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Abstract

Motor Neurone Disease is a rapidly progressing, fatal and relatively rare neurodegenerative disease of unknown aetiology. People diagnosed with Motor Neurone Disease develop a range of symptoms including dysphagia (swallowing impairments). Although generally recognised to cause serious medical and psycho-social consequences, little is known how this population experiences dysphagia.

Aim

To investigate the experiences of dysphagia from the perspective of people diagnosed with Motor Neurone Disease.

Method

This study employed Interpretative Phenomenological Analysis to investigate the experiences of dysphagia in ten people with Motor Neurone Disease who participated in individual, multiple interviews (n = 44) and meal-time observations.

Results

Participants' experiences of dysphagia were inseparable from their broader experience of Motor Neurone Disease. Apart from specific circumstances and when dysphagia was severe, dysphagia was not experienced as a constant issue for participants. Participants reported a changed perception of food and fear of choking. They generally aimed to manage dysphagia independently rather than seeking professional help and employed strategies such as choosing easy to swallow foods and limiting mealtime distractions.

Conclusion

This study provides a unique contribution in advancing our understanding of dysphagia in Motor Neurone Disease. Professionals need to view dysphagia within the disease as a whole,

and recognise personal values, preferences and coping strategies of people with Motor Neurone Disease, in the management of dysphagia.

Key words: motor neurone disease, amyotrophic lateral sclerosis, deglutition disorders, dysphagia, qualitative research, perception, IPA

Introduction

Motor Neurone Disease (MND) is understood to be a multisystem neurodegenerative disorder [1]. Worldwide incidence of MND is estimated at 1.9 per 100,000 annually [2]. Although MND is relatively rare its socioeconomic impact is considered greater than other neurological diseases [3]. In Ireland, the median individual cost of formal health and social care in MND is estimated at 21,540 euro per year, which is higher than the cost of services in the first year of stroke [4]. In addition, studies predict a 69% global increase of the incidence of MND by 2040 [5]. The average survival in MND is estimated at 2 - 4 years post diagnosis with only 10 – 20 % surviving longer than 10 years [6, 7, 8]. As there is no cure for MND the treatment is largely symptomatic [9] and a palliative approach from the moment of diagnosis is recommended [10].

Dysphagia often occurs in MND causing a range of medical [11, 12, 13, 14, 15] and psycho-social consequences [16] ultimately leading to a lower quality of life [17]. Although the exact rates of dysphagia in MND are unknown [18], it is estimated that almost all people with MND will experience dysphagia at some stage of the disease [19]. Dysphagia in MND can manifest in disorders of oral and pharyngeal phases of swallowing [20, 21, 22, 23] and can potentially cause choking, aspiration, pneumonia, and death [11, 15]. Non-oral feeding may be introduced to prevent malnutrition and weight loss [24, 25, 26] although a Cochrane Review concluded that the evidence supporting the nutritional benefits of non - oral feeding

in MND is still weak [25]. New evidence is emerging in relation to the potential of rehabilitation for dysphagia in MND [27].

To fully inform the management of health conditions and to provide optimal patient-centred care it is essential to explore the experiences and preferences of people living with the condition in question [28]. Therefore we reviewed the literature investigating the experiences of adults living with dysphagia. We established that the majority of publications focused on the experiences of people with head and neck cancer [29, 30, 31, 32, 33, 34, 35, 36, 37] and a smaller number focused on stroke [38, 39, 40]. There appears to be a general consensus that dysphagia leads to psychosocial consequences and impacts on quality of life. A range of negative emotions related to dysphagia have been documented, for example fear [30, 34, 35, 38], shame [38], hopelessness [34], embarrassment [30, 35], dissatisfaction about changed physical and social appearance [36, 38], and anxiety [30].

Although a rich body of qualitative research has illuminated many important dimensions of the MND experience with significant relevance for clinical practice [41], to date, there is a paucity of research investigating the experiences of dysphagia in MND. The qualitative studies that have explored dysphagia with this population have focused their investigations on the experiences of non-oral feeding as an option to manage dysphagia [42, 43, 44, 45]. A decision making process of accepting or refusing non - oral feeding emerged as complex in MND [42, 43, 45]. One study stated that following commencement of non – oral feeding participants reported a reduction in anxiety related to prolonged meals, the stabilisation of weight, and perceived life prolongation, but also increased anxiety related to keeping the tube intact, tube discomfort and the loss of the social aspects of meals [44]. It emerged that the recommendation of non-oral feeding should be carefully discussed by the whole multidisciplinary team to ensure individualised approach [45]. Although the qualitative literature highlighted the complexity of patients' experiences of non – oral feeding in MND,

to our knowledge no studies to date have researched the experiences of other aspects of living with dysphagia in this population. An investigation into the personal experiences of dysphagia is identified as a priority for Speech and Language Therapy professionals in Ireland [46]. The impact of dysphagia on the individual should be perceived as a significant concern [47]. A recent review investigating the trends in dysphagia research in MND highlighted the need to better understand the secondary consequences of dysphagia, such as changes in participation and quality of life [48]. At present, the literature investigating the experience of dysphagia in MND is limited and we aimed to address this gap.

Aim

The main aim of our research was to investigate the experiences of dysphagia in MND from the perspective of people diagnosed with MND. It was envisaged that this knowledge could contribute to the professional management of dysphagia in MND and to the organisation of service provision.

Methods

A qualitative methodology was employed to investigate the experience of dysphagia from the perspectives of people with MND. The particular approach chosen was Interpretative Phenomenological Analysis, as it is considered to be particularly suitable for investigating unique and complex lived experiences [49, 50], such as the occurrence of dysphagia in MND. Although IPA originated in health psychology [50, 51], it has gained significant interest within other disciplines. The majority of IPA studies appear to investigate the experience of illness or psychological stress [52].

IPA has complex philosophical underpinnings, which are beyond the scope of this article (see [50, 51, 53]). In summary, IPA is phenomenological (i.e. its core focus is a

detailed examination of an individual's experiences), hermeneutic (i.e. concerned with the interpretation of meaning) and idiographic (i.e. committed to individual participants even in group studies) [50]. Data collection in IPA typically involves single individual semi-structured interviews [50], but multiple interviews have also been used [54]. It is recommended to keep the sample reasonably homogeneous to ensure that all participants share the phenomena under investigation [50, 55].

Recruitment

It is generally recommended for an IPA study to keep the sample relatively small to preserve the idiographic focus and prevent the analysis from being too descriptive [50]. We estimated that recruiting ten participants would provide valuable insight into the experiences of dysphagia and would allow the maintenance of the idiographic approach during cross-case analysis. Prior to the commencement of the study we ensured the probability of finding the required number of participants (10) within the specified geographical area (South-West of Ireland) by consulting the Irish Motor Neurone Disease Association, which maintains the national database of people living with MND in Ireland.

In adherence to the IPA approach to data collection the aim was to purposively select participants who met our eligibility criteria and were willing to provide insight into their experiences of living with dysphagia and MND [50]. The eligibility criteria were: ≥ 2 months post diagnosis of MND and ≥ 1 month post diagnosis of dysphagia (as assessed by a Speech and Language Therapist (SLT)), cognition within normal limits (as per the Edinburgh Cognitive and Behavioural ALS Screen [56]), self-rating at levels 1-5 of the Functional Oral Intake Scale [57], and functional communication (verbal or not). The communication skills of verbal people with MND who did not use any augmentative or alternative means of communication were assessed using 10 sentences with wide phonological representation

selected from the Sentence Intelligibility Test [58]. Additionally, communication was evaluated using ALS Severity Scale: Speech where scores at levels 10 – 6 were required [59]. People with MND who scored < level 6 on the above scale were eligible if they had some form of augmentative and alternative communication support enabling expressive communication at sentence level.

Prior to recruitment ethical approval was granted by the Clinical Ethics Research Committee of the Cork Teaching Hospitals. Participants were recruited through Speech & Language Therapists and an MND Nurse, who identified people with MND and dysphagia and provided them with a written invitation to participate in our study; 16 people with MND expressed interest in participating in this research. Following initial contact with the researcher (XX), and prior to any data collection, two people with MND declined to participate due to poor stamina, one became too unwell to participate, and three were excluded due to cognitive impairment. In total ten people with MND were recruited and completed this research. A summary of participant demographics is presented in table 1 (group demographic is presented to protect participant anonymity).

Table 1 to be inserted here.

Data Collection

Prior to data collection a pilot study was completed to test the research design and interview schedule (which was initially developed based on our clinical knowledge and experience). The main findings were that: 1) interviewing a person with MND alone (without a caregiver) generated richer data, 2) participants preferred to talk about their general experience of living with MND rather than about dysphagia, and 3) the topic of dysphagia naturally emerged when the caregiver offered some snack and tea. Following the pilot, a decision was made to interview all participants individually and more than once and to

include mealtime observations to provide a more natural context for talking about dysphagia. The interview guide was finalised with some modifications, such as gradually introducing questions related to dysphagia. Data obtained from the pilot was analysed in-depth, but not included in the further stages of this research.

Data was collected over 9 months and included multiple interviews and mealtime observations. At the initial meeting a witnessed informed consent was obtained and an assessment of suitability took place. All participants were informed about their right to withdraw their participation at any stage and without any consequences, and of the possibility of having their data destroyed at their request (up to two weeks after the final interview). For the majority of participants (6/10) the first interview was conducted a few days after the initial meeting, 4/10 requested to start the interview at the initial meeting. The interviews took place at participants' choice of location, which for 9/10 was their own home. One person with MND was interviewed in a palliative care centre. All interviews were individual, only one person with MND requested that her daughter be present at the start of the initial interview, which was honoured. Interviews were conducted by the first author (XX), who is a SLT with over ten years of clinical experience in MND. At the time of this research XX was not associated with any clinical service for people with MND. An interview guide (Supplementary material) was used in a flexible manner. Natural opportunities for observations were sought such as having a cup of tea and a snack during the interviews. People with MND on non-oral diets were observed during administration of feeds or medication via gastrostomy, which naturally overlapped with the timing of the interviews. No structured observation guide was used, but observations were recorded immediately after the interview (using a voice recorder). The audio clips were later transcribed and analysed jointly with interview transcripts.

A minimum of two interviews were conducted with each participant. Every initial interview was face-to-face. Follow up interviews were either face-to-face or indirect (via email or handwriting) to minimise the burden of research by offering flexibility to write answers at participants' own convenience [60]. This decision was taken after the initial interview with the first participant, who was observed to significantly fatigue while using his communication device and was only able to answer two questions in 35 minutes (generating 389 words in total). In total, 44 interviews and 13 mealtime observations were conducted; 17 interviews were face-to-face and 27 follow-up interviews were indirect (email or hand-written as per participant's choice). After the initial interview the preliminary data analysis took place to reveal the main concepts, points for clarification and expansion. The questions for follow up interviews were therefore planned individually based on the content of the previous interview. If follow-up interviews were indirect, a set of open-ended questions was sent to participants either electronically or by post. In case of emails, a thread that formed subsequently was counted as one interview. The gap between multiple interviews ranged from 2 weeks to 2 months (80% were conducted within 2 - 4 weeks, and 20% within 2 months), as per participants' availability. Face-to-face interviews took on average 44 min (ranging from 31min to 61 min), they were audio-recorded and translated verbatim. Details of data collection for each participant are presented in table 2.

Table 2 to be inserted here.

Data Analysis

Data analysis followed six steps, as recommended particularly for novice IPA researchers [50]. These were: 1) Reading and re-reading, 2) Initial noting, 3) Development of emergent themes, 4) Searching for connections across emergent themes, 5) Moving to another case, 6) Searching for connections between cases. As IPA is an interpretative

approach during data analysis the researcher is engaged in double hermeneutic when aiming to make sense of participants' attempts to make sense of their experience [50, 52, 56]. Data collected from each participant (interview transcripts, observations and field notes) was organised in a chronological order (individually for each person with MND) to create one 'mega-interview' [54]. An idiographic analysis preceded the cross-case analysis of the whole group. During each stage of data analysis regular discussions with senior researchers (XX and XX) took place, for example to agree the hierarchy of themes.

Validity

Validity was maintained by fulfilling Yardley's criteria: (1) Sensitivity to context, (2) Rigour and commitment, (3) Transparency and coherence, and (4) Impact and importance [61], as recommended for an Interpretative Phenomenological Analysis study [50]. Sensitivity to context manifested, for example, through our responsiveness to participants' needs to ensure that the burden of research was minimised. The interviewer (XX) completed training on qualitative interviewing and practiced her interviewing skills with people with communication impairments prior to this research. Non-verbal people with MND were assured that perfect spelling was not required. Yes-no questions were asked to clarify or expand on participants' reports, although this is not typically recommended in qualitative interviewing [62, 63], it facilitated data collection and member checking. Rigour and commitment refers to conducting the study thoroughly and can be shown, for example, by a reasonably homogenous sample adequately selected to match research questions, conducting a pilot study to inform the research design, and systematic analysis of the data. Member checking was conducted during follow up interviews and a small number of people with MND provided additional descriptions and examples to augment their accounts. Member checking was not conducted in relation to cross-case analysis as this took place at a later

stage of analysis and when the majority of our participants became too unwell or had passed away. Transparency and coherence refers to a clear description of all steps undertaken during the study. A detailed trail of all decisions made during the project was maintained including a reflective diary documenting the data analysis process. Impact and importance relates to the influence of research findings on the profession. The findings of this study aspire to provide a new understanding of dysphagia in MND and this new knowledge could potentially contribute to changes in service provision for the people living with MND.

Results

A hierarchy of themes related to the experiences of participants was established. One theme (Living in the here and now) was assigned an over-arching status as it emerged for every participant in relation to all aspects of living with MND, including dysphagia. Two themes emerged specifically in relation to experiencing dysphagia at home: (1) Self-management techniques and (2) Consequences of dysphagia.

Over-arching Theme: Living in the Here and Now

This theme presents how participants aimed to live with MND once they overcame the initial shock of their diagnosis. MND was described as devastating and unpredictable with resultant feelings of insecurity. One lady reported (words in italics were said with emphasis): "You just couldn't explain it to people how *fragile* everything is in your life. (…) I go to mass on a Saturday night and [my husband] comes with me and you might even feel nervous during the mass. (…) In case *something* would happen" (Eileen, age > 65, MND diagnosis < 12 months, modified oral diet). Although almost every participant described negative emotional experiences of being diagnosed with MND, they attempted to "make life as normal as can be" as they perceived having "no other choice but to accept MND" (Joseph, age > 65, MND diagnosis >12 months, modified oral diet). They also strived to preserve their

independence, for example Joseph who was one of the most physically disabled participant "still run the house from [his] I-Pad. (…) I sit here and answer emails, do banking etc." Participants avoided thinking about the future and distanced themselves from their past. They chose to cope with MND by being focused on the present and aiming to continue participation in their hobbies, work, and routines. Bob, for example "used to do the market [sell books] in the summer and (unintelligible) but I can't do that now. Then we moved it in the house [started to sell books from his house]" (age < 65, MND diagnosis < 12 months, modified oral diet).

The desire to live in the here and now influenced participants' perceptions of dysphagia. It was noted that half of people with MND denied having dysphagia at least once during the interviews, while the other half was consistently reporting experiencing dysphagia. All participants, who denied having dysphagia at least once self-rated at level 5 of the Functional Oral Intake Scale (FOIS) [57] at the entry to this research (all reported requiring special preparation of food), and none of them had a gastrostomy tube in situ. It emerged that these participants did not perceive dysphagia as affecting them if the symptoms of dysphagia were under control on the day of the interview. Therefore, they intermittently reported not having any eating, drinking, or swallowing problems and often redirected the topic of interview to other aspects of living with MND which were affecting them at that time. Most frequently they spoke about deteriorating communications skills as having greater impact on their lives. For example, Joseph was "fed up of being misinterpreted because of [his] deteriorating speech" and that he "used to get very frustrated and angry because [he] had to repeat things" (age > 65, MND diagnosis > 12 months, modified oral diet). Contrary, every participant who consistently reported having dysphagia had a gastrostomy tube in situ (four self-rated at FOIS levels 1-3: full or partial non-oral diet, and one self-rated at level 5, as despite having a gastrostomy tube in situ he refused to ever use it).

Two main themes emerged in relation to living with dysphagia at home: (1) Self-management of dysphagia, such as modifying food textures and excluding risky food, and (2) Consequences of dysphagia, such as fear of choking, altered mealtime environment, and changes perception of food.

Self-Management Techniques

This theme relates to how participants, who were on full or partial oral diet (8/10) managed their dysphagia at home. It emerged that they attempted to manage dysphagia independently before looking for professional help for as long as they perceived themselves able to control dysphagia. For example, a range of self-developed dysphagia management techniques was reported by participants, such as swallowing tablets, modifying foods and altering mealtime environments. In relation to swallowing tablets, Eileen "put the tablet into her mouth first, then she took some food and swallowed it all together with liquid" (age > 65, MND diagnosis < 12 months, modified oral diet). Fiona placed a tablet "at the rear of her tongue and swallow it with water" (age > 65, MND diagnosis < 12 months, modified oral diet). Terence swallowed his tablets "with porridge or yoghurt" (age > 65, MND diagnosis > 12 months, modified oral diet plus gastrostomy tube in situ). Ted used "only food" to swallow tablet (age > 65, MND diagnosis < 12 months, modified oral diet), whereas Carmel "mixed [tablets] with [her nutritional] supplements" (age < 65, MND diagnosis < 12 months, oral & non-oral diet).

Participants reported applying certain techniques to modify food textures and make them easier to swallow. This included cooking food for longer to soften it, cutting food into small pieces or mashing it with a fork, and using electronic devices for food preparation, such as a mincer or blender. Eileen, for example, "put lots of butter on it [toast] when it's hot. To soften it" (age >65, MND diagnosis < 12 months, modified oral diet). Terence reported:

> I remove the peel when making the marmalade. For lunch I have mince beef, chicken, fish or other chopped up small. I have mash potatoes and some vegetables. Sometimes I make a stew with mince, potatoes and veg. That would be best.

As the dysphagia progressed and texture modifications were perceived as not sufficient participants started to gradually exclude problematic food from their diet.

> Interviewer: If we were to go back in the past few months, let's say 6 months… Has anything in the way you eat changed?
>
> Terence: Changed diet.
>
> Interviewer: Can you tell me a bit more about the diet? What has changed?
>
> Terence: Porridge instead of muesli. Soft dinners, minced meat.
>
> Interviewer: Instead of what? What would you have before that?
>
> Terence: Bacon. Beef. (age > 65, MND diagnosis > 12 months, modified oral diet, gastrostomy tube in situ).

Some participants aimed to reduce their efforts related to food preparation to free time for activities more important to them, such as hiking, swimming, or gardening. To save time, they restricted their diets to specific brands only, and often ate "*exactly* the same meals everyday" (Ted, age > 65, MND diagnosis < 12 months, modified oral diet).

It emerged that participants who continued full or partial oral diet, did not report missing the foods excluded from their diet due to dysphagia. Contrary, participants on full non-oral diets appeared to have strong emotional reactions while talking about not being able to eat anymore. One participant highlighted the impact of dysphagia on her inability to fully part-take in celebrations. Sally became upset when recalling her 80th birthday party: "I was 80 last week. All the children came and we were all together. Lidia [daughter] had a nice meal … but I could not eat. Or have a glass of champagne" (age > 65, MND diagnosis < 12 months, non-oral diet).

Consequences of Dysphagia

This theme presents three main consequences of dysphagia identified in this research: fear of choking, altered mealtime environment, and changed perception of food.

Fear of Choking

All participants, including those who were no longer able to eat orally, expressed a strong fear of choking, and some provided descriptions of terrifying choking experiences. For Eileen (age > 65, MND diagnosis < 12 months, modified oral diet) choking caused "the most ferocious feeling of panic":

> Interviewer: (…) You're sitting there, eating dinner, and what's happening?
>
> Eileen: And I'm eating away and I'm fine and the next thing I eat a bit of this [broccoli] and it won't swallow. (…).
>
> Interviewer: So what do you do then?
>
> Eileen: I went out because your first reaction is air. (…) And I ran out and I was (makes choking sound), you know.
>
> Interviewer: You were trying to cough it up, okay, and was it coming up?
>
> Eileen: It wasn't for a minute or … a few seconds, you know. (…) When it was the first time it happened then needless to say when I wasn't expecting it, you came in and you were, you were in shock and I suppose nervous.

Choking was generally considered as unpredictable and participants attempted to prevent choking by being extra careful during meals. Joseph, for example, was "very conscious" about food "going the wrong way" or "get[ting] stuck in my digestive tract. (…) I guess nobody can foresee when a choking episode will occur" (age > 65, MND diagnosis >12 months, modified oral diet).

Altered Mealtime Environment

In order to maximise own safety participants who were still eating orally (8/10) attempted to limit distractions during meals. Carmel, who lived alone, reported switching off her phone during mealtimes and she was observed to reduce the volume of the TV while eating.

Interviewer: How is that happening [coughing during meals]?

Carmel: If I eat too fast. (…) Or if I am texting...

Interviewer: Are you saying if you're distracted from eating it can cause you to cough?

Carmel: Yeah. (Writing). I turn off my phone when eating. (age < 65, MND diagnosis < 12 months, oral & non-oral diet).

Participants generally believed that being careful during meals reduces the risk of experiencing swallowing problems, for example, Fiona stated: "Sometimes I cough when I am not paying attention to drinking. (…) If I am careful it is okay" (age > 65, MND diagnosis < 12 months, modified oral diet). Joseph was "continuously on my guard. I drink slowly to ensure that solid foods are moist and mashed" (age > 65, MND diagnosis > 12 months, modified oral diet). Mike had to be "careful. (…) about bite size" (age < 65, MND diagnosis >12 months, modified oral diet). Although eating alone was "easier", most participants enjoyed sharing meals with others, despite eating being "messy" as the "food tends to fall out" (Terence, age > 65, MND diagnosis > 12 months, modified oral diet, gastrostomy tube in situ).

Interviewer: Do you enjoy that [eating with family] or do you prefer to eat on your own?

Terence: Easier to eat (…) on your own, but like company too.

Interviewer: And why do you say it's easier when you are on your own?

Terence: No talking, concentrating on best way.

Two participants reported that they had stopped going out for meals. For Eileen, the fear of choking was so severe that she limited her diet to food prepared by herself only. Mike reported not having enough stamina to go out for meals.

Changed Perception of Food

Participants' perceptions of food appeared to transform shortly after their diagnosis of MND when they were informed about the importance of adequate nutrition and maintaining the

weight. Unexpectedly for them food rich in calories, which they used to avoid for cardio-vascular reasons, was now considered as good for them. Participants indicated their own belief that losing weight was associated with decreased survival, therefore food was considered as important in influencing the course of MND. Carmel (age < 65, MND diagnosis < 12 months, oral & non-oral diet) admitted "not caring about food" prior to MND, but now she believed it "was really important for the muscles". Joseph (age > 65, MND diagnosis > 12 months, modified oral diet) referred to food as "fuel". Nutritional value of food was frequently prioritised over its taste or appearance and having a full meal appeared to positively influence participants.

> I can become very agitated if I miss out on main meals. I must have a *healthy* meal, breakfast, lunchtime and evening dinner. I also need a caffeine boost every two or three hours. I feel *invigorated* after a healthy meal. (Joseph, age > 65, MND diagnosis > 12 months, modified oral diet).

Participants' attitudes towards food further evolved as their dysphagia progressed and swallowing became harder, which diminished eating related pleasure. Ted, for example, described his swallowing as "a bit off putting". (…) "I drank two cups of tea. I didn't enjoy it" (age > 65, MND diagnosis < 12 months, modified oral diet). Decreased appetite and feeling full after only eating small amounts were commonly reported, which for some was related to decreased stamina: [I] "get full quicker and maybe tiredness is a factor" (Mike, age < 65, MND diagnosis > 12 months, modified oral diet). This diminished enjoyment of food subsequently leading to decreased oral intake, appeared to have significant psychological consequence for some people with MND, such as stress and fear, as it made them more aware of their unavoidable deterioration and having no or not much control over the progression of MND. All participants frequently used words which indicated their expectation of change, such as adding the phrase "at the moment" when talking about their current abilities or using the word "yet" indicating their expectation of further deterioration. For example, when Fiona

was talking about her ability to eat she stated “I don’t have any problems yet”, and then she added: “I don’t know how my illness will progress or what I will need down the line (age > 65, MND diagnosis < 12 months, modified oral diet). Eileen spoke about her ongoing nervousness (“I got nervous of everything”) and insecurity:

> And I think you have to go through it to understand it. (…) You couldn’t explain it. You just couldn’t explain it to people how fragile everything is in your life. I think that is probably what gives you the feeling of insecurity. (…) And lack of confidence whatever you like, you know. (Eileen, age > 65, MND diagnosis < 12 months, modified oral diet)

Discussion

The motivation behind this study was to investigate the personal experiences of dysphagia in MND and communicate the findings to health care professionals. The initial aim was to collect and analyse data directly relevant to the experience of dysphagia, however, this study revealed that participants’ experiences of dysphagia were inseparable from their broader experiences of MND and therefore could not be investigated in isolation. It emerged that the underlying cause of dysphagia (MND) was the predominant concern for participants, rather than the presence of dysphagia itself. Similar findings have already been reported in relation to head and neck cancer (where the primary concern was the re-occurrence of cancer rather than dysphagia [64]), and stroke (where dysphagia was viewed as inseparable from the overall impact of stroke): “Eating difficulties is just a part of the whole package” [39pg. 257].

The personal process of acknowledging the presence of dysphagia emerged as a complex issue in MND. Only people with MND on a non-oral diet (partial or total) consistently reported experiencing dysphagia, whereas people with MND on a full oral diet intermittently denied having dysphagia. The relation between the presence of non-oral feeding and the personal perception of having dysphagia was also reported in head and neck

cancer [64], even though the type of dysphagia in cancer may differ from MND. The process of recognising or admitting that one had dysphagia appeared to be guided by participants' understanding of the term "dysphagia". It emerged that people with MND may not necessary understand the clinically used terms of "dysphagia" or "eating, drinking, swallowing problems" in the same ways as healthcare professionals. The majority of people with MND in our study did not consider themselves to have eating, drinking, or swallowing problems if their symptoms were localised in the oral phase of the swallow (even if, for example, reduced chewing led to the elimination of particular types of food from their diet). However, if dysphagia symptoms were experienced in the pharyngeal stage of the swallow (such as difficulties with passing the bolus through the pharynx or coughing when swallowing), participants' own swallowing ability was more often reported as being compromised. This mirrors the findings of the literature related to head and neck (Tong et al., 2011) and stroke (Parker et al., 2004) populations indicating that some patients (irrespective of aetiology) may relate the term "dysphagia" or "eating, drinking, or swallowing problems" to difficulties in the pharyngeal stage of swallowing only [64]. In addition, Parker et al. (2004) concluded that asking a standard clinical question about the presence of a swallowing problem can have little clinical relevance, which appears in line with the findings of our study.

Another factor that appears to influence our participants' reports about their experience of dysphagia was the over-arching theme: Living in the here and now. Participants in our study reported having dysphagia or perceived dysphagia as an issue only when it affected their lives in the current moment. Once the symptoms of dysphagia were perceived as being under control dysphagia was not an issue of concern and other symptoms of MND took priority. Although the desire to live in here and now has been already reported in MND [42, 65] as lessening the feeling of stress and promote better mental well-being [66], this may be the first study indicating that living here and now can influence personal perceptions of dysphagia.

This finding has potential implications for researchers employing self-reported scales to measure dysphagia in MND, as participant reports may be influenced by which symptom of MND they perceive as an issue in the current moment. If symptoms of dysphagia are perceived as being under control, some people with MND may deny experiencing any dysphagia or may underreport the severity of their symptoms.

Among various consequences of dysphagia the fear of choking emerged as particularly traumatic for people with MND. Fear of choking has already been recognised in dysphagia associated with other medical conditions, such as Parkinson's disease [67], head and neck cancer [68], and stroke [38]. In MND, the fear of choking was reported in relation to respiratory insufficiency [69, 70], which is considered as common symptom in MND [71]. In the current study, the fear of choking had severe impact on participants' life even in the early stages of MND; it influenced their food choices and altered mealtime environment. People with MND attempted to self-manage their risk of choking, predominantly by being very careful while eating and by excluding 'risky foods'. When asked about the ways of managing the risk of choking none of participants reported looking for professional advice, which emerged in line with their general attempts to manage dysphagia independently.

Independence has already been recognised as one of the most commonly used coping strategies in MND [72] and people with MND have been reported to compensate for their dysphagia at the earlier stages of MND [18]. In the current study, participants often preferred to manage dysphagia alone rather than seeking professional help. The strategies reported as self-developed to manage dysphagia included diet modification and alterations in the mealtime environment, for example, some people with MND eliminated distractions during meals to ensure their full concentration on swallowing, which subsequently led to avoiding company during meals. For some people with MND this avoidance created a dilemma, as they enjoyed having company during meals while at the same time they were not able to fully

focus on self-managing the symptoms of dysphagia whilst eating in company. This finding is relevant to anyone who may share a meal with a person with MND, as facilitating the person with MND to concentrate while eating may enable them to continue having company during meals and reduce their risk of social isolation.

The literature recognises the importance of nutrition in MND [25, 73, 74, 75]. However, the maintenance of weight is problematic in MND due to cachexia, hypermetabolism and loss of appetite [74, 76]. All of our participants believed that calorie-rich diet can slow the progression of MND, but worsening dysphagia reduced their food related pleasure subsequently leading to fear of losing weight and reducing their own survival. It appears that the secondary consequences of dysphagia (such as decreased enjoyment of food) may also reduce the dietary intake of people with MND and have psychological consequences for them. These findings have also been found in the population of people with head and neck cancer, who also perceive dysphagia from the wider perspective of their illness and are often motivated to maintain good nutrition despite reporting poor enjoyment from food [35, 77]. In both populations (MND and head and neck cancer) maintaining or increasing their body weight is often perceived as improving their own prognosis. Additionally, people with head and neck cancer may perceive nutrition as a factor improving their own appearance by reducing the visibility of having cancer [35, 77]. Some people with head and neck cancer are reported to regain their full enjoyment with food in time [36], which could not be expected for people with MND.

Finally, some people with MND reported that their communication impairment had a greater profound impact on their everyday life than dysphagia. Unlike dysphagia, which for some people with MND emerged as an intermittent issue, impaired communication was perceived to be an ongoing problem that was impossible to conceal. Communication impairment (for example, dysarthria) has already been identified as one of the most significant stressors by

people with MND, along with muscle weakness and worry about how the progression of the disease will impact on their independence [78]. A recent study reported that both the anticipation of communication changes and the process of adaptation to these changes caused significant psychological and emotional impact in people with MND, and that communication services should focus on communication holistically and consider the views of people with MND [79]. The findings above are of significant relevance to SLTs who provide services for both dysphagia and communication in MND. Although dysphagia can be associated with a higher medical risk, the need of communication support can be more important for people with MND. In addition, living with the progressive communication impairment requires ongoing psychological support.

Conclusions

This is the first study which explored the experiences dysphagia in people with Motor Neurone Disease (on full oral, mixed, and full non-oral diets). We acknowledge that the experience of our particular participants may not be the same as others with different demographics and clinical presentation. We recruited participants who happened to be older adults (80% were ≥ 65), however, the mean age of 67.2 is considered as within the peak incidence of MND in the Republic of Ireland estimated at 65-69 [80, 81]. Participants were mainly retired (80%) and without a cognitive impairment. Most participants lived in rural parts of Ireland (the average distance to the nearest MND clinic was over 50 km), which could have influenced participants in their attempts to manage dysphagia alone. Nevertheless our study provides a unique contribution in advancing our understanding of what is means for people with Motor Neurone Disease to live with symptoms of dysphagia and the impact it has on their quality of life. For instance, our study indicates that healthcare professionals should approach the management of dysphagia associated with a multisystem, progressive illness, such as MND, from a wider perspective, where the general experiences of living with the

disease are explored. This perspective may help illuminate the perceptions, beliefs, motivations and intentions behind the patient's self-management of dysphagia. For example, some people with MND may cope by living in the here and now and not perceive dysphagia to be a constant issue of concern or may wish to self-manage their dysphagia by making alternations to their diet and mealtime environment. They may consider the impact of communication impairment to be more profound than dysphagia. Most importantly, health care professionals might need to switch their clinical perspective from "dysphagia" to the "person with MND" who may ultimately desire to live life in the current moment while having to cope with multiple issues caused by MND.

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Table 1. Summary of Participants' Demographic (N=10)

Variable		N
Gender	Female	5
	Male	5
Age	55 – 65	5
	> 65 – 75	4
	> 75 – 85	1
County of origin	Ireland	9
	England	1
Employment status	Retired	8
	Employed	2
Marital status	Married	8
	Widowed	1
	Single	1
Children	Has children	8
	Does not have children	2
Geographical area	Urban	1
	Sub-urban	3
	Rural	6
MND onset	Bulbar	9
	Spinal	1
Time since diagnosis of MND	2 – 6 months	5
	> 6 – 12 months	1
	1.5 – 2 years	2
	> 2 – 3 years	1
	> 6 years	1
Verbal communication	At study outset	5
	At study end	1
Diet type (at study outset)	Full oral (modified)	7
	Full non-oral	2
	Oral & non-oral	1
Diet type (at study end)	Full oral (modified)	6
	Full non-oral	2
	Oral & non-oral	2

Table 2: Details of Data Collection per Participant

Person with MND	Age	Communication system	No. face-to-face interviews	No. email interviews	No. handwritten interviews	No. mealtime observations
Bob	64	Handwriting plus limited speech	1	4	0	1
Carmel	58	Handwriting plus limited speech	2	0	1	1
Eileen	73	Speech	2	0	0	2
Fiona	69	Speech (1st interview) handwriting (2nd interview)	2	0	0	1
Joseph	65	Electronic device, no speech	2	8	0	1
Mike	55	Electronic device plus limited speech	2	3	0	2
Sheila	65	Handwriting, no speech	1	0	1	1
Sally	80	Handwriting, no speech	2	0	1	1
Ted	75	Handwriting, no speech	1	0	1	1
Terence	68	Electronic device, no speech	2	7	1	2