

“Know the risks but balance that with their enjoyment”: Impacts of dysphagia on quality of life from the perspectives of allied health professionals

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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.

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METHODS: 15 allied health professionals (12 speech and language therapists 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.

Keywords: 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, 2022a); 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 & Hemsley, 2022a) 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 have a high price to pay in terms of the impact of dysphagia and its interventions (Smith et al., in press). However, the views of allied health professionals on these impacts are less well understood. In a recent survey of 144 community speech and language therapists (SLTs) 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

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Australian Therapy Outcome Measures (Perry et al., 2004) and the SWAL-QOL (Howells et al., 2019b). In follow-up interviews with the SLTs, Howells et al. (2019a) identified that community SLTs 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 SLTs to determine how they viewed and addressed quality of life for people with dysphagia. The authors suggested that community-based SLTs addressed quality of life issues more appropriately than SLTs in acute services who focused primarily on medical status. Both of these studies indicate a need for further research understanding 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 SLTs but also members of the wider multidisciplinary dysphagia management team (e.g., occupational therapists (OTs), 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 enables or impedes mealtime-related quality of life for people with dysphagia.

Methods

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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. This 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 SLT and a doctoral candidate prior to giving consent.

Fifteen allied health professionals (12 SLTs and three OTs) 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

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following focus groups recommendations to enhance rigour (Hennink et al., 2019) and this aim was met. Three further SLTs 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 in Table 1.

Table 1*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
FG1SLT3	31-45	F	SLT	Private	Metropolitan	Medical - outpatient
FG1SLT11	18-30	F	SLT	NGO	Regional/ rural	Disability, aged-care
FG1SLT12	18-30	F	SLT	Public	Metropolitan	Medical – acute
FG2SLT4	18-30	F	SLT	Private, NGO	Metropolitan	Disability, medical – rehabilitation
FG2SLT9	18-30	F	SLT	NGO	Metropolitan	Disability
FG2SLT6	18-30	M	SLT	Public	Regional/ rural	Medical – acute
FG2SLT9	18-30	F	SLT	NGO	Metropolitan	Disability
FG2SLT15	18-30	M	SLT	Private	Metropolitan	Disability, Medical – rehabilitation
FG3OT3FG3 SLT10	31-45	F	OT SLT	NGOPrivate	Metropolitan Regional/ metropolitan	Disability, aged-care
FG3SLT5	31-45	F	SLT	Private, University	Regional	Medical- acute and outpatient
FG3OT3	31-45	F	OT	NGO	Metropolitan	Disability
FG3SLT10	31-45	F	SLT	Private	Regional/ metropolitan	Disability, aged-care
FG3SL13	31-45	F	SLT	Public	Metropolitan	Medical-rehabilitation

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FG4SLT2	18-30	F	SLT	Private, University	Metropolitan	Disability
FG4SLT7	18-30	F	SLT	Public, University	Metropolitan	Medical – acute and outpatient

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

Data collection and analysis

Participants provided written consent prior to attending one of four focus groups through Zoom (Zoom Video Communications Inc, 2011) 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, an SLT 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 SLTs 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, 2022a; Smith, Bryant, Reddacliff et al., 2022) (see Appendix A) 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

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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, 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 2). Illustrative quotes supporting these themes and sub-categories are presented in Table 3. 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.

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Table 2

Unmitigated risk of not addressing quality of life for people with dysphagia and ways to manage it

Central Theme	Sub-Theme	Areas of interest											
		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							

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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).

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Table 3

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.” (FG1SLT11)
	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.” (FG1SLT3)
	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.” (FG1SLT3)
	Negative food experiences	“The meals do come out looking like four 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.’” (FG2SLT6)
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!” (FG4SLT2)
	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.” (FG4SLT7)
	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

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Opinions of others and a flexible, person-centred approach

family to make changes that are more possible in the home rather than in the hospital setting yeah.” (FG2SLT6)

“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.” (FG3SLT10)

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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” (FG4SLT2). FG2SLT4 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 FG1SLT3 stated: “eating and drinking is innate to socialising.” Participants in FG2 agreed that people with dysphagia may be socially excluded particularly if they experience

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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’”. FG1SLT12 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”.

FG2SLT4 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. FG2SLT4 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.” FG2SLT4 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

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texture recommendations, their risk of aspiration pneumonia and hospitalisation would be reduced and their quality of life increased. FG1SLT3 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. FG4SLT7 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. FG4SLT7 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. FG4SLT2 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 that food

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presentation was 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” (FG2SLT6), and FG3SLT5 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. FG4SLT7 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. FG1SLT12 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. FG1SLT12 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.” FG1SLT3 reported having previously used food moulds, but this was discontinued as the silicon moulds became mouldy through a lack of careful drying. FG3SLT5 viewed that food shaping was 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” (FG3SLT5) 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

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barrier to mealtime quality of life for people with dysphagia if meals were presented as scoops of “goo” (FG3SLT5). As an alternative, FG1SLT11 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” (FG1SLT11).

Dysphagia management choices

Participants across groups agreed that mealtime management should be multidisciplinary to maintain mealtime-related quality of life. FG2SLT4 in particular described fellow SLTs as “swallow focused” who needed to “zoom out” and look at the whole person. FG1 participants viewed that providing a texture-modified diet may increase a person’s confidence to engage in events with reduced fear of choking. FG1SLT3 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 and said: “once they found they could get thickened fluids in coffee flavour... they were the happiest person”. FG3SLT13 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 FG2SLT9, 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

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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. FG4SLT7 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 viewed 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. FG1SLT11 stated: “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. FG1SLT3 encouraged family members to taste test modified foods to increase their understanding of food consistency and the importance of taste. FG1SLT3 suggested that such learning experiences facilitated empathy and increased acceptance of texture-modified food. FG1SLT3 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 appetizing meals. FG3SLT5 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

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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 that family members and support workers applying flexibility in a person-centred approach (e.g., in modifying mealtime routines, food preparation procedures) helped 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" (FG1SLT11). 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, FG2SLT9 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".

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FG3 and FG4 participants recognised the importance of understanding a person's social and cultural background to shape social participation at mealtimes. FG3SLT5 and FG4SLT7 acknowledged that SLTs need flexibility when considering social and cultural events and the types of food served. FG3SLT5 stated, "there's highly likely [foods] that they might be able to have without feeling like their 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 dysphagia in the meal. FG4SLT7 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 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. FG2SLT15 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 to eat 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

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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). 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

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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), 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). It also demonstrates the importance of dysphagia interventions being a facilitator for quality of life (Smith et al., in press).

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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, 2022c). 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

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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.

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Conflict of interest

The authors declare no conflict of interest to report.

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Appendix A

Focus Group Question Guide

1. What is your role in relation to supporting with people with dysphagia and their mealtime experiences?
2. 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. Are there any other impacts of texture-modified meals on a person that would also affect their health or quality of life?
4. What's 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)