Disability and Rehabilitation

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/idre20

Enabling decision-making: what assists people with motor neurone disease when they consider gastrostomy insertion?

Anne Hogden, Julie Labra & Emma Power

To cite this article: Anne Hogden, Julie Labra & Emma Power (28 Aug 2024): Enabling decision-making: what assists people with motor neurone disease when they consider gastrostomy insertion?, Disability and Rehabilitation, DOI: 10.1080/09638288.2024.2395473

To link to this article: https://doi.org/10.1080/09638288.2024.2395473

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2024.2395473

Taylor & Francis
Taylor & Francis Group

RESEARCH ARTICLE

OPEN ACCESS

Check for updates

Enabling decision-making: what assists people with motor neurone disease when they consider gastrostomy insertion?

Anne Hogden[a], Julie Labra[b] and Emma Power[c]

[a]School of Public Health, Faculty of Medicine & Health, University of New South Wales, Kensington, Australia; [b]MND Australia, ACT, Australia; [c]Speech Pathology, Graduate School of Health, University of Technology Sydney, Ultimo, Australia

ABSTRACT

Purpose: This study explores the views of people living with Motor Neurone Disease (MND) when they consider Percutaneous Endoscopic Gastrostomy (PEG) insertion, to understand their priorities and how their decisions were informed or supported.

Materials and methods: The study took place in single multidisciplinary specialised MND clinic in New South Wales, Australia. Nine people with MND (5 male and 4 female; age range 52–73 years; disease duration 6–99 months) who were considering, or had recently undergone PEG insertion, participated. Semi-structured interviews were conducted with participants to examine individual's experience of decision-making about PEG. The data were synthesised and analysed thematically.

Results: Three main themes and two sub-themes captured participant views on their decision-making. The first, "What matters most to me," comprised optimising quality of life and maintaining family membership. The second theme explored "Understanding PEG and the clinical pathway." The third theme was "Thoughts on using a decision aid."

Conclusions: This study provides a foundation for future studies examining the longer-term outcomes of accepting, delaying or declining PEG. Insights from this study may be applicable to decision-making for any aspect of MND care where the outcomes or benefits are uncertain.

IMPLICATIONS FOR REHABILITATION

- People living with Motor Neurone Disease (MND) have complex and individual reasons for accepting or declining Percutaneous Endoscopic Gastrostomy (PEG).
- The quality of communication between people with MND and healthcare providers may be improved by a shared understanding of how people with MND view quality of life and carer burden in their own circumstances.
- Enhanced communication for informed choice and patient-centred decision-making have potential to reduce decision regret and support care pathways for those who decline PEG.

ARTICLE HISTORY
Received 2 December 2023
Revised 11 August 2024
Accepted 19 August 2024

KEYWORDS
Patient decision-making; informed choice; carer burden; quality of life; multidisciplinary care

Introduction

Motor neurone disease (MND), also known as amyotrophic lateral sclerosis (ALS) is a progressive neurological disorder that destroys the motor neurones that control essential voluntary muscle activities [1]. There is no cure, and current treatments extend survival for a short time only [2]. While disease progression rates vary considerably [1,3,4], approximately 50% of patients die within 30 months of symptom onset [5]. Frequently occurring symptoms affect swallowing, mobility, communication and limb function [6] requiring a multidisciplinary approach to care [7]. Death typically results from respiratory failure [5].

Swallowing and breathing problems, alone or in combination, create complex issues for the care and quality of life of people living with MND, and the decisions they make to manage these symptoms [8]. Those who have difficulty swallowing, and/or compromised respiratory function, may experience coughing or choking on food and drink, or fatigue that increases the time and effort needed to complete meals [9]. Loss of appetite is also prevalent in MND, often worsening as the disease progresses [10]. These difficulties can lead to reduced oral intake, weight loss, lower BMI and loss of fat mass [10]. This subsequently results in increasing fatigue, malnutrition, dehydration, and potentially shorter survival time [9,11,12]. Maintaining nutrition, hydration and oral medications becomes stressful for both people with MND and their family members. The option of gastrostomy, most commonly by percutaneous endoscopic gastrostomy (PEG), may be suggested by the care team to stabilise weight loss, preserve quality of life [13] and potentially prolong survival [14–16].

Decisions for care and quality of life are supported by evidence-based guidelines for symptom management. Current practice guidelines for PEG insertion in MND recommend: PEG placement before significant respiratory impairment [17,18]; swallowing and nutrition risk screening 3-monthly; and that PEG should be offered to patients with swallowing difficulties, weight loss or impaired nutrition at least once a year [2]. Earlier PEG insertion may improve quality of life and reduce health complications, including skin breakdown [15,16]. Early referral is therefore

CONTACT Anne Hogden a.hogden@unsw.edu.au School of Population Health, Faculty of Medicine & Health, University of New South Wales, Kensington, Australia

Supplemental data for this article can be accessed online at https://doi.org/10.1080/09638288.2024.2395473.

encouraged to achieve better outcomes and to ensure placement occurs before the occurrence of possible crisis events, such as dehydration and severe weight loss [19]. Moreover, early insertion ensures the surgery is undertaken before significant respiratory impairment occurs [20,21]. Uptake of PEG is increased if the procedure is introduced by a multidisciplinary nutritional support team, including representatives from gastroenterology, speech pathology and dietetics [22]. Nevertheless, the best approach for the introduction and timing of PEG discussions for people with MND is unclear [15,23,24]. Subsequently, people living with MND often experience a lack of clear guidance from healthcare professionals on the "right time" for PEG insertion [25]. While evidence-based guidance is emerging [23,26,27], specific indicators for gastrostomy insertion, such as the degree of swallowing difficulty, respiratory dysfunction or nutritional compromise, require further investigation.

Adjusting to a diagnosis of MND can take considerable time, and for many, discussions of equipment and procedures to manage symptoms are very confronting and overwhelming [28]. In making their decisions, people living with MND may focus on their immediate circumstances rather than their future care needs [29]. The decision-making environment (such as during clinical consultation, or when exploring options independently), patient experiences of MND (such as reactions and ability to engage with the multidisciplinary care team (MDT) and personal philosophies can also influence how prepared people are to make decisions about their care [30,31]. Patients and families may take months to agree to PEG insertion following recommendation from the multidisciplinary care team [32]. Delayed consent to PEG becomes a problem if it leads to unplanned or emergency insertions which have a higher 30-day mortality rate, increased hospital length of stay [33] and fewer home discharges [34].

Intrinsic and extrinsic factors have been found to influence patients' decision-making for or against PEG [35]. Intrinsic, or internal factors, may stem from patients' perceptions of their MND status [25], their experiences of dysphagia [36] or acceptance of their prognosis [35]. Delays in PEG insertion or wanting to maintain oral nutrition and hydration for as long as possible can result in PEG being requested at the last minute [24]. Moreover, patients' perceptions of their nutritional status and swallowing capability may not correlate with more objective measures [24,32]. Negative views of gastrostomy [24] and reactions to changes in swallowing ability, such as sense of control [25] sense of self [37] and quality of life concerns [37,38] also play a role. In turn, individuals' values and belief system [29,35,39] may influence their choices, although the extent of this is unclear. Extrinsic, or external, influences on decisions for or against PEG include health professional guidance and support, particularly from specialised MND clinic teams [25,35]. Even so, professional advice appears to be of less influence than individuals' perceptions of their own situation [24,32]. Additionally, patients' concerns for the wellbeing of their family members may influence their choices [39]. While intrinsic and extrinsic factors give some insight into patients' choices, less is understood about the complexities that people with MND work through as they consider PEG [8]. From a clinical viewpoint, few treatment options are available to choose between once people with MND are ready to make their decision [30,35]. Where there is rapid progression of the disease, decisions about PEG are time-sensitive [24,40], limiting options to "wait and see" [29]. From an emotional viewpoint, being forced to look to the future, rather than dealing with the "here and now" may be in direct conflict with individuals' usual coping strategies and sense of autonomy [8].

To assist people with MND to make decisions in accordance with their values and preferences, decision support tools (or decision aids) have been developed from shared decision-making frameworks, within the multidisciplinary care setting [41–43]. The influence of these evidence-based tools on the care and quality of life choices of people with MND is yet to be determined. Our previous study of decision-making for MND care revealed connection between individual's perceptions of their own swallowing ability and nutritional status, and how this influenced their decision to accept or decline gastrostomy [32]. This current study takes a deeper look at the views of people living with MND when considering PEG, to further understand their priorities and how their decisions could be informed or supported.

Methods

Design

This study was designed in consultation with a person living with MND, and clinicians from the clinic site who provided comments on the interview guide. A descriptive qualitative approach was taken to provide deep understanding of participant perspectives and experiences with decision-making for PEG. We sought to understand their priorities, values and preferences, and information they received for making or supporting their decision. This qualitative study forms part of a larger, mixed-methods study [32], which aimed to explore demographic and disease-related factors influencing gastrostomy uptake; and reasons why people with MND accept or decline gastrostomy. This larger study focused on how perceptions of swallowing and nutrition might influence their decision making. Specific methods for the qualitative dataset are outlined below.

Reflexivity

Two of the researchers (JL and AH) were experienced in MND clinical care and the service delivered at the study site. Familiarity with MND care and the clinic setting helped inform the researchers' interpretation of participants' responses, promoting deep engagement with the data and giving context to the experiences reported by the participants.

Tools

The interview guide was developed following a literature scan of previous studies of decision-making for PEG in MND, and then further refined by the research team. Sixteen open-ended questions were designed to elicit participants' perceptions of their swallowing and nutrition, their experience with PEG decision-making, and factors contributing to their decision (Supplementary file 1: Interview guide). The interview guide was trialled by one person living with MND and one health professional, with no amendments suggested. Additionally, participants were shown a paper version of a decision support tool during their interview, and asked to comment on how useful they thought it might have been for their decision-making - or could be for others.

Setting

Data collection took place in a single multidisciplinary MND clinic in New South Wales (NSW), Australia. The clinic was based in a Rehabilitation hospital, with the multidisciplinary treating team including a Clinic Coordinator, Rehabilitation and Neurology medical specialists, Palliative Care nurses, and allied health professionals (speech pathology, dietitian, physiotherapy, occupational therapy, social work). Representatives from the Pastoral Care service and the state MND Association (MND NSW) also regularly attended the clinic. Consultations for Gastroenterology and Respiratory medicine were conducted at the nearby tertiary care hospital.

Participants

Potential participants were people diagnosed with MND, who were considered candidates for PEG by the treating rehabilitation physician [32]. People with MND attending the clinic at 3-monthly intervals were recruited to the study between May 2016 and February 2018. One hundred and thirty-nine clinic sessions took place with people with MND during this period.

Inclusion criteria were: cognitive ability to provide informed consent and participate in an interview, [determined by a score of ≥25/30 on the Mini-ACE [44]]; English-language skills to allow informed consent and optimal participation in data collection activities; ability to respond to open-ended questions using speech, writing or a communication device; and residing up to an hour's drive from the hospital to enable data collection at home. People with MND were not invited to participate if the treating team considered gastrostomy to be an unsuitable option (e.g., those with poor health status or very limited prognosis). Those meeting the inclusion criteria ($n = 33$) were referred to the study team by the treating physician and were then approached by the interviewer, either in person, *via* phone or email.

Data collection

Semi-structured interviews were conducted by a speech pathologist from the MND Clinic site who was unknown to the participants, and who was trained in research interview skills by members of the study team. Eight participants completed their interview verbally. The remaining participant responded using handwriting due to difficulties with speech, and the interviewer clarified these responses immediately after the interview. Six interviews were conducted in participants' homes, two on the inpatient unit at the study site, and one in the outpatient clinic. Interviews lasted up to one hour and were audio recorded for the eight patients using speech. Member checking was conducted throughout the interview process to confirm with participants that their viewpoints were accurately represented [45].

Analysis

Thematic analysis was completed on the collected data. Interview transcripts were analysed in two ways to meet the dual requirements of the larger mixed-method study and this qualitative exploration of participant views. A stepwise process of deductive coding was followed by an inductive approach using reflexive thematic analysis [46,47] to synthesise and analyse the spoken and written interview data in greater depth.

First, interviews were transcribed and imported into QSR NVivo 11 software (QSR International Pty Ltd, Melbourne, Australia) for data management. Three researchers read through the transcripts to develop an open coding framework [46]. This initial framework grouped data into five domains to understand participants' current concerns; the anticipated benefits of their decision; their decision-making processes; information sources; and any decisional conflict experienced. These groupings were discussed by the research team to ensure representation of participants' experiences until consensus was reached, and the results are reported in our previous publication for the larger mixed method study [32].

For the study reported here, one researcher (AH) analysed the interview data to review the initial codes from the deductive analysis undertaken previously. These codes were then expanded through coding the whole data set inductively to develop sub-themes and themes to represent what participants had reported. The themes and subthemes were then discussed with the research team, and consensus was reached that these themes represented the findings accurately. Data were explored in depth as individuals, and then synthesised as a whole to identify similarities and differences in participants' approaches to their decision-making.

The COREQ checklist domains [48] were applied to ensure rigour of the reporting process (Supplementary file 2: COREQ).

Results

Nine people with MND took part in interviews. Eight participants had chosen to have PEG inserted, while one participant declined (Table 1). Three participants had PEG inserted before enrolling in the study.

Three main themes with two sub-themes captured participant views on their decision-making processes (Table 2). Anonymised participant quotes are used below to illustrate the findings.

Theme 1: what matters most to me

Participants framed their reasoning to have or decline PEG in terms of what was most important to them, the benefits they saw for themselves and their family members, and how their decision supported these priorities and perceived benefits. Improved quality of life was considered the most important goal, but what constituted quality of life varied between participants.

Optimising quality of life

Many participants acknowledged that PEG might only extend their life for a short time but were willing to undergo the procedure to enhance the quality of the time they had. Some viewed PEG

Table 1. Participant characteristics at the time of study enrolment.

Participant	Gender	Age	Uptake of PEG	Site of disease onset	Disease duration (months)
P1	M	70	Yes	Limb	16
P3	F	68	Yes	Bulbar	6
P4	F	69	Yes	Limb	99
P5	M	73	Yes	Limb	16
P6	M	64	Yes	Limb	12
P7	F	63	Yes	Limb	24
P8	M	64	Yes	Limb	39
P9	F	72	Yes	Bulbar	13
P10	M	52	No	Limb	10

Table 2. Themes and sub-themes.

Theme	Sub-theme
What matters most to me	Optimising quality of life Maintaining family membership
Understanding PEG and the clinical pathway	
Thoughts on using a decision aid	

as the best of few options available to them. “There is no third option, it’s either a yes or a no to this” (P6)

Even though it would not change the outcome, participants saw PEG as a way of living better through optimising their nutrition and hydration. Those who viewed PEG as benefitting quality of life also prioritised improving their quality of life over lengthening their survival. Only one participant commented on the idea that PEG might allow him to live longer. Even so, he did not consider it the main reason for having PEG inserted:

> I will be adjusted to when it is done, and I know that that is what is going to give me better quality of life (P3)

Similarly, a participant who declined PEG also prioritised his quality of life overextending his survival. In contrast to those who accepted PEG, he felt that the trade-off of possible additional time came at a cost to life quality.

> No, all it’s going to do is maybe give me an extra month or something like that in life, in quality that I don’t want, and make it uncomfortable now. (P10)

Several participants discussed the benefits of PEG in managing their physical health and defined the contribution this would make to their quality of life. For example, four patients (P3, P5, P7, P9) anticipated that PEG would help them feel less anxious about eating, drinking and taking medication. The most frequently raised concerns were loss of appetite and interest in food, followed by the effort required to eat. Participants reported effortful chewing, difficulty coordinating breathing with eating, and managing fatigue.

> My main reason for getting the PEG was my swallowing and the timing of my decision was mainly impacted by worsening breathing. (P9)

Following education from their clinical care team, participants were aware that a window of opportunity existed to have a PEG inserted and knew that earlier insertion was encouraged. While the timing of participants’ decision-making about PEG varied, their readiness to undertake the procedure was aligned to their wishes for optimising their quality of life.

> If my breathing gets any worse, they won’t be able to put it in, because … they can’t put me under anaesthetic … they said, “It’s up to you, you don’t have to, what do you think about doing that early?” I thought, “Well, at least we’ll do it early, just in case.” (P8)

Being comfortable at the end of life was an important aspect of quality of life. It was given as a reason to both have PEG, and to decline it. Several participants considered that PEG would improve their end-of-life comfort.

> I thought, well if I’m going to be - I’ve got to be comfortable in my last days - make it the best I can. (P8)

Conversely, the participant who declined PEG preferred not to depend on artificial feeding at the end of his life. He anticipated that not having PEG would improve his comfort and quality of life.

> My main thing about this is, it’s uncomfortable enough as it is … and I do get a bit of reflux sometimes and I don’t want to exacerbate that and I don’t want something to be uncomfortable on top of what I’ve already got when it’s not going to change the length of – you know what I mean – it’s not going to make that much difference. (P10)

Maintaining family membership

Participants linked their quality of life to their relationships with family and friends. As well as benefits for their personal comfort, participants considered what having a PEG might allow them to do. Optimising physical health through improved nutrition and hydration gave hope that their usual relationships, and roles within those relationships could be maintained. Reported benefits included being able to participate in family activities.

> I am thinking that it will help me because you can still go out and you know, I like to go shopping with my daughter … and I am having Christmas Day here (P3)

Moreover, participants anticipated the benefits having a PEG would give their family members. These included making themselves easier to care for - maintaining PEG feeds and equipment was considered less stressful than ensuring the person with MND was meeting their nutritional needs through eating and drinking - and helping to maintain their independence as long as possible to lessen any burden on their family.

> It’s gonna help [wife’s name] a heck of a lot (P1)

P10 also considered the impact his decision might have on his family, believing that not having a PEG and potentially shortening his life would make things easier for his wife.

> I’ve discussed this way before my life situation with my wife. We’ve gone through it because she knows it’s driving me mad doing what I’m doing – nothing - I’m not that kind of person, and I don’t like being a pain in the arse. (P10)

Six of the nine participants experienced conflict during their decision-making about PEG. These participants had initially declined PEG insertion but overturned their decision as their circumstances changed. While artificial feeding was in conflict with their values, the need for quality of life or comfort at the end of life overrode these values.

> I always felt that I would just go with however this disease progressed, and in some ways, having the PEG goes against that. (P7)

> The idea of extending – having a surgical procedure is probably a bit intrusive but it happens, but just wonder about the practicality of it – is it worth having done to extend your life for 10 weeks? (P6).

Ultimately, most participants perceived the benefits of PEG to be greater than the disadvantages. This led them to their decision to undergo PEG insertion, despite their conflicted values.

Theme 2: understanding PEG and the clinical pathway

Participants reported making the decision to accept or decline PEG through discussion with their clinic team and, for three, with support from MND Association Advisors.

As participants attended the same clinic site, they had received the same health information and participated in similar discussions with clinic team members about PEG. Nevertheless, participants emphasised different aspects of the same process as helpful to their decision-making. These were gaining an understanding of PEG and the clinical pathway available to them for PEG insertion.

Most participants had received health literature about PEG, provided by the clinic coordinator. Discussion with the health professionals made participants aware that a decision needed to be made sooner rather than later.

> And so they go away and I am thinking hmmm, goodness, this is something I might have to think about … and then I say because they say, I am this now but, I am better to have PEG than [it] is no good, gone, too late. (P3)

Taking in the amount of information required was reported to be challenging. Five participants reported that seeing PEG equipment demonstrated by the clinic team helped their understanding.

Four participants also reported prior knowledge of PEG feeding from their work, family or friends. While the approaches used by individual participants to arrive at their decision varied according to their circumstances and experiences, there were common elements to this process due to the clinical pathway implemented by the clinic site. This PEG pathway comprised admission to an acute care hospital for the surgical insertion, followed by a short stay in the rehabilitation hospital for surgical aftercare and education on how to manage their PEG, with referrals to community-based health professionals to oversee ongoing management of the PEG. Four participants valued the information health professionals provided on where and how the procedure would be done, and the follow up care that would be available. Information was provided through discussion with a range of health professionals, including the rehabilitation specialist, gastroenterologist, clinic coordinator, dietitian, respiratory physician, speech pathologist, clinic nurse and community nurse.

> …we went to [the hospital] and we spoke to the guy – what do they call – gastroenterologist. Yep, so I spoke to him and asked him questions I wanted to know and he gave me the pluses and the minuses and then we made up our minds there. (P10)

Theme 3: thoughts on using a decision aid

Participants were asked their views on a decision aid designed to assist people with MND in their decision-making about PEG. Participants commented on both the content of the decision aid and the processes for using it. The information contained in the decision aid was considered helpful when deciding to either accept or decline PEG. Participants identified several aspects of the content that was useful to them:

> I think it would have helped in as much as it prepares you. Like it gives you an idea of what it's about so that you can ask intelligent questions because it is very difficult if you don't understand something to even ask a question … as an introduction, so you're not ignorant. (P7)

> They had some pros and cons in there which gives you a good idea of what might be the case … and I remember, like it did go through stuff like hydration and everything like that. (P10)

> Because it's telling them, you know, showing them what they want – whether they want it or not, or what their decision is. (P4)

Four participants commented on the process for using the decision aid, relating to their experience during clinic consultations. Three people indicated a preference for being introduced to the decision aid during their consultation with health professionals. This was to assist understanding of the content and to tailor this content to individual's needs, as illustrated in the following exchanges:

> Interviewer: [Is this] something that you think a speech pathologist or a dietitian, or a coordinator should go through with people or should they just give it to people to walk away with and read?
>
> P10: No, I think they should go through it.
>
> P6: I would favour somebody going through and I say that because not everyone's level of comprehension is the same.

The issue of optimal timing for introducing the decision aid to people with MND was raised. One participant stated that the content of the decision aid might be challenging if given too early: I understand it because I am having a swallowing problem … [if they don't have swallowing problems] … this might be a bit confronting. (P3)

Finally, one participant emphasised taking Theme 3: on the information given in the decision aid. This was considered beneficial to a patient-centred decision-making process, by not having to decide instantly:

> Well, with a bit of quiet time at home, go over this and something that might have occurred to you, you know, of your own volition. Might be easier than making a decision under the perception of speed or duress… (P6)

Discussion

This study examined the priorities of people living with MND when deciding to accept or decline PEG, and how their decisions were informed or supported. Our findings reveal nuances of how these priorities are expressed, particularly in terms of individuals' quality of life. While more studies are examining quality of life in MND [8], the effects of PEG on quality of life for people with MND have not been fully explored [49], particularly from the point of view of those who refused PEG insertion.

In this study, participants consistently prioritised quality of life [37] over length of life [50,51] reflecting the findings of a recent review of gastrostomy and non-invasive decision-making [8]. While interventions such as PEG offered some benefit towards being comfortable at the end of life, not all participants were convinced that the trade-off between PEG insertion and improvement in their quality of life was worth it. That some changed their mind to accommodate PEG indicates that having an option to maintain nutrition and hydration until death, while not ideal, was better than nothing. Even so, it is unclear how much fear of an uncomfortable death plays a part in this. This view of decisional conflict in a terminal condition, where long held beliefs and values against artificially prolonging life are overturned, suggests the desire to make the best of the time they have left. As demonstrated, views on what constitutes quality of life for people with MND vary between individuals. While quality of life is prioritised, what constitutes quality of life needs to be determined individually.

These findings add to previous work revealing that improvement to quality of life following gastrostomy is unpredictable [49] and should not be an expectation of people with MND or their healthcare professionals [38]. The decision of the youngest participant in our study to refuse PEG suggests that some people with MND view quality of life in terms of their autonomy and control [8] rather than an expectation of a comfortable end to life. Nevertheless, what remains unclear is to what extent people with MND make their choices to harmonise with family expectations [8] rather than exert a conflicting choice for themselves.

Concern for family members [8], expressed as the wish to avoid carer burden, was a reason to both accept or decline PEG. Carer's quality of life could be seen to either benefit or be disadvantaged by the daily workload of managing gastrostomy equipment and feeds. This echoes findings by (39) "… that concerns for significant others contribute to participant's QoL because of their existential value. It was important … to minimise the impact of limitations and burdens associated with ALS on significant others, even at a cost to self" (p.1). Finally, people with MND do not always view swallowing difficulties as their main concern, with their priorities often differing from their health professionals' concerns [32,36]. This creates space for discussion of what matters most to people with MND before offering professional guidance based on clinical testing and professional judgement. Understanding of patients' fears and priorities should be ascertained before discussions about interventions are begun. Knowing what people considering gastrostomy *don't want* is just as important as understanding what they do [52].

Strengths

Our findings inform models of decision-making for MND care [30]; in particular, health professionals' understanding of patients' fears, priorities and attitudes to carer burden will enhance their discussions during the initial phase of participant engagement [30].

As part of a larger study, this paper explores decision-making priorities of people living with MND in addition to factors that influence their decision. While this current study focused on the uptake of PEG, their priorities and the support used by people with MND, it has broader implication for other treatment decisions that may extend survival or aim to promote a better quality of life as the disease progresses [49]. Insight gained into decision-making may also apply to people living with other rapidly progressive, terminal conditions. Understanding of the reasons people with MND accept or decline treatment options (not just PEG) can inform clinical guidelines and potentially minimise the impact of delayed decision-making and treatment uptake.

Limitations

This was a single site study with nine participants. As the numbers of participants who accepted PEG outweighed those who declined, larger studies including higher proportions of participants who declined PEG are needed to understand this complex decision [49]. Larger, prospective, multisite studies could also provide further insight into broader issues that influence decision-making by people living with MND, such as social determinants of health, socioeconomic or health literacy influences on patient engagement in decision-making, and attitudes towards carer burden in life-limiting conditions.

Conclusion

The decision to have PEG insertion is complex and individual. Health professionals' awareness of the fears that people with MND experience, and how they define and prioritise quality of life, can only benefit personalised discussions for care.

Further research is needed to compare outcomes between people with who accepted or declined PEG with a focus on their quality of life, and quality of death. To add to this, carer perspectives on the acceptance or refusal of PEG could give deeper context of how an individual's decision affects those who care most for them.

Information and support for patients and families to understand PEG and the clinical pathway for insertion is indicated. Decision support tools that allow people with MND and their families to work through care decisions with health professionals and discuss their priorities, fears and attitudes may help to promote well-timed and well-informed care decisions.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by a St Vincent's Clinic Foundation "Multidisciplinary Patient-Focused Research Grant". Approval for the study was granted by St Vincent's Health Australia (SVHA) Human Research Ethics Committee (HREC/15/SVH/428).

References

[1] Goutman SA, Hardiman O, Al-Chalabi A, et al. Recent advances in the diagnosis and prognosis of amyotrophic lateral sclerosis. Lancet Neurol. 2022;21(5):480–493. doi:10.1016/s1474-4422(21)00465-8.

[2] Miller RG, Jackson CE, Kasarskis EJ, et al. Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology. 2009a;73(15):1218–1226. doi:10.1212/WNL.0b013e3181bc0141.

[3] Labra J, Menon P, Byth K, et al. Rate of disease progression: a prognostic biomarker in ALS. J Neurol Neurosurg Psychiatry. 2016;87(6):628–632. doi:10.1136/jnnp-2015-310998.

[4] Westeneng H-J, Debray TPA, Visser AE. Prognosis for patients with amyotrophic lateral sclerosis: development and validation of a personalised prediction model. Lancet Neurol. 2018;17(5):423–433. doi:10.1016/s1474-4422(18)30089-9.

[5] Kiernan MC, Vucic S, Cheah BC, et al. Amyotrophic lateral sclerosis. Lancet. 2011;377(9769):942–955. doi:10.1016/S0140-6736(10)61156-7.

[6] Miller RG, Jackson CE, Kasarskis EJ, Quality Standards Subcommittee of the American Academy of, N., et al. Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology. Neurology. 2009b;73(15):1227–1233. doi:10.1212/WNL.0b013e3181bc01a4.

[7] Sukockien E, Iancu Ferfoglia R, Truffert A, et al. Multidisciplinary care in amyotrophic lateral sclerosis: a 4-year longitudinal observational study. Swiss Med Wkly. 2020;150(2324):w20258. doi:10.4414/smw.2020.20258.

[8] White S, O'Cathain A, Halliday V, et al. Factors influencing decisions people with motor neuron disease make about gastrostomy placement and ventilation: A qualitative evidence synthesis. Health Expect. 2023;26(4):1418–1435. doi:10.1111/hex.13786.

[9] O'Rourke F, Vickers K, Upton C, et al. Swallowing and oropharyngeal dysphagia. Clin Med (Lond). 2014;14(2):196–199. doi:10.7861/clinmedicine.14-2-196.

[10] Ngo ST, van Eijk RPA, Chachay V, et al. Loss of appetite is associated with a loss of weight and fat mass in patients with amyotrophic lateral sclerosis. Amyotroph Lateral Scler Frontotemporal Degener. 2019;20(7-8):497–505. doi:10.1080/21678421.2019.1621346.

[11] Heffernan C, Jenkinson C, Holmes T, et al. Nutritional management in MND/ALS patients: an evidence based review. Amyotroph Lateral Scler Other Motor Neuron Disord. 2004;5(2):72–83. doi:10.1080/14660820410020349.

[12] Wei Q, Ou R, Chen Y, et al. RNM-01 weight stability is associated with longer survival in amyotrophic lateral sclerosis. Amyotroph Lateral Scler Frontotemporal Degener. 2019;20(sup1):309–326. doi:10.1080/21678421.2019.1647001.

[13] Chhetri SK, Bradley BF, Majeed T, et al. Enteral feeding in motor neurone disease: patients' perspectives and impact on quality of life. Palliat Med. 2017;31(7):676–677. doi:10.1177/0269216316679928.

[14] Burkhardt C, Neuwirth C, Sommacal A, et al. Is survival improved by the use of NIV and PEG in amyotrophic lateral sclerosis (ALS)? A post-mortem study of 80 ALS patients. PLoS One. 2017;12(5):e0177555. doi:10.1371/journal.pone.0177555.

[15] Katzberg HD, Benatar M. Enteral tube feeding for amyotrophic lateral sclerosis/motor neuron disease. Cochrane Database Syst Rev. 2011;2011(1):CD004030. doi:10.1002/14651858.CD004030.pub3.

[16] ProGas Study Group. Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): a prospective cohort study. Lancet Neurol. 2015;14(7):702–709. doi:10.1016/S1474-4422(15)00104-0.

[17] MND New Zealand. *New Zealand best practice recommendations for the care of people with motor neurone disease*; 2022. Retrieved 28 June 2023 from https://mnd.org.nz/for-professionals.

[18] Shoesmith C, Abrahao A, Benstead T, et al. Canadian best practice recommendations for the management of amyotrophic lateral sclerosis. CMAJ. 2020;192(46):E1453–E1468. doi:10.1503/cmaj.191721.

[19] Fasano A, Fini N, Ferraro D, et al. Percutaneous endoscopic gastrostomy, body weight loss and survival in amyotrophic lateral sclerosis: a population-based registry study. Amyotroph Lateral Scler Frontotemporal Degener. 2017;18(3-4):233–242. doi:10.1080/21678421.2016.1270325.

[20] Lateral S, Andersen PM, Abrahams S, EFNS Task Force on Diagnosis Management of Amyotrophic. et al. EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)–revised report of an EFNS task force. Eur J Neurol. 2012;19(3):360–375. doi:10.1111/j.1468-1331.2011.03501.x.

[21] Nagashima K, Furuta N, Makioka K, et al. An analysis of prognostic factors after percutaneous endoscopic gastrostomy placement in Japanese patients with amyotrophic lateral sclerosis. J Neurol Sci. 2017;376:202–205. doi:10.1016/j.jns.2017.03.029.

[22] Zhang L, Sanders L, Fraser RJL. Nutritional support teams increase percutaneous endoscopic gastrostomy uptake in motor neuron disease. World J Gastroenterol. 2012;18(44):6461–6467; discussion p.6466. doi:10.3748/wjg.v18.i44.6461.

[23] Benstead T, Jackson-Tarlton C, Leddin D. Nutrition with gastrostomy feeding tubes for amyotrophic lateral sclerosis in Canada. Can J Neurol Sci. 2016;43(6):796–800. doi:10.1017/cjn.2016.28.

[24] Stavroulakis T, Baird WO, Baxter SK, et al. Factors influencing decision-making in relation to timing of gastrostomy insertion in patients with motor neurone disease. BMJ Support Palliat Care. 2014;4(1):57–63. doi:10.1136/bmjspcare-2013-000497.

[25] Greenaway LP, Martin NH, Lawrence V, et al. Accepting or declining non-invasive ventilation or gastrostomy in amyotrophic lateral sclerosis: patients' perspectives. J Neurol. 2015;262(4):1002–1013. doi:10.1007/s00415-015-7665-z.

[26] National Institute for Health and Care Excellence. *NICE guidance for motor neurone disease*. National Institute for Health and Care Excellence; 2016. Retrieved 2 September 2021 from https://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions/motor-neurone-disease.

[27] Stavroulakis T, Walsh T, Shaw PJ, et al. Gastrostomy use in motor neurone disease (MND): a review, meta-analysis and survey of current practice. Amyotroph Lateral Scler Frontotemporal Degener. 2013;14(2):96–104. doi:10.3109/17482968.2012.723722.

[28] Martin NH, Lawrence V, Murray J, et al. Decision making about gastrostomy and noninvasive ventilation in amyotrophic lateral sclerosis. Qual Health Res. 2016;26(10):1366–1381. doi:10.1177/1049732315583661.

[29] Hogden A, Greenfield D, Nugus P, et al. What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives. Patient Prefer Adherence. 2012;6:829–838. doi:10.2147/PPA.S37851.

[30] Hogden A, Greenfield D, Nugus P, et al. Development of a model to guide decision making in amyotrophic lateral sclerosis multidisciplinary care. Health Expect. 2015;18(5):1769–1782. doi:10.1111/hex.12169.

[31] Murphy PL, Albert SM, Weber CM, et al. Impact of spirituality and religiousness on outcomes in patients with ALS. Neurology. 2000;55(10):1581–1584. doi:10.1212/Wnl.55.10.1581.

[32] Labra J, Hogden A, Power E, et al. Gastrostomy uptake in motor neurone disease: a mixed-methods study of patients' decision making. BMJ Open. 2020;10(2):e034751. doi:10.1136/bmjopen-2019-034751.

[33] Tsou A, Long J, McCluskey L, et al. Predictors of 30 Day Mortality after Gastrostomy in Amyotrophic Lateral Sclerosis (P01.102). Neurology. 2012;78(Meeting Abstracts 1): P01.102. http://n.neurology.org/content/78/1_Supplement/P01.102.abstract doi:10.1212/WNL.78.1_MeetingAbstracts.P01.102.

[34] Tsou A, Karlawish J, McCluskey L, et al. Predictors of emergent feeding tubes and tracheostomies in amyotrophic lateral sclerosis (ALS). Amyotroph Lateral Scler. 2012;13(3):318–325. doi:10.3109/17482968.2012.662987.

[35] Paynter C, Mathers S, Gregory H, et al. How people living with motor neurone disease and their carers experience healthcare decision making: a qualitative exploration. Disabil Rehabil. 2020;44(13):3095–3103. doi:10.1080/09638288.2020.1855261.

[36] Lisiecka D, Kelly H, Jackson J. How do people with Motor Neurone Disease experience dysphagia? A qualitative investigation of personal experiences. Disabil Rehabil. 2021;43(4):479–488. doi:10.1080/09638288.2019.1630487.

[37] Ando H, Cousins R, Young CA. Flexibility to manage and enhance quality of life among people with motor neurone disease. Disabil Rehabil. 2022;44(12):2752–2762. doi:10.1080/09638288.2020.1846797.

[38] Pols J, Limburg S. A matter of taste? Quality of life in day-to-day living with ALS and a feeding tube. Cult Med Psychiatry. 2016;40(3):361–382. doi:10.1007/s11013-015-9479-y.

[39] Ando H, Cousins R, Young CA. Exploring and addressing 'concerns' for significant others to extend the understanding of quality of life with amyotrophic lateral sclerosis: a qualitative study. J Cent Nerv Syst Dis. 2019;11:1179573519859360. doi:10.1177/1179573519859360.

[40] Van Eenennaam RM, Kruithof WJ, Kruitwagen-Van Reenen ET, et al. Current practices and barriers in gastrostomy indication in amyotrophic lateral sclerosis: a survey of ALS care teams in The Netherlands. Amyotroph Lateral Scler Frontotemporal Degener. 2022;23(3-4):242–251. doi:10.1080/21678421.2021.1973505.

[41] Légaré F, Stacey D, Gagnon S, et al. Validating a conceptual model for an inter-professional approach to shared decision making: a mixed methods study. J Eval Clin Pract. 2011;17(4):554–564. doi:10.1111/j.1365-2753.2010.01515.x.

[42] Les Turner ALS Foundation. *ALS decision tools, guidelines and webinars*; 2023. Les Turner ALS Foundation. https://lesturnerals.org/als-decision-tools-guides-and-webinars/.

[43] Wheelwright S, Maunsell R, Taylor S, et al. Development of 'gastrostomy tube – is it for me?', a web-based patient decision aid for people living with motor neurone disease considering having a gastrostomy tube placed. Amyotroph Lateral Scler Frontotemporal Degener. 2023:24(7-8):605–613. doi:10.1080/21678421.2023.2220743.

[44] Hsieh S, McGrory S, Leslie F, et al. The Mini-Addenbrooke's Cognitive Examination: a new assessment tool for dementia. Dement Geriatr Cogn Disord. 2015;39(1-2):1–11. doi:10.1159/000366040.

[45] Creswell JW, Creswell JD. Research design: qualitative, quantitative & mixed methods approaches. 5th ed. SAGE; 2018.

[46] Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health. 2019;11(4):589–597. doi:10.1080/2159676X.2019.1628806.

[47] Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Research in Psychology. 2021;18(3):328–352. doi:10.1080/14780887.2020.1769238.

[48] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042.

[49] Barć K, Kuźma-Kozakiewicz M. Gastrostomy and mechanical ventilation in amyotrophic lateral sclerosis: how best to support the decision-making process? Neurol Neurochir Pol. 2020;54(5):366–377. doi:10.5603/pjnns.a2020.0081.

[50] Ando H, Williams C, Angus RM, et al. Why don't they accept non-invasive ventilation?: insight into the interpersonal perspectives of patients with motor neurone disease. Br J Health Psychol. 2015;20(2):341–359. doi:10.1111/bjhp.12104.

[51] Foley G, Timonen V, Hardiman O. Understanding psycho-social processes underpinning engagement with services in motor neurone disease: a qualitative study. Palliat Med. 2014;28(4):318–325. doi:10.1177/0269216313512013.

[52] Muoki DC. Decisional conflict in percutaneous gastrostomy tube placement in adults: an integrative review of the literature. Gastroenterol Nurs. 2020;43(5):355–362. doi:10.1097/SGA.0000000000000460.