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RESEARCH REPORT

'I only eat 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

Rebecca Smith[1,2] | **Lucy Bryant**[1] | **Bronwyn Hemsley**[1]

[1]Graduate School of Health, The University of Technology Sydney, Sydney, NSW, Australia

[2]School of Health Sciences, Western Sydney University, Campbelltown, NSW, Australia

Correspondence
Rebecca Smith, School of Health Sciences, Western Sydney University, Campbelltown, NSW, Australia, 2560.
Email: rebecca.smith@westernsydney.edu.au; rebecca.smith@uts.edu.au

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Abstract

Background: A recent literature review identified that past research has described the impacts of dysphagia on quality of life; but there is limited research on these impacts from the perspective of people with dysphagia, their supporters and allied health professionals. Recent qualitative research has provided details about these perspectives, but researchers have also called for verification of these findings with a larger group of participants.

Aims: To expand upon the findings of the prior qualitative research on 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.

Methods & Procedures: 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 for content categories of meaning.

Outcomes & Results: Participants with dysphagia reported that dysphagia and texture-modified foods had a greater impact on their physical health than on their choice and control or social engagement. Supporters and allied health professionals viewed that dysphagia impacted the physical health and their choice and control of people with dysphagia. 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.

Conclusions & Implications: Dysphagia and its interventions negatively impact quality of life for people with dysphagia. People with dysphagia were the most affected by the physical impacts of dysphagia. Their perspectives contrasted with those of supporters and allied health professionals in some domains, highlighting the need for people with dysphagia to be included in research. Future research exploring how these perspectives are integrated into person-centred dysphagia management is warranted.

KEYWORDS
dysphagia, inclusion, participation, quality of life, survey

WHAT THIS PAPER ADDS

What is already known on the subject

- Recent qualitative research has provided 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. However, the small scale of these studies means that further research is needed with a larger group of people with dysphagia, supporters of people with dysphagia, and allied health professionals.

What this paper adds to existing knowledge

- This paper verifies and extends upon the findings of prior qualitive research on the views of people with dysphagia, supporters of people with dysphagia, and allied health professionals on the impacts of dysphagia and its interventions on quality of life, participation, and inclusion.

What are the potential or actual clinical implications of this work?

- This research shows the importance of supporters of people with dysphagia and allied health professionals discussing mealtime quality of life with the person with dysphagia so that their perspectives are considered in the mealtime decision-making process. Furthermore, people with dysphagia should be able to specify strategies they want to trial to enhance their mealtime participation and inclusion.

INTRODUCTION

Dysphagia (difficulty swallowing) is associated with several lifelong disabilities (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). Dysphagia can also be managed through range of strategies including texture modified food, assistive technologies (e.g., adaptive cups), or enteral tube feeding when oral feeds are not adequate or safe to meet the person's needs (Smith et al., 2022a). Texture modified foods are now classified using the International Dysphagia Diet Standardisation Initiative Framework (IDDSI) (Cichero et al., 2017), where foods range from Regular/Easy to Chew (Level 7) to Liquidised (Level 3) and fluids range from Extremely Thick (Level 4) to Thin (Level 0). The implementation of the IDDSI framework allows for internationally consistent terminology for modified food and fluid textures used across settings and contexts (Cichero et al., 2017).

A recent review of 106 studies on dysphagia-related quality of life identified a wide range of impacts of dysphagia—including reduced quality of life, loss of independence, frustration, and fear of choking (Smith et al., 2022a). In the review, 95 (90%) of the studies focused on people with acquired health conditions, and only seven (7%) focused on people with lifelong health conditions (Smith et al., 2022a). Regardless of the cause of dysphagia, the review revealed that (1) dysphagia can impact negatively on physical health, well-being, and social participation and inclusion; and (2) dysphagia interventions can have both positive and negative impacts (Smith et al., 2022a). For example, texture-modified foods or tube feeding could improve the person's physical safety but result in isolation (Ang et al., 2019; Seshadri et al., 2018). This review highlighted the need for further research examining the lived experiences of people with dysphagia, their supporters and allied health professionals.

The role of supporters and allied health professionals, including speech and language therapists (SLTs), occupational therapists and dietitians in treating and managing dysphagia, can have a notable impact on a person's experience of dysphagia. Howells et al. (2019) conducted interviews with 15 SLTs and reported that those working in the community setting aimed to provide holistic care that encompassed client autonomy and caregiver engagement. This differed somewhat from those working in the acute setting, where the main aim was to ensure the person's physical safety and did not necessarily promote quality of life (Howells et al., 2019). Although Howells et al. (2019) outlined the change in values of SLTs in the community, the perspective of other allied health professionals (e.g., occupational therapists and dietitians) were not examined. Howells et al. (2021) also investigated the lived experiences of 15 people living with dysphagia in the community. People living with dysphagia faced many psychosocial impacts relating to the loss and changes they faced because of their swallowing difficulties. Participants with dysphagia also highlighted the importance of support from family, friends, and health professionals, including SLTs, in maintaining a positive mealtime experience (Howells et al., 2021). However, most of those interviewed presented with mild dysphagia and did not require significant food modifications. This is likely to have impacted their perception of the impact of their swallowing difficulties on their mealtime experiences, as the impacts of dysphagia increase as the severity of dysphagia increases (Jones et al., 2018). Further research was required examining the perceptions of people who higher levels of dietary modification.

Recently, Smith et al. (2023) gained further insights into the impacts of dysphagia on quality of life through interviews with nine people with dysphagia and four of their supporters (including family members and paid support workers). Participants reported having to 'pay the price' of dysphagia in that it reduced their choice and control, social engagement, physical safety, and resulted in them having poor food experiences (Smith et al., 2023). Separately, the perspective of allied health professionals has also been examined through a series of focus groups (Smith et al., 2022b). Smith et al. (2022b) 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, choice, and control). The above studies were not inclusive of all participant groups, with separate studies being completed for people with dysphagia and allied health professionals meaning their perspectives could not be compared. As a result, further research that included people with dysphagia, their supporters and allied health professionals was required for a comparison of results. Furthermore, further research gathering the views of a larger group of people with dysphagia, supporters of people with dysphagia, and allied health professionals was needed to verify the findings of the prior research (Patton, 2014). Therefore, the aim of this survey research was to understand more about the views of people with dysphagia, supporters of people with dysphagia (including family members and paid support workers), and allied health professionals on the impacts of dysphagia on quality of life.

MATERIALS AND METHODS

This ethically approved research (ETH21-6781) involved an online survey as the most appropriate way to follow up the interview and focus group studies to (1) enhance the data analysis and increase confidence in the findings (Braun et al., 2021; Wolff et al., 1993) and (2) verify and deepen understanding of the phenomenon explored in qualitative methods (Lyons et al., 2022; Wolff et al., 1993). As this survey used both quantitative and qualitative data, drawn from 13 categorical and seven open-ended questions, 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 self-identified as (1) adults with dysphagia (associated with any health condition); (2) adults who were supporters of people with dysphagia (e.g., family members and direct support workers); and (3) allied health professionals who worked with people with dysphagia. These groups were selected as often working together as part of dysphagia management team to maintain or improve a person's quality of life. Professionals based in either aged care facilities, community, or hospital settings were eligible to participate, recognizing that dysphagia management occurs across acute and rehabilitation settings, aged care facilities, and community settings. Although the researchers of this project were based in Australia, international participation was encouraged and each participant's country of residence was recorded (e.g., Australia, the US or the UK). If participants reported they were in Australia, they were then asked to describe their location (city, regional, rural, or remote).

Researchers used purposive and convenience sampling, which involved (1) contacting local organizations supporting people with dysphagia; (2) inviting staff to distribute information about the survey via their email networks or newsletters; and (3) distributing information about the survey through their social media networks. Thus, a participant response rate could not be determined (Emmel, 2013). A consenting process followed in which participants were asked to read information about the purposes of the research and the investigators involved. They were then asked if they agreed to continue with the survey. By continuing the survey, participants gave their implied consent for their data to be included in the research.

Materials

All authors were involved in the co-design and development of the survey which was created using RedCap (Harris et al., 2009) and accessed through a URL link or QR code. The survey, designed to take approximately 15–20 min to complete, was based on findings from a literature review (Smith et al., 2022a) and prior interviews and focus group research with similar groups of participants (Smith et al., 2022b, 2023) examining the impact of dysphagia on quality of life.

Branching logic was used within the survey to ensure questions were relevant for the participant and their role (i.e., as a person with dysphagia, supporter, or 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, however the question types were varied to help maintain attention and limit the possibility of participants responding in a set pattern (Wolf et al., 2016). In total, the survey contained 20 questions for participants with dysphagia and 16 questions for support people and allied health professionals. A further 5 questions specifically related to food design for people with dysphagia, which being unrelated to the aim of this study, are reported elsewhere (Smith et al., 2024). The survey (see the Appendix in the supplemental data online) was piloted by two colleagues of the first author who were SLTs with changes being made to increase clarity, and the survey was released to the public once ethical approval was obtained.

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 (Wolf et al., 2016). None of the questions was compulsory, resulting in the response rate between questions being different. As a result, the number of responses for each question is provided in reporting the results.

Analysis

Responses to categorical questions 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 categorical content analysis (Patton, 2014) using NVivo (QSR International, 2018) to identify the developing categories (Braun et al., 2021). Content codes and categories 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., 2022b, 2023). The content codes and categories were developed through a reading and re-reading of the comments by the first author. All authors then engaged in repeated discussions held fortnightly over a 2-month period to ensure accuracy and increase credibility in the results. The content themes identified are shown as subheadings in the results section of this paper. 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). During the analysis, it was found that supporters of people with dysphagia and allied health professionals had similar views on the topic. Since the participant groups of supporters of people with dysphagia and allied health professionals were similar along two dimensions (i.e., in not having dysphagia and in assisting people with dysphagia) a decision was made to reduce repetition across the paper and report the findings of supporters and allied health professionals together rather than separately in the results.

RESULTS

Participants

While 101 people commenced the survey, 49 only provided demographic data and were therefore excluded from the analysis; and 52 (51%) answered most of the questions and were included in the analysis. A total of 45 (86.5%) participants were in Australia, with 34 (75.6%) of those being based in a city; and the remainder being in a regional (n = 9, 20%) or rural (n = 2, 4.4%) location. Of the 52 participants, 30 (57.7%) had dysphagia, four (7.7%) were supporters of a person with dysphagia, and 18 (34.6%) were allied health professionals. Participants with dysphagia were aged between 31 to 80+ years of age with both median and mode of age being 71–80 years (n = 16, 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 < 1 to 25 years, with most (n = 15, 50%) having difficulties for 6–10 years. This duration of dysphagia symptoms reflected that all participants with dysphagia had acquired dysphagia in adulthood. The supporters of people with dysphagia were aged between 41–80 years of age with the median and mode being 51–60 years of age (n = 2, 50%). Supporters identified as female (n = 3) or male (n = 1), with two (n = 1) to 20+ years' experience working with people with dysphagia (n = 3).

Allied health professionals were aged from 18 to 80 years with median and mode age range of 31–40 years (n = 6, 33.3%). All allied health professionals identified as female (n = 18, 100%). Participants were SLTs (n = 11, 61.1%), dietitians (n = 5, 27.8%), an occupational therapist (n = 1, 5.6%), and an SLT researcher/academic (n = 1, 5.6%). They reported having from 3 years (n = 4, 22.2%) to 20+ years' (n = 6, 33%) experience working with people with dysphagia. Further information on participants is provided in Table 1.

Participants with dysphagia: Profiles on food, fluid, and mealtime assistance

Participants identified that their diet was made up of foods that were Regular Easy to Chew (IDDSI Level 7) (n = 14, 29.8%); Soft & Bite-Sized (IDSSI Level 6) (n = 12, 25.5%); Minced & Moist (IDDSI Level 5) (n = 12, 25.5%); Pureed (IDDSI Level 4) (n = 3, 6.4%); and Liquidised (IDDSI Level 3) (n = 3, 6.4%) food. Thirteen (43.3%) of the participants with dysphagia described being able to eat foods across a range of IDDSI levels. However, four (8.5%) could only eat IDDSI Level 5 Minced & Moist, IDDSI Level 4 Pureed, or IDDSI Level 3 Liquidised foods and one (2.1%) only ate Liquidised food (International Dysphagia Disorder Standardisation Initiative, 2019).

Regarding drinks, 41.9% of participants reported having Thin fluids (IDDSI Level 0) (n = 13); 16.1% reported having Slightly Thick fluids (IDDSI Level 1) (n = 5); 3.2% reported having Mildly Thick fluids (IDDSI Level 2) (n = 1); 9.7% reported having Moderately Thick fluids (IDDSI Level 3) (n = 3); and none were on Extremely Thick fluids (IDDSI Level 4). A further nine participants (29.3%) did not report on the thickness of their fluids. Only one participant (P8) described having fluids of two consistencies: IDDSI Level 1 Slightly Thick and IDDSI Level 0 Thin fluids. Of the 15 (50%) participants who responded to the question about assistive technologies used during meals, seven used adaptive cutlery (23.3%), four used straws for drinking (13.3%), three used adaptive cups (10%), and two utilized non-slip mats (6.7%). Five participants reported using no adaptive tools (16.7%). Three participants (10%) used multiple assistive technologies, with the non-slip mat and adaptive cutlery commonly used together.

In addition to describing their oral food textures, participants with dysphagia commented on foods they considered as safe and enjoyable; reporting sometimes in great detail about the modifications they needed to make to food to ensure their swallowing safety. For example, P67, P83, and P98 described eating well-cooked vegetables, and P57, P80, and P92 detailed 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, when asked the same question, 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; while others received assistance 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%). Three participants (P66, P86, and P94) required no assistance in relation to any aspect of the meal; one, P89, needed assistance with all aspects of the meal; and one, P70, required assistance for all tasks but menu planning. Three participants did not provide information about their need for any mealtime assistance or associated impacts 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., 2023): choice and control, physical safety, social engagement, and experiences with food. Participants with dysphagia most often considered swal-

TABLE 1 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	SLT researcher	Female	51–60	Australia	City/metropolitan	NA	20+ years
P9	SLT	Female	18–30	Australia	City/metropolitan	NA	3–5 years
P11	SLT	Female	31–40	Australia	City/metropolitan	NA	11–15 years
P13	SLT	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	SLT	Female	31–40	Australia	Regional	NA	3–5 years
P29	SLT	Female	51–60	Australia	City/metropolitan	NA	20+ years
P31	SLT	Female	31–40	Australia	City/metropolitan	NA	6–10 years
P33	Dietitian	Female	31–40	Australia	City/metropolitan	NA	3–5 years
P35	SLT	Female	51–60	Australia	City/metropolitan	NA	11–15 years
P37	PWD	Male	71–80	Australia	City/metropolitan	6–10 years	NA
P38	SLT	Female	18–30	Australia	City/metropolitan	NA	6
P40	SLT	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	SLT	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
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	SLT	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

(Continues)

TABLE 1 (Continued)

ID#	Mealtime role	Gender	Age range (years)	Location	Region (if in Australia)	Time with dysphagia	Time working with people with dysphagia
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; SLT, speech and language therapist.

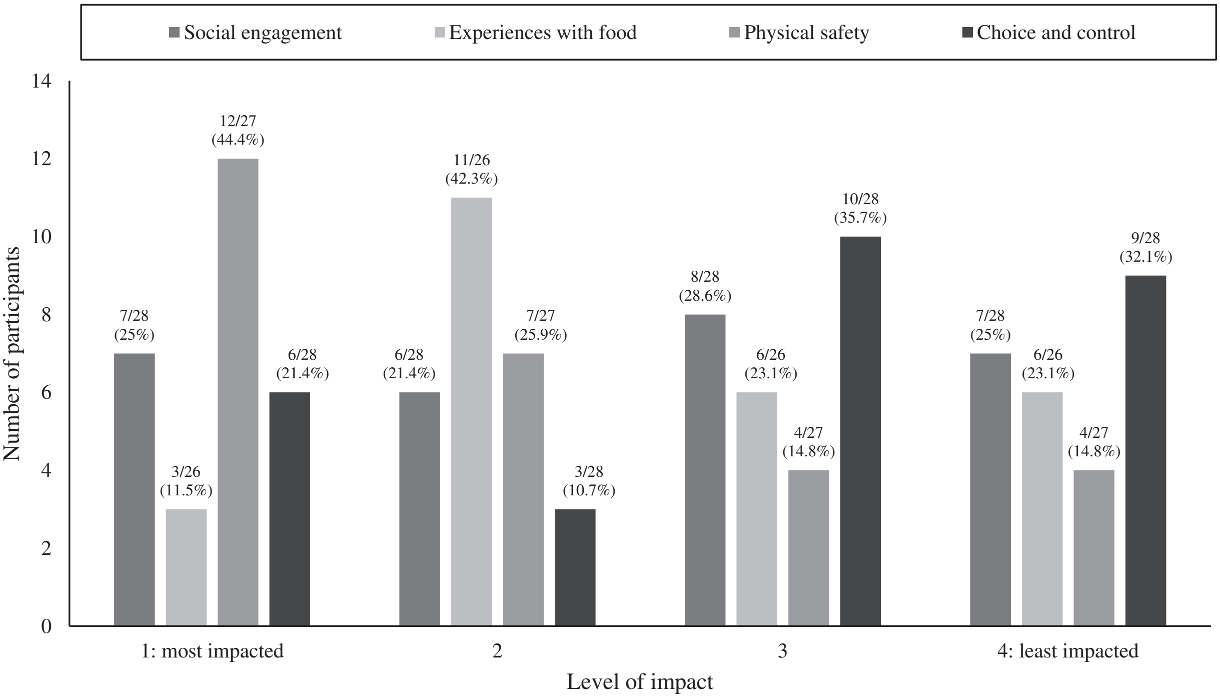

FIGURE 1 Impact of swallowing difficulties for people with dysphagia.

lowing difficulties to have the greatest impact on physical safety ($n = 12$, 44.4%), whereas choice and control was most frequently rated as being the least impacted ($n = 9$, 32.1%) (Figure 1). P89 indicated that she prioritized reducing choking risk over her desire to keep preferred foods and flavours as part of her diet, writing 'I choose foods based on "potential choke value"'. Overall, participants' 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 Figure 1. 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 prioritized eating out, accepting that this meant limiting their control over food choices. The intersection of the various impacts of dysphagia on the person influenced decisions participants 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.'

After physical health, the area rated most impacted for people with dysphagia was social engagement ($n = 7$, 25%) (Figure 1). People with dysphagia rated the impacts of dysphagia as being greater on social engagement than did either supporters of people with dysphagia or allied health professionals (Figure 2). Supporters and allied health professionals together considered social engagement to be the least impacted ($n = 10$, 47.6%) and less impacted than the

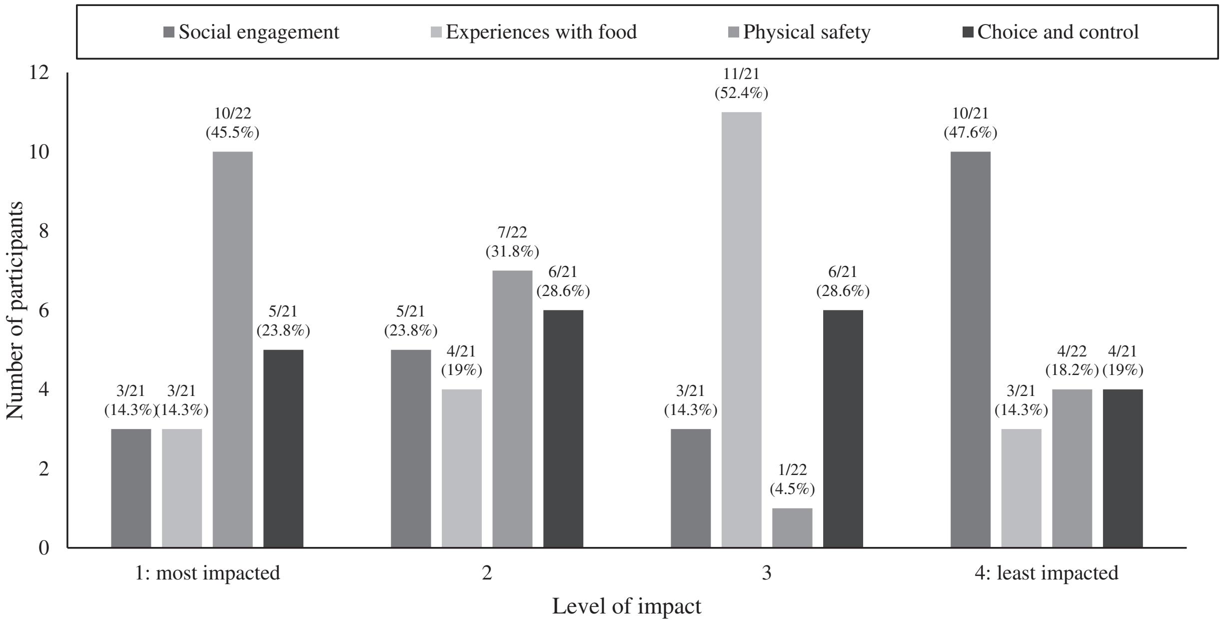

FIGURE 2 Impacts of swallowing difficulties from the perspective of supporters of people with dysphagia and allied health professionals.

experiences with food (n = 11, 52.4%). However, participants across all groups also recognized the relationship between the physical features of food and social engagement. As 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'.

Perceived impacts of dysphagia interventions on health and social engagement

Participants across the groups 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. 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 respectively (Figure 3). P72 wrote, 'physical safety is something I have to be mindful of every meal'. Almost all the participants with dysphagia considered that their dysphagia had a greater impact on their social experiences than did their dysphagia interventions, including modifications food or fluid textures. Only one participant with dysphagia (4.3%) reported that their need for texture-modified food had impacted more on their social engagement than their 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 by dysphagia interventions (Figure 4). 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, an SLT commented that 'most [people] report being upset that they will not be able to have preferred foods or the things that they want'.

Participants with dysphagia described the impact of dysphagia interventions on their social inclusion through being able to eat out with others. Of the 55 responses provided, the greatest 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 to make sure that texture-modified foods were available (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

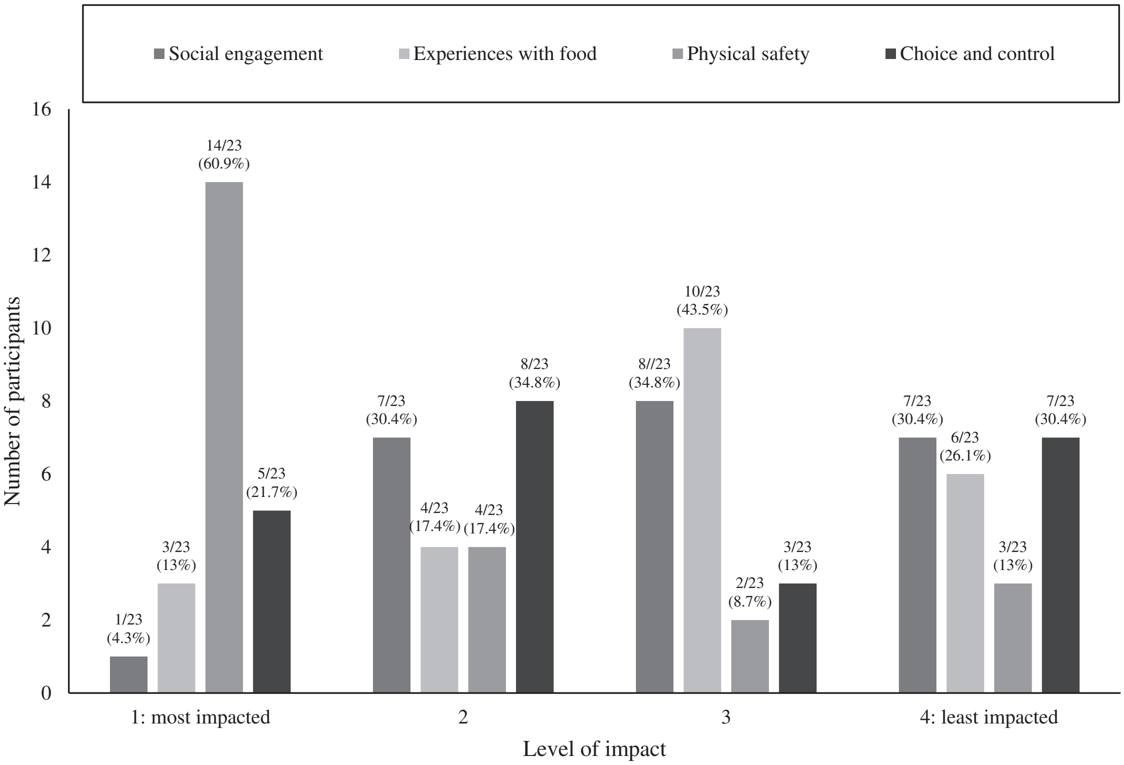

FIGURE 3 Impacts of texture-modified food for people with dysphagia.

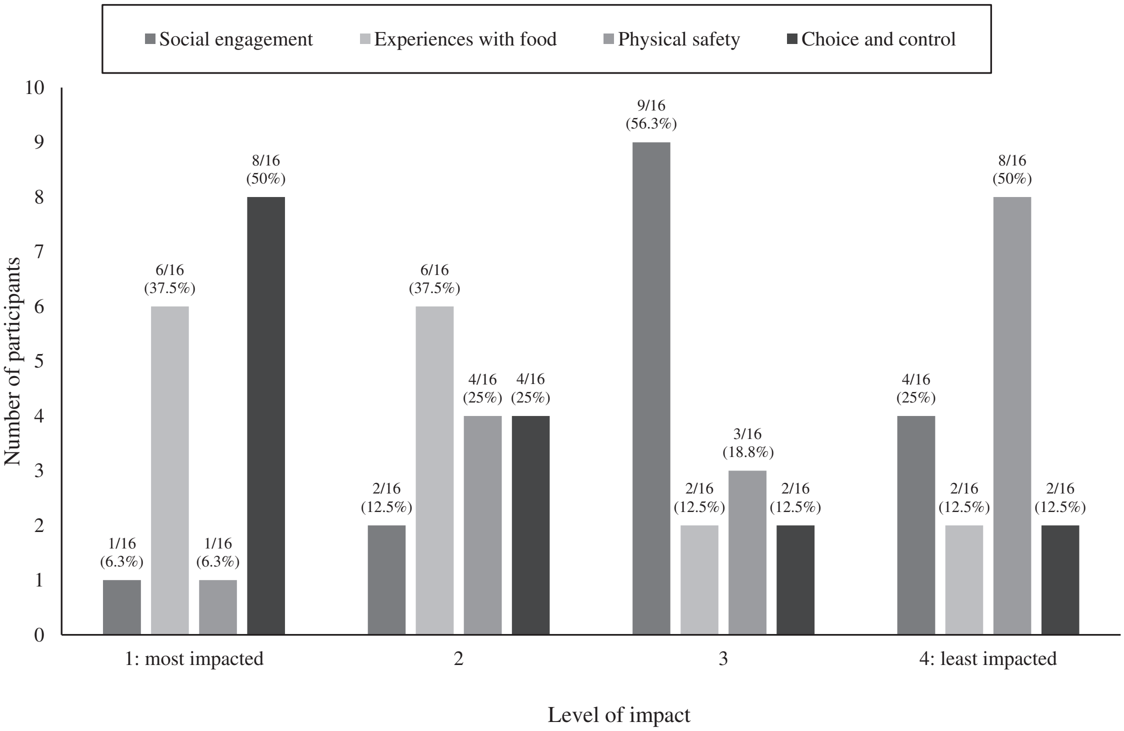

FIGURE 4 Impacts of texture-modified food on quality of life from the perspective of supporters of people with dysphagia and allied health professionals.

> 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 across groups 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 with dysphagia 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 the 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 the participants 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'.

Impacts of dysphagia or its interventions on choice and control

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, while 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 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 not accommodate their choices', and P9 wrote that participation was limited by others 'assuming incompetence, doing everything for the individual without asking'. Indeed, P9, an SLT, 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, highlighting that the various and intersecting impacts of dysphagia influence how people with dysphagia design their mealtimes to support their own quality of life (Smith et al., 2022a, 2023). 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 than was seen in the prior literature (Smith et al., 2022a). For example, there is now a greater understanding of how people with dysphagia might weigh up and trade off the restrictions on food texture, types, or variety with increases in feelings of safety and control in relation to the swallow. The findings, in adding to literature on mealtime experiences, 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 (Smith et al., 2022a). By adding to prior research outlining impacts of dysphagia on quality of life (Smith et al., 2022b, 2023), the findings of this study 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 along with the priorities of different parties in relation to those impacts. This highlights the need for the perspectives of all parties involved in mealtimes to be considered when implementing dysphagia therapies as different people may not place the same weight on different mealtime elements.

The findings of this study verify and expand upon concepts identified in earlier research with highly heterogenous participant groups (Smith et al., 2022b, 2023). In examining the perspectives of a larger number of people from a wider geographical area than in prior research (including Australia, the US, and the UK), this study increased appreciation of key stakeholders' views on concepts identified in prior qualitative studies with similar aims (Smith et al., 2022b, 2023). 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 which did not occur in prior research (Balandin et al., 2009; Howells et al., 2021; Smith et al., 2022a).

Findings of this study also provide some further insights into assistive technology for mealtimes, and mealtime assistance or supports being provided (Reddacliff et al., 2022). For example, the present study highlights the importance of multiple items of assistive technology being used by people with dysphagia during mealtimes (i.e., adaptive cutlery, cups, plates, non-slip mats, and straws) in impacting on quality of life, as these technologies provided them a way to maintain their choice and control along with their physical safety. Furthermore, the mealtime assistance provided to people with dysphagia, whether in preparation or eating or both, enabled them to participate in mealtime activities that they were not able to complete independently, and this positively impacted their quality of life. While participants in this study did not identify as having intellectual disability, these findings align with prior research examining the mealtime assistance needs of people with dysphagia and intellectual disability; particularly on the need for and benefit of support for a wide range of mealtime-related tasks (e.g., modifying food textures, making environmental modifications) (Ball et al., 2012; Lin et al., 2021). Indeed, this research provides further support to the notion that mealtime assistive technologies and assistance should be flexible and be tailored to the person's individual needs 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 the person with dysphagia's quality of life. A recent systematic literature review (Jones et al., 2018) similarly concluded 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, this research highlighted that the views of people with dysphagia on the impacts of dysphagia on choice and control, social engagement, and the overall mealtime experience differed from the views of supporters and allied health professionals. The findings of this study suggest 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). While Ettinger et al. (2014) illustrated differences in opinion on taste and acceptability of texture-modified food, survey results suggested that these differences extend beyond food to views regarding the impact of swallowing difficulties. These differences in perspectives suggest that a person's direct lived experiences shape their perception of mealtimes and highlights the importance of taking the views of the person 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 (Hemsley et al., 2019; McCarthy et al., 2022). By providing these insights, this study demonstrates the need for 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 (Hemsley et al., 2019). This may include having a safety alert button to contact a neighbour or family member in an emergency. 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 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 were identified across participant groups in terms of ratings of impact. 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-related 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 study also 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., 2019, 2021). The written comment responses from people with dysphagia, supporters of people with dysphagia, and allied health professionals extend the findings of Smith et al. (2022b, 2023). In particular, it extended on the notion that mealtimes require a balance between maintaining the person's physical health along with their mealtime enjoyment, choice and control, and social engagement (Smith et al., 2022b, 2023). 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., 2022b, 2023), the relatively small sample of completed surveys returned was not representative of any of the participant groups and results cannot be generalized across all 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.

People with dysphagia who took part in the survey reported completing their written responses independently. Thus, the findings may not reflect the views of people with health conditions who also have a communication disability, that rely on other people to access the internet, or have lower levels of literacy. Further research should include consideration of the impact of diagnosis, severity, and the course of the person's dysphagia for identifying further impacts on quality of life. Further research should also seek to include people with dysphagia who live in supported accommodation or residential settings and who may need assistance for participation in research.

This research did not collect information on the aetiology of the participant's swallowing difficulties, only the timing of onset, therefore the impact of the specific dysphagia diagnosis on quality of life cannot be determined from this study. Participants' dysphagia diagnosis was based on self-report only and their level of understanding of the IDDSI terminology also could not be confirmed by researchers. Furthermore, although not seeking to exclude people with lifelong dysphagia, this research only included those with acquired dysphagia. Future research should aim to include more people with a lifelong dysphagia across the age ranges 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; and all allied health professionals identified as female. Further research should focus recruitment efforts on including the perspectives of a greater number and diversity of allied health professionals involved in dysphagia management, including occupational therapists and dietitians, and supporters including family members, direct support workers, and advocacy organization workers. These parties have a vital role in mealtime planning and management for people with dysphagia (Ball et al., 2012; Lin et al., 2021). A larger participant group would most likely yield further insights into the factors impacting on quality of life for people with dysphagia. Lastly, 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.

CONCLUSIONS

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 intersecting 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 regarding food texture modification 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., 2022b, 2023). By including each participant group, this study demonstrated the differences in opinion of participants with and without dysphagia, emphasizing the importance of speaking to people with dysphagia about their own mealtime preferences to improve their quality of life. Future research should look to generalize findings to a wider range of people with dysphagia, supporters of people with dysphagia, and allied health professionals.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ORCID

Rebecca Smith https://orcid.org/0000-0001-9523-785X
Lucy Bryant https://orcid.org/0000-0001-8497-7406
Bronwyn Hemsley https://orcid.org/0000-0002-6255-3140

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