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Healthcare professionals' views on psychological factors affecting nutritional behaviour in people with motor neuron disease: a thematic analysis

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Keywords

Motor neurone disease, MND, amyotrophic lateral sclerosis, ALS, nutrition, perceived control.

Ethics

Ethical approval for this study was granted by the Research Ethics Committee of the School of Health and Related Research at the University of Sheffield (ref: 018781), and governance approval was granted by the Health Research Authority (ref: 245296). All participants provided written informed consent to take part in the focus group and for this to be audio recorded.

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Appendix A

The HighCALs study group:

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Statement of Contribution

What is already known on the subject?

Since weight loss and reduced body mass index (BMI) have been identified as independent risk factors for prognosis and survival in motor neuron disease (MND), nutritional management represents an important component of the symptomatic care of people with MND (pwMND) aimed at prolonging survival and maintaining or improving quality of life. However, the current guidelines and quantitative and qualitative literature on the topic are mainly focused on issues around enteral feeding and gastrostomy insertion, and very little is currently known about potential psychological enablers or barriers to earlier nutritional management, especially from the perspectives of healthcare professionals (HCPs) involved in the delivery of nutritional care in people with MND.

What does this study add?

- First qualitative investigation of enablers or barriers to nutritional care in pwMND from the perspective of HCPs.
- New insight into psychological factors (e.g., adjustment, avoidance, loss of control) in nutritional care for pwMND.
- Practical implications and novel clinical suggestions for HCPs involved in nutritional care of pwMND.

Abstract

Background: Motor neuron disease (MND), also known as amyotrophic lateral sclerosis, is a neurodegenerative disorder that causes progressive muscle paralysis and typically leads to death within three years. As no cure is currently available, symptomatic management is the mainstay of treatment. An important part of this is optimising nutritional intake with evidence that this may positively affect survival and quality of life. Healthcare professionals (HCPs) play a pivotal role in nutritional management of people with MND but, to date, their views on the psychological barriers faced by people with MND have not been explored. Such an exploration may identify ways in which the delivery of nutritional care for people with MND can be optimised.

Methods: Five qualitative focus groups were carried out across the UK in June 2018 with 51 participants, including 47 healthcare professionals involved with MND care and four service user representatives. Data were analysed through thematic analysis.

Results: Four overarching themes were identified: psychological adjustment and patient engagement; nutrition and the need for control; knowledge of nutrition and the complexity of MND; and the psychosocial nature of eating.

Conclusions: The findings suggest that the nutritional management of people with MND should be mindful of factors such as the impact of distress at the time of diagnosis, the availability of clear information on nutrition and MND, as well as the importance of illness perceptions and coping strategies. Moreover, tailored psychological interventions should be considered to mitigate the impact on MND on the experience of eating.

Introduction

Motor neuron disease (MND), also referred to as amyotrophic lateral sclerosis (ALS), is a devastating neurodegenerative disorder affecting both the upper and lower motor neurons that leads to progressive muscle weakness and wasting which, in turn, cause impaired movement, speech, swallowing, respiratory functioning, and eventually death (Hardiman et al., 2017; McDermott & Shaw, 2008). It has an incidence of about 2 in 100 000 worldwide (Logroscino et al., 2010; Marin et al., 2017) and is usually sporadic, although in up to 10% it is observed to be familial with a number of causative genes identified (Zarei et al., 2015). There is currently no cure, and the average survival after the onset of symptoms is three years (Hobson & McDermott, 2016). In most cases the onset is characterised by weakness of the limbs ('limb onset'), although around a third of the patients experience an onset characterised by swallowing and speech difficulties ('bulbar onset'; Hardiman et al., 2017). While it was initially believed that MND solely affects neurons responsible for movement whilst sparing cognition (Phukan, Pender, & Hardiman, 2007), later population-based studies have shown that around 40 to 50% of affected individuals present signs of cognitive impairment (in particular executive functioning), and about 10% meet the criteria for a diagnosis of frontotemporal dementia (Phukan et al., 2012). Since no cure has been identified yet for MND, the clinical management of the disease relies predominantly on symptomatic interventions aimed at prolonging survival and maintaining or improving quality of life (Hobson & McDermott, 2016).

An important component of symptomatic care is nutritional management. Weight loss and reduced body mass index (BMI) have been identified as independent risk factors for prognosis and survival in MND, with a two-fold increase in risk of death in affected

individuals who show loss of 5% or more of their pre-morbid weight at diagnosis (Paganoni, Deng, Jaffa, Cudkowicz, & Wills, 2011; ProGas Study Group, 2015; Stavroulakis & McDermott, 2017). Maintenance of good nutrition in people with MND is hampered by factors such as reduced mobility, limb weakness, dysphagia, lack of appetite (Stavroulakis & McDermott, 2016), and increased resting energy expenditure due to hypermetabolism (Bouteloup et al., 2009). These factors contribute to a reduced oral intake and in many cases lead to gastrostomy feeding tube placement (Stavroulakis & McDermott, 2016).

Despite the clinical importance of nutrition in MND, current guidelines and previous research on this topic are mainly focused on issues around enteral feeding and gastrostomy insertion (e.g., decision making processes, timing of insertion, and impact on quality of life) rather than earlier stages of nutritional management (Andersen et al., 2012; Greenaway et al., 2015; Martin et al., 2016; Stavroulakis et al., 2014, 2016). There is little evidence to guide early nutritional management in MND, with no qualitative investigations so far focusing on the perspectives of HCPs. However, in other long-term conditions HCPs have provided valuable insights into the psychological factors, such as patients' attitudes and motivations, which may be overlooked when focusing solely on patients' perspectives (Eide, Halvorsen, & Almendingen, 2015; Golla, Galushko, Pfaff, & Voltz, 2012; Lambert, Potter, Lonergan, Tapsell, & Charlton, 2017; Matthias et al., 2010). As a consequence, the aim of the present study was to investigate the views and perceptions of healthcare professionals on the patient factors affecting nutritional behaviours and the delivery of nutritional care in people with MND.

Methods

Methodological approach

A qualitative design was adopted for the present study (Cresswell, 2007). Five focus groups were conducted with MND healthcare professionals across five different locations across the United Kingdom (Bristol, Edinburgh, London, Manchester, and Sheffield). The data were analysed through thematic analysis (TA).

Sampling and recruitment

HCPs involved in the management of patients with MND and service user representatives were invited to participate through several organisations. These included the Motor Neurone Disease Association, MND Scotland, the British Dietetic Association, the UK Motor Neuron Disease Clinical Studies Group, and the Sheffield Motor Neuron Disorders Research Advisory Group. In addition, MND care centres as well as other hospitals, Clinical Commissioning Groups, and MND Regional Care Development Advisers were approached. Invitation emails were distributed to contacts in all organisations, and the focus groups were advertised on dedicated study social media. Convenience sampling methods were used, whereby eligible and potentially interested participants were asked to opt-in to the study based on their availability to attend one of the focus groups. In following this approach, we sought to maximise variation in the sample attending each focus group, i.e., to capture the experiences in different organisations and include different clinical specialties or job roles. Service user representatives were also included due to the recognised importance of their involvement for enhancing the quality of results from qualitative research (Mjøsund et al., 2017), as well as the findings from health research in general (Bee, Brooks, Fraser, & Lovell, 2015; Shippee et al., 2015).

Participants

In total, 51 participants from 41 different organisations took part in the five focus groups of the study. These included community and hospital dietitians, dietetics managers, motor neuron disease specialist nurses, community nurses, hospital and community speech and language therapists, MND coordinators, service user representatives, doctors, and physiotherapists. Focus group participants were predominantly female (n = 46, 90%). Table 1 summarises the participants by profession, as well as the composition of each focus group.

Table 1: Summary of the focus group participants by profession.

Profession	Specialty	FG1	FG2	FG3	FG4	FG5	N
Dietitian	Community based dietitian		1	1	2	2	6
	Dietetic team leader		1				1
	Hospital-based dietician	6	2	2	4	4	18
Doctor	Neurology				1		1
	Palliative care			1			1
MND Co-ordinator		1				1	2
Nurse	Community nurse					1	1
	MND nurse		3	3	1	2	9
	Nutrition nurse	1					1
Physiotherapist					1		1
Service user representative	Carer	1		1	1		3
	Patient				1		1
Speech and language therapist		1		3	1	1	6
Total		10	7	11	11	12	51

Note: FG = Focus group; N = sub-total in the sample.

Procedure

All focus groups were conducted during June 2018 and were held at non-NHS sites located near a central transport hub, in order to facilitate the attendance of participants living outside of the area. The number of participants at each focus group varied from seven to 12. The mean duration of the focus group discussions was 60 minutes (range: 55 – 65 minutes). Each focus group was divided into three parts. Following introductions and presentation of the study aims, the participants were asked an open-ended warm up question in part one ('How important is to provide nutritional advice and support to people with MND/ALS?'). In part two, an elicitation exercise was conducted, whereby participants were divided into small groups and asked to record summary descriptive information about the delivery of nutritional care to people with MND in their area. This provided a useful starting point for part three, during which a semi-structured group interview schedule was adopted to generate discussion of barriers and enablers to delivering nutritional management services. The focus group discussions from parts 1 and 3 were digitally recorded, and quotes from both parts are provided in the analysis.

Data analysis

The recordings of all focus groups were transcribed verbatim, organised with the NVivo 12 qualitative data management software, and analysed using thematic analysis (TA). TA was used to allow both a deductive and inductive approach to the emerging themes (Harper & Thompson, 2011), and in light of its long tradition of implementation within psychological research (Braun & Clarke, 2006, 2012). To guide the analysis, the six steps outlined by Braun and Clarke (2006) were adopted. First, a data familiarisation session was carried out, characterised by reading and re-reading the transcripts several times

and noting down initial ideas. Second, initial codes for interesting features were generated and collated to potential themes recognised across the whole dataset. Third, the initial themes were reviewed to ensure consistency with the codes (Review Level 1) and, fourth, to the whole dataset (Review Level 2). Fifth, a thematic map of the analysis was created, and specific names for the themes were generated, allowing for the generation of clear definitions for each. Sixth, a final report was produced, consisting of a selection of the most compelling extracts examples and their analysis.

Table 2: Summary of the identified themes and relative codes.

Theme	Codes
1. Taking the <i>“first step”</i> : psychological adjustment and the issue of patient engagement	Denial Engagement and compliance Psychological adjustment
2. Retaining decision-making: nutrition and the need for control	Decision-making Empowerment Having something to work on Need for control
3. Knowledge of nutrition and the complexity of MND	Clinical language as a barrier Combatting “healthy” messages Disease progression Knowledge of nutrition in MND
4. MND and the psychosocial nature of eating	Depression and lack of appetite Emotional distress Fear of choking Social aspects of eating Withdrawal and disinterest in eating

Results

Overview of identified themes and codes

Transcriptions from the recorded parts of the focus groups (parts one and three) were integrated into a final dataset for the analysis. Upon familiarisation with the data, an initial list of 26 codes was developed. Following multiple revisions, a final list of 16 codes was generated. These codes were then distilled down to four main themes that were relevant to the research questions and aims, and on which all the members of the team agreed. No differences were observed in terms of themes for the focus groups (FG) which included service user representatives. Table 2 provides a summary of the main themes and the breakdown into their respective codes. Single quotes were labelled based on the specific FG they belonged to.

Theme 1. Taking the “*first step*”: psychological adjustment and the issue of patient engagement

One of the most recurrent nutritional factors reported by healthcare professionals (HCPs) was the importance of patients’ early engagement. HCPs reported that getting the right level of involvement early on after diagnosis is often a demanding task:

“We appreciate how important it [nutrition] is. But if you’ve got someone walking through your door in the very first instance and they’re saying ‘there’s nothing wrong with my diet, I’m managing, I’m managing everything’.” – FG2

“It [nutrition] is not something [that has to do] with everything else that’s going on, if there’s not anything that’s directly impacting upon their eating, they’re just not really interested at the early stages.” – FG2

HCPs felt that problems with patients' reactions to and acceptance of their diagnosis could impede their ability to address nutrition with patients:

"There are some times when they don't [get engaged] and that's really difficult, to help those patients if they're not accepting their diagnosis, and you just can't, you can't get into it." – FG1

"People will swear blind that 'I never mentioned anything of this'. And I've done that and I've talked about swallowing, and we've done it from day one, gradually trying to drip feed the information but they're not ready for it until they need it, so there's a limit. We can keep on educating and informing, but they'll only do it when they're ready." – FG3

Several HCPs believed that psychological factors such as adjustment to the disease and denial may play a pivotal role in the level of patient engagement with nutritional advice in both the short- and long-term. The impact of denial in particular appeared to be so great to some HCPs that they felt that some patients' first reactions could translate into a negative coping style. These coping styles were thought to be characterised by a lack of motivation to seek advice and support; a "psychic prison" in which they get stuck while keeping out family members and carers:

"There seems to be some patient paralysis once you're diagnosed. [...] There seems to be this psychic prison that they're stuck in about doing anything or seeing that there is something that might mean some kind of support and I think an awful lot of denial is a block to them seeking that support or wanting it in the first place." – FG5

Some HCPs also believed that, in more extreme cases, this coping response may have the potential to evolve into avoidance. This could lead to some patients to become isolated and refuse to accept any sort of intervention, even when HCPs approach them directly:

“There’s... well, patients that go completely off the radar and won’t answer the phone. And they are completely uncontactable.” – FG1

“It’s all kind of veering towards a crisis and it’s really sort of frustrating sometimes, to kind of have to stand back and watch and wait.” – FG1

As a consequence, according to some of the HCPs, the impact of denial and its evolution towards avoidance may be a significant barrier to the delivery of early nutritional management of people with MND. However, more than just being the expression of denial as an end in itself, the adoption of avoidant coping styles could also be seen as a way to express the need for control over a psychologically distressing situation.

Theme 2. Retaining decision-making: nutrition and the need for control

When considering the psychological impact of a diagnosis such as MND, several HCPs identified the need for patients to retain control over nutritional decision-making. This was viewed as a potentially empowering factor for patients and consisted of the possibility to retain decision-making and control within the context of nutrition:

“I think supporting them to still be able to have nutrition is a key thing, in sort of empowering them, to still be able to have ownership of that.” – FG2

The importance of taking independent action and retaining agency was seen to be critical not only for the patients themselves, but also their families:

“I think around nutrition as in eating and drinking... I think that it is sometimes one of the things people still feel [...] it’s in their control and isn’t taken out of their hands, cos it’s a basic thing in nutrition.” – FG2

“I think it’s very important, too. But I think it’s also because you can give the families something to do.” – FG 2

However, some HCPs also highlighted how the manifestations of need for control may vary across the MND population, as avoidance or disengagement are not the only ways in which control can be exerted. Some reported how this can also take on a more positive form, through an early proactive attitude aimed at taking more control over nutrition and their condition in general:

“You know, one of the first questions we’ve had recently from somebody was, you know, they just wanted an assessment, a full assessment of nutrition from the first appointment. So they can sort of find out what they need to do in advance, sort of control that bit of action so they can work on themselves.” – FG2

Therefore, it could be hypothesised that promoting patients’ levels of perceived control may be an effective way to improve their attitudes towards early nutritional advice and interventions. In particular, by channelling the same motivations that could lead to avoidance into supporting a more proactive and informed notion of nutritional agency, need for control may ultimately be conceived as a means to increase patient engagement and adherence to nutritional interventions. However, to achieve this, the HCPs believed it would be necessary to first address a number of other issues related to the attitudes and motivations of patients, starting with the need for adequate clinical information.

Theme 3. Knowledge of nutrition and the complexity of MND

As the majority of the HCPs reported, one of the most significant barriers they face when delivering nutritional advice is a lack of knowledge about nutrition both generally and in MND specifically. This applies to patients, carers, as well as HCPs themselves, and often translates into a number of negative attitudes and misconceptions that can prove quite hard to change. A clear example that was reported consisted of ‘healthy eating’ messages

that, despite relevance to the general population, may not be applicable to people with MND.

"...there are so many messages out there about healthy eating, about low fat diets, you know, high fibre diets, low sugar diets and gluten-free and wheat-free, and it's quite a shock to people when I'm saying as a dietitian 'Throw those messages out the window. You need energy, you need calories and you should be taking, you know, full fat, full sugar products.' And people say 'oh, what about my heart?'" – FG2

"Particularly when they're less active, that's a classic, and trying to say to them 'look you might be less active, but you're hypermetabolic you are actually like a child ripping through calories.'" – FG4

The impact of misconceptions about nutrition may prevent patients from taking a positive perspective on nutritional advice. For example, they may view it as being given a number of options, rather than "taking something away" from them:

"Cos a lot of people when they get any kind of diagnosis often feel they've gotta eat very healthily, cut all this out and that. I'm then saying 'actually, there you can have a bar of chocolate, you can have cream cakes and stuff like that', and I think sometimes it allows us a slightly more positive slant onto things." – FG1

The use of technical clinical language was another barrier to knowledge of nutrition in MND perceived by HCPs. The use of clinical terms, especially at an upsetting time such as post-diagnosis consultations, was reported to frighten people with MND and increase misconceptions and negative perspectives about nutrition:

There's an informative aspect as well, in that letting people know what potentially is gonna happen in the future, but also what can be done about it cos the 99% of the population are not aware of things like textured diets or nutrition support. [...] To them a lot of the language is quite scary as well. – FG2

This was also related to a further issue in supporting positive attitudes around towards accepting nutritional advice, as well as achieving comfortable levels of perceived control, which is represented by the rapid and unpredictable rate of progression of MND. This can cause the needs and priorities of affected individuals to change abruptly in very short periods of time, which may render supportive measures ineffective very quickly:

“Trying to keep up on that journey, so that you’re kind of able to give them the relevant information at the relevant time, in the ideal scenarios, whether it’s possibly then time to introduce something whatsoever, but just so we have as much information as possible.” – FG2

Theme 4. MND and the psychosocial nature of eating

Many HCPs commented on the impact of MND on psychological and social aspects of eating which may provide a further barrier to delivering effective nutritional care:

“There’s also the stress aspect among the patients, ‘cos eating is such a social thing that, I mean, it comes with so many problems that it becomes quite worrying... [...] Food isn’t just the nutrition, it’s everything else that comes with it, and if that’s wrong it has a big impact on the family as a whole as well as the individual.” – FG 1

In addition, some HCPs reported that mealtime stress can be exacerbated by a number of emotional difficulties, and in particular the fear of choking that patients may experience. This is related to problems with swallowing (dysphagia) that are estimated to affect at least 75% of all MND patients, with the associated risk of aspiration of liquids and food (Stavroulakis & McDermott, 2017). It was also believed to exacerbate the psychological challenges caused by the diagnosis of MND in general, which often have the potential of turning the experience of eating into a significant source of emotional distress. This, in turn, may lead patients to reject feeding altogether:

“I mean it’s the emotional toll of it as well. People lose weight even when they’re under stress. [...] At diagnosis people often said ‘I don’t feel like eating’, especially if they’ve only found out.” – FG4

Therefore, the interaction between physical changes (e.g., dysphagia) and psychosocial difficulties at mealtimes (e.g., stress, embarrassment) were felt by HCPs to be a considerable barrier to delivering a nutritional intervention.

Discussion

Overview of main findings

The present paper reports the results of an in-depth qualitative analysis of health professionals’ (HCPs) perceptions of the psychological factors experienced by people with MND that may impact on their nutritional behaviour. This study adds to the literature on the nutritional management of patients with ALS as, to date, no previous research has been conducted on nutritional factors in MND from the perspective of HCPs, especially regarding potential enablers or barriers which may affect the delivery of good nutritional care.

Four main themes were identified from the data. The first theme concerned the views of HCPs on patients’ psychological adjustment to the diagnosis of MND, and how they believe that issues such as denial and avoidance may affect patients’ engagement and compliance with nutritional advice. Traditionally considered more akin to an end goal, psychological adjustment to chronic illness has recently been reconceptualised as a more dynamic process, which is multifaceted in nature and context-dependent, and thus “neither linear nor lockstep” (Stanton, Revenson, & Tennen, 2007, p. 568). This is particularly relevant in the case of MND, where the disease trajectory has often been

described as leading to patterns of continuous adaptation to ongoing changes (A. Hogden, Greenfield, Nugus, & Kiernan, 2013; King, Duke, & O'Connor, 2009). The HCPs in the present study reported how patients' adoption of an avoidant coping strategy had the potential to cause significant delays in the implementation of an effective nutritional management strategy. This finding was consistent with several descriptions in the literature of avoidant coping styles that some people may be predisposed to adopt in the face of a chronic or life-threatening diagnosis (Stanton & Revenson, 2012). This appears to be particularly relevant for people with MND, since this kind of coping has shown to be linked with poorer quality of life in long-term conditions (Abdel-Kader et al., 2009) as well as in MND specifically (Lee et al., 2001). This may also affect the information seeking behaviour of affected individuals, leading them to become 'information avoiders' in the context of their condition (O'Brien, 2004). The adoption of avoidant coping strategies may represent a compelling problem to consider in the context of nutritional behaviour of people with MND, and during the first stages of their nutritional management.

A potential solution to the issue of avoidant coping strategies came in the form of the second theme in which HCP's highlighted patients' need to retain decision-making over nutrition and their perception of control in general. Indeed, while avoidance may be seen as a means to retain control during the early phase of psychological adjustment to the disease, most HCPs believed that giving patients the chance to discuss assessments and being directly responsible for nutritional actions early on had the potential to be a more empowering alternative approach to coping and control. This approach, if channelled correctly, may in turn allow for the development of even more positive attitudes towards the receipt of nutritional advice in general. This observation is in line with current theorisations around the psychological adaptation to chronic illness. In particular, it

resonates with the self-regulation model (SRM; Leventhal & Cameron, 2001; Leventhal, Meyer, & Nerenz, 1980), which sees illness perceptions (i.e., how affected individuals perceive characteristics of the disease such as duration, severity, identity, and cause) and levels of perceived control as critical factors associated with psychological adjustment to chronic conditions (Dempster, Howell, & McCorry, 2015; Egede & Ellis, 2008; Sharpe & Curran, 2006). Under this perspective, people with MND may see the opportunity to make their own nutritional decisions and act on the proposed dietetic plans as a better way to retain control on aspects of their lives in face of the condition, as opposed to avoiding engagement with the HCPs and clinical care in general. This view is supported by evidence that people diagnosed with MND may cope with the perception of general loss of control caused by the disease by exerting control over their interactions with HCPs (Foley, Timonen, & Hardiman, 2014a). The sense of autonomy regarding decision-making has also been reported to be reinforced by patients' interactions with specialised multidisciplinary team members (Hogden, Greenfield, Nugus, & Kiernan, 2012). At a more general level, this also resonates with a large body of evidence on the influence of perceived control and illness perceptions in people with neurological and neurodegenerative disorders, including Huntington's disease (Arran, Craufurd, & Simpson, 2014; Zarotti, Simpson, & Fletcher, 2017), Parkinson's disease (Hurt et al., 2014; Simpson, Chatzidamianos, Fletcher, Perpetuo, & Eccles, 2018), Alzheimer's disease and mild cognitive impairment (Matchwick, Domone, Leroi, & Simpson, 2014; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008), and MND (Ando et al., 2015; Eccles & Simpson, 2011; Foley, Timonen, & Hardiman, 2014b). To date, the SRM has not been applied to nutritional management in people with MND, although our findings suggest that its application could help to inform nutritional management programs tailored around the specific illness perceptions and coping needs of people with MND.

The third theme revolved around a lack of general as well as MND specific knowledge about nutrition reported by the HCPs. The HCPs believed that this, combined with the complexity and unpredictability of the disease course – which varies greatly depending on factors such as disease subtype as well as age and type of onset (Chiò et al., 2009; Gordon et al., 2010) – may contribute towards a number of negative attitudes towards nutrition. This is consistent with previous accounts of the factors that influence decision making by people with MND about enteral feeding after gastrostomy, including issues with acceptance and adjustment to the disease, uncertainty over the disease trajectory, fear of losing quality of life and pleasure from eating, as well as loss of control (Greenaway et al., 2015; Martin et al., 2016; Stavroulakis et al., 2014, 2016). The HCPs also believed these issues may be exacerbated by the fact that the suggested nutritional regimes for MND are often characterised by higher calorific intakes (Stavroulakis & McDermott, 2017), which are inconsistent with the healthy eating messages frequently advocated to the public. This inconsistency may represent a source of misunderstandings and misconceptions. Many HCPs also reported a significant detrimental impact of the disease's heterogeneous course, which is also consistent with the previous literature on prognostic factors in MND. In particular, current evidence suggests that bulbar onset represents a strong predictor of psychological distress in newly diagnosed patients (Goldstein, Atkins, Landau, Brown, & Leigh, 2006) due to the strong correlation between swallowing impairment, depression and anxiety (Hillemacher et al., 2004). While the HCPs in our study did not explicitly mention patients' onset types, it could be hypothesised that the more prominent impact of dysphagia in bulbar onset disease may have the potential to impact more significantly on psychological well-being. These issues would be consistent with previous reports by healthcare professionals on the perceptions of the psychological impact of dysphagia (e.g., depression, vulnerability, and

food avoidance) in people with both acute and chronic conditions (Martino, Beaton, & Diamant, 2010).

Finally, the fourth theme was related to the detrimental effect of MND on the experience of eating. HCPs believed that the psychological difficulties this can trigger may lead to significant disruptions of the relational and social meaning of eating and quality of life in general. This view is not surprising, since eating has been historically recognised as a major component of visceral and sensory-focused pleasure (Cornil & Chandon, 2015), and psychological health (Remick, Pliner, & McLean, 2009), as well as psychosocial functioning (Higgs & Thomas, 2016). Many participants reported how issues such as lack of appetite and the risk of choking can significantly affect patients' attitude towards eating and nutrition in general. This is consistent with previous evidence of fear of choking (Greenwood, 2013; Muscaritoli et al., 2012), as well as loss of appetite and the deterioration of the sense of taste (Holm et al., 2013; Pelletier, Abou-Zeid, Bartoshuk, & Rudnicki, 2013) in people with MND. Similar findings have been highlighted in qualitative research with people with Parkinson's disease, who reported psychosocial consequences such as feelings of stigma and disruption of eating habits (Miller, Noble, Jones, & Burn, 2006). Together, these findings support the suggestion that MND's influence on the experience of eating may represent a significant stress-inducing factor for both the patients and their families or carers (Johnson et al., 2012), which may ultimately contribute to a negative attitude towards food and nutrition in general.

Study limitations and future directions

When considering the results of the present study, a number of limitations should be taken into consideration. First, the lack of direct patient input represents a limitation of the study design, as HCPs' perceptions may differ significantly from those of people with

MND. Future research should investigate the psychological factors affecting nutritional behaviour in people with MND from the perspectives of patients and caregivers, as well as healthcare professionals. This would provide a valuable opportunity for triangulating the current findings. Second, the small sample size required by a qualitative approach, as well as its convenience nature, can limit the generalisability of the results to larger groups of HCPs, as it is possible that only those HCPs with a strong interest in nutrition agreed to participate in the present study. Future investigations involving larger and more comprehensive samples should be developed in order to survey the views and perceptions of a wider audience of HCPs on the factors affecting nutritional behaviour in people with MND.

Clinical implications for healthcare professionals

The results outlined in the present study suggest a number of clinical implications for professionals involved in both the psychological and nutritional care of people with MND. First, the impact of psychological distress at the time of diagnosis, and in particular adjustment and engagement difficulties and the risk of denial, should be considered in the context of planning the delivery of effective nutritional management. Affected individuals and their carers should be allowed to take the time they require to adapt to the news of the diagnosis, in order to prevent avoidance. It is important to account for the specific clinical characteristics of MND, including differences between limb and bulbar onsets and the rapid and heterogeneous trajectory of the condition, and how these may impact the timescale of nutritional management (e.g., earlier impact of dysphagia in bulbar MND).

Second, clear information and guidance on the impact of MND on nutrition should be provided at an early stage whenever possible, in order to tackle limited knowledge and

feelings of uncertainty that may cause negative attitudes towards nutritional advice. This should avoid overly complex clinical terminology because this can create a barrier to effective communication between healthcare professionals, patients, and their caregivers.

Third, the planning and delivery of effective nutritional management should be mindful of the illness perceptions and coping strategies of people with MND, and how these can be severely affected by the condition. In this respect, HCPs may incorporate principles from the SRM into their interventions and boost patients' feelings of control by involving them in early nutritional decision-making processes and allowing for as much nutritional autonomy as possible, as this could help prevent avoidant coping strategies and disengagement.

Fourth, HCPs may also support this process by integrating tailored psychological interventions aimed at tackling the emotional distress caused by the disruption of eating habits and their social and relational meaning. This may be implemented by way of interventions focused on the development of emotion regulation strategies, and especially cognitive reappraisal (Buhle et al., 2014; Gross, 2015). Indeed, reports from previous quantitative and qualitative investigations suggest that individuals living with long term neurological conditions including MND can benefit greatly from successful emotion regulation (Williams, Howlett, Levita, & Reuber, 2018; Williams, Levita, & Reuber, 2018; Zarotti, Fletcher, & Simpson, 2018; Zarotti et al., 2017; Zarotti, Simpson, Fletcher, Squitieri, & Migliore, 2018). In addition, HCPs may be able to provide practical suggestions to mitigate the impact on MND on the mealtime experience, such as the use of adapted cutlery and providing advice on tailoring portions around specific mealtime needs (e.g., need for greater time).

Conclusion

The present findings indicate that healthcare professionals (HCPs) involved with the nutritional care of people with motor neuron disease (MND) believe that factors such as psychological adjustment to the diagnosis, avoidant coping strategies, denial, perceived loss of control, and lack of knowledge all play a critical role in shaping patients' attitudes and motivations towards nutritional advice. The psychosocial aspects of eating, and their distressing disruption caused by MND's unpredictable trajectory, are believed to further impact on patients' ability and motivation towards adequate nutritional intake. Nutritional care of people with MND should be mindful of factors such as the effect of psychological distress at the time of diagnosis, the availability of clear information and guidance on the impact MND on nutrition, as well as the importance of shaping illness perceptions and developing coping strategies. Tailored psychological interventions, possibly combined with practical dietetic input, should be considered to mitigate the impact on MND on the experience of eating.

References

- Abdel-Kader, K., Myaskovsky, L., Karpov, I., Shah, J., Hess, R., Dew, M. A., & Unruh, M. (2009). Individual quality of life in chronic kidney disease: Influence of age and dialysis modality. *Clinical Journal of the American Society of Nephrology*, 4(4), 711–718. <https://doi.org/10.2215/CJN.05191008>
- Andersen, P. M., Abrahams, S., Borasio, G. D., de Carvalho, M., Chio, A., Van Damme, P., ... Weber, M. (2012). EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis (MALS) - revised report of an EFNS task force. *European Journal of Neurology*, 19(3), 360–375. <https://doi.org/10.1111/j.1468-1331.2011.03501.x>

- Ando, H., Williams, C., Angus, R. M., Thornton, E. W., Chakrabarti, B., Cousins, R., ... Young, C. A. (2015). Why don't they accept non-invasive ventilation?: Insight into the interpersonal perspectives of patients with motor neurone disease. *British Journal of Health Psychology, 20*(2), 341–359. <https://doi.org/10.1111/bjhp.12104>
- Arran, N., Craufurd, D., & Simpson, J. (2014). Illness perceptions, coping styles and psychological distress in adults with Huntington's disease. *Psychology, Health & Medicine, 19*(2), 169–179. <https://doi.org/10.1080/13548506.2013.802355>
- Bee, P., Brooks, H., Fraser, C., & Lovell, K. (2015). Professional perspectives on service user and carer involvement in mental health care planning: A qualitative study. *International Journal of Nursing Studies, 52*(12), 1834–1845. <https://doi.org/10.1016/j.ijnurstu.2015.07.008>
- Bouteloup, C., Desport, J. C., Clavelou, P., Guy, N., Derumeaux-Burel, H., Ferrier, A., & Couratier, P. (2009). Hypermetabolism in ALS patients: An early and persistent phenomenon. *Journal of Neurology, 256*(8), 1236–1242. <https://doi.org/10.1007/s00415-009-5100-z>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2012). *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological. 2.* <https://doi.org/10.1037/13620-000>
- Buhle, J. T., Silvers, J. A., Wage, T. D., Lopez, R., Onyemekwu, C., Kober, H., ... Ochsner, K. N. (2014). Cognitive reappraisal of emotion: A meta-analysis of human neuroimaging

studies. *Cerebral Cortex*, 24(11), 2981–2990.
<https://doi.org/10.1093/cercor/bht154>

Chiò, A., Logroscino, G., Hardiman, O., Swingler, R., Mitchell, D., Beghi, E., & Traynor, B. G. (2009). Prognostic factors in ALS: A critical review. *Amyotrophic Lateral Sclerosis*, 10(5–6), 310–323. <https://doi.org/10.3109/17482960802566824>

Cornil, Y., & Chandon, P. (2015). Pleasure as an ally of healthy eating? Contrasting visceral and Epicurean eating pleasure and their association with portion size preferences and wellbeing. *Appetite*, 104, 52–59. <https://doi.org/10.1016/j.appet.2015.08.045>

Cresswell, J. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). London: SAGE.

Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of Psychosomatic Research*, 79(6), 506–513. <https://doi.org/10.1016/j.jpsychores.2015.10.006>

Eccles, F. J. R., & Simpson, J. (2011). A review of the demographic, clinical and psychosocial correlates of perceived control in three chronic motor illnesses. *Disability and Rehabilitation*, 33(13–14), 1065–1088.
<https://doi.org/10.3109/09638288.2010.525287>

Egede, L. E., & Ellis, C. (2008). The Effects of Depression on Diabetes Knowledge, Diabetes Self-Management, and Perceived Control in Indigent Patients with Type 2 Diabetes. *Diabetes Technology & Therapeutics*, 10(3), 213–219.
<https://doi.org/10.1089/dia.2007.0278>

Eide, H. D., Halvorsen, K., & Almendingen, K. (2015). Barriers to nutritional care for the

undernourished hospitalised elderly: Perspectives of nurses. *Journal of Clinical Nursing*, 24(5–6), 696–706. <https://doi.org/10.1111/jocn.12562>

Foley, G., Timonen, V., & Hardiman, O. (2014a). Exerting control and adapting to loss in amyotrophic lateral sclerosis. *Social Science and Medicine*, 101, 113–119. <https://doi.org/10.1016/j.socscimed.2013.11.003>

Foley, G., Timonen, V., & Hardiman, O. (2014b). Understanding psycho-social processes underpinning engagement with services in motor neurone disease: A qualitative study. *Palliative Medicine*, 28(4), 318–325. <https://doi.org/10.1177/0269216313512013>

Goldstein, L. H., Atkins, L., Landau, S., Brown, R. G., & Leigh, P. N. (2006). Longitudinal predictors of psychological distress and self-esteem in people with ALS. *Neurology*, 67(9), 1652–1658. <https://doi.org/10.1212/01.wnl.0000242886.91786.47>

Golla, H., Galushko, M., Pfaff, H., & Voltz, R. (2012). Unmet needs of severely affected multiple sclerosis patients: The health professionals' view. *Palliative Medicine*, 26(2), 139–151. <https://doi.org/10.1177/0269216311401465>

Gordon, P. H., Cheng, B., Salachas, F., Pradat, P. F., Bruneteau, G., Corcia, P., ... Meininger, V. (2010). Progression in ALS is not linear but is curvilinear. *Journal of Neurology*, 257(10), 1713–1717. <https://doi.org/10.1007/s00415-010-5609-1>

Greenaway, L. P., Martin, N. H., Lawrence, V., Janssen, A., Al-Chalabi, A., Leigh, P. N., & Goldstein, L. H. (2015). Accepting or declining non-invasive ventilation or gastrostomy in amyotrophic lateral sclerosis: patients' perspectives. *Journal of Neurology*, 262(4), 1002–1013. <https://doi.org/10.1007/s00415-015-7665-z>

- Greenwood, D. I. (2013). Nutrition management of amyotrophic lateral sclerosis. *Nutrition in Clinical Practice*, 28(3), 392–399. <https://doi.org/10.1177/0884533613476554>
- Gross, J. J. (2015). Emotion Regulation: Current Status and Future Prospects. *Psychological Inquiry*, 26(1), 1–26. <https://doi.org/10.1080/1047840X.2014.940781>
- Hardiman, O., Al-Chalabi, A., Chio, A., Corr, E. M., Logroscino, G., Robberecht, W., ... Van Den Berg, L. H. (2017). Amyotrophic lateral sclerosis. *Nature Reviews Disease Primers*, 3. <https://doi.org/10.1038/nrdp.2017.71>
- Harper, D., & Thompson, A. R. (2011). *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*. Wiley-Blackwell.
- Higgs, S., & Thomas, J. (2016). Social influences on eating. *Current Opinion in Behavioral Sciences*, 9, 1–6. <https://doi.org/10.1016/j.cobeha.2015.10.005>
- Hillemacher, T., Graäßel, E., Tigges, S., Bleich, S., Neundörfer, B., Kornhuber, J., & Hecht, M. J. (2004). Depression and bulbar involvement in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders*, 5(4), 245–249. <https://doi.org/10.1080/14660820410021294>
- Hobson, E. V., & McDermott, C. J. (2016). Supportive and symptomatic management of amyotrophic lateral sclerosis. *Nature Reviews Neurology*, 12(9), 526–538. <https://doi.org/10.1038/nrneurol.2016.111>
- Hogden, A., Greenfield, D., Nugus, P., & Kiernan, M. C. (2013). What are the roles of carers in decision-making for amyotrophic lateral sclerosis multidisciplinary care? *Patient*

Preference and Adherence, 7, 171–181. <https://doi.org/10.2147/PPA.S40783>

Hogden, A. V., Greenfield, D., Nugus, P., & Kiernan, M. C. (2012). What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives. *Patient Preference and Adherence*, 6, 829–838. <https://doi.org/10.2147/PPA.S37851>

Holm, T., Maier, A., Wicks, P., Lang, D., Linke, P., Münch, C., ... Meyer, T. (2013). Severe loss of appetite in amyotrophic lateral sclerosis patients: Online self-assessment study. *Journal of Medical Internet Research*, 15(4), e8. <https://doi.org/10.2196/ijmr.2463>

Hurt, C. S., Burn, D. J., Hindle, J., Samuel, M., Wilson, K., & Brown, R. G. (2014). Thinking positively about chronic illness: An exploration of optimism, illness perceptions and well-being in patients with Parkinson's disease. *British Journal of Health Psychology*, 19(2), 363–379. <https://doi.org/10.1111/bjhp.12043>

Johnson, J., Leigh, P. N., Shaw, C. E., Ellis, C., Burman, R., & Al-Chalabi, A. (2012). Eating-derived pleasure in amyotrophic lateral sclerosis as a predictor of non-oral feeding. *Amyotrophic Lateral Sclerosis*, 13(6), 555–559. <https://doi.org/10.3109/17482968.2012.704925>

King, S. J., Duke, M. M., & O'Connor, B. A. (2009). Living with amyotrophic lateral sclerosis/motor neurone disease (ALS/MND): Decision-making about “ongoing change and adaptation.” *Journal of Clinical Nursing*, 18(5), 745–754. <https://doi.org/10.1111/j.1365-2702.2008.02671.x>

Lambert, K., Potter, J., Lonergan, M., Tapsell, L., & Charlton, K. E. (2017). Qualitative study of patients and health-care professionals' views on the efficacy of the nutrition as

medication oral nutrition supplement program. *Nutrition and Dietetics*, 74(4), 341–348. <https://doi.org/10.1111/1747-0080.12152>

Lee, J. N., Rigby, S. A., Burchardt, F., Thornton, E. W., Dougan, C., & Young, C. A. (2001). Quality of life issues in motor neurone disease: The development and validation of a coping strategies questionnaire, the MND Coping Scale. *Journal of the Neurological Sciences*, 191(1–2), 79–85. [https://doi.org/10.1016/S0022-510X\(01\)00619-0](https://doi.org/10.1016/S0022-510X(01)00619-0)

Leventhal, E. A., & Cameron, L. (2001). Representations, procedures, and affect in illness self-regulation: A perceptual-cognitive model. In A. Baum, T. Revenson, & J. E. Singer (Eds.), *Handbook of health psychology*. Hillsdale: Lawrence Erlbaum.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Contributions to medical psychology*. New York, NY: Pergamon.

Logroscino, G., Traynor, B. J., Hardiman, O., Chió, A., Mitchell, D., Swingler, R. J., ... Beghi, E. (2010). Incidence of amyotrophic lateral sclerosis in Europe. *Journal of Neurology, Neurosurgery and Psychiatry*, 81(4), 385–390. <https://doi.org/10.1136/jnnp.2009.183525>

Marin, B., Boumé diene, F., Logroscino, G., Couratier, P., Babron, M. C., Leutenegger, A. L., ... Beghi, E. (2017). Variation in world wide incidence of amyotrophic lateral sclerosis: A meta-analysis. *International Journal of Epidemiology*, 46(1), 57–74. <https://doi.org/10.1093/ije/dyw061>

Martin, N. H., Lawrence, V., Murray, J., Janssen, A., Higginson, I., Lyall, R., ... Goldstein, L. H. (2016). Decision Making about Gastrostomy and Noninvasive Ventilation in

Amyotrophic Lateral Sclerosis. *Qualitative Health Research*, 26(10), 1366–1381.
<https://doi.org/10.1177/1049732315583661>

Matchwick, C., Domone, R., Leroi, I., & Simpson, J. (2014). Perceptions of cause and control in people with alzheimer's disease. *Gerontologist*, 54(2), 268–276.
<https://doi.org/10.1093/geront/gnt014>

Matthias, M. S., Parpart, A. L., Nyland, K. A., Huffman, M. A., Stubbs, D. L., Sargent, C., & Bair, M. J. (2010). The Patient–Provider Relationship in Chronic Pain Care: Providers' Perspectives. *Pain Medicine*, 11, 1688–1697. <https://doi.org/10.1111/j.1526-4637.2008.00511.x>

McDermott, C. J., & Shaw, P. J. (2008, March). Diagnosis and management of motor neurone disease. *BMJ*, Vol. 336, pp. 658–662.
<https://doi.org/10.1136/bmj.39493.511759.BE>

Mcllvane, J. M., Popa, M. A., Robinson, B., Houseweart, K., & Haley, W. E. (2008). Perceptions of Illness, Coping, and Well-being in Persons With Mild Cognitive Impairment and Their Care Partners. *Alzheimer Disease & Associated Disorders*, 22(3), 284–292. <https://doi.org/10.1097/WAD.0b013e318169d714>

Miller, N., Noble, E., Jones, D., & Burn, D. (2006). Life with communication changes in Parkinson's disease. *Age and Ageing*, 35(3), 235–239.
<https://doi.org/10.1093/ageing/afj053>

Mjøsund, N. H., Eriksson, M., Espnes, G. A., Haaland-Øverby, M., Jensen, S. L., Norheim, I., ... Vinje, H. F. (2017). Service user involvement enhanced the research quality in a study using interpretative phenomenological analysis – the power of multiple

perspectives. *Journal of Advanced Nursing*, 73(1), 265–278.
<https://doi.org/10.1111/jan.13093>

Muscaritoli, M., Kushta, I., Molfino, A., Inghilleri, M., Sabatelli, M., & Rossi Fanelli, F. (2012). Nutritional and metabolic support in patients with amyotrophic lateral sclerosis. *Nutrition*, 28(10), 959–966. <https://doi.org/10.1016/j.nut.2012.01.011>

O'Brien, M. R. (2004). Information-seeking behaviour among people with motor neurone disease. *British Journal of Nursing*, 13(16), 964–968.
<https://doi.org/10.12968/bjon.2004.13.16.15972>

Paganoni, S., Deng, J., Jaffa, M., Cudkowicz, M. E., & Wills, A.-M. (2011). Body mass index, not dyslipidemia, is an independent predictor of survival in amyotrophic lateral sclerosis. *Muscle & Nerve*, 44(1), 20–24. <https://doi.org/10.1002/mus.22114>

Pelletier, C. A., Abou-Zeid, E., Bartoshuk, L. M., & Rudnicki, S. A. (2013). Is taste altered in patients with ALS? *Chemosensory Perception*, 6(2), 101–107.
<https://doi.org/10.1007/s12078-013-9144-1>

Phukan, J., Elamin, M., Bede, P., Jordan, N., Gallagher, L., Byrne, S., ... Hardiman, O. (2012). The syndrome of cognitive impairment in amyotrophic lateral sclerosis: A population-based study. *Journal of Neurology, Neurosurgery and Psychiatry*, 83(1), 102–108. <https://doi.org/10.1136/jnnp-2011-300188>

Phukan, J., Pender, N. P., & Hardiman, O. (2007). Cognitive impairment in amyotrophic lateral sclerosis. *Lancet Neurology*, 6(November), 994–1003.

ProGas Study Group. (2015). Gastrostomy in patients with amyotrophic lateral sclerosis (ProGas): A prospective cohort study. *The Lancet Neurology*, 14(7), 702–709.

[https://doi.org/10.1016/S1474-4422\(15\)00104-0](https://doi.org/10.1016/S1474-4422(15)00104-0)

Remick, A. K., Pliner, P., & McLean, K. C. (2009). The relationship between restrained eating, pleasure associated with eating, and well-being re-visited. *Eating Behaviors*, *10*(1), 42–44. <https://doi.org/10.1016/j.eatbeh.2008.11.001>

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science and Medicine*, *62*(5), 1153–1166. <https://doi.org/10.1016/j.socscimed.2005.07.010>

Shippee, N. D., Domecq Garces, J. P., Prutsky Lopez, G. J., Wang, Z., Elraiyah, T. A., Nabhan, M., ... Murad, M. H. (2015). Patient and service user engagement in research: A systematic review and synthesized framework. *Health Expectations*, *18*(5), 1151–1166. <https://doi.org/10.1111/hex.12090>

Simpson, J., Chatzidamianos, G., Fletcher, I., Perpetuo, L., & Eccles, F. J. R. (2018). A new scale measuring adaptive perceived control for people with Parkinson's: Initial construction and further validation. *Journal of the Neurological Sciences*, *391*(June), 77–83. <https://doi.org/10.1016/j.jns.2018.05.023>

Stanton, A. L., & Revenson, T. A. (2012). Adjustment to Chronic Disease: Progress and Promise in Research. In *The Oxford Handbook of Health Psychology*. <https://doi.org/10.1093/oxfordhb/9780195342819.013.0011>

Stanton, A. L., Revenson, T. A., & Tennen, H. (2007). Health Psychology: Psychological Adjustment to Chronic Disease. *Annual Review of Psychology*, *58*(1), 565–592. <https://doi.org/10.1146/annurev.psych.58.110405.085615>

Stavroulakis, T., Baird, W. O., Baxter, S. K., Walsh, T., Shaw, P. J., & McDermott, C. J. (2014).

- Factors influencing decision-making in relation to timing of gastrostomy insertion in patients with motor neurone disease. *BMJ Supportive and Palliative Care*, 4(1), 57–63. <https://doi.org/10.1136/bmjspcare-2013-000497>
- Stavroulakis, T., Baird, W. O., Baxter, S. K., Walsh, T., Shaw, P. J., & McDermott, C. J. (2016). The impact of gastrostomy in motor neurone disease: Challenges and benefits from a patient and carer perspective. *BMJ Supportive and Palliative Care*, 6(1), 52–59. <https://doi.org/10.1136/bmjspcare-2013-000609>
- Stavroulakis, T., & McDermott, C. J. (2016). Enteral feeding in neurological disorders. *Practical Neurology*, 16(5), 352–361. <https://doi.org/10.1136/practneurol-2016-001408>
- Stavroulakis, T., & McDermott, C. J. (2017). Nutritional support in amyotrophic lateral sclerosis. In *Nutrition in Neurological Disorders* (pp. 91–104). <https://doi.org/10.1007/978-3-319-53171-7>
- Williams, I. A., Howlett, S., Levita, L., & Reuber, M. (2018). Changes in Emotion Processing following Brief Augmented Psychodynamic Interpersonal Therapy for Functional Neurological Symptoms. *Behavioural and Cognitive Psychotherapy*, 46(3), 350–366. <https://doi.org/10.1017/S1352465817000807>
- Williams, I. A., Levita, L., & Reuber, M. (2018). Emotion dysregulation in patients with psychogenic nonepileptic seizures: A systematic review based on the extended process model. *Epilepsy and Behavior*, 86, 37–48. <https://doi.org/10.1016/j.yebeh.2018.06.049>
- Zarei, S., Carr, K., Reiley, L., Diaz, K., Guerra, O., Altamirano, P., ... Chinaea, A. (2015). A

comprehensive review of amyotrophic lateral sclerosis. *Surgical Neurology International*, 6(1), 171. <https://doi.org/10.4103/2152-7806.169561>

Zarotti, N., Fletcher, I., & Simpson, J. (2018). New perspectives on emotional processing in people with symptomatic Huntington's disease: impaired emotion regulation and recognition of emotional body language. *Archives of Clinical Neuropsychology*, *acy085*, 1–15. <https://doi.org/10.1093/arclin/acy085>

Zarotti, N., Simpson, J., & Fletcher, I. (2017). 'I have a feeling I can't speak to anybody': A thematic analysis of communication perspectives in people with Huntington's disease. *Chronic Illness*, 174239531773379. <https://doi.org/10.1177/1742395317733793>

Zarotti, N., Simpson, J., Fletcher, I., Squitieri, F., & Migliore, S. (2018). Exploring emotion regulation and emotion recognition in people with presymptomatic Huntington's disease: The role of emotional awareness. *Neuropsychologia*, 112(Suppl 1), 1–9. <https://doi.org/10.1136/jnnp-2018-ehdn.151>