printed food experience (Study 1b), focus groups with allied health professionals (Study 2), and an online survey (Study 3). These studies were conducted to answer the following questions: (a) what are the impacts of dysphagia and dysphagia interventions on quality of life, participation, and inclusion; (b) what are the barriers and facilitators to improved mealtime quality of life, participation, and inclusion for adults with dysphagia; (c) what are the impacts of the specific elements of food design on the mealtime experience of people with dysphagia; and (d) what is the feasibility, usability, and potential impact of involving adults with dysphagia in the processes of 3D food printing, to increase their participation and inclusion in food design, preparation, and eating of texture-modified foods. This chapter provides information on the procedures chosen, the tools utilised in the studies and data analysis methods used. It also discusses the limitations of using these research methods.

Rationale for Research Methods Used

The qualitative nature of 'quality of life' demands the use of qualitative research methods, as these provide (a) an in-depth understanding of quality of life and how it is influenced by dysphagia and its interventions, as described in Chapter 2 (Smith, Bryant & Hemsley, 2022c); and (b) the ability to examine the feasibility of 3D food printing for people with dysphagia, discussed in Chapter 3 (Smith, Bryant, Reddacliff et al., 2022).

The scoping literature review informing this research examined 106 studies on the impacts of dysphagia and its interventions on quality of life (Chapter 2; Smith, Bryant & Hemsley, 2022c). However, very few of these studies were in-depth qualitative studies, and even fewer examined the impacts of dysphagia from the perspective of people with lifelong dysphagia or children with dysphagia. This review also highlighted the negative impacts of a texture-modified diet on a person's quality of life, demonstrating that further research needs to be done to develop visually appealing texture-modified food to improve the person's mealtime experience and quality of life. Further in-depth qualitative research in this area will also help to shape a rich understanding of mealtime quality of life for people with dysphagia that can be used to shape future clinical guidelines for dysphagia management.

Following on from the scoping literature review of the impacts of dysphagia on quality of life (Chapter 2), a narrative review examining the impacts of food design on the mealtime experience for people with dysphagia was completed (Chapter 3; Smith, Bryant, Reddacliff et al., 2022). The review of 35 studies demonstrated how the visual appeal, texture, taste, smell, and temperature of the food, along with the mealtime environment and support provided, can impact on the mealtime experience for people with dysphagia. Once again, few included studies examined the lived experiences of people with dysphagia, in particular the experiences of those with lifelong dysphagia (Chapter 3; Smith, Bryant, Reddacliff et al., 2022). This review also demonstrated there was little evidence available regarding the feasibility of 3D food printing from the perspective of people with dysphagia, supporters of people with dysphagia, or allied health professionals who work with people with dysphagia. Further qualitative research in this area will continue to develop the understanding of health professionals working with people with dysphagia on strategies that may assist their mealtime experience, engagement, and dignity.

Three studies were conducted to help close the gaps in the literature identified in the two literature reviews completed in this doctoral research. Each study involved the collection of information from a different participant group (e.g., people with dysphagia, supporters of people with dysphagia, or allied health professionals) and used a different research method to collect the most in-depth information on the topic possible (e.g., interviews or focus groups). The ultimate goal of data collection when using a constructivist grounded theory approach (as described in Chapter 4) is to develop categories and then describe their properties until saturation is reached (Skeat & Perry, 2008). The research questions addressed in each of the studies is described in Table 4 below.

Table 4

Research Questions Answered in Each Study

Research question	Study addressing question	Chapters in thesis
(a) What are the impacts of dysphagia and dysphagia interventions on quality of life, participation, and inclusion?	Study1a, Study 2, and Study 3	7, 8, 9
(b) What are the barriers and facilitators to improved mealtime quality of life, participation, and inclusion for adults with dysphagia?	Study1a, Study 2, and Study 3	7, 8, 9
(c) What is the impact of the specific elements of food design on the mealtime experience of people with dysphagia?	Study 1a, Study 2, and Study 3	7, 8, 12
(d) What is the feasibility, usability, and potential impact of involving adults with dysphagia in the processes of 3D food printing, to increase their participation and inclusion in the food design, preparation, and eating of texture-modified foods?	Study1b, Study 2, and Study 3	10, 11, 12

Data Collection and Analysis Techniques for a Constructivist Grounded Theory Approach

In keeping with constructivist grounded theory methods, analysis began while data collection was occurring as data analysis could help identify gaps in the research and shape further data collection methods (Skeat & Perry, 2008). Open coding was used where meaningful concepts and their properties were identified (Patton, 2014). This form of coding was used to identify the concepts and themes that emerged from Studies 1, 2, and 3. Following open coding to identify the categories, matrix coding was used as an organisational strategy to determine the interaction between codes on dysphagia, quality of life, and 3D food printing (Patton, 2014). The cross-analysis between any characteristic or aspect of dysphagia and components of quality of life or 3D food printing produced a cell in the matrix that described how the components were related. This process also reinforced relationships that had already been identified by participants in interviews, surveys, or focus groups.

Memo-writing

Memo-writing was used to analyse ideas that were established by the researcher through coding. Consistent use of memos was essential to promote analysis throughout the coding process (Charmaz, 2006). Memo-writing was used in this project as a way to capture ideas and make connections and comparisons concrete, particularly between interview, survey, and focus group data, in a manageable format. Memos were also helpful as they allowed the researcher to establish explicit analytic notes that could be compared and placed into categories (Charmaz, 2017). Memos remained unstructured but highly specific, particularly after the first few interviews, as the main purpose of the memos was to have ideas written down to advance thinking (Charmaz, 2017). These memos helped to develop the narrative of the results and set the precedent for further coding. Memo-writing encouraged the researcher to find meaning from data and it provided the opportunity to carry the conceptual framework throughout the analysis process (Charmaz, 2017). Memos were created using the free-writing method in this project, with the researcher writing thoughts on the page without worrying about the text organisation or the argument (Charmaz, 2017).

Study 1: Mealtimes Observations, Document Data, and Interviews

Study 1 included two integrated studies involving people with dysphagia and supporters of people with dysphagia discussing the impacts of dysphagia on quality of life (Study 1a), along with food design strategies used and the feasibility of 3D food printing (Study 1b). Data collected in Study 1a included interviews, mealtime observations applying the Dysphagia Disorder Survey (Sheppard et al., 2014), and analysis of mealtime documents (e.g., speech pathology report, mealtime management plan) and Study 1b involved video-recorded data of the participant in an immersive 3D food printing experience, followed by an interview. Data collection for Study 1 occurred from April 2020 to February 2022. Overall, nine adults with dysphagia and four supporters of people with dysphagia were recruited and participated in Study 1. Saturation was not reached in the analysis of interview data as there were only nine participants and new concepts were still being identified in each interview. Therefore, Study 3 (a survey) was used to expand upon and verify the findings of Study 1.

Study 1a

Observation of Mealtimes

Mealtime observations increased the researcher's understanding of the person's swallowing difficulties and provided insights into the impact of these difficulties on their daily life (Patton, 2014). The observations were implemented to provide contextual evidence on the nature and severity of the participants' dysphagia. For the purpose of this project, observation of the participant with dysphagia eating a typical meal was completed in the person's regular mealtime environment, with their typical food, and their supporter present (if this person was typically present during mealtimes). This was done to enable completion of the Dysphagia Disorder Survey and Dysphagia Management Staging Scale (Sheppard et al., 2014; Sheppard et al., 2017). Participants were fully informed they were being observed and the overt observations were conducted in the participant's natural setting to reduce any negative connotations associated with the assessment.

Mealtime observations took approximately 45 minutes and were audio- and video-recorded to ensure accuracy of the data collected. The direct observations allowed the researcher access to the person's regular mealtime environment and allowed the researcher to observe any routine behaviours that escaped the participant's or the support person's notice (Patton, 2014). Observations also allowed the researcher to observe events or behaviours that the participant did not necessarily discuss in an interview. A safety protocol was also in place if an adverse event occurred (e.g., choking on food). The safety protocol and standard operating procedures for mealtime observations are in Table 5 (overleaf).

Table 5

Standard Operating Procedure for Mealtime Observations at Home

Note: In the context of COVID-19, these procedures are easily adapted to an online format by using a smart phone or iPad in the person's home, which is operated by the participant or their support worker or family member. Dysphagia assessments are currently conducted using telepractice safely in Australia, using a camera set up and a video-conferencing call. The procedures outlined below are possible in person or online, and are similar regardless of format. This is because the same safety procedures apply whether the researcher is present or online.	1. Before the observation, the researcher will request a copy of the procedure on choking. On the day of the observation, the researcher will introduce themselves to the site manager and to the Participant and remind them of the purpose of the visit. 2. In the participant's own home, in a location that is convenient for them, a camera will be set up (e.g., by the participant or a support person) for appropriate recording of the participant's mealtime and interview. 3. The participant will eat their usual meal and drinks under observation of the researcher, who will record observations in field notes and complete the Dysphagia Disorder Survey. Whether in person or online, the same procedures will be followed. In the observation, the researcher will instruct the participant and their support person to eat their usual foods and drink their usual drinks while being observed. The person would have supervision during the meal from their usual mealtime assistant (as it is a typical meal, including their typical foods and assistance provided). As they would now also need assistance for access to the Internet, and set up of that and camera, we can ensure that the assistant remains present with the person in the event of an unusual choking incident or coughing that needs intervention (e.g., back blows) which would be rare but could happen just by chance. 4. If coughing occurs during the meal, the participant and support person will be instructed to have no further food will be provided until the person has recovered their usual breathing pattern. Coughing is protective and is a reflex to clear food away from the airway area in the throat (e.g., the larynx). If the coughing is not effective in clearing the food away (i.e., is persistent, weak, or ineffectual), or the person does not return to their usual breathing pattern, the support person present during the meal will be asked by the researcher to notify the site manager for their advice and to supervise first aid. 5. If the Participant exhibits signs of choking or any distress, or sign of allergic reaction, the mealtime observation will cease and the site's first-aid procedures will be followed.

All but one of the nine mealtime observations occurred online using Zoom and one occurred in person. In each online observation, the participant or family member/support person was asked to position the recording device in the room where they typically ate their meals so that the view of the researcher was clearly on the participant and their immediate environment. The same safety procedures applied online as in person; however, it was the responsibility of the support person to implement the intervention (see Table 5). If a choking or coughing event occurred, no further food was to be provided until the person recovered their typical breathing pattern. If coughing was not effective at clearing the food, or the person did not return to their regular breathing pattern, the support person was to administer first aid and the mealtime observation was ceased. Although this procedure was put in place, it was not implemented with any of the participants.

The clinical assessment and mealtime observations were conducted through participant observation. The Dysphagia Disorder Survey (DDS), the Dysphagia Management Staging Scale, and the Choking Risk Assessment and the Pneumonia Risk Assessment (Sheppard et al., 2014; Sheppard et al., 2017) were used in these observations to assess participants' swallowing skills, as the DDS has high inter-observer reliability and validity. Although the DDS has been validated for use with people with a developmental disability, it can be used as a descriptive tool with any population, with no normative data for other populations. It was possible that the mealtime observation would reveal that a participant had difficulty eating their typical foods and demonstrated coughing or choking. If this occurred, a referral was to be made to engage with a speech pathologist for follow-up on the person's diet and mealtime interventions; however, this did not occur. The DDS was also completed by one of the supervisors, a Certified Practising Speech Pathologist who has experience with dysphagia assessment and intervention and has received training in the administration and scoring of the DDS. Zoom was deemed suitable for conducting the mealtime observations during this research as telehealth procedures have been deemed a viable option for dysphagia assessment (Ward & Burns, 2014), particularly while COVID-19 restrictions were in place (Malandraki et al., 2021).

Five of the mealtime observations were attended by both the doctoral research candidate and her primary supervisor to allow for comparison of swallow ratings. During these observations, only one researcher had their camera and microphone turned on to reduce the feeling of 'being watched' for the participants. The remainder of the observations were conducted by the doctoral research candidate, and her primary supervisor watched the recording of the mealtime observation to complete her DDS rating.

In-depth Interviews

In-depth interviews were utilised to provide participants the opportunity to give detailed information on their perspectives and experiences. In-depth interviewing was suitable as it allowed the researcher to uncover how past mealtime experiences shaped participants' current behaviours and opinions (Kolb, 2016). The underlying nature of interviews, where participants respond in their own words rather than using the terminology of a survey, enhanced the flexibility of this data collection method. Lastly, although interview data can have limited generalisability, the method was suitable in establishing an evidence-based framework through the constructivist grounded theory approach (Giorgi, 2009).

An interview protocol (Table 6) was established based on findings of the previous systematic and narrative literature reviews completed by the researcher (Chapter 2 and Chapter 3; Smith, Bryant & Hemsley, 2022c; Smith, Bryant, Reddacliff et al., 2022). Participants were asked a set of common questions which allowed for comparison of responses from different participants to occur. Additional individualised questions were also asked depending on the participant's responses.

Table 6

Interview Topic Guide

Q1. Tell me about your usual mealtimes, for breakfast, lunch, and dinner, what do they involve for you?	*Examples of possible probing questions, depending on the responses to initial question.* • Do all meals meet the texture-modified diet recommendations? • Who determines food selection? • Who prepares meals? Is assistance required for cutting or opening cans/bottles? • What support do you need to cook the food? • There can be a lot of preparation in making pureed meals, how long does it take to make the meals? • Do you enjoy eating these foods? • Does the food look good, taste good, smell good, or is it served at the right temperature in comparison to food that is not pureed? • Do you consider mealtimes as a social event or a chore? • Do you make meals in bulk and then store some for another day? If so, how do you store the food?
Q2. What support do you receive from health professionals in managing your dysphagia?	*Examples of possible probing questions, depending on the responses to initial question.* • How did they help, what did they do? • Do you have a written mealtime management plan? • Were you involved in writing your mealtime plan (e.g., did you include your favourite foods)? • If you ask for something to be changed, do they try and change it or do they continue to follow your normal routine?
Q3. Can you explain any impact of your swallowing difficulty on your quality of life, social life, or ability to take part in social events?	*Examples of possible probing questions, depending on the responses to initial question.* • What are social events involving food like for you? • Do you enjoy going to social gatherings that involve a meal? • Do you have to find out the types of food that will be served before you go to an event? Is this embarrassing? • Have you ever refused an invite to a social gathering because you did not want to eat around others? • How easy is for you to get food that meets your dietary requirements when out? • If you cannot eat the foods served when out with others, how does that make you feel? • Do you require any other assistance at mealtimes (e.g., adapted cutlery)? How do you feel about using these tools when eating with other people?
Q4. How is your pureed food usually presented on the plate? What do you think of the way the foods looks in terms of being appetizing?	*Examples of possible probing questions, depending on the responses to initial question.* • Are the foods appetizing to you? Do they look attractive? • Do they use food moulds or piping bags? • Were these methods successful? What made it successful or unsuccessful? • What could make these food design methods more successful?

Interviews were conducted by the researcher and took approximately 60 minutes. Each interview was audio- and video-recorded for later analysis. Rapport-building with interview participants was an essential component of the in-depth interviews to ensure the quality of data collected. As the interview process involved discussing personal and sensitive information relating to health and wellbeing, the researcher needed to be seen as someone who could be trusted (Kolb, 2016). Through the in-depth interviews, the researcher took meaning not only from participant's verbal responses but also their body language (Kolb, 2016). In regards to prompts during the interviews, descriptive questions were asked and the researcher used further probing questions if needed to expand the participants' response (see Table 6). Participants were provided the opportunity to have a break from questions if they were fatigued. This was particularly important for participants who presented with health conditions that impacted on their overall energy and fatigue levels (Kolb, 2016).

The views of supporters of people with dysphagia were important to collect as they could provide further insights into the impacts of dysphagia on the quality of life of carers – previously described by Mahant et al. (2011). The perspectives of the supporter of the person with dysphagia were also important to include, as Lisiecka et al. (2021) reported that participants with motor neurone disease and dysphagia did not identify dysphagia as a difficulty if it was not affecting them on the day of the interview; consequently, the presence of a support person may assist in verifying their experiences with dysphagia. Although this research did not specifically include people with motor neurone disease, this was still viewed as an important consideration for all participants, particularly for those who required support at mealtimes.

As noted above, all but one of the interviews were conducted online using Zoom and one was conducted at the person's own home. Online data collection allowed the researchers to continue to collect data that shaped the evidence-based framework emerging when face-to-face data collection could not be implemented (Curasi, 2001). Previous research has found that interviews conducted online instead of face-to-face do not have poorer data outcomes, as online interviews can be conducted at a time and place most convenient to the participant (Janghorban et al., 2014). Furthermore, online video-conferencing allowed the researcher to observe the same verbal and nonverbal cues as seen in face-to-face interviews (Janghorban et al., 2014). Researchers acknowledged that data collection issues may have arisen during online interviews if the interviewer was unable to build rapport in the same way as a face-to-face interview and could lead to participants providing shorter and less informative responses (Curasi, 2001). However, this did not occur and the participants were motivated and engaged in the research and able to provide the same level of detail online that would be provided in a face-to-face interview (Curasi, 2001). All participants in this study appeared to be motivated to engage in the interviews as dysphagia is a condition they live with on a day-to-day basis. Furthermore, the researcher is experienced in engaging with people via telehealth and this assisted in building rapport.

Narrative Analysis of Interview Data

Although this study follows the analysis principles of a constructivist grounded theory approach, narrative analysis techniques were also used to analyse the data from the participant interviews regarding the impacts of dysphagia on quality of life. NVivo 12 (QSR International, 2018) was used to store and analyse the data. A narrative or story is any form of text that is joined together to carry a sequence of ideas (Polkinghorne, 1995). For the purpose of this study, a narrative was defined as a unit of text that has a clear beginning and end and could be separated from the rest of the text (Riessman, 2007). When telling narratives, people tell their truth of an event, thus providing insight into their standpoint on events that require interpretation (Holstein & Gubrium 2012; Riessman, 2007). Because of this, narratives were analysed to fully appreciate and increase understanding of events rather than controlling how they were expressed (Crossley, 2007).

Narrative understanding and analysis have been increasingly used in research, particularly within the human science fields (Connelly & Clandinin, 1990). Narrative analysis refers to the process whereby a large amount of text is transformed into a meaningful story that gives rich details of an event experienced by the participant (Crossley, 2007). In terms of this research project, the participants' stories were collected through the in-depth interviews to assist the researcher to understand the participant's experiences of swallowing difficulties. Narratives were then analysed to describe the participant's views, emotions, and personal motivators across a specific sequence of events (Crossley, 2007; Holstein & Gubrium 2012).

As part of narrative analysis, five levels of representation in examining narratives and the impacts were considered to understand the participants' experiences (Riessman, 2007). Due to the level of interpretation required at each stage of this process, an overall master narrative of events does not exist (Riessman, 2007). These stages of narrative analysis are (a) the person's choice of what they noticed in a situation (e.g., if the person prioritised what they could see rather than what they heard); (b) the person who experienced the event telling the story to the researcher (some details of events may be missed); (c) the researcher transcribing the story (an interpretive practice, as nonverbal components of language cannot be transcribed); (d) the researcher completing explicit analysis of the narrative to find integral moments of the story; and (e) the researcher creating an overall summary of the events described (re-storying) (Holstein & Gubrium 2012; Riessman, 2007).

The process of re-storying was useful when examining the stories provided by interview participants, as they were often not told in a sequential order and required reordering (Crossley, 2007). The process also helped to provide meaning to specific audiences, including people with dysphagia, supporters of people with dysphagia, and allied health professionals. Narrative analysis started during the transcription process to gain greater insights into the stories told and approaches to problem-solving implemented regarding their experiences with dysphagia (Crossley, 2007). The narratives related to the emerging content themes identified in the inductive analysis process.

Collection and Analysis of Mealtime Documents

With participants' consent, documents related to the participant's dysphagia diagnosis were examined to provide insights into the information provided by health professionals on mealtime quality of life (Bowen, 2009; Patton, 2014). These documents were requested from the participants with dysphagia, not their health care providers, which gave them the choice in the information they provided. Mealtime plans and speech pathology assessment reports were especially helpful as they provided information about the participant prior to their involvement in the research (Bowen, 2009; Patton, 2014). In particular, these documents provided information on the person's recommended diet, any compensatory strategies the person used at mealtimes to assist their swallowing, and any reference to the impacts of the recommendations on quality of life, participation, and inclusion. If documents were provided prior to the interview, the researcher used the information as stimulus for lines of inquiry during interviews (Patton, 2014).

Mealtime documents were examined against a document data extraction checklist to determine components of the person's mealtime discussed (see Table 7 for the document data extraction form). Data extracted included type of diet, body positioning during meals, equipment used, participation in mealtimes, inclusion in mealtimes, compensatory swallowing strategies used, mealtime assistance provided, and after-meal care provided. The collection of these documents was efficacious as the additional information from reports assisted researchers to uncover conditions that impact on participants to establish a thorough evidence-based framework of quality of life in dysphagia management (Mills et al., 2006).

Table 7

Mealtime Document Data Extraction Sheet

Document type	Plan / report / other
What is the severity of dysphagia?	
What symptoms of dysphagia are reported? (e.g., coughing, food pooling in mouth)	
Oral diet: textures recommended / foods that the person can and cannot have	
Position: Specific positioning for mealtimes (e.g., princess chair, upright in bed)?	
Equipment: assistive devices used at mealtimes, if so are all devices listed (e.g., glasses, dentures, hearing aids)?	
Participation: Any comment on the person's involvement in the decision about the plan / compliance or otherwise	
Participation: Description of types of food the person likes/ dislikes?	
Participation: How to make meals accessible to the person during the mealtime (e.g., in their reach and visual field)?	
Inclusion: What environment does the participant eat their meal in (e.g., at table with others)?	
Compensatory strategies: that can be used during mealtimes to reduce risk (e.g., alternating boluses, chin tuck, extra time for each mouthful of food)?	
Mealtime assistance: Assistance required during the meal (e.g., assistance in putting food on utensil and bringing to mouth, cutting food)?	
Mealtime assistance: What verbal directions are used at mealtimes (e.g., directing person what to do)?	
Mealtime assistance: Response to choking if it occurs during mealtime?	
After-meal care: Does the report mention oral care required after meal, if so what is it (e.g., make sure mouth is empty)?	

Study 1b: 3D Printed Food Experience

3D printed food experiences were conducted with the Foodini 3D Food Printer (Natural Machines, 2022a) at the University of Technology Sydney (UTS). All of the 3D printed food experiences of Study 1b were completed online using Zoom. Participants chose the shape and ingredient used for the print, then watched the printing process. Although the 3D printed food experiences could not occur face-to-face and participants could not eat the food, the researcher was trained in safe food handling techniques to reduce the risk of any adverse effects occurring upon consumption of the 3D printed food. Each participant with dysphagia and their support person attended individual 3D printed food experiences to receive an immersive experience that was not influenced by the opinions of others. Each 3D printed food experience took approximately 60 minutes to allow participants enough time to observe all of the steps involved in the printing process. This period included a short interview to determine the participants' perceptions of the 3D food printing process (see Table 8 for question guide). The 3D food printing experiences were also video and audio recorded for later analysis. The 3D printed food experience (Study 1b) was conducted with participants from Study 1a: nine participants with dysphagia and four of their supporters. Similar to Study 1a, the findings of the 3D printed food experiences were verified through Study 3 (surveys).

Table 8

3D Printed Food Experience Question Guide

Thoughts on 3D food printing	1. Have you seen or used a similar device before? 2. What is your first impression about the machine? Would you like to use the machine? 3. What do you think about the ingredients being put into capsules, do you think this could be used for everyday food preparation? 4. Do you think you would be able to use the machine with support? 5. There is enough variety of meals to choose between so you're not eating the same food or ingredients. (strongly disagree, disagree, neutral, agree, strongly agree) 6. The Foodini is currently on sale for $7,000 Australian dollars. Do you think this is a good investment? (strongly disagree, disagree, neutral, agree, strongly agree) 7. Do you think the 3D food printing machine could be improved? 8. Do you think you could use a similar device at home?
Usability questions based on Nielsen (1994) usability heuristics	1. **Visibility of system:** Does the machine have appropriate icons to show machine status? Does it provide adequate feedback for actions? Can you tell what the machine is doing? 2. **System and real-world match:** Does the machine use words you understand? Can it be learnt in a natural way, does it build upon your previous knowledge? 3. **Use control/freedom:** Does the machine allow you to reverse/undo actions or allow you to get out of completing a specific action? 4. **Consistency/standards:** Are information and instructions provided in a consistent manner for all tasks? Are icons always in the same place across different screens? 5. **Error prevention:** Can machine prevent error from occurring before it happens? Does it identify when a user action may lead to a mistake? 6. **Recognition rather than recall:** Do visuals on the machine promote recognition of a task? (Is it simple to remember the following step in a task or are constant reminders needed?) 7. **Flexibility and efficiency:** Can machine functions be tailored for use? E.g., are there shortcuts available? Can you change the order of tasks?

Analysis of Usability of 3D Food Printing

Participants' 3D food printing experiences were evaluated through usability heuristics (Nielsen, 1994). Usability heuristics are a set of principles used to identify or examine any problems or usability issues with a computer-operated device. Heuristic evaluation aims to judge the user interface of a computer-operated device for its compliance with usability principles (Nielsen, 1994). These usability heuristics include the visibility of the system, the correlation between the computer system and the real world, the ability of the user to control the device, the consistency of processes, ability to prevent errors, ability for the users to recognise processes, flexibility of use, the aesthetic design, and the ability of the device to assist user recognition of its features and processes (see Table 8) (Nielsen, 1994). As a specific set of usability heuristics has not been developed for 3D food printers, the heuristics presented by Nielsen (1994) were adapted for the 3D printed food experiences. The device was examined by multiple participants as Nielsen (1994) demonstrated that while individual examiners only caught 35% of usability issues, the use of many examiners may find 60–75% of issues. Through these usability heuristics, comments about the 3D food printer could be categorised based on the heuristics of general computer systems. The use of these heuristics also allowed the researcher to identify relationships between characteristics discussed between participants. The 3D printed food experiences provided in-depth qualitative data, however, may not be generalizable to all people dysphagia as many also have co-occurring difficulties with motor difficulties which would impact on their ability to use the machine.

Confirmation of Analysis

Participants who engaged in Study 1 were sent a written summary of the discussion from the interview, mealtime observation, and 3D printed food experience to verify the researcher's interpretation. Five of the interview participants responded by email to confirm that the summary was an accurate interpretation of discussion and one participant confirmed the findings through a short follow-up interview. This was one method used to confirm the rigour of the study.

Study 2: Focus Groups

While Study 1 showed the views of people with dysphagia, it did not provide the perspective of allied health professionals who work with people with dysphagia. As a result, focus groups with allied health professionals who work with people with dysphagia (e.g., speech pathologists, occupational therapists) were held between March and May 2021. Focus groups aimed to (a) verify and expand upon the findings of Study 1, and (b) obtain further insights from allied health professionals on the impacts of dysphagia on quality of life and the feasibility of 3D printing of food as a means to improve mealtime quality of life. Focus groups also explored strategies to remove barriers to and enhance facilitators of better mealtime experiences for people with swallowing disability. The research questions examined by this study are presented in Table 4 above.

Participants were purposively recruited through social media and the same organisations as Study 1 (i.e., disability organisations in Sydney, Australia). Snowballing recruitment techniques were also used to gain further participants. Allied health professionals and managers were eligible to participate in focus groups if they had provided services to people with dysphagia for at least two years. The groups were moderated by the PhD candidate. A co-moderator was also present at the first two focus groups to assist the moderator. The co-moderators were the supervisors of this PhD project who are also Certified Practising Speech Pathologists with extensive experience in qualitative data collection.

Focus groups were held to achieve understanding of the study topic through the collective views and common experiences of the world (Morgan, 2019). Focus groups were also used in conjunction with interviews to help generalise the scope of the project and to establish new ideas (Morgan, 2019). Focus groups were utilised to reveal views and opinions that may not have been apparent in a one-on-one interview (Kitzinger, 1995). Focus group methods were well-suited to generate new ideas through interaction of participants who had similar levels of knowledge and experience (Kitzinger, 1995; Krueger & Casey, 2014; Morgan et al., 1998). The group environment also provided participants the opportunity to learn from other health professionals and re-evaluate their own opinions. Furthermore, focus groups were an effective method of collecting quality of life data as participant experiences could be explored and validated by other participants (Lane et al., 2001).

Four focus groups were conducted, as Hennink et al. (2019) reported that 88% of codes were identified within the first three focus groups and no new codes were found after the sixth focus group. Focus groups typically contain three or more participants to allow the researcher to examine the behaviours and opinions of the participants in an in-depth manner (Hennink et al., 2019). The fourth focus group in this study only included two participants and could be considered a small group interview. However, Focus Group 4 followed the same format and methods using the topic guide, and thus the discussion that occurred was similar to that in the first three focus groups. As a result, it was considered a focus group for the purpose of this study. The average number of participants in the group was four participants. Each focus group went for two hours which allowed for delays that occurred in the virtual environment (e.g., turning microphones on to speak) (Turbitt & Jacobs, 2021). The focus groups were homogeneous in that participants had shared experiences, i.e., they were health professionals who work with people with dysphagia (Liamputtong, 2011). Even if heterogeneity existed with their social and cultural backgrounds, the discussion was still highly successful due to their shared experiences and the diversity among the participants, which encouraged further discussion (Liamputtong, 2011).

Once participants agreed to engage in a focus group, they were sent a link to an online poll (Doodle, 2021) to select days and times they were available to take part. Participant preferences were compared to determine a time that was the most suitable. Groups were established based on the availability of the participants, not on the participants' role, years of practice, or geographical region. This maintained some diversity and heterogeneity within the groups. Participants were then sent an invitation using Outlook Calendar to join the focus group using Zoom. Holding the groups online allowed for recruitment to occur internationally to gain the perspectives of a wider variety of perspectives on the issue. Online groups reduced travel time for all participants and researchers as they could participate from home or work without travelling to a venue of the researcher's choice. By running focus groups online, the researcher was also able to reduce costs associated with running a focus group (e.g., venue costs, refreshments) (Turbitt & Jacobs, 2021).

Once each group commenced, the moderator established a relaxed and friendly environment for the participants to create an effective group atmosphere (Litosseliti, 2003). The moderator provided an explanation of the focus group purpose, outlined the focus group rules, and then asked the opening question to ease any feelings of awkwardness or anxiety in being part of the group (Litosseliti, 2003). In the opening question, participants were asked to introduce themselves, provide their profession, and describe their role in working with people with dysphagia. This ensured all participants were heard from the beginning of the group (Krueger & Casey, 2014). Participants were also encouraged to mute their microphone if they were not talking to reduce potential interruptions. As Zoom was used for the focus groups, participants could also interact with the moderator privately or with the whole group using the comments function. This allowed for flexibility in communication, as participants could verbally make a comment or write it as a written comment (Turbitt & Jacobs, 2021).

There were benefits of conducting the focus groups online. Online focus groups can facilitate a significantly greater amount of communication than traditional focus groups held face-to-face (Reid & Reid, 2005). This increased communication may give greater depth in the content that is collected; however, it may not lead to a significant difference in the number of ideas and themes generated by the group (Reid & Reid, 2005). Virtual focus groups can be useful for observing facial expressions of the participants as they typically remain facing their camera the entire session and are not sitting at an angle at which the researcher is unable to see their face (Turbitt & Jacobs, 2021). Furthermore, participants could remain anonymous to other participants if desired by turning their camera off or by using a pseudonym instead of their real name (Liamputtong, 2011). This meant that participants may have been more likely to make critical comments and engage in the generation of novel ideas.

The focus group participants were asked key questions based on the findings of the previous literature reviews (Chapter 2, Smith, Bryant & Hemsley, 2022c; Chapter 3, Smith, Bryant, Reddacliff et al., 2022), and the results from Studies 1a and 1b (Chapter 7 and Chapter 10; Smith, Bryant & Hemsley, 2022a; Smith et al., in press-b) (see Table 9 for the focus group topic guide). Participants were asked to generate ideas on how quality of life, participation, and inclusion could be improved for people with dysphagia. In doing this, they had to consider 3D food printing and the experiences of people with dysphagia. Each focus group went for approximately two hours, allowing all participants an opportunity to speak. Each focus group was audio- and video-recorded for later analysis by the researcher.

Table 9

Focus Group Topic Guide

1. Participant role	What is your role in relation to supporting with people with dysphagia and their mealtime experiences?
2. Impact of dysphagia	How do you think dysphagia (or food modifications needed for people with dysphagia) impacts on a person's quality of life, participation, or inclusion?
3. Effectiveness of texture-modified food and food shaping	How do you currently provide texture-modified foods? (e.g., food shaping, moulds, piping bags, etc.) How effective are these methods?
4. Impacts of texture-modified food	Are there any other impacts of texture-modified meals on a person that would also affect their health or quality of life?
5. Role in food design	What is your role in supporting people with dysphagia to participate in food design and selection: (e.g., choosing meals, meal preparation/ cooking, eating meal with others, mealtime discussion, party foods)
6. Short intro to the 3D food printing with a picture Sequence of the 3D food printing. "This is the Foodini 3D food printer which prints food in the form of puree or paste. The puree put into capsules and then pushed out to make the food item (similar to an inkjet printer). Once the food is printed, it can be eaten as is, cooked or frozen to be reheated at a later time."	What do you think of using 3D printed food in mealtimes for people with dysphagia? Would it potentially work? What barriers/facilitators to using this technology might there be?

The focus group moderator observed how each participant engaged and communicated within the group. The moderator than provided comments to shape the discussion and participation so all participants had an opportunity to provide their views (Litosseliti, 2003). Picture aids and videos of 3D printed food (see Chapter 11 Appendix) were used to direct group discussion. The researcher also provided a brief summary of the discussion at the end of the group to stimulate any further discussion between participants if anything had been missed (Litosseliti, 2003).

Analysis of Focus Group Data

The focus group analysis involved using NVivo (QSR International, 2018) to store, code, and retrieve all data into content themes and categories. Various factors were considered during analysis, including the context in which participants made statements and the participants' experiences (Krueger, 2002). This allowed for triggers to be identified for further analysis. All statements made by participants were reviewed for internal consistency to determine if participants maintained their views throughout the focus group. Statements were examined to determine how frequently topics were discussed (Krueger, 2002). The interpersonal dynamic between participants was also observed to determine if it impacted on the data collected (e.g., if there were regular interruptions or if there was a power dynamic influencing responses) (Hennink & Leavy, 2014). Once this occurred, the data was examined as a whole to determine the overall themes discussed in the focus group. Due to the fact that no dietitians were successfully recruited for the focus groups, saturation was not achieved.

Systematic analysis of the focus group data began while the focus groups were being held. The focus group moderator listened for any vague or inconsistent comments and probed for clarification (Krueger, 2002). The researcher also debriefed immediately after the focus group with co-moderators to record any themes or ideas that emerged from the focus group. The recording of the focus group was then transcribed verbatim by the researcher and a summary of each focus group was created. This information was clarified with co-moderators present to ensure the accuracy of the results before being sent to focus group participants by email to confirm the summary matched the discussion that occurred. Participants were invited to make modifications to the summary and to verify that it accurately reflected their discussion. One participant from each focus group responded and no changes to summaries were required. The results from all focus groups were then compared and contrasted to determine variations or consistencies in the discussions and the researchers found a high level of internal consistency with the comments made during the group discussions (Krueger, 2002). The researchers then identified all emerging themes that were highlighted with quotes and decided follow-up focus groups were not required. The final component of analysis required results to be combined and themes to be reported upon. This analysis aligned closely with social constructivism as the knowledge and data of the focus group was established through interactions with others.

Study 3: Survey Data and Analysis

An amendment was accepted for the original approved project to allow data collection to occur through an online survey (Study 3) to support the findings of Studies 1 and 2 (ETH21-6568 and ETH21-6781). A survey was used to support the findings of Studies 1 and 2 as Wolff et al., (1993) reported that the implementation of a survey after focus groups or interviews could enhance the quality of the data analysis and increase confidence in the research findings. The survey was created using RedCap (Harris et al., 2009) and questions were based on the emerging findings from Studies 1a, 1b, and 2 (Chapters 7, 8, 10, and 11; Smith, Bryant & Hemsley, 2022a, 2022b; Smith et al., in press-a, in press-b) as recommended by Wolff et al., (1993). Participants were recruited through the social media networks of the researcher and supervisors. For the survey, participants with dysphagia, supporters of people with dysphagia (including direct support workers or family members), and allied health professionals who work with people with dysphagia were eligible to participate. Once participants clicked on the link to the survey, they were taken to the participant information statement where they gave consent for their involvement in the study. The survey was open from November 2021 to February 2022. See Appendix F for the complete survey tool.

Surveys are often used in quantitative research, and can also be used in qualitative research to examine the diversity of perspectives on a topic in a specific population group. In this context, surveys may contain open-ended questions that allow participants to respond in their own words (Braun et al., 2021). The purpose of a qualitative open-ended survey questions was not to count the occurrence of a specific characteristic within a population but to find meaningful variation and diversity within that group (Jansen, 2010). Analysis of such information allowed the researcher to examine a person's experiences and the meaning attached to them (Jansen, 2010). Qualitative open-ended survey questions were particularly useful due to their ease of access in comparison to other qualitative methods (e.g., face-to-face interviews) (Braun et al., 2021; Glasow, 2005).

The wording of survey questions was particularly important to encourage participant responses as, unlike interviews, the researcher could not ask probing questions or ask for clarification (Braun et al., 2021). Providing definitions of the terminology used provided further clarity for participants and ensured they did not make incorrect assumptions about the questions. The survey questions were also designed similarly to the questions of Study 1 and 2 to confirm the findings; however, the structure was modified for the survey by asking close-ended questions before asking for further details (Braun et al., 2021). The survey contained an array of question types (e.g., Likert scales, multiple choice, or open-ended questions for text responses) (Wolf et al., 2016). Motivation was also maintained in the survey by it being relatively short; it was designed to take participants approximately 15–20 minutes to complete, significantly less time than required for the interviews or focus groups.

The use of survey questions designed to elicit open-ended responses was suitable as this allowed for a wide range of perspectives to be collected on a topic (Braun et al., 2021). This was particularly important when examining a condition such as dysphagia, where the population is highly heterogeneous, and when examining a concept – the impact of dysphagia on quality of life and the feasibility of 3D food printing – that is under-researched (Braun et al., 2021). Furthermore, online surveys are affordable and easily accessible by people living in a wide range of geographical areas. Online surveys can also be completed at a time that suits the participant. For example, in the organisation of interviews and focus groups for this study, participants and researchers had to find a time that was mutually suitable. This was not required for the survey, which could be completed at any time (Braun et al., 2021; Glasow, 2005).

There were some drawbacks of online surveys that needed to be considered to ensure successful survey implementation. Online surveys required participants to have access to a suitable device and to have adequate cognitive and literacy skills to read the questions and compose answers. These requirements may have excluded potential participants who did not have the skills or the equipment to access the survey (Braun et al., 2021). These impacts were reduced in this project by giving people the opportunity to fill the survey out with the assistance of a support person or, if requested, to provide a verbal account of their perspective and experiences instead.

Although surveys may not provide the same level of detailed and in-depth information as can be collected in interviews (Braun et al., 2021), the survey method enabled the researcher in this study to collect the experiences and perspectives of people who were not able to participate in the interviews or focus groups. For example, a person who did want to engage in a one-on-one interview could engage in the survey while remaining anonymous. Lastly, potential participants for the interviews or focus groups may have decided not to engage in the project due to the time commitments. The survey provided a more time efficient method for these participants to be involved in the study (Braun et al., 2021).

The survey was piloted with two speech pathology colleagues of the researcher and changes were made to the survey accordingly. By piloting the survey, the researcher confirmed the question logic used to ensure that people with swallowing difficulties, supporters of people with dysphagia, and allied health professionals all received the correct questions. It also allowed the researcher to confirm that questions were written in a manner that encouraged a response. As the survey in this project supplemented information collected through interviews and focus groups, the sample collected of 52 complete surveys was deemed appropriate to achieve a suitable analysis of results (Groves et al., 2009; Patton, 2014).

The survey could be accessed by participants directly through a QR code or URL link. Participants were provided information about the study on the landing page, and by continuing onto the questions participants gave implied consent to be involved in the study. The survey was divided into three sections: demographics, the impacts of dysphagia on quality of life, and 3D food printing. The first survey question asked participants their role in relation to mealtimes (i.e., a person with dysphagia, a support person of someone with dysphagia, or a health professional who worked people with dysphagia). Branching logic was implemented to provide the participant the correct questions for each participant group. This ensured all the questions were relevant to the participant. Although the questions were worded differently, they were based on the same fundamental concept, which allowed comparison to occur. The survey was anonymous other than the last question, which allowed participants to provide their contact details to be involved in a further interview if desired. This was optional and not a requirement for participants.

Analysis. Once the survey data collection period ended, survey responses that were left unfinished (i.e., if the participant did not complete any questions or if they only completed questions regarding demographic information) were excluded from analysis to reduce the occurrence of non-response errors during the analysis process (Wolf et al., 2016). Responses to open-ended survey questions were exported to NVivo (QSR International, 2018) for content themes to be determined through open and matrix coding methods (Braun et al., 2021). Closed ended question responses were exported to Microsoft Excel and analysed using descriptive statistics (Groves et al., 2009). Descriptive statistics were used as there were only 52 complete survey responses, too few to allow for statistical comparisons to occur within or across participant groups.

In regard to the open-ended qualitative survey questions, three levels of analysis were required to ensure the data was examined as a cohesive data set rather than individual responses to questions (Braun et al., 2021; Jansen, 2010). The first level, unidimensional description, related to coding into categories or themes. In the second level of analysis, a multidimensional description of data was created as analysis became concept-oriented and holistic synthesis of data occurred based on the core concepts (Jansen, 2010). In the third level of analysis, an explanation was provided through combinatory analysis (Jansen, 2010). Through these three levels of analysis, meaning was not connected to specific questions but to the concepts, and a deeper level of understanding of a social issue was achieved (Braun et al., 2021).

Qualitative Research Meta-Synthesis

Qualitative research synthesis, a type of theory-generated meta-synthesis, was used to develop a conceptual framework through the synthesis of the literature reviews in Chapters 2 and 3 (Smith, Bryant & Hemsley, 2022c; Smith, Bryant, Reddacliff et al., 2022), and Studies 1–3, which are reported in Chapters 7–12 of this thesis (Smith, Bryant & Hemsley, 2022a, 2022b, 2022d, 2022e; Smith et al., in press-a, in press-b). Through this synthesis, all included studies were combined and analysed to develop an overall guiding framework to shape future dysphagia practice on quality of life and 3D food printing. The framework described (a) the impacts of dysphagia on quality of life, participation, and inclusion, (b) barriers and facilitators to quality of life, and (c) the feasibility of using 3D food printing to improve the mealtime experience of people with dysphagia (Major & Savin-Baden, 2010). This meta-synthesis assisted in improving the transferability and applicability of the results from the individual qualitative studies conducted (Finfgeld-Connett, 2018). As noted in Chapter 4, it was also acknowledged that the researcher's clinical and research background shaped the findings of the overall synthesis.

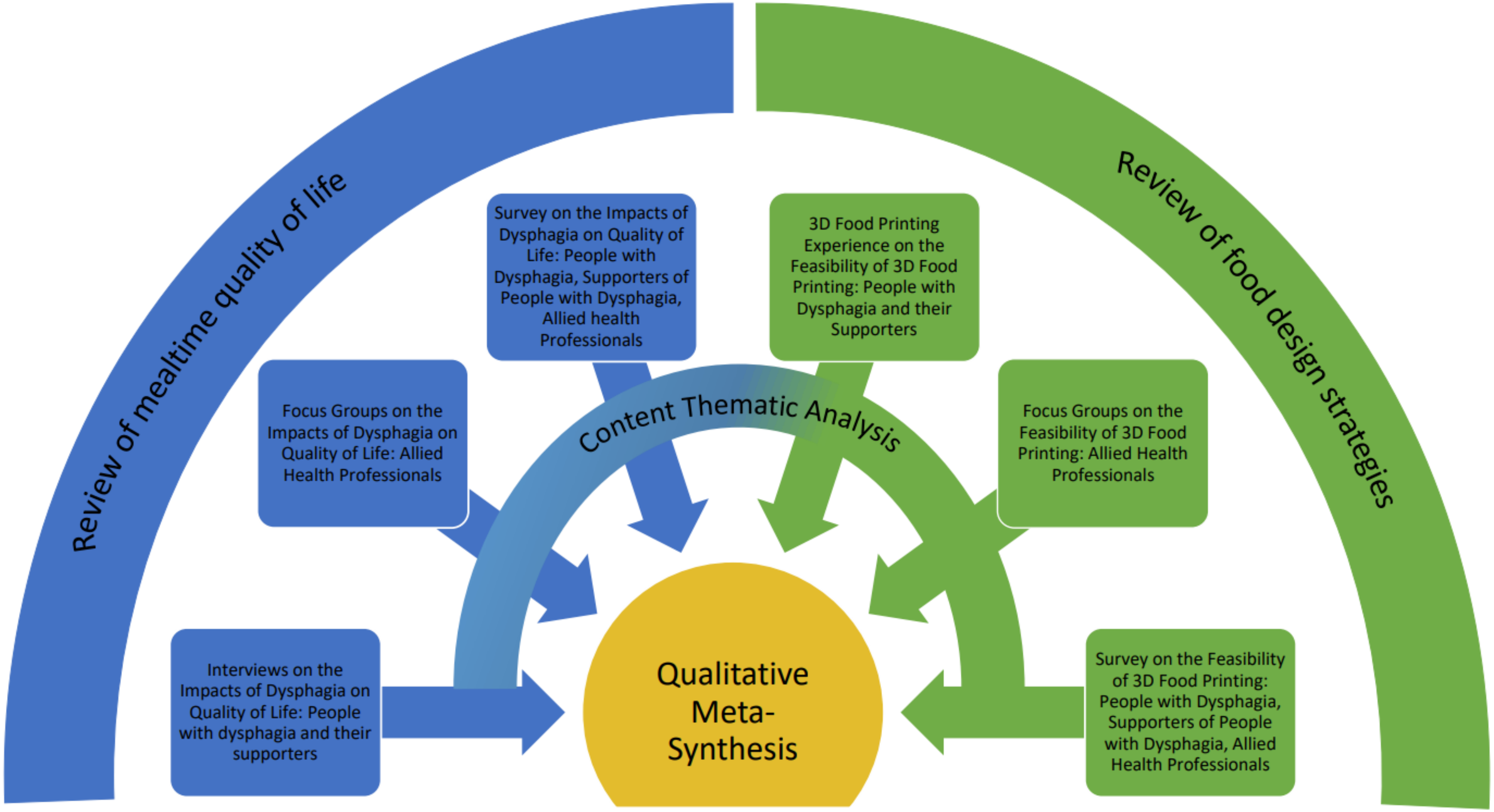
The trustworthiness of the qualitative meta-synthesis was embedded within the individual qualitative studies included, with a number of strategies implemented in each to maintain the credibility, transferability, and dependability of the data and analysis within each (Major & Savin-Baden, 2010). All of the studies included in this qualitative research synthesis had similar methodological standpoints which improved the rigour of the synthesis. The triangulation of the studies as part of the synthesis and the discussion and confirmation of the results between researchers also assisted with the credibility of this qualitative synthesis study (Major & Savin-Baden, 2010).

Analysis and Synthesis of Studies

Reciprocal translation analysis, which refers to the process of incorporating concepts from one study with concepts from another study, was used. The results of Chapters 7-12 were combined and directly compared. This reciprocal translation occurs when through this comparison, the researcher identified key themes and categories in the studies to be translated (Major & Savin-Baden, 2010). Each individual study was examined and information collected on the context, participants, methodology, methods, and main findings. A visual representation of this process can be seen below in Figure 3.

Figure 3

Conceptual Map of the Reviews and Studies Informing the Analysis



In the analysis process, relationships between studies were identified by organising content themes and component categories reported in each study. Thematic coding was used and researchers started data exploration without prior assumptions of the data (Major & Savin-Baden, 2010). This coding method followed the methodological standpoint of the overall project (Mills et al., 2006). Matrix coding was then used to determine the relationships between these codes. The researcher used these methods to move through level one analysis, level two synthesis, and level three interpretations (Major & Savin-Baden, 2010). Hence, it was not only the data that were compared between the studies but also the themes and similarities and differences between the various parts of the studies and different data sources. Once this final synthesis was completed, the researcher invited all participants who provided their contact details to attend an online seminar discussing the results of the study.

Reflexivity

The researcher made written reflective notes in a journal on a weekly basis, noting any thoughts or new insights relating to the investigation underway, as a strategy to maintain reflexivity (Charmaz, 2017). This included making a note of any theoretical assumptions at the beginning of the research process (e.g., the theory of health related quality of life and dysphagia related or mealtime quality of life). These notes were reviewed regularly and updated as new data came into the project. In conjunction with keeping a weekly journal, the researcher also listened back to the recordings of the interviews and focus groups to determine how the researcher's comments and questions influenced the data collected. The interview and focus group question guides assisted the researcher to maintain a certain level of objectivity through this process. Lastly, all results and analysis from studies 1a, 1b, 2, and 3 were checked by research supervisors, who acted as second and third raters to maximise reliability and dependability of results (Lane et al., 2001). This ensured all data was interpreted correctly and agreed upon. It also allowed for the data to be validated and enhanced the credibility of data collected from Studies 1a, 1b, 2, and 3 (Lane et al., 2001).

Feasibility of the Research

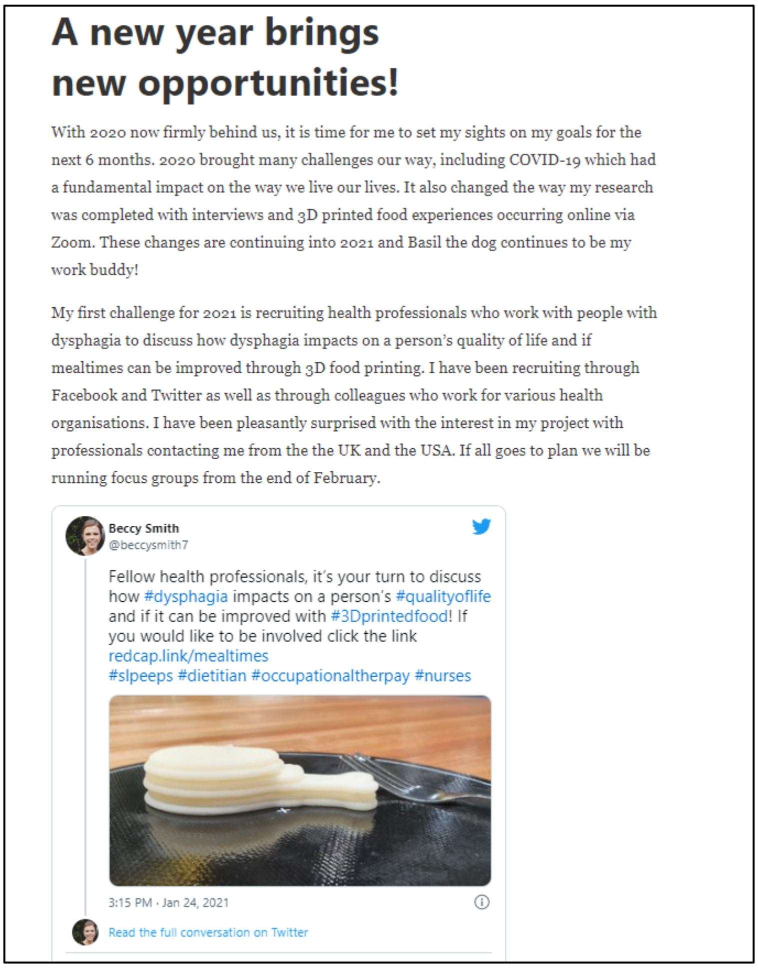
This research was conducted by a Certified Practising Speech Pathologist with clinical experience completing assessments and intervention with people with dysphagia and their family members. The candidate also has research experience, having received First Class Honours in 2016 at the University of Newcastle, Australia, and published her work in 2018 in the *Clinical Journal of Speech-Language Pathology*. In regards to funding, the research candidate was awarded a UTS Doctoral Scholarship (March 2019–December 2019), a National Health and Medical Research Council (NHMRC) Post Graduate Scholarship (APP1191359) (January 2020–March 2022), and an Australian Government Research Training Program Scholarship (March 2019–September 2022) for this project. The University of Technology Sydney was in possession of a 3D food printer, Foodini (Natural Machines, 2022a), through an NHMRC Resource Grant received by Professor Bronwyn Hemsley. The research candidate was trained and experienced in using the 3D food printer through her involvement as a research assistant in the Transdisciplinary Tastes project led by Professor Hemsley. The 3D food printer could be used to successfully print pureed foods that meet IDDSI standards (IDDSI, 2019), indicating the food was appropriate for people with dysphagia who required a pureed diet.

Research Dissemination

A wide range of strategies for research dissemination were used throughout this project. To date, two literature reviews and one results paper have been published in international peer-reviewed journals and five more articles are at the stage of first or second review for publication. Research has also been published in the proceedings of several international and national conferences, which has assisted in improving the research impact. A research blog and social media (mainly Twitter) were also utilised to communicate the findings of the research. An example screenshot of the research blog can be seen below in Figure 4. The implementation of these strategies allowed for the researcher to reach a wider population, including those who may not have access to academic research databases. The researcher also sought opportunities to present in a wide range of settings which are highlighted below in Table 10.

Figure 4

Screenshot of Research Blog (From: https://rebeccasmithsp.wordpress.com)



A new year brings new opportunities!

With 2020 now firmly behind us, it is time for me to set my sights on my goals for the next 6 months. 2020 brought many challenges our way, including COVID-19 which had a fundamental impact on the way we live our lives. It also changed the way my research was completed with interviews and 3D printed food experiences occurring online via Zoom. These changes are continuing into 2021 and Basil the dog continues to be my work buddy!

My first challenge for 2021 is recruiting health professionals who work with people with dysphagia to discuss how dysphagia impacts on a person's quality of life and if mealtimes can be improved through 3D food printing. I have been recruiting through Facebook and Twitter as well as through colleagues who work for various health organisations. I have been pleasantly surprised with the interest in my project with professionals contacting me from the the UK and the USA. If all goes to plan we will be running focus groups from the end of February.

Beccy Smith
@beccysmith7

Fellow health professionals, it's your turn to discuss how #dysphagia impacts on a person's #qualityoflife and if it can be improved with #3Dprintedfood! If you would like to be involved click the link redcap.link/mealtimes
#slpeeps #dietitian #occupationaltherpay #nurses

3:15 PM · Jan 24, 2021

Read the full conversation on Twitter

Table 10

Research Dissemination Methods Employed

Output method	Number
Peer-reviewed journal articles (includes published or submitted)	8
International conference oral and poster presentations	4
National conference oral and poster presentations	3
Invited speaker (national)	1
Invited speaker (local)	2
Blog posts	10
Twitter posts	42

The implementation of these strategies assisted in promoting the research beyond the academic environment as well as improving confidence in and the credibility of the research.

For example, the researcher was invited to present at a meeting of the Myositis Association Australia to a group of people with myositis, many of whom had dysphagia, and their family members. As the people with dysphagia and their family members who attended this meeting were the potential end users of the 3D food printing technology discussed, they provided further insights, which confirmed the results found during data collection.

Conclusion

The constructivist grounded theory approach discussed in Chapter 4 was implemented through the qualitative data collection methods outlined in Chapter 5: in-depth interviews, mealtime observations, mealtime document analysis, 3D printed food experiences and interviews, surveys, and focus groups. Due to restrictions in place for COVID-19, most data collection for this project was completed online. Chapter 6 will provide greater details of the impacts of COVID-19 on this project.

Chapter 6: COVID-19 Impacts

The outbreak of COVID-19 had significant impacts on the progress of this research project and on the researcher. As a result, this chapter is written in first person. In this chapter I will discuss how this project was impacted by COVID-19 and the lockdown restrictions that followed. I will also briefly discuss the personal impacts the pandemic had on me as these events shaped my decisions in 2020 for my project.

In February 2020 I received approval from the UTS Human Research Ethics Committee (HREC) for face-to-face data collection to occur through interviews and 3D printed food experiences. This fitted within my project timeline, as I planned to begin data collection in March 2020. Data collection for Study 1 commenced in April 2020; however data collection was paused until September 2020 due to public health measures and lockdowns in Australia.

In response to the World Health Organization's declaration of COVID-19 as a pandemic in March 2020 and the rising number of cases in Australia, the Australian Government implemented a number of lockdown restrictions (Lupton, 2020). Within this uncertain environment, face-to-face data collection was no longer allowed and I submitted an amendment to my ethics application to complete all data collection – including interviews, mealtime observations, and 3D food printing experiences – online using Zoom. This amendment was approved. At this stage my supervisors and I expected this would extend my PhD project by six months due to low recruitment rates, particularly as people with dysphagia were often under stricter restrictions as they were at high risk of COVID-19 infection due to underlying health conditions and their age (Australian Government Department of Health, 2021). It was due to these low recruitment rates that a survey was introduced as part of this project in November 2021, as a wider range of people may have been willing to complete a survey.

Once I started speaking to representatives for disability organisations and staff at aged-care facilities, it became apparent that many organisations were reluctant to be involved in research at a time where there was significant uncertainty about the current environment and the future. For example, a nursing home in Melbourne which had agreed to participate in the research prior to the COVID-19 outbreak ceased contact with my supervisors and me once the lockdown of nursing homes began in March 2020 (Henriques-Gomes, 2020). Another aged-care facility in Sydney told me in November 2020 that they would like to be involved in the study, however it would have to wait until 2021 due to the visitor restrictions in place. I was then informed in 2021 that "to be honest COVID has meant that everyone is extremely busy and it is difficult to get anyone engaged in research" (Nursing Home General Manager, personal communication, January 19, 2021). This gave an indication of the ongoing impact of COVID-19 on residential care facilities.

The impacts of the lockdowns extended beyond data collection. Completing a PhD can be isolating at times as much of the work is driven by one person (Bendemra, 2013). I had been prepared for this when starting my PhD in early 2019; however, I could not have predicted working from home by myself for more than eight months of the year with minimal human interaction. For me, this isolation came to a head in April 2020 when my niece was born and my grandfather passed away within a week of each other. I saw my niece over Zoom and only 10 people were allowed to attend my grandfather's funeral, at which we sat separately within the church. This was a difficult period for me and the culmination of COVID-19 isolation as well as my conflicting emotions of grief and happiness became overwhelming. I am not ashamed to say I sought psychological assistance at this time. It was the Three Minute Thesis Competition (3MT) of 2020 that gave me something tangible to focus on. My grandfather, like the participants in my study, required texture-modified foods towards the end of his life. I used a picture of one of his meals as a central component of my visual for the 3MT slide (see Figure 5). I won the Graduate School of Health 3MT competition with that slide and I dedicated my win to him. The picture of his pureed meal played a role in many of my PhD presentations as it depicted the unappealing nature of texture-modified foods that people with dysphagia live with on a daily basis.

Figure 5

The Reality of a Pureed Meal

Data collection during the COVID-19 period also brought its own challenges. As this project was qualitative in nature, I needed to build a certain level of rapport with the participants for them to feel comfortable talking to me. Although online data collection can be just as effective as in-person data collection for qualitative research (Curasi, 2001), I found it to be a learning curve as I was accustomed to completing clinical work in a face-to-face setting (i.e., a clinic). However, online data collection was suitable as it allowed me to talk to people from across Australia; for example, I spoke to a participant with dysphagia who lived in South Australia and to speech pathologists from the United States of America and the

United Kingdom. The use of Zoom allowed for the privacy and the confidentiality of participants to be upheld, as participants were required to wait in a virtual waiting room before entering the call, and recordings were password-protected. However, this did create further difficulties related to accessibility, as participants needed a device with internet connection as well as video and audio capabilities to participate. Some participants also required assistance to access the technology effectively (e.g., placing the camera at the correct height) from a family member or support person present.

As part of the mealtime observation, the Dysphagia Disorder Survey (DDS) was conducted online using Zoom. Past research has shown that the use of online technologies such as Zoom is a viable option for completing dysphagia assessments (Ward & Burns, 2014), particularly while COVID-19 restrictions were in place (Malandraki et al., 2021). Initially, I planned to become a certified DDS user; however, due to COVID-19, DDS training sessions were not held in 2020 or 2021 and, as a result, swallowing observations were completed by my primary supervisor, who is a certified DDS user. I completed the DDS training online in April 2022.

In October 2020, as restrictions eased in New South Wales, I established a COVID-19 Safe Action Plan for face-to-face data collection, which was approved by the UTS Graduate School of Health. Through this plan, I was able to re-establish some face-to-face data collection with strict protocols in place for the safety of participants and myself. Some of these protocols included remaining 1.5 metres away from the participant and wearing a face mask. As these protocols were based on government guidelines for the general public, participants were generally accepting of the requirements. Although these procedures were in place, face-to-face data collection would cease if restrictions ever increased and until it was safe for these activities to recommence. In 2021, due to the changing nature of the COVID-19 outbreak and various Australian cities being placed in lockdown again, online data collection was re-instated for the remainder of the project.

Thus, COVID-19 has changed the shape of this project in ways that I could not have predicted when I first started in March 2019. I have also discussed the impacts of COVID-19 on my PhD journey in an article for Speech Pathology Australia's *Speak Out* magazine, written with fellow UTS Higher Degree Research candidates Rebecca Sullivan and Harmony Turnbull (Smith et al., 2020) (see Appendix D). Recruitment for this project was significantly impacted and participant numbers were reconsidered. Restrictions forced us to consider different avenues of data collection (i.e., Study 3: Survey) which, prior to COVID-19, may not have been required. The resulting project is a truly COVID-19 safe PhD.

Section Three: Results

The established methodology (Chapter 4) and methods (Chapter 5) used to develop the evidence-based framework were implemented throughout April 2020 to February 2022. The outcomes of these studies are reported in this section. The results of this research are presented in three parts: Part A, which describes the results on the impacts of dysphagia on quality of life; Part B, which describes the results relating to the feasibility of 3D food printing; and Part C, which synthesis Chapters 2, 3, and 7-12 to create an evidence-based framework.

Within Part A, Chapter 7 describes the results of Study 1a (interviews and mealtime observations with people with dysphagia), Chapter 8 describes the results of the focus group related to quality of life, and Chapter 9 describes the survey results completed with people with dysphagia, supporters of people with dysphagia, and allied health professionals related to the impacts of dysphagia on quality of life.

Within Part B, Chapter 10 describes the results of the 3D printed food experiences with people with dysphagia, Chapter 11 describes the results of the focus group discussion related to 3D food printing, and Chapter 12 describes the survey results related to 3D food printing.

Then in Part C, as the constructivist grounded theory approach was implemented (see Chapter 4), the results of each individual study in Section 3a and 3b were synthesised to construct an evidence-based framework of the impacts of dysphagia on quality of life and the feasibility of 3D food printing to improve the mealtime experience. Chapter 13 provides a qualitative meta-synthesis of the research findings of Chapters 2, 3, and 7–12.

Chapters 7-12 have been written in academic article format while Chapter 13 has been written in a chapter format. One chapter is now published (Chapter 11) (Smith, Bryant & Hemsley, 2022b), two are in press (Chapters 7 and 8) (Smith et al., in press-a, in press-b), and three are under first or second review (Chapters 9, 10, and 12). Results from Studies 1, 2, and 3 have also been presented at The European Society of Swallowing Disorders Congress 2021, the UK Swallowing Research Group Conference 2022, and the Dysphagia Research Society Annual Meeting 2022 (see international conference presentations on page viii of this thesis).

Part A: The Impacts of Dysphagia on Quality of Life, Participation, and Inclusion

Part A of the results provides an in-depth description of the impacts of dysphagia on quality of life, participation, and inclusion of people with dysphagia. This is done from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals.

Chapter 7: The Impacts of Dysphagia on Quality of Life from the Perspective of People with Dysphagia and their Supporters

The first step in creating an evidence-based framework was to complete a multi-methods study that assisted in answering the research questions related to the impacts of dysphagia on quality of life, along with the barriers and facilitators to quality of life for people with dysphagia. People with dysphagia and their supporters engaged in this study to ensure their lived experiences of dysphagia could be examined in an in-depth manner. Participants included three people with lifelong dysphagia and six people with acquired dysphagia. Chapter 7 reports on the findings of interviews, mealtime observations, and examination of mealtime plans and reports.

This chapter has been accepted for publication in the *International Journal of Language and Communication Disorders*. The formatting has been modified for this thesis.

Smith, R., Bryant, L., & Hemsley, B. (in press-b). The true cost of dysphagia on quality of life: The views of adults with swallowing disability. *International Journal of Language & Communication Disorders.*

Elements of the findings of this chapter have been presented in poster presentations at the European Society of Swallowing Disorders Congress 2021, the UK Swallowing Research Group Conference 2022, and the Dysphagia Research Society Annual Meeting 2022.

Abstract

Background: Dysphagia impacts negatively on quality of life, however there is little in-depth qualitative research on these impacts from the perspective of people with dysphagia.

Aims: This study aimed to examine the lived experiences and views of people with lifelong or ongoing dysphagia on the impacts of dysphagia and its interventions on quality of life, and barriers and facilitators to improved quality of life related to mealtimes.

Methods and procedures: Nine adults with lifelong or acquired chronic dysphagia engaged in in-depth interviews and a mealtime observation. The observations were recorded and scored using the Dysphagia Disorder Survey (DDS). Interviews were recorded, transcribed and de-identified prior to content thematic and narrative analysis, and verification of researcher interpretations.

Outcomes and results: Participants presented with mild to severe dysphagia as assessed by the DDS. They viewed that dysphagia and its interventions reduced their quality of life and that they had 'paid a high price' in terms of having reduced physical safety, reduced choice and control, poor mealtime experiences, and poor social engagement. As part of their management of dysphagia, participants identified several barriers to and facilitators for improved quality of life including: being involved in the design of their meals, being adaptable, having ownership of swallowing difficulties, managing the perceptions of others, and resisting changes to oral intake.

Conclusions and implications: This research improves understanding of the primary concerns of people with dysphagia about their mealtime experiences and factors impacting on their quality of life. Clinicians working with people with dysphagia need to consider how self-determination, autonomy, and freedom of choice could be improved through involvement in food design of texture-modified foods. It is important that future research

considers the views of health professionals on how these findings could impact on policy and practice particularly in ways to address the barriers and enhance facilitators to improved quality of life for people with dysphagia.

What This Paper Adds

Section 1: Dysphagia impacts on quality of life, particularly as the severity of the dysphagia increases. Research to date has focused on people with dysphagia associated with an acquired health condition and has used quantitative assessment methods to measure quality of life.

Section 2: This study provides a qualitative examination of the impacts of dysphagia on quality of life from the perspective of people with lifelong or ongoing acquired dysphagia and their supporters. This study also provides qualitative insights into the barriers and facilitators of mealtime-related quality of life.

Section 3: Health professionals should engage in open communication with their clients with dysphagia regarding the impacts of dysphagia on their lifestyle and quality of life. By considering these impacts, health professionals may be able to recommend interventions that are more acceptable to the person with the dysphagia which may have a positive impact on their mealtime experience.

Introduction

Dysphagia (difficulty swallowing) and its interventions can significantly impact on a person's physical health as well as their quality of life, participation, and inclusion (Smith, Bryant & Hemsley, 2022c). Dysphagia is associated with a wide range of health conditions, including developmental disabilities (e.g., cerebral palsy, or intellectual disability), and acquired health conditions (e.g., stroke, Parkinson's, or motor neuron disease) (Groher & Crary, 2016). Estimates suggest that approximately 8% of the world's population have dysphagia (Cichero et al., 2017; Groher & Crary, 2016), and that prevalence increases in particular populations; for example, the estimated prevalence of dysphagia in older people living in aged care facilities is 52.7% (Engh & Speyer, 2022). Despite this, the impacts of dysphagia on quality of life are under-researched (Smith, Bryant & Hemsley, 2022c). Quality of life is defined as a person's understanding of their position in life regarding their environmental and cultural context (World Health Organization, 1998). When examining quality of life of people with dysphagia, mealtime participation should be considered, particularly to appreciate how the person with dysphagia engages in mealtime activities (e.g., choosing their meal), with different people, and in different mealtime environments (Balandin et al., 2009).

The significant negative health impacts of dysphagia, for example on respiratory health or nutrition (Broz & Hammond, 2014), can have further impacts on the person's health-related quality of life. Dysphagia can lead to dehydration and malnutrition (Broz & Hammond, 2014), along with choking events and hospitalisation (Hemsley et al., 2019). Dysphagia interventions (e.g., modifying food textures, positioning modifications, or modified equipment) are designed to reduce risk to the person's health and increase efficiency in the swallow through rehabilitation or compensation strategies (Groher & Crary, 2016; Wu et al., 2020). Texture-modified foods are frequently recommended and used as a compensatory strategy for people with dysphagia, such that foods are softer and fluids may be thickened to reduce the risk of choking (Steele et al., 2015). Although texture-modified food is provided to increase health and reduce the risk to nutritional or respiratory health, it may also impact on a person's quality of life. Texture-modified foods may increase a person's mealtime-related quality of life if they can eat meals without choking, or could decrease mealtime-related quality of life if it restricts their access to preferred or familiar foods outside the recommended textures (Smith, Bryant & Hemsley, 2022c).

Prior Literature on the Impacts of Dysphagia on Quality of Life

A prior scoping literature review informed this research (Smith, Bryant & Hemsley, 2022c). Following a published protocol (Smith et al., 2019), the review included 106 studies analysed according to the Health Related Quality of Life (HRQOL) model (Ferrans et al., 2005) to examine the peer-reviewed evidence on the impacts of dysphagia and its interventions on quality of life, participation, and inclusion of people with dysphagia (Smith, Bryant & Hemsley, 2022c). The HRQOL model describes quality of life as being influenced by the person's functional status along with environmental and individual characteristics that shape their perceived health (Ferrans et al., 2005). The vast majority of studies reviewed related to adults with acquired conditions (*n*=95, 90%) and only seven (7%) related to people with lifelong dysphagia. Furthermore, 44 of the included original research studies involved the application of quantitative assessments of quality of life and did not use qualitative methods offering in-depth insights into the impacts of dysphagia from the perspective of people with dysphagia or their supporters.

Nonetheless, across this large body of prior research, the central finding from prior research was that dysphagia negatively impacts on the affected person's quality of life, increasing as the severity of the dysphagia increased (Smith, Bryant & Hemsley, 2022c).

However, dysphagia interventions also impact on quality of life, with 25 of the 32 intervention studies examining the impact showing that the interventions improved quality of life, but this was not always the case. Enteral tube feeding had both positive and negative impacts, as it helped maintain physical health but was also isolating (Ang et al., 2019; Stavroulakis et al., 2016). Texture-modified food similarly had positive and negative impacts on quality of life (Seshadri et al., 2018) as the appearance of the foods made people feel self-conscious and excluded from others (Shune & Linville, 2019).

To understand the impact of modifying food textures on perceptions of food or mealtime enjoyment, a recent narrative review of 35 studies examined how visual appeal, texture, taste, smell, temperature, and mealtime environment may impact on the mealtime experience for people with dysphagia (Smith, Bryant, Reddacliff et al., 2022). The authors reported that the use of food moulds, piping bags, spherification, gelification, or 3D food printing may help improve the appeal of texture-modified foods. However, only 17 of the 35 studies included participants with dysphagia, and only one of these included people with a lifelong swallowing disability. Furthermore, only six of the studies with participants with dysphagia were qualitative studies, shedding little light on the lived experiences of people with dysphagia (Smith, Bryant, Reddacliff et al., 2022). Consequently, further evidence is needed to determine the extent of the impacts of food design on the lived mealtime experiences for people with lifelong or ongoing dysphagia. Understanding more about how people with dysphagia view the impacts of dysphagia on quality of life will help to design person-centred interventions (Howells et al., 2019a). To fill the gaps in the literature relating to the views of people with dysphagia and their supporters on the impact of dysphagia and its interventions on quality of life, the aims of this study were to examine the views and lived experiences of people with lifelong or ongoing dysphagia on (a) the impacts of dysphagia and its interventions on quality of life, participation, and inclusion, and (b) the barriers and facilitators to HRQOL and mealtime-related quality of life.

Methods

Ethical approval for this study was granted by the University Human Research Ethics Committee (ETH19-3708). An interpretive, constructivist grounded theory approach was taken to enable the exploration and integration of data from a variety of sources (Charmaz, 2017; Mills et al., 2006) in seeking to understand the impacts of dysphagia on quality of life, from the perspectives of people with dysphagia and their supporters. This approach also took into account their dysphagia severity based on an observational mealtime assessment using the Dysphagia Disorder Survey (DDS) (Sheppard et al., 2014). The methods used in this study were selected in order to inform and integrate with future studies obtaining the views of allied health professionals on the quality of life impacts of dysphagia, as part of a larger doctoral research project of the first author. The Standards for Reporting Qualitative Research (SRQR) were used to report findings (O'Brien et al., 2014). The mixed methods study involved observations of each participant eating a typical meal to describe their dysphagia severity and management using the DDS (Sheppard et al., 2014). Following this, in-depth interviews explored participants' views on the impacts of dysphagia and texture-modified food on their quality of life. In addition, where available, document data analysis of the participant's mealtime plans or speech pathology reports was used to triangulate and verify information relating to their diet and dysphagia. During COVID-19 restrictions, observations and interviews were conducted and recorded online using Zoom for all but one participant (P6), who was interviewed in-person at home.

Participants

Participants were eligible to take part if they were capable of giving written informed consent to participate; able to read, speak, and understand English; had dysphagia; and were on a texture-modified diet. All of the participants volunteering to participate in the study and providing informed consent were included; while all reported having had dysphagia for more than one year, five reported having had dysphagia for more than 10 years. Participants were recruited using purposeful and theoretical sampling methods by contacting local organisations supporting people with disability and older people with dysphagia, and by distributing information about the study through social media networks. As it is not possible to determine how many people saw the information advertising the study, a recruitment response rate could not be determined. Cultural heritage and background of participants was not collected beyond that which they raised or referred to in their own interviews. The first author knew one participant (P2) prior to her involvement in the study. All participants were aware of the first author's position as a female speech pathologist with clinical experience in dysphagia management; and as a doctoral candidate conducting qualitative research. Her experience as a speech pathologist, as well as having reviewed the prior literature on quality of life, was acknowledged as informing her stance on participants having lived experience that was important to gather in relation to their quality of life. Interpretive, constructivist approaches to research recognise that reality is subjective and the researchers in this study acknowledged that their experiences as speech pathologist shaped the interpretation of the data while acting as a facilitator to gather the perspectives of participants (Mills et al., 2006). Participants were given a AU$30 gift voucher for their time.

Participants presented with dysphagia associated with a range of health conditions and ranging from mild dysphagia (P1 and P9) to severe (P7) dysphagia. Demographic information about participants including age, condition associated with dysphagia, dysphagia severity, and living arrangements is presented in Table 11.

Table 11

Chapter 7 Participant Demographic Information

Participant ID	Gender	Age (years)	Dysphagia aetiology	Dysphagia severity (DDS)	Current diet (IDDSI)	Type of residence
P1	M	30	Klinefelter Syndrome	Mild	Soft and bite-sized food, carbonated thin fluids	Private home
P2	F	80	Age-related changes and a pharyngeal pouch	Moderate–severe	Easy to chew and soft foods, thin fluids	Private home
P3	F	54	Traumatic brain injury	Moderate–severe	Soft and bite-sized food, thin fluids	Private home
P4	F	42	Athetoid cerebral palsy	Moderate	Soft and bite-sized food, thin fluids	Private home
P5	F	55	Head and neck cancer	Moderate–severe	Soft and bite-sized food, thin fluids	Private home
P6	F	55	Pierre Robin Anomaly	Mild–moderate	Soft and bite-sized food, thin fluids	Group home
P7	M	81	Dementia and aged-related	Severe	Soft and bite-sized food (diabetes), thin fluids	Aged-care facility
P8	M	76	Inclusion body myositis	Moderate	Regular/easy to chew foods and thin fluids	Private home
P9	M	77	Inclusion body myositis	Mild	Regular foods and thin fluids	Private home

Note. DDS = Dysphagia Disorder Survey, F = female, IDDSI = International Dysphagia Diet Standardisation Initiative, M = male, P = participant.

The nine participants were aged from 30 to 81 years with a median age of 55 years. Two participants, P8 and P9, had chronic myositis, a condition associated with dysphagia due to inflammation of muscles of the oesophagus and oropharynx which may also increase risk of aspiration pneumonia (Oh et al., 2008). Seven participants lived in private homes in the community, one lived in a group home, and one lived in an aged-care facility. Of the nine participants, two were interviewed with one or more supporters present. They assisted the person with dysphagia to engage in the interview and provided any supplementary or further information on past events as requested by the participant (Lisiecka et al., 2021). Specifically, P7’s spouse and P6’s three supporters (a parent and two paid support workers) provided such support, playing a minor part only in the interview as required.

Procedures

Mealtime Observation. The observational assessment of mealtimes provided important contextual evidence of the nature and severity of participants' dysphagia, which in turn provided context informing the views of the participants in relation to their dysphagia and its impacts on their quality of life. At a time of the participant's choosing, a member of the research team (first or last author) observed the participant eating a typical meal in their regular mealtime environment, using an iPad or mobile phone on a Zoom call for this to be viewed and recorded. While safety protocols (e.g., in the event of food choking) were in place in case of an adverse event (Table 5 of thesis), no safety incidents occurred during or after the observations. Using the video recording taken of the meal, the DDS and Dysphagia Management Staging Scale (DMSS) were completed by the first and last authors, who are both certified users, to provide a description of each participant's mealtime difficulties (Sheppard et al., 2014). The use of Zoom in this research during COVID-19 was selected as suitable, as such telehealth procedures are reported to be a viable clinical modality for assessment of dysphagia (Ward & Burns, 2014), particularly during COVID-19 (Malandraki et al., 2021).

Mealtime Document Review. Four of the participants provided a copy of available written reports (e.g., swallowing clinical assessment report, instrumental assessment report) and mealtime plans to the researcher to include as historical and documented context to their perspectives (Patton, 2014). A document data extraction form was used to extract and collate relevant information about the participants (Table 7 of thesis).

In-Depth Interviews. Each of the 60-minute interviews were conducted by the first author, who had experience in conducting qualitative interviews, between September 2020 and December 2021. The interviews were designed to gain a comprehensive understanding of the participants' views on the impacts of dysphagia on quality of life. Recognising the diversity and heterogeneity of people with dysphagia, the researchers aimed to recruit participants until theoretical saturation was reached (Guest et al., 2006). While content themes were strong in the interviews analysed, saturation was not achieved due to difficulties with recruitment during the COVID-19 pandemic; owing to substantial impacts on the health and disability support sectors with social distancing restrictions.

The first author conducted the conversational-style in-depth interviews using an interview protocol, developed on the basis of two prior literature reviews (Smith, Bryant & Hemsley, 2022c; Smith, Bryant, Reddacliff et al. 2022). While the interview guide was designed to ask similar questions across interviews, the conversational style of the interview meant that probing questions could be modified according to the participant's relevant lived experiences (Table 6 of thesis). The first interview served as a pilot of the interview schedule which did not require changes and was fit for purpose as it allowed for individual responses throughout the interview. After the interview, the researcher made detailed field notes on her observations and insights gained to help guide initial stages of analysis.

Content Thematic and Narrative Analysis

Interviews were de-identified and transcribed verbatim by the first author. NVivo (QSR International, 2018) was used for the coding, storage, and retrieval of the data. Analysis involved content thematic analysis with open coding, identifying categories across those codes, and matrix coding was conducted (Patton, 2014). Open coding, which involved identifying units of meaning within the data, was based on a reading and re-reading of each text and identifying units of meaning, and discussing these across the research team. The authors discussed categories of meaning that connected the codes, and matrix coding which involved looking for relationships that connected the open codes, and any concepts that helped to explain the meaning both within and across the participants' interviews. Any themes connecting the data within and across participants are referred to as 'content themes' that are built or constructed across the participant group (Charmaz, 2017).

A narrative analysis of the data was also undertaken, to identify and fully appreciate the views and lived experiences of participants (Crossley, 2007). In this process, the researcher first located stories within the interview transcripts, identifying explanations of events and situations and any story themes that could add to the content analysis (Riessman, 2007). In their interviews, participants were encouraged to narrate mealtime events, problems, and resolutions, along with explaining their own interpretation of what their experiences meant to them (Crossley, 2007; Riessman, 2007). This narrative analysis enabled participants' stories of experience to be appreciated and highlight specific situations where their quality of life had been impacted and what they had done in response. The stories contributed an understanding of important elements of time, sequence of events, and approaches to problem-solving around their lived experiences of dysphagia.

Field notes written by the first author after each data collection event were also used in the analysis process and added to the NVivo file for coding (QSR International, 2018). Each transcript was read and re-read by researchers to ensure the accuracy of coding. Researchers also frequently engaged in discussion about the transcripts and to ensure they agreed that the categories and codes developed reflected the interview transcripts. The first author wrote a summary interpretation and discussed this with co-authors to confirm interpretations and reduce researcher bias and ensure trustworthiness (Morgan et al., 1998). Each participant was emailed the written summary of the researchers' agreed interpretations which highlighted the content themes and stories of experience to verify the researchers' interpretations. Participants were asked to confirm the interpretations, to suggest changes, or additions to better reflect their view. In total, six participants responded to confirm the information either by sending an email (*n*=5), or in a short face-to-face online interview (*n*=1).

Results

At their convenience, all participants were observed eating a lunchtime meal which, for completion of the DDS, included their usual chewable food, non-chewable food, and a drink. In terms of positioning for the observed meal, P7 sat in a recliner chair, and all others were seated at a table. P6 required some assistance in eating with some hand-over-hand assistance provided, and P7 was mostly dependent requiring full support (i.e., unable to hold the spoon). P5 and P6 used adaptive plastic cutlery. The severity of dysphagia as determined using the DDS is presented in Table 11 above and ranged from mild to severe.

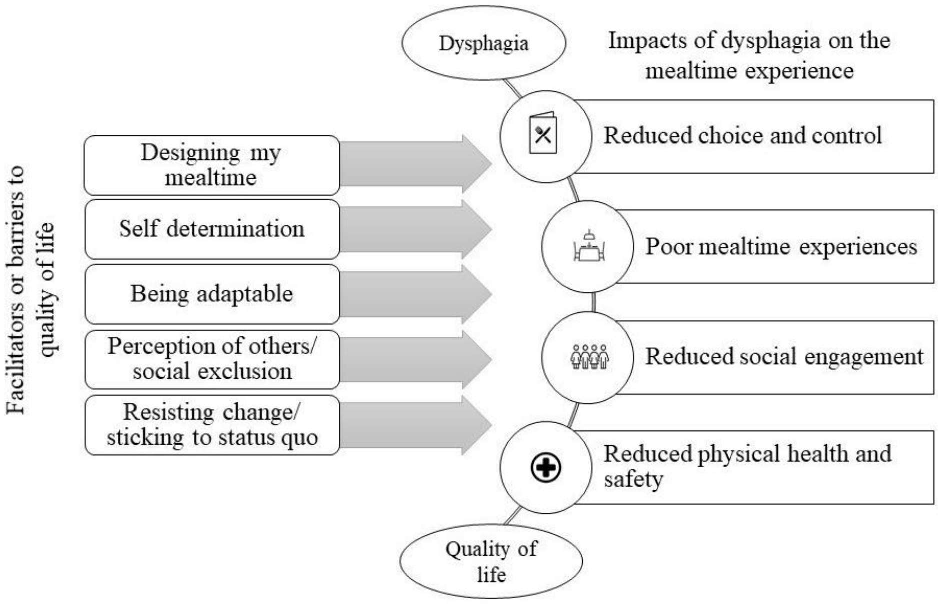
Mealtime documents provided by four of the participants included instrumental barium swallow assessment reports (P1 and P2), clinical speech pathology and dietetics assessment reports (P1 and P6), and mealtime plans written by a speech pathologist (P4 and P6). Both mealtime plans and P6's clinical speech pathology assessment report provided information regarding mealtime participation and inclusion. For example, P4's plan stated "[Participant] knows what she can and cannot eat and will choose her own meals based on what she feels like", while P6's mealtime plan gave recommendations for foods to avoid including bread and watermelon.

Across the interviews, and perhaps reflecting the relatively small sample size, there were two major connecting themes, one encapsulating four content themes and the other five themes. The first major connecting theme related to 'costs on quality of life', in that dysphagia is associated with substantial costs to mealtime-related quality of life, and participants had to 'pay the price' of dysphagia in four main thematic areas, in terms of their:

choice and control, mealtime experiences, social engagement, and *physical health and safety.* The second major connecting theme related to dysphagia management impacting on quality of life, and included themes of *designing my mealtime, self-determination of swallowing difficulties, adaptability at mealtimes, the perceptions of others,* and *sticking to the status quo or resisting change.* The way these content themes impacted on their mealtime-related quality of life and mealtime experiences is conceptualised in Figure 6. The two overarching connecting themes and four main content themes, along with barriers and facilitators to quality of life, are presented in detail in the following section with supporting quotes to increase plausibility and confirmability of the findings (Patton, 2014).

Figure 6

Facilitators, Barriers, and Impacts on Quality of Life



Paying the Price for Dysphagia: Impacts on Quality of Life

The Cost of Dysphagia on Health and Safety. All participants described choking or almost choking (i.e., a near miss event), often in public, reflecting the threat of dysphagia to their health and safety. P8 described a time he choked on a chocolate bar, noting that "it didn’t end well”. He also described the length of time it often takes to clear his throat, “if I get something small stuck in my throat, I go into a coughing fit and that might take me 5, 10 minutes to get over.” In comparison, P3 described choking on potato while eating at a café with colleagues and a nearby doctor administered the Heimlich manoeuvre. P3 recalled how “embarrassing” the situation was, but also how “relieved” she was that someone came to her aid. Such narratives illustrate the interconnected nature of the impacts of dysphagia on health and safety, social engagement in terms of choking occurring in social situations and being embarrassing, and reliance on others particularly in relation to choking rescue.

Participants described the cost of dysphagia and texture-modified food on quality of life, when they could not maintain their physical health through an appropriate diet. P5 described the difficulties she had faced maintaining her physical health whilst facing a new dysphagia diagnosis. After chemotherapy, radiotherapy, and surgery for head and neck cancer, P5 had difficulties maintaining weight due to her dysphagia. She reported that eating “takes forever, and you never put on weight cos you can’t eat that much.” Similarly, gaining appropriate nutrients from food was an ongoing challenge for P7 and his wife who reported “I can feed P7 yeah sweets and mousses and things all, any day of the week”, however he would often refuse savoury texture-modified food based on the smell or taste. To accommodate for this, his wife supplemented the food provided at his facility by bringing him bananas and avocados from home. P7’s wife recognised that these foods did not replace the nutrients he missed from vegetables and proteins, but it was better than skipping the meal. This demonstrated the importance of the support network in supplementing a person’s diet.

The Cost of Dysphagia on Choice and Control. A number of participants described times when their choice was reduced because of their swallowing difficulties. P6 did not cook her own meals and required significant support from support staff to cook appropriate food for her swallowing needs. However, P6 enjoyed helping by choosing meals and by holding the support worker's hand to stir food or peel vegetables. P2 described how her choice was limited when eating out for morning tea as she would only have coffee to reduce the risk of choking in front of others. She also described ordering dessert when out for dinner with family as the dessert options were often easier to swallow than the main meals. Although her food choices were reduced in these situations, P2 had come to terms with these changes: "years ago I would have felt out of it if I didn't follow everyone but that doesn't even register with me anymore. I just have what I have to have."

The loss of choice and control appeared to have a greater impact on participants who had acquired dysphagia in adulthood in comparison to those who had lived with swallowing difficulties since childhood. P7 previously enjoyed cooking and sharing food with others; his wife stated, "people still ring up and say to me, 'oh I remember P7's curries.'" P7's loss of mealtime choice and control was not only based on the textures he could eat; he was also generally limited to foods provided by the aged-care facility that were not always to his taste and he could not see his food due to a vision impairment. In comparison, P4, who has lifelong dysphagia, said "I think it has just been part of my life just like all the other fun aspects of CP [cerebral palsy]." Although she would have preferred to have better swallowing skills, she had learned to accept that swallowing difficulties as part of her life and consequently she avoided some foods (e.g., nuts and chips).

The Cost of Dysphagia on Food and the Mealtime Experience. Texture modification had a substantial impact on the mealtime experience for participants. P1 and P5 in particular reported that the visual appeal of their meal impacted on their enjoyment. As P5 stated, "I'm a foodie, I come from a food and wine background, and it's like I really don't want to eat vitamised Big Mac and fries, thanks very much." She then reinforced this and stated, “all the food is like wet dog food” (P5). This highlighted how limited effort was exerted in adapting foods for people who require texture-modified food. P1 also described reheating his food during a meal due to his extended eating time. As a result of constant re-heating, his food was often soggy and no longer maintained its original form. P8 described taking extra time to eat meals and this detracted from the mealtime experience when eating out: “now it takes a lot longer. Whereas before I was always first finished eating. But now having to cough up in front of people… it’s something that I’d prefer not to do.” Participants also agreed that mealtimes were a “chore” due to their swallowing difficulties. For example, P3 described mealtimes as a chore “unless I am with really good friends or family” to cut the food up. Participants reported avoiding or restricting their access to specific foods or mealtime environments because of their swallowing difficulties. For example, P6 could no longer have her favourite meal of a curry with naan bread as bread had been removed from her diet.

The Cost of Dysphagia on Social Engagement. Dysphagia impacted on participants’ feelings associated with eating with others. P2 reported she felt nervous when eating out with others and said she was “just super careful and you try to order something that’s easy” so she did not draw attention to herself. P4 was also careful when ordering out, but she was driven by her mother: “I try and order appropriate foods in order to avoid Mum’s death stares.” This demonstrates the tension associated with swallowing difficulties and food choices when eating in a social environment. P1 described how his swallowing difficulties shaped how others perceived him. For example, when describing his difficulties ordering appropriate food out, he said “it makes me look like a drama queen.” P1 also described how the reactions of others shaped his social experiences: “as much as it was fun occasionally pulling things out of my nose that I’d swallowed and do my party trick...they thought it was hilarious every time cos they were laughing at me as opposed [to] helping.”

Dysphagia also impacted on participants' decisions regarding their attendance at social events. P3 declined event invites if the food being served was not appropriate. P3 found cocktail parties the most difficult and said there was "nowhere to sit and nowhere to put food." In making these decisions, P3 also considered other comorbidities she faced including difficulties with mobility and communication. P5 was also reluctant to attend social gatherings, "I've missed weddings of my own family, I've missed sixtieths, fiftieths, christenings, baby I have missed them all." P5 reported feeling "pressure" when eating out and preferred trying new foods at home as she did not have to follow social etiquette (e.g., she could clear food from her mouth with a finger sweep).

Management of Dysphagia

Participants described mealtime management-related factors that could be manipulated or modified to improve or reduce mealtime quality of life, which are depicted on the left hand side of Figure 6. These factors can change or be adjusted to form *either* a barrier *or* a facilitator to a person's mealtime-related quality of life. Factors serving as *both* barriers *and* facilitators to quality of life included the person's involvement in designing their own meal, taking ownership of their swallowing difficulties, being adaptable, the opinions of others, and resistance to changes involving skills and food.

Designing My Mealtime: Autonomy and Control Influencing Quality of Life. Participants used different strategies to modify flavour, environment, and assistance received in attempts to make their mealtimes more enjoyable, and a failure to implement these strategies led to reduced quality of life. P1 reported that he added herbs and spices to his meals to improve the flavour, and different colours to improve the visual appeal, "sometimes I put food colouring in things… sometimes I add purple carrot instead of orange." P9 similarly discussed the importance of the food's flavour and said, "when it's really tasty … I almost don’t think about the swallowing part of it when I’m eating.” Mealtimes for P7 were also based around the taste and smell of food due to his vision impairment. P7 reportedly refused meals based on smell and so his wife focused on flavours and smells he enjoyed to ensure he received enough nutrients. For example, P7’s wife saved lunchtime sandwiches in case P7 refused his dinner. In comparison, P6 designed her mealtimes by telling the support workers or her mother what she wanted to eat, and they accommodated her requests in line with her mealtime plan. P6’s group home manager encouraged these choices and said, “she loves helping which great because it’s her meal.” P6 also chose the mealtime environment when staying with her mother: “she sets down little requirements like we should have dinner in the dining room not the kitchen.”

The use of different cutlery and crockery was another way for participants to design their own mealtime experience. P5 used decorative crockery to improve the visual appeal of her meals and stated, “I tend to err on the side of, get yourself a beautiful bowl, get yourself a beautiful plate.” By choosing crockery of different colours and sizes, P5 could moderate her portion sizes when transitioning from percutaneous endoscopic gastrostomy (PEG) to oral feeds. P5 also used the plastic spoon provided by the hospital speech pathologist and Chinese soup spoons as she could not tolerate metal cutlery after chemotherapy.

P3 and P4 often relied on mealtime assistance from others to improve their mealtime experience. P3 asked restaurant wait staff to cut up her meal before bringing it to her as this gave her more time to focus on eating her meal without asking someone at her table for help. Similarly, P4 relied heavily on assistance from her mother and support workers to prepare meals. P4 accepted this assistance and was happy for someone else to be in control of meals, “I guess because I can’t really do it and because I’m too busy thinking about other things.”

Self-Determination and Ownership of Swallowing Difficulties. Participants with dysphagia handled ownership of swallowing difficulties and the consequences of dysphagia in different ways. P1 described how he took control and involved himself in his dysphagia management: "[allied health professionals] must be able to work as part of a multidisciplinary team in conjunction with me." P9 also took ownership of his own mealtime enjoyment and said "the psychology works for me … [I] think about I'm really enjoying this mouthful of food. And it seems to go down easier." P3 described re-claiming ownership of her dysphagia management during a hospital admission, as she was placed on a texture-modified diet that was more modified than food she typically ate. She said, "the catering staff on supper even refused to give me a biscuit cos of modified diet so I demanded to come off it." If P3 had not taken this ownership, she reported her quality of life would have been reduced against her wishes.

P2 and P4 demonstrated self-determination by refusing to let their swallowing difficulties impact on their attendance at social gatherings. P2 said "we don't go out that much and I do look forward to it when we do." Hence, her decision to attend social events was not shaped by her swallowing difficulties but by the general wellbeing of herself and her elderly husband. P4 similarly did not let swallowing difficulties impact on her decisions. P4 agreed that her lifelong experiences with dysphagia shaped her acceptance of her skills, and she did not decline invitations.

Participants also described their own way of living with their difficulties and managing their lifestyle. P8 engaged with other people with myositis through an Australian networking and research organisation for people with myositis. P8 used the group's social media page to hear the perspectives of others who had faced similar concerns and stated "I found it's the only time you can ask questions…. unless you can remember when you see your specialist” (P8). P8 also attended their social gatherings where he was further able to engage with people living with the same condition. P8 used his membership as an opportunity to learn about new myositis research studies, many of which he engaged in which increased his sense of purpose and community engagement.

Being Adaptable About Mealtimes. Each participant described their own adaptive strategies which they viewed as making mealtimes easier and safer for them to manage. P2 described pulling the crusts off her sandwiches while P7’s wife described giving P7 breakfast food for dinner to ensure he ate something: “I just say it’s a Weet-Bix night.” P1 described how the mealtime schedule at his house was adapted so he never ate alone in case of a choking event. Participants also described being adaptable and experimental with their food and drink choices to reduce the choking risk. P3 described finding suitable alternative drink options and she often enjoyed banana milk shakes instead of coffee. Without these changes, P3 would not have been able to engage in outings. P1 and P9 also made adaptations when ordering food and would ask for food to be cooked until it was soft. P9 stated “when I go [out] … I say to the people I want my vegetables well done. And if they don’t come well done, I send them back.”

Sticking to the Status Quo and Resisting Change. Participants with acquired dysphagia described how they tried to continue as they were prior to their dysphagia diagnosis to maintain their lifestyle. Maintaining a sense of normality and quality of life was particularly important for P2 who did not believe she needed to see a speech pathologist and said, “our food always looks the same, if it’s meat and three veggies, its meat and three veggies. If it’s casserole, its casserole.” P5 similarly told researchers that she was able to eat a wide range of foods, “I can eat steak, I eat chips, I eat pork crackle… sometimes I like to eat like an adult.” Both participants demonstrated a desire to maintain normality by eating food that did not meet their texture-modification needs. This may positively impact on quality of life as they can continue to engage in mealtimes as they always have, but resisting the changes in swallowing may also reduce quality of life if it impacts negatively on their health.

The Perceptions of Others and Social Exclusion. Participants explained how the perceptions of others could impact their quality of life through social inclusion or exclusion, depending on whether their needs were considered. P1 described how a lack of knowledge by other people when eating out negatively impacted on his attempts to improve his mealtime experience. P1 stated that wait staff often did not act in an accommodating manner when he asked for a meal to be modified due to a lack of understanding: “wait staff put it down to I’m being an arrogant person … who’s trying to get away with as many changes as they can.” P4 also described being excluded when people chose a restaurant or café without considering if the food was appropriate for her needs. P4 said her colleagues “insisted on going to a café that only had really hard bread” which resulted in her having a choking episode. In comparison, P4 had other positive experiences where her colleagues considered her swallowing needs, “one of the groups I am involved with, they have been terrific. They say here you go [participant] you can eat this, I make it especially.”

Narrative Analysis: Lived Experiences of the Content Themes

The stories narrated by participants reflected that each participant perceived and approached their diagnosis and progression of swallowing difficulties differently. Their lived experiences shaped their views on the impacts of dysphagia on quality of life as well as the barriers and facilitators that influenced their mealtimes. Their stories reflected much diversity in the approach or strategies used to adapt to and change their own mealtime circumstances. For example, P5 narrated rebuilding her lifestyle after the losses to mealtime enjoyment faced after her cancer and dysphagia diagnoses; whereas P4, who had cerebral palsy, narrated her having experienced early acceptance of having dysphagia, but also frustration at ongoing limitations "after 42 years I'm kind of over it!"

Participants also described finding ways to fight for themselves and others to improve their mealtime experiences. Self-determination drove each of the participants to push for their rights to be met by others (e.g., catering services). P3, who had lived with and managed dysphagia since childhood, described lobbying for better food choices at a disability conference where the food served was inappropriate for people with swallowing difficulties. She said, "it was [disability organisation]!… I did give feedback!" (P3). Conference attendees were served tough meat and half cooked vegetables for dinner, so P3 put in a complaint over the quality of the food. She said, "sometimes when I expect better choice there is none like at the [disability organisation] dinner in [city] years ago." P3 reported the organisation should have provided more appropriate foods to match people's needs, particularly as the conference aimed to support people with disability. P5 also advocated for more positive mealtime experiences and supported others in implementing positive change by writing a dysphagia-friendly cookbook, outlining ways to create and present texture-modified foods, to support others in their dysphagia and mealtimes journey. She narrated doing so as she could not find the resources needed to successfully self-manage her swallowing difficulties, in particular how to transition back to oral feeds from enteral tube feeding. P5 used her experience in the food and wine industry to write the cookbook and an online training course to help other people. From this, P5 has worked with health professionals to promote her program to others.

All participants, regardless of cause or severity of dysphagia, described learning to live with their difficulties. Through their mealtime experiences, participants gained their own understanding of how dysphagia impacted on their lives, and they also identified barriers or facilitators that shaped their experiences. P2 learned to conceal her difficulties to maintain social etiquette, particularly in public. However, with time, she accepted the change, stating, “it wouldn’t worry me … it doesn’t anymore.” For others, their experience was related to learning how they could be supported at mealtimes. P6’s mother described lifelong learning to meet P6’s preferences and needs as her skills changed through childhood and into adulthood. P6’s support worker also described the difference in P6’s swallowing, recently stating, “it’s more intense in the last couple of months than what it usually is” highlighting the variable nature of P6’s swallowing skills and the need for flexible support. This highlighted that although participants had lived with dysphagia for a number of years, they were still open to learning to meet their changing needs and to improve their mealtime experience.

Discussion

This research provided an in-depth understanding of the impacts of dysphagia and its management on quality of life for people with lifelong and ongoing acquired dysphagia, in particular, the impacts on their choice and control, social engagement, experiences with food, physical health, and the ways that they move to self-manage and implement dysphagia and mealtime management strategies. This helped to close the gap identified in Smith, Bryant and Hemsley (2022c) in understanding the lived experiences of people with lifelong or ongoing dysphagia; providing insights from people with dysphagia and their supporters. In doing so, it also highlighted barriers and facilitators that may influence the person’s mealtime-related quality of life and the importance of self-advocacy. The examination of mealtime documents and the mealtime observations provided extra depth into these findings by providing the context for the issues raised in the interviews.

Past research identified in the scoping review by Smith, Bryant and Hemsley (2022c) demonstrated that quality of life, a qualitative phenomenon, is often assessed using quantitative assessments, including the Swallowing Quality of Life Questionnaire (McHorney et al., 2002). By using in-depth interviews and qualitative analysis, this research provided a greater understanding of the impacts of dysphagia on the quality of life of people with health conditions associated with dysphagia. Triangulating these views with data from observational measures of dysphagia (Sheppard et al., 2014), as used in this study was useful in terms of providing context to the views and lived experiences examined. While not intended as diagnostic measures of the person's dysphagia, the methods used in this study enabled reporting of severity of dysphagia based on the observational, online assessment (Malandraki et al., 2021; Ward & Burns, 2014). These insights demonstrate the importance of health professionals discussing a person's mealtime experiences with them and analysing this information for in-depth personalised insights to inform their ongoing dysphagia management and improve their quality of life. These discussions were particularly important as past research has shown that texture-modified foods (a commonly implemented intervention) are often unappealing and reduce the person's food intake, impacting on their quality of life and the mealtime experience (Seshadri et al., 2018; Shune & Linville, 2019). The findings also reflect that a person's dysphagia-related quality of life is, as in the HRQOL model, influenced by the person's individual factors including their swallowing skills, and their environment (Ferrans et al., 2005). This serves to emphasise the importance of not only considering the health-related impacts of dysphagia, but also the personal and environmental factors, including the stories of the person learning to live with their swallowing difficulties and self-advocacy, as influencing quality of life. This expands upon previous research by Moloney and Walshe (2018) who reported that people with dysphagia faced not only physical changes but also changes to their relationships with others and their social engagement. The study by Moloney and Walshe (2018) only included people with dysphagia after a stroke; thus, this research extends upon these findings to include people with dysphagia associated with other acquired and lifelong health conditions.

This study included participants with lifelong dysphagia related to developmental disabilities. This population face the longevity and substantial experience of both the cost impact and the management needed to maintain both health and safety and quality of life, as described in previous research by Balandin et al., (2009). They may have substantial need for self-advocacy if their needs are not met in various mealtime situations, through lack of knowledge or experience of others in relation to dysphagia (Warren & Manderson, 2013). This is important, as prior research including the views and perspectives of those with lifelong dysphagia is limited (Smith, Bryant, & Hemsley, 2022c). This research built upon the findings presented by Balandin et al., (2009) by presenting facilitators that may assist in improving quality of life for people with dysphagia of a variety of aetiologies.

This research provides further evidence of the need for health professionals to include social participation and wellbeing as part of dysphagia intervention as recommended by Howells et al., (2019b). It is essential that health professionals involved in dysphagia management are aware of the impacts of dysphagia on quality of life and the management factors forming barriers and facilitators to a person's dysphagia or mealtime-related quality of life. They also need to be aware of their positioning as health professionals in perpetuating or ameliorating negative impacts on the person's quality of life brought about by assuming that dysphagia interventions would improve quality of life by improving health. Clinicians should engage in open communication with the client, eliciting stories that look beyond physical health to determine how exactly dysphagia is influencing the person's lifestyle, to allow for interventions to be implemented that maintain and improve quality of life and psychosocial wellbeing (Howells et al., 2019b). By considering the impacts on quality of life outlined in this study, clinicians’ recommendations may be more acceptable to the person with dysphagia with flow-on positive impacts on their physical health. The inclusion of facilitators to quality of life in this study also provides strategies that health professionals can encourage people with dysphagia to consider (Howells et al., 2019b). By identifying barriers, this study highlights factors that need to be addressed through, often through education, to improve a person’s quality of life (e.g., if a person is resisting change).

Limitations and Directions for Future Research

This was a small study and the findings should therefore be interpreted with caution and cannot be generalised to all people with lifelong or chronic dysphagia. Although small, the in-depth nature of the interviews and diversity of participants provided good insights into the lived experience for these participants which may be similar for people in similar situations. The findings could be used in awareness-raising campaigns and inform clinical practice in terms of stimulating clinicians to ask their clients more about the quality of life impacts from their perspective, and about what improves their mealtime experiences. The requirement for participants to have access to a computer, internet, and ability to use Zoom may have meant participants with more severe dysphagia or those without support were not able to participate, and their insights could further develop the content themes and experiences narrated in this study.

Overall, despite the relatively small sample size, the content themes and narratives identified came through strongly across the interviews. Further research should look to gain an in-depth understanding of the impacts of dysphagia on quality of life from a larger number of people with dysphagia, from a variety of cultural backgrounds, with a range of associated communication disabilities, and a range of other lifelong or acquired health conditions than those included in this study. Given the successful use of observational online measures in this study, future qualitative research on dysphagia quality of life impacts should include observational measures of the person's dysphagia severity at the time of the interviews to give context to the findings. Research investigating the views of health professionals who work with people with dysphagia would provide important triangulating insights into the themes and concepts outlined above. Their views may also help researchers to uncover further strategies for improving a person's mealtime-related quality of life. Furthermore, research examining how clinicians' exploration of the clients' own lived experiences of the 'costs' of dysphagia influences dysphagia assessment and intervention goals is also indicated.

Conclusion

Dysphagia has several impacts on quality of life, relating both to the 'costs' of dysphagia and to its management. The personal stories collected also highlight the importance of self-advocacy and the ability to learn to live with dysphagia to encourage positive mealtime experiences. People with dysphagia, whether of lifelong or acquired and ongoing origin, have lived experiences of the condition that must be explored and taken into account in any dysphagia management strategies suggested by health professionals and should continue to be included in assessment reports and mealtime plans. Dysphagia or mealtime-management related impacts on quality of life shape the way that people with dysphagia engage in mealtimes. The need for people with dysphagia to strongly self-advocate for receiving appropriate food at events hints at the fact that inclusive menus and foods should be considered at any event designed to include people with disability. This research should be used to shape policy and practice regarding (a) dysphagia assessment and management, including the design of interventions that improve not only health but also quality of life, and reduce any negative impact of interventions on quality of life; and (b) the provision of foods which the person views as being safe and enjoyable and that are of an appropriate texture for people with dysphagia. Policies and practices that support a person-centred and inclusive approach to interventions and recognising the many impacts outlined by participants in this study could benefit those with similar experiences to the participants in this study. Health professionals working with people with dysphagia should take the barriers and facilitators found in this study into consideration when providing assistance for swallowing difficulties. This will ensure health professionals are able to identify and reduce the impacts of the barriers to quality of life while enhancing the impacts of facilitators for their clients with dysphagia.

Chapter 8: The Impacts of Dysphagia on Quality of Life from the Perspective of Health Professionals

This chapter (Chapter 8) continues the development of an evidence-based framework related to the research aims of the impacts of dysphagia on quality of life, and barriers and facilitators to quality of life for people with dysphagia. Chapter 8 builds upon the perspectives of people with dysphagia and their supporters described in Chapter 7 by reporting on the perspectives of allied health professionals who work with people with dysphagia on the impacts of dysphagia. Allied health professionals play an important role in the diagnosis and management of dysphagia, thus it was important to consider their perspective on the impacts of dysphagia on quality of life.

This chapter has been written in manuscript form. It has been accepted for publication in the journal *Advances in Communication and Swallowing*.

Smith, R., Bryant, L., Hemsley, B. (in press-a). “Know the risks but balance that with their enjoyment”: Impacts of dysphagia on quality of life from the perspective of allied health professionals. *Advances in Communication and Swallowing.*

Parts of this chapter have been presented in poster presentations at the European Society of Swallowing Disorders Congress 2021, the UK Swallowing Research Group Conference 2022, and the Dysphagia Research Society Annual Meeting 2022.

Abstract

BACKGROUND: Numerous quantitative and descriptive studies show that dysphagia impacts on quality of life. However, there is little in-depth qualitative research exploring the nature of quality of life impacts of dysphagia from the perspectives of people with chronic or lifelong dysphagia or allied health professionals.

OBJECTIVE: To determine the views of allied health professionals who work with people with dysphagia on (a) the impacts of dysphagia on a person's quality of life, participation, and inclusion; and (b) barriers and facilitators to mealtime-related quality of life for people with dysphagia.

METHODS: 15 allied health professionals (12 speech pathologists and three occupational therapists) each attended one of four 2-hour focus groups. Their discussions were recorded, de-identified, and analysed for content themes. Summaries of the researchers' interpretations were sent to participants for verification.

RESULTS: Allied health professionals view that dysphagia impacts negatively on a person's quality of life, affecting choice and control, engagement in social activities, physical health, and positive food experiences. Barriers and facilitators to improved quality of life include: the opinions of others towards the person's texture-modified food, implementation of dysphagia interventions, knowledge of and education on dysphagia, and the person's control over mealtime design components.

CONCLUSIONS: The impacts of dysphagia on quality of life extend beyond enjoyment of the food itself and into the person's social activities and inclusion. Further research should examine the impacts of dysphagia on quality of life from the perspective of people with dysphagia and their supporters and identify ways to reduce this impact.

Key words: Dysphagia, Quality of life, Focus group.

Introduction

Dysphagia, or swallowing difficulty, can impact significantly on quality of life and these impacts increase for people with more severe dysphagia (Arslan et al., 2019). Emotional and social impacts of dysphagia include humiliation, loss, frustration, and a fear of choking (Moloney & Walshe, 2018; Nyberg et al., 2018). In the literature there is little research examining the impacts of dysphagia on quality of life (Smith, Bryant & Hemsley, 2022c); which is defined as a person's understanding of their position in life in regard to their beliefs, values, standards, and expectations (World Health Organisation, 1998). A recent scoping review by Smith, Bryant and Hemsley (2022c) identified that interventions addressing dysphagia can have both positive and negative impacts on a person's quality of life. For example, texture-modified diets and enteral tube feeding may improve swallow safety and health-related quality of life, but also increase feelings of isolation (Seshadri et al., 2018; Stavroulakis et al., 2016). The review included 106 studies, of which 44 used quantitative measures, frequently the Swallowing Quality of Life Questionnaire (SWAL-QOL) (McHorney et al., 2002) or the Eating Assessment Tool (Belafsky et al., 2008), to assess the impacts of dysphagia on quality of life. With little qualitative research on this issue to date, there is less knowledge available revealing in-depth insights on the impacts of dysphagia on quality of life.

People with dysphagia and their supporters interviewed about quality of life impacts revealed that people with dysphagia pay a high price in terms of the impact of dysphagia and its interventions (Smith et al., in press-b). However, the views of allied health professionals on these impacts are less well understood. In a recent survey of 144 community speech pathologists who worked with adults with acquired dysphagia, Howells et al. (2019b) reported that only 28.5% of respondents routinely measured the quality of life of clients with dysphagia. The most commonly used assessments were the Australian Therapy Outcome Measures (Perry et al., 2004) and the SWAL-QOL (Howells et al., 2019b). In follow-up interviews with the speech pathologists, Howells et al. (2019a) identified that community speech pathologists had to consider the impact of dysphagia beyond the meal, including on the person's mood; and the importance of client autonomy and caregiver engagement in therapy (Howells et al., 2019a). Moloney and Walshe (2019) surveyed 223 speech pathologists to determine how they viewed and addressed quality of life for people with dysphagia. The authors suggested that community-based speech pathologists addressed quality of life issues more appropriately than speech pathologists in acute services who focused primarily on medical status. Both of these studies indicate a need for further research exploring the views of members of the dysphagia-management team who have an influence over dysphagia interventions and might be in a position to mitigate the negative impacts of dysphagia on a person's quality of life.

It is important to identify how allied health professionals, including not only speech pathologists but also members of the wider multidisciplinary dysphagia management team (e.g., occupational therapists or dietitians) view the impact of dysphagia and interventions on a person's quality of life. As allied health professionals play a key role in the diagnosis and management of dysphagia, knowledge of their views on quality of life impacts could inform strategies to improve management plans for people with dysphagia. It is also important to understand the perspectives of allied health professionals so their views can be considered alongside those of people with dysphagia. This will help clinicians to determine where their views align or differ to people with dysphagia and recognise the person with dysphagia as the expert in their own condition. Therefore, this study aimed to determine the views of allied health professionals involved in dysphagia management on (a) the impacts of dysphagia and its management on a person's quality of life, participation, and inclusion; and (b) what they consider increases or reduces mealtime-related quality of life for people with dysphagia.

Methods

The study followed a constructivist grounded theory approach (Charmaz, 2017) and the focus group method used allowed for in-depth understanding of participants' practice in dysphagia management (Morgan, 2019; Patton, 2014). Online data collection enabled participant inclusion from different geographical locations and for safe participation with social distancing during COVID-19 (Turbitt & Jacobs, 2021) and focus groups supported participants' interactive discussion and the generation of new ideas (Morgan, 2019; Patton, 2014). The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist is used in reporting this study (Tong et al., 2007). The University's Human Research Ethics Committee approved the study (ETH19-3708).

Participants

Allied health professionals with at least two years' experience working with people with dysphagia (i.e., conducting dysphagia assessments and intervention) and speaking English were recruited through purposeful sampling and snowballing methods using the authors' social media networks and connections with local multidisciplinary health organisations. Therefore, a response rate could not be determined. The researchers recruited people with two or more years of experience working with people with dysphagia so that they had clinical experiences on which to base their views. These criteria assisted in the collection of rich, meaningful data for analysis. No further criteria were applied in recruitment. Participants were fully informed of the reasons behind the research and of the researcher's status as a female speech pathologist and a doctoral candidate prior to giving consent.

Fifteen allied health professionals (12 speech pathologists and three occupational therapists) engaged in four focus groups between March-May 2021. Three participants were previously known to the first author with no conflict of interest preventing their participation. The aim was to recruit enough participants to conduct at least three focus groups with three participants each following focus groups recommendations to enhance rigour (Hennink et al., 2019) and this aim was met. Three further speech pathologists expressed interest in the research but did not respond to email contact. This research was conducted in Australia with 12 of the participants having worked clinically in Australia. A further two participants lived and worked in the United States and another had worked in the United Kingdom. Information about participants, including their discipline and caseload is presented in Table 12.

Table 12

Chapter 8 Participant Demographic Information

Participant label	Age (years range)	Gender	Profession	Service type	Location	Client group
FG1OT1	18–30	F	OT	Private	Regional	Disability
FG1OT2	18–30	F	OT	NGO	Metropolitan	Disability
FG1SP3	31–45	F	SP	Private	Metropolitan	Medical – outpatient
FG1SP11	18–30	F	SP	NGO	Regional/ rural	Disability, aged care
FG1SP12	18–30	F	SP	Public	Metropolitan	Medical – acute
FG2SP4	18–30	F	SP	Private, NGO	Metropolitan	Disability, medical – rehabilitation
FG2SP6	18–30	M	SP	Public	Regional/ rural	Medical – acute
FG2SP9	18–30	F	SP	NGO	Metropolitan	Disability
FG2SP15	18–30	M	SP	Private	Metropolitan	Disability, Medical – rehabilitation
FG3OT3	31–45	F	OT	NGO	Metropolitan	Disability
FG3SP5	31–45	F	SP	Private, University	Regional	Medical- acute and outpatient
FG3SP10	31–45	F	SP	Private	Regional/ metropolitan	Disability, aged care
FG3SP13	31–45	F	SP	Public	Metropolitan	Medical – rehabilitation
FG4SP2	18–30	F	SP	Private, University	Metropolitan	Disability
FG4SP7	18–30	F	SP	Public, University	Metropolitan	Medical – acute and outpatient

Note. Female (F), Focus group (FG), Male (M), Non-government organisation (NGO), Occupational Therapist (OT), Speech Pathologist (SP).

Data Collection and Analysis

Participants provided written consent prior to attending one of four focus groups through Zoom at a time and location convenient to them. The fourth focus group, with only two participants, could be considered a small group interview. It followed the same method and format in terms of the topic guide and the resulting discussion did not differ from the other three focus groups. Therefore, it is referred to as a focus group in this paper. The first author, a speech pathologist and PhD candidate, who had experience in qualitative research methods and dysphagia management, including assessment and intervention, moderated all focus groups. The second and third authors, both speech pathologists with extensive experience in focus group research, each co-moderated one focus group. In the constructivist approach taken, the researchers past experiences shaped analysis (Charmaz, 2017). A focus group topic guide developed from previous research (Smith, Bryant & Hemsley, 2022c; Smith, Bryant, Reddacliff et al., 2022) (see Table 9 of thesis) was piloted with the first focus group and subsequently used with no changes in the following groups.

After making field notes following each discussion, the first author transcribed each 2-hour focus group video recording verbatim, de-identified the transcripts, and uploaded these to NVivo (QSR International, 2018) for content thematic analysis which involved inductive open and matrix coding (Braun et al., 2021; Krueger, 2002). Once the first author coded the data, all authors read and re-read the transcripts to determine alignment of participants' comments with the codes, and identify any further open codes and categories of meaning. Researchers met frequently throughout the period of data analysis to discuss the coding reports and connecting content themes within and across the transcripts in a constant comparison method. This was done to increase credibility, rigour, and trustworthiness, and to reduce researcher bias in the process of this research following a constructivist grounded theory approach (Morgan, 2019). This analysis revealed internal consistency within and across focus group discussions. The first author wrote a summary of each focus group's content themes and emailed these to the group's participants who were invited to make changes and to verify that the summary accurately represented their discussions. One participant from each group responded by email to verify that the written summaries reflected the groups' discussion and requested no changes. No follow-up focus groups were held. In reporting the results, quotes are provided to increase the transparency of the interpretation (Krueger & Casey, 2014) and a code label is used for each group (e.g., Focus Group 2 is FG2) and each participant (e.g., an occupational therapist in FG1 is FG1OT1).

Results/ Findings

Across the four focus groups there were two central themes, ‘Costs’ and ‘Management’, encapsulating and connecting eight sub-categories of meaning (see Table 13). Illustrative quotes supporting these themes and sub-categories are presented in Table 14. The first central theme relates to the ‘Costs’ of dysphagia on quality of life. The sub-categories of meaning within this theme related to negative impacts or ‘Costs’ on choice and control, reduced social engagement, negative or positive impacts on physical health, and restrictive mealtime experiences. The second central theme relates to the ‘Management’ of dysphagia, specifically factors forming barriers or facilitators to quality of life. These were: designing components of the mealtime; dysphagia interventions; knowledge and education provided to the person with dysphagia, their families, and supporters; and the attitudes and person-centred approach of others.

Table 13

Unmitigated Risk of Not Addressing Quality of Life for People with Dysphagia and Ways to Manage It

		Areas of interest											
Central Theme	Subtheme	Avoiding or restricting	Be adaptable	Be cautious, careful and safe	Impact on families	Keeping the status quo maintaining quality of life	Mood and psychological impact	Meeting social norms, trying to fit in, inclusion	Negative emotional responses	Negative perceptions	Resisting change	Self-awareness of own limitations	Self-determination
Costs of Dysphagia	Limited Choice and Control	X	X	X			X				X	X	X
	Reduced Social Engagement	X	X	X	X	X	X	X	X	X			X
	Negative or positive impacts on physical health	X		X	X		X		X				
	Negative food experiences	X							X				

		Appearing as a facilitator	Appearing as a barrier
Mealtime and Dysphagia Management	Food shaping choices	Designing: food taste, visual appeal, mealtime environment, mealtime companion, food texture, food temperature, mealtime assistance.	Failing to implement food design strategies to improve mealtime enjoyment.
	Dysphagia interventions	Texture-modified diet, tube feeding, rehabilitative techniques.	Texture-modified diet, tube feeding.
	Knowledge and education	The person with dysphagia, family members, or support staff have good knowledge about dysphagia and its interventions because education has been provided by health professionals.	The person with dysphagia, family members, or support staff have poor knowledge about dysphagia and its interventions as education has not been provided by health professionals.
	Opinions of others and a flexible, person-centred approach	Positive attitude of health professionals and support staff towards people with dysphagia and highly flexible/ agreeable to routine changes (i.e., person-centred approach).	Poor attitudes of health professionals or support staff towards person with dysphagia and unwilling to modify mealtime routines (i.e., non-person-centred approach).

Table 14

Quotes Describing Quality of Life for People with Dysphagia and Ways to Manage It

Central theme	Subtheme	Quote
Costs of dysphagia	Limited choice and control	"There's so many things around those day-to-day rituals that are taken away when all of a sudden somebody is preparing your food for you and you know there's less choice and I guess a gap in your day." (FG1SP11)
	Reduced social engagement	"They feel like they can't go to the café anymore, a restaurant … or you know let's just go for a walk and grab a coffee, that's kind of gone so then it weighs in on people's relationships and that connectedness that they have with the spouses even." (FG1SP3)
	Negative or positive impacts on physical health	"The biggest thing that I can see from my patients on their quality of life would be there malnutrition and dehydration." (FG1SP3)
	Negative food experiences	"The meals do come out looking like four like little lumps of puree. And some even need to be like mixed cos some of the juice has sort of floated to the top or it has developed a skin and it looks gross. And so and I've had patients who have said, 'I don't want to eat this slop you know this is gross.'" (FG2SP6)
Management of dysphagia and mealtimes	Food shaping choices	"I don't think I've ever seen, I know this a big call, puree or mixed moist not just mixed together in the disability sector … why would you want to wash the blender multiple times!" (FG4SP2)
	Dysphagia interventions	Provision of therapeutic swallowing techniques: "Again it comes down to that control, can I do something, can I at least give it a crack. And I always say this is no guarantee that this is going to work, we are potentially dealing with fibrosis... but if they can give it a go and it's indicated you know EMST (Expiratory Muscle Strength Training) is at least going to improve their cough strength, let's give it a go." (FG4SP7)
	Knowledge and education	"On the same handout there are strategies on how to modify [food] that may not just be blending it up … instead of avoiding the drier foods it's just adding a little bit of moisture you know extra sauce, extra butter whatever so you're not eliminating it or just pureeing it. You're giving strategies for that person or their family to make changes that are more possible in the home rather than in the hospital setting yeah." (FG2SP6)
	Opinions of others and a flexible, person-centred approach	"In these situations time is of the essence for everyone so it's a challenge for the staff I think to present [food] differently to, and it's probably also that's just what they're used to, that's what's been done. So sometimes it's just that's what we're used to so that's what we've done. So a lot of the time it is like scoop, scoop, scoop, that's what it is." (FG3SP10)

The 'Cost' of Dysphagia on Quality of Life: Multiple Impacts

Limited Choice and Control. Participants agreed that mealtime choices were often reduced for people with dysphagia, impacting on both their mood and mental health. FG1OT2 considered that, for people with dysphagia on a texture-modified diet, "the motivation to eat is gone"; particularly if desirable foods are restricted or removed from the menu to maintain safety and reduce the risk of respiratory illness or choking. Participants considered that limited choice and control may lead people to engage in risk-taking behaviours regarding mealtime choices, ignoring dietary recommendations to uphold the status quo and maintain quality of life (e.g., eating preferred regular foods). They also viewed that people with dysphagia may have limited choice and control over mealtime planning, particularly if they are excluded from choosing the foods, the mealtime location, who they eat with, or the timing of meals. For example, FG4 participants reported that in a supported accommodation (e.g., group home) environment, one pureed meal may be made for all residents requiring diet modification, "if one client is on minced moist and everyone else is on puree, everyone is getting puree" (FG4SP2). FG2SP4 reinforced this, saying "things are adjusted heavily for convenience but sometimes people … on modified diets… may be fed earlier, then they'd just be sitting with a puzzle during dinner while everyone else is eating." Participants viewed that these actions reflected staff putting their own or the supported accommodation provider's needs first; which could come at the 'Cost' of a person's quality of life.

Reduced Engagement in Social Activities. Participants agreed that social events often revolve around sharing meals; as FG1SP3 stated, "eating and drinking is innate to socialising." Participants in FG2 agreed that people with dysphagia may be socially excluded particularly if they experience significant changes in their swallowing skills and they avoid eating out with others. FG1OT1 highlighted the embarrassment that comes with eating out as many dysphagia characteristics go against social norms (e.g., coughing on food, food left in or around the mouth). This may result in people with dysphagia declining invitations to social events. FG1OT1 stated, “they just feel so self-conscious it becomes the ‘why bother’”. FG1SP12 also described the loss felt by people faced with a recent dysphagia diagnosis or change in diet, saying “if you’re someone who loves your food…it’s one of those little pleasures in life that’s maybe been taken away”.

FG2SP4 stated that social exclusion may also occur within group residential settings if a person cannot engage in social events because the food provided is unsuitable (e.g., pizza night) or because of their mealtime assistance needs (e.g., they are assisted to eat before or after others). FG2 agreed that the patterns of mealtime assistance might inhibit the social aspects of mealtimes. FG2SP4 reflected on the process outweighing the importance of the experience, particularly if “medicalised”, saying “making dinner becomes just like giving medication. It’s stressful, it takes the fun out of it.” FG2SP4 also described a staff member in aged-care referring to a person with dysphagia as a “feeder”. Focus group participants viewed that defining the person according to their need for mealtime assistance reflected reductionist stereotyping attitudes, having a potentially negative impact on the person’s mealtime experience.

Negative or Positive Impacts on Physical Health. Across the groups, participants considered how a person’s physical health could impact upon their dysphagia-related quality of life, noting that these impacts increased if the person could not maintain appropriate nutrition while on a texture-modified diet. FG1 participants anticipated that if people with dysphagia acted cautiously and followed food texture recommendations, their risk of aspiration pneumonia and hospitalisation would be reduced and their quality of life increased. FG1SP3 stated “they’re being compliant [with diet], that’s wonderful because we are keeping them out of hospital … their chest is nice and safe … they're not sick with, you know, infection. That's a huge positive." FG4 suggested that enteral tube feeding could supplement oral feeds to reduce the pressure on eating food orally, increasing quality of life. FG4SP7 explained that through enteral tube feeding "you really can give them the quality of life", by maintaining nutritional health and wellbeing.

Mealtime restrictions impacting on a person's food choices (e.g., texture-modified food) were also considered a potential threat to physical health and quality of life. The increased time to prepare and eat texture-modified food may result in a person avoiding meals and becoming malnourished or dehydrated, having greater impacts on their quality of life. The provision of more suitable cuts of meat for a texture-modified diet was suggested as one way to easily manage and maintain oral intake. Both FG3 and FG4 discussed how mealtime safety was often the burden of family members who needed to provide appropriate foods of the correct texture (e.g., a Christmas meal). Participants considered that the whole family could assist in maintaining the person's mealtime safety, physical health, and enjoyment. FG4SP7 stated: "everyone can be a little bit accountable and take a little bit of responsibility."

Negative Mealtime Experiences with Unappealing Texture-Modified Food. Participants agreed that across settings the appearance of texture-modified food for people with dysphagia was problematic and frequently led to negative emotional responses including feelings of grief and loss. FG4SP2 described texture-modified foods in disability residential facilities and day centres as "standard orangey brown puree in a plastic bowl" with food items blended together into a homogenous mass. Indeed, FG2 viewed food presentation as not a priority for group home staff who had limited food preparation training, and that time restraints in supported accommodation often shaped meal presentation and did not enhance, but rather reduced, mealtime-related quality of life. Presentation of texture-modified foods in hospitals was variable, potentially related to funding. Hospital pureed meals were described as unappetising “lumps of puree” (FG2SP6), and FG3SP5 admitted to referring to these meals in derogatory terms as “the dog box” being “little cellophane-lidded puree goo” with fellow staff members. However, participants felt responsible to promote food presentation, as it was not driven at the organisational level due to the costs and time of food shaping. FG4SP7 reported providing strategies for improving the appeal of texture-modified meals for people in the community, including recommending dysphagia cookbooks, and ideas for appropriately texture-modified meals.

The Management of Mealtimes and Dysphagia Impacts on Quality of Life

Food Shaping Choices. Participants described food shaping strategies they had trialled to improve the appeal of texture-modified food. FG1SP12 reported that in her experience, hospital patients liked food shaped using food moulds; however, they often could not continue with moulded food at home as it was difficult to make, and pre-made moulded food was expensive. FG1SP12 stated “I think that people would worry that to get a meal that looks like that, it looks quite labour intensive. You’ve got to cook it, blend it, and shape it.” FG1SP3 reported having previously used food moulds, but this was discontinued as the silicon moulds became mouldy through a lack of careful drying. FG3SP5 viewed food shaping as difficult in large hospitals or aged-care facilities due to the time required in food preparation, difficulties in heating shaped foods, and the level of “buy-in” (FG3SP5) needed from all levels of staff to justify the additional costs and time involved. A lack of such “buy-in” from all staff could be a barrier to mealtime quality of life for people with dysphagia if meals were presented as scoops of “goo” (FG3SP5). As an alternative, FG1SP11 suggested that presenting a texture-modified meal with a photograph of the original food item may help to create a link between the person's meal and the original food. She said: "if it was a steak and chips, [they] see that and then be thinking about it as they eat" (FG1SP11).

Dysphagia Management Choices. Participants across groups agreed that mealtime management should be multidisciplinary to maintain mealtime-related quality of life. FG2SP4 in particular described fellow speech pathologists as "swallow focused" and needing to "zoom out" and look at the whole person. FG1 participants held the view that providing a texture-modified diet may increase a person's confidence to engage in events with reduced fear of choking. FG1SP3 stated the importance of this around holiday periods: "I think Christmas is the biggest one …we talk early on about … what typically do you eat and then how they could modify it." To this end, new products like texture-modified ice-cream or pre-made thickened fluids might also increase the number of safe and enjoyable foods available. FG1OT1 recalled one client's experience saying, "once they found they could get thickened fluids in coffee flavour… they were the happiest person". FG3SP13 also considered that therapy techniques to increase the frequency of safe swallows (e.g., an effortful swallow) might improve quality of life. However, according to FG2SP9, people with lifelong dysphagia may not engage in rehabilitative therapy due to the ongoing nature of their condition. Overall, participants perceived that dysphagia therapy may be a barrier to quality of life if it is not available or does not increase opportunities for positive mealtime engagement.

Knowledge and Education. Participants agreed that education is particularly important to ensure people with dysphagia and their families understand, and to some extent accept, their swallowing difficulties and skills, dietary requirements, and how they may engage in food-related community activities. FG4SP7 stated, "I encourage family members to come to my consults, I help talk to them, educate them as well… here's a list of meals, here's a list of recipes and things like that.” Participants considered that providing education allowed the person to make decisions about their diet to maintain their autonomy and control over their health. For example, they expressed the view that people with dysphagia should be educated on the risks associated with particular foods before making any decisions. This could allow people with dysphagia to make an informed choice to eat preferred foods in certain situations (e.g., when supervised at a party). As a risk-minimisation strategy, participants also identified being vigilant about oral hygiene as an important element of safety for people with dysphagia. FG1SP11 stated that “it’s about offsetting and balancing those risks and quality of life.”

Participants reported that allied health professionals should provide education to support workers and family members to improve the person’s quality of life. FG1SP3 encouraged family members to taste-test modified foods to increase their understanding of food consistency and the importance of taste. FG1SP3 suggested that such learning experiences facilitated empathy and increased acceptance of texture-modified food. FG1SP3 stated: “encourage them to thicken everybody’s drinks in the house - like not just them so they don’t feel so isolated and different” even if they only do it once.

Regarding staff training in dysphagia management, FG3 agreed that support workers would benefit from training to use positive language around mealtimes and to take things at the person’s pace to reduce choking risk, as well as to present appetising meals. FG3SP5 said, “we unfortunately see that we feed our sick and vulnerable things that aren’t very appetizing and they’re the people who actually need the food and the nutrition”. Participants also provided education and information to support workers around risk-minimisation, and made some allowances (e.g., a person having sips of thin fluids between meals). Participants suggested that such compromises helped to improve adherence to texture modification and quality of life. Participants also perceived that poor knowledge of these strategies may limit a person’s overall mealtime experience and their quality of life.

Flexibility in Person-Centred Approaches to Increase Mealtime Participation and Inclusion. Participants viewed family members and support workers applying flexibility in a person-centred approach (e.g., in modifying mealtime routines, food preparation procedures) as helping people with dysphagia to maintain mealtime participation. Conversely, a lack of a flexible or person-centred approach may reduce a person’s mealtime participation. FG1 participants agreed that a functional assessment may assist in determining how mealtime participation could be improved. However, they viewed that direct support workers may not consistently implement mealtime participation recommendations if these were more difficult than their usual, familiar methods. For example, one participant described meeting resistance from group home staff in enabling residents to assist in food preparation, as “someone else [staff] could do it in a third of the time, it just doesn’t happen” (FG1SP11). Support staff may require specific instruction on ways to implement the recommendations to release roles back to the person with dysphagia and increase their independence and control over mealtime choices. Being involved in the meal preparation was seen as beneficial, even if taking a minor role in proceedings. For example, FG2SP9 suggested that engagement in mealtime preparation could be as simple as moving the person’s wheelchair to the kitchen so “they can sit close to and can see and watch what is happening”.

FG3 and FG4 participants recognised the importance of understanding a person’s social and cultural background to shape social participation at mealtimes. FG3SP5 and FG4SP7 acknowledged that speech pathologists need flexibility when considering social and cultural events and the types of food served. FG3SP5 stated: “there’s highly likely [foods] that they might be able to have without feeling like they’re being isolated … or sort of feeling like, you know, they've been left out of a situation." This also gave family members the confidence to safely include the person with dysphagia in the meal. FG4SP7 stated that family members "get a real sense of enjoyment to cater for someone at a social event or even if it's just like [coming] for dinner." FG1OT2 suggested that people with dysphagia, particularly those with lifelong health conditions, implemented flexible and creative strategies to continue engagement in social mealtime experiences. For example, FG1OT2 described a mother asking her child's schoolteacher to prepare cake for the child so they could enjoy their birthday cake with friends, "even though their child might be PEG [percutaneous endoscopic gastrostomy] fed they're still having their little bits of food for purely quality of life and it's only things like their birthday cake."

Participants considered that flexibility in mealtime procedures and therapeutic interventions to increase mealtime engagement should follow the person's individualised goals. FG2SP15 described people with dysphagia taking part in "smoothie" and "cupcake" groups and choosing the flavours used. In another example, a person with Huntington's disease who has chorea movements may have the goal of eating their meal, even if not helping to make it: "their function in the meantime is to engage in the mealtime, they don't necessarily have the capacity to be helping prepare the meals at the same time" (FG1OT2). Both of these cases highlight participants' perceived importance of individualising intervention.

Discussion

The findings of this research support and extend prior research (Howells et al., 2019a; Moloney & Walshe, 2019) regarding the importance of examining the impacts of dysphagia beyond the meal, considering client autonomy and the engagement of supporters. This research identified four key impacts of dysphagia on quality of life that need to be considered: physical health, choice and control, mealtime experiences, and social engagement. The fourth impact, affecting social engagement, is particularly important as social gatherings often involve sharing a meal (Balandin et al., 2009). These four key impacts also align with the impacts of dysphagia identified by adults with dysphagia and their supports in interviews by Smith et al. (in press-b). This study suggests that those working with adults with dysphagia need to demonstrate flexibility and have adequate knowledge of dysphagia and risk-minimisation techniques to enhance quality of life. This follows the well-reasoned drive for holistic and client-centred dysphagia management (Howells et al., 2019b). Taking a holistic approach and involving the person with dysphagia in mealtime decisions maintains choice and control, such that both improved safety and enjoyment during meals are supported (Balandin et al., 2009; Hemsley et al., 2019). Furthermore, as part of this holistic approach, clinicians need to check their own views alongside those of their clients to ensure they do not prioritise their own views over those of the person with dysphagia. Reflecting over how the person's views align and differ with their own will help clinicians to put the needs and desires of their clients first in aiming to provide holistic care and potentially improve quality of life.

The views of allied health professionals towards dysphagia interventions could also impact upon how these are discussed and presented to people with dysphagia. Some participants made statements regarding the health-related quality of life impacts of dysphagia (e.g., that a texture-modified diet alone will keep a person out of hospital, or that tube feeding would reduce a person's risk of aspiration pneumonia). However, dysphagia alone is unlikely to result in aspiration pneumonia (Langmore et al., 1998) and tube feeding may increase a person's risk of aspiration and reduce quality of life (Gomes et al., 2003; Mahant et al., 2011).

In this study, allied health professionals reported that a lack of knowledge or education in those supporting people with dysphagia could negatively impact on the person's quality of life; as could a lack of flexibility when providing mealtime support. This highlights the importance of training direct support staff in the provision of effective mealtime assistance and support for people with dysphagia. Mealtime assistance is not always provided in an appropriate manner (Steele et al., 1997) and support worker training is needed to ensure staff implement appropriate strategies that encourage participation in mealtime preparation and inclusion in all decisions about meals (Reddacliff et al., 2022).

The emotional and social consequences of dysphagia discussed in this study reflect the findings of Moloney and Walshe (2018) and Nyberg et al. (2018). Miller et al. (2006) also highlighted the lack of mealtime interest and motivation for people with dysphagia due to the increased effort and reduced enjoyment of eating. The repeated appearance of these findings across studies emphasises the importance of person-centred care for people with dysphagia. In previous research by Smith et al. (in press-b) people with dysphagia described advocating for their own mealtime enjoyment and engagement as this facilitated their mealtime quality of life. In this study, participants also highlighted the importance of advocacy, however participants described achieving this through the provision of dysphagia interventions and education. The provision of these interventions and education by allied health professionals may ensure people have the correct tools and strategies in place to advocate for their own successful mealtimes (Smith et al., in press-b). It also demonstrates the importance of dysphagia interventions being a facilitator for quality of life (Smith et al., in press-a).

Although improving the visual appeal of texture-modified food may not by itself be sufficient to improve a person's quality of life, it should be part of a wider intervention approach to improve mealtime engagement (Smith, Bryant, Reddacliff et al., 2022). The findings of this study suggest that allied health professionals struggle with the visual appearance of texture-modified meals and some may refer to modified foods using derogatory terms. The poor presentation of texture-modified food may also cause issues concerning mealtime dignity and reduce the quality of the person's overall mealtime experience. Lecko (2017) recommended that everyone has the right to appetising meals that maintain their dignity, however the descriptions provided by allied health professionals suggest this does not always occur. To improve mealtime-related dignity and quality of life, allied health professionals and the direct support workers and others assisting in food preparation may need to use a wider range of food design strategies, which may include the use of food moulds and 3D food printing (Hemsley et al., 2019; Smith, Bryant & Hemsley, 2022b). This needs to be examined further in a wide range of settings including group homes and hospitals, as the provision of poorly presented texture-modified food can lead to a reduced appetite (Shimizu et al., 2021). Greater consideration of quality of life in dysphagia management may improve therapy implementation and outcomes for the physical, psychological, and social needs of people with dysphagia (Shune & Linville, 2019).

Limitations and Directions for Future Research

This was a small study with the majority of participants from Australia, and data saturation was not achieved; hence the results should be interpreted cautiously. Attempts were made to recruit various allied health professionals; however, no dietitians took part, and their inclusion may have provided additional insights into the intersection of dysphagia, nutrition, and quality of life. However, the small sample size in this qualitative research allowed for an in-depth examination of the topic which could be used to shape further dysphagia assessment and intervention. The inclusion of participants from a range of work settings (e.g., disability organisations, acute hospitals) may also assist in the transferability of this research to dysphagia clinicians working in a range of environments; as similar views were collected across the settings. Future research should consider the views of a wider range of health professionals including medical staff, dietitians, and clinical psychologists. This is particularly important as the findings of this study indicate various impacts on a person with dysphagia, including reduced quality of life and wellbeing, which should be considered in clinical management.

Conclusion

Allied health professionals' views reveal much about the complexity of dysphagia, its management, and how aspects of this complexity impact negatively on quality of life. Participants identified several 'Costs' associated with dysphagia and restricted food choices, as well as several 'Management' strategies forming barriers to or facilitators for improved quality of life. The impacts or 'Costs' on the person with dysphagia included reduced choice and control, reduced social engagement, negative mealtime experiences, and impacts on physical health. Barriers and facilitators for improved quality of life included the provision of education, greater knowledge of dysphagia management strategies, being flexible to the person's needs, implementing dysphagia interventions, and supporting the person to be more involved in designing their own meal. Further efforts should be made to identify the views of all key stakeholders including dietitians, people with dysphagia, and supporters of people with dysphagia aiming to implement dysphagia management recommendations.

Chapter 9: Survey Findings on Quality of Life

Due to low recruitment, additional measures were needed to verify findings. An online survey allowed for this. It also extended the constructivist grounded theory (Chapter 4) by providing a third data point for triangulation. This chapter presents the results of the online survey related to the impacts of dysphagia on quality of life from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals in earlier interviews. The purpose of this survey was to verify the findings from earlier interviews, focus groups, and mealtime observations (results described in Chapters 7 and 8). This was particularly important due to the low recruitment faced by the researcher in these studies. The use of the online survey allowed for some descriptive comparison to occur between the participant groups included in this research. Data triangulation of data collected in studies 1a, 2, and 3 could also be conducted to further the development of the evidence-based framework describing the impacts of dysphagia on quality of life and the feasibility of 3D food printing. This chapter reports on survey data related to the impacts of dysphagia on quality of life. This online survey was distributed on RedCap (Harris et al., 2009) and was open for participants between November 2021 and February 2022.

This chapter has been written in manuscript form and is currently under review for publication in *Disability and Rehabilitation.* The findings have also been accepted for a technical presentation at the 2022 American Speech-Language-Hearing Association (ASHA) Convention.

Smith, R., Bryant, L., Hemsley, B. (2022d). *"I only eat to because I have to – to live": The impacts of dysphagia on quality of life from the perspectives of people with dysphagia, supporters of people with dysphagia, and allied health professionals* [Manuscript submitted for publication]. Graduate School of Health, The University of Technology Sydney

Abstract

Purpose: To determine the views of people with dysphagia, supporters of people with dysphagia, and allied health professionals on the impacts of dysphagia and texture-modified food on quality of life.

Materials and Method: An online survey of adults with dysphagia (*n*=30), supporters of people with dysphagia (*n*=4), and allied health professionals (*n*=18) was conducted between November 2021 and February 2022. Categorical questions were analysed descriptively, and open-ended questions were analysed using content thematic analysis.

Results: Participants with dysphagia reported that dysphagia and texture-modified food had a greater impact on their physical health, and lesser impact on their choice and control or social engagement. Supporters and allied health professionals viewed that dysphagia impacted on both physical health and choice and control. Across groups, participants considered that mealtime enjoyment, participation, and inclusion were influenced by the control the person had over their meals, the accessibility of the mealtime environment, and the attitudes of others.

Conclusion: Dysphagia and its interventions negatively impact on quality of life. People with dysphagia were the most affected by the physical impacts of dysphagia. Their perspectives contrasted with those of supporters and allied health professionals. Future research exploring how these perspectives are integrated into person-centred management is warranted.

Key words: Dysphagia, Quality of life, Survey, Inclusion, Participation.

Introduction

Dysphagia (difficulty swallowing) is associated with number of lifelong disabling health conditions (e.g., cerebral palsy, Down syndrome, autism) (Sheppard et al., 2014) and acquired health conditions (e.g., stroke, Parkinson's, motor neuron disease, myositis) (Groher & Crary, 2016; Oh et al., 2008). Across populations, dysphagia can have significant negative impacts upon quality of life, particularly for people with more severe forms of dysphagia (Jones et al., 2018).

In a recent review of the literature on mealtime quality of life, a wide range of impacts on the person with dysphagia were identified including reduced quality of life, loss of independence, frustration, and a fear of choking (Smith, Bryant & Hemsley, 2022c). In the review of 106 studies, 95 (90%) focused on adults with acquired health conditions, and only seven (7%) focused on people with lifelong health conditions. Nonetheless, the review across populations revealed that (a) dysphagia can impact negatively on many aspects of life, including physical health, wellbeing, and social participation and inclusion, and (b) dysphagia interventions can have both a positive and negative impacts, for example, texture-modified foods or tube feeding may improve the person's physical safety, or result in isolation (Ang et al., 2019; Seshadri et al., 2018).

In regard to the support provided by speech pathologists to people with dysphagia, Howells et al. (2019a) conducted interviews with 15 speech pathologists and described that speech pathologists working in the community setting aimed to provide holistic care that encompassed client autonomy and caregiver engagement. This differed from the acute setting, where the main aim was to ensure the person's physical safety and did not necessarily to promote quality of life (Howells et al., 2019a). Although this study described the change in values of speech pathologists in the community, it did not describe the perspective of other allied health professionals involved in providing multi-disciplinary care for people with dysphagia (e.g., occupational therapists and dietitians). Howells et al. (2021a) then examined the lived-experiences of people living with dysphagia in the community. Howells et al. (2021a) interviewed 15 people with dysphagia and found that people living with dysphagia faced many psychosocial impacts regarding the loss and changes they faced as a result of their swallowing difficulties and how they managed their dysphagia outside of the home. Participants also highlighted the importance of support from family, friends, and health professionals, including speech pathologists in maintaining a positive mealtime experience (Howells et al., 2021a). However, most participants in this study presented with mild dysphagia characteristics and did not require significant food modifications. This may have impacted on their perception of the impact of their swallowing difficulties on their mealtime experiences as research has shown that the impacts of dysphagia grow as the severity of dysphagia increases (Jones et al., 2018).

In other recent research, Smith et al. (in press-b) interviewed nine people with dysphagia and four of their supporters about how dysphagia had impacted their quality of life. Participants reported having to ‘pay the price’ for dysphagia in that it reduced their choice and control, social engagement, physical safety, and resulted in them having poor food experiences (Smith et al., in press-b). In a separate study involving focus groups of allied health professionals, Smith et al. (in press-a) identified the perceived ‘costs’ borne by people with dysphagia and that dysphagia interventions and management strategies formed both barriers to and facilitators for a person’s quality of life. These barriers and facilitators included the person’s knowledge of dysphagia and education provided, the provision of dysphagia interventions, and the person with dysphagia’s engagement in designing their own mealtimes (i.e., participation, inclusion, and choice and control). Owing to the relatively small scale of both studies (conducted during COVID-19, which impacted recruitment) further research utilising methods to gather the views of a larger number of people with dysphagia, supporters of people with dysphagia, and allied health professionals was needed to triangulate with the findings of prior qualitative research (Patton, 2014). Therefore, the aim of this research was to understand more about the views of people with dysphagia, supporters of people with dysphagia, and allied health professionals, on the impacts of dysphagia on quality of life as a way to verify and expand upon the findings of the prior qualitative methods with these groups. By verifying and deepening present understanding of these issues, this study will inform future evidence-based and person-centred dysphagia management practices.

Methods

This ethically approved research (ETH21-6568 and ETH21-6781) involved an online survey (Braun et al., 2021) as an appropriate follow-up method to verify and deepen understanding of the phenomenon explored in qualitative methods (Lyons et al., 2022). The Good Reporting of a Mixed Methods Study (GRAMMS) checklist (O'Cathain et al., 2008) was used to report the methods and results.

Participants

Participants in this study included adults with dysphagia associated with any health condition; supporters of people with dysphagia (e.g., family members and direct support workers); and allied health professionals who work with people with dysphagia. Convenience and purposeful sampling methods were used to recruit participants through the researchers' social media networks; thus, a participant response rate could not be determined (Emmel, 2013). Information about the study was provided on the landing page of the survey so that prior to taking part, participants were informed of the purpose of the research and the position of the researchers involved as a PhD candidate and speech pathologist. By continuing the survey, participants gave their implied consent for their responses to be included.

Materials

The online survey was created using RedCap Software (Harris et al., 2009) accessed through a URL link or QR code. The survey was based on findings from a literature review (Smith, Bryant & Hemsley, 2022c) and prior interviews and focus groups with similar groups of participants (Smith et al., in press-a, in press-b) examining the impact of dysphagia on quality of life.

The survey was designed to take approximately 15-20 minutes to complete. Branching logic was used within the survey to ensure questions were relevant for the participant and their mealtime role (e.g., person with dysphagia or an allied health professional). The survey contained a range of questions including multiple choice, questions with Likert Scale responses, yes/no questions, and open-ended questions for text responses. The type of questions and the order in which they were presented was the same for each participant, to encourage the accuracy and truthfulness of the participants when responding to questions (Wolf et al., 2016). The survey was piloted by two colleagues of the first author who were speech pathologists with changes being made to increase clarity, and the survey was released to the public once ethical approval was obtained. A full copy of the online survey is in Appendix F of this thesis.

Procedures

The survey was open to the public for 15 weeks from November 2021 to February 2022. Survey responses in which participants had only completed demographic questions were excluded to reduce non-response errors occurring in the descriptive analysis of the results (Wolf et al., 2016).

Analysis

Categorical quantitative survey responses were extracted to an Excel file and analysed descriptively using frequency, average, and range statistics (Groves et al., 2009). There were insufficient responses for statistical comparisons within or across subgroups of respondents. Open-ended text-based responses were analysed qualitatively using content thematic analysis (Patton, 2014) using NVivo (QSR International, 2018) to identify the developing categories and content themes (Braun et al., 2021). Content codes and themes were developed both inductively from the data and deductively based on the content codes developed in the prior focus group and interview results (Smith et al., in press-a, in press-b). The development of the content codes, categories, and connecting themes were identified through a reading and re-reading of the comments and repeated discussions by all authors fortnightly over a two-month period to ensure accuracy and increase credibility. Quotes from participants are provided to increase the plausibility and trustworthiness of the results and participants are identified using their survey number (e.g., Participant 7 is labelled P7).

Results

Participants

While 101 people commenced the survey, only the 52 (51%) who included more than demographic data and answered questions about quality of life impacts were included. These 52 participants, who all provided complete or almost complete survey responses, included 30 (57.7%) people with dysphagia, four (7.7%) supporters of a person with dysphagia, and 18 (34.6%) allied health professionals. Participants with dysphagia were for the most part older people aged between 31 and 80+ years of age; the median and mode age range was 71-80 years (*n*=16 participants, 53.3%). Participants with dysphagia identified as female (*n*=15, 50%), male (*n*=14, 46.7%), or non-binary (*n*=1, 3.3%). They described having swallowing difficulties for a range of less than one year up to 25 years, with most (*n*=15, 50%) having difficulties for 6-10 years. This duration of dysphagia symptoms reflected that the majority of participants had acquired dysphagia in adulthood. The supporters of people with dysphagia were aged 41-60 years of age with the mode being 51-60 years of age (*n*=3, 75%). Supporters identified as female (*n*=3) or male (*n*=1), with two (*n*=1) to 20 or more years' experience working with people with dysphagia (*n*=3).

Allied health professionals were aged 18-80 years with median and mode age of 31-40 years (*n*=6, 33.3%). Participants in this group identified as female (*n*=18, 100%), speech pathologists (*n*=11, 61.1%), dietitians (*n*=5, 27.8%), an occupational therapist (*n*=1, 5.6%), or a speech pathology researcher/academic (*n*=1, 5.6%). They reported from three years (*n*=4, 22.2%) to 20 or more years (*n*=6, 33%) of experience working with people with dysphagia; providing assessment (*n*=10, 55.6%), intervention (*n*=13, 72.2%), and mealtime assistance training (*n*=9, 50%). Further participant information is provided in Table 15.

Table 15

Chapter 9 Participant Demographic Information

ID#	Mealtime role	Gender	Age range (years)	Location	Region (if in Australia)	Time with dysphagia	Time working with people with dysphagia
P1	SP researcher	Female	51–60	Australia	City/metropolitan	NA	20+ years
P9	SP	Female	18–30	Australia	City/metropolitan	NA	3–5 years
P11	SP	Female	31–40	Australia	City/metropolitan	NA	11–15 years
P13	SP	Female	18–30	Australia	City/metropolitan	NA	6–10 years
P16	OT	Female	18–30	Australia	City/metropolitan	NA	6–10 years
P23	PWD	Female	71–80	Europe	NA	0–5 years	NA
P24	Care facility CEO	Female	51–60	Australia	City/metropolitan	NA	20+ years
P26	Dietitian	Female	31–40	Australia	City/metropolitan	NA	3–5 years
P28	SP	Female	31–40	Australia	Regional	NA	3–5 years
P29	SP	Female	51–60	Australia	City/metropolitan	NA	20+ years
P31	SP	Female	31–40	Australia	City/metropolitan	NA	6–10 years
P33	Dietitian	Female	31–40	Australia	City/metropolitan	NA	3–5 years
P35	SP	Female	51–60	Australia	City/metropolitan	NA	11–15 years
P37	PWD	Male	71–80	Australia	City/metropolitan	6–10 years	NA
P38	SP	Female	18–30	Australia	City/metropolitan	NA	6
P40	SP	Female	51–60	Australia	City/metropolitan	NA	20+ years
P41	Dietitian	Female	41–50	USA	NA	NA	20+ years
P42	Dietitian	Female	71–80	USA	NA	NA	20+ years
P45	SP	Female	41–50	UK	NA	NA	20+ years
P52	Dietitian	Female	51–60	Australia	City/metropolitan	NA	6–10 years
P53	PWD	Female	61–70	USA	NA	11–15 years	NA
P54	Support person	Female	41–50	Australia	City/metropolitan	NA	20+ years
P56	PWD	Male	80+	Australia	City/metropolitan	6–10 years	NA
P57	PWD	Male	71–80	Australia	Rural	6–10 years	NA
P58	PWD	Female	71–80	Australia	City/metropolitan	0–5 years	NA
P59	PWD	Male	80+	Australia	City/metropolitan	0–5 years	NA
P61	PWD	Male	71–80	Australia	Regional	0–5 years	NA
P62	PWD	Female	51–60	Australia	City/metropolitan	6–10 years	NA
P64	PWD	Male	80+	Australia	City/metropolitan	6–10 years	NA
P66	PWD	Male	71–80	Australia	City/metropolitan	0–5 years	NA
P67	PWD	Female	71–80	Australia	City/metropolitan	6–10 years	NA
P70	PWD	Male	61–70	Australia	City/metropolitan	6–10 years	NA

ID#	Mealtime role	Gender	Age range (years)	Location	Region (if in Australia)	Time with dysphagia	Time working with people with dysphagia
P71	PWD	Female	71–80	Australia	City/metropolitan	6–10 years	NA
P72	PWD	Male	61–70	Australia	Regional	11–15 years	NA
P73	PWD	Female	61–70	Australia	City/metropolitan	6–10 years	NA
P74	PWD	Male	71–80	Australia	Regional	0–5 years	NA
P75	PWD	Female	61–70	Australia	Regional	0–5 years	NA
P80	PWD	Male	61–70	Australia	Regional	0–5 years	NA
P83	PWD	Male	71–80	USA	NA	0–5 years	NA
P86	PWD	Female	71–80	Australia	Rural	6–10 years	NA
P87	PWD	Male	61–70	Australia	City/metropolitan	6–10 years	NA
P89	PWD	Female	31–40	Australia	City/metropolitan	0–5 years	NA
P90	SP	Female	31–40	USA	NA	NA	11–15 years
P91	PWD	Female	71–80	Australia	Regional	0–5 years	NA
P92	PWD	Female	71–80	Australia	City/metropolitan	0–5 years	NA
P94	PWD	Female	61–70	Australia	Regional	6–10 years	NA
P96	PWD	Female	71–80	Australia	City/metropolitan	21–25 years	NA
P97	PWD	Female	61–70	Australia	City/metropolitan	6–10 years	NA
P98	PWD	Non-binary	71–80	Australia	City/metropolitan	6–10 years	NA
P99	Support person	Male	71–80	Australia	City/metropolitan	NA	Up to 2 years
P100	Support person	Female	51–60	Australia	Regional	NA	20+ years
P101	PWD	Male	71–80	Australia	City/metropolitan	0–5 years	NA

Note. CEO = Chief Executive Officer, ID# = Identification Number, NA= Not Applicable, OT = Occupational Therapist, PWD = Person with Dysphagia, and SP = Speech Pathologist

Participants with Dysphagia: Profiles on Food, Fluid, and Mealtime Assistance

According to the International Dysphagia Diet Standardisation Initiative Framework (IDDSI) (Cichero et al., 2017), the types of food participants with dysphagia included in their oral intake included foods that were Regular or Easy to Chew (IDDSI Level 7) (*n*=14, 29.8%); Soft and Bite-Sized (IDSSI Level 6) (*n*=12, 25.5%); Minced and Moist (IDDSI Level 5) (*n*=12, 25.5%); Puree (IDDSI Level 4) (*n*=3, 6.4%); and Liquidised (IDDSI Level 3) (*n*=3, 6.4%). Thirteen (43.3%) of the participants with dysphagia described being able to eat foods across a range of consistencies. However, four could only eat IDDSI Level 5 Minced and Moist, IDDSI Level 4 Pureed, or IDDSI Level 3 Liquidised foods and one only ate Liquidised food (IDDSI, 2019).

When classified according to the IDDSI (IDDSI, 2019), participants reported having Thin fluids (IDDSI Level 0) (*n*=13, 41.9%); Slightly Thick fluids (IDDSI Level 1) (*n*=5, 16.1%); Mildly Thick fluids (IDDSI Level 2) (*n*=1, 3.2%); Moderately Thick fluids (IDDSI Level 3) (*n*=3, 9.7%); and none were on Extremely Thick fluids (IDDSI Level 4). A further nine participants (29.3%) did not report on their current fluids. Only one participant (P8) described having fluids of two consistencies: Slightly Thick and Thin drinks (i.e., IDDSI Levels 1 and 0). Participants also reported using assistive technologies at mealtimes, including adaptive cutlery (*n*=7, 18.9%), a straw (*n*=4, 10.8%), an adaptive cup (*n*=3, 8.1%), and a non-slip mat (*n*=2, 5.4%). Five participants reported using no adaptive tools (13.5%). Some participants (*n*=3, 8.1%) used multiple assistive technologies, with the non-slip mat and adaptive cutlery commonly used together. However, only 15 (50%) participants responded to this question.

In addition to describing their oral food textures, participants commented on foods they considered as safe and enjoyable. Participants were highly aware of the modifications they made to food to ensure their swallowing safety. For example, P67, P83, and P98 all described eating well-cooked vegetables, and P57, P80 and P92 gave a clear indication of foods they had to exclude from their diet, including bread, steak, and raw vegetables. Participants also described using a range of strategies during the meal to make foods easier to swallow. For example, P58 described having a drink with meals to clear the food and P72 described doing the same with ice-cream, writing: “I usually eat ice-cream after every meal to remove residual food from my throat”. However, these strategies did not improve mealtime enjoyment, as P23 wrote: “I don't enjoy eating anymore” and P56 also noted “I really don't enjoy eating food anymore as it is too hard to swallow”.

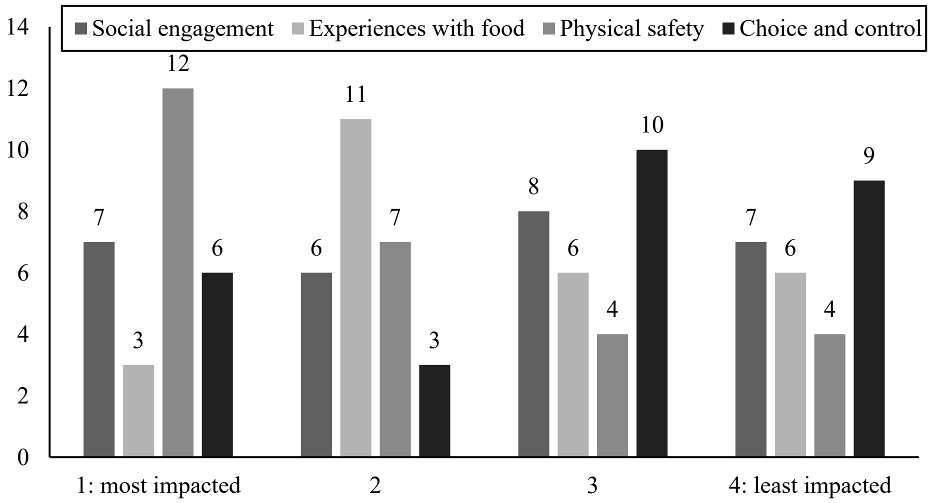
Mealtime Assistance Needs. Almost half of the participants with dysphagia (*n*=14, 46.7%) reported they received assistance in preparing and cooking meals; with food shopping (*n*=10, 33.3%), menu planning (*n*=5, 16.7%), assistance to eat (*n*=4, 13.3%), and assistance after the meal (*n*=6, 20%). Two participants required no assistance in relation to any aspect of the meal; one, P89, needed assistance with all aspects of the meal, and P70 required for all tasks but menu planning. Three participants did not provide information about their need for mealtime assistance or its impact on quality of life.

Perceived Impacts of Dysphagia on Health and Social Engagement

Participants were asked to rate the impact of dysphagia on four areas of mealtime quality of life identified in prior research (Smith et al., in press-b): choice and control, physical safety, social engagement, and experiences with food. Participants with dysphagia most often considered swallowing difficulties to have the greatest impact on physical safety (*n*=12, 42.9%), whereas choice and control was most frequently rated as being the least impacted (*n*=9, 32.1%) (see Figure 7). P89 indicated that she prioritised reducing choking risk over her desire to keep desired foods and flavours as part of her diet, writing “I choose foods based on 'potential choke value'". Overall, the participant ratings of impact on social engagement varied greatly within and across participant groups, and there was little agreement on ratings. These results are presented in graphic form in Figure 7. In terms of social impacts, some participants with dysphagia exercised their choice and control by choosing not to eat out with others; P73 reported "I don't dine out socially". Others prioritised eating out, accepting that this meant limiting their control over food choices. The intersection of the impacts of dysphagia on the person influenced decisions people with dysphagia made in designing their own mealtimes. As P91 wrote, "I am still able to make a choice as to what I eat, but in public I feel more comfortable having smooth soup."

Figure 7

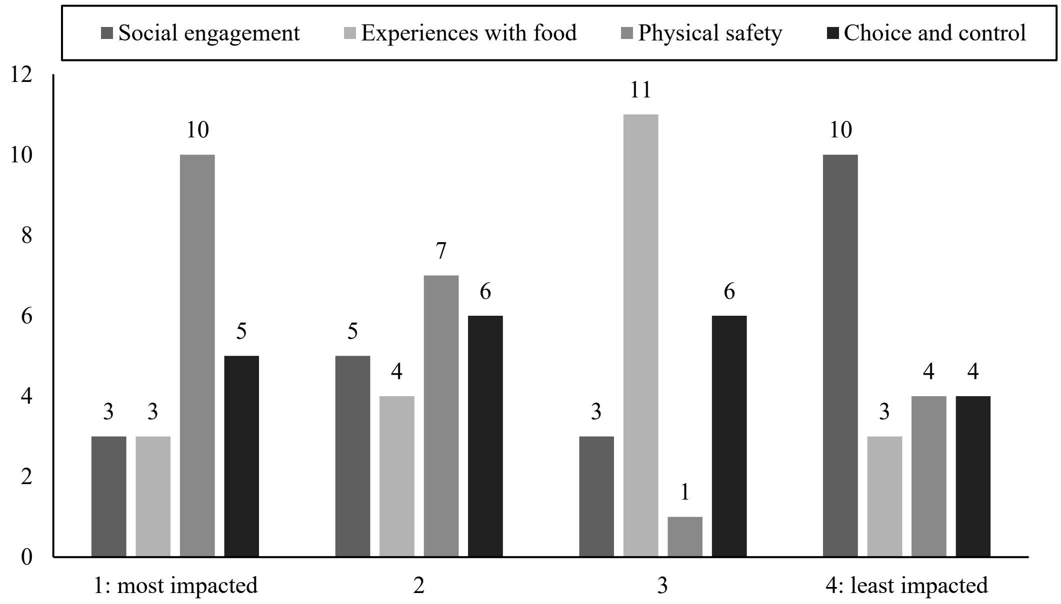
Impact of Swallowing Difficulties for People with Dysphagia



After physical health, the area rated most impacted by people with dysphagia was social engagement (n=7, 25%) (see Figure 7). Indeed, people with dysphagia rated the impacts of dysphagia as being greater on social engagement than did supporters of people with dysphagia or allied health professionals (see Figure 8). Supporters and allied health professionals considered social engagement to be the least impacted (n=10, 47.6%) and less impacted than the experiences with food (n=11, 52.4%). However, the participants also recognised the relationship between the physical features of food and social engagement; P33 wrote “if the textured food does not taste good or is the preferred choice, the resident's overall experience will be affected, which in turn, negatively affects social engagement and choice and control."

Figure 8

Impacts of Swallowing Difficulties from the Perspective of Supporters of People with Dysphagia and Allied Health Professionals

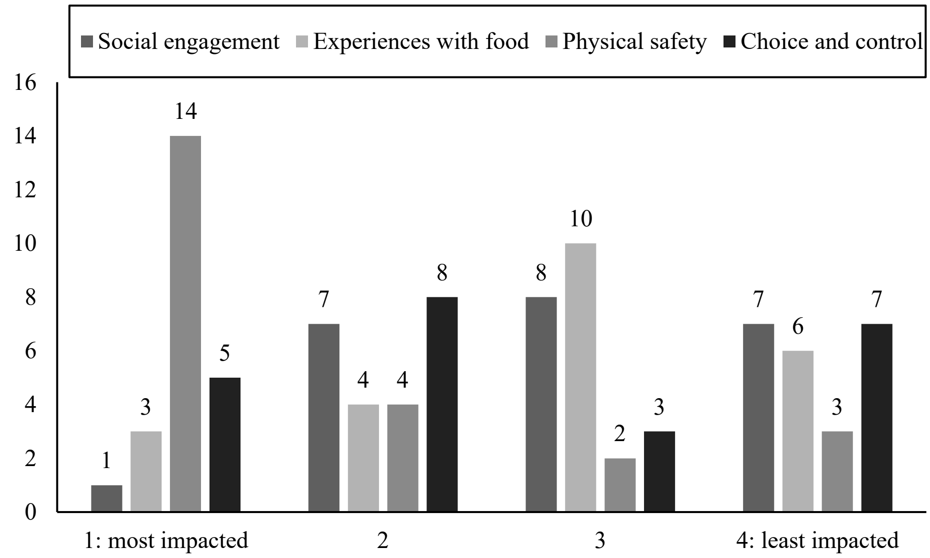


Perceived Impacts of Dysphagia Interventions on Health and Social Engagement

Participants also rated the impact of modifying food or fluid textures, a common dysphagia intervention, on physical safety, social engagement, experiences with food, and choice and control. Once again, participants with dysphagia reported that modifying food textures had the greatest impact on physical safety (*n*=14, 60.9%) and rated ‘choice and control’ (*n*=8, 34.8%) and ‘experiences with food’ (*n*=10, 43.5%) as the areas second and third most impacted by modifying food textures (see Figure 9). P72 wrote: “physical safety is something I have to be mindful of every meal.” Almost all participants with dysphagia considered that their dysphagia had a greater impact on their social experiences than did their dysphagia interventions to modify food or fluid textures. Only one participant with dysphagia (3.3%) reported that their need for texture-modified food had impacted more on their social engagement than their dysphagia.

Figure 9

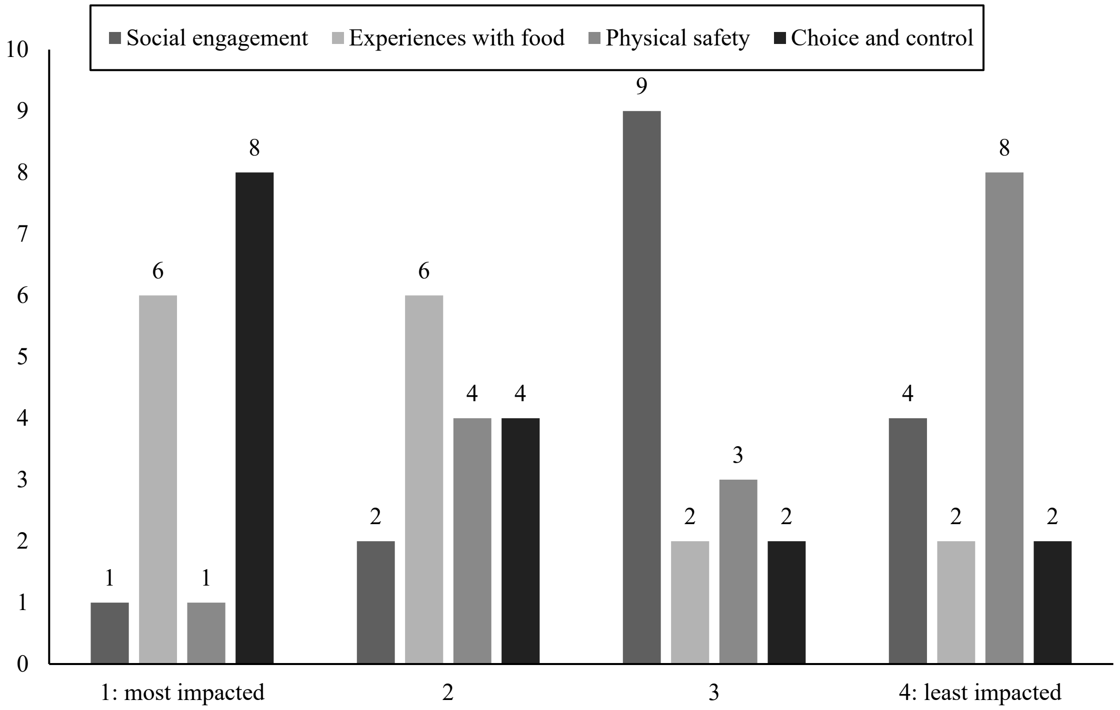
Impacts of Texture-Modified Food for People with Dysphagia



Supporters of people with dysphagia and allied health professionals viewed choice and control (*n*=8, 50%) as most impacted by dysphagia interventions (i.e., texture-modified food) and physical safety (*n*=8, 50%) as least impacted (see Figure 10). These two groups of participants considered that once physical safety was maintained by the introduction of a texture-modified diet, the impacts on choice and control, experiences with food, and social inclusion were more evident. P31, a speech pathologist commented that “most [people] report being upset that they will not be able to have preferred foods or the things that they want.”

Figure 10

Impacts of Texture-Modified Food on Quality of Life from the Perspective of Supporters of People with Dysphagia and Allied Health Professionals



Participants with dysphagia described the impact of dysphagia on their social inclusion through being able to eat out with others. Of the 55 responses provided, the greatest identified impact on eating out was the time it took to finish their meal (*n*=21, 38.1%). Some participants reported looking through a menu before visiting a restaurant (*n*=13, 23.6%). Only three participants described being judged by others; however, P74 reported he only eats out "with people I know and then not very often", so there was limited chance for judgement. Almost one quarter of participants with dysphagia (*n*=13, 23.6%) reported that they do not eat with others. P91, who reportedly only ate smooth soup when out, described her difficulties and lack of acceptance by others when eating out as follows:

> I have rung restaurants and explained my situation but have been refused a booking if I want to bring a thickened drink. I love food for flavour and texture but due to choking I can't eat in public, for the sake of fellow diners and fear of choking.

Impacts of Dysphagia or its Interventions on Mealtime Experiences and Enjoyment

In their written responses, participants described the barriers and facilitators they faced in relation to mealtime enjoyment. Mealtime enjoyment was impacted by the fear of choking and other physical impacts (e.g., nutritional loss); and the loss of choice and control at mealtimes. This was further reflected in participants reportedly having limited food choices or the inability to eat regular foods. Participants reported that enjoyment was reduced due to the increased time it took them to eat a meal, as P98 wrote: "I'm slow at preparing and very slow eating." In regard to increasing mealtime enjoyment, participants with dysphagia reinforced the importance of flavour of the food and its enhancement; P73 wrote, "taste and flavour are important for enjoyment." Two other participants with dysphagia described that nothing helped to improve their enjoyment; as P37 wrote, "now that I live alone, I only eat because I have to - to live."

Supporters of people with dysphagia and allied health professionals shared similar views to people with dysphagia in relation to impacts on mealtime experiences and enjoyment. P26, a dietitian, described the limited enjoyment of mealtimes related to reduced physical safety, writing "the risk of choking can become a fear that negates the joy of eating." Participants in these groups viewed the flavour of food as improving the enjoyment of a meal; however, they also suggested that enjoyment was improved through other environmental factors, including social interactions and the mealtime location. P1 suggested that "enjoyment can be the ambience, the timing, the food, a whole combination of things."

Participants with dysphagia often described mealtime inclusion as being influenced by the level of choice and control they had in the mealtime decision-making process. They viewed that the greater level of choice a person had, the greater their opportunity for inclusion. For example, P72 wrote: "I have most say in what I will eat. I eat in my shed, I prefer it.” Inclusion was reportedly reduced due to the way they ate their meal (e.g., P56 described himself as a “messy eater. Have to wear a bib”), and the fear of choking in front of others. Accessibility issues related to reduced mobility (e.g., use of a wheelchair) also negatively influenced inclusion if the person could not access cafes, restaurants, or shops to buy their own food. However, many participants with dysphagia (*n*=13, 43.3%) reported they had indeed continued to prepare, serve, and eat their own texture-modified meals, and others reported only being involved in eating the meal (*n*=2, 6.7%). Some participants viewed their physical movement difficulties as preventing their involvement in meal preparation. P70 explained: “I do not prepare meals because I drop things often.” One participant reported having assistance in the kitchen to lift heavy objects, and access to adaptive cutlery which enabled their participation in mealtime preparations. Participants who lived alone usually ate alone and had to complete all tasks for themselves. The COVID-19 pandemic and risks or restrictions associated with social distancing also appeared in some comments as reducing opportunities to participate in mealtimes with others: “the COVID factor has put a halt to my weekly meal at my son and daughter's homes (P98).”

Supporters of people with dysphagia and allied health professionals alike viewed a person’s choice and control as being important in maintaining mealtime inclusion and that other people could assist in this process. For example, P28 described a client’s friend learning about dysphagia-friendly food: “she adapted the morning teas available to include items that were ordinary foods my client could eat so they could participate in their social circle without drawing attention.” P35 considered that inclusion was about “being able to have choices around what they are eating, where and when.” Inclusion was also limited by poor food options, negative stereotypes, or treatment by other people (e.g., P72 wrote his wife became “frustrated” with him at mealtimes), and lack of provision of appropriate assistive technologies for mealtimes (e.g., modified cutlery). P33, a dietitian wrote: “there are too many limiting factors that prevent people with dysphagia from the simple act of eating." They considered that reduced mealtime participation was associated with the higher levels of support a person with dysphagia needed to prepare and eat meals – particularly if the person assisting did not provide choice and control in each of the steps involved in mealtime preparations. P90 described this limitation as: "caregivers acting like they can't accommodate their choices", and P9 wrote that participation was limited by others "assuming incompetence, doing everything for the individual without asking." Indeed, P9 , a speech pathologist, suggested that mealtime participation and inclusion could be improved by giving the person with dysphagia more choices, "helping them to participate as much as possible in the meal prep and decision making, they could choose where to sit, who to sit with, what cup/crockery to use" (P9).

Discussion

The results of this survey confirm the findings of prior research that quality of life impacts are intersectional and vary widely across individuals with dysphagia (Smith, Bryant & Hemsley, 2022c; Smith et al., in press-b). The areas of alignment and difference in perspectives across participants with dysphagia, supporters of people with dysphagia, and allied health professionals reveal more about the impacts of both dysphagia and its interventions on quality of life for the person with dysphagia. The findings provide further insights into how greatly the person's dysphagia and dysphagia management strategies might impact upon quality of life, inclusion, and enjoyment in their mealtime experiences. The findings also provide information on the *relative* impacts of dysphagia on the person's physical health and safety, choice and control, social engagement, and experiences with food (Smith et al., in press-a, in press-b) and the priorities of different parties in relation to those impacts.

Our findings triangulate with and expand upon the concepts identified in earlier research involving (a) interviews with nine people with dysphagia and four of their supporters (Smith et al., in press-b), and (b) focus groups with 15 allied health professionals (Smith et al., in press-a). In examining the perspectives of a larger number of people from a wider geographical area than in prior research, this study increased appreciation of key stakeholders' views on concepts identified in prior qualitative studies with similar aims (Smith et al., in press-a, in press-b). It also allowed for some further comparison of responses between participant groups and increased insights into the importance of including people with dysphagia in all decisions regarding mealtimes (Balandin et al., 2009; Howells et al., 2021a; Smith, Bryant & Hemsley, 2022c).

The range of assistive technology options used by people with dysphagia (e.g., adaptive cutlery and straws) was an important factor impacting on their quality of life, as these strategies provided them a way to maintain their choice and control along with their physical safety. Similarly, assistance provided to people with dysphagia at each stage of the meal (e.g., preparing food and eating food) enabled them to be included in tasks they may not be able to complete independently, and this positively impacted on quality of life. By describing the types of support required and the benefits, this aligns with previous research examining the mealtime support needs of people with an intellectual disability that reported support for a wide range of tasks (e.g., food modifications, environmental modification) and that these needs increased over time (Ball et al., 2012). Hence mealtime supports provided should be flexible and continue to change along with the person's needs in order to maintain their quality of life.

For people with dysphagia, supporters of people with dysphagia, and allied health professionals alike, the physical impacts of dysphagia were seen as having the greatest impact on quality of life. This aligns with a past systematic literature review by Jones et al. (2018), which reported that quality of life was influenced by the severity of dysphagia symptoms (i.e., the physical impacts of dysphagia were directly linked to overall quality of life). However, their views on the impacts of dysphagia on choice and control, social engagement, and the overall mealtime experience differed. This difference in views of the relative impact of dysphagia on different aspects of quality of life and mealtime experiences suggests that, aside from a mutual appreciation of the impacts of dysphagia on physical health and safety, the priorities and recommendations of supporters and allied health professionals might differ substantially from those of people with dysphagia. This difference in opinion is also reflected in past research illustrating how people with dysphagia and people without dysphagia perceive texture-modified food differently (Ettinger et al., 2014). These differences in perspectives suggest that a person's direct lived experiences shapes their perception of mealtimes and highlights the importance of taking the views of people with dysphagia into consideration when making decisions about their mealtime management.

Although people with dysphagia reported dysphagia had the greatest impact on their physical health, their decisions around eating out with others provided insights into the extent of the impacts on their social engagement. Participants described deliberately eating alone out of embarrassment which follows the experiences of people with dysphagia described in Balandin et al. (2009). However, this decision may put them at a greater risk of having a fatal choking event owing to limited support available as described in the review by Hemsley, Steel et al. (2019). Following recommendations from Hemsley, Steel et al. (2019), people with dysphagia should know how to self-rescue or call for help in case of a choking event to ensure their safety, especially if they are eating alone. This may include having a safety alert button to contact a neighbour or family member. People with dysphagia should also discuss what should be done in a choking event with their friends and family members so that appropriate support can be provided regardless of their mealtime environment or companions (Hemsley, Steel et al., 2019).

Gathering the Views of All Involved

By enabling descriptive comparisons across participant groups in this study, through both categorical and qualitative analysis, some important differences of opinion across participant groups in terms of ratings of impact were identified. The survey responses regarding the impacts of dysphagia on the person's life, participation, and inclusion highlight complexity in the intersection of several factors influencing mealtime quality of life. The findings reflect several personal factors, including values and priorities of the individual and the wide variety of environments impacting the mealtime experience and choices to be made that were also noted in previous research (Ferrans et al., 2005). Ferrans et al. (2005) reported that elements of the social or physical environment that may shape quality of life include the person's culture, the influence of family, and the neighbourhood in which they live. These factors influence the person's decisions about the prevention and treatment of health issues (Ferrans et al., 2005). The highlighted differences in views of people with dysphagia, supporters of people with dysphagia, and allied health professionals in this research could help to shape future clinical guidelines that consider the impact of these factors on dysphagia management to maintain quality of life. It is important to consider the perspectives of all groups as their priorities do not always align in in terms of the importance of different aspects of the intervention on mealtime decisions.

The findings of this survey provide further evidence of the importance of discussing mealtime quality of life with clients, as a lack of consideration of their views on these factors may impact treatment decisions, implementation of therapy recommendations or diet modifications, and the person's implementation of these recommendations (Balandin et al., 2009; Colodny, 2005; Howells et al., 2019a; Howells et al., 2021a). The difference in survey responses between people with dysphagia, supporters of people with dysphagia, and allied health professionals extend the findings of Smith et al. (in press-a) and Smith et al. (in press-b) which did not include this comparison. Furthermore, the results of this survey highlight the importance of providing education to family and friends on mealtime inclusion for the person with swallowing difficulties to reduce isolation, particularly for those who are isolated in the community due to living alone.

Limitations and Directions for Future Research

While providing important findings expanding upon and verifying prior research, this research has some limitations that indicate that the findings should be interpreted with caution. While including a greater number of participants than the prior qualitative studies (Smith et al., in press-a, in press-b), the relatively small sample of completed surveys returned was not representative of any of the participant groups and as such the results cannot be generalised across populations of people with dysphagia, supporters of people with dysphagia, or allied health professionals. The low completion rate (51%) reduced the number of survey responses that could be used in the data analysis and meant statistical comparisons within and between groups were not possible, limiting the strength of any comparisons of the data across groups. Rather, the results draw further attention to important elements for consideration in future research and could be used to inform clinical practice.

Participants with dysphagia who engaged in the survey reported filling in the survey independently. Thus, the findings may not reflect the views of people with more severe health conditions who rely on other people to access the internet, or of people who have lower levels of literacy. Lack of knowledge of the diagnosis or self-rating of severity of the dysphagia does not limit the findings, considering that there were insufficient responses for subgroup comparisons (e.g., comparing groups with mild or severe dysphagia). However, future research should include consideration of the diagnosis, self-report of severity, and any course of change in severity of the person's dysphagia in order to assess any association that might exist between these factors and impacts on quality of life. Further research should also aim to include people with dysphagia who may require support to complete the survey as they may require different levels of mealtime supports which were not observed in this study (e.g., people living in a group home or aged-care facility).

This research was weighted towards older people and those who had acquired their dysphagia in adulthood, and thus had low generalisability to people with lifelong dysphagia. Future research should aim to include more people with a lifelong dysphagia across the age range to understand how the quality of life impacts of dysphagia and its interventions might change across the lifespan. Furthermore, this research only included four supporters of people with dysphagia and only one occupational therapist. Further research using this same survey tool should focus recruitment efforts on including the perspectives of a greater number of allied health professionals involved in dysphagia management, including occupational therapists and dietitians, and supporters including family members, direct support workers, and advocacy organisation workers. These parties have a vital role in mealtime planning and management for people with dysphagia (Ball et al., 2012). A larger participant group would most likely yield further insights into the factors impacting on quality of life for people with dysphagia. Purposively sampling these participant groups might be helped by first recruiting people with dysphagia or speech pathologists then using snowball recruitment to locate colleagues in the management of dysphagia. Further research should examine how the findings of this research could be incorporated into dysphagia assessment and intervention to improve the quality of life of people with dysphagia and ensure that quality of life is considered at all stages of dysphagia management.

Conclusion

This study described the impacts of dysphagia and dysphagia interventions on quality of life from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals. Results demonstrated that there are several intersectional impacts and that both dysphagia and its interventions impact on decisions affecting mealtimes and hence quality of life for people with dysphagia. Overall, dysphagia and its interventions to modify food textures had the greatest impact on a person with dysphagia's physical health and a lesser relative impact on choice and control and social engagement. People with dysphagia should be provided the opportunity to specify strategies that enhance their mealtime participation and inclusion – for example, maintaining their choice and control when purchasing and preparing food. Supporters of people with dysphagia and allied health professionals should also continue to support the person to overcome barriers to their mealtime inclusion, which may include trialling different mealtime assistive technologies or enhancing enjoyable elements of a meal (e.g., flavour of the food).

This research served to verify and expand on the importance of maintaining the person's control over mealtime components, such as the food eaten or the mealtime location, for overall mealtime enjoyment, inclusion, and participation as shown in previous studies (Smith et al., in press-a, in press-b). By including each participant group, this study demonstrated the differences in opinion of participants with and without dysphagia, emphasising the importance of speaking to people with dysphagia about their own mealtime preferences to improve their quality of life. Future research should look to generalise findings to a wider range of people with dysphagia, supporters of people with dysphagia, and allied health professionals.

Part B: The Feasibility of 3D Food Printing to Improve the Mealtime Experience for People with Dysphagia

While Part A of Section 3 addressed the first two aims of this thesis, it did not provide in-depth information on the second two aims relating to food design and 3D food printing. Part A of this thesis demonstrated that dysphagia interventions could be a barrier or facilitator to quality of life. The provision of a texture-modified diet affects the way the way that the food is presented and its visual appeal. Thus, examination of 3D food printing as one method to improve the visual appeal of texture modified food for people with dysphagia is warranted. Furthermore, previous research presented in Chapters 2 and 3 highlighted the significant impact of food design on quality of life and indicated a need to explore this in further depth. This is done from the perspectives of people with dysphagia, supporters, and allied health professionals over the next three chapters, which constitute Part B of the results.

Chapter 10: The Feasibility of 3D Food Printing from the Perspective of People with Dysphagia and their Supporters

Part A of Section 3 provided an in-depth examination of the impacts of dysphagia on quality of life, participation, and inclusion from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals who work with people with dysphagia. From these studies it was determined that dysphagia interventions (including the provision of a texture-modified diet) could be a barrier or a facilitator to quality of life. In the narrative review in Chapter 3, 3D food printing was included as a potential food design strategy to improve the mealtime experience for people with dysphagia (Smith, Bryant, Reddacliff et al., 2022). In this chapter, nine people with dysphagia (three with lifelong dysphagia and six with acquired dysphagia) and their supporters were given the opportunity to engage in a 3D printed food experience to determine their perspective on the feasibility of 3D food printing to improve the mealtime experience for people with dysphagia. The inclusion of people with dysphagia and their supporters in this study was particularly important, as the narrative review in Chapter 3 found that none of the studies examining the use of 3D food printing for people with dysphagia include participants who have dysphagia (Chapter 3; Smith, Bryant, Reddacliff et al., 2022). Participants engaged in a virtual immersive 3D food printing experience with the researcher using the 3D food printer at UTS due to COVID-19 travel and social distancing restrictions. Data was analysed using content thematic analysis and Usability Heuristics by Nielsen (1994).

This chapter has been submitted for publication in *Disability and Rehabilitation: Assistive Technology*, and is currently under second review. The references have been formatted to follow the format used in this thesis.

Smith, R., Bryant, L., Hemsley, B. (2022a). *3D food printing to improve mealtime quality of life: The perspective of people with dysphagia and their supporters* [Manuscript submitted for publication]. Graduate School of Health, The University of Technology Sydney.

Results from this chapter made up some of the data presented in poster form at the UK Swallowing Research Group Conference 2022 and the Dysphagia Research Society Annual Meeting 2022.

Abstract

Purpose: To understand the views of people with dysphagia and their supporters on the feasibility of using 3D food printing to improve the visual appeal of texture-modified foods and their mealtime experiences.

Materials and Methods: Nine people with dysphagia and four of their supporters engaged in a virtual 3D food printing experience and interview over Zoom about their impressions and usability of the printer and potential for it to improve their mealtime experiences. The in-depth interviews were analysed using thematic analysis and usability heuristics.

Results: Four content themes in the interviews impacted on the feasibility of 3D food printing. They related to the practicality, design acceptability, population suitability, and cost of 3D food printing. Usability heuristic analysis revealed that print quality, user control, error prevention, and handling of food consistencies would impact on use. Perceived low efficiency and increased time required to create food shapes meant participants were cautious in their overall impressions of the role of the device.

Conclusion: After an immersive virtual experience with a 3D food printer, people with dysphagia and their supporters identified a wide range of usability issues that would need to be addressed prior to implementation and in the future design of user-friendly 3D food printers for people with dysphagia. Future research should include people with dysphagia and their supporters in 3D food printer design and implementation trials.

Keywords: Dysphagia, 3D food printing, food shaping, interviews, qualitative, usability.

Introduction

Dysphagia, Texture-Modified Diets, and the Visual Appeal of Foods

Dysphagia (difficulty swallowing) is associated with a wide range of health conditions, including: acquired health conditions (e.g., stroke, traumatic brain injury, head and neck cancer), lifelong disability (e.g., cerebral palsy, intellectual disability, autism), and progressive health conditions (Parkinson's, motor neuron disease, dementia, myositis) (Groher & Crary, 2016; Kumar, 2010). Dysphagia affects an estimated 8% of the world's population (Cichero et al., 2017), who experience a range of impacts on their respiratory and nutritional health (Hemsley, Steel et al., 2019) and negative impacts on their quality of life (Smith, Bryant & Hemsley, 2022c). People with dysphagia often require texture-modified foods, which are softer and easier to swallow than regular food textures (Groher & Crary, 2016; Robins et al., 2022). Texture-modified foods are classified according to the International Dysphagia Diet Standardisation Initiative (IDDSI): Level 7 Regular Easy to Chew, Level 6 Soft and Bite-Sized, Level 5 Minced and Moist, Level 4 Pureed, and Level 3 Liquidised (IDDSI, 2019). Texture-modified foods can also have a negative impact on quality of life (Smith, Bryant & Hemsley, 2022c).

According to people with dysphagia (Smith et al., in press-b) and allied health professionals working with this population (Smith, Bryant & Hemsley, 2022b), texture-modified foods often lack visual appeal. In interviews about the impact of the shape of texture-modified foods on quality of life, people with dysphagia have compared their food to "wet dog food" (Smith et al., in press-b, para. 24). This was reinforced by allied health professionals who referred to pureed meals as "the dog box" (Smith et al., in press-a, para. 15). As a result of this poor visual appeal, people with dysphagia may not follow recommendations for texture-modified foods, increasing their risk of malnutrition and potentially choking, as identified in prior research (Colodny, 2005; Keller & Duizer, 2014). Colodny (2005) highlighted the scale of this problem in in-depth interviews with 63 people with dysphagia; reporting that almost 40% of participants who needed texture-modified food rejected it due to its presentation. Balandin et al., (2009) reported that people with dysphagia felt isolated at social gatherings because their food looked different, and they feared choking in public if they ate the same food as others. This demonstrates the importance of improving the visual appeal of texture-modified foods, to enhance the mealtime experience for people with dysphagia (Balandin et al., 2009).

Dysphagia and Food Design

Smith, Bryant, Reddacliff et al. (2022) conducted a recent review of the impacts of food design (e.g., structure and visual appeal) on mealtime experiences for people with dysphagia. The review highlighted how texture-modified food can be deliberately designed and manipulated to improve the mealtime experience (Smith, Bryant, Reddacliff et al., 2022). These mealtime components include the environment, assistance from supporters, food texture, flavour, visual appeal, temperature, and the nutritional value of the food. A relatively new method identified to improve the visual appeal of texture-modified food is 3D food printing. In 3D food printing, the pureed food is printed into layers to create a shape through additive manufacturing (Hemsley, Palmer et al., 2019; Liu et al., 2017). In their review, Smith, Bryant, Reddacliff et al. (2022) considered five literature reviews (Hemsley, Palmer et al., 2019; Liu et al., 2017; Liu et al., 2018; Tan, Chua et al., 2018; Tan, Toh et al., 2018) which identified a wide range of foods that could potentially be printed for people with dysphagia or nutritional disorders. The authors noted that hydrocolloids could also be added to improve the food's printability and the visual appeal of the finished product. However, each ingredient required tailored preparation methods for a successful print (Liu et al., 2017;

Tan, Chua et al., 2018; Tan, Toh et al., 2018). The findings of the review suggests that 3D food printing is possible, but might yet be beyond the reach of people with dysphagia preparing foods at home. Hemsley, Palmer et al. (2019) also noted the lack of evidence testing the claims made in food engineering literature that 3D food printing would solve the problem of unsightly texture-modified foods for people with dysphagia, or the feasibility and usability of this technology for people with dysphagia.

Subsequently, further research has reiterated the need for continued exploration and development in 3D food printing methods to improve the visual appeal of texture-modified food. Burke-Shyne et al. (2021) engaged 10 experts in 3D food printing and nutrition in semi-structured interviews to identify their views on potential applications. Results related to: the potential uses of 3D food printers, the sustainability of the process, technical issues arising with the printing process, and ethical or social issues of 3D food printing. Reiterating prior research, the experts identified that people with dysphagia or people who have had bariatric surgery would potentially benefit (Burke-Shyne et al., 2021). The authors suggested that although 3D food printing provided a potential solution to improve the visual appeal of texture-modified foods, further advances were needed to improve feasibility, particularly in relation to cost, time to use, and the integration of 3D food printing with other cooking methods.

The physical characteristics of food produced using a 3D food printer are particularly important to consider for the feasibility and viability of involving people with dysphagia and their supporters in the 3D food printing process. Strother et al. (2020) compared the sensory and textural properties of 3D printed pureed carrots to moulded pureed carrot. Using a texture profile analysis and sensory analysis by 12 trained panellists, authors found no significant difference in the textural or sensory properties of the two shaping methods regarding denseness, smoothness, adhesiveness, cohesiveness, oily coating, sweetness, saltiness, bitterness, or aftertaste. A difference in texture rating only occurred when gum was added to the pureed carrot (Stroher et al., 2020). In comparison, Dick et al. (2021) examined the impact of reheating 3D printed pureed meat and reported that microwave and convection ovens were not effective, as a the microwave oven changed the shape of the print while the convection oven impacted on the meat's texture. When the meat was reheated using steam, it maintained its shape and texture; however, the amount of xanthan gum used to hold to shape of the food influenced the overall outcomes in the extent to which the food maintained its shape (Dick et al., 2021).

The results of 3D food printing research to date have highlighted a range of potential benefits and perceived limitations from a structural food design and food engineering perspective. However, research has not yet examined the views of people with dysphagia and their supporters as to potential use and benefit of 3D food printing. As end-users of domestic 3D food printers, people with dysphagia and their supporters could provide unique insights on the usability of a domestic-scale 3D food printer. Such devices should be considered for usability in the population who might benefit from the food shaping technologies. Therefore, this study aimed to determine the perspectives of people with dysphagia and their supporters on the feasibility and usability of 3D food printing to improve the appearance of texture-modified foods and their mealtime-related quality of life.

Materials and Methods

This study involved participants being 'immersed' in a virtual visit to a 3D food printing experience in the university's 3D printing laboratory. The study was conducted online over Zoom due to COVID-19 restrictions on face-to-face research. This study was ethically approved by the University Human Research Ethics Committee (ETH19-3708) and the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) is used to guide the reporting of this study.

Participants

Adults with dysphagia provided written informed consent prior to their involvement to participate in this study; with a support person if desired. Purposeful sampling selected only adults with swallowing difficulties able to give informed consent. The researchers distributed information about recruitment of adults with swallowing difficulties on social media through the use of topic-related hashtags (e.g., #dysphagia, #swallowing); hence a response rate cannot be reported. A supporter was defined as someone that assisted a person with dysphagia at mealtimes on a regular basis. This included assisting with food preparation or providing mealtime assistance to eat. Supporters were recruited through the participants with dysphagia. The supporters included P7's wife, P6's mother, and two support workers. The role of the supporters in this study was to support the person with dysphagia to access the technology and assist with communication with the researcher where needed. Researchers continued recruitment until data saturation was achieved (Patton, 2014) which occurred, as Guest et al. (2006) suggested, soon after 10 participants had been interviewed. Diversity in participants' severity and cause of dysphagia was valued as providing a range of perspectives. Saturation was achieved when no further codes were developed. This was confirmed by discussion between authors on data analysis.

Thirteen participants, including nine with dysphagia and four of their supporters, took part in this research. Participants with dysphagia had previously been observed eating a typical meal to confirm their dysphagia and interviewed about the impacts of dysphagia on their quality of life (Smith et al., in press-b). The severity of dysphagia was measured using the Dysphagia Disorder Survey (DDS) and Dysphagia Management Staging Scale (DMSS) by the first and last authors who are both certified users (Sheppard et al., 2014). Quotes and excerpts included in reporting the results are de-identified with participants referred to using a participant code (i.e., P1 for Participant 1). One of the participants (P2) knew the researcher prior to the study and all participants were aware of the researcher's standpoint as a female speech pathologist and doctoral research candidate. As participants based their opinions of the demonstration provided by the researcher, the researcher aimed to make her demonstrations objective and free from her opinions. She developed a verbal script to ensure all participants were provided a similar description of the device and gave all participants similar food shape options for selection. When asked about their prior exposure to 3D food printing, two of the participants reported that they had previously seen a 3D food printer, one (P4) had observed an in-person demonstration, and one (P5) had seen the technology promoted online. One participant (P9) had substantial experience in the 3D printing of plastics. Table 16 provides further information about the participants.

Table 16

Chapter 10 Participant Demographic Information

Participant ID	Gender	Age (years)	Dysphagia cause	Residence type	Dysphagia severity (DDS)	Current diet (IDDSI)	Experience with 3D food printing
P1	M	30	Klinefelter Syndrome	Private home	Mild	Soft and bite-sized food, carbonated thin fluids	No
P2	F	80	Age-related changes and a pharyngeal pouch	Private home	Moderate–severe	Easy to chew and soft foods, thin fluids	No
P3	F	54	Traumatic brain injury	Private home	Moderate–severe	Soft and bite-sized food, thin fluids	No
P4	F	42	Athetoid cerebral palsy	Private home	Moderate	Soft and bite-sized food, thin fluids	Yes
P5	F	55	Head and neck cancer	Private home	Moderate–severe	Soft and bite-sized food, thin fluids	Yes
P6	F	55	Pierre Robin Anomaly	Group home	Mild–moderate	Soft and bite-sized food, thin fluids	No
P7	M	81	Dementia and age-related changes	Aged-care facility	Severe	Soft and bite-sized food (diabetes), thin fluids	No
P8	M	76	Inclusion body myositis	Private home	Moderate	Regular/ easy to chew foods and thin fluids	No
P9	M	77	Inclusion body myositis	Private home	Mild	Regular foods and thin fluids	No

Materials

The 3D Food Printer. The Foodini 3D Food Printer was used during the virtual visit to the lab for the 3D food printing immersion experience (Natural Machines, 2022a). The printer is pre-loaded with food shape designs, which are selected using a touch-screen control panel on the front of the printer. The five capsules within the device can each hold 100 ml of food. Some food shapes require more than one capsule or ingredient (e.g., printing both vegetables and meat).

The Pureed Food. The researcher (first author) provided both sweet and savoury IDDSI Level 4 Pureed (IDDSI, 2019) food substrates for the participants to choose from for each item printed (e.g., mashed potato, chocolate ganache). Once participants had selected the food to be printed, the researcher filled the printer capsules using a long-handled teaspoon-size silicon spoon. The filled printer capsules acted as ‘ink’ for the printer.

Procedures

Recognising that this was an area in which little was known, this research followed a constructivist grounded theory approach. This involved the use of immersive 3D printed food experiences and interviews to explore the concept of 3D food printing from the perspective of people with dysphagia. From September 2020 to November 2021, each participant (with a supporter present if desired) engaged in a one-hour immersive virtual 3D food printing experience with the first author over Zoom. All participants engaged in the immersive experience individually and gave instructions on their choices to the researcher. By including multiple participants in individual interviews, researchers could also compare their perspectives which was important as one individual examining a device may identify 35% of usability issues, whereas multiple examiners may identify 60-75% of usability issues (Nielsen, 1994). While online, these virtual immersive experiences enabled participants to see everything that occurred with the printer and to direct the researcher throughout the experience of choosing foods and shapes, watching the printing of the food, and seeing the outcomes. The experiences were audio and video recorded using Zoom. After each experience, the researcher wrote field notes about the data collected and noted details about the printing outcomes and participants' responses.

Throughout the 3D food printing experiences, participants chose (a) the food substrate to be used in the 3D food printing, from a selection of pre-prepared pureed foods (i.e., Deb powdered mashed potato made according to the packet instructions; Betty Crocker chocolate ganache made according to the packet instructions, vanilla icing, or fresh mashed sweet potato made as a smooth puree); and (b) the shapes to be printed, from five pre-stored three dimensional patterns (chicken leg, flower tower, twisted star, sliced carrots, or a snowflake). Once participants had selected the food substrate to be printed, and the shape, they observed researcher filling the printer capsules using a long-handled teaspoon-size silicon spoon. The researcher than activated the printer and joined the participant in watching the device. All purees were printed, using a nozzle 4mm in diameter onto either a glass plate or a silicon mat. Once the print was complete, the researcher removed the printed item from the printer and held it to the camera to show the participants from all angles, before moving on to interview the participants about their perspectives. An interview guide, based on usability heuristics (presented in Table 17) (Nielsen, 1994), and finalised through consultation with an expert reference group, was used in the conduct of a conversational-style in-depth individual interview (see Table 8 of thesis for the interview guide). Nielsen's usability heuristics (Nielsen, 1994) were developed to help users of computer devices to recognise, diagnose, and recover from errors. The heuristics also allow for the identification of new usability issues. Applying the usability heuristics in the analysis was useful as the use of the 3D food printer by people with dysphagia had not been previously examined (Hemsley, Palmer et al., 2019; Smith, Bryant, Reddacliff et al., 2022).

Table 17

Usability Heuristics (Nielsen, 1994)

Usability heuristic	Description
Visibility of system status	Device shows what is happening within the system
Real-world system match	Device should follow real-world rules and protocols
User freedom and control of device	Extent that the device keeps the user in specific state without an exit option
Consistency of actions and standardisation	Device should maintain consistency with terminology and actions required in a process
Preventing errors	Device design that prevents errors from occurring in the first place
Error handling	How the device helps users identify and recover from errors
User recognition rather than recall	Device makes future options obvious to users
Device flexibility and efficiency	Device provides users extra options to change how regular procedures are completed
Aesthetic and minimalist design	Design looks good, graphics are simple and the design follows patterns of interface without introducing unnecessary images or concepts

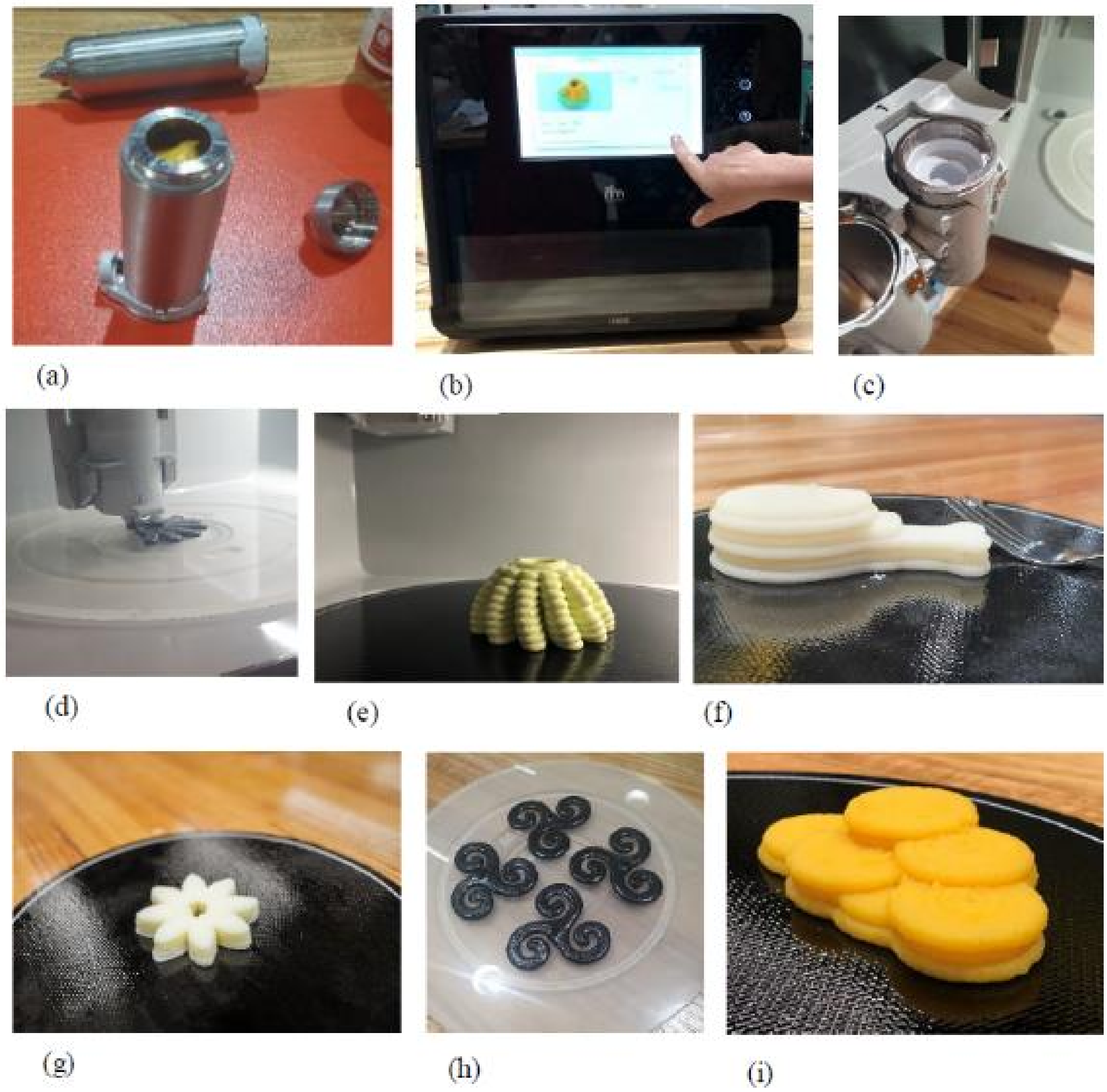
Recordings from the 3D printed food experiences were transcribed verbatim and de-identified by the first author. The data collected from a participant with dysphagia and a supporter dyad were transcribed verbatim and analysed together as a dyad, thus the perspectives of participants with dysphagia were integrated and not compared to the perspectives of their supporters. All data, including the transcripts and field notes, was imported into NVivo (QSR Interntional, 2018) and thematic analysis was implemented to provide a qualitative, in-depth, and detailed account of the data. Thematic analysis involved open and matrix coding (Morgan et al., 1998; Vaismoradi et al., 2013). Open coding was used to identify categories and themes and matrix coding looked for any relationships among those themes (Patton, 2014). Data was also analysed according to the nine usability heuristics by Nielsen (1994) and triangulated with data from earlier interviews with the same participants investigating how the shape of texture-modified food impacted upon their quality of life (Smith et al., in press-b). Transcripts were read and discussed by all authors to agree on and finalise the arrangement of categories of meaning and themes, and to ensure the credibility and trustworthiness of the results (Morgan, 1998; Vaismoradi et al., 2013). Following analysis, a summary of each participant's experience and interview was written by the first author in discussion with the co-authors, who confirmed the summaries reflected both participants' views and the researchers' agreed interpretations. Summaries were emailed to participants to give them the opportunity to verify that the summaries reflected their own views, and they were invited to expand on the summaries, change, or remove information as desired. Six participants confirmed the summary reflected their views of the 3D food printing experience and three did not reply. Quotes and excerpts from the interview transcripts are provided in the results to support the content themes and increase confirmability and plausibility of the findings.

Results

The immersive, virtual 3D food printing experience was novel for all participants, and none had previously chosen what ingredient was printed and the shape printed (see figure 11 for examples). Overall, four main themes were identified in the researchers' analysis of the interviews from the 3D food printing experiences with subthemes explicitly tied to Neilson's (1994) usability heuristics: practicality of 3D food printing, suitability of 3D food printing, acceptability of 3D printed food, and the cost of 3D food printing.

Figure 11

3D Printed Foods Created with the 3D Food Printer



Note. (a) a filled printer capsule, (b) the printer display screen showing the print-shape for selection, (c) a filled capsule in the 3D food printer, (d) a partially printed 'Flower Tower' during print, (e) printed 'Twisted Star', (f) Printed chicken leg, (g) printed 'Flower Tower', (h) printed spirals, and (i) printed carrot slices.

Overall Usability of the Printer

Most participants identified difficulties with the usability of the 3D food printer in a domestic environment. Participants commented on the time required to prepare pureed food suitable for use in the printer and agreed that filling capsules seemed time consuming and messy. P2 queried the purpose of this increased labour to achieve a mashed potato shape: "it's too much fuss and it takes too long and once you put potato in it, that's already mashed, isn't it?" Participants also viewed the time required to clean the device and printer capsules as reducing its practicality, especially for people at home who are often short of time owing to support needs or caregiver responsibilities. As P5 stated, "the main thing is the washing up and cleaning it up… I think that might be one of the things that might inhibit its domestic sale." P9 reinforced the notion of the reduced practicality for the home environment and related this to the relatively small amount of food that could fit into the capsule (100 ml): "to make it viable … you don't want to spend a whole lot of time, you want to be able to say to the printer, ok print out two of these, one for me and one for my husband."

Questionable Practicality in the Home. In relation to the Nielsen (1994) heuristic analysis, results in this theme reflected 3D food printing having poor 'visibility' (i.e., whether the device makes it clear to the user what is happening within its system via the control screen). Participants commented on the 3D food printer's touch-screen portraying the progress of the printer, including the percentage of the print complete or any print errors. Participants familiar with touch-screen technologies compared the device responsiveness unfavourably to their own touch-screen mobile devices. P1 noticed that the printer's touch screen did not consistently or rapidly activate the device to complete the desired task, saying "the screen doesn't seem to respond properly." As well as reduced responsiveness, this indicated some inconsistencies in the visibility of the system (i.e., the screen did not consistently provide real-time updates of the printer's progress), impacting negatively on the usability.

Aesthetics and Design of the Printer. The system layout garnered mixed responses regarding the aesthetics and design of the printer based on participants' own experiences and personal systems preferences. For example, P1 liked that the system was Android-based and said, “good because I hate iPhones”, while P6’s carer stated, “Android are too hard.” Hence, the layout and design of the operating system may encourage some people to use the device and discourage others. These results also suggest that users will have individual requirements as to the computing systems driving the 3D food printer. To improve the design of the system and ease of use in finding the food shapes, P1 suggested that the shape designs in the printer could be grouped according to “categories of either food likeness, the ingredients, or what type of shape category you’d go to.”

User Freedom and Control. In this study, users only had control to select the food substrate and the shape. For this device, once the printing has commenced, the design cannot be modified. Thus, the device provides little flexibility for modifications and follows a specific pattern. However, users can make choices about the food contents and the addition of nutritious additives. P1 and P2 raised concerns regarding the additives required to achieve the desired shape with the puree. P1 stated, “I’m concerned with what else they’ve had to put in there to get it to that.” P5 similarly raised concerns about the foods suggested for the prints (e.g., cookie dough, chocolate ganache) and said that the preprogramed designs “seem to be very sugar-based … someone has gone [said] ‘that’s a really good cookie design or biscuit design’.” However, P5 appreciated that she could use any food group, saying “you could quite easily put in there: avocado, any vegetable, any meat, fish, you could just about cover the five food groups as long as you have the texture right.”

Preventing and Handling Print Errors. Participants identified potential difficulties in preparing puree to the correct consistency and suggested strategies to prevent and handle errors that occurred during the printing process. P9 suggested difficulties with the puree consistency could be overcome by connecting the printer to a high pressure food processing unit that would force the food through a fine sieve: “it’s a simple process of squeezing through pressure … through a strainer to make it the consistency you want.” P9 also suggested that this may save time and would allow for a continuous flow of food to be fed through the nozzle rather than the filling the capsules, stating users “only have one printer head that’s doing what it’s supposed to do and it’s on the outside you have any of the cylinders that you want to hook up to that.” In comparison, P5 who also saw the difficulties with food consistency suggested a kitchen sieve (specifically a mouli) to be the “first step of prepping the stuff to go in it” to reduce the likelihood of errors.

Participants suggested that further solutions were needed to recover from errors, and to improve the consistency of foods created with the 3D food printer. P4 was “nervous” for this immersion, her second experience with the 3D food printer, and stated she wanted to see the printer and shapes “working and not exploding”. P4 perceived there were limited methods available to overcome issues as they occurred while printing which would impact on the feasibility of the device for people with dysphagia independently using it in the community.

Suitability for Populations with Dysphagia

All participants indicated that the printer may be beneficial and suitable for some but not all populations with dysphagia, owing to the technical demands of its use. In particular, participants expected limitations in use or suitability for older people with little computer experience, or people with reduced fine motor function or hand strength. These and other factors appeared within the ‘suitability’ content theme and are detailed in this section.

Past Experiences Impacting on Suitability. In relation to Nielsen’s (1994) usability heuristic, user ‘recognition’ rather than ‘recall’ (see Table 17) with the 3D food printer was influenced by the person’s past experience, or lack of experience, with computers. This heuristic refers to how the device makes future options obvious to the user, i.e., the user can see the option on the screen rather than needing to remember the next step themselves (e.g., opening the menu of print designs and choosing a design). P1 and P8 both considered that use of the 3D food printer required the user to have a certain level of computer knowledge for effective use. P8 viewed that a younger person with dysphagia, if a “gadget person”, may be more likely to recognise the processes involved in 3D food printing than older adults in aged-care with limited prior computer experience. P9 considered that when designing items to be printed, people would need to understand the wider process required to program an image into a language the printer could read (i.e., G-code) for the computer assisted design to be completed. P9 described his 3D printing design experience and said, I “make it into a G-code so that the printer can make it work. If it [image print instructions] doesn’t come as a G-code the printer doesn’t know what to do with it [image].” Overall, participants had diverse computer experiences and were unsure if the device provided enough visual prompts to guide users through the printing process if they did not have appropriate computer experience and understanding.

Role of Support Workers Impacting Suitability. Analysis using the Nielsen (1994) heuristic on consistency of actions (see Table 17) revealed some issues related to how support workers might maintain the consistency in food preparation. Participants’ interviews reflected the importance of support workers being able to create consistent pureed food textures for successful printing, however this could be difficult to achieve. P4 reported requiring assistance from support workers to prepare meals and recognised that support workers may have difficulty achieving the level of texture consistency required when making puree and filling the capsule to achieve printing success. P4 also stated “it has to be so consistent, and I know support workers wouldn’t be very consistent.” However, P1 viewed the process positively, stating “when I cook, I don’t do it perfect… that machine does a better job than I do even with its error.”

Flexibility and Efficiency. Participants' discussions reflected the need for flexibility of the 3D food printer in regard to its use with different populations with dysphagia. P7's spouse said that for "children with swallowing difficulty who are not getting to feed properly, I think that could actually be a very beneficial health thing." P6's support worker also described the benefits of making novel shapes for children, "like I want to make a dinosaur today… if it looks good the kids will want to eat it." In comparison, P4 and P8, who had difficulty with fine motor hand movements, suggested that the 3D food printer may not provide adequate flexibility for people with reduced hand function. P8 stated "it would be too heavy… especially at my age now and in my physical condition" and P4 recognised that she would have difficulties filling the capsules "I couldn't, I would get it everywhere." Hence, these participants may need further assistance to complete tasks associated with using the 3D food printer.

In regard to printer efficiency, P2 reported that the time to prepare the food, fill the printer capsules, print a shape, and clean the machine did not match the needs of person preparing meals for themselves. This was her main objection to the 3D food printer, she said "it takes a long time to get it ready and it's a lot of washing up." Similarly, P3, who often bought pre-cut frozen vegetables to save time, said that the printing process was "too much work." However, P5 stated "I think if you're cooking for dysphagia anyway, you're used to having to do things in steps and stages. So I don't see it really being a barrier." These mixed opinions highlight that perceptions of the time taken to use the device might vary across users and influence the feasibility of using the device.

Acceptability of 3D Food Printing

Lack of Alignment between the Real World and the System. Having recognised that 3D food printing is not a commonplace domestic food preparation process and does not follow standard food preparation procedures or protocols, participants imagined how it might be used in their own situation. Most viewed it as important that printed foods resemble familiar food items, rather than be abstracted or distant from the original food substrate, to be acceptable and support inclusion. When shown the finished product of a flower shaped print, P2 stated outright: “I don’t know how they’d [people with dysphagia] feel having to order food or sit and eat food with friends that’s different and like that.” P9 also described a desire for printed food to resemble the original food product and related this to an improved mealtime experience: “I would like the printer to be able to print it out but maybe it looks like a T-bone or a piece of flank steak.” P3 suggested that printing foods into shapes that did not resemble the food ingredients (e.g., carrots shaped like a flower) would remove the relative advantage of the printer over spooning the food onto the plate, quipping if the food looked nothing like its ingredients, then “blobs will do”. Participants’ discussions indicated that many of the non-food-like shapes pre-loaded into the 3D food printer might not necessarily help to meet the user’s goal of printing food that looks like the original food product or align with the real world.

Cost Currently Out of Reach

The relatively high cost of the 3D food printer was viewed as undermining potential benefits, particularly in the context of the low practicality and suitability issues described above. Participants viewed the relatively high cost of the 3D food printer compared to other food shaping methods (US$4,000 at the time of purchase in 2018, now available through a subscription service or for outright purchase for US$6,000 at the time of writing (Natural Machines, 2022b)) was beyond the reach of many people with dysphagia. Although participants recognised that the printer would be expensive due to the technology involved, this was not a cost that they felt could be justified by the potential benefit. P7’s spouse said “I would have to pay that to get a new kitchen.” Other participants suggested that the cost may not be an issue for larger institutions (e.g., aged-care facilities) who may be willing to pay for the device, and that the technology may become cheaper if it became more widely used and available.

Discussion

This study examined the feasibility and usability of 3D food printing to improve mealtime experiences and mealtime-related quality of life for people with dysphagia, from the perspectives of people with dysphagia and their supporters. The four main themes identified were the practicality of 3D food printing, suitability for different populations, acceptability of printed food, and the relatively high financial cost of a 3D food printer. By implementing Nielson’s usability heuristic (1994), some of the usability issues that could confront people with dysphagia and their supporters who wish to use a 3D food printer and which could form barriers to the uptake and use of 3D food printing were identified. These usability barriers would need to be addressed for 3D food printing to improve mealtime quality of life for people who need texture-modified foods. This analysis helps to address the gaps in 3D food printing research identified by Smith, Bryant, Reddacliff et al. (2022). Specifically, it identifies a range of usability and affordability issues that need to be resolved if 3D food printing is to fulfil its potential for people with dysphagia to control and design their own meal for improved mealtime experiences or mealtime-related quality of life (Robbins et al., 2002; Smith, Bryant & Hemsley, 2022b).

3D food printing research to date provides readers with multiple examples of 3D printed foods that are suitable for people with dysphagia to eat (e.g., Dick et al., 2020; Liu et al., 2021; Pant et al., 2021). This prior research provided a basis for the current study as it reported on the rheological properties of different food products needed for successful prints.

The current research expanded upon the results of previous 3D food printing research (Liu et al., 2017; Strother et al., 2020) raising similar design and usability questions regarding the sustainability, technical, and ethical challenges of 3D food printing. Ultimately, 3D food printers should provide the user with options to print foods that resemble the original food substrate and promote inclusion at social events. This confirmed the findings of Smith, Bryant and Hemsley (2022b) who examined the feasibility of 3D food printing from the perspective of health professionals who also found that 3D printed foods would be more widely accepted if it resembled the original food product. Given that the proposed benefit of 3D food printing is to improve the shape of the food (from shapeless, indiscriminate ‘blobs’ on the plate), the findings suggest that not just any shape will do. Indeed, people with dysphagia and their supporters may judge the success of a 3D food printer according to how closely it can print a food to resemble the actual food’s shape.

Examining the perspectives of people with lived experience with dysphagia is important, as Ettinger et al. (2014) reported that people with dysphagia who were on a texture-modified diet had significantly different ratings to people without dysphagia on the visual appearance and texture of pureed turkey. Although past 3D food printing research may have reported on the sensory properties of 3D printed food (Strother et al., 2020), trained panellists in that prior research who did not have dysphagia might not have the same insights as those with dysphagia. This research adds to prior understanding of the potential impact of 3D food printing on the mealtime experience, quality of life, and inclusion from the perspective of people with dysphagia, which could help inform person-centred improvements to the usability of 3D food printers.

The inclusion of people with dysphagia and their supporters in 3D food printing research and development further illustrates the importance of considering the user and their physical and computer abilities to improve printer usability. Swallowing difficulties often do not occur in isolation, and are associated with a wide range of health conditions accompanied by other physical and cognitive impairments that impact independence in mealtime preparation (Groher & Crary, 2016; Kumar, 2010). These limitations, which may include poor fine motor skills or reduced hand strength, have not yet been considered in the design of 3D food printers for people with dysphagia. 3D food printing should uphold a person's dignity and independence as much as possible and reduce their reliance on a third party to access safe and enjoyable meals. The results of this research suggest that 3D food printers making use of touch-screen access points will need to consider the person's visual and fine motor abilities and consider alternative access points, such as voice-activated user controls. The filling of capsules by hand also appeared to be a usability barrier, with participants suggesting adaptations that involve the printer pureeing the food and filling the capsules automatically to circumvent time and quality issues, and ensure a consistent texture of food is provided with no additional effort.

Overall, the views of people with dysphagia and their supports are consistent with prior research, viewing 3D food printing as a somewhat emergent technology with as yet low familiarity and usability in the community. By including participants with varying levels of computer and 3D printing skills, this study provides insights into how the device might be viewed by novice users in the community. For example, the complexity of designing a shape to print might mean that users with dysphagia and their supporters would rely on the pre-programmed food shapes available from the touch-screen display. Hence, a person with dysphagia using a 3D food printer may require a greater knowledge and awareness of the printing process, not only experience using a touch-screen device, to use the 3D food printer to its full potential and create their own food shape designs.

Implications

This study indicates that efforts should be made to improve the usability of 3D food printing, with various suggestions provided by participants. These changes included better categorisation of food shapes stored in the system to make them easier to find and improved responsiveness from the device in the event of a food printing error. There should also be a better match with the real world in terms of the shapes printed. This research suggests that if these usability issues are addressed and people are provided a way to print foods that look like the original food, 3D food printing may be an acceptable option to help improve the quality of life of people with dysphagia. It may be that 3D food printing would be within reach for people with dysphagia who have experience of using computers and are engaged in meal preparation. It is therefore important for clinicians working with people with dysphagia to consider ways to increase the involvement of people with dysphagia in the preparation of foods that require texture-modification, and how they might access technologies designed to assist in food design and production foods to improve their mealtime experiences.

Limitations and Directions for Further Research

This research was limited primarily by the fact that participants could not enter the university 3D food printing laboratories to view or use the 3D food printer in person, owing to COVID-19 social distancing restrictions at the time. Furthermore, although all participants included pureed foods in their diet, not all were restricted to *only* eating pureed food and this may have influenced their perceptions of the expected relative benefits. Future research should also include people who require all food to be of an IDSSI Level 4 Pureed consistency. The perceptions of the 3D printed food may differ for people who only have pureed food, and do not have the opportunity to eat foods in their original form. Furthermore, the Nielsen (1994) usability heuristics were designed prior to the emergence of advanced touch-screen technologies, and as such might not have captured some usability issues relevant to 3D food printers and associated human-food-technology interactions. As a result, some parameters of the model may not have met the true nuances of the feasibility of 3D food printing.

In the management of dysphagia, health professionals, particularly speech pathologists, often provide information and support in relation to ways that people with dysphagia and their supporters should prepare food to be of a safe and suitable texture for swallowing. Therefore, future research should also seek the opinions of a wide range of allied health professionals and support personnel, including food services staff, who work with people with dysphagia on the feasibility of 3D food printing. Future research should also examine the concerns raised by participants regarding any additives being used to sustain the shape of the puree; particularly if this impacted nutritional value of the food.

Conclusion

This study examined the views of people with dysphagia and their supporters on the feasibility of 3D food printing to improve their quality of life. People with dysphagia were cautious in their estimations of the 3D food printer and highlighted several usability issues that might form barriers to implementation for the management of dysphagia. These included poor user recognition of the device, increased time and effort required to produce the 3D printed food, and perceptions of the process being more difficult for people with less experience in the use of touch-screen devices or computers. The findings also suggest that people with dysphagia may prefer food that is shaped to resemble the original food product rather than abstract or artistic designs. Further research enabling people with dysphagia, their supporters, and health professionals to use the device and taste the food printed would be helpful to understand more about how this population and their supporters might respond to 3D food printing.

Chapter 11: The Feasibility of 3D Food Printing from the Perspective of Health Professionals

Chapter 10 of this thesis described the perspective of people with dysphagia and their supporters on the feasibility of 3D food printing to improve their mealtime experience. Chapter 11 extends upon this to build the evidence-based framework by examining the feasibility of 3D food printing from the perspective of allied health professionals. The perspectives of allied health professionals on 3D food printing were included in this research due to their substantial role in the implementation of dysphagia interventions with people with dysphagia. Data for this chapter was collected during the focus groups described in Chapter 8. Allied health professionals watched a video of 3D printing food being created and then provided their perspective on its usability. De-identified transcripts were analysed using content thematic analysis.

This chapter has also been published in the *American Journal of Speech-Language Pathology*. As a result, it follows the formatting, spelling, and terminology guidelines (e.g., speech pathologists are referred to as speech-language pathologists) provided by this journal. Material is copyrighted by the American Speech-Language-Hearing Association (ASHA) and is used with permission as part of a thesis (CC BY-NC-ND).

Smith, R., Bryant, L., Hemsley, B. (2022b) Allied health professionals’ views on the use of 3D food printing to improve the mealtime quality of life for people with dysphagia: Impact, cost, practicality, and potential. *American Journal of Speech-Language Pathology*, *31*(4), 1868–1877. https://doi.org/https://doi.org/10.1044/2022_AJSLP-21-00391

Focus group data was used as part of the poster presentations at the UK Swallowing Research Group Conference 2022 and the Dysphagia Research Society Annual Meeting 2022.

ASHA American Speech-Language-Hearing Association

AJSLP

Research Note

Allied Health Professionals' Views on the Use of 3D Food Printing to Improve the Mealtime Quality of Life for People With Dysphagia: Impact, Cost, Practicality, and Potential

Rebecca Smith,[a] **Lucy Bryant,**[a] **and Bronwyn Hemsley**[a,b]

[a] Graduate School of Health, University of Technology Sydney, New South Wales, Australia [b] Faculty of Arts and Education, The University of Newcastle, Callaghan, New South Wales, Australia

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ABSTRACT

Purpose: Much is promised in relation to the use of three-dimensional (3D) food printing to create visually appealing texture-modified foods for people with dysphagia, but little is known of its feasibility. This study aimed to explore the perspective of allied health professionals on the feasibility of using 3D food printing to improve quality of life for people with dysphagia.
Method: Fifteen allied health professionals engaged in one of four 2-hr online focus groups to discuss 3D food printing for people with dysphagia. They discussed the need to address the visual appeal of texture-modified foods and watched a video of 3D food printing to inform their discussions on its feasibility. Focus group data were transcribed verbatim, de-identified, and analyzed using thematic content analysis. Participants verified summaries of the researchers' interpretation of the themes in the data.
Results: Participants suggested that 3D food printing could improve the mealtime experience for people with dysphagia but noted several barriers to its feasibility, including the time and effort involved in printing the food and in cleaning the printer. They were not convinced that 3D-printed food held higher visual appeal or looked enough like the "real food" it represented.
Conclusions: Allied health professionals considered that 3D food printing could benefit people with dysphagia by reducing the negative impacts of poorly presented texture-modified foods. However, they also considered that feasibility barriers could impede uptake and use of 3D food printers. Further research should consider the views of people with dysphagia and address barriers reported in this study.

The provision of texture-modified food is a common intervention in dysphagia management (Robbins et al., 2002). However, it can impact greatly on a person's mealtime-related quality of life, by disrupting the visual appeal of a meal (Keller et al., 2012; Smith et al., 2022). Ullrich et al. (2014) have previously raised the importance of visually appealing texture-modified foods for people with dysphagia, in that poorly plated food can negatively impact on food identification. Also, the pleasing appearance of food is associated with more positive flavor ratings (Ettinger et al., 2014). Several food-shaping techniques are designed to reduce the risk of unappealing food reducing the person's quality of life and improve the visual appeal of texture-modified foods (see Smith et al., in press). Techniques used to increase the visual appeal of texture-modified foods include food molds (Higashiguchi, 2013; Ullrich et al., 2014), piping bags, emulsification, spherification, gelification (Reilly et al., 2013), and three-dimensional (3D) food printing (Hemsley et al., 2019).

Correspondence to Rebecca Smith: rebecca.j.smith@student.uts.edu.au. ***Disclosure:*** *The authors have declared that no competing financial or nonfinancial interests existed at the time of publication.*

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However, the effectiveness of these techniques in improving the visual appeal of texture-modified foods is not well established. Furthermore, there is little research on the impact of food-shaping technologies for people with dysphagia, on either mealtime enjoyment or food intake (Smith et al., in press). Hemsley et al. (2019) noted that 3D food printers are an internet-enabled device, which may hold other benefits in the "smart home," allowing users to share food shape designs, reinforcing and capitalizing upon the "social" and community aspects of mealtimes and interest in sharing recipes and photos of food.

A recent and relatively unfamiliar technology developed for food shaping and production, 3D food printing is a form of "additive manufacturing," in that it involves a printer being used to build up or "add" layers of the food onto a flat surface so that it builds up into a 3D shape. In a 3D food printer, pureed food material (or "food ink") is pushed through a "food ink cartridge" or nozzle (much like an ink-jet printer) into layers to create a shape (Hemsley et al., 2019). The 3D food printer can be programmed to print preset or novel food shapes. 3D printing technologies were reportedly first used with food in 2007, and recent research has examined its use for creating personalized food items (i.e., to meet nutritional, textural, or flavoring needs). 3D food printing is also used commercially by some food corporations including Barilla, Hershey, and Ruffles who achieve the desired food consistency by procedures undertaken after the print (e.g., cooking the food that was printed; Pereira et al., 2021). 3D food printing technology is gaining popularity due to the taste, appearance, and texture of the food. By potentially creating foods that are texturally appropriate and visually appealing for people with dysphagia, the use of 3D food printing technologies may help to reduce food refusal and malnutrition (Hemsley et al., 2019; Pereira et al., 2021).

Emergent 3D food printing research (Hemsley et al., 2019; Raheem et al., 2021) indicates that 3D food printing could potentially bring visual appeal and customized shape to texture-modified food for people with dysphagia. However, little is known about the feasibility of 3D food printing for populations with dysphagia or their supporters, and any claims of benefit and suitability for this population are as yet largely untested (Hemsley et al., 2019). As pureed food substrates for printing can be fortified with powders (e.g., protein and vitamins), 3D-printed foods might also be used in interventions to improve nutrition. Burke-Shyne et al. (2021) explored the nutritional benefits and challenges that may arise with 3D food printing through semistructured interviews with 10 participants with a background in 3D food printing, including five dietitian–nutritionists, one allied health professional (unspecified discipline), two scientists (unspecified discipline), one social researcher (unspecified discipline), and one participant who worked for a technology company (unspecified). Participants considered that 3D food printing could be useful for people on texture-modified diets, enabling personalized nutrition, novelty food products, or nutritionally enriched foods. However, they held reservations as to the feasibility of implementation, citing technical and ethical issues related to the cost of the machine, food safety, printing speed, the stability of the printed food, the acceptability of printed food, and the level of food processing required (Burke-Shyne et al., 2021).

Given the claims of potential benefit of 3D food printers (Hemsley et al., 2019), and the findings reported by Burke-Shyne et al. (2021), which included input from dietitians, nutritionists, scientists, and technologists (but not speech pathologists or occupational therapists), it is important to broaden the field of 3D food printing research to include other allied health professionals with expertise in dysphagia management. Dysphagia management requires a multidisciplinary approach, and speech pathologists and occupational therapists, absent from Burke-Shyne et al.'s study, have an important role in dysphagia and mealtime management to improve health, quality of life, and enjoyment (Howells et al., 2019; Moloney & Walshe, 2019). Expanding the scope of 3D food printing research consultation to include these two disciplines in particular is important, so that (a) the food being designed is the correct consistency for a dysphagia diet; and (b) any additional occupational, sensory, or accessibility issues are considered in the 3D food printer design. Understanding more about potential risks and benefits of 3D food printing from the perspectives of the professionals directly involved in dysphagia management is important as 3D food printers, if effective, could be considered an assistive technology for people with dysphagia. Therefore, the aim of this research was to determine (a) the views of allied health professionals involved in dysphagia assessment and management on the feasibility of 3D food printing to increase the visual appeal of texture-modified foods, and (b) any potential impact on the participation and inclusion of people with dysphagia in designing and sharing the shape of their meals.

Method

This research was ethically approved by the University of Technology Sydney Human Research Ethics Committee. It was part of a larger doctoral research study examining dysphagia, quality of life, and 3D food printing that is reported elsewhere (Smith et al., 2022, in press).

This study followed the guidelines for reporting qualitative research using the Consolidated Criteria for Reporting Qualitative Research checklist (Tong et al., 2007). Focus groups are useful for exploring areas where little is known and for generating new ideas (Patton, 2002), which could be useful for this relatively new technology.

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The collective nature of views and experiences gained through focus groups allows for further understanding of the topic of interest from the perspective of participants (Morgan, 2019). Online focus groups allowed participants from a range of geographical locations to participate in a COVID-19 safe way while COVID-19 social distancing and travel restrictions were in place (Turbitt & Jacobs, 2021).

Participants

Participants with at least 2 years' experience of working with people with dysphagia were recruited purposefully through social media and researcher networks. Snowballing recruitment was also used as participants passed on recruitment information to others. The participants were aware of the researcher's background as a female speech-language pathologist and PhD candidate prior to providing consent. In total, 15 allied health professionals (comprising 12 speech-language pathologists and three occupational therapists) took part in four focus groups. Participants were assigned to one of the focus groups based on the date and time most convenient to them. The number of participants in each group ranged from two (Focus Group 4) to five (Focus Group 1). Participants all described having had experience providing texture-modified diets for people with dysphagia, applying the classifications of the International Dysphagia Diet Standardisation Initiative (IDDSI), and considering and advising on the shaping or serving of foods for people with dysphagia.

As recruitment materials were distributed through social media, the response rate for people taking part could not be calculated. Three other speech-language pathologists expressed an interest in the research but did not respond to e-mail communication to participate in the study and were not included. Recruitment information welcomed any discipline in allied health, along with group home managers, but no other disciplines responded (e.g., dietitians, nutritionists, and physiotherapists). The four focus groups enabled researchers to gather sufficient data in terms of development of content themes through inductive analysis (Hennink et al., 2019). Table 1 provides further information on participants including their discipline, client groups seen, and the service type in which they were employed.

Procedure

Participants who provided written consent and informed the authors of their preferred date for focus group engagement were sent a Zoom link (Zoom Video Communications Inc, 2011) to attend the online focus group. All participants engaged in one of four 2-hr focus groups held from March to May in 2021. All focus groups were moderated by the first author who was experienced in qualitative research data collection and analysis and also had used a 3D food printer. Two of the focus groups were co-moderated by the second and third authors who are speech-language pathologists with experience conducting focus group research and in use of the 3D food printer. The topic guide for the focus groups was developed based on prior research (Smith et al., 2022, in press). Due to the novel nature of 3D food printing, the focus group procedure included showing participants pictures and video footage of the 3D food printing process, using a Foodini 3D Food Printer (Natural Machines, 2019; see Appendix for the topic guide and example pictures shown in the focus group). The foods used in the 3D food printing video met the texture requirements of Level 4 (Pureed) according to the International Dysphagia Diet Standardisation Initiative

Table 1. Participant information.

Participant ID label	Age	Gender	Profession	Years working with people with dysphagia	Service type	Client group
FG1OT1	18–30	F	OT	5–9	Private	Disability
FG1OT2	18–30	F	OT	5–9	NGO	Disability
FG3OT3	31–45	F	OT	10–14	NGO	Disability
FG4SLP2	18–30	F	SLP	1–4	Private, university	Disability
FG1SLP3	31–45	F	SLP	10–14	Private	Medical
FG2SLP4	18–30	F	SLP	5–9	Private, NGO	Disability, medical – rehabilitation
FG3SLP5	31–45	F	SLP	15–19	Private, university	Medical – acute and outpatient
FG2SLP6	18–30	M	SLP	1–4	Public	Medical – acute
FG4SLP7	18–30	F	SLP	5–9	Public, university	Medical – acute and outpatient
FG2SLP9	18–30	F	SLP	5–9	NGO	Disability
FG3SLP10	31–45	F	SLP	1–4	Private	Disability, aged care
FG1SLP11	18–30	F	SLP	5–9	NGO	Disability, aged care
FG1SLP12	18–30	F	SLP	1–4	Public	Medical – acute
FG3SLP13	31–45	F	SLP	15–19	Public	Medical – rehabilitation
FG2SLP15	18–30	M	SLP	5–9	Private	Disability, medical – rehabilitation

Note. ID = identification; FG = focus group; OT = occupational therapist; F = female; SLP = speech-language pathologist; NGO = nongovernment organization; M = male.

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(Cichero et al., 2017) with no food additives used in the printing process (e.g., gels). During the focus group, the moderator took notes and afterward made field notes for discussion with the research team (Morgan, 2019). A constant comparison analysis was conducted across the focus groups.

The focus groups were transcribed and de-identified by the first author and imported into NVivo (QSR International, 2018) for storage and retrieval of the data, as well as thematic content analysis, which involved open and matrix coding to derive the content themes (Braun et al., 2021). All participant statements were read and re-read to determine the consistency of their comments throughout the discussion (Krueger & Casey, 2002). Discussion in focus groups can generate new ideas and lead to a change of mind. However, participants' views were internally consistent; that is, their views did not change over the course of the discussion. The researchers met several times after reading and re-reading the transcripts to discuss a wide range of open codes and agree on categories of the codes that reflected the meaning in the transcripts (Morgan et al., 1998). These iterative analyses and discussions as a research team were used to increase rigor, credibility, and trustworthiness in the analysis and reduce researcher bias (Morgan et al., 1998). Content and meaning saturation was achieved with iterative and constant comparative analysis, as no new codes were developed nor were there any new nuances within the codes once all data had been thoroughly examined by the researchers (Hennink et al., 2019). Focus groups were not reconvened to further discuss or verify the researchers' interpretations. Therefore, in order to verify the researchers' interpretations, a written summary of each focus group's content themes was e-mailed to each group's participants. Participants were invited to add, change, or remove information that they considered did not reflect their group's discussion. Ultimately, one participant from each group replied to this invitation and confirmed that the written summary reflected the group's discussions. In this research note, quotes and excerpts from the focus groups are used to illustrate the findings and increase the plausibility of the results. In the results, participants are referred to with a code reflecting focus group number and discipline. For example, Speech-Language Pathologist 3 in Focus Group 1 is identified as FG1SLP3.

Results

Experience in Food Shaping: Current Practice

Across the focus groups, participants commonly used derogatory terms to describe texture-modified foods, using descriptors such as "pureed goo" (FG3SLP5) and an "orangey brown puree in a plastic bowl" (FG4SLP2). However, participants also described trialing food-shaping strategies to improve the appearance of pureed foods and avoid a negative mealtime experience for the person with dysphagia. They described having variable experiences in using food molds, piping bags, and presenting the client a photo of the original unmodified meal beside the pureed meal. FG1SLP12 described positive outcomes (in terms of improving the appearance of pureed foods) of using food molds in a hospital setting, where foods had been shaped to look like the original food product (e.g., pureed carrot in the shape of a carrot). However, FG1SLP3 reported a negative experience with food molds, relating to food safety: "we had to get rid of those moulds because they went mouldy" (FG1SLP3). FG3SLP5 had trialed a range of food-shaping strategies across diverse settings to improve the visual appeal of texture-modified meals. FG3SLP5 considered that the adoption of these strategies depended on "buy-in" within the setting, from managers to kitchen staff, due to the additional commitment of time and effort in using strategies to improve food shape. As FG3SLP5 stated, "it really does need that drive from all angles and staff buy-in otherwise it doesn't work whatsoever."

Feasibility of 3D Food Printing: Is it Worth the Effort?

There were four main content themes identified across the focus groups: (a) Visual Appeal: the impact of the visual appearance of 3D-printed food; (b) Costs: the financial and time costs involved in 3D food printing; (c) Practicality: the practicality of people with dysphagia or their supporters using the 3D food printer; and (d) Potential: the potential for 3D printing to be a "technology for good" in improving mealtime-related quality of life. Each of these themes informed and encapsulated several subcategories of meaning, which are presented in Figure 1. The distribution of coding across the focus groups is presented in Table 2.

Visual Appeal of the 3D-Printed Food

Participants in FG3 agreed on the importance of 3D-printed food looking like the original food product (e.g., a chicken leg) rather than nonfood-like shapes (e.g., gecko or flower) to create a sense of familiarity and normality. They viewed that people with dysphagia "want their food to look like their food… they just want it to look like everybody else's food" (FG3SLP5). They also suggested that printing nonfood-like shapes could be seen as "childish" (FG3SLP13) and further set the person with dysphagia apart from their fellow diners rather than support their inclusion. Furthermore, participants agreed that food shapes that do not resemble the original food may limit mealtime engagement for people with dementia or

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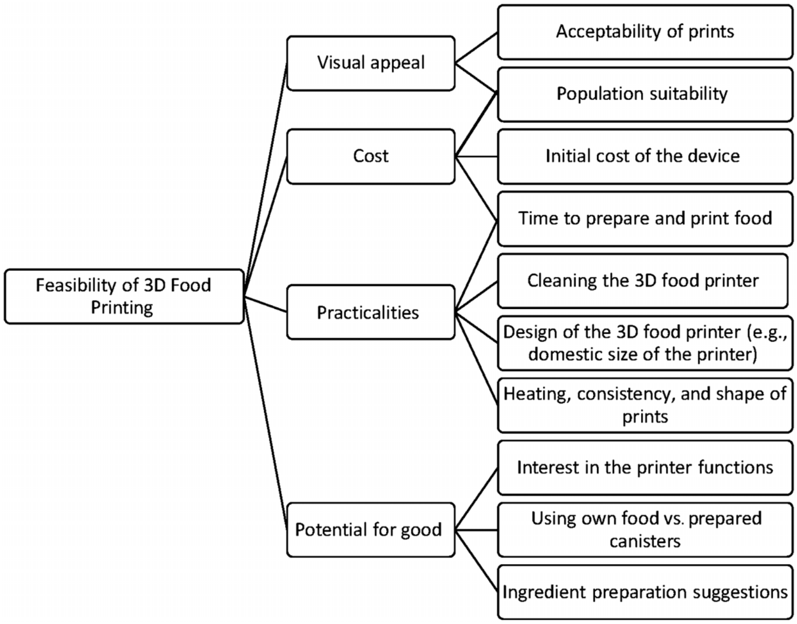
Figure 1. Feasibility of three-dimensional (3D) food printing.



traumatic brain injury, if they are unable to recognize the food item. FG2 and FG4 participants also considered naturalistic presentation of the pureed food as being important for mealtime enjoyment. They did not consider that the 3D food printer achieved naturalistic or authentic presentation due to visible ridges on what remained a relatively flat, albeit thick 3D form. Commenting on the photo of a printed chicken leg, FG4SLP2 said "a food mould would give a more accurate representation of the chicken leg… it doesn't look that chicken-leggy." However, participants recognized that 3D food printing might allow people to be more "adventurous" (FG4SLP2) in creating shapes than they could if using the predefined shapes of food molds. Participants across FG1, FG3, and FG4 also considered that 3D-printed food may make pureed food more appealing for children, if a favorite toy or character could be printed.

Cost of the 3D Food Printer

Across focus groups, participants agreed that the 3D food printer had a relatively high financial cost of $4,000 (USD; at the time of the study) when compared with the relatively low cost of current food-shaping technologies (e.g., food molds and piping bags) and, in comparison, other kitchen appliances (e.g., food blenders and microwaves). The printing process itself was perceived to incur a cost of time that group members considered should be taken into account. The financial cost was considered a substantial barrier to the uptake of 3D food printers by people with dysphagia in hospitals, the community, or

Table 2. Distribution of coding across groups.

Three-dimensional (3D) food printing subthemes	Focus Group 1	Focus Group 2	Focus Group 3	Focus Group 4	Total number of codes in theme
Acceptability of prints	5 (20%)	0 (0%)	5 (20%)	15 (60%)	25
Population suitability	17 (50%)	5 (14.7%)	4 (11.8%)	8 (23.5%)	34
Initial cost of the device	2 (10%)	6 (30%)	9 (45%)	3 (15%)	20
Time to prepare and print food	2 (14.3%)	4 (28.6%)	5 (35.7%)	3 (21.4%)	14
Cleaning the 3D food printer	1 (5.9%)	2 (11.8%)	6 (35.3%)	8 (47.1%)	17
Design of the 3D food printer (e.g., domestic size of the printer)	0 (0%)	3 (50%)	3 (50%)	0 (0%)	6
Heating, consistency, and shape of prints	2 (20%)	2 (20%)	6 (60%)	0 (0%)	10
Interest in the printer functions	3 (17.6%)	7 (41.2%)	0 (0%)	7 (41.2%)	17
Using own food versus preprepared canisters	3 (30%)	2 (20%)	5 (50%)	0 (0%)	10
Ingredient preparation suggestions	2 (15.4%)	8 (61.5%)	0 (0%)	3 (23.1%)	13

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group homes. FG2SLP6 questioned the suitability of a costly device for populations with dysphagia and suggested that many might not be able to afford a 3D food printer. In addition, funding bodies may see a costly 3D food printer as "superfluous" (FG2SLP6). This discussion reflected that cost currently was not justified by any incremental improvements in the visual appeal of the food. FG2SLP9 also stated that while access to safe food is accepted as a human right, access to visually appealing food does not have the same recognition. As a result, and considering their own views of 3D food printing, participants suggested it may be difficult for allied health professionals to advocate for the purchase of 3D food printers unless these devices could be shown to markedly improve nutrition and food intake along with mealtime enjoyment.

Practicalities of Using the 3D Food Printer

Across the groups, participants raised several perceived concerns about the usability of the 3D food printer, including the time required to prepare or print foods, clean the device, reheat the food, and ensure the suitable transportation of the food from the point of production to the table to keep its shape (see Figure 1). Participants suggested that cleaning and filling the printer capsules would be more time consuming and "not user friendly" (FG4SLP2) when compared with the time taken in other food-shaping methods (i.e., scooping food onto the plate). FG3SLP10 also commented that mealtimes at larger residential settings would continue for several hours if each meal component took 3–4 min to print. FG2SLP15 suggested that the time required to print multiple meals could be reduced if the printer was large enough to hold several plates and print multiple meals simultaneously (i.e., on an industrial scale). FG3SLP5 likened the extra cleaning requirements of the 3D food printer to the perceived inconvenience of cleaning other food processors, such as a Thermomix, exclaiming "I love my Thermomix but god I hate cleaning it." The time required to clean the small components of the 3D food printer was also seen as a barrier to its use in the community, as FG3SLP5 suggested that people with dysphagia and their family members are often time-poor owing to their increased support needs.

Participants in FG1 also discussed the logistics of printing, reheating, and transporting the food. FG1SLP3 considered that reheating 3D-printed meals may be problematic for residential settings where food temperature is closely monitored for food safety purposes. Last, participants considered the time required to transport a meal from the kitchen (e.g., in a hospital kitchen) to the person, and FG3SLP5 queried if a 3D-printed meal could maintain its shape integrity: "it might look good when it leaves [the kitchen], but does it still look like that . . . it's not leaving the kitchen and getting to the patient in five minutes."

Potential: The 3D Food Printer as a "Technology for Good"

Participants across groups agreed that improvements to the design and reduction in the cost of 3D food printers would be needed if 3D food printing was going to be a feasible option for improving the appearance of texture-modified foods and any onward benefits related to that (e.g., enjoyment, quality of life, or participation) for people with dysphagia. FG1OT1 suggested that 3D food printing could make food more exciting and give the person a sense of ownership over the food if they helped in choosing the shape and preparing or printing the food. FG1OT2 suggested the 3D food printer could be used as a therapeutic tool to engage people with the mealtime preparation process. The process could be made into a "one step" task or "multistep" task by choosing the steps the person was involved in. FG1OT2 suggested the 3D food printer could be used in social skill development groups where people could share recipes and creative food presentation ideas. FG4 participants also saw the future benefits and FG4SLP7 stated "yes there is barriers at the moment… but for that one person it could actually mean [making a difference to] their quality of life."

Participants also suggested ideas to improve the preparation of pureed food for 3D food printing. Participants in FG3 described the benefits of using customized pureed foods for printing, particularly for people with dietary requirements (e.g., allergies or gluten intolerance). For example, FG3SLP5 considered that preparing their own food for the printer could give users control over what is included in the puree, driving engagement in menu planning and purchasing of ingredients. FG3SLP5 stated "part of it is actually going to the shops and being part of a community that eats food." In contrast, FG1OT1 saw the benefits of purchasing prefilled capsules with a premade puree for the 3D food printer, as it may give people who cannot typically prepare their own meals the chance to participate, "they can get that sense of achievement and at least start being able to [participate] in that modified sense" (FG1OT1).

Discussion

In considering the potential use and benefit of 3D food printers for people with dysphagia, the speech-language pathologists and occupational therapists in this study recognized the potential benefits of 3D food printing to create more visually appealing texture modified foods. They considered these potential benefits in light of traditional food presentation methods used for texture-modified foods (e.g., scooping a spoonful of pureed food onto the plate). However, they viewed that while 3D food printing may provide another option for food shaping to

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improve the mealtime experience of people with dysphagia, it does not yet yield realistic or necessarily more appealing food shapes. Ullrich et al. (2014) identified that the realism of food shapes was an important factor in allowing a consumer to identify what they were eating and subsequently in the enjoyment of their meal. The novel food shapes created by the 3D printer and discussed by participants did not support food identification and therefore fell short of achieving this aim.

Furthermore, the 3D food printer was perceived as having several usability issues forming barriers to uptake and use, as well as financial and time costs, which would also need to be addressed to increase feasibility of 3D food printing in this population. These issues included the apparent complexity in skill required to fill the canisters with the food for printing and the several steps and stages involved in preparing, printing, and serving the food. People with dysphagia associated with physical or intellectual disabilities could indeed face several barriers to their use of a device, which requires use of a touch screen interface and manual filling of the printer ink cartridges. Nonetheless, participants also recognized that should 3D food printing become more usable and less costly and be improved in design, it could indeed promote a person's empowerment in designing their own food shapes and engaging in menu planning (Smith et al., in press).

The results of this research further the discussion on methods of food shaping as an important consideration for people on texture-modified diets, which include food molds and piping bags (Higashiguchi, 2013; Reilly et al., 2013). The findings support prior research on the perceived relatively low feasibility of 3D food printing for people with dysphagia (Burke-Shyne et al., 2021) and reflect mixed experiences with the use of food molds (Smith et al., in press; Lepore et al., 2014). With allied health professionals reporting barriers to food molds (including the time and difficulties with cleanliness), substantial efforts will still be needed to address the problem of the visual appeal of texture-modified foods, particularly to prevent pureed food from looking like "goo."

This study provides an in-depth understanding of the views of speech-language pathologists and occupational therapists on the feasibility of 3D food printing for people with dysphagia that reinforces and adds to the technical issues raised in Burke-Shyne et al. (2021; including print speed and cost of the printer). Prior 3D food printing research has not included speech-language pathologists or occupational therapists, and their perspectives are important, particularly in the multidisciplinary context of dysphagia management (Burke-Shyne et al., 2021; Hemsley et al., 2019). The perceived practical or usability issues are particularly important when considering 3D food printing for people with dysphagia associated with health conditions impacting mobility or cognitive skills, who would foreseeably require additional support to successfully use a 3D food printer.

Clinical Implications

This study has a range of clinical implications for the implementation of food-shaping strategies with people with dysphagia who require a texture-modified diet. The views of participants suggest that efforts should be made to shape the food so that it resembles the original food shape, for maximum benefit. Although 3D food printing may not yet be viewed as feasible, this research suggests that presenting the food in an attractive way, which is similar in shape to that of the original food product, may assist with mealtime enjoyment for people with dysphagia. The barriers to implementation outlined in this study, however, raise questions as to whether the "cost" of time and effort in attending to the visual appeal of pureed foods will help to mitigate the cost on quality of life for people with dysphagia who do not have access to visually appealing meals. Last, this study provides information on the usability of 3D food printing and barriers, which need to be overcome if it is to be implemented as a "technology for good" or assistive technology for people with dysphagia. Clinicians supporting people with dysphagia, their families, and support workers should encourage "buy-in" from all levels on the importance of food presentation, even if current techniques are limited. This may also assist in ensuring mealtime preparation is a task that the person with dysphagia is involved in as a therapeutic task.

Limitations and Directions for Further Research

This research included speech-language pathologists and occupational therapists but not dietitians or nutritionists who are also essential in the management of dysphagia in terms of meeting the person's dietary requirements. Had members of these groups been included, the ideas generated might have been expanded in relation to the claims of 3D food printers aiding nutrition and insights into adoption or usability might have been expanded. They may have also identified further opportunities for personalized nutrition for people with dysphagia as introduced by Burke-Shyne et al. (2021) and Pereira et al. (2021; e.g., diabetic or vegetarian diet). A wider multidisciplinary view may also help identify other populations that 3D food printing may be beneficial for including people with sensory food difficulties. A further limitation was the lack of opportunity for participants to see the 3D food printer being used in person. The study was conducted online by necessity owing to COVID-19 restrictions on travel and social distancing rules. Consequently, participants' views on 3D food printing were based on the information, pictures, and videos shown by

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the focus group moderator rather than an in-person experience in using the printer, which might have yielded additional insights as to usability and potential benefit. For example, the occupational therapists may have identified fine motor skills that needed consideration.

Future research should examine how dietitians and nutritionists, people with dysphagia, and their supporters engage with a 3D food printer and their views of the acceptability or use of these devices. Further research involving in-depth interviews with people with dysphagia and their supporters about their mealtimes and views on 3D food printing are currently being conducted. Future research with allied health professionals involved in texture modification may also allow for testing of printed food to determine if the food continued to meet IDDSI guidelines or if the flavor is compromised. The themes identified in this study could help to inform future controlled trials comparing 3D-printed foods with other food-shaping techniques (e.g., piping bags and food molds), particularly in terms of usability, perceptions of the realistic nature of the food printed, and comparing visual appeal and acceptance. A cost–consequences or cost–benefit analysis could also help to identify parameters to be considered beyond the financial cost of a 3D food printer. The findings of this research should also be seen as further impetus to drive improvements in the user-centered co-design and engineering of 3D food printers to increase feasibility for use by people with dysphagia and their supporters.

Conclusions

This study examined the views of allied health professionals, specifically speech-language pathologists and occupational therapists involved in dysphagia management, on the use of 3D food printing to improve the visual appeal of texture-modified foods for people with dysphagia. Their discussions revealed the importance of considering whether 3D food printers do actually improve the visual appeal of the food and of balancing both financial and time costs relating to the purchase and use of a 3D food printer. Several barriers were discussed, and these would be likely to impede the use of the 3D food printer as a “technology for good” to improve mealtime experiences and the acceptance of pureed food. The barriers noted in this study need to be addressed before any benefits of 3D food printing for people with dysphagia may be realized. Further research should include people with dysphagia, their supporters, and other allied health professionals to determine their views on the acceptability of 3D-printed foods in comparison to other food-shaping methods. This will ensure that a holistic view of the feasibility of 3D food printing for people with dysphagia is achieved.

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Appendix

Topic Guide for Focus Groups

1. How do you currently provide texture-modified foods? (e.g., food shaping, molds, and piping bags) and how effective are these methods?
2. Short introduction to three-dimensional (3D) food printing and a picture sequence of 3D food printing (Natural Machines, 2019).

Introduction to Foodini 3D printer: “This is the Foodini 3D food printer which prints food in the form of puree or paste. The puree is put into capsules and then pushed out to make the food item (similar to an inkjet printer). Once the food is printed, it can be eaten as is, cooked or frozen to be reheated at a later time.” Participants are shown a video and eight photos of the 3D food printer and printed foods (see example photos of 3D-printed food).

1. What do you think of using 3D-printed food in mealtimes for people with dysphagia? Would it potentially work? What barriers/facilitators to using this technology might there be?

3D Food Printing Pictures

Foodini 3D printer

Capsules inside printer

Fish and chips

Guacamole Gecko

Wafer and buttercream dessert

Hummus and olive paste pots

Chocolate ganache cup

Filled biscuit

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Chapter 12: Survey Findings on the Feasibility of 3D Food Printing

The studies reported in Chapters 10 and 11 on the feasibility of 3D food printing to improve the mealtime experience for people with dysphagia had low participant numbers. To verify the results presented in Chapters 10 and 11, an online survey was required. Chapter 12 presents the results of an online survey results relating to the feasibility of 3D food printing for people with dysphagia from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals. This survey assisted in the data triangulation required to develop the evidence-based framework being developed as part of this thesis. This chapter reinforces findings of the 3D printed food experiences with people with dysphagia and focus groups with health professionals (Chapters 10 and 11). In the survey, participants watched a video of 3D printed food being created then responded to a set of questions based on their views of the video. Survey results were analysed using descriptive statistics and content thematic analysis.

This chapter has been written in manuscript form and is currently under review for publication in the *American Journal of Speech-Language Pathology.* The spelling has been modified for inclusion in this thesis.

Smith, R., Bryant, L., Hemsley, B. (2022e). *"It looks better than a bowl of mush": Views on food design and 3D food printing to improve the mealtime experience for people with dysphagia* [Manuscript submitted for publication]. Graduate School of Health, The University of Technology Sydney.

Abstract

Purpose: To identify and examine (a) food design strategies used to improve the mealtime experiences of people with dysphagia; and (b) the views of people with dysphagia, supporters of people with dysphagia, and allied health professionals on the expected benefits of 3D food printing to improve texture-modified foods for people with dysphagia.

Methods: An online survey of 30 adults with dysphagia, four supporters of people with dysphagia, and 18 allied health professionals was conducted between November 2021 and February 2022. Categorical data were analysed using descriptive statistics and written comments were analysed for content themes.

Results: Approximately two thirds of participants with dysphagia, and almost all supporters of people with dysphagia and allied health professionals, reported using at least one food design strategy for texture-modified foods. Most supporters of people with dysphagia and allied health professionals considered that 3D food printing could improve the visual appeal and enjoyment of texture-modified food; a view less supported by participants with dysphagia. A content analysis revealed several issues potentially reducing the feasibility of 3D food printing.

Discussion: Implementing food design strategies with texture-modified foods may not improve the visual appeal of food for people with dysphagia. Supporters of people with dysphagia and allied health professionals considered that food shaping techniques increased choices. 3D food printing remains largely untested, with potential for positive impacts. Further research exploring the way people with dysphagia and their supporters engage with food design and 3D food printing could identify further barriers to and facilitators to their use of these technologies.

Introduction

One of the most common compensatory interventions recommended for people with dysphagia (difficulty swallowing) is the provision of texture-modified food (Cichero et al., 2017). Texture-modified foods are softer and easier to swallow, helping to maintain the person's nutritional and respiratory health (Groher & Crary, 2016). Recommendations for people with dysphagia to eat texture-modified food are typically based on observational clinical and instrumental assessments of swallowing (Ricci Maccarini et al., 2007). The consistencies of texture-modified foods are described in a systematic way using the International Dysphagia Diet Standardization Initiative (IDDSI, 2019). According to the IDDSI framework, food and fluids are classified into eight levels; with five levels related to food: Regular/ Easy to Chew (IDDSI Level 7), Soft and Bite Sized (IDDSI Level 6), Minced and Moist (IDDSI Level 5), Pureed (IDDSI Level 4) and Liquidised (ISSDI Level 3).

While modifying food textures is intended to increase the person's swallowing safety (e.g., by avoiding or reducing the risk of coughing or choking on food) and good health, people who eat texture-modified foods may continue to face health risks. Firstly, pureed food (IDDSI Level 4) may continue to pool in the vallecular spaces of the neck increasing the person's risk of choking (Gustafsson & Tibbling, 1991). The addition of liquid to pureed food may reduce the food's nutritional benefits unless the nutritional value is supplemented during the food preparation process (Keller et al., 2012). Furthermore, due to the nature of the modification required in preparing the food, texture-modified meals are often unappealing and poorly accepted (Colodny, 2005). This can reduce food consumption and lead to people taking more risks in eating foods of a regular texture that are not safe for them to swallow (Colodny, 2005; Keller et al., 2012).

A recent review of the literature examined the impacts of food design (e.g., the structure, shape, visual appeal, smell, or taste of food) on the mealtime experiences and quality of life of people with dysphagia (Smith, Bryant, Reddacliff et al., 2022). Of the 34 studies reviewed, only 10 included people with dysphagia. Smith, Bryant, Reddacliff et al. (2022) reported that food design strategies used to improve the visual appeal of food (e.g., the use of food moulds) did not necessarily improve the mealtime experience for people with dysphagia (citing Stahlman et al., 2001; Stahlman et al., 2000). None of the studies included in the review by Smith, Bryant, Reddacliff et al. (2022) presented the views of people with dysphagia or supporters of people with dysphagia on the impacts of using new technologies proposed to improve mealtime experiences, such as 3D food printing.

Recently, Burke-Shyne et al. (2021) conducted semi-structured interviews with experts in nutrition and 3D food printing and reported that although 3D food printing could be used to create texture-modified foods, there were several important issues yet to be considered and resolved. These included the sustainability of 3D food printing, its potential uses (e.g., to increase the nutritional value of food), technical issues, and the ethical matters of printing food (Burke-Shyne et al., 2021). Ethical matters included issues around consent, acceptance of food, and the provision of processed foods (Burke-Shyne et al., 2021). Strother et al. (2020) tested 3D printed food and food shaped with food moulds using a texture profile analysis and compared the perceptions of 12 trained panellists. There was no significant difference in the sensory or textural properties between the 3D printed pureed carrot and the moulded pureed carrot. However, neither Burke-Shyne et al. (2021) nor Strother et al. (2020) examined the views of people with dysphagia, supporters of people with dysphagia, or allied health professionals involved in dysphagia management on these food design issues.

To expand on prior research, Smith, Bryant and Hemsley, (2022b) reported on the views of 15 allied health professionals in focus groups discussing the impacts of dysphagia on quality of life and the feasibility of 3D food printing to improve the mealtime experience. Like Burke-Shyne et al. (2021), Smith, Bryant and Hemsley, (2022b) reported that 3D food printing may improve a person's mealtime experience; however, there were a number of feasibility issues that needed to be addressed before this technology could be widely used. These issues included the cost of 3D food printing, the suitability for people with health conditions associated with dysphagia, and the acceptability of the printed food (Smith, Bryant & Hemsley, 2022b).

In addition to the views of allied health professionals, people with dysphagia need to be consulted about their food preferences as the visual appeal of food is rated differently by people who do have dysphagia and those who do not (Ettinger et al., 2014). In order to achieve this consultation, Smith, Bryant and Hemsley (2022a) interviewed nine people with dysphagia and four of their supporters on their perspectives on the feasibility of 3D food printing. Through usability heuristics (Nielsen, 1994) and content thematic analysis, the authors reported that people with dysphagia and their supporters were cautious about using 3D food printers due to the print quality, user control, error prevention, and handling of food consistencies (Smith, Bryant & Hemsley, 2022a). However, the small number of participants in the study meant that the results need to be verified, confirmed, and expanded upon with larger studies. Triangulation using a survey method as a follow-up to interviews and focus groups is appropriate (Patton, 2014). The findings of survey research as a follow-up could help to inform future evidence-based guidelines on food design and specifically food shaping techniques for people with dysphagia. Considering the gaps in prior research, the aims of this research were to examine the (a) food design strategies commonly used to improve the shape of texture-modified foods, and attitudes towards these methods; and (b) views on the feasibility of using 3D food printing as a food shaping technique to improve the visual appeal of food and quality of life for people with dysphagia.

Methods

This study was approved by the University of Technology Sydney's Human Research Ethics Committee (ETH21-6568 and ETH21-6781). The methods and results of this study are reported using the Mixed Methods Studies in Health Services Research checklist (Good Reporting of a Mixed Methods Study, GRAMMS) (O'Cathain et al., 2008). The online survey method was selected as a follow-up to prior qualitative research with a larger number of participants that assisted researchers to understand the phenomenon being studied (Lyons et al., 2022).

Participants

People with dysphagia, supporters of people with dysphagia (e.g., family members, or paid carers), and allied health professionals who work with people with dysphagia were invited to take part in the research. Participants were recruited through purposeful sampling in which participants were only selected if they were an adult with dysphagia, a supporter of a person with dysphagia, or an allied health professional that could provide consent. As well as convenience sampling, researchers also used purposeful sampling procedures to recruit specific health professionals (e.g., occupational therapists, dietitians) and people with dysphagia. This was done through the social media networks of the researchers and topic-related hashtags (e.g., #dysphagia, #OT #Dietetics); as such, the participant response rate could not be calculated (Emmel, 2013). Social media posts included a link to the landing page of the survey which provided an information statement about the research. All participants gave implied consent by proceeding to the survey from the landing page.

Materials

An online survey was created and distributed using the online survey software, RedCap (Harris et al., 2009). Participants could access the survey through a URL link or QR code. The survey questions were based on a prior review of the literature (Smith, Bryant, Reddacliff et al., 2022), and research with similar aims involving interviews (Smith, Bryant & Hemsley, 2022a), and focus groups (Smith, Bryant & Hemsley, 2022b).

The survey was designed to take approximately 15-20 minutes to complete and used branching logic so that participants received questions relevant to their role. The 16 questions included multiple choice, Likert scales, open ended questions, and yes/no questions. The questions and their order were designed to maintain participants' accuracy and truthfulness in responding (Wolf et al., 2016). Before the first question on 3D food printing, participants watched an embedded 30 second video of the 3D printing process, created by Natural Machines, to introduce them more fully to the topic (Natural Machines, 2022a). Survey questions also related to the impacts of dysphagia on quality of life; these are reported elsewhere (Smith, Bryant & Hemsley, 2022d). Two colleagues of the first author who were speech pathologists piloted this survey prior to its release to the public and the final version is in Appendix F of this thesis.

Procedures

This survey was open online for 15 weeks, until no further responses were obtained with social media distribution, from November 2021 to February 2022. Prior to survey analysis, an exclusion process reduced non-response errors during the analysis process (Wolf et al., 2016). Surveys were excluded from analysis if the participant attempted the survey but exited prior to responding to any questions, or after completing only the demographic questions.

Analysis

Descriptive statistics (including percentage, mean, and mode) were used to analyse the quantitative categorical survey data using Microsoft Excel. There were insufficient survey responses for statistical comparisons between groups of respondents. The content thematic analysis (Patton, 2014) involved importing the qualitative survey data into NVivo for content coding (Braun et al., 2021; Patton, 2014). The codes, categories, and themes within the data were identified through an inductive analysis process and consensus across the research team. Each theme was reviewed, discussed, and agreed on by all authors. This was particularly beneficial for examining a topic that is under-researched (Braun et al., 2021), like the use of food design and 3D food printing for people with dysphagia. Quotes from the written responses to open-ended questions are used to illustrate the content themes and increase the credibility and trustworthiness of the findings (Eldh et al., 2020). In reporting the results, participants are referred using their survey participant number (e.g., P1).

Results

Participants

Although 101 participants attempted the survey, almost half exited prior to answering anything more than demographic questions; ultimately, only 52 (51%) of the surveys were completed and included for analysis. Participants included 30 (57.7%) people with dysphagia, four supporters of people with dysphagia (7.7%), and 18 (34.6%) allied health professionals across the disciplines of speech pathology, dietetics, and occupational therapy. Information about participants is provided in Table 18.

Table 18

Chapter 12 Demographic Information

Characteristic	People with Dysphagia	Supporters	Allied Health Professionals	Total
Total number	30 (57.7%)	4 (7.7%)	18 (34.6%)	52 (100%)
Age				
18–30 years	0	0	4 (22.2%)	4 (7.7%)
31–40 years	1 (3.3%)	0	6 (33.3%)	7 (13.5%)
41–50 years	0	1 (25%)	2 (11.1%)	3 (5.8%)
51–60 years	1 (3.3%)	3 (75%)	5 (27.7%)	9 (17.3%)
61–70 years	9 (30%)	0	0	9 (17.3%)
71 80 years	16 (53.3%)	0	1 (5.6%)	17 (32.7%)
81+ years	3 (10%)	0	0	3 (5.8%)
Gender				
Male	14 (46.7%)	1 (25%)	0	15 (28.8%)
Female	15 (50%)	3 (75%)	18 (100%)	36 (69.2%)
Non-binary	1 (3.3%)	0	0	1 (1.9%)
Time with dysphagia				
0–5 years				
6–10 years	13 (42.3%)	NA	NA	13 (25%)
11–15 years	14 (46.6%)	NA	NA	14 (26.9%)
16–20 years	2 (6.7%)	NA	NA	2 (3.8%)
21–25 years	0	NA	NA	0
26–30 years	1 (3.3%)	NA	NA	1 (1.9%)
30+ years	0	NA	NA	0
	0	NA	NA	0
Years' experience with Dysphagia				
Up to 2 years	NA	1 (25%)	0	1 (1.9%)
3–5 years	NA	0	4 (22.2%)	4 (7.7%)
6–10 years	NA	0	5 (27.8%)	5 (9.6%)
11–15 years	NA	0	3 (16.7%)	3 (5.8%)
16–20 years	NA	0	0	0
20+ years	NA	3 (75%)	6 (33.3%)	9 (17.3%)

Note. NA = not applicable.

Participants with Dysphagia. Most participants who identified as having dysphagia were older, aged over 61 (*n*=28, 93.3%), and had acquired dysphagia in the past 6-10 years (*n*=14, 46.7%). The remainder were younger (31-50 years of age) (*n*=2, 6.7%). Participants across the age range reported being on a diet of Regular or Easy to Chew (IDDSI Level 7) (*n*=14, 29.8%); Soft and Bite Sized (IDDSI Level 6) (*n*=12, 25.5%); Minced and Moist (IDDSI Level 5) (*n*=12, 25.5%); Pureed (IDDSI Level 4) (*n*=3, 6.4%); or Liquidised food (IDDSI Level 3) (*n*=3, 6.4%). Thirteen of the 30 participants (43.3%) reported having foods of more than one consistency; four (13.3%) could only manage IDDSI Level 5 and below; one could only eat IDDSI Level 4 Pureed food; and one could only manage IDDSI Level 3

Liquidised food. Participants with dysphagia also reported consuming Thin Fluids (IDDSI Level 0) (*n*=13, 41.9%); Slightly Thick Fluids (IDDSI Level 1) (*n*=5, 16.1%); Mildly Thick Fluids (IDDSI Level 2) (*n*=1, 3.2%); or Moderately Thick Fluids (IDDSI Level 3) (*n*=3, 9.7%); one reported having both thin and slightly thick fluids; the remainder did not provide a response. Only half of the participants with dysphagia responded to the question relating to assistive technology for mealtimes. They reported using adaptive cutlery (*n*=7, 18.9%), a straw (*n*=4, 10.8%), an adaptive cup (*n*=3, 8.1%), a non-slip mat (*n*=2, 5.4%), or no adaptive technologies (*n*=5, 13.5%).

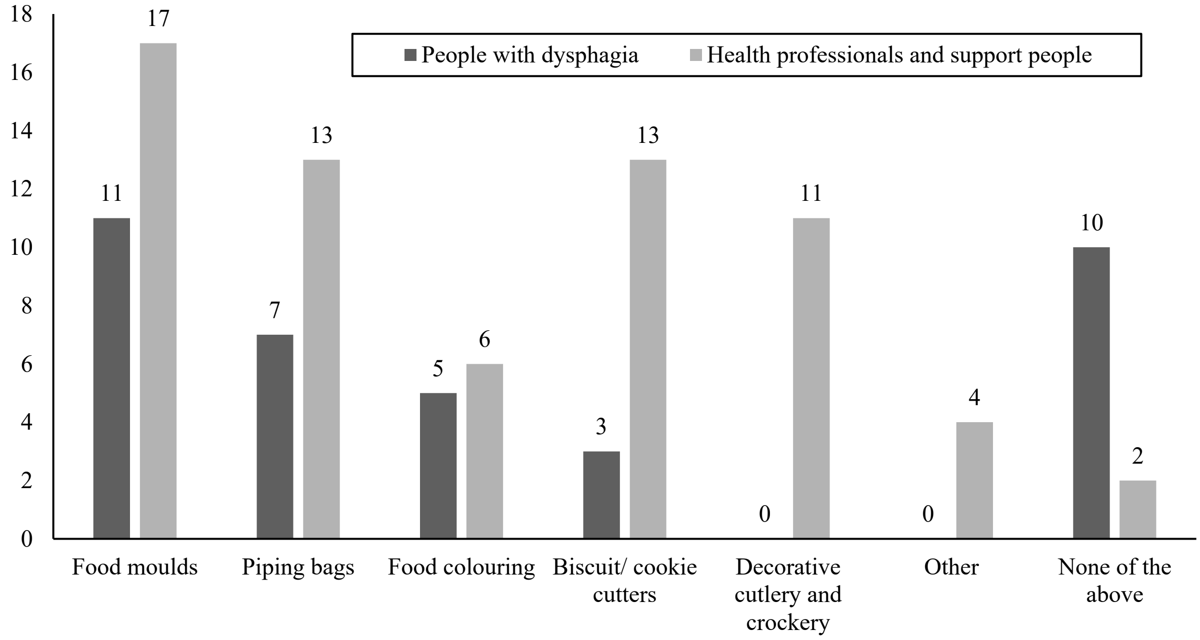
Supporters of People with Dysphagia and Allied Health Professionals. Most participants who were supporters of people with dysphagia were aged 51-60 years. Of the allied health professionals, speech pathologists made up the majority (*n*=12, 66.7%), followed by dietitians (n=5, 27.8%), and an occupational therapist (*n*=1, 5.6%) with a range of 3-20+ years of experience in working with people with dysphagia.

Food Design Strategies Implemented

When asked about food design strategies used in presenting texture-modified foods, participants with dysphagia were less likely to use each of the methods (i.e., piping bags, food moulds) than supporters of people with dysphagia or allied health professionals (see Figure 12). Participants with dysphagia who used any strategies at all were most likely to use food moulds (*n*=11, 30.5%); other methods reportedly used included piping bags (*n*=7, 19.4%), different coloured foods or food colouring techniques (*n*=5, 13.9%), or biscuit/cookie cutters (*n*=3, 8.3%). On average, participants with dysphagia who reported using any strategies used only one. However, 10 (27.8%) did not use any food shaping or food design methods. Seven of the written comments reflected the antipathy of participants towards food design strategies, as illustrated by P37 who wrote: “it is still pureed food no matter what it looks like.”

Figure 12

Food Design Methods Implemented by People with Dysphagia, Supporters of People with Dysphagia, and Allied Health Professionals



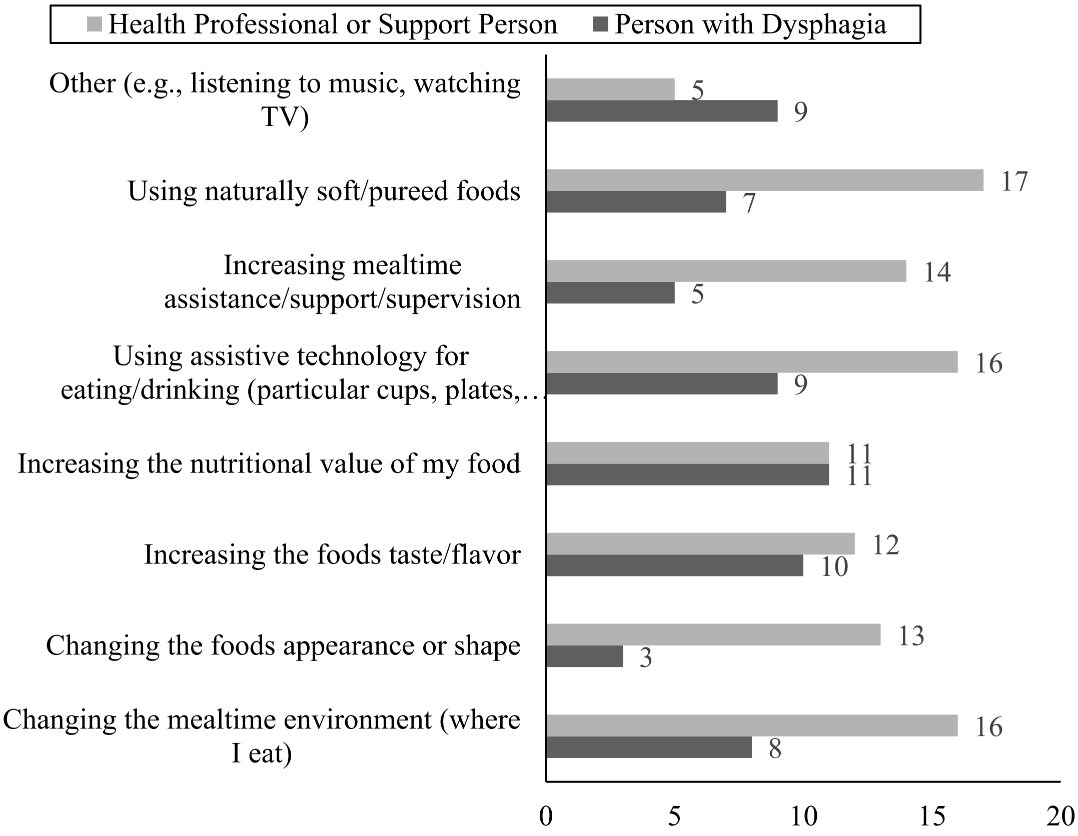
Almost two thirds (*n*=14, 63.6%) of supporters of people with dysphagia and allied health professionals reported using food shaping and food design strategies. These participants reported using a wider range of food shaping and design strategies than people with dysphagia, on average using three strategies each. These included food moulds (*n*=17, 25.8%), piping bags (*n*=13, 19.7%), different coloured foods and food colouring (*n*=6, 9.1%), biscuit/cookie cutters (*n*=13, 19.7%), decorative cutlery and crockery (*n*=11, 16.7%), and other strategies (*n*=4, 6.1%), including placing different foods on separate plates, or placing foods of different colours on a plate to create greater colour contrasts. Only one supporter and one allied health professional (5.6%) reportedly did not use any food design strategies. Figure 12 presents these results in graphic form. P16, an occupational therapist, reported using “any method to make it as close as possible to the original food, or more fun for the person to engage." P54, a supporter of a person with dysphagia, similarly described the benefits of improving the visual appeal of the food writing, "shape and appearance can be the reason why you want to eat food."

Strategies to Improve the Mealtime Experience

Participants were asked to list strategies they used to improve mealtime experiences for themselves as people with dysphagia or else for the person they supported, or clients on a texture-modified diet. People with dysphagia most commonly reported increasing the nutritional value of food (*n*=11, 17.7%), and least commonly reported changing the appearance of food (*n*=3, 4.8%). In contrast, supporters of people with dysphagia and allied health professionals most frequently used or recommended using naturally soft foods (*n*=17, 16.4%), changing the mealtime environment (*n*=16, 15.4%), and using assistive mealtime technology (*n*=16, 15.4%) to improve the overall mealtime experience. P11, a speech pathologist, also described adjusting lighting and having conversations at mealtimes. The total number of strategies identified by all 30 participants with dysphagia (*n*=62) was just over half of the total number of strategies provided by all supporters of people with dysphagia and allied health professionals combined (*n*=104). Figure 13 illustrates the distribution of strategies used to improve the mealtime experience across groups of participants with dysphagia, supporters of people with dysphagia, and allied health professionals.

Figure 13

Strategies Implemented to Improve the Mealtime Experience by People with Dysphagia, Supporters of People with Dysphagia, and Allied Health Professionals

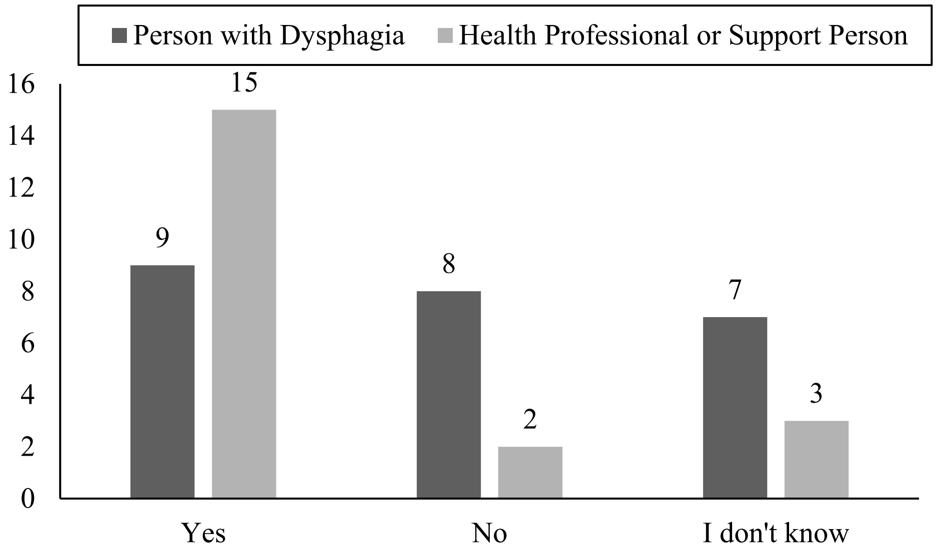


The Feasibility of 3D Food Printing for Improving the Mealtime Experience

Expectations of Benefit across Groups. While no participants reported having used a 3D food printer to shape texture-modified foods, almost half (46.2%) of the participants expected that 3D food printing would improve the appearance of texture-modified food. Approximately one third of participants with dysphagia (*n*=9, 30%) expected that 3D food printing would improve the appearance and enjoyment of texture-modified food; some (*n*=8, 26.7%) did not think it would be beneficial and others were unsure of its benefits (*n*=7, 23.3%). In contrast to these results, the majority of supporters of people with dysphagia and allied health professionals expected that 3D food printing could improve the appeal and enjoyment of texture-modified food (*n*=15, 68.2%); three were unsure it would provide any benefit (13.6%), and two did not expect it to improve the appearance or enjoyment of texture-modified food (*n*=2, 9.1%). These findings across groups are illustrated in Figure 14. P28, a speech pathologist, expected that 3D food printing "would normalise texture modified foods, increasing individual acceptance and social acceptance." However, P9, a family member of a person with dysphagia, wrote: "I would much rather artistically serve different purees on a plate with a very nice sauce than serve something out of a printer in a fancy artificial shape that looks machine produced."

Figure 14

Participant Perspectives on whether 3D Food Printing Improves the Appearance and Enjoyment of Texture Modified Food

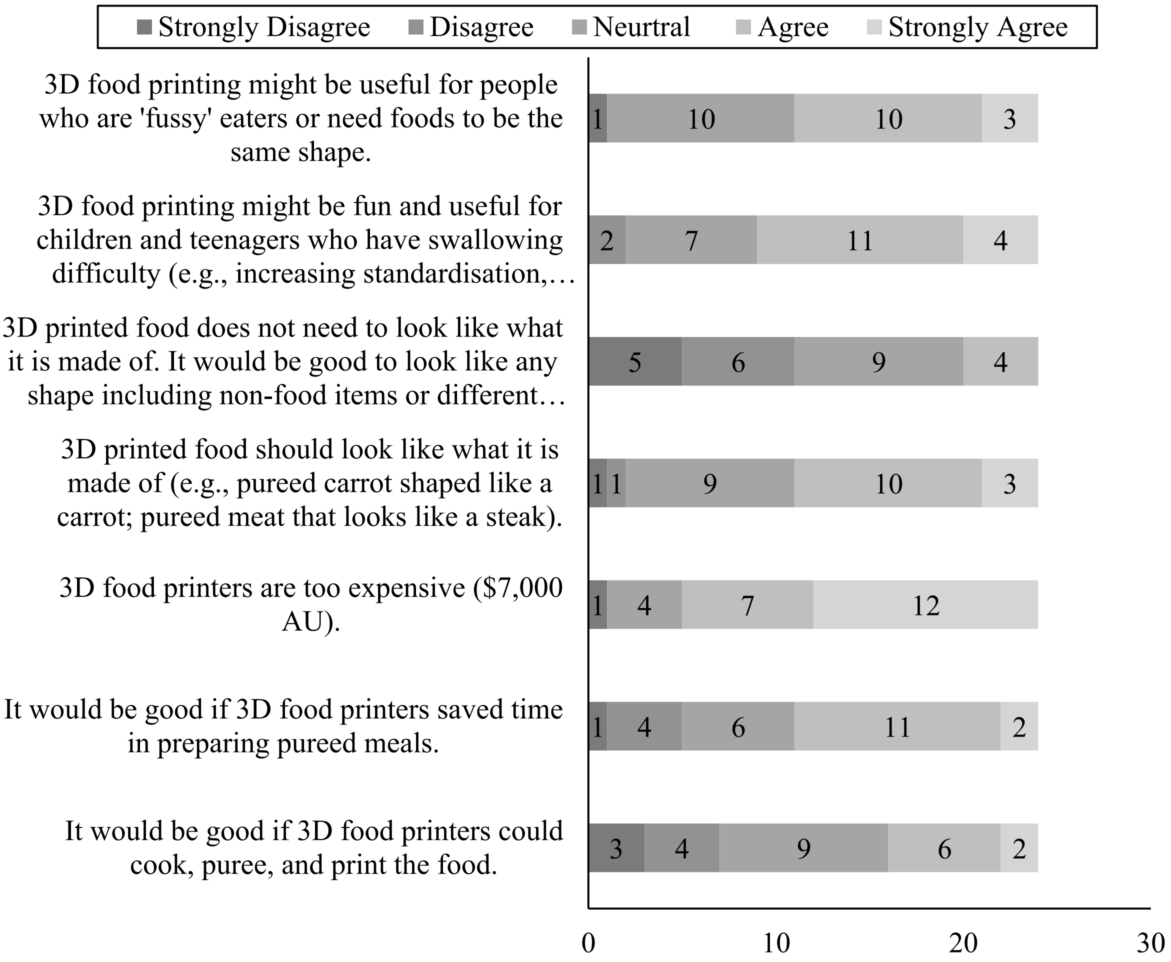


Views on 3D Food Printing

Views of People with Dysphagia. More than half of the participants with dysphagia either agreed or strongly agreed that "3D food printing might be useful for people who are 'fussy' eaters or need foods to be the same shape" (*n*=13, 54.2%) (see Figure 15). However, a neutral response was also reported (*n*=10, 41.7%), indicating some uncertainty and lack of conviction around the effectiveness of the technology. P73 suggested that 3D food printing involved an element of deception for the person eating the food, writing: “I think it's unnecessary to try and disguise the food by shaping it differently”. Participants responded in a similar manner to the statement “3D food printing might be fun and useful for children and teenagers who have swallowing difficulty”. The majority (*n*=15, 62.5%) agreed or strongly agreed with the statement, some were neutral (*n*=7, 29.1%) and only two disagreed (8.3%). The majority of participants (*n*=19, 79.2%) agreed or strongly agreed with the statement: “3D food printers are too expensive ($7,000 AU)” and only one (3.3%) stron gly disagreed with the statement.

Figure 15

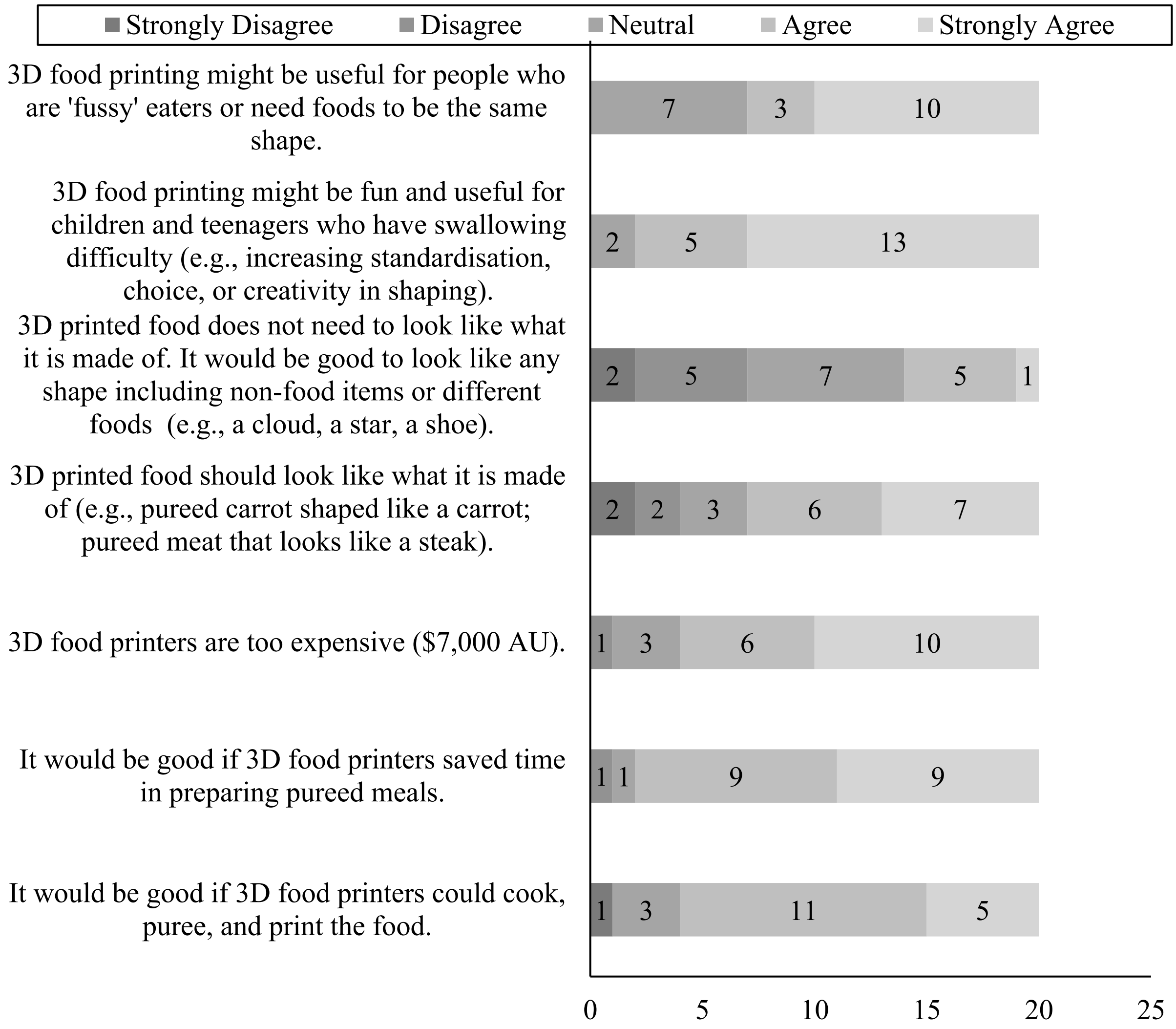
Opinions of Participants with Dysphagia



Views of Supporters of People with Dysphagia and Allied Health Professionals. The majority (*n*=13, 65%) of participants who were supporters of people with dysphagia or allied health professionals agreed or strongly agreed with the statement "3D food printing might be useful for people who are 'fussy' eaters or need foods to be the same shape" and seven (31.8%) provided a neutral rating. The majority (*n*=18, 81.8%) agreed or strongly agreed with the statement "3D food printing might be fun and useful for children and teenagers who have swallowing difficulty". P100 wrote "this would be a wonderful tool for both young children and teenagers - imagine the creativity you could unleash within and then there's always the 'you made it, you eat it' aspect!" Participants also demonstrated a high level of agreement on the cost of the device being too high, as most participants (*n*=16, 72.7%) agreed or strongly agreed with the statement "3D food printers are too expensive ($7,000 AU)." These results are illustrated in Figure 16.

Figure 16

Opinions of Supporters of People with Dysphagia and Allied Health Professionals on 3D Food Printing



What 3D Printed Food Should Look like

Views of People with Dysphagia. The majority of participants with dysphagia either agreed or strongly agreed that “3D printed food should look like what it is made of” (*n*=13, 54.2%) and resemble the same real foods. P70, who had dysphagia, wrote “all food should look like what it is.” Others gave a neutral response (*n*=9, 37.5%). These ratings aligned with ratings of a related statement, “3D printed food does not need to look like what it is made of. It would be good to look like any shape including non-food items or different foods”, in that only four participants agreed with the statement (*n*=4, 16.7%), nine (37.5%) provided a neutral rating, 11 (45.8%) disagreed or strongly disagreed, and none strongly agreed. One comment reflected on the video of a puree being printed into a leaf shape, stating “the food shown on video did not look appealing” (P57).

Views of Supporters of People with Dysphagia and Allied Health Professionals. Like people with dysphagia, the majority of supporters of people with dysphagia and allied health professionals (*n*=13, 59.9%) either agreed or strongly agreed that “3D printed food should look like what it is made of”, with three neutral responses (13.6%). Regarding the statement: “3D printed food does not need to look like what it is made of. It would be good to look like any shape including non-food items or different foods”, responses were almost equally spread as participants agreed or strongly agreed (*n*=6, 27.3%), were neutral (*n*=7, 31.8%), or disagreed or strongly disagree (*n*=7, 31.8%).

Usability of 3D Food Printers

Views of People with Dysphagia. In response to the statement “it would be good if 3D food printers saved time in preparing pureed meals”, the majority of people with dysphagia agreed or strongly agreed (*n*=13, 54.2%); while others (*n*=6, 25%) provided a neutral response. In responding to the statement “it would be good if 3D food printers could cook, puree, and print the food”, one third of people with dysphagia either agreed or strongly agreed (*n*=8, 33.3%), while the remainder were neutral (*n*=9, 37.5%), disagreed, or strongly disagreed (*n*=7, 29.2%). P56, a participant with dysphagia, wrote: “I don't think I could be bothered with using a 3D printer to present food. I don't think it would make any difference once you can no longer swallow.”

Views of Supporters of People with Dysphagia and Allied Health Professionals. In response to the statement “it would be good if 3D food printers saved time in preparing pureed meals”, most supporters of people with dysphagia and allied health professionals either agreed or strongly agreed (*n*=18, 81.8%), responding positively to the prospect of 3D food printing being a time saving device (see Figure 16). However, P52, a dietitian, wrote “it's not necessarily the time taken to prepare the food but providing assistance to those who have difficulties in hand, body stance and movements necessary to prepare food”, indicating that time is not the only factor that needs to be considered for 3D food printer usability. The majority of supporters of people with dysphagia and allied health professionals agreed or strongly agreed (*n*=16, 72.7%) with the statement “it would be good if 3D food printers could cook, puree, and print the food”, indicating some value being placed on a multi-purpose device for producing texture-modified foods and shaping these for consumption.

Discussion

The views of people with dysphagia, supporters of people with dysphagia, and allied health professionals reported in this study provide important insights into the value of the visual appeal of texture-modified foods and the use of food shaping strategies to enhance mealtime enjoyment and quality of life. Previously, people with dysphagia have described the importance of having choice and control over the design of their own meals (Smith et al., in press-b) and the findings of this research suggest that some people might find this consideration outweighs the importance of the food being visually appealing. That is, regardless of the visual appearance of texture-modified foods, a person with dysphagia values the choice over what they eat and should be asked about the way they want their foods presented, without assumptions being made as to their preferences. Their views on the point of ‘visual appeal’ of texture-modified foods may differ from the views of their supporters or of allied health professionals.

This contemporary research extends the findings of prior research into views on 3D food printing by Burke-Shyne et al. (2021) and Strother et al. (2020) in exploring the views of end users more specifically. In particular, while Burke-Shyne et al. (2021) identified various ethical and technical issues of 3D food printing, the current research provided a deeper understanding of usability issues for people with different physical abilities (e.g., their ability to lift heavy objects). Similarly, while Strother et al. (2020) found that the textural and sensory properties of 3D printed and moulded pureed foods were not significantly different, the current research provided greater insights into the importance of using these strategies in a way to ensure that the food resembled the original food product. This was achieved by including the perspective of the end users of the 3D food printer: people with dysphagia, supporters of people with dysphagia, and allied health professionals.

The online survey method and purposive sampling of people with dysphagia, supporters of people with dysphagia, and allied health professionals allowed for the inclusion of more people from a range of geographical locations, increasing the number of people with a key role in mealtime management being included in 3D food printing research in comparison to past studies that did not include these participant groups (Burke-Shyne et al., 2021; Strother et al., 2020). While small in scale, this study expands upon current knowledge established through qualitative methods by Smith, Bryant and Hemsley (2022a) and Smith, Bryant and Hemsley (2022b) on the impacts of food design and 3D food printing on mealtime experiences from the perspective of key stakeholders and potential future users of the devices. This was achieved by collecting information related to the look of the food as well as the usability of the device. Although a relatively small sample size and non-representative sample, the triangulation of these survey results with the findings of qualitative studies on the same research questions allows for a deeper understanding of issues surrounding food design for people with dysphagia (Patton, 2014).

The results of this study also add to the findings of prior research that there are several barriers to and facilitators of using 3D food printing described by Smith, Bryant and Hemsley (2022a) and Smith, Bryant and Hemsley (2022b). The relatively low level of agreement across groups as to the value of 3D food printing as a feasible method for improving mealtimes for people with dysphagia indicates that it may remain an emergent technology with little impact on the field unless advances in design are forthcoming. This follows recommendations provided in previous texture-modified food and 3D food printing research Burke-Shyne et al. (2021) who reported that further research was needed on the technical issues identified including food safety issues and time requirements. Nonetheless, some findings of prior research are echoed here: the perceived low usability of the device (i.e., how easy the device is to use and clean) by people with dysphagia, and the relatively high financial cost (at the time of writing, AU$14,390) would need to be addressed for any future benefit to be realised (3D APAC, 2021; Smith, Bryant & Hemsley 2022a).

In this study, food design strategies were reported as being more frequently implemented by supporters of people with dysphagia and allied health professionals than by people with dysphagia. This finding may reflect the important role of these parties in attending to how foods are presented on the plate. As reported in interviews by Smith et al. (in press-b), people with dysphagia and their supporters use various strategies to improve the presentation of meals including the use of different coloured foods and decorative cutlery. The strategies reported in the present study also echo the findings of Smith, Bryant, Reddacliff et al. (2022) as impacting on quality of life. These strategies were wide ranging and included modifying the nutritional value of the food to the mealtime environment. The diverse views across participant groups in this study suggests that supporters of people with dysphagia and allied health professionals may be more likely and willing to experiment with food shape for texture-modified foods than are people with dysphagia. However, the finding in this study that people with dysphagia reported using food moulds and piping bags less frequently suggests that the benefits of these strategies are not well established. Supporting the finding of Ettinger et al. (2014), who reported that people with dysphagia rate the visual appeal of foods differently to people without dysphagia, this study's results suggest that food shaping might not be as highly valued by people with dysphagia as it may by supporters or allied health professionals. Indeed, results reflect that people with dysphagia may place a higher value on the act of swallowing foods they could manage safely than on the visual appeal of the food. They may also value foods being a recognisable shape like their component ingredients and being 'natural' rather than processed further by 3D food printing. This may also explain their lower frequency and range of food design or food shaping strategies used, even if these strategies are recommended and valued by allied health professionals and supporters of people with dysphagia. The results of this study also suggest that people with dysphagia and co-existing physical or other disabilities might not consider food shaping techniques as a priority. As people with dysphagia often rely on other people for access to their food and preparation of meals (Ball et al., 2012), the use of food design or shaping techniques might rest upon the skills or attitudes of supporters. This raises questions about whether the 'cost of time and effort' in using 3D food printing would form another barrier for people with dysphagia participating in food design and using food shaping technologies. This supports the findings of Burke-Shyne et al. (2021) that technical issues including cost, time, and food safety requirements would impede adoption of 3D food printing. 3D food printers should be easy to use and require little additional effort over what is already expended by people with dysphagia and their supporters in preparing texture-modified meals. Indeed, such technologies should be designed to reduce the effort and save users time in the preparation and production of texture-modified foods that are appealing, for net benefits to quality of life and mealtime experiences for people with dysphagia.

Limitations and Directions for Further Research

This was a small-scale survey with a non-representative sample including few supporters of people with dysphagia involved in supporting the preparation of texture-modified meals. Including a larger number of supporters of people with dysphagia might have yielded additional insights to the use of a wider range of food shaping techniques reported across groups in this study. There were also few dietitians and occupational therapists included in the research. While this might reflect the emergent nature of 3D food printing research and hence low awareness across health professions involved in dysphagia, their views on food design technologies are important as these views could affect decisions regarding the use of assistive technology for food shaping, nutritional, and occupational outcomes.

Future 3D food printing research should examine how people with dysphagia, supporters of people with dysphagia, and allied health professionals actually use a 3D food printer, to gain a true understanding of the usability of the device and feasibility of 3D food printing in populations with dysphagia. People with dysphagia tasting the 3D printed food and rating their enjoyment would help to identify how participants' expectations and views expressed in this study translate beyond the 3D food printing laboratory (Burke-Shyne et al., 2021; Strother et al., 2020) to naturalistic, in-home settings. Given the reservations expressed about feasibility of use in this study, people with dysphagia, their supporters, and allied health professionals should also be included in research aiming to improve the design and accessibility of 3D food printing.

Conclusion

People with dysphagia, their supporters, and allied health professional use a range of food design and food shaping strategies to improve the visual appeal of texture-modified foods. Supporters of people with dysphagia and allied health professionals were more likely to use food design strategies than people with dysphagia, although reasons for this were not clear. There is a preference for 3D printed food to look like real food and for any new food design technology using texture-modified foods to save time and effort. Any new technology should also be cost-effective. Future research should include usability trials of 3D food printers with people with dysphagia, including the opportunity to engage in the design process of food shaping and taste the printed food for further insights into the adoption of this food shaping technology.

Part C: Establishing an Evidence-Based Framework

In Parts A and B of Section 3, Chapters 7–12, the outcomes of the interviews, focus groups, 3D printed food experiences, and surveys conducted with people with dysphagia, supporters of people with dysphagia, and allied health professionals have been reported. Part C, which includes Chapter 13 of this thesis, draws on the findings of these studies, and also on the reviews of the literature presented in Chapters 2 and 3, in a qualitative meta-synthesis of findings which results in a new evidence-based framework to guide practice. The framework outlines the many impacts of dysphagia on quality of life, barriers and facilitators to quality of life for people with dysphagia, and the feasibility of 3D food printing to improve mealtime experiences for people with dysphagia.

Chapter 13: Meta-Synthesis of Findings

Qualitative Meta-Synthesis of Findings on Dysphagia, Quality of Life, and 3D Food Printing

This thesis contributes new knowledge on the impacts of dysphagia on quality of life, participation, and inclusion; and the feasibility of 3D food printing for improving the mealtime experience. Underpinning the original research studies were two reviews: one scoping review on the impacts of dysphagia on quality of life, and one narrative review examined evidence on the use food design strategies to improve the mealtime experiences of people with dysphagia (Chapters 2 and 3, Smith, Bryant & Hemsley, 2022c; Smith, Bryant, Reddacliff et al., 2022). These informed the design of original, mixed-methods research: (a) in-depth interviews involving people with dysphagia and their supporters examining the impacts of dysphagia on their quality of life (Study 1a); (b) research on an immersive virtual 3D food printing experience with people with dysphagia and their supporters examining the feasibility of 3D food printing (Study 1b); (c) focus group research examining the impacts of dysphagia on quality of life and the feasibility of 3D food printing from the perspective of allied health professionals (Study 2); and (d) survey research examining the impacts of dysphagia on quality of life and the feasibility of 3D food printing from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals (Study 3). By synthesising the findings presented in Chapters 2, 3, 7-12, the aim of this meta-synthesis was to build an evidence-based framework informing clinical practice, explaining (a) the impacts of dysphagia on quality of life, participation, and inclusion, (b) barriers and facilitators to quality of life, (c) the use of food design strategies to improve the mealtime experience, and (d) the feasibility of using 3D food printing to improve the mealtime experience from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals. This was done to assist in translation of the findings into clinical practice across the disciplines of health professionals involved in dysphagia management, including those supporting mealtime environments and food design.

Qualitative Research Synthesis Methodology

Qualitative research synthesis, a type of theory-generated meta-synthesis, was used to combine and analyse the findings of this doctoral research. It was selected to establish a conceptual guiding framework that translates data from the studies involved for further consideration. The qualitative research synthesis approach allowed for the studies within the wider doctoral project to be viewed as a group to reveal more on the concept of dysphagia and quality of life (Major & Savin-Baden, 2010). The purpose, therefore, was not to summarise the findings of existing studies but rather to create a newly synthesised framework that may assist in research translation and shape future dysphagia practice focusing on sustaining and improving quality of life and considering food design as an important part of that practice. By the process of qualitative synthesis across studies, the resulting framework grounded in the data may have greater transferability than the individual qualitative studies alone. Furthermore, the increased diversity and heterogeneity of the participant groups and multiple data sources included in the synthesis improves the applicability of the results (Finfgeld-Connett, 2018).

The rigour of each of the individual studies has been outlined in prior chapters of this thesis and peer-reviewed publications. The design and integration of studies included in this meta-synthesis were all informed by the constructivist grounded theory approach (see Chapter 4). Thus, the rigour of this study is strengthened by the triangulation of the component published studies where sufficient strategies were implemented to maintain credibility, transferability, and dependability (Major & Savin-Baden, 2010).

Data Synthesis Methods

In completing this qualitative synthesis, the researcher followed an inductive, iterative analysis that involved reading and re-reading of the data and reports on the prior studies, identifying concepts, categories, and themes appearing repeatedly across the studies, and confirmed these through regular discussions with the supervisory team (Major & Savin-Baden, 2010). Initially, to enable the findings of the individual studies to be compared and synthesised, the content thematic analysis used in analysing the data of the individual studies was reviewed to extract content themes and categories of meaning from within and across the studies. As in the individual studies, an inductive approach and rigorous data sampling, analysis, and synthesis were implemented to inform development of a guiding framework (Finfgeld-Connett, 2018; Mills et al., 2006). In this process, all studies, whether qualitative (i.e., interviews, focus groups) or descriptive in design (i.e., the survey study), were examined and findings extracted to contribute to the concepts, categories and themes. To provide an overview, the characteristics of each included study are presented in Table 19, which also presents the key findings from each study as reported in the published or submitted articles.

Once the findings were extracted from each component review and original research report, the content themes and component categories of meaning across all of these sources were identified and are presented in Table 20. This interpretive informed writing of the framework guiding practice on assessment and intervention related to dysphagia, quality of life; and the feasibility of 3D food printing (Major & Savin-Baden, 2010). This approach that enabled the meta-synthesis of data also helped to identify any areas where further research was needed (Major & Savin-Baden, 2010). The contribution of each study towards the meta-synthesis of themes across the papers as a group is presented in Table 21. Figure 17 presents a graphic, visual representation of the framework constructed from the meta-synthesis in a model to explain the relationships between the themes and categories of meaning across the studies.

Table 19

Overview of the Included Research Studies and Results

Study	Data collection method	Data analysis method	Participants	Data type	Key findings related to dysphagia, quality of life, and food design
(Smith, Bryant & Hemsley, 2022c)	Systematic literature search	Qualitative analysis of included studies	Participant groups ranged from 1-796 people with dysphagia	Text data from 106 included studies	Dysphagia had negative impacts on quality of life, particularly with more severe dysphagia diagnoses. Dysphagia interventions predominantly had a positive impact on quality of life, however texture-modified diets and enteral tube feeding also had negative impacts. 44 studies only used quantitative assessments to measure quality of life, and overall there was limited in-depth findings on the impact of dysphagia on quality of life.
(Smith, Bryant, Reddacliff et al., 2022)	Systematic literature search	Qualitative narrative analysis of included studies	Inclusion criteria did not specify that included studies needed to have participants	Text data from 35 included studies	The visual appeal, food texture, aroma, temperature, mealtime environment and mealtime assistance all need to be considered during food production, preparation and service to ensure a positive mealtime experience for people with dysphagia. Further research should examine the impact of these factors from the perspective of people with dysphagia.
(Smith et al., in press-b)	Interviews, mealtime observation, collection of reports and mealtime plans	Qualitative thematic and narrative analysis	9 people with dysphagia and 4 of their supporters	Text data: Interview transcripts, DDS scores, text data from mealtime documents	Participants with dysphagia described the cost dysphagia had on their quality of life, it led to: reduced physical safety, reduced choice and control, poor mealtime experiences, and reduced social engagement. Barriers and facilitators to quality of life included: designing their own meals, being adaptable, having ownership of swallowing difficulties, resisting change, and the perceptions/ opinions of others.
(Smith, Bryant, & Hemsley, 2022a)	Immersive 3D food printing experience	Qualitative content thematic analysis and against (Nielsen, 1994) Usability Heuristics	9 people with dysphagia and 4 of their supporters	Text data: Experience transcripts	The four themes identified on the feasibility of 3D food printing were: practicality of 3D food printing, suitability for different people, cost of the printer, and the acceptability of printed designs. Analysis using the usability heuristics also demonstrated usability issues of the printer in a number of areas including error prevention and the real-world match of the printed shapes.

Study	Data collection method	Data analysis method	Participants	Data type	Key findings related to dysphagia, quality of life, and food design
(Smith et al., in press-a)	Online focus groups	Qualitative content thematic analysis	15 allied health professionals (12 speech pathologists, three occupational therapists)	Text data: Focus group transcripts	Health professionals perceived that dysphagia impacted on quality of life by reducing their choice and control, limiting physical safety, limited social engagement, and negative food experiences. Education, knowledge of dysphagia, and the implementation of dysphagia interventions could be a barrier or facilitator to quality of life depending on how they were implemented.
(Smith, Bryant & Hemsley, 2022b)	Online focus groups	Qualitative content thematic analysis	15 allied health professionals (12 speech pathologists, three occupational therapists)	Text data: Focus group transcripts	3D food printing may improve the mealtime experience of people with dysphagia. However, there were barriers that needed to be addressed before this technology would be widely used in the community including the time required to use the printer, and the acceptability of the printed designs.
(Smith, Bryant & Hemsley, 2022d)	Online survey	Descriptive statistics and content thematic analysis	Adults with dysphagia (*n*=30), supporters of people with dysphagia (*n*=4), and health professionals (*n*=18).	Numerical data and text data	For participants with dysphagia texture-modified food had the greatest impact on their physical health, while other factors including choice and control and social engagement were less impacted. Supporters and health professionals agreed that dysphagia had the greatest impact on physical health, however they reported that texture-modified foods had a greater impact on choice and control.
(Smith, Bryant & Hemsley, 2022e)	Online survey	Descriptive statistics and content thematic analysis	Adults with dysphagia (*n*=30), supporters of people with dysphagia (*n*=4), and allied health professionals (*n*=18).	Numerical data and text data	Support people and allied health professionals were more likely to use food shaping strategies (i.e., piping bag, or food moulds) to improve the appearance of texture-modified foods and 10 (27.8%) participants with dysphagia reported using no food shaping techniques at all. A smaller proportion of people with dysphagia (*n*=9, 37.5%) considered 3D food printing could improve the visual appeal and enjoyment of texture-modified food; than did support people and allied health professionals (*n*=15, 75%) who were more optimistic of the impacts.

Table 20

Content Themes and Categories of Meaning in the Component Studies

Component study	Content theme	Categories of meaning
(Smith, Bryant & Hemsley, 2022c) Scoping review examing the impacts of dysphagia and quality of life	Attempts to maintain quality of life	(a) Personal attempts to maintain quality of life (b) Eating regular food
	Biopsychosocial impacts	(a) Fatigue and sleep effects (b) Increased time to eat (c) Negative mental health impacts (d) Reduced desire to eat (e) Associated risk factors to dysphagia
	Emotional response	(a) Fear of choking (b) Frustration (c) Humiliation (d) Incompetency (e) Loss
	Impact on families/carers	(a) Emotional impact on family (b) More support required (c) New role in mealtime support/responsibility
	Social isolation	(a) Avoiding eating in social situations (b) Communication difficulties (c) Loss of independence (d) Reduced participation (e) Saving face around others (f) Treatment by others
	Measurement of impacts	(a) Assessment use and development to measure quality of life (b) Correlation between severity of dysphagia and the impact on quality of life (c) Correlation between time with dysphagia and quality of life (d) Confirmation of the impacts of dysphagia on quality of life
	Dysphagia therapy effects on quality of life	(a) No difference between different therapies on quality of life (b) Therapy had no impact on quality of life (c) Therapy improved quality of life (d) Therapy had a negative impact on quality of life (e) Self-taught methods to improve quality of life (f) Therapy recommendations

Component study	Content theme	Categories of meaning
(Smith, Bryant, Reddacliff et al., 2022) Narrative review on food design strategies used with people with dysphagia	Food preparation	(a) Techniques for creating texture-modified foods (e.g., high pressure food processing) (b) Designing sensory appeal: Taste and aroma (c) Designing nutritious food
	Food formulation	(a) Designing the visual appearance of texture-modified food (e.g., food moulds, 3D food printing) (b) Designing the food temperature
	Mealtime service	(a) Designing the mealtime environment (b) Designing mealtime assistance
(Smith et al., in press-b) Study 1a: Interviews describing the impacts of dysphagia on quality of life	Paying the price	(a) Choice and control (b) Mealtime experiences (c) Social engagement (d) Physical health and safety
	Dysphagia management: barriers and facilitators	(a) Designing my mealtime (b) Self-determination of swallowing difficulties (c) Adaptability at mealtimes, the perceptions of others (d) Sticking to the status quo or resisting change
(Smith, Bryant & Hemsley, 2022a) Study 1b: 3D printed food experience for people with dysphagia	Practicality of 3D food printing	(a) Questionable practicality in the home (b) Aesthetics and design (c) User freedom and control (d) Preventing and handling print errors
	Suitability of 3D food printing	(a)Past experiences impacting on suitability (b) Role of support workers impacting suitability (d) Flexibility and efficiency
	Acceptability of 3D printed food	Lack of Alignment between the Real World and the System
	Cost of 3D food printing	Cost currently out of reach
(Smith et al., in press-a) Study 2: Focus groups with allied health professionals discussing impacts of dysphagia on quality of life	Costs of dysphagia	(a) Limited choice and control (b) Negative or positive impacts on physical health (c) Reduced social engagement (d) Negative food experiences
	Management of dysphagia and mealtimes	(a) Food shaping choices (b) Dysphagia interventions (c) Knowledge and education (d) Opinions of others and a flexible, person-centred approach
(Smith, Bryant & Hemsley, 2022b) Study 2: Focus groups with allied health	Visual appeal	(a) Acceptability of prints (b) Population suitability
	Cost	(a) Population suitability

Component study	Content theme	Categories of meaning
professionals discussing food design and 3D food printing		(b) Initial cost of the device (c) Time to prepare and print food
	Practicalities	(a) Time to prepare and print food (b) Cleaning the 3D food printer (c) Design of the 3D food printer (e.g., domestic sized printer) (d) Heating, consistency, and shape of prints
	Potential for good	(a) Interest in the printer functions (b) Using own food vs. prepared canisters (c) Ingredient preparation suggestion
(Smith, Bryant & Hemsley, 2022d) Study 3: Survey examining impacts of dysphagia on quality of life	Perceived impacts of dysphagia and dysphagia interventions on health and social engagement	(a) Physical safety (b) Choice and control (c) Experiences with food (d) Social engagement
	Impacts of dysphagia or its interventions on mealtime experiences	(a) Impact on enjoyment (b) Impact on inclusion (c) Impact on participation
(Smith, Bryant & Hemsley, 2022e) Study 3: Survey examining food design and 3D food printing	Food design strategies implemented	-
	Strategies to improve the mealtime experience	-
	The feasibility of 3D food printing to improve the mealtime experience	(a) Expectations of benefit across groups (b) Views on 3D food printing (c) What 3D food printing should look like (d) Usability of the 3D food printer

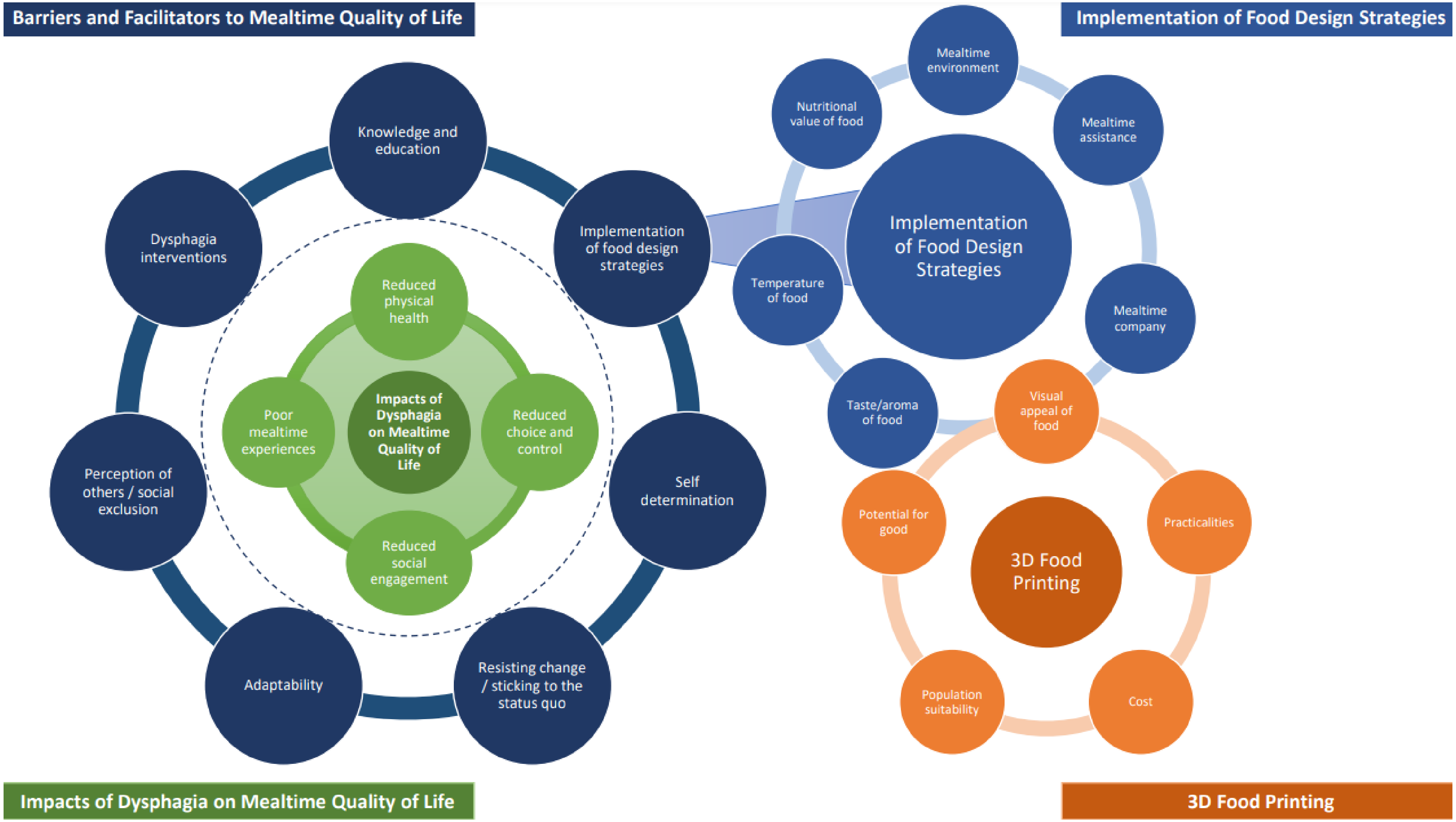
Table 21

Distribution of Meta-Synthesis Content Themes

Themes	(Smith, Bryant & Hemsley, 2022c)	(Smith, Bryant, Reddacliff et al., 2022)	(Smith et al., in press-b)	(Smith, Bryant & Hemsley, 2022a)	(Smith et al., in press-a)	(Smith, Bryant & Hemsley, 2022b)	(Smith, Bryant & Hemsley, 2022d)	(Smith, Bryant & Hemsley, 2022e)
The true cost of dysphagia on quality of life	X		X		X		X	
Reduced physical safety	X		X		X		X	
Reduced choice and control	X		X		X		X	
Reduced social engagement	X		X		X		X	
Poor mealtime experiences	X	X	X		X		X	
Barriers or facilitators to quality of life	X	X	X		X		X	
Knowledge and education					X		X	
Adaptability			X		X		X	
Dysphagia interventions	X				X		X	
Perception of others/ social exclusion	X		X		X		X	
Resisting change/ sticking to the status quo			X					
Self-determination			X				X	
Implementation of food design strategies		X	X	X	X	X		X
Mealtime environment		X	X		X			
Mealtime assistance		X	X		X			X
Mealtime company		X	X		X			
Taste/ aroma of food		X	X		X			X
Temperature of food		X			X			
Nutritional value of food		X	X		X			X
Visual appeal of food		X	X	X		X		X
3D food printing		X		X		X		X
Visual appeal of food				X		X		X
Practicalities				X		X		X
Population suitability				X		X		X
Potential for good				X		X		X

Figure 17

Framework of Mealtime Quality of Life for People with Dysphagia



Complexity in the Impacts of Dysphagia on Quality of Life

There were three main themes identified in the meta-synthesis: **the true cost of dysphagia on quality of life; factors acting as barriers or facilitators to quality of life depending on the context;** and **the use of food design strategies** that may include 3D food printing to improve the mealtime experience for people with dysphagia. Each of these themes encapsulated several categories which are explained in this section and illustrated in Figure 17 above.

The True Cost of Dysphagia on Quality of Life

The *true cost of dysphagia on quality* of life theme had four component categories: (i) reduced physical health, (ii) reduced choice and control, (iii) reduced social engagement, and (iv) poor mealtime experiences. These concepts are shown in the centre of the green circle in Figure 17.

(i) Reduced Physical Health was one of the areas most impacted by dysphagia and its interventions. This impact appeared across the studies: in the review on dysphagia and quality of life (Chapter 2), Study 1a (Chapter 7), Study 2 (Chapters 8 and 11), and Study 3 (Chapters 9 and 12). The impact of physical symptoms and poor health outcomes meant that people with dysphagia had to weigh up the risks of choking or eating a particular food, and the physical symptoms or health risks be the deciding factor on what foods were selected, as conveyed by P89, a person with dysphagia, who wrote, “I choose foods based on ‘potential choke value’” (Chapter 9; Smith, Bryant & Hemsley, 2022d, para. 17). Overall, the physical impacts of dysphagia consistently had the greatest impact on a person’s quality of life and this needs to be considered for dysphagia management.

(ii) Reduced Choice and Control in meal preparation and at mealtimes appeared as a major category in the impacts of dysphagia, appearing across all of the studies and referring to any restrictions relating to mealtimes. This included restrictions on the types of food or fluid the person with dysphagia could have, where they could eat, who they could eat with or the number of mealtime decisions they could make if they required mealtime assistance. This category was observed through the scoping literature review, Study 1a, Study 2, and confirmed in Study 3 (Chapters 2 and 7–9 respectively). The extent of restrictions related to choices being made by other people (e.g., support workers, family members) was highlighted by allied health professionals, who commented that "if one client is on minced moist and everyone else is on puree, everyone is getting puree" (FG4SP2) (Smith et al., in press-a, para. 10). Allied health professionals responding to the survey in Study 3 similarly reported that texture-modified food had a greater impact on the person's choice and control than the swallowing difficulty itself (Smith, Bryant & Hemsley, 2022d). This indicated the extent of limitations that people faced when controlling their own meals while on texture-modified diet.

(iii) Reduced Social Engagement was also described through the literature review on dysphagia and quality of life, and also in Study 1a, Study 2, and Study 3, particularly if the person could not engage in social situations that centred around a meal because the food options were not appropriate or they feared choking. In Study 3, people with dysphagia rated social engagement as being the area second most impacted by dysphagia, after their physical health (Smith, Bryant & Hemsley, 2022d). In a Study 1a interview, P1 reported being treated like a "drama queen" (para. 25) due to his food requests, while P3 described how she found eating out a chore "unless I am with really good friends or family" (Smith et al., in press-b, para. 24).

(iv) Poor Mealtime Experiences (e.g., eating visually unappealing or tasteless texture-modified food) also impacted on the person with dysphagia's overall quality of life.

This was reported across all studies, including the scoping review on dysphagia and quality of life, the review on the impacts of food design, in Study 1a, and Study 2, and was confirmed in Study 3. While some survey participants rated this area as having less impact on quality of life than the person's physical safety or social engagement (Smith, Bryant & Hemsley, 2022d), this was still problematic in some settings (e.g., large residential settings) where texture-modified food was often presented in an unappealing manner. This was highlighted by the allied health professionals working in these environments, with one speech pathologist calling texture-modified food "the dog box" (FG3SP5) (Smith et al., in press-a, para. 15).

Interaction of Impacts. Through the meta-synthesis, it was also determined that each of these four areas that impacted on quality of life *interacted* to further impact and influence a person's quality of life. For example, a choking event that had a direct impact on the person's physical health may also lead to a poor mealtime experience or poor social engagement. This was highlighted in the Study 1a interviews and the Study 3 survey. Survey participant P91 wrote, "I love food for flavour and texture but due to choking I can't eat in public, for the sake of fellow diners and fear of choking" (Smith, Bryant & Hemsley, 2022d, para. 21). These poor mealtime experiences described in Studies 1a and 3 also linked to the negative emotional responses described in the scoping review (e.g., fear, embarrassment).

Barriers and Facilitators Moderated by Contextual Factors

This theme encapsulated seven categories, including a person's level of knowledge and education (e.g., having a good understanding of their diagnosis and management, Study 2), being adaptable (Study 1a, Study 2, Study 3), provision of dysphagia interventions (i.e., texture-modified diets) (scoping review, Study 2), perceptions of others/social exclusion (scoping review, Study 1a, Study 2, Study 3), resisting change/ sticking to the status quo

(Study 1a), self-determination (Study 1a, Study 3), and implementation of food design strategies (narrative review, Study 1a, Study 1b, Study 2, Study 3).

Barriers and facilitators to improved mealtime experiences or quality of life were evident across the two literature reviews and the original research in Study 1a, Study 2, and Study 3. In Figure 17, factors appearing as barriers and/or facilitators to quality of life for people with dysphagia are presented on the left of the figure, around the outside of a broken line, to indicate that these factors influence the person's quality of life in the middle of the circle. The factors in the surrounding circle were considered as barriers and/or facilitators as they could have a positive or negative influence on quality of life depending on the situation and context (e.g., enteral tube feeding could positively or negatively influence a person's quality of life; see Smith, Bryant & Hemsley, (2022c)).

(i) Knowledge and Education of people with dysphagia and their support people about dysphagia and its management were particularly important to maintaining their quality of life. This was highlighted in Study 2 (Chapter 8; Smith et al., in press-a). Through the provision of education, the person with dysphagia was in a position to make good decisions about their diet that would not reduce their physical safety while also allowing them to continue their engagement in food-related community activities. In contrast, if a person with dysphagia had a low level of knowledge about dysphagia and received minimal education, it could mean greater negative impacts on their quality of life if they made decisions that placed their physical health or social engagement at risk (e.g., if the person was unaware of foods that were safe for them to eat at a family gathering) (Smith et al., in press-a).

(ii) Adaptability was identified as a factor within this theme of barriers and facilitators that may potentially impact positively or negatively on the person's quality of life; as demonstrated in Study 1a, Study 2, and Study 3. Adaptability may be a *facilitator* to improved quality of life if a person was highly adaptable to new dietary needs; or it may be a *barrier* if the person had difficulty adapting to changes in their swallowing (Smith et al., in press-b). Making adaptations often meant modifying food textures or avoiding problematic foods. Adaptability was particularly evident in the Study 1a interviews, as a number of participants described adapting their diet to suit their swallowing needs. For example, people with dysphagia making changes to their food and drink order when eating out, so they could continue their engagement in social situations. This was demonstrated by P3, who often ordered a banana milkshake when out rather than a coffee as the milkshake was thicker and met her swallowing needs (Smith et al., in press-b).

(iii) Provision of Dysphagia Interventions was particularly important as a facilitator to quality of life as it provided the person a way to improve their swallowing skills or to compensate for their swallowing difficulties. However, it could be a barrier to quality of life if it influenced their mealtime experience or social engagement. For example, Study 2 participants described seeing texture-modified food being given to people with dysphagia as "standard orangey brown puree in a plastic bowl" which had a negative impact on the person's mealtime experience (Chapter 8; Smith et al., in press-a, para. 15). The provision of dysphagia interventions also interacts with the person's level of social engagement, as it could give the person confidence to eat food in front of others without choking. This reflected the findings of the scoping review in Chapter 2, which reported that texture-modified food and tube feeding could have negative impacts on a person's quality of life and interact with their social engagement (Smith, Bryant & Hemsley, 2022c).

(iv) Perception of Others/Social Exclusion played an important role in the mealtime experiences of people with dysphagia, as positive interactions with others improved their mealtime experience while negative interactions had a negative impact on their mealtime experience. This was highlighted in the Study 3 survey, where P28 described such a situation when a client's friend "adapted the morning teas available to include items that were ordinary foods my client could eat so they could participate in their social circle without drawing attention" (Smith, Bryant & Hemsley, 2022d, para. 25). In contrast, in Study 1a, P1 described how others had a poor perception of and reaction to his swallowing difficulties and said, "as much as it was fun occasionally pulling things out of my nose that I'd swallowed and do my party trick...they thought it was hilarious every time 'cos they were laughing at me as opposed [to] helping" (Smith et al., in press-b, para. 25).

(v) Resistance to Change or 'sticking to the status quo' was a facilitator of quality of life as it meant people could continue to eat desired food. However, it was also a barrier, as resistance to change their diet may lead to increased choking events or reduced physical health. For example, in the interviews of Study 1a (Chapter 7), P5 stated "I can eat steak, I eat chips, I eat pork crackle … sometimes I like to eat like an adult", even though she recognised it increased her likelihood of choking (Smith et al., in press-b, para. 35).

(vi) Self-Determination was evident in participants with dysphagia**,** leading to them rejecting diet recommendations that modified a diet further than necessary. This was highlighted in the Study 1a interviews by P3, who reported that when she was in hospital "the catering staff on supper even refused to give me a biscuit cos of modified diet so I demanded to come off it" as it went against her typical diet that she had when at home (Smith et al., in press-b, para. 31). The interaction of the factors (i.e., P3's safety and her ability to make choices) highlights the importance of allied health professionals considering all influencing factors together, holistically, rather than relying on a limited range of factors to determine decisions in dysphagia management. Other participants drew upon their self-determination, and self-advocacy, when eating out. For example, P9 asked for his food to be cooked softer:

"when I go [out] … I say to the people I want my vegetables well done. And if they don't come well done, I send them back" (Smith et al., in press-b, para. 34).

(vii) Implementation of Food Design Strategies can impact on quality of life and were identified through the meta-synthesis of the narrative review, Study 1a, Study 1b, Study 2, and Study 3. The ability to design their own meal included their involvement in choosing the flavour of the food, the nutritional value of the food, the temperature of the food, the presentation of the food, the location of the meal, the type of support received during the meal, or the people they ate with, as described in the narrative review (Smith, Bryant, Reddacliff et al., 2022). Once again, food design was considered as a barrier to or a facilitator of quality of life, as effective use of a food design strategy may improve the mealtime experience; however if a strategy is not implemented at all or implemented incorrectly, it may act as a barrier to the person's quality of life. Participants of the interviews and focus groups (Study 1a and Study 2) described a variety of different ways a person could be involved in this process. For example, in the interviews it was reported by P6's support person that P6 "sets down little requirements like we should have dinner in the dining room not the kitchen" (Smith et al., in press-b, para. 28). Improving the visual appeal of texture-modified food was one strategy identified in the narrative review, Study 1a, Study 2, and Study 3 that people used to design their mealtime experience, including the use of food moulds and plating different foods on separate plates (Smith et al., in press-a). However, the Study 3 survey identified that although strategies may be recommended by allied health professionals, they may not be consistently used by people with dysphagia in the community if they did not have the tools or time to implement these strategies (Smith, Bryant & Hemsley, 2022e). This was one way in which these strategies could be a barrier to quality of life if the strategies are not implemented.

3D Food Printing as a Food Design Strategy

Findings related to 3D food printing appeared in the “visual appeal of food” category in Figure 17. Across the studies, and where it was examined in this doctoral research more broadly, 3D food printing was viewed as a novel food design strategy to improve the visual appeal of texture-modified food. The narrative review of food design, Study 1b, Study 2, and the Study 3 survey all point to a *potential* benefit of 3D food printing, but a range of limitations impacting its feasibility appeared strongly across studies and the meta-synthesis.

The relatively low feasibility of 3D food printing in improving mealtimes was informed by five key concepts: (i) the visual appeal of the food printed, (ii) the practicalities of using a 3D food printer (e.g., cleaning and time to prepare food), (iii) the cost of the 3D food printer, (iv) the population suitability, and (v) a potential for good (Smith, Bryant & Hemsley, 2022a, 2022b). The opinions on the feasibility of using 3D food printing for texture-modified foods varied across participant groups, however there was a general consensus that the perceived impracticalities of using the machine and the cost of the 3D food printer could outweigh the benefits (see Study 1b, Study 2, and Study 3). Analysis of the included studies demonstrated that future 3D food printing research and development should include people with dysphagia, supporters of people with dysphagia, and allied health professionals through a person-centred design approach to ensure 3D food printing is made more suitable and feasible for people with dysphagia.

(i) Visual Appeal of the Food printed using the 3D food printer was also considered. In the online survey, 30% of participants with dysphagia viewed that 3D food printing would improve the appearance and enjoyment of texture-modified food. In comparison, 68.2% of supporters of people with dysphagia and allied health professionals considered that 3D food printing would be beneficial (Smith, Bryant & Hemsley, 2022e). Triangulation of the findings of each study on 3D food printing confirmed that the *look* or *acceptability* of the printed food was particularly important. Specifically, there was consensus across the studies that the food needed to be similar in appearance to the original food product, with abstract or non-food designs (e.g., flowers) seen as less desirable.

(ii) Practicalities of the 3D food printer were considered regarding the amount of work required to prepare the food, print the food, and clean the 3D food printer cartridges for re-use. Participants across the studies were more interested in time-saving solutions to improve food design, and did not perceive the 3D food printer as delivering on this point (Smith, Bryant & Hemsley, 2022b, 2022e).

(iii) Cost of the 3D food printer – US$4000 at the time of the research – was also considered as being too high (Smith, Bryant & Hemsley, 2022a, 2022b, 2022e). In Study 1b, the 3D printed food experiences, when the participants raised the issue of cost; P7’s wife said, “I would have to pay that to get a new kitchen” (Smith, Bryant & Hemsley, 2022a, p. 28).

(iv) Population Suitability of the 3D food printer was seen as an influencing factor impacting feasibility. For example, Study 1 participants considered that people with reduced hand function may have more difficulty using the device, and P4 stated “I couldn’t, I would get it everywhere” (Smith, Bryant & Hemsley, 2022a, para. 25). Some participants considered 3D food printing may be beneficial for children with swallowing difficulties to print a design of their choice to increase their interest in food (Smith, Bryant & Hemsley, 2022a).

(v) A Potential for Good in 3D food printing appeared repeatedly across the studies, including Study 2, in which participants suggested 3D food printing might, with further improvements in design, enable the user to use their own or pre-prepared foods and could potentially provide a new method of preparing ingredients. It was also suggested that 3D printed food may be beneficial for some people's individualised nutritional and physical needs (Smith, Bryant & Hemsley, 2022b). This concept was summarised by FG4SP7, who stated "yes there is barriers at the moment … but for that one person it could actually mean [making a difference to] their quality of life" (Smith, Bryant & Hemsley, 2022b, p. 250).

Clinical Implications

Dysphagia has a variety of impacts on quality of life that need to be considered by clinicians as part of dysphagia assessment and interventions. This research provides an in-depth description of areas of quality of life impacted by dysphagia and the barriers and facilitators that may be utilised to improve the person's quality of life. Figure 17 presents the *Framework of Mealtime Quality of Life for People with Dysphagia* and Box 1 (see overleaf) provides some guidance to clinicans in implementing the framework in their clinical practice.

Box 1. Implementing the Framework of Mealtime Quality of Life for People with Dysphagia

Clinicians may use this list to help guide their assessment and management of dysphagia, considering the findings of research on mealtime quality of life in adults.

A. IMPACTS OF DYSPHAGIA ON MEALTIME QUALITY OF LIFE

- Reduced physical health (e.g., ask the person about their general health, refer for general health checks)
- Reduced choice and control (e.g., attend to the variety of options and ask about choice and control)
- Reduced social engagement (e.g., find out about mealtimes and social connections and discuss)
- Poor mealtime experiences (e.g., identify problematic mealtime assistance techniques and address these)

B. BARRIERS AND FACILITATORS TO MEALTIME QUALITY OF LIFE

1. Knowledge and Education

- Provide the client with education to increase knowledge about swallowing and food textures

2. Implementation of Food Design Strategies

- Nutritional Value of Food (e.g., be aware of the impact of modifying food textures on nutrition, referral to a dietitian, information on increasing nutritional value of texture-modified foods)
- Mealtime Environment (e.g., where the mealtime is eaten, the ambience and surroundings)
- Mealtime Assistance (e.g., the assistance provided to set up the meal or to eat or drink; assistive technologies for eating or drinking – cups/plates/spoons etc)
- Mealtime Company (e.g., who is present during the meal)
- Visual Appeal of Food
    - Practicalities of shaping food (e.g., spoons, piping bag, food moulds, 3D food printing)
    - Cost (e.g., of preparing the foods to the correct texture, the equipment and time cost)
    - Population Suitability (e.g., of the food shaping techniques and engagement in the food shaping method themselves, choosing the shape, choosing the technique)
    - Potential for Good (e.g., considering new technologies as they arrive to improve the food shaping)
- Taste/Aroma of Food (e.g., preferences in taste and any additions to food for flavour)
- Temperature of Food (e.g., hot food being served hot and cold food served cold)

3. Self-Determination

- Including the client in decisions about texture-modified foods, the mealtime environment, and any aspect of the food design, to support choice and control
- Enabling the client to direct their own pathway in the process of any transitions in the management of dysphagia, that consider quality of life impacts

4. Resisting Change / Sticking to the Status Quo

- Being aware that the client may not wish to make changes and the impacts of change on quality of life to be considered in decisions affecting mealtimes

5. Adaptability

- Support the person’s ability to adapt and change to new mealtime situations arising due to dysphagia and the need for texture-modified foods

6. Perception of Others / Social Exclusion

- Support the client to manage responses from other people (e.g., ableism, disablism) in relation to their dysphagia and to any food texture modifications

7. Dysphagia Interventions

- Offer appropriate dysphagia interventions to the client that help to address their dysphagia and management as indicated

Figure 17 highlights that the “implementation of food design strategies” is only one of several barriers or facilitators that need to be considered in dysphagia management. Consequently, clinicians need to engage in open communication with their clients to determine what factors are currently acting as barriers to their quality of life and how these can be improved to instead be facilitators. Clinicians should also consider whether any other facilitators could be introduced to improve the person’s quality of life. This should be done through regular consultation with the person with dysphagia and their supporters, as research shows that people with dysphagia perceive food differently to people without dysphagia so understanding their views is vital (Ettinger et al., 2014; Smith, Bryant & Hemsley, 2022d).

In reviewing literature on texture-modified food and its impact on quality of life for people with dysphagia, Smith, Bryant, Reddacliff et al. (2022) demonstrated that the visual appeal of food is only one component of food design that impacts on the mealtime experience for people with dysphagia (see Figure 17). As a result, strategies such as 3D food printing, which may improve the visual appeal of texture-modified food, could be used as part of a holistic approach that considers other influencing factors on the mealtime experience including the mealtime environment and the flavour of food provided. The feasibility issues of 3D food printing raised in this research also need to be considered in relation to a person’s functional capacity in mealtime-related activities which could impact on their engagement in the 3D food printing procedures.

Future research on the framework developed as a result of this meta-synthesis should test the validity and strength of the model. This may include examining the components of the model against a larger sample of people with dysphagia, supporters of people with dysphagia, and allied health professionals. This could be paired with an expert consensus panel, including people with dysphagia, to determine how the model could be implemented into practice and to create a comprehensive qualitative mealtime quality of life and food design assessment for people with dysphagia. Such an instrument would expand upon currently available instruments designed to measure mealtime quality of life (Chapter 2; Smith, Bryant & Hemsley, 2022c).

Conclusion

The findings of this meta-synthesis show that dysphagia can impact negatively on quality of life in multiple ways and that several factors can form barriers and/or facilitators that can influence a person with dysphagia's quality of life. These factors need to be considered in the provision of dysphagia interventions to maintain the person's social, emotional, and physical health. This research synthesis yielded a framework that could influence services provided when working with people with dysphagia, moving beyond the individual's health condition and dysphagia interventions to the broader environment and contextual factors that could make a difference to the person's quality of life. This framework includes the consideration of food design strategies that may improve the mealtime experience for people with dysphagia, including 3D food printing. There are a number of feasibility issues in the operation of 3D food printing that need to be addressed before it can be widely taken up in the community. However, the technology is considered to have the potential to be a tool for good for people with dysphagia. Further research should examine how the feasibility issues raised in this research about 3D food printing can be addressed to create a 3D food printer that meets the needs of people with dysphagia.

Section Four: Discussion

The evidence-based framework established in Section Three of this thesis provided a direction to guide future developments in dysphagia assessment and intervention to ensure quality of life and mealtime engagement are considered when making mealtime management decisions with people with dysphagia and their supporters. Section Four discusses the overall findings of the research, the clinical implications, and areas for further research in more detail.

Chapter 14: Discussion and Conclusions

In this research a constructivist grounded theory approach (Charmaz, 2017), using multiple methods, provided original research evidence to gain further understanding of the impacts of dysphagia on quality of life, participation, and inclusion of people with dysphagia. In summary, the results of this research demonstrate that:

(a) Dysphagia and its interventions have a number of negative impacts on the mealtime quality of life, participation, and inclusion of people with dysphagia;

(b) Barriers and facilitators can shape the mealtime experience for people with dysphagia;

(c) Multiple food design strategies can be implemented to improve the mealtime experience for people with dysphagia (e.g., improving the visual appeal or the flavour of a texture-modified meal); and

(d) 3D food printing may be beneficial for people with dysphagia who require a texture-modified diet but only if the feasibility issues identified in this research are addressed.

The following section discusses each of the aims and the outcomes of this research in the light of prior research and also includes consideration of the clinical implications of each of the findings.

1. The Impacts of Dysphagia and its Interventions on Mealtime Quality of Life, Participation, and Inclusion for People with Dysphagia.

The scoping review (Chapter 2; Smith, Bryant & Hemsley, 2022c) demonstrated there is a large amount of evidence on the negative impacts of dysphagia on quality of life; however, there were very few in-depth qualitative studies that provided a detailed description of the impacts from the perspective of people with dysphagia. Furthermore, there was even less research examining the impacts of dysphagia on people with lifelong dysphagia. It was clear that further in-depth qualitative evidence was needed in this area. In this study, interviews with people with dysphagia and supporters of people with dysphagia, focus groups with allied health professionals, and online surveys with these three participant groups provide further insights into concepts connected to quality of life for people with dysphagia associated with a range of health conditions. In particular, the results chapters including the evidence-based meta-synthesis (Chapter 13), add to prior literature by specifying, in greater detail, four main impacts of dysphagia on quality of life: reduced physical health, reduced choice and control, reduced social engagement, and poor mealtime experiences. This research adds to the knowledge on mealtime quality of life for people with dysphagia, identifying across multiple studies that: (a) retaining choice and control over the shape of food within a safe food texture contributes to mealtime quality of life; (b) participation and inclusion in mealtime related activities including shopping, meal preparation, and the setting up of eating envirnments, are important elements of mealtime experiences; and (c) the balancing of mealtime safety with enjoyment of food textures requires ongoing consideration and engagement with health professionals with experience in dysphagia and nutrition.

As previously reported, interventions provided by speech pathologists and other health professionals involved in dysphagia management need to consider the person’s overall quality of life and psychosocial wellbeing (Howells et al., 2019b). Howells et al. (2019b) found that only 47.9% of speech pathologists participating in their research, which involved an online survey, regularly monitored for signs of anxiety and depression in their clients; and only 43.8% recommended their clients receive social support or attend social groups as part of their dysphagia management plan. The insights gained from the original research in this thesis highlight the importance of people with dysphagia discussing their mealtime experiences with allied health professionals, so that these experiences can inform their ongoing dysphagia management and improve their quality of life. These discussions should become a core component of dysphagia management, particularly as past research has shown that texture-modified foods are often unappealing and, as a result, people may eat less, which can impact on their quality of life and the mealtime experience (Seshadri et al., 2018; Shune & Linville, 2019). Modifications to current dysphagia practice clinical guidelines may assist in this implementation. The findings of this research also extend prior research describing the physical, social, and emotional changes associated with dysphagia after a stroke (Moloney & Walshe, 2018), by including participants with dysphagia related to a wide range of acquired and lifelong conditions and exploring the impacts of food shaping as mitigating the negative impacts of dysphagia or its interventions.

2. Barriers and Facilitators to Improved Mealtime Quality of Life for People with Dysphagia. The findings of this research extend the model proposed by Ferrans et al. (2005), who described environmental factors that may impact on a person's health-related quality of life. People with dysphagia, supporters of people with dysphagia, and allied health professionals in this study identified and described barriers and facilitators to quality of life, including: knowledge and education, being adaptable, dysphagia interventions, the perceptions of the people around them, designing mealtimes, self-determination, and resisting change/sticking to the status quo. These factors played a deciding role in the person's overall mealtime enjoyment and engagement. As also highlighted by Smith, Bryant and Hemsley (2022d), the differences in perspectives on the barriers and facilitators to quality of life and food shaping techniques across the participants groups highlights the importance of including the person with dysphagia in any decisions regarding dysphagia management and food design (Smith, Bryant, Reddacliff et al., 2022).

The present study provides greater insights into the lived experiences of people with dysphagia and supporters of people with dysphagia on the impacts of dysphagia on quality of life (Smith, Bryant & Hemsley, 2022d; Smith et al., in press-b). These insights provide further evidence from the perspective of people with dysphagia for the inclusion of social participation and wellbeing in dysphagia management, as recommended by Howells et al., (2019b). Their perspectives of the impacts of dysphagia and its interventions should be considered by health professionals who work with people with dysphagia to provide support that meets their social and psychological needs as well as their physical health. In particular, the framework built and presented in Chapter 13 could add to prior published tools (e.g., SWAL-QOL, McHorney et al. (2002); EAT-10, Belafsky, et al. (2008)) and be used as a tool to guide assessment questions and guide exploration in management recommendations related to quality of life and the use of food design strategies to improve mealtime experiences.

3. The Impact of the Specific Elements of Food Design – Food Structure and Visual Appeal – on the Mealtime Experiences of People with Dysphagia.

It is widely recognised that texture-modified diets are one of the main interventions used for people with dysphagia (Groher & Crary, 2016); however, the visual appeal of the food can often be problematic and lead to non-compliance with dietary recommendations (Colodny, 2005; Robbins et al., 2002). The present study (see Chapter 3) explains how various elements of the mealtime experience can be modified through the use of food design strategies to increase the visual appeal of the food, the taste of the food, or the nutritional value of the food (Smith, Bryant, Reddacliff et al., 2022). Although allied health professionals recommend a variety of food design strategies, these are not necessarily or commonly being used by people with dysphagia in the community (Chapter 12; Smith, Bryant & Hemsley, 2022e). This lack of implementation of recommended strategies in the community could be explained by considering the findings of Howells et al., (2019a), who suggested the reduced access to resources (e.g., modified mealtime equipment) in the community could be a barrier to implementation of dysphagia-management strategies.

There are a number of elements of food design that impact on the mealtime experiences of people with dysphagia (Smith, Bryant, Reddacliff et al., 2022). Food design as a field considers more than just the shape of food, it is also a field which recognises the importance of the mealtime environment (Zampollo, 2016). This study, therefore, broadens the approach in dysphagia management to consider more than just 'IDDSI food texture' when it comes to making mealtime or food recommendations for a person with dysphagia. The findings indicate that health professionals might also need to include discussion with the person with dysphagia, ideas, strategies, and recommendations about food presentation and food serving, lest the provision of texture-modified foods impact negatively on quality of life.

Aspects of food design elaborated upon in this study include the visual appeal of food, the taste/aroma of food, temperature of food, nutritional value of food, the mealtime environment, mealtime assistance required, and social engagement or the company of others at mealtimes. Strategies discussed to improve the visual appeal of food included the use of food moulds, piping bags, and 3D food printing. Prior literature examining food design strategies (e.g., Burke-Shyne et al. (2021)) has rarely included people with dysphagia, supporters of people with dysphagia, or allied health professionals involved in dysphagia management. Through the interviews, focus groups, and survey in this study, it was determined that people used a range of food design strategies to improve their mealtime experience including food moulds, the use of decorative cutlery and crockery, adding flavour to food, and using foods of different colours (e.g., purple carrots) for variety and interest in meals. However, the findings also suggest that food design strategies are implemented more frequently by supporters of people with dysphagia or allied health professionals, although it was not clear why this might be the case. The variable use of food design strategies could indicate that either people with dysphagia do not see the same need for the food shaping techniques; or that they are unable to implement the food shaping techniques independently.

4. The Feasibility of 3D Food Printing to Improve the Mealtime Quality of Life of People with Dysphagia.

Prior research has indicated that 3D food printing holds potential for improving the mealtime quality of life of people with dysphagia (e.g., Dick et al., 2020; Hemsley, Palmer et al., 2019). However, the findings of this study do not necessarily support this contention, given that participant groups raised several feasibility problems on the basis of viewing the use of the 3D printer. Nonetheless, research provided greater insights into the concepts raised in previous research (Burke-Shyne et al., 2021; Dick et al., 2020); which did not examine the feasibility or the acceptability of 3D printed food from the perspective of people with dysphagia, supporters of people with dysphagia, or allied health professionals (Smith, Bryant, Reddacliff et al., 2022). This present study has found that people with dysphagia, supporters of people with dysphagia, and allied health professionals alike consider that while 3D food printing *could* be used as a tool for good to improve the mealtime experience for people with dysphagia, several feasibility issues would need to be addressed for 3D food printing to be used widely in the community, including: practicality, cost, acceptability of the food, and its appropriateness for different populations with dysphagia. These feasibility issues build on research by Burke-Shyne et al. (2021), who examined the use of 3D food printing for people with dysphagia with experts in nutrition and 3D food printing, not people with dysphagia. As the end users of the technology, people with dysphagia could provide insights shaped by their past experiences making visually appealing texture-modified food.

Regardless, and potentially reflecting an inherent optimism towards inevitable advancements in food design technology (Smith, Bryant & Hemsley, 2022b), there was also a general consensus that there was potential for positive outcomes with 3D food printing if these feasibility issues were overcome. This research found that allied health professionals and supporters of people with dysphagia had a more positive or optimistic view of 3D food printing than people with dysphagia. This indicates that engagement with these groups will also be important if the science of 3D food printing and food design more generally is to advance with the needs of these potential user groups in mind.

Clinical Implications

Based on the findings of this research, this section presents three main recommendations for clinicians working in the field of dysphagia and its management are presented. These recommendations promote a holistic approach, considering the wide-ranging impacts of dysphagia on quality of life, the identified barriers and facilitators to quality of life, and the potential use of 3D food printing as a form of food shaping. The recommendations are underpinned by the evidence presented in this thesis that shows people with dysphagia and supporters of people with dysphagia need to be actively involved in all decisions regarding their swallowing and any dietary changes. In addition, the recommendations are created for implementation across the disciplines involved in dysphagia management to ensure the person’s needs are met.

Recommendation 1. A Comprehensive Assessment the Includes Quality of Life and Food Design

The research demonstrated that there are a number of dysphagia-related factors that can act as barriers or facilitators to quality of life. These barriers include the emotional, social, or biopsychosocial impacts associated with swallowing difficulties (Smith, Bryant & Hemsley, 2022c). A comprehensive assessment of the person's mealtime with their typical food and in their typical environment is needed (Smith, Bryant & Hemsley, 2022d; Smith et al., in press-a; in press-b). This should include an in-depth conversation with the person with dysphagia and their supporter to determine the barriers that are leading to a poor mealtime experience. This would also help identify or enhance facilitators in the person's environment. The health professional should consider all components of the Health Related Quality of Life model in this assessment (Ferrans et al., 2005).

Comprehensive assessments should also include trials of strategies to improve the mealtime experience – for example, having the person trial different mealtime environments. This will ensure that strategies provided meet the person's individual needs. Assessments should also be multidisciplinary to support all areas of a positive mealtime experience An occupational therapist may be involved to improve the person's positioning at mealtimes or to provide any adaptive tools such as modified cutlery. A dietitian may also be consulted to ensure the meal meets the person's nutritional needs (Smith et al., in press-a). It is important these areas are considered as they were identified as elements of food design that can influence the mealtime experience (Smith, Bryant, Reddacliff et al., 2022).

Recommendation 2. Inclusive Practice in Dysphagia Management

The findings of this research have reinforced previous research findings that people with dysphagia rated the visual appeal of food differently to people without dysphagia

(Ettinger et al., 2014; Smith, Bryant & Hemsley, 2022e). If a person with dysphagia or their support person are not included in discussion about diet modifications, there may be a higher chance of dietary recommendations not being followed (Colodny, 2005). This would put not only their quality of life at risk but also their physical health. Furthermore, the inclusion of people with dysphagia and their support person in discussions about mealtimes may lead to a greater understanding of the external factors driving their mealtime enjoyment that should be retained and protected as much as possible in any new dysphagia management plans. This also follows a Health Related Quality of Life model as it considers all influencing factors around the person (Ferrans et al., 2005) and allows for highly personalised intervention to be developed.

Health professionals need to provide the person with dysphagia and their support person adequate education of their swallowing difficulties and the recommendations being made for them to truly be part of the decision-making process. This will ensure the person is not only making a decision based on their personal preferences, but they are also making a well-educated decision based on their knowledge of the situation. This education also needs to be provided at a level the person can understand; for example, if the person with dysphagia also has a co-occurring cognitive impairment or cognitive-communication disability, education should be provided in a form that the person can understand and refer back to on a daily basis.

Recommendation 3. Considering Food Shaping Techniques and Food Design

This research demonstrated that various elements of food design influence the mealtime experience for people with dysphagia (Smith, Bryant, Reddacliff et al., 2022). These factors encompass the visual appeal of food along with the temperature of food, nutritional value of food, taste of food, mealtime environment, and mealtime support provided. It is particularly important that all areas of food design are considered, as the survey results of Study 3 demonstrated that people with dysphagia focused on improving a variety of aspects of their meal (e.g., some chose to improve the flavour of their food while others focused on using assistive technologies) (Smith, Bryant & Hemsley, 2022e). Allied health professionals should consider using multiple food design strategies with each person with dysphagia as this may lead to greater improvements in quality of life than the use of single strategies alone (Smith, Bryant, Reddacliff et al., 2022). Health professionals may benefit from further training to support an increased use of food design strategies (Smith et al., in press-a; Smith, Bryant & Hemsley, 2022b). Again, the person with dysphagia needs to be included in all decisions to implement different food design strategies to improve the mealtime experience due to the differences in opinions in people with and without dysphagia on texture-modified food (Ettinger et al., 2014; Smith, Bryant & Hemsley, 2022d). Any decision should also include input from a multidisciplinary team to ensure the person's functional skills and physical needs are considered (Smith, Bryant & Hemsley, 2022b).

Should the use of new technologies such as 3D food printing also be considered, the findings of this research yielding several usability and feasibility problems that should be taken into account. Further development of 3D food printing in collaboration with people with dysphagia and supporters of people with dysphagia is needed. Before investing funds in 3D food printing for a person with dysphagia, the person's physical ability, financial situation, demands on time, and their perceptions of the appearance of foods need to be considered (Smith, Bryant & Hemsley, 2022a).

Research Significance and Impact

This study provides in-depth insights into the impacts of dysphagia on quality of life from the perspective of people with dysphagia, supporters of people with dysphagia, and allied health professionals. These insights will help guide health professionals to consider the person holistically when providing dysphagia intervention. The study also provides insights into the feasibility of 3D food printing from the perspectives of people with dysphagia, supporters of people with dysphagia, and allied health professionals that can be applied to improve future 3D food printing research efforts. By identifying feasibility barriers, the findings on 3D food printing as a novel food design strategy could be used to inform developments in technologies designed to improve the visual appeal of texture-modified foods.

Social media engagement throughout this project improved community awareness of the research and allowed the researcher to engage with the global dysphagia community, particularly during COVID-19 when research events and conferences were cancelled. The researcher was contacted on Twitter to discuss 3D food printing with a speech pathology researcher in Austria and by the *Royal College of Speech and Language Therapists Bulletin* editor to provide updates on research publications from the project. Through social media, the researcher also contacted members of the Myositis Association of Australia, and presented the research results at the Association's national meeting in February 2022. Thirty-four people attended the meeting and another 10 association members who could not attend requested access to the recording. The study's research blog also assisted the researcher to share important information and achievements during the project. As of September 2022, the blog has received over 141 views since it was created, with readers from Australia, the United States of America, Singapore, Belgium, Turkey, Canada, the United Kingdom, Ghana, Austria, New Zealand, Ecuador, and Ireland.

At the time of submission of the thesis for examination, there are five published articles included in the thesis, communicating with the scientific community and with the public through open access publication. As of September 2022, the scoping review on the impacts of dysphagia on quality of life (Smith, Bryant & Hemsley, 2022c) (Chapter 2) has been cited four times and downloaded 1,204 times while the narrative review examining the impacts of food design (Chapter 3) (Smith, Bryant, Reddacliff et al., 2022) has been cited three times. Furthermore Smith, Bryant and Hemsley (2022b) (Chapter 11), which provided the results on the focus group discussions with allied health professionals, has been downloaded 1,192 times (as of September 2022). The rate of downloads for these studies shows there is a high amount of research interest in the topic in a relatively short period of time. The fourth and fifth studies (Smith et al., in press-a, in press-b) (Chapters 7 and 8) are in press.

Limitations and Directions for Future Research

The sample size in this study allowed for collection of data for an in-depth examination of the issue of mealtime quality of life and the feasibility of 3D food printing as a means to improve the enjoyment of meals. However, the small number of participants in each of the qualitative studies means that caution should be applied in interpreting the results, which cannot be generalised to all people with dysphagia associated with a wide range of health conditions or their supporters or allied health professionals. There are also limitations in relation to the *type* of participant included in the allied health professional participant groups, as there were no dietitians in the focus groups and only one occupational therapist completed the survey. These limitations also mean that this research could not close the gaps in the research identified in the scoping review, including the recruitment of people with lifelong disability (Smith, Bryant & Hemsley, 2022c). This and other gaps in the research relating to investigation of the same issues in children with dysphagia or using longitudinal methods remain areas for future research.

This study was greatly impacted by COVID-19 due to University restrictions on face-to-face research during the ‘hard’ lockdowns in Sydney and ongoing social distancing and travel restrictions throughout March 2020- Jan 2022. Although modifications were made to the ethics application for data collection to continue online during the pandemic and associated lockdowns, online data collection did not allow for people with dysphagia and supporters of people with dysphagia to engage fully in the 3D food printing experience or to taste 3D printed food. The University’s restriction on face-to-face data collection also meant that people who did not have access to a computer and reliable internet connection could not participate in the study using the ethically approved online methods. This affected the recruitment efforts and sample size as well as the extent to which the results related to people who lacked proficiency or access to computer technologies. This is particularly important for a concept like 3D food printing, where use of the device relies on knowledge and access to computer and smart devices.

There is a need for further research on the impacts of dysphagia on quality of life and the development of more effective 3D food printing to improve mealtime experiences. Future research should include a larger sample of people with dysphagia associated with a range of health conditions, supporters of people with dysphagia, and allied health professionals to provide further insights from dietitians and occupational therapists. The inclusion of a wider range of allied health professionals would provide greater insights into the nutritional and participation impacts of involving people with dysphagia in novel food shaping technologies such as 3D food printing.

Future research could also include controlled trials examining participants’ perceptions of comparing 3D printed foods with other food shaping techniques (e.g., food moulds or piping bag methods of food shaping) for acceptability, visual appeal, and rating along a range of dimensions. Such comparative studies could help organisations seeking to implement changes to their food design methods and expanding menus to include options relating to food shapes that appeal to different populations with dysphagia.

Further research on 3D food printing should allow people with dysphagia, supporters of people with dysphagia, and allied health professionals to engage with the 3D food printer in person and to taste the food. This would provide greater knowledge on the usability of the device from the consumer perspective. People with dysphagia, supporters of people with dysphagia, and allied health professionals should also engage in designing the 3D printed foods to ensure the foods meet their needs. 3D food printing research could also consider the technology against an implementation science framework, such as the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) Framework, to more comprehensively consider the feasibility of 3D food printing for people with dysphagia (Greenhalgh et al., 2017). The NASSS framework considers the value proposition of a device in regard to the health condition, the technology being used, and the adopters (e.g., staff or people with dysphagia) before considering if it could be implemented within the wider political and professional environment (Greenhalgh et al., 2017). The technology then needs to be examined for its scope of adaptation over time. In particular, the current research has demonstrated that 3D food printing technology was often seen as a novel or niche food shaping method that was experimental in nature, rather than a device that could be used on a daily basis or at a mass food production level. Further research is needed to determine whether the technology could be implemented at an industrial level through a “scale-up” process (Greenhalgh et al., 2017, p. 1).

Future research should also explore co-design of interventions to *improve* quality of life for people with dysphagia that take into account the factors identified in this study. The concepts mapped in the meta-synthesis of results chapters could be used in quantitative studies designed to determine the relative weight of each of the concepts in influencing a greater or lesser quality of life. It is also clear that 3D food printing should move into a co-design phase, given the several feasibility issues outlined in this study. Research examining the content of dysphagia management reports and strategies for quality of life or food design targets could help to extend upon this research to examine how clinicians are currently considering and addressing these matters in their dysphagia management services.

Conclusion

This doctoral research has provided an in-depth understanding of the impacts of dysphagia on quality of life, participation, and inclusion for people with dysphagia. It also examined the feasibility of 3D food printing to improve the mealtime experience for people with dysphagia. Eating and drinking are an integral component of socialising, and swallowing difficulties can significantly impact on a person’s ability to engage in social experiences. This can lead to feelings of loss and isolation for the person with dysphagia and their supporters (Smith, Bryant & Hemsley, 2022c). There are also a number of barriers and facilitators that can impact on the mealtime experience for people with dysphagia, some of which are within their control and others not. For example, the person can control their adaptability to their swallowing difficulties, however they cannot control the perceptions of others.

Health professionals working with people with dysphagia need to complete a comprehensive dysphagia assessment that looks at the impacts of dysphagia on quality of life, not just the person’s physical health. This should include the impacts of the swallowing difficulties on the person’s choice and control, level of social engagement, and their overall mealtime experiences. Health professionals should also consider any barriers and facilitators that may impact on the person’s quality of life, including the person’s level of knowledge about their swallowing difficulties, their adaptability, their self-determination, and the implementation of any dysphagia interventions. Any mealtime recommendations or interventions provided should take these factors into consideration, as they may in turn have positive impacts on the person's physical health.

Food design strategies should also be considered by health professionals in consultation with the person with dysphagia and supporters of people with dysphagia when making decisions about texture modification. Strategies implemented should be chosen based not only on the person's physical needs (e.g., the provision of adaptive cutlery, or foods rich in specific nutrients) but also on the person's preferences and values, by reflecting on the specific flavours the person likes or the way they like their food presented. To ensure all these factors are considered, mealtime assessments should be multidisciplinary and include a speech pathologist, dietitian, and an occupational therapist.

This research demonstrated that 3D food printing could be one strategy used to improve the visual appeal of food. 3D food printing was deemed a *potential* tool for good by people with dysphagia, supporters of people with dysphagia, and allied health professionals. However, there were several usability issues that need to be considered before 3D food printing could be widely used by people with dysphagia. Some of these issues may be overcome by including people with dysphagia, supporters of people with dysphagia, and allied health professionals in the design process. Their input in the design process could lead to improved visual appeal of the print designs or the inclusion of features to make it more practical to use in the home environment.

With regards to the cost of the 3D food printer, findings suggested that the price (US$4000 at the time of data collection) was too high for the average person with dysphagia to consider purchasing. This cost, along with the perceived low practicality of the device, meant the device was perceived more as a novelty or boutique product rather than something that could be used on a daily basis. Interview and focus group participants commented that the price of the device may come down as the technology becomes more widely available following the trends of other electronic devices (Smith, Bryant & Hemsley, 2022a, 2022b). However, this appears to remain a theoretical proposition for the Foodini 3D food printer, with the price increasing to US$6,000 to purchase outright (as of September 2022) (Natural Machines, 2022b). For people in Australia considering a Foodini 3D food printer, it currently costs AU$14,390 from the Australian supplier (3D APAC, 2021), potentially placing the technology further out of reach. As a result, more cost-effective devices may need to be designed and developed for the domestic market.

Dysphagia has substantial impacts on quality of life for people with dysphagia and as such their quality of life must be considered in both dysphagia assessment and intervention to improve their overall physical, social, and psychological outcomes. In particular, barriers and facilitators present in the person's environment need to be considered to ensure that barriers can be removed and facilitators enhanced. Enabling the person to engage in designing their own mealtimes may be particularly important. The visual appeal of the food may be an important consideration for the person with dysphagia and supporters of people with dysphagia. While innovative food shaping techniques such as 3D food printing could potentially improve the visual appeal of texture-modified food, the feasibility issues identified in this study would need to be addressed in order for this potential to be realised.

Section Five: References

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Section Six: Appendices

Appendix A: Definitions

3D Food Printing

An additive production process where layers of food are printed to create a shape (Hemsley, Palmer et al., 2019). The Foodini 3D Food Printer (Natural Machines, 2022a) is used for this research project. For the purpose of this project, 3D food printing is trialled as a strategy to improve the mealtime experience for people with dysphagia.

Dysphagia

Swallowing difficulties that may affect the function of the mouth, pharynx, oesophagus, or the gastroesophageal junction (American Speech-Language-Hearing Association, 2019). Swallowing difficulties can be classified from mild, where the person has some difficulties swallowing, to profound where difficulties are managed through non-oral feeding for either some or all of a person's diet (Sheppard et al., 2014).

Food Design

Food design is a broad interdisciplinary field that includes "design with food, design for food, food space design or interior design for food, food product design, design about food, and finally, eating design" (Zampollo, 2016, p.4). In regards to texture-modified food and people with dysphagia, this often relates to design with food where decisions are made about the temperature, texture, shape, colour, and taste of the food.

Inclusion

For the purpose of this research inclusion refers to the person's ability to take part in the mealtime experience. For example, by attending a social gathering involving a meal.

Participation

Participation refers to how a person is involved within the mealtime experience. Participation in a mealtime may involve deciding on the meal, purchasing ingredients, preparing ingredients, cooking the meal, or eating the meal.

Quality of Life and Mealtime Quality of Life

In this research, the World Health Organization definition of quality of life is followed. Quality of life refers to a person's understanding of their position in life in regards to their culture and values. It also relates to the individual's personal goals and expectations, standards of living, and any concerns for their life they may have (WHO, 1998). From this, mealtime quality of life refers to the impact of the person's swallowing skills, diet, and ability to complete other food related tasks on their quality of life.

Texture-Modified Food

Foods that have been thickened, pureed or cut up into smaller pieces so it was easier to swallow for people with difficulties chewing and swallowing (Groher & Crary, 2016). According to the IDDSI framework, foods can be classified as Regular Easy to Chew (Level 7), Soft and Bite-Sized (Level 6), Minced and Moist (Level 5), Pureed (Level 4), or Liquidised (Level 3) (IDDSI, 2019).

Appendix B: Conference Abstracts and Posters

2022 ASHA Convention

Smith, R., Bryant, L., Hemsley, B. (2022, November 17-19). *The Cost of Dysphagia: Impacts of Dysphagia on Quality of Life for People with Dysphagia*. [Technical presentation]. 2022 ASHA Convention, New Orleans, Louisiana. https://convention.asha.org

Learner Outcomes

1. Recognise the impacts of dysphagia on quality of life of adults with dysphagia

2. Explain how people with dysphagia, their supporters, and health professionals view the impacts of dysphagia on mealtime quality of life

3. Identify the barriers and facilitators to mealtime participation, inclusion, and enjoyment for adults with dysphagia

Session Description

This research aimed to examine the impacts of dysphagia on mealtime quality of life, participation, and inclusion for adults with a range of health conditions. An online survey included 30 people with dysphagia, four of their supporters and 18 health professionals. Analysis involved descriptive statistics on categorical data and content thematic analysis on qualitative data. Participants with dysphagia reported the greatest impact of dysphagia was on their physical safety. They viewed that this impacted on their quality of life more than other factors affecting quality of life, being choice and control, social engagement, and their mealtime experience. Health professionals suggested that texture-modified food had a greater impact on a person's choice and control than did the participants with dysphagia.

Abstract/Summary

Main argument. Dysphagia negatively impacts on quality of life, particularly as the severity of difficulties increases. A scoping review of the literature (Smith et al., 2022) examined 106 studies examining the impacts of dysphagia and dysphagia interventions on quality of life, participation, and inclusion. Most studies (n=95) included adults with acquired dysphagia and only seven included people with lifelong conditions resulting in dysphagia. There were few qualitative investigations of quality of life, and 40 studies relied on quantitative measures of quality of life, which lacked in-depth exploration of participants' experiences (Smith et al., 2022). Most interventions for dysphagia impacted positively on quality of life, however some (including texture-modified food) also had negative impacts, including increased isolation.

The aim of this research was to determine the views of people with dysphagia, their supporters, and health professionals on the impacts of dysphagia on quality of life, participation and inclusion.

Procedures. This ethically approved online survey, hosted on RedCap®, used purposive and convenience sampling to recruit adults with dysphagia, their supporters (e.g., family members), and health professionals who work with people with dysphagia (e.g., speech-language pathologists). Survey questions were based on findings of the scoping literature review (Smith et al., 2022) and designed to help identify how participants would rank the various impacts on quality based on their own perspective and experiences. The survey took approximately 15-20 minutes to complete and was piloted by two health professionals. A mixed methods analysis involved descriptive statistics for the categorical data and open and matrix coding for qualitative data. Analysis was completed via Microsoft Excel and NVivo©.

Results. In total, 52 surveys were completed and included for data analysis. Participants included 30 people with dysphagia (57.7%), 18 health professionals (34.6%), and four supporters (7.7%). Participants with dysphagia described foods they found safe and enjoyable. They used a number of strategies to make mealtimes safe including over-cooking vegetables, having a drink with meals, and finishing a meal with ice-cream or something easy to swallow. However, these strategies did not always mean meals were more enjoyable, as P56 (adult with dysphagia) stated: "I really don't enjoy eating food anymore as it is too hard to swallow". Indeed, 13 (26%) of the participants with dysphagia reported they do not eat out with others. To improve mealtime enjoyment some participants with dysphagia suggested increasing the flavour of food. Health professionals agreed that increasing the flavour of food could improve mealtime enjoyment, as well as environmental factors (e.g., ambiance, timing of food).

Participants were asked to rate the impact of dysphagia and texture-modified food on the following areas of mealtime quality of life: physical safety, choice and control, social engagement, and the mealtime experience. Participants with dysphagia considered that dysphagia had the greatest impact on physical safety (n=12, 42.9%), and choice and control were least impacted (n=9, 34.6%). As P72 (person with dysphagia) stated "physical safety is something I have to be mindful of every meal." They also reported physical safety was the most impacted by texture-modified food (n=14, 60.9%). Health professionals and supporters also considered physical safety was the most impacted by dysphagia (n=10, 47.6%), however they considered that social engagement was the least impacted (n=10, 47.6%). Health professionals and supporters rated choice and control to be the most impacted by a person who requires texture-modified food (n=8, 50%). These differences between the participant groups reflected that people with dysphagia placed a higher importance on their social engagement and how it was impacted by dysphagia than did health professionals and supporters.

Mealtime inclusion was influenced by a person's ability to be involved in decisions regarding the meal (e.g., what is eaten), and by accessibility issues including the person's ability to access a range of mealtime environments (e.g., kitchen, home, or a restaurant). Barriers to inclusion in mealtime experiences included inappropriate or poor food options, or the way other people treated the person, as P91 (person with dysphagia) said: "I have rung restaurants and explained my situation but have been refused a booking if I want to bring a thickened drink". Improved mealtime participation was linked to a person's ability to assist in the preparation of food; however this was shaped by physical capabilities, as P70, a person with dysphagia stated "I do not prepare meals because I drop things often." Health professionals and supporters suggested that mealtime participation could also be limited if a support person (e.g., family member or caregiver) made mealtime decisions without consideration of the person's choices.

The results of this survey highlight the importance of asking people with dysphagia for their own perceptions of impacts on quality of life directly. While seeking the views of supporters and healthcare providers yields important insights, these views cannot be considered a proxy for people with dysphagia themselves. There are several implications for speech-language pathologists working with people with dysphagia which will be presented and discussed. This research is limited in being a relatively small sample and results should be interpreted with caution.

People with dysphagia need to be involved in discussions about their meals and have every opportunity to be involved in menu planning and food preparation. They may need assistive technologies for increased accessibility of food preparation areas and to eat out in restaurants with appropriate food items being available. Education should be provided to people with dysphagia and their supporters to increase mealtime inclusion and participation. Further research should look to gain the perspectives of people with dysphagia who could not access the online survey, through in-depth interviews. People with dysphagia need every support available to be able to choose appropriate texture-modified food so their social engagement and inclusion is not unduly impacted by their dysphagia and its interventions.

Thirtieth Annual Dysphagia Research Society Meeting

Smith, R., Bryant, L., Hemsley, B. (2022, March 15-18). *"All the food is like wet dog food": Could 3D food printing improve mealtime management and quality of life for people with dysphagia who need pureed food?* [Poster presentation]. Thirtieth Annual Dysphagia Research Society Meeting, San Juan Puerto Rico. https://www.dysphagiaresearch.org/page/30th_Annual_Meeting_Attendee_Information

Purpose: To understand key stakeholders' views on (a) the impacts of dysphagia and food texture modification on quality of life, participation, and inclusion; (b) barriers and facilitators to mealtime quality of life; and (c) the use of 3D food printing to improve the visual appeal of texture-modified food. There are widespread untested assumptions in the 3D food printing literature that it will help people with dysphagia.

Methods: This ethically approved mixed-methods research involved interviews with seven people with dysphagia and four of their supporters; and four focus groups with 15 allied health professionals who work with people with dysphagia. Interviews and focus group questions focused on dysphagia and quality of life and feasibility of 3D food printing, after participants were shown how a 3D food printer is used. Data was analysed within and across the data sources using narrative analysis and content thematic analysis.

Results: Across the interviews and focus groups, participants viewed that dysphagia led to reduced choice and control, poor physical health, reduced social inclusion, and negative experiences with food. Barriers and facilitators to quality of life included the opinions of others on the appearance of the food, education and knowledge about texture-modified diets, and a person with dysphagia's input to design components of their own meals. Although participants suggested that 3D food printing could potentially be beneficial as it provided a strategy for people to design their own meal, several barriers to use were identified, including the extended time required to prepare and print the food and to clean the device, without necessarily improving the visual appeal of the food.

Conclusions: Expanding on what is already known about the impacts of dysphagia on quality of life, this study adds rich qualitative insights into the ways that the appearance of the food could be manipulated to improve quality of life. Its findings provide further impetus for dysphagia professionals to include the person with dysphagia in food design strategies, when introducing a texture-modified diet. Future development in 3D food printing should include key stakeholders in the co-design, considering the barriers raised by participants in this study.

Learning objectives

- Participants will be able to describe the impacts of dysphagia and dysphagia interventions on a person's quality of life, participation, and inclusion.
- Participants will understand more about how 3D food printing works and its impact on the visual appeal of food.
- Participants will be able to identify and understand the potential benefits of using 3D food printing to improve the visual appeal of texture-modified food.

“All the food is like wet dog food”: Could 3D food printing improve mealtime management and quality of life for people with dysphagia who need pureed food?

Ms Rebecca Smith (BSpPath(Hons))1, Dr Lucy Bryant (PhD) 1 and Professor Bronwyn Hemsley (PhD) 1, 2,
1 Graduate School of Health, The University of Technology Sydney, Sydney, NSW, Australia,
2 Faculty of Arts and Education, The University of Newcastle, Callaghan, NSW, Australia

INTRODUCTION

Dysphagia impacts negatively on quality of life particularly as the severity increases. Most research to date is quantitative in nature and few studies include participants with dysphagia related to a life long developmental condition (Smith et al, 2022).

There are also widespread under researched assumptions in the 3D food printing literature that the technology will help improve mealtimes for people with dysphagia.

AIM

To examine the view of key stakeholders on:

(a) The impact of dysphagia and food texture modification on a person's quality of life, participation, and inclusion

(b) Barriers and facilitators to mealtime quality of life; and

(c) The use of 3D food printing to improve the appearance of texture-modified food.

METHODS

This study was approved by the UTS Human Research Ethics Committee [ETH19-3708].

Nine people with dysphagia and four of their supporters engaged in interviews and a 3D food printing experience, while 15 allied health professionals engaged in one of four focus groups to discuss the impacts of dysphagia on quality of life and their views on 3D food printing.

Audio recordings were transcribed verbatim and de-identified. Narrative analysis and thematic content analysis were used to analyse data via NVivo®. Data collection occurred between March and May 2021.

RESULTS

Impacts of dysphagia on quality of life

Reduced choice and control

- “Once I was with colleagues … and they insisted on going to a café that only had really hard bread… I had an episode [choked].” P4

Poor physical health

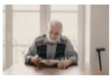
- “Biggest [impact] … on their quality of life would be there malnutrition and dehydration” FG1SP3

Reduced social inclusion

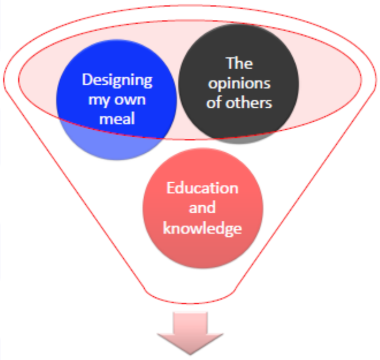
- “I've missed weddings of my own family, I've missed 60ths 50ths, christenings, baby I have missed them all. It's just simply not worth people paying for me to sit down to a 3-course meal” P5

Negative experiences with food

- “The meat would go in, the vegetables would go in, the carbohydrate would go in and it would all be blended as one … the standard orangey brown puree in a plastic bowl with a plastic spoon” FG4SP2



Barriers and facilitators to quality of life



Mealtime experience

<u>Designing my own meal:</u>
“when it's really tasty … I almost don't think about the swallowing part of it when I'm eating.” P9
<u>The opinions of others:</u>
“wait staff put it down to I'm being an arrogant person … who's trying to get away with as many changes as they can.” P1

The use of 3D food printing

Visual appeal of 3D printed food

Practicalities: time to use and clean

Cost of the 3D food printer

Aside from these barriers, participants saw the potential:
“Yes there is barriers at the moment… but for that one person it could actually mean [making a difference to] their quality of life.” FG4SP7

CONCLUSIONS

This study provides qualitative insights into the impacts of dysphagia on quality of life and how the mealtime experience may be shaped by changing the appearance of the food.

Dysphagia professionals need to include people with dysphagia in implementing food design strategies for texture-modified food.

Future research of 3D food printing should include key stake-holders in the design of the machine and consider the barriers raised by this study.

References

Smith, R., Bryant, L., Hemsley, B. (2022). Dysphagia and Quality of Life, Participation, and Inclusion Experiences and Outcomes for Adults and Children with Dysphagia: A Scoping Review. *Perspectives of the ASHA Special Interest Groups*. https://doi.org/10.1044/2021_PERSP-21-00162

Acknowledgments

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rebeccasmithsp.wordpress.com | @beccysmith7 rebecca.j.smith@student.uts.edu.au

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Ninth United Kingdom Swallow Research Group Conference

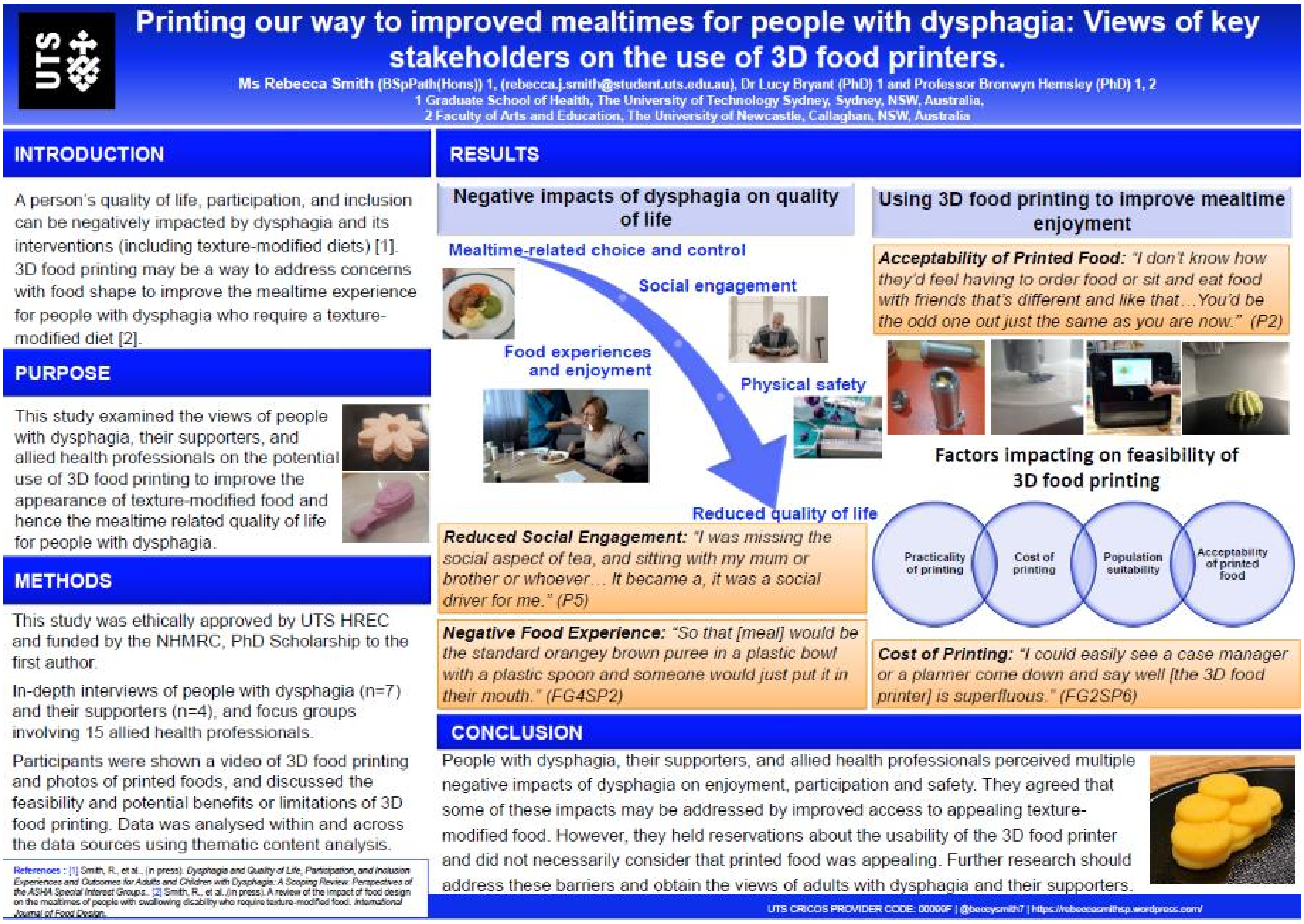
Smith, R., Bryant, L., Hemsley, B. (2022, February 3-4). *Printing our way to improved mealtimes for people with dysphagia: Views of key stakeholders on the use of 3D food printers* [Poster presentation]. Ninth United Kingdom Swallow Research Group Conference, Online virtual conference. http://www.uksrg.org.uk/conferences/uksrg-2022/

Purpose: This research examined the views of people with dysphagia, their supporters, and allied health professionals on the potential use of 3D food printers to improve the appearance of texture-modified food and hence mealtime-related quality of life for people with dysphagia.

Methods: The ethically approved study involved in-depth interviews of people with dysphagia (n=7) and their supporters (n=4), and focus groups involving 15 allied health professionals. Participants were shown a video of a domestic-scale commercially available 3D food printer and photos of printed foods, and asked to discuss the feasibility and potential benefits or limitations of 3D food printing. Data was analysed within and across the data sources to synthesise the results into themes.

Results: The interviews and focus groups revealed similar content themes. Participants viewed that dysphagia impacted negatively on a person's choice and control, social engagement, food experiences, and physical safety. Participants saw several potential benefits of 3D food printing, particularly for people being able to 'design their mealtime', however several feasibility and usability issues were raised that need to be addressed.

Conclusion: People with dysphagia, their supporters, and allied health professionals perceived multiple negative impacts of dysphagia on mealtime enjoyment, participation and safety. They agreed that some of these impacts may be addressed by improved access to attractive and appealing texture-modified food. However, they held reservations about the usability of the 3D food printer and diverse views on whether the printed food was appealing. Further research on the co-design and usability of 3D food printers is indicated.



Printing our way to improved mealtimes for people with dysphagia: Views of key stakeholders on the use of 3D food printers.

Ms Rebecca Smith (BSpPath(Hons)) 1, (rebecca.j.smith@student.uts.edu.au), Dr Lucy Bryant (PhD) 1 and Professor Bronwyn Hemsley (PhD) 1, 2
1 Graduate School of Health, The University of Technology Sydney, Sydney, NSW, Australia,
2 Faculty of Arts and Education, The University of Newcastle, Callaghan, NSW, Australia

INTRODUCTION

A person's quality of life, participation, and inclusion can be negatively impacted by dysphagia and its interventions (including texture-modified diets) [1]. 3D food printing may be a way to address concerns with food shape to improve the mealtime experience for people with dysphagia who require a texture-modified diet [2].

PURPOSE

This study examined the views of people with dysphagia, their supporters, and allied health professionals on the potential use of 3D food printing to improve the appearance of texture-modified food and hence the mealtime related quality of life for people with dysphagia.

METHODS

This study was ethically approved by UTS HREC and funded by the NHMRC, PhD Scholarship to the first author.

In-depth interviews of people with dysphagia (n=7) and their supporters (n=4), and focus groups involving 15 allied health professionals.

Participants were shown a video of 3D food printing and photos of printed foods, and discussed the feasibility and potential benefits or limitations of 3D food printing. Data was analysed within and across the data sources using thematic content analysis.

References : [1] Smith, R., et al., (in press). *Dysphagia and Quality of Life, Participation, and Inclusion Experiences and Outcomes for Adults and Children with Dysphagia: A Scoping Review. Perspectives of the ASHA Special Interest Groups.*. [2] Smith, R., et al. (in press). A review of the impact of food design on the mealtimes of people with swallowing disability who require texture-modified food. *International Journal of Food Design.*

RESULTS

Negative impacts of dysphagia on quality of life

Mealtime-related choice and control

Social engagement

Food experiences and enjoyment

Physical safety

Reduced quality of life

Reduced Social Engagement: *"I was missing the social aspect of tea, and sitting with my mum or brother or whoever… It became a, it was a social driver for me." (P5)*

Negative Food Experience: *"So that [meal] would be the standard orangey brown puree in a plastic bowl with a plastic spoon and someone would just put it in their mouth." (FG4SP2)*

Using 3D food printing to improve mealtime enjoyment

Acceptability of Printed Food: *"I don't know how they'd feel having to order food or sit and eat food with friends that's different and like that…You'd be the odd one out just the same as you are now." (P2)*

Factors impacting on feasibility of 3D food printing

Practicality of printing

Cost of printing

Population suitability

Acceptability of printed food

Cost of Printing: *"I could easily see a case manager or a planner come down and say well [the 3D food printer] is superfluous." (FG2SP6)*

CONCLUSION

People with dysphagia, their supporters, and allied health professionals perceived multiple negative impacts of dysphagia on enjoyment, participation and safety. They agreed that some of these impacts may be addressed by improved access to appealing texture-modified food. However, they held reservations about the usability of the 3D food printer and did not necessarily consider that printed food was appealing. Further research should address these barriers and obtain the views of adults with dysphagia and their supporters.

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Eleventh Annual Congress of the European Society for Swallowing Disorders

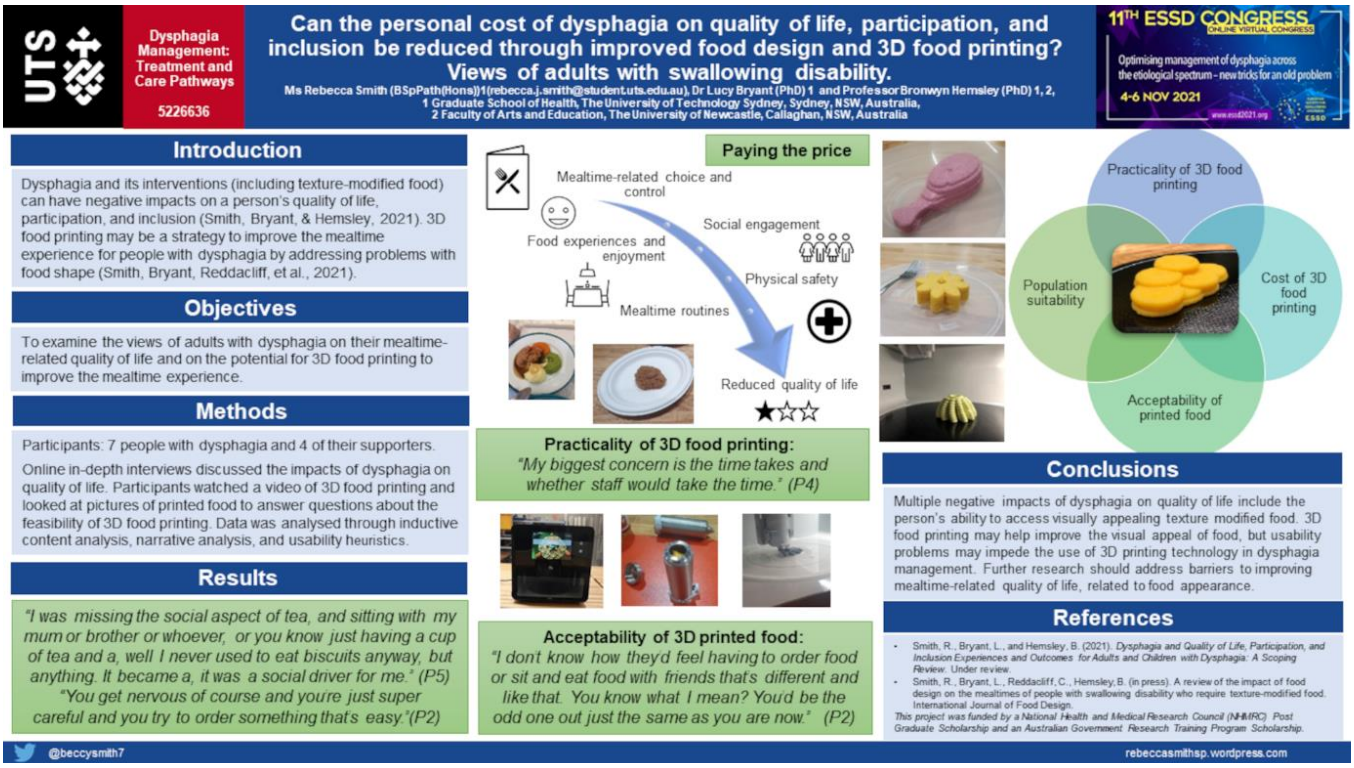
Smith, R., Bryant, L., Hemsley, B. (2021, November 4-6). *Can the personal cost of dysphagia on quality of life, participation, and inclusion be reduced through improved food design and 3D food printing? Views of adults with swallowing disability.* [Poster presentation]. Eleventh Annual Congress of the European Society for Swallowing Disorders, Online virtual conference. https://essd2021.org/

Introduction: 3D food printing potentially improves mealtime safety and quality of life of people with dysphagia by addressing problems with food shape. The aims of this research were to examine the views of adults with dysphagia on their mealtime-related quality of life and on the potential for 3D food printing to improve mealtime experiences.

Material/methods: Qualitative methods were used to examine the views and experiences of people with dysphagia (n=7) and some of their supporters (n=4). As well as being asked six key questions about the impacts of dysphagia, participants were shown a video of the Foodini 3D food printer being used and photos of the foods printed. They were then asked to discuss the usability of 3D food printing and the potential impact on their meals and mealtime-related quality of life. Inductive content coding and narrative analysis were used to identify content themes in the data.

Results: Participants reported a negative impact of dysphagia on (a) mealtime-related choice and control, (b) social engagement, (c) food experiences and enjoyment, (d) routines around mealtimes, and (e) physical safety. Participants described “paying the price” regarding time, money, and emotional costs of dysphagia. They viewed that 3D food printing may allow them to be more involved in designing their own texture-modified foods. However, they also identified several usability barriers to using 3D food printers and did not necessarily find the printed foods appealing.

Discussion/ conclusion: People with dysphagia identified multiple impacts on their mealtime-related quality of life which may be addressed by improved access to attractive texture-modified foods. Perceived problems with usability and ambivalence about the attractiveness of the 3D printed food may impede use of this food technology. User-centred co-design of 3D food printers is needed to further the potential for 3D food printing to improve mealtime-related quality of life or mealtime safety.



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Dysphagia Management: Treatment and Care Pathways

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Can the personal cost of dysphagia on quality of life, participation, and inclusion be reduced through improved food design and 3D food printing? Views of adults with swallowing disability.

Ms Rebecca Smith (BSpPath(Hons))1(rebecca.j.smith@student.uts.edu.au), Dr Lucy Bryant (PhD) 1 and Professor Bronwyn Hemsley (PhD) 1, 2,
1 Graduate School of Health, The University of Technology Sydney, Sydney, NSW, Australia,
2 Faculty of Arts and Education, The University of Newcastle, Callaghan, NSW, Australia

11TH ESSD CONGRESS
ONLINE VIRTUAL CONGRESS
Optimising management of dysphagia across the etiological spectrum – new tricks for an old problem
4-6 NOV 2021
www.essd2021.org

Introduction

Dysphagia and its interventions (including texture-modified food) can have negative impacts on a person's quality of life, participation, and inclusion (Smith, Bryant, & Hemsley, 2021). 3D food printing may be a strategy to improve the mealtime experience for people with dysphagia by addressing problems with food shape (Smith, Bryant, Reddacliff, et al., 2021).

Objectives

To examine the views of adults with dysphagia on their mealtime-related quality of life and on the potential for 3D food printing to improve the mealtime experience.

Methods

Participants: 7 people with dysphagia and 4 of their supporters.

Online in-depth interviews discussed the impacts of dysphagia on quality of life. Participants watched a video of 3D food printing and looked at pictures of printed food to answer questions about the feasibility of 3D food printing. Data was analysed through inductive content analysis, narrative analysis, and usability heuristics.

Results

"I was missing the social aspect of tea, and sitting with my mum or brother or whoever, or you know just having a cup of tea and a, well I never used to eat biscuits anyway, but anything. It became a, it was a social driver for me." (P5)

"You get nervous of course and you're just super careful and you try to order something that's easy."(P2)

Paying the price

Mealtime-related choice and control

Food experiences and enjoyment

Social engagement

Physical safety

Mealtime routines

Reduced quality of life

★☆☆

Practicality of 3D food printing:

"My biggest concern is the time takes and whether staff would take the time." (P4)

Acceptability of 3D printed food:

"I don't know how they'd feel having to order food or sit and eat food with friends that's different and like that. You know what I mean? You'd be the odd one out just the same as you are now." (P2)

Practicality of 3D food printing

Population suitability

Cost of 3D food printing

Acceptability of printed food

Conclusions

Multiple negative impacts of dysphagia on quality of life include the person's ability to access visually appealing texture modified food. 3D food printing may help improve the visual appeal of food, but usability problems may impede the use of 3D printing technology in dysphagia management. Further research should address barriers to improving mealtime-related quality of life, related to food appearance.

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This project was funded by a National Health and Medical Research Council (NHMRC) Post Graduate Scholarship and an Australian Government Research Training Program Scholarship.

@beccysmith7

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Eleventh Annual Congress of the European Society for Swallowing Disorders

Smith, R., Bryant, L., Hemsley, B. (2021, November 4-6). *Mealtimes are a balancing act: Health professionals' views on the quality of life impacts of dysphagia and potential for improvements through 3D food printing.* [Poster presentation]. Eleventh Annual Congress of the European Society for Swallowing Disorders, Online virtual conference. https://essd2021.org/

Introduction: Dysphagia and its interventions can impact negatively on a person's quality of life, participation, and inclusion. 3D food printing is claimed to address the negative impact of modifying food texture upon its visual appeal for people with dysphagia, and improve their mealtime experiences. We aimed to examine the views of allied health professionals working with people with dysphagia on the impacts of dysphagia on a person's quality of life, and on the feasibility of 3D food printing to improve mealtime experiences.

Materials/ methods: Focus groups were used to determine the views of 15 allied health professionals who worked with people with dysphagia. The focus groups each lasted two hours and explored six key questions. Participants were also shown videos of the Foodini 3D food printer being used and photos of the resultant pureed food shapes. Data was analysed using content thematic analysis and results were verified with participants.

Results: Participants agreed that dysphagia could negatively impact a person's choice and control, social engagement, physical safety, and food experiences. Participants recognised the potential for 3D food printers to increase choice and control in enabling people with dysphagia to 'design their own mealtime'. However, they were unsure about the feasibility of people with dysphagia or their supporters using 3D food printers, and identified usability issues that need to be addressed before 3D food printers can be a widely accepted assistive technology.

Discussion/ conclusion: Allied health professionals identified the potential benefits of 3D food printing to provide visually appealing texture-modified food. Dysphagia has complex impacts on a person's mealtime-related quality of life and 3D food printers offer potential benefits. Usability issues may impede uptake and use of this new technology. Further research on the user experience of people with dysphagia and health professionals using 3D food printers is indicated.

UTS

Dysphagia Management: Treatment and Care Pathways

5226632

Mealtimes are a balancing act: Health professionals' views on the quality of life impacts of dysphagia and potential for improvements through 3D food printing.

Ms Rebecca Smith (BSpPath(Hons))[1](rebecca.j.smith@student.uts.edu.au), Dr Lucy Bryant (PhD)[1] and Professor Bronwyn Hemsley (PhD)[1, 2],
[1] Graduate School of Health, The University of Technology Sydney, Sydney, NSW, Australia,
[2] Faculty of Arts and Education, The University of Newcastle, Callaghan, NSW, Australia

11TH ESSD CONGRESS
ONLINE VIRTUAL CONGRESS
Optimising management of dysphagia across the etiological spectrum - new tricks for an old problem
4-6 NOV 2021

Introduction

Dysphagia negatively impacts on quality of life (Smith, Bryant, & Hemsley, 2021). 3D food printing is claimed to improve the negative impacts of texture-modified food on the quality of life (Smith, Bryant, Reddacliff et al., 2021). Health professionals recognise the importance of quality of life in dysphagia management and the need to look beyond the person's swallowing skills and promote client autonomy.

Objectives

To examine the views of allied health professionals who work with people with dysphagia on the impacts of dysphagia on a person's quality of life and on the feasibility of 3D food printing to improve their mealtime experience.

Methods

Four focus groups were held with 15 health professionals who worked with people with dysphagia. In total, 12 speech pathologists and 3 occupational therapists took part. Participants viewed photos and videos of the 3D food printer creating shapes from pureed food to answer questions about the feasibility of 3D food printing to improve quality of life. Data was analysed using content thematic analysis. Results were verified by participants who were sent a summary of their focus group.

Results

"We unfortunately see that we feed our sick and vulnerable things that you know aren't very appetising – and they're the people who actually need the food and the nutrition." (FG3SP5)

The Negative Outcomes of Dysphagia

Reduced quality of life

Social engagement

Choice and control

Physical safety

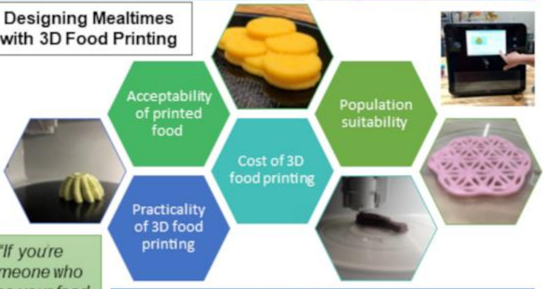
Food experiences

"If you're someone who loves your food in this situation, it's one of those little pleasures in life that's maybe been taken away." (FG1SP12)

I can't see [3D food printing] working because of how fiddly it is and because of how much time it takes. (FG4SP2)

"Something like this [3D food printing] is really cool and yes there is barriers at the moment, price, time you know, but for that one person it could actually mean their quality of life." (FG4SP7)

Designing Mealtimes with 3D Food Printing



Acceptability of printed food

Population suitability

Cost of 3D food printing

Practicality of 3D food printing

Conclusions

Allied health professionals identified that dysphagia had a variety of impacts on quality of life. 3D food printing has potential benefits in providing visually appealing texture-modified food. Usability issues of 3D food printing may impede the general uptake of this assistive technology. Further research examining the user experience of people with dysphagia, their supporters, and health professionals when using 3D food printing technology is indicated.

References

- Smith, R., Bryant, L., and Hemsley, B. (2021). *Dysphagia and Quality of Life, Participation, and Inclusion Experiences and Outcomes for Adults and Children with Dysphagia: A Scoping Review.* Under review.
- Smith, R., Bryant, L., Reddacliff, C., Hemsley, B. (in press). A review of the impact of food design on the mealtimes of people with swallowing disability who require texture-modified food. International Journal of Food Design.

This project was funded by a National Health and Medical Research Council (NHMRC) Post Graduate Scholarship and an Australian Government Research Training Program Scholarship.

@beccysmith7

rebeccasmithsp.wordpress.com

Speech Pathology Australia National Conference 2021

Smith, R., Bryant, L., Hemsley, B. (2021, May 31- June 2). *A review of food design for people on texture-modified diets: The shape of things to come* [Conference presentation]. Speech Pathology Australia National Conference 2021, online virtual conference.

Background: The modification of food and fluid textures is one of the main interventions for people with dysphagia. While food design principles are important, little is known about how food design principles have been applied in dysphagia research to date, nor how these could impact on a person's quality of life and enjoyment of meals.

Aim: To determine how different principles of food design have been considered in texture-modified diets and how these impact on the quality of life of people on texture-modified diets.

Method: In July 2020, a systematic search of five scientific databases was conducted. Narrative synthesis techniques including content thematic analysis were applied to identify common themes across studies and gaps in the research.

Results: In total, 34 studies reported on the visual appeal, taste, temperature, texture, and nutritional properties of texture-modified foods. Changes to these elements influence mealtime quality of life as they influence pleasure associated with the meal, enable the person to maintain good respiratory health and nutrition, and impact upon the convenience of meals. Only 10 studies included participants with dysphagia, and the shape of texture-modified foods, particularly purees, remains problematic. No studies examined the views of people with dysphagia on new technologies designed to improve visual appeal of puree foods, such 3D food printing.

Conclusion: To date, little research on food design elements of texture-modified foods includes people with dysphagia. Little is known about how food design principles impact on mealtime-related quality of life. Future research should consider a wide range of food design options in creating texture-modified foods, particularly puree food options.

Key words: dysphagia, quality of life, mealtimes, literature review, 3D food printing, food design.

Speech Pathology Australia National Conference 2021

Smith, R., Bryant, L., Hemsley, B. (2021, May 31- June 2). *The impacts of dysphagia on quality of life, participation, and inclusion for adults and children with dysphagia: A systematic review* [Poster presentation]. Speech Pathology Australia National Conference 2021, online virtual conference.

Background: Dysphagia impacts on a person's quality of life, participation and inclusion, however most research to date has focused on the nature and impact of dysphagia on a person's physical health.

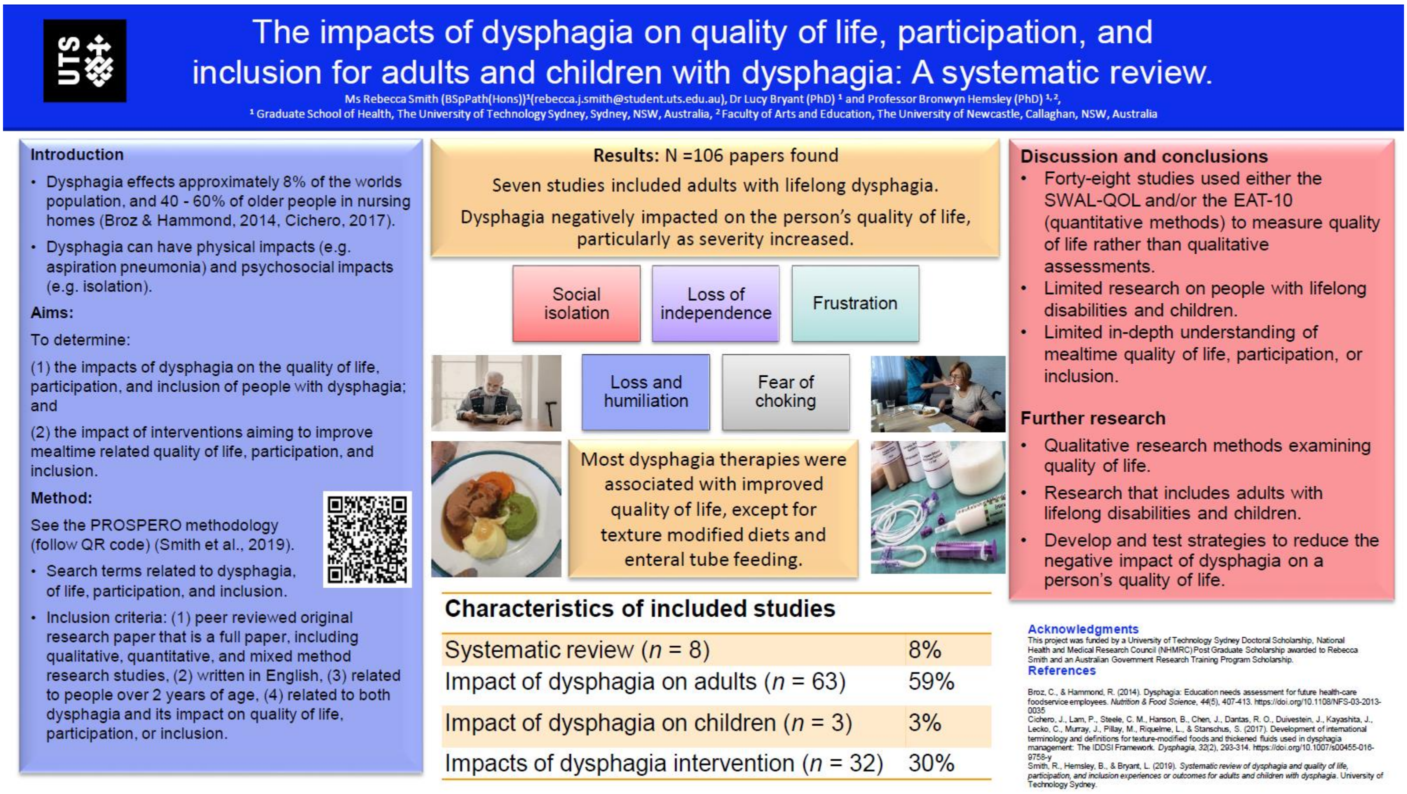
Aim: To determine (a) the impacts of dysphagia on the quality of life, participation and inclusion of people with dysphagia; and (b) the impact of interventions aiming to improve mealtime-related quality of life, participation, and inclusion.

Method: In July 2019, and again in August 2020, five scientific databases were searched for original, peer-reviewed research examining dysphagia and quality of life. Although most studies were quantitative in design, due to the heterogeneity of populations in the included studies, meta-analyses was not possible and qualitative synthesis was used to identify themes across the studies.

Results: One-hundred and six studies were included, most involving participants with acquired dysphagia (n=95).Only seven studies included adults with lifelong disability and four included children. Furthermore, 45% of studies only contributed quantitative data using the Swallowing Quality of Life Questionnaire or the Eating Assessment Tool with little in-depth exploration of experiences of people with dysphagia. Food texture modification remains problematic in its negative impacts on quality of life, participation, and inclusion, which are not yet addressed in food design research.

Conclusion: Current research is largely absent of the voice of people with dysphagia on their quality of life impacts, with few studies including people with lifelong dysphagia. Future research should use qualitative and longitudinal methods to determine how dysphagia and its interventions impact on a person's quality of life over time and across the lifespan.

Key words: dysphagia, quality of life, participation, inclusion, mealtimes, systematic literature review.



The impacts of dysphagia on quality of life, participation, and inclusion for adults and children with dysphagia: A systematic review.

Ms Rebecca Smith (BSpPath(Hons))[1](rebecca.j.smith@student.uts.edu.au), Dr Lucy Bryant (PhD) [1] and Professor Bronwyn Hemsley (PhD) [1,2],
[1] Graduate School of Health, The University of Technology Sydney, Sydney, NSW, Australia, [2] Faculty of Arts and Education, The University of Newcastle, Callaghan, NSW, Australia

Introduction

- Dysphagia effects approximately 8% of the worlds population, and 40 - 60% of older people in nursing homes (Broz & Hammond, 2014, Cichero, 2017).
- Dysphagia can have physical impacts (e.g. aspiration pneumonia) and psychosocial impacts (e.g. isolation).

Aims:

To determine:

(1) the impacts of dysphagia on the quality of life, participation, and inclusion of people with dysphagia; and

(2) the impact of interventions aiming to improve mealtime related quality of life, participation, and inclusion.

Method:

See the PROSPERO methodology (follow QR code) (Smith et al., 2019).

- Search terms related to dysphagia, of life, participation, and inclusion.
- Inclusion criteria: (1) peer reviewed original research paper that is a full paper, including qualitative, quantitative, and mixed method research studies, (2) written in English, (3) related to people over 2 years of age, (4) related to both dysphagia and its impact on quality of life, participation, or inclusion.

Results: N =106 papers found

Seven studies included adults with lifelong dysphagia.

Dysphagia negatively impacted on the person's quality of life, particularly as severity increased.

Social isolation

Loss of independence

Frustration

Loss and humiliation

Fear of choking

Most dysphagia therapies were associated with improved quality of life, except for texture modified diets and enteral tube feeding.

Characteristics of included studies

Systematic review (*n* = 8)	8%
Impact of dysphagia on adults (*n* = 63)	59%
Impact of dysphagia on children (*n* = 3)	3%
Impacts of dysphagia intervention (*n* = 32)	30%

Discussion and conclusions

- Forty-eight studies used either the SWAL-QOL and/or the EAT-10 (quantitative methods) to measure quality of life rather than qualitative assessments.
- Limited research on people with lifelong disabilities and children.
- Limited in-depth understanding of mealtime quality of life, participation, or inclusion.

Further research

- Qualitative research methods examining quality of life.
- Research that includes adults with lifelong disabilities and children.
- Develop and test strategies to reduce the negative impact of dysphagia on a person's quality of life.

Acknowledgments

This project was funded by a University of Technology Sydney Doctoral Scholarship, National Health and Medical Research Council (NHMRC) Post Graduate Scholarship awarded to Rebecca Smith and an Australian Government Research Training Program Scholarship.

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Broz, C., & Hammond, R. (2014). Dysphagia: Education needs assessment for future health-care foodservice employees. *Nutrition & Food Science*, *44*(5), 407-413. https://doi.org/10.1108/NFS-03-2013-0035

Cichero, J., Lam, P., Steele, C. M., Hanson, B., Chen, J., Dantas, R. O., Duivestein, J., Kayashita, J., Lecko, C., Murray, J., Pillay, M., Riquelme, L., & Stanschus, S. (2017). Development of international terminology and definitions for texture-modified foods and thickened fluids used in dysphagia management: The IDDSI Framework. *Dysphagia*, *32*(2), 293-314. https://doi.org/10.1007/s00455-016-9758-y

Smith, R., Hemsley, B., & Bryant, L. (2019). *Systematic review of dysphagia and quality of life, participation, and inclusion experiences or outcomes for adults and children with dysphagia*. University of Technology Sydney.

Speech Pathology Australia National Conference 2020

Smith, R., Bryant, L., Hemsley, B. (2020, May 24-27). *The impacts of dysphagia on quality of life, participation, and inclusion experiences or outcomes for adults and children with dysphagia: A systematic review* [Accepted Conference presentation]. Speech Pathology Australia National Conference 2020, Darwin, NT, Australia.

Background: Dysphagia affects approximately two million Australians and 20% of the world's population. Dysphagia impacts on a person's quality of life, and their participation and inclusion in mealtimes. To date, most research has shown the impacts of dysphagia on a person's respiratory and nutritional health, rather than the wider psychosocial or quality of life impacts.

Aim: To determine (a) the impacts of dysphagia on the quality of life, inclusion and participation of people with dysphagia; and (b) the impact of interventions aiming to improve mealtime-related quality of life, participation, and inclusion.

Method: In July 2019, five scientific databases were searched for original, peer-reviewed research relevant to dysphagia and quality of life. Studies must be original research or systematic reviews, published as full papers in English. Data to be extracted will include study type, number of participants with dysphagia, quality of life impacts, and the impacts of interventions on quality of life.

Results: At this stage, 15,448 papers have been located, screened on title and abstracts, and full texts examined by the first rater to leave 101 potentially relevant studies to be checked by a second rater for inclusion in the review. Data extraction on this highly heterogeneous group of studies will precede a descriptive and content thematic analysis across studies to answer the aims of the review.

Conclusion: This review is underway and will be completed in 2019, with findings presented and discussed in relation to implications for speech pathologists working with people with dysphagia and aiming to improve their quality of life.

Key words: dysphagia, quality of life, participation, inclusion, mealtimes, systematic literature review.

Appendix C: Awards

Fw: VC's Conference Fund - 2021 Online Round 3 Outcome - Rebecca SMITH [redacted]
Rebecca Smith <Rebecca.J.Smith@student.uts.edu.au>
Tue 19/10/2021 11:26
To:
Bronwyn Hemsley <Bronwyn.Hemsley@uts.edu.au>;
Lucy Bryant <Lucy.Bryant@uts.edu.au>

From: Graduate Research School <research.scholarships@connect.uts.edu.au>**Sent:** 19 October 2021 11:21**To:** Rebecca Smith <Rebecca.J.Smith@student.uts.edu.au>**Subject:** VC's Conference Fund - 2021 Online Round 3 Outcome - Rebecca SMITH [redacted]
View online

VC's Conference Fund 2021 Online Round 3 Outcome

Dear Rebecca SMITH,

I am delighted to advise that your recent application for funds from the **Vice-Chancellor's Postgraduate Research Students Conference Fund 2021- Online Round 3** was successful for the amount of **AUD $290** for the **11th European Society of Swallowing Disorders Congress**.

The funding is awarded on the following conditions:

1. You will need to provide a copy of your conference acceptance if you have not done so already to research.scholarships@uts.edu.au via your UTS Student Email Account. Acceptance is required before payment can be processed. You will not be able to see your grant on My Student Admin until you have provided us with an evidence of acceptance.
2.You will need to provide a confirmed estimate of your 2021 conference registration fee cost if you have indicated this has yet to be announced by the conference organisers or 'to be confirmed*' in your application. You will not be able to see your grant on My Student Admin until you have provided us with a confirmation of registration fee. Note that if the registration costs are significantly higher than the estimated cost, further approvals need to be sought from the panel.
3. Please provide also any other requested documents requested to you by email. You will not be able to see your grant on My Student Admin until you have provided us with these requesting documents.
4. You will need to submit an online **Conference Report** to the Graduate Research School within two months of attending your conference; and
5. You can only use these funds for the conference and type of presentation as indicated in your original application.
6. If you are unable to attend the conference, you will be required to notify GRS immediately and return the funds granted in full.

If you have sent us your conference acceptance and confirmed 2021 registration cost along with any other documents requested to you by email, please view and accept these funds via My Student Admin by **31 October 2021.**

If you have not received your conference acceptance by 31 October, please notify us. **Your payment will be processed for the next available payment date, provided that you have submitted your conference acceptance and completed the online scholarship acceptance as mentioned above.**

If you are no longer attending this conference or have any questions, please contact us via email.

Graduate Research School
research.scholarships@uts.edu.au

Congratulations

Rebecca Smith

Runner Up - Best 3 Minute Thesis and
People’s Choice Award 3 Minute Thesis

Health Research Student Forum Autumn 2020

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Professor Debra Anderson
Associate Dean Research
Faculty of Health, University of Technology Sydney

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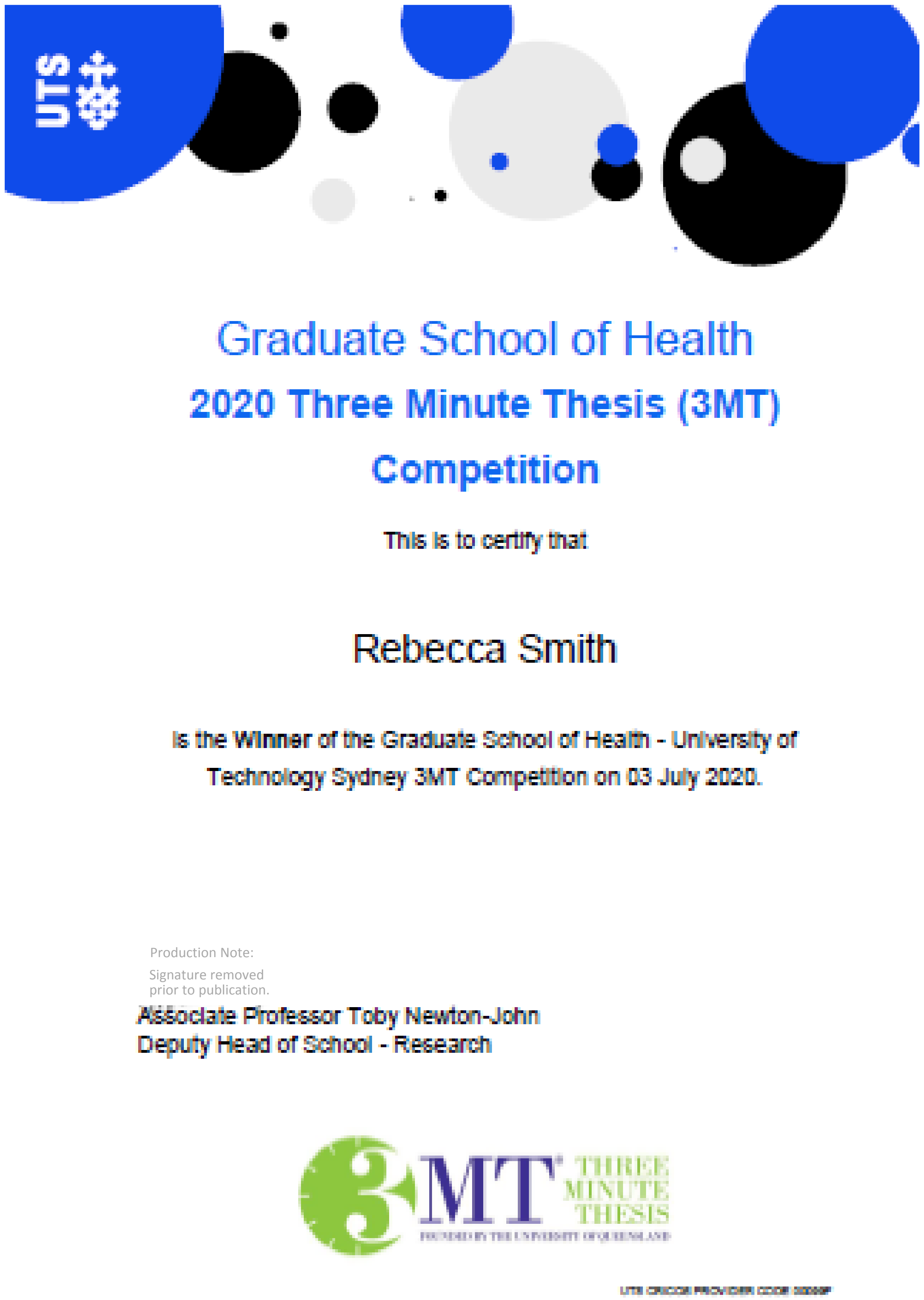

Graduate School of Health

2020 Three Minute Thesis (3MT) Competition

This is to certify that

Rebecca Smith

is the Winner of the Graduate School of Health - University of Technology Sydney 3MT Competition on 03 July 2020.

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Associate Professor Toby Newton-John
Deputy Head of School - Research

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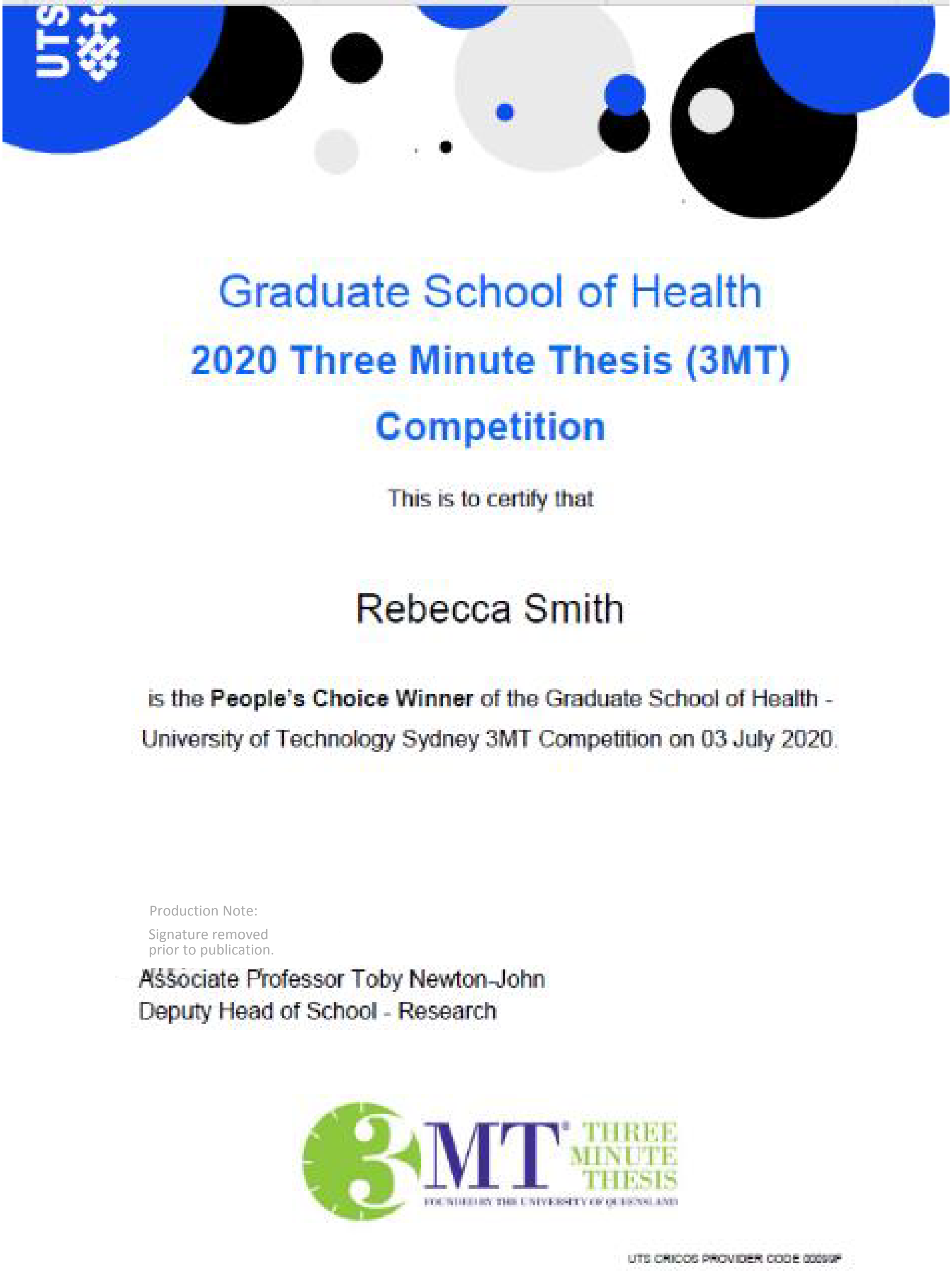

UTS

Graduate School of Health

2020 Three Minute Thesis (3MT) Competition

This is to certify that

Rebecca Smith

is the **People's Choice Winner** of the Graduate School of Health - University of Technology Sydney 3MT Competition on 03 July 2020.

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Associate Professor Toby Newton-John
Deputy Head of School - Research

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Appendix D: Other Publications during PhD

This appendix includes a non-peer-reviewed article on the impacts of COVID-19 on higher degree by research students that was published in Speak Out by Speech Pathology Australia in October 2020. Permission was provided for this article to be used within a thesis (see copyright permission at the end of the article). This article is also available online to Speech Pathology Australia members at https://speechpathologyaustralia.cld.bz/Speak-Out-October-2020-DIGITAL-EDITION-FINAL/32/. Material is copyrighted by Speech Pathology Australia (SPA) and is used with permission as part of a thesis. Publisher permissions for use in this thesis are at the end of the article. The reference for this article is:

Smith, R., Sullivan, R., & Turnbull. H. (2020). The COVID-19 curveball: Impacts on higher degree research students. *Speak Out,* October 2020, 32-34.

The COVID-19 curveball

Impacts on higher degree research students

Rebecca Smith, Rebecca Sullivan & Harmony Turnbull

When making the decision to commit to a PhD or research masters, it is well known that the road is unlikely to be smooth. However, the desire to contribute to the knowledge base of our profession and improve services for people with communication or swallowing difficulties drives us in this journey. With acknowledgement of common challenges, three speech pathology higher degree research (HDR) students at the University of Technology Sydney (UTS) could not have predicted the impacts of a global pandemic. Ethical considerations for vulnerable participant populations of people with communication and/or swallowing difficulties who are at a higher risk of contracting COVID-19 necessitate alternatives to face-to-face data collection and alterations to research design. With participant recruitment set to begin in early 2020 for full-time research students, Rebecca Sullivan and Rebecca Smith, both found themselves asking how they could alter their research. Part-time research student Harmony Turnbull also found herself in a similar situation as restrictions continued into the year which held implications for her research as well role as her part-time role as Associate Lecturer and Clinical Educator for speech pathology students. In this article, Rebecca Smith, Harmony Turnbull (both based in Sydney) and Rebecca Sullivan (based in Melbourne) reflect on how they continue to adapt and adjust as they work on their research projects in the time of COVID-19 pandemic.

Need for resources and supports

Commitment and success in any HDR work requires access to many internal (resilience, flexibility, creativity) and external (mentoring, training, readings) resources and supports. Progressing with HDR during a global pandemic required even greater support. We looked for ways to innovate and trialled various online communication strategies as a way of providing peer support within and across research groups, particularly since we no longer had the casual, in-person chats with colleagues. Microsoft Teams became a place where we were able to send instant messages of support, share memes of joy or sorrow, ask questions, and bounce ideas off each other. Our Microsoft Teams chat started as a casual chat and has since firmed into a solid friendship - some days it was just beneficial to speak to someone going through the same experiences. We also found ourselves scheduling more.

“shut up and write” sessions (SUAW) to aid focus and make the most of valuable writing time. The group work environment kept us accountable to the task at hand since

Rebecca Smith ready to battle it out in the Three Minute Thesis competition in lockdown style.

"Through these collaborative and ongoing experiences, we are stronger, wiser and more resilient..."

it can be easy to be distracted by things happening around the house.

COVID-19 and data collection: The changing mindset of a researcher

Rebecca Smith: Face-to-face interviews, mealtime observations, and 3D food printing experiences for people with dysphagia in the community were all modified to be completed online. This reduced some of the ethical risks around working with people with dysphagia as they would no longer be eating the pureed 3D printed food, they would only be able to see it. Other risks remained regarding the completion of mealtime observations over Zoom. Because of this, protocols were put in place to reduce the risk of choking.

Rebecca Sullivan: Conducting research in a hospital environment raised ethical concerns about the additional risk I was posing to vulnerable hospital patients. Additionally, asking staff to participate when they were likely changing their service delivery models was not feasible. Redesigning the study which for me was upsetting and I thought about giving up. However, I persisted because I want to change how we think about the role of communication disability in falls in hospital. I am the first person in my family to graduate from University, let alone attempt HDR, and a lot of people have worked with me and made sacrifices to help me on this journey, and I want this achievement for myself and family.

Harmony Turnbull: To investigate allied health report writing, my research involved face-to-face interviews with people with lifelong disability. Being a vulnerable group who are also experiencing significant impacts from COVID-19, the switch was made to online interviews. In consideration of people who also may have complex communication needs, it is important to consider capturing the wider communication environment over Zoom. Finding ways to keep participants safe while being true to research philosophies and achieving research aims is vital.

First and foremost, we are frontline allied health professionals

Rebecca Smith: Throughout my PhD, I have continued to work clinically in a paediatric private practice on the weekend so with the outbreak of COVID-19 I faced the challenges of working with clients over telehealth and then face-to-face with masks and cough guards, although without the intensity of colleagues who faced it on a daily basis. Because of my PhD experiences of online learning, I found myself being able to empathise more with the experiences my clients faced with home learning.

Rebecca Sullivan: I have felt an underlying current of guilt at being a research student and not being on the frontline in a hospital using my skills and knowledge to help people get through this. Listening to my friends who are working in hospitals reflect and work through their emotions over the phone has been hard. Some of the ways I have managed has been to provide resources I have found that may help their patient population (e.g., aphasia friendly COVID-19 information) to save them time searching, taking a supportive listener role with my friends and checking in regularly as well as recognising and reflecting on how I'm feeling.

Harmony Turnbull: Four years ago, I moved from a long clinical career in the disability sector to the higher education sector. Teaching speech pathology students and seeing them as the future of our profession took on a whole new perspective as the COVID-19 impacts on clinical practice meant they needed the capacity and skills to enter a workforce experiencing unprecedented change.

LEFT Harmony Turnbull's quest to find her space, and, Rebecca Sullivan dealing with the derailment of LEGO trains and data collection (i.e. ethics amendment).

Working from home

Rebecca Smith: Although I had been working from home one day a week prior to COVID-19, the jump to working from home full-time was big. The line between "work" and "home" was totally gone so I had to make a conscious effort to give myself mental health breaks. I considered myself lucky as I already had a home office set up. However, I faced days where I had minimal interaction with the outside world. I tried to counteract this isolation by spending time with my miniature schnauzer, Basil, as well as my sister and newborn niece who live nearby as restrictions eased.

Rebecca Sullivan: My husband began working from home in March, in our unit with no spare room or study, so we set up one desk in a bedroom and the other in the loungeroom. Things intensified for us when stage 4 lockdowns came into effect and we no longer had access to childcare meaning our 4-year-old son was home with us every day. We took shifts each day sharing the parenting, domestic and working duties; however, for me, the writing often took place amongst Lego, train layouts and Toy Story 4. I had dedicated time in the afternoon and evenings but starting work at 3pm after a morning of playing with a 4 year-old required extra motivation and skills to transition from my Mum role into my HDR role.

Harmony Turnbull: After two years of part-time HDR experience, I had developed many strategies for juggling family, work and HDR roles. I lost all routines overnight. Writing and thinking while commuting 3 hours a day on the train. Gone. A couple of hours in a café with my headphones to kick-start a productive HDR day. Gone. SUAW at the local library while my teenage daughter worked a weekend shift at Maccas. Gone. Suddenly, the desk in the corner of my bedroom became the place I was teaching and keeping up with my HDR work. Two months of furniture-shifting ensued, where no room in the house was left unturned. New routines have emerged and will continue evolve as the year progresses.

A lesson in flexibility

The impact of COVID-19 has been far reaching. We are sharing parts of our HDR journey through the time of COVID-19 in solidarity with the other speech pathology HDR students that are also persevering, innovating and laying the path for future speech pathology practice. We have faced its impacts on our HDR alongside life events including hospital admissions and surgeries, the birth of a niece, the death of grandparents and navigating the grieving process in isolation. Through it all, we have persisted and progressed with our research. We have built blogs, utilised Twitter, presented at HDR student events, amended ethics protocols and continued to prepare and submit manuscripts for publication and abstracts for online conferences. As an example, Rebecca Smith engaged in the Three Minute Thesis competition over Zoom this year, in true lockdown style: looking perfectly presentable on top in a blouse and blazer while wearing track pants and Ugg boots under the desk. This was successful for round-one of the competition and carried it through to round-two.

Through these collaborative and ongoing experiences, we are stronger, wiser and more resilient, we know that nobody could have predicted COVID-19 or the far-reaching implications across the speech pathology profession. We have learned to make personal and professional connections and continue our research, all the while dealing with toys, pets, partners, the merging of all our roles into one environment and an increase in the number of track pants we own. We persevere because we know that our research will influence the way people with communication and swallowing difficulties are supported in the future.

Level 1 / 114 William Street T 61 3 9642 4899 office@speechpathologyaustralia.org.au
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Appendix E: Prospero Protocol

Systematic review

To edit the record click *Start an update* below. This will create a new version of the record - the existing version will remain unchanged.

1. * Review title.

Give the title of the review in English
Systematic review of dysphagia and quality of life, participation, and inclusion experiences or outcomes for adults and children with dysphagia

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.
08/07/2019

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.
01/11/2019

5. * Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.
Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.
This field uses answers to initial screening questions. It cannot be edited until after registration.
The review has not yet started: Yes

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	Yes

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.
Rebecca Smith
Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:
Rebecca

7. * Named contact email.

Give the electronic email address of the named contact.
rebecca.j.smith@student.uts.edu.au

8. Named contact address **PLEASE NOTE this information will be published in the PROSPERO record so please do not enter private information, i.e. personal home address**

Give the full institutional/organisational postal address for the named contact.

The University of Technology Sydney
15 Broadway
Ultimo
New South Wales
Australia
2007

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.
(+61)[redacted]

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

The University of Technology Sydney
Organisation web address:
https://www.uts.edu.au/

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Ms Rebecca Smith. The University of Technology Sydney

Professor Bronwyn Hemsley. The University of Technology Sydney

Dr Lucy Bryant. The University of Technology Sydney

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.
University of Technology Sydney Doctoral Scholarship from the UTS Graduate Research School
Australian Government Research Training Program (RTP) Fee Offset Scholarship
Grant number(s) State the funder, grant or award number and the date of award

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.
This review aims to determine:
(a) The impact of dysphagia on the quality of life, inclusion, and participation of individuals with dysphagia;
(b) The impact of any interventions (including food texture modifications) designed to improve a person with dysphagia’s quality of life, inclusion, or participation in mealtime activities; and
(c) Aspects of the mealtime environment including equipment, the role of mealtime assistants, timing, and place that impact on the person with dysphagia’s quality of life, mealtime inclusion, or participation.

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)
The following databases will be searched: MEDLINE, CINAHL, Embase, PsycINFO, and Web of Science.
The search will use terms relating to dysphagia AND quality of life. Terms will include:

o Dysphagia OR deglutition disorder OR swallowing disorder OR choking OR feeding OR eating OR swallowing impairment OR swallowing therapy
AND
o Quality of life OR enjoyment OR participation OR inclusion OR self-determination OR independence OR autonomy OR community participation OR patient participation OR social inclusion OR social participation OR wellbeing OR lifestyle OR avoidance OR distress OR depression

The results will be imported into an EndNote library for further consideration.
After duplicates and papers not in English are removed, the first author will screen all titles and abstracts for inclusion according to the inclusion/exclusion criteria. All decisions will be checked by a second reviewer (LB), and inclusion and exclusion will be agreed by consensus. Any papers where uncertainties remain, will be retained for full text review.

The full texts for remaining studies will be retrieved and assessed separately by two reviewers (RS and LB) against the inclusion/exclusion criteria, using a blinded review process. Each rater will complete a cover sheet checklist to identify if the study meets inclusion criteria. Inclusion decisions will be compared, and any differences of opinion are resolved by consensus. If consensus cannot be reached, then a third reviewer (BH) will assess the study, and a majority decision will be used. Reasons for exclusion at all stages will be documented in the EndNote library.
In an ancestry search, the reference lists of the included studies will be searched to identify any relevant studies to be considered. Forward citations of included studies will be checked for relevant studies and the first author surnames will be used to search Google Scholar for any further studies.

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords)in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**
.Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.
This review will examine dysphagia and the impacts that the condition and its interventions have on quality of life, inclusion and participation.

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.
People with dysphagia (swallowing disorders, swallowing difficulties) of all ages (adults and children 2 years or older).

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.
Studies that discuss dysphagia and/or any form of dysphagia intervention (e.g. exercises to restore swallow function or compensatory strategies such as a modified diet) will be included in this review, as long as the study also examines the effects the condition or its treatment has on the individual’s quality of life, participation or inclusion.
If a study does not examine the effects of dysphagia or dysphagia intervention on quality of life for the person with dysphagia, it will not be included in the review.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.
Within studies, there may be participants with dysphagia being compared to participants without dysphagia, or sub-groups of participants with dysphagia may be compared according to a number of features.

22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.
Inclusion criteria
Studies will be included in this review if they: are peer reviewed full papers; written in English; and; relate to both ‘dysphagia’ and quality of life or participation or inclusion concepts i.e., ‘quality of life’, ‘participation’ OR

‘inclusion’. All study types will be included (e.g., Systematic reviews, case studies, single case designs, experimental studies, qualitative studies, mixed methods design).
Exclusion criteria

Studies that are not peer reviewed, not systematic reviews or original research (e.g. narrative reviews, commentary articles, editorials, issues papers, policy documents), not in English, not available in a full paper (e.g., conference paper or abstract), or not relating to both dysphagia and quality of life, participation or inclusion (e.g., relating only to dysphagia and nutrition or respiratory health) will be excluded. Studies that relate to infants and babies under 2 years of age will also be excluded.

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.
The study will look at swallowing or mealtimes in any setting (e.g. nursing home, group home, own home).

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.
To determine: (a) the impacts of dysphagia or dysphagia intervention on a person’s quality of life, inclusion and participation; and (b) the impact of any interventions discovered to improve mealtime related quality of life, participation and inclusion of the person with dysphagia or their family members or others who work with people with dysphagia. Quality of life is defined by the World Health Organisation as "an individual's perception of their position in life" and "a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment." (World Health Organisation, n.d). Quality of life may be measured using either standard instruments (e.g., SWAL-QOL, Swallowing related quality of life; or EAT-10) or may be evaluated using qualitative research methods investigating views or experiences of quality of life, participation, or inclusion related to dysphagia or dysphagia-related interventions. Concepts of participation and inclusion are related to the activities that impact on the person's mealtime experiences are often included in quality of life instruments and may also be reported using qualitative methods.
Measures of effect
Not applicable

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state ‘None’ or ‘Not applicable’ as appropriate to the review
None
Measures of effect
Not applicable

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.
Data extracted from the studies in this review will include:
- Author
- Year
- Country
- Aim
- Methodology
- Design
- Setting of the study (e.g. nursing home, group home, own home)
- Indicators of quality of life or participation or inclusion
- Participants (i.e. professional discipline, age, gender, diagnosis, dysphagia diagnosis)
- Mealtime characteristics (e.g. equipment, supports, assistance)
- Intervention provided
- Findings relevant to quality of life, participation and inclusion
- Directions for future research

A second reviewer will check the accuracy of data extracted from included studies. If any disagreements arise, these two reviewers will discuss extraction to reach a consensus decision. If necessary, a third reviewer will be called to reach a majority decision.

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

The first author (RS) will assess the quality of included studies using the Quality Assessment Tool (QATSDD) as it shows good reliability and validity in assessing the quality of both quantitative and qualitative studies (Sirriyeh, Lawton, Gardner, &Armitage, 2012). Each included study will be evaluated according to the 16 QATSDD criteria with a score of zero to three for each criterion, where zero signifies the study does not meet the specific criteria and three signifies the study completely meets that criteria. This will give an overall score out of 48 (Sirriyeh et al., 2012). A second reviewer will then conduct a blind assessment of the quality of each paper using the same criteria, and results will be compared. Any differences in opinion will be discussed until a consensus is reached, with disagreements resolved by a third reviewer and a majority decision.

28. * Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

One reviewer (RS) will extract and code the data from the included full texts. Data extraction and coding will be confirmed by a second reviewer. The main themes and content from the qualitative data will be determined using thematic content analysis to allow for common themes to be explored (Joffe & Yardley, 2004). All authors will read the included studies and meet to discuss impressions of the content themes and develop the open coding structure. The first author will then complete the open coding of all included studies, and also conduct matrix coding to determine (a) categories of meaning within the content themes, and (b) any relationships between the categories or content themes; and any overarching theme connecting all categories. Data from quantitative studies will be analysed using descriptive statistics and considered in relation to how it provides insights to the overall analysis or triangulate with the qualitative analysis.

29. * Analysis of subgroups or subsets.

State any planned investigation of ‘subgroups’. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

Some analysis of subgroups may be warranted based on the studies found as this review is examining dysphagia in both adults and children.

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness No

Diagnostic No

Epidemiologic No

Individual patient data (IPD) meta-analysis No

Intervention Yes

Meta-analysis No

Methodology No

Narrative synthesis No

Network meta-analysis No

Pre-clinical No

Prevention

Prognostic

Prospective meta-analysis (PMA)

Review of reviews

Service delivery

Synthesis of qualitative studies

Systematic review

Other

Health area of the review

Alcohol/substance misuse/abuse No

Blood and immune system No

Cancer No

Cardiovascular No

Care of the elderly No

Child health No

Complementary therapies No

COVID-19 No

Crime and justice No

Dental No

Digestive system Yes

Ear, nose and throat No

Education No

Endocrine and metabolic disorders No

Eye disorders No

General interest No

Genetics No

Health inequalities/health equity No

Infections and infestations No

International development No

Mental health and behavioural conditions No

Musculoskeletal No
Neurological No

Nursing No

Obstetrics and gynaecology No

Oral health No

Palliative care No

Perioperative care No

Physiotherapy No

Pregnancy and childbirth No

Public health (including social determinants of health) No

Rehabilitation No

Respiratory disorders No

Service delivery No

Skin disorders No

Social care No

Surgery No

Tropical Medicine No

Urological No

Wounds, injuries and accidents No

Violence and abuse No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
There is an English language summary.
English

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.
Australia

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them.

If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format) No I do not make this file publicly available until the review is complete

35. Dissemination plans. Do you intend to publish the review on completion? Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.
systematic review; dysphagia; quality of life.

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.

Update review status when the review is completed and when it is published. New registrations must be ongoing so this field is not editable for initial submission.

Review_Completed_published

39. Any additional information.

Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Smith, R., Bryant, L., Hemsley, B. (2022). Dysphagia and Quality of Life, Participation, and Inclusion Experiences and Outcomes for Adults and Children with Dysphagia: A Scoping Review. Perspectives of the ASHA Special Interest Groups, 7(1), 181-196. https://doi.org/10.1044/2021_PERSP-21-00162

Give the link to the published review or preprint.

https://pubs.asha.org/doi/10.1044/2021_PERSP-21-0016

Appendix F: Survey Tool

More than a meal: Survey examining the impacts of dysphagia on quality of life, participation, and inclusion.

Thank you for your interest in the project.

Please answer the following questions and press submit below.

Section 1: Consent

UTS UNIVERSITY OF TECHNOLOGY SYDNEY

ONLINE SURVEY INFORMATION SHEET

More than a Meal: A Constructivist Grounded Theory of Mealtime Quality of Life and Inclusion for People with a Swallowing Disability

[ETH21-6781]

WHO IS CONDUCTING THIS RESEARCH?

My name is Rebecca Smith. I am a PhD candidate at the University of Technology Sydney (UTS).
My primary supervisor is Professor Bronwyn Hemsley and my co-supervisor is Dr Lucy Bryant. This project is running from 2019-2022.

WHAT IS THE RESEARCH ABOUT?

The purpose of this online survey is to examine the impacts of dysphagia (swallowing difficulties) and dysphagia-related interventions (e.g., food texture modifications) on quality of life, participation, and inclusion for people with swallowing difficulties. It will also explore the use of 3D food printing as a potential strategy to improve enjoyment of puree foods and the inclusion and participation of people with swallowing difficulties in mealtimes.
You have been invited to participate because you:

- Have swallowing difficulties (dysphagia), are on a modified diet (e.g., puree food, soft foods, minced/mashed), and are able to swallow puree foods safely

  Or

- Are a support person for someone with swallowing difficulties (e.g., direct support worker, family member) or a support and supervisory role (e.g., house manager, senior support worker).

  Or

- Are a health professional (e.g., speech pathologist, occupational therapist, or dietitian) and have worked with people with dysphagia for at least the last two years and have been involved in their mealtime management.

FUNDING

This project is funded through a National Health and Medical Research Council (NHMRC) Postgraduate Scholarship and a Research Training Program (RTP) Scholarship awarded to Rebecca Smith.

WHAT DOES MY PARTICIPATION INVOLVE?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. If you decide to participate, you will be invited to read the information on this form carefully before agreeing to take part in the survey. This should take approximately 20 minutes.

You can change your mind at any time and stop completing the survey without consequences.

At the end of the survey you will be given the option to provide your contact details if you or someone you know has swallowing difficulties and would like to take part in an interview to further discuss the impacts of dysphagia on their quality of life and the use of 3D food printing. Once again there are no negative consequences if you do not provide your contact details.

WHAT ARE THE BENEFITS OF MY INVOLVEMENT?

We cannot guarantee there will be any personal benefits for completing this survey. We hope the results will help shape dysphagia management in the future.

ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there are some inconveniences. You may feel **embarrassment** or **distress** in relation to talking about swallowing difficulties and mealtimes. If this happens – you decide whether to continue or not.
If you find the research difficult or stressful please contact:

- Lifeline: 13 11 14 or https://www.lifeline.org.au/
- Beyond Blue: 1300 22 4636 or https://www.beyondblue.org.au/
- Your mental health professional or your GP who is already familiar with your history. If you are in Australia, Medicare will cover 10 sessions of counselling per annum which you can access via a referral from your GP.
- If you are not in Australia, please contact your local networks of support including your local health service provider.

HOW DO I TAKE PART?

Access to the online survey is via a secure online survey program. Submission of the online survey is an indication of your consent.

WHAT WILL HAPPEN TO INFORMAITON ABOUT ME?

All this information will be treated confidentially. All data will be stored on secure UTS servers using a secure online storage platform. This data will only be accessible by the researchers involved in the project. You can choose to remain anonymous throughout the survey. Alternatively, if you provide your name and email at the end of the survey, you consent to the research team collecting and using personal information about you for the research project. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. A code label will be used to refer to information about you (e.g., P1 for participant 1).

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have any concerns about the conduct of this research, please feel free to contact me at rebecca.j.smith@student.uts.edu.au or my Primary Supervisor Professor Bronwyn Hemsley at Bronwyn.Hemsley@uts.edu.au
If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on 02 9514 9772 or Research.ethics@uts.edu.au and quote this number [ETH21-6781].

Do you agree to continue with the survey?	○ Yes ○ No

Section 2: About you

1	What is your current age?	○ 18-30 ○ 31-40 ○ 41-50 ○ 51-60 ○ 61-70 ○ 71-80 ○ 80 +
2	With which gender do you most closely identify?	○ Female ○ Male ○ Non-binary ○ Other ○ Prefer not to specify
	Please describe "other"	________________________________
3	Geographical location	○ Australia ○ Canada ○ Europe ○ Japan ○ Singapore ○ Taiwan ○ United Kingdom ○ USA ○ Other
	Which "other" location?	__________________________
	Region	○ City/Metropolitan ○ Regional ○ Rural ○ Remote
4	What is your role in relation to mealtimes? (Select all that apply)	☐ Person with swallowing difficulty ☐ Support person: Direct support worker/ family member ☐ Supervisor (e.g., house manager) ☐ Health professional ☐ Other
	Please describe "other"	________________________________
	Do you have a health condition associated with your swallowing difficulty? (Select all that apply)	☐ Cerebral Palsy ☐ Stroke ☐ Traumatic Brain Injury ☐ Parkinson's ☐ Multiple Sclerosis ☐ Motor Neuron Disease ☐ Head and Neck Cancer ☐ Myositis ☐ Other

	Please describe "other"	__________________________
	How long have you dealt with this condition?	○ 0-5 years ○ 6-10 years ○ 11-20 years ○ 21-30 years ○ 31-40 years ○ 41 + years ○ My whole life
5	What is your health profession?	○ Speech pathology ○ Occupational therapy ○ Dietetics ○ Physiotherapy ○ Medical ○ Other
	Please describe "other".	_____________________
6	What is your role in relation to managing a person's mealtimes and swallowing difficulties? (Select all that apply)	☐ Assessment of swallowing difficulties (Please describe) ______ ☐ Intervention for swallowing difficulties (Please describe) ______ ☐ Mealtime assistance training (Please describe) ______ ☐ Other
	Please describe "other".	__________________________
7	How many years' experience do you have working with people with swallowing difficulty?	○ None ○ Up to 2 ○ 3-5 ○ 6-10 ○ 11-15 ○ 16-20 ○ 20+
8	How do you assist the person's mealtimes? (Select all that apply)	☐ Menu planning ☐ Shopping for food ☐ Preparing food/cooking meals ☐ Providing assistance during the meal ☐ Providing assistance after the meal ☐ I do not have a direct role ☐ Other
	Please describe "other".	__________________________

9	How long have you had swallowing difficulties?	○ 0-5 years ○ 6-10 years ○ 11-15 years ○ 16-20 years ○ 21-25 years ○ 26-30 years ○ 30 + years
10	Are you completing this form independently?	☐ Yes, I am filling it out by myself. ☐ No, I need some support using the computer ☐ No, I need some support reading the questions ☐ No, other
	Please describe "other".	__________________________

Section 3: Swallowing difficulties and their impacts

1 Rank the degree of impact of SWALLOWING DIFFICULTY on quality of life. 1 is the most impacted and 4 is the least impacted. (You can only give each rank once)

	1- most impacted	2	3	4- least impacted
Choice and control	○	○	○	○
Social engagement	○	○	○	○
Experiences with food	○	○	○	○
Physical safety (e.g., choking on food)	○	○	○	○

Explain your rankings here. ______________________________

2 Rank the degree of impact of FOOD TEXTURE CHANGES (e.g., puree/minced) on quality of life. 1 is the most impacted and 4 is the least impacted. (You can only give each rank once)

	1- Most impacted	2	3	4- Least impacted
Choice and control	○	○	○	○
Social engagement	○	○	○	○
Experiences with food	○	○	○	○
Physical safety (e.g., choking on food)	○	○	○	○

Explain your rankings here. ______________________________

3a What helps the mealtime enjoyment of people with dysphagia (e.g., being content and satisfied, with taste, flavour, overall experience and choices)? ______________________________

3b What gets in the way of mealtime enjoyment for people with dysphagia? ______________________________

4a What helps the mealtime inclusion of people with dysphagia (e.g., being included in decisions and activities around a meal, where to eat, who to eat with)? ______________________________

4b What gets in the way of mealtime inclusion for people with dysphagia? ______________________________

5a What helps with the mealtime participation for people who have dysphagia (e.g., the role they play in preparing or eating a meal, serving or using cutlery)? ______________________________

5b What gets in the way of mealtime participation for people with dysphagia? ______________________________

6	What strategies you have used to improve a person's mealtime experience on a texture-modified diet? (Select all that apply)	☐ Modifying the mealtime environment ☐ Changing the food's appearance or shape ☐ Increasing the food's taste/ flavour ☐ Increasing the nutritional value of the food ☐ Using assistive technology for eating/drinking (particular cups, plates, spoons) ☐ More mealtime assistance or supervision ☐ Using naturally soft/ pureed foods ☐ Other (e.g., listening to music)
	Please add any other strategies have you used.	__________________________________
7	Select the options that best describe your current diet for food and drinks. (Select all that are relevant)	☐ Food: Regular or easy to chew ☐ Food: Soft and bite-sized ☐ Food: Minced and moist ☐ Food: Pureed ☐ Food: Liquidised ☐ Drinks: Extremely thick ☐ Drinks: Moderately thick ☐ Drinks: Mildly thick ☐ Drinks: Slightly thick ☐ Drinks: Thin ☐ Other
	What type of food and drinks do you currently have?	__________________________________
8a	Tell us about the foods/drinks that you enjoy and are safe for you to eat.	__________________________________
8b	Are there any foods that you cannot have or must avoid?	○ Yes ○ No
	Please explain.	__________________________________
9	Please select all of the relevant assistive tools you use as part of your meal.	☐ Adapted cup ☐ Adaptive plate ☐ Adaptive bowl ☐ Straw ☐ Non-slip mat ☐ Adaptive cutlery ☐ I do not use any assistive tools ☐ Other
	Please describe "other".	__________________________________

10	What assistance do you currently receive for your meals? (Select all that apply)	☐ Menu planning ☐ Shopping for food ☐ Preparing food/cooking meals ☐ Providing assistance during the meal ☐ Providing assistance after the meal ☐ Other
	What other assistance do you receive?	__________________________________
11a	What helps to improve your mealtime enjoyment (e.g., how content and satisfied you are, the taste or flavour meal, or the choices, overall experience)?	__________________________________
11b	What gets in the way of your mealtime enjoyment?	__________________________________
12a	What helps with your mealtime inclusion (e.g., how you are involved in mealtime decisions or activities, where you eat or who you eat with)?	__________________________________
12b	What gets in the way of your mealtime inclusion?	__________________________________
13a	What helps you with mealtime participation (e.g., your role in preparing, serving, eating, use of adaptive cutlery)?	__________________________________
13b	What gets in the way of mealtime participation?	__________________________________
14	How have your swallowing difficulties impacted on your ability to be included and participate in a social event? (Select all that are relevant)	☐ I do not go out to eat with others ☐ Other people judge me when I eat out ☐ Eating out is more expensive ☐ It takes me longer to finish my meal than others ☐ I look through the menu before I go ☐ Other
	How else have your swallowing difficulties impacted on how you engage in social events?	__________________________________
15	What strategies you have used to improve your mealtime experience? (Select all that apply)	☐ Changing my mealtime environment (where I eat) ☐ Changing the food's appearance or shape ☐ Increasing the food's taste/flavor ☐ Increasing the nutritional value of my food ☐ Using assistive technology for eating/drinking (particular cups, plates, spoons) ☐ Increasing my mealtime assistance/support/supervision ☐ Using naturally soft/pureed foods ☐ Other (e.g., listening to music, watching TV)

What other strategies do you use?

____

Section 4: 3D Food Printing in the Future

1 Watch the YouTube video below.

Natural Machines. (2021, January 12). Oncofood - 3D food printing with Foodini [Video]. YouTube. https://www.youtube.com/watch?v=xVPzatIyucE&list=PLMBLoSYpQfBUTUdzuB42u5nl02wW5jM7T&index=9

2 Do you think using 3D food printing would improve the appearance and enjoyment of texture-modified food?	○ Yes ○ No ○ I don't know

Please comment on your answer. ______________________________

3 To what extent do you agree with the following statements.

	Strongly disagree	Disagree	Neural	Agree	Strongly agree
It would be good if 3D food printers could cook, puree, and print the food.	○	○	○	○	○
It would be good if 3D food printers saved time in preparing pureed meals.	○	○	○	○	○
3D food printers are too expensive ($7,000 AU).	○	○	○	○	○
3D printed food should look like what it is made of (e.g., pureed carrot shaped like a carrot; pureed meat that looks like a steak).	○	○	○	○	○
3D printed food does not need to look like what it is made of. It would be good to look like any shape including non-food items or different foods (e.g., a cloud, a star, a shoe).	○	○	○	○	○
3D food printing might be fun and useful for children and teenagers who have swallowing difficulty (e.g., increasing standardisation, choice, or creativity in shaping).	○	○	○	○	○
3D food printing might be useful for people who are 'fussy' eaters or need foods to be the same shape.	○	○	○	○	○

What can you tell us about your your choices? ______________________________

4 Which methods do you think improve the visual appeal of minced or pureed meals?
(select all that apply)

☐ Food moulds
☐ Piping bags
☐ Food colouring
☐ Biscuit/ cookie cutters
☐ Decorative cutlery and crockery
☐ Other
☐ None of the above

Can you please explain your response?

____

What other methods do you use to improve the visual appeal of texture-modified food?

____

We are also wanting to speak to people with swallowing difficulty about the impact of these difficulties on their quality of life and their thoughts on using of 3D food printers.

If you are interested in taking part, we can send you an information sheet explaining the study.

5 Would you like to receive information on how you can be involved?

○ Yes
○ No

6 Please provide your name and email address so we can send you this information.

____

You have now finished this survey. Thank you for your time.

If you found this research difficult or stressful please contact:
- Lifeline: 13 11 14 or https://www.lifeline.org.au/
- Beyond Blue: 1300 22 4636 or https://www.beyondblue.org.au/
- Your mental health professional or your GP who is already familiar with your history. If you are in Australia, Medicare will cover 10 sessions of counselling per annum which you can access via a referral from your GP.
- If you are not in Australia, please contact your local networks of support including your local health service provider.