



**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)

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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.

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Signature: Signature removed prior to publication.

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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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- 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.

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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](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.ukserg.org.uk/conferences/ukserg-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*.

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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.

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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.

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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.