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How people living with Motor Neurone Disease and their carers experience healthcare decision making: A qualitative exploration

Abstract (no more than 200 words)

Purpose: Healthcare decision making in motor neurone disease (MND) focuses on symptom management and quality of life. Decision making may be affected by personal approach to receiving information, decision making style, and disease symptoms. This study explored decision making from the perspectives of people living with motor neurone disease (plwMND). The issues impacting engagement and involvement in healthcare decisions were investigated.

Methods: Semi-structured interviews were conducted with 19 plwMND and 15 carers. Interview data was inductively analysed to identify and describe patterns and themes.

Results: Data analysis identified six overarching themes: Dimensions of decision making; Window of opportunity for choice; Intrinsic influences on decision making; Extrinsic influences impacting decision making; Planning in uncertainty; and, Communication is core. Many participants did not identify a process of 'decision-making' except if considering early gastrostomy placement. Information provision requires a balance between ensuring patients are informed but not overwhelmed. Communication impairment impacts involvement. Healthcare professionals' communication style influences engagement in decision making.

Conclusion: PlwMND perceive a lack of clinical decisions to make because disease symptoms and clinical phenotypes dictate necessary interventions. PlwMND describe communication impairment as a barrier to involvement in decision making and extra support is required to ensure they maintain engagement.

Keywords: Amyotrophic Lateral Sclerosis, dysarthria, gastrostomy, Motor Neurone Disease, qualitative research, shared decision making

Word count: 6611

Implications for Rehabilitation

- *People living with MND (plwMND) perceive they have few clinical decisions to make and viewed this process as 'accepting a recommendation', rather than 'making a decision' although early gastrostomy placement is the exception with considerable deliberation evident.*
- *Specialist multidisciplinary clinic advice is especially helpful for plwMND without dysphagia (swallowing problems) when considering early gastrostomy placement.*
- *Communication impairment may be a barrier to involvement in healthcare decisions and extra support to remain engaged is required.*
- *Some plwMND choose not to involve others in their decisions, and patients/families with medical or scientific backgrounds are more likely to collaborate with each other outside the context of clinic appointments.*

Introduction

Motor neurone disease (MND), or amyotrophic lateral sclerosis (ALS), is an adult-onset, progressive neurodegenerative disease characterised by insidious weakness of voluntary muscles leading to loss of limb function, communication, swallowing and breathing. Cognition and behaviour can be affected in up to 50% of people [1]. Disease course, site of onset and progression, as well as symptoms experienced, vary greatly [2]. Person-centred care is considered particularly important in complex medical conditions such as MND where the clinical focus is optimising symptom management and quality of life [2]. The care team includes family and other informal carers. Patient engagement in healthcare requires a person-centred approach. Identifying the factors that influence how people living with motor neurone disease (plwMND) and their carers make decisions will support healthcare professionals (HCPs) in their delivery of person-centred care. Health systems that are aligned to person-centred goals are collaborative

and coordinated, and focus on emotional well-being as well as physical comfort [3]. Person-centred care highlights the importance of sharing knowledge, values and preferences between clinicians and patients to promote patient autonomy.

Patient autonomy requires competent communication abilities. Most people diagnosed with MND will develop a motor speech impairment during the disease course [4] and 25-50% of patients may develop cognitive deficits [5]. As cognition is associated with communication, both are important to consider in disease management. There is limited evidence addressing the impact of these deficits on decision making in MND. In a 2019 review, 76 articles about decision making in MND were examined yet only six addressed the issue of cognitive or communication impairments in relation to decision making [6]. Those studies often described the process of decision making and acknowledged that communication and cognition are important determinants of decision-making capacity and patient autonomy. However, the information was rarely extrapolated to the patient's *personal* decision making experience.

PlwMND are sometimes required to make treatment decisions that anticipate future symptoms, such as the early placement of a feeding tube before dysphagia (difficulty swallowing) has occurred. This adds further complexity to healthcare decision making. The responsibility of decision making is often shared with family members or carers who make a significant contribution to decisions [7,8], especially when there are communication difficulties or cognitive deficits. There is often a tension between the plwMND and their family, or the plwMND and their HCP with regards the timing of information provision and the available timeframe for decisions [9]. The influence of personal decision-making style is evident, with some plwMND choosing to postpone decisions due to denial or wishing to focus on the present [10,11]. PlwMND report not wanting information before it's needed [12], tend to seek less information

compared to carers [7,13], and despite reporting a wish to be well informed often choose not to use that information to plan ahead [14]. As far as the authors are aware, optimal timing of information provision from the perspective of plwMND has not been explored. Family members report valuing early information provision as a means to feel empowered and in control [8]. HCPs often advocate for early decisions to optimise clinical outcomes. This approach is supported by international clinical guidelines that encourage HCPs to engage in early discussions [15-17]. Early decision making is often encouraged, and justified, due to the expected decline of speech skills and possible development of cognitive deficits [18] impacting decision-making capacity. Personal values, attitudes and lived-experiences may all influence the preferences of plwMND as well as their HCPs. A greater understanding of the complex, multidimensional nature of how individuals face and approach decision-making is needed if we are to better support people with MND and their carers.

This study explored decision making from the perspective of plwMND and a family member (described as carer). Interviews explored involvement and engagement in decision making, and how this was affected by communication or cognitive impairments[1] (if present). Data offer insights into the lived-experiences of plwMND and carers as they engaged with clinicians and information to manage their disease.

[1] This paper reports on data from time point one (T1) in a longitudinal study, and communicative and cognitive deficits were expected to manifest more over the duration of the study.

Methods

Recruitment

This qualitative study was undertaken in Victoria, Australia, and recruited plwMND and their carers from the statewide progressive neurological disease service - a specialised multidisciplinary clinic which cares for approximately 350 people with MND annually. PlwMND and their carers were initially informed about the study by their neurology nurse or speech pathologist. Those who were interested were provided with a Patient Information and Consent Form (PICF). The primary researcher was available in person or on the phone to provide more information, answer questions and determine willingness to proceed. Written consent was obtained on the day of the interview. Participants were asked to nominate a family member to participate. Three participants declined involving family members, and one carer declined to participate. One participant responded to the study information poster placed on the clinic waiting room notice board and emailed the primary researcher directly. All but two potential participants contacted agreed to be involved in the study.

Capacity to consent to participate was determined by a neurologist or other appropriate clinician at the specialist MND clinic. Ethical approval was given by the Calvary Health Care Bethlehem Research Ethics & Ethics Committee (REEK reference: 17081701) and the University of Melbourne's Behavioural and Social Sciences Human Ethics Sub-Committee (reference: 1750285).

Data Collection

Semi-structured interviews (see appendix 1) were conducted by the first author. Three pilot interviews were undertaken; one with a volunteer with a chronic health condition but not MND; one with a plwMND regularly involved in medical student training and

accustomed to being interviewed; and one with a carer. The latter two interviews were included in the data set. This paper reports on data obtained from participant interviews conducted between December 2017 and August 2018. Interviews lasted between 30-75 minutes and were conducted in their own homes as per their preference. Some participants were interviewed separately as intended, and some interviewed jointly in accordance with their preference. This resulted in 28 interviews. Data collection included demographic information and assessment of current function via administration of the ALS Functional Rating Scale (ALSFRS-R) [19] on the day of the interview. Field notes were made during and after the interview to capture salient information not recorded as well as interviewer reflections.

Sampling

Purposeful maximum variation sampling method was used, consistent with the aim of the research, to describe the experience of the phenomena not its distribution [20]. Participants were sampled to gain a diversity of age, gender, MND phenotype, rate of progression, and verbal and/or non-verbal communicators. Potential participants were identified at a clinical meeting or by a neurology nurse or speech pathologist and considered by the researcher. Potential participants were approached over a rolling basis for six months. People unable to converse in English, diagnosed with fronto-temporal dementia type MND, or presenting with cognitive or behavioural deficits prohibiting their ability to provide informed consent (as determined by their treating Neurologist) were not recruited. Nineteen people with MND and 15 carers were recruited (see table 1.) The cohort of plwMND included 10 males and nine females (mean age = 63 years (range 40-79)). The 15 carers included five males and 10 females (mean age = 59 years (range 38-73)). To preserve anonymity, participants are referred to throughout the paper

as P# (plwMND) or C# (carer) and the gender neutral singular pronoun (e.g. they or them) has been used.

Table 1. **Participant Characteristics**

Maximum variation sampling variable	*Number of participants (N = 35)*
PlwMND	***19***
Female	10
Male	9
Age (years)	
Range 40 - 79; mean = 63	
MND Phenotype	
Amyotrophic Lateral Sclerosis (ALS) / familial ALS	12
Bulbar onset	4
Primary Lateral Sclerosis (PLS)	3
Years post symptom onset	
ALS including bulbar onset: range 1.1 - 17.6; mean^{+} = 2.9	
PLS: range 3.8 - 8.4; mean = 5.8	
ALSFRS-R* (score 48 indicates unimpaired function)	
Range 10 - 44; mean 32	
Communication	
Non-verbal	3
Severe dysarthria	1
Verbal	15
Carers	***15***
Female	10
Male	5
Age (years)	
Range 38 - 73*; mean* 59	

*ALSFRS-R: ALS Functional Rating Scale [19]
+ participant 17.6years post symptom onset not included in mean calculation

Methodology

The researchers aimed to describe the lived-experience of making healthcare decisions for plwMND and their carers, with the intent to produce clinically relevant and applicable findings. Interpretive description methodology allowed the researchers to identify patterns and themes, and also to explain variations from participants' perceptions and experiences [21]. Interpretive description evolved from nursing research as a methodology situated in social constructionist epistemology, it utilises inductive analysis, and allows for the production of descriptive findings with clinical applicability [22]. In contrast to descriptive phenomenology methodology, interpretive description views clinical expertise or knowledge as useful for orienting and setting research boundaries [23]. Interpretive description methodology has been successfully used in a range of clinical areas to explore, for example, patient experiences in ALS [24], decision making [25], patient perspectives [26], and communication disorders [27].

Data analysis and method

All interviews were conducted by the first author, audio-recorded, transcribed, de-identified, and entered into NVivo 12 (QSR International 2019) for collation and management. One interview was not recorded due to a technical error; in this case, the notes taken during and after the interview were verified with the participant and used for analysis. Reflexive thematic analysis was used for data analysis and interpretation [28,29]. Open inductive coding was completed by the first author, and the codes were reviewed and refined through discussion between the research team. The whole dataset was inductively coded, and reviewed again using the coding structure to ensure all salient data was captured. Data was examined for areas of convergence and divergence,

and grouped into related central concepts or themes [29,30].

Rigour

Rigour of qualitative research is established through the demonstration of trustworthiness [31]. This was achieved through the following: conducting pilot interviews, regular review of the interview guide to eliminate ambiguity, and an audit trail (i.e. documentation of data collection and analysis decisions). The first author (and interviewer) has clinical experience (as a speech language pathologist) in managing patients with progressive neurological and palliative conditions, and has skills to interact with people with communication impairments. Transcripts and emergent concepts were checked and discussed regularly by authors CP and MC to ensure interpretations were defensible and strongly linked to the data source. In addition, data analysis involved actively searching for negative cases. Interpretation of results was discussed at regular team meetings by authors CP, SM and HG acknowledging the potential influence of clinical experience, and identifying any sources of potential bias. Finally, rigour is supported in the reporting process through the use of thick description, illustrative quotations, and a comparison of findings with the existing literature [32]. Additionally, the reporting of this paper is aligned with the COREQ guidelines [33].

Results

Data analysis related to the research question (‘how do plwMND and their carers experience healthcare decision making?’) identified a diverse range of attitudes towards, and influences on, decision making for these participants. Six overarching themes were identified: Dimensions of decision making; Window of opportunity for choice; Intrinsic influences on decision making; Extrinsic influences impacting decision making; Planning in uncertainty; and, Communication is core.

Dimensions of decision making

Specific decisions made

Participants were asked to describe an important decision they had or were about to make. Their responses related to healthcare, lifestyle and personal wishes, such as specialist MND clinical management, medical interventions (e.g. Riluzole or alternative medicine choices), clinical trials, mobility aids, house modifications, non-invasive ventilation (NIV), communication aids, and gastrostomy. Of all the healthcare considerations, gastrostomy (percutaneous endoscopic gastrostomy or PEG) deliberations provoked the most detailed discussion and warrant specific mention.

All participants were asked if they had considered a feeding tube. Participants experiencing dysphagia and/or weight loss reported the decision to proceed with PEG was straightforward; "[Name] was losing weight. So it was clear it was going to be an issue and do it sooner rather than later…It wasn't anything that we needed to think about" (C06). One participant accepted a gastrostomy despite not wanting "invasive tubes" drawing a distinction between a feeding tube and a breathing tube despite the percutaneous insertion of both interventions. For participants asymptomatic for dysphagia, planning for gastrostomy was more complex and varied. The context being that the specialist MND clinic offers patients with deteriorating respiratory function early PEG placement. This allows for insertion under sedation. Later in the disease, gastrostomy insertion may be less safe, performed with less sedation or may no longer be possible. Participants without dysphagia symptoms often waited until disease progression *forced* a decision, or else relied heavily on healthcare professionals to guide that decision; "[The clinical team] are all saying well, you should have it [PEG] done while you can. So I went with their advice" (P12). One participant declined PEG.

> Everyone said you must have this and you must do that. No, if I can't eat or drink through here [points to mouth], not down there [points to stomach]. ... [It's] because of my lung tests. They go on figures. But I thought, I don't live on figures mate. Anyway, I was going to, then I wasn't going to. So, I'm not going to. The speech pathologist was happy with me last time. So, if they're happy, I'm happy. (P13)

Varied decisions regarding lifestyle included reducing or giving up employment, and selling property, for example buying more suitable residential accommodation or selling a holiday home due to anticipated difficulty travelling. Personal decisions related to funeral or burial wishes, and brain donation for research, were more commonly discussed by participants in the later stage of disease.

What do you mean by 'decision'?

Except for the above articulated decisions, in almost half the interviews (13/28) participants reported feeling there were very few *actual decisions* to make. In fact, the researcher was asked by a number of participants to explain what was meant by 'decision making' and subsequently used 'choice' or 'change' to probe for decisions.

> There's things that you have to do, so I don't know what type of decisions you're talking about really. Like now the decision to stop working, I mean I wouldn't have wanted to stop working, but I had to. (P07)

This feeling of *no decisions* appeared to stem from both a lack of treatment options, and the inevitability of disease progression necessitating intervention.

> If I had something like cancer, I actually would have some difficult decisions. … At the moment [there's] no standard treatment [for MND] so there's really no difficult decision to take. (P11)

> It's hard to think of them as decisions…because you definitely don't have a choice. (C04)

Interventions such as non-invasive ventilation (NIV) and mobility aids were approached as accepting a recommendation rather than making a decision. Participants explained that NIV would relieve the symptoms, provide comfort, and extend survival.

> That one [ventilation] wasn't really a hard one [decision] to make. It was, yeah okay, because I needed help. And that was the answer. (P17)

These *no decision* views were expressed by a wide range of participants including those newly diagnosed, those with long disease duration, and towards end of life, and participants with a variety of education or medical/scientific backgrounds.

Window of opportunity for choice

Despite this *no decision* concept described, it became evident that for some participants, a window of opportunity existed where there *was* choice and control. This was the time between receiving information and/or recommendations about interventions (likely as a precursor for expected functional decline), and before disease progression necessitated their implementation. During this period some participants reflected, gathered more information, accepted and/or planned for the intervention.

> I went to the physiotherapist, they said to me, 'Have you thought about getting a walker?' I said, 'No. Not yet. I don't want to get that.' ... then I rethought it and I contacted them. I said, 'Listen, I've changed my mind. Can I have a walker, please?' There's a flexibility in there for me to be controlling my care. (P10)

Some participants ignored, denied, and/or sought no further information until disease progression necessitated acceptance interventions; by then there was no decision, because there was no choice.

> We had thought for some time we'd eventually get a unit with a downstairs bedroom, but of course, that's [MND] made the decision for us. (P18)

The opportunity for choice, was impacted by disease trajectory and having access to information in advance. Therefore, for people with rapidly progressive disease, this window was either brief or difficult to access. For some having this information early came at the expense of quality of life.

> It's maybe inevitable but it can really affect quality of life to bring that stuff up too soon. It's a fine line. It's a fine line between preparing someone so that they get the best management possible without just traumatising them. (C04)

> It [getting information from HCP about NIV and PEG] also makes you think you're worse than what you are. You know, you tell yourself think positive, think positive, and now look the worst. (P02)

Intrinsic influences on decision making

Decision making style

Participants' personality and values affected timing of decisions. Participants were probed on their pre-morbid decision making which were generally reported not to have changed.

> I am very independent and private person. I'm not a procrastinator, I make a decision quickly. (P04)

> I think if it's thrown in my face, I accept it. But otherwise I tend to push it away.. deal with it tomorrow. (P02)

Only one participant reflected that their decision-making style had changed.

> I think one of the things I'm learning is to be a little bit more, be less independent. I've been living by myself for about 30 years, so I'm used to making decisions. (P10)

Decision making style was analysed in relation to how plwMND involved their family

members. Three different styles were identified: independent, collaborative, and assumptive (meaning to suppose it is the case). Independent decision makers described processing information, both on their own or with friends and family, but made decisions autonomously. Seven (of the 19) plwMND were identified as independent decision makers. This was common, but not exclusive to, participants living alone and for those whose spouses identified as being in denial or having difficulty accepting the diagnosis. Therefore, this may be a strategy to reduce or avoid stress for their loved ones. Two participants living alone described a limited family/social network which may have imposed an independent decision making style, however others demonstrated this style being a choice. For example, when asked if they involved their spouse, they reported "Not a lot, no. I tend to make my own decisions. [Name] doesn't really have a lot of input" (P09).

> "I called a family meeting. At that time, I wasn't just too sure what I was going to do. I said, "Just listen to me. I don't want you to tell me what to do. These are the things I'm mulling over at the moment. Just be aware that that's what I'm doing." (P10)

Collaborative decision makers shared information (often sought or obtained separately) and discussed it outside of clinical appointments. This was the most common style evident (9/19) and it was strongly connected with participants or family members having a medical or scientific backgrounds.

> Researcher: Did you talk about it at the clinic or do you sit down …
> Some discussion when we're sitting here [in the lounge room] and then we formalised it [at the clinic]. (C13) We got ideas from everyone I guess. Taken all the bits we like, and um, put it all together. (P17)

Collaboration as a family was reported by two couples. One carer reported how it was essential for them and their children to be involved, and expressed frustration at a

perceived lack of understanding from HCPs at how the family functioned as a unit not just as a couple.

The third style evident is described as assumptive as participants assumed knowledge and understanding of their spouse without overt joint discussion; “I trust my [spouse] on that [advanced care planning decisions], they know what I want and what I don’t want. Well, if they don’t after 35 years, we’re in trouble!” (P07). Three participants demonstrated this style.

Acceptance

Acceptance, of diagnosis or progression, appeared linked to decision making style, and to positively influence engagement.

> As things change, around the house, whatever, will have to change. I will have to accept the difference. And sometimes the decision *is* hard. But you can’t bury your head in the sand and do nothing. You have to move forward. (P04)

Two participants recently accepted mobility aids with contrasting attitudes. For P06 using a mobility scooter was essential for accessing the community however perceived this would increase their vulnerability; “I'm paranoid about going anywhere by myself, you hear people in wheelchairs and electric carts and all that, getting mugged all the time.” Whereas P09 stated, “I hate it [four wheel walker] with a passion. But it allows me the freedom and the security to move around independently”.

Acceptance of interventions was the pragmatic thing to do for some. When asked about their motivation for doing voice banking, one participated reported, “It just seemed like a prudent thing to do. I thought since the technology is there it makes sense to take advantage of it” (P11). Participants were asked specifically about their

perceptions as to what helped and what challenged decision making; this can be found in supplementary material table 1 and table 2.

Extrinsic influences impacting decision making

Support

The support spouses and families provided to plwMND to facilitate participation in decision making was both informative and practical. Support included acting as healthcare advocates by seeking and sharing information, driving to clinical appointments, 'translating' where communication impairment was present, assisting with augmentative and alternative communication (AAC) devices, and organising appointments. Family involvement was maximised when plwMND and/or family members had medical, scientific, or health backgrounds. One participant specifically did not involve their children due to concerns it may burden them; possibly due to the age of the children who were in their early 20s. The support carers provided to family members to enable engagement in decision making sometimes came at a personal cost.

> I've been giving things up because, everything else that's been going on it's been very difficult to concentrate on some of these things and give them attention. I guess in that respect, my life is narrowing, if you like. I've got other things to focus on now. (C09)

> Because you think, 'Okay, well I've only got, probably, one to two years left with [Name].' Obviously that's going be a first priority, so I haven't really dated in the last five or six years. You know, there was a time I was thinking I might be meeting someone, having kids, things like that. All that got put, well, it just became low priority, it wasn't even consciously put on hold. (C04)

Carers' capacity to support family members was constrained by employment. Two carers spoke of difficulty getting time off work to attend clinic appointments.

Furthermore, working full-time sometimes meant not being home when the Motor Neurone Disease Association (MNDA) advisor visited (advisors from the national peak advocacy association provide regular support, information and connect people to services). Not being present for these visits meant missing out on information and education, both of which are likely barriers to collaborative decision making.

The specialist clinic

Being managed by a specialist MND clinic supported both plwMND and carers with their clinical choices, intentionally and unintentionally. Two participants deliberately chose specialist MND multidisciplinary management, rather than opting for management by a private neurologist; "There is a sense that they're all working together, which is very good for the confidence" (P10). The specialist clinic processes supported collaborative decision making:

> There's written care management plans, so you're clear on who does. … It's actually really helpful to see things written and to have those updates at each appointment they put into the plan. That helps, too, when there's multiple family members, to stay involved. (C04)

Increased flexibility with financial security

Personal financial security allowed greater choice and supported timely implementation of decisions. One participant in public housing experienced a long wait for bathroom modifications and another decided the cost of car modifications outweighed the benefit given a potentially short period of use. This contrasted with those who could afford to buy more appropriate accommodation promptly or modify their car without having to consider the financial burden.

> I think most of the decisions revolve around financial issues. When you don't have financial problems, everything's a bit easier. Not in the sense health-wise but when you need something, you can always do it, when you have your finances are good. When you can't afford things, decisions become a bit harder. (P07)

Planning in uncertainty

The challenge of making pre-emptive decisions was broad (disease related) and specific (disability support planning, advance care planning, and gastrostomy). For some, a sense of uncertainty regarding disease trajectory challenged planning and anticipating future needs.

> How do I know what I want, if I don't know what's going to happen? (P05)

> [Name]'s had motor neurone for six years, so it's been unusual in that way. You don't know initially what it's going to be, so you spend those first couple of years just waiting for the end to come and then it doesn't come. (C04)

For carers, concern related to disease uncertainty was expressed independent of disease duration.

> I guess the other thing about it is it's the unknown course of this. [Name] is really good at the moment, but who knows for how long. I guess that uncertainty is sort of another part of the problem. (C14; family member diagnosed two months prior to interview)

> They have told us [about the PEG], so it's trying to decide whether you want actually a physical tube sitting there for 6 months, a year, two years before you even need it. Or do they need it like next week, and we're too late? Dunno. (C07; family member diagnosed 12 months prior to interview)

Logistical and emotional challenges were evident when preparing disability support plans and advance care plans.

> When you sit down and you plan it, it's like [inhales to indicate a shock], you're actually putting things in place for when they do [die]. So, I find it quite confronting and it's just confirming the play, well, this is it. (C13)

Advance care planning (ACP) facilitated planning and promoted autonomy but not all participants were aware of, or had completed, ACP. Six plwMND reported they had a documented ACP and it was more common for participants in the later stages of disease. The decision to formalise ACP was sometimes motivated when decisions had potential to be controversial (e.g. brain donation).

> [Name] more did it for me, so that I wouldn't have any battles coming to the end. So, I could say, well I'm doing exactly what they wanted without having to fight people. (C13)

Communication is core

Communication is embedded in all the above, and therefore played a significant role in decision making involvement. Communication in this context also encompassed strategies and devices, HCP communication, and carer support for communication. When plwMND relied on written communication to communicate decisions (due to dysarthria) answers were restricted and complex ideas difficult to communicate. This resulted in the requirement to prepare for clinical appointments in advance by writing statements or having discussions with carers. It also resulted in reduced involvement; "[During my appointment] with the gastroenterologist, I probably asked fewer questions than I would have otherwise" (P08). AAC devices were often time consuming for interactions, and in the context of busy clinical environments, this had a significant consequence: "Sometimes I just comply. I don't want to be seen as a difficult patient" (P16).

Participants reported that information presented as a conversation, and in a non-condescending way, facilitated their involvement during clinic appointments.

Engagement was encouraged, and resistance reduced, when HCPs used qualifications when providing information about future interventions; “She did speak to us about the feeding tube and say it’s not that you need it now, but we want to give you the information so that, IF in the future…” (P03). One participant, a high-tech eye-gaze AAC user, stated the importance of HCPs using communication strategies to promote involvement in decision making, such as patience, allowing extra time for both communicating and deliberating on information, and using the communication aids used by the individual with MND.

> One doctor [at the acute hospital] refused to use the letter board, because they didn’t know how to set up the laser pointer, but the letter board can be used without the pointer, you just need patience to run through it first line, second line etc. (P16)

When speech impairment was significant, carers acted as translator or proxy speaker, due to difficulties being understood or the effort required to explain; “They'll start the sentence and kind of look at me like, can you finish explaining?” (C04). Carers also made or received phone calls, assisted in managing clinical appointments, and completed written or on-line forms (due to motor impairment and subsequent problems writing or typing:): “For the telehealth consult, like I *had* to be there, they wouldn’t have been able to read the electronic blackboard on the screen, so I *had* to be there to translate” (C06).

Discussion

The perception held by participants that there are *no decisions* to make because there are *no choices* is interesting. The juxtaposition of semantics between ‘decision’ and ‘choice’ is conspicuous; some participants viewed decision and choice to be the same, others viewed them differently. For some, decisions were primarily viewed as *when*, rather than *if*, to accept an intervention, and therefore not necessarily conceptualised as

a *decision*. The process was often described as *accepting a recommendation*, rather than *making a decision*. Interventions are needed because they enable dignity, participation in daily or community activities, or maintain survival. For some, *no choice* was due to the inescapable result of disease progression [10]. People living with progressive neurological disease, including MND, have reported limited choice due to the limitations set by the disease [11,34], and also reported by people living with Parkinson's disease wherein 'no choice' was a barrier for shared decision making [35].

Early PEG placement decisions are, however, the exception to the *no choice/no decision* rule. Participants described in detail their deliberations when recommended early PEG insertion. This is unique in the context of neurodegenerative conditions as PEG and/or early PEG insertion is *not* routinely offered in other neurodegenerative condition including dementia and Parkinson's disease [36]. PEGs are predominantly inserted due to dysphagia post-stroke or in anticipation of dysphagia and/or weight loss due to head and neck cancer [37]. Recommendations for early PEG in MND is usually made on the basis of reducing risk associated with insertion, and improving future quality of life although evidence regarding improved quality of life is equivocal [38]. Decision making in this context is further complicated when people are asymptomatic of dysphagia and asked to make treatment choices for a symptom they are not yet experiencing. Zarotti et al. [39] found a comparable issue with HCPs reporting difficulty engaging plwMND in early discussions about optimising nutrition in the absence of weight loss or dysphagia. The heterogeneous nature of gastrostomy decision making is influenced by gender, site of MND onset, and disease progression rate but not necessarily by the presence of dysphagia or compromised nutrition [40]. Consequently, this issue does represent a real choice for plwMND. They are facing decisions regarding *if*, as well as *when*, to proceed, which is often made more difficult due to the unknown

length of time the PEG will be in place but not used. Participants clearly described how the expertise, support, and information provided by the clinical team guided and assisted their decisions. Interestingly, in contrast to previous literature [39,41], there was limited discussion from participants regarding the social and emotional importance of eating and drinking and their consideration on PEG placement. This may reflect the fact that participants considering early PEG insertion were asymptomatic of dysphagia and had not yet considered that issue.

Participants expressed a range of views regarding uncertainty despite being seen by a team within a single service (and thereby eliminating factors that may contribute to variation). Concepts of uncertainty were primarily related to disease trajectory, with some discussion about future interventions or practical support. Without obtaining the perspectives of HCPs for this study the researchers can only speculate as to the cause of this uncertainty. Participants may be influenced by information from the internet, MND associations, celebrity faces of MND, or personal experiences. Information provision is possibly ambiguous; patients are provided with a combination of population specific information (i.e. group effects and statistical means) as well as personally specific prognostic information, from which they may have difficulty differentiating. The experience of living with a life limiting disease may well feel uncertain even if disease trajectory has been explicitly explained by HCPs. Some literature specifically exploring the issue of uncertainty in MND has been published; two recent qualitative studies, both with a sample size of four, report uncertainty as a significant theme[42,43]. These perceptions of uncertainty indicate that further research is needed to uncover what contributes to patient's experiences of uncertainty.

Concerns regarding receiving unexpected pre-emptive information, or making decisions in advance, at a cost to quality of life was expressed by some participants.

These results are analogous with the findings of Clarke et al. who described participants who wished information about diagnosis and prognosis had never been given [11]. The emotional cost of receiving condition-specific information or making decisions early has previously been reported by people living with Parkinson's disease and carers of plwMND [44,45]. It is clear there is a "fine line" between providing information in advance so that plwMND can have an opportunity for enhanced control over choices and the emotional cost this may incur. HCPs have a duty of care to minimise risk and ensure patients are making informed decisions as well as being physically safe and emotionally prepared. Symptoms and clinical phenotypes dictate timeframes of interventions necessitating information provision from HCPs. Judging the optimal timing of information provision, without overwhelming patients can be challenging [9,11] but the way HCPs provide information can enhance engagement.

Impairments in communication act as a barrier to participation in healthcare decision making, but this can be overcome by practitioners who explicitly value, prioritise and support communication. Engagement in decision making for plwMND is frequently enabled by the scaffolding carers provide during, and outside of, healthcare appointments which has been reported previously [7]. Whilst AAC is known to improve independence and increase social closeness for both plwMND and carers [46], without physical and/or logistical assistance to set up communication aids, plwMND are unable to use them, illustrating the need for support that is available and skilled. Of concern is that participants reported instances where HCPs unfamiliar with AAC were unable or unwilling to use them. Communication is a human right [47]. It is the agent for providing and participating in healthcare and for facilitating patient autonomy. Patients with communication impairment are three times more likely to experience a preventable adverse event during an acute hospital admission compared to patients without

communication impairment [48]. This highlights the importance of HCPs using communication aids to ameliorate this risk and the benefit of providing care for plwMND at specialist MND facilities, where staff are familiar with and skilled to meet all care needs.

Themes reported in this study highlight that decision making can be complex, dynamic, unique to an individual's skills and values, and frequently relies on supportive relationships. These findings can be framed by the concepts of health literacy to help us understand the complexity of decision making. Health literacy is a dynamic skill, beyond personal literacy and numeracy skills, involving cognition and social skills to access, understand and use information in ways which maintain good health [49]. Further to this, health literacy should be considered an interactive process shaped by supportive relationships with HCPs and the health system at large [50]. Health literacy has previously been explored in MND in relation to decisions regarding eating and drinking in progressive neurological conditions [11] although the definition of health literacy employed in that paper appears restricted to patient's knowledge of their condition. Hogden et al. (2013) offers an expanded appreciation of health literacy in MND in relation to carers' health literacy behaviours to scaffold decision making capacity for plwMND. The health literacy of plwMND presenting with communication impairment requires further research.

Limitations

Firstly, only one side of the decision-making experience has been investigated in this study, that of plwMND and their nominated family member. Decision making is highly dynamic and complex process in which issues are discussed with a variety of HCPs, whose perspectives were not elicited in this study. It would be important to consider the experiences of HCPs to gain a holistic understanding of care provision. Secondly, the

sample was derived from a single MND clinic with a multidisciplinary model of care, potentially limiting the generalisability of findings. Issues raised may not reflect the experiences of plwMND who do not attend specialist MND clinics or access multidisciplinary care whose experiences are likely to be different. Thirdly, due to limited funding (in terms of accessing translation services), the sample only included English speaking participants. This is likely to have limited the diversity of perspectives obtained and future research should consider recruiting from a more culturally and linguistically diverse population. This reflects bias in the field [2] which needs addressing. Finally, despite cognitive and behavioural impairment being present in MND, these issues were neither apparent when conducting interviews nor recounted as influencing participants' engagement in decision making. This is likely due to participants with significant cognitive difficulties being excluded from the sample, and that within the topic guide there were no questions that probed participants about their memory or cognition.

Implications

Decision making is dynamic and patients and families may have different experiences between clinicians and/or between appointments. The implications of personal decision making styles on clinical care should be acknowledged with HCPs mindful that some patients choose not to involve others in their decisions and assumptions about decision making styles should not be based on patients' living situations. Furthermore, in this study, patients and family members with medical or scientific backgrounds were more likely to be collaborative in their decision-making. Therefore, whilst remaining cognisant of the patient's values, provision of consistent information and focus on family-centred care may be appropriate in these situations. Additionally, it is important to ensure that family carers who are working full-time have received all the information

and education they want.

There are implications for clinicians with regards to healthcare communication. Firstly, plwMND who rely on written communication may benefit from advance notice of appointment goals in order to prepare. Secondly, HCPs choice of language when presenting prognostic information, as well as their use of patient's personal communication devices and strategies will encourage engagement. Lastly, there needs acknowledgment of the various communication supports carers need to provide to facilitate involvement. Results from this research add to the extant literature that HCPs need to better identify the time when each patient and each family member are ready to receive prognostic information [9,11,45]. The benefits of being managed by a specialist MND multidisciplinary clinic (see for example [17,51]) are clearly articulated by these participants, particularly those without symptoms of dysphagia who are considering PEG insertion.

Conclusions

This exploratory study highlights the varied experiences plwMND and their carers have when making healthcare decisions. Within the concept of 'decision making', some plwMND perceive they have few clinical decisions to make because disease symptoms dictate necessary interventions. Consistent with existing research, the emotional cost of receiving condition-specific information or making decisions early is evident and challenges the assumption that early information provision is beneficial for all. The challenge facing HCPs is how to identify the most appropriate time to provide this information for each patient and family. Experiencing a communication impairment presents a unique set of challenges for plwMND to remain actively involved in healthcare decisions, and requires support from carers and HCP to circumnavigate. Exploring healthcare decision making in the context of health literacy frameworks may

provide some insight. Furthermore, exploring how decision making changes as disease progresses may provide greater understanding of the multidimensional nature of this issue.

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Declaration of interest

The authors report no conflict of interest.

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Appendix 1. Interview Guide

Decision-making

Tell me about a healthcare decision you've had to make (or are about to make).

Who else do you involve in these decisions? How much, or how, do you discuss this elsewhere e.g. at home?

What makes you feel involved, or not involved, in making these decisions?

Have you heard of Advance Care Planning? If so, can you tell me about your experience with ACP?

Communication changes (if applicable)

Tell me how have changes in your speech or communication changed the way you are doing things? (e.g. making phone calls, completing forms, writing cards/letters, typing emails?)

Have changes in your speech changed the way you interact with your health professionals? Or changed decision-making in any way?

Gastrostomy (if applicable)

Tell me about any decisions you have made regarding eating and drinking, and/or a feeding tube?

How has the feeding tube changed things for you?

In what ways has the feeding tube made things easier/better versus more difficult/worse?

Interview closure

Tell me, what do you think is the most challenging thing about decision-making?

Tell me, what do you think helps your decision-making?

Supplementary Material

Table 1. Participants' opinions on their perceived facilitators to decision making

Participants' views on what assists with decision making
A non-judgemental attitude of healthcare professionals
Financial security which allows for greater choice and access to (privately funded) support
Clear link to why an intervention is being recommended and how it will help. Information and understanding the pros and cons of interventions
Possessing a positive outlook and attitude
Acceptance of diagnosis and the limitations of the disease
Time to process information and reflect on options or information
Having medical knowledge, or involving family with medical knowledge
Healthcare professionals using 'soft' suggestions. For example, "Have you thought about …?", or "In the future you might need …", "*If* [this] happens, you might need…"
Possessing religious faith

Table 2. Participants' opinions on their perceived barriers to decision making

Participants' views on what challenges decision making
Confronting reality and considering the future
Uncertainty and variability of the disease; "You can only predict so much"
Personal decision making style creates challenges at times e.g. over-researching issues
Disease symptoms such as communication difficulties, lability and fatigue make being involved or providing input difficult
A sense of urgency makes decision making difficult. Being rushed makes things difficult
Lack of understanding of family dynamics or personal values by health services or healthcare professionals
Lack of financial security which can lead to reduced options
Time to adjust to diagnosis before having to make choices
Denial of diagnosis or symptoms