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Experiences of being diagnosed with motor neuron disease: "I just want to know"

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Experiences of being diagnosed with motor neuron disease: "I just want to know"

Abstract

Background: The diagnosis of a life limiting condition such as motor neurone disease (MND) is a challenging process for all affected by it. There is little research exploring the experience of living with MND. Understanding people's experiences of a diagnosis of MND can help improve diagnosis experiences and relationships with health professionals. **Aim:** This paper reports on a study exploring the diagnosis experiences of people living with MND, and how these experiences have impacted their lives. **Methods:** A qualitative descriptive approach was used. Semi-structured interviews were undertaken with six participants diagnosed with MND. Interviews were transcribed verbatim and analysed using thematic analysis. **Findings:** Four themes emerged, namely Barriers to early diagnosis increase uncertainty; Being treated like a person; Regaining self and control of life; and Support. The results support the need for timely diagnosis to reduce uncertainty and increase trust and interaction with health professionals. Findings also emphasise the importance of early referral to support services and provision of disease specific resources to augment the input of health professionals. **Conclusion:** The diagnosis period is a crucial and sensitive time for people with MND. These findings highlight how understanding the experiences of those being diagnosed with MND can guide health professionals in their management of the diagnosis process. Improved outcomes for patients may be achieved through enhancing the diagnosis experience.

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Experiences of being diagnosed with Motor Neurone Disease: “I just want to know”

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Abstract

Background: The diagnosis of a life limiting condition such as MND is a challenging process for all affected by it. There is little research exploring the experience of living with MND. Understanding people's experience of a diagnosis of MND can help improve diagnosis experiences and relationships with health professionals.

Aim: This paper reports on a study exploring the diagnosis experiences of people living with MND, and how these experiences have impacted their lives.

Methods: This qualitative study adopted a qualitative approach using thematic analysis. Semi-structured interviews were undertaken with six participants diagnosed with MND. Interviews were transcribed verbatim for thematic analysis.

Findings: Four themes emerged, namely *Barriers to early diagnosis increase uncertainty*; *Being treated like a person*; *Regaining self and control of life*; and *Support*. The results support the need for timely diagnosis to reduce uncertainty and increase trust and interaction with health professionals. Findings also emphasise the importance of early referral to support services and provision of disease specific resources to augment the input of health professionals.

Conclusion: The diagnosis period is a crucial and sensitive time for people with MND. These findings highlight how understanding the experiences of those being diagnosed with MND can guide health professionals in their management of the diagnosis process. Improved outcomes for patients may be achieved through enhancing the diagnosis experience.

Introduction

Motor neurone disease (MND), also known as amyotrophic lateral sclerosis and Lou Gehrig's disease, is a devastating neurodegenerative disease. It is characterised by a rapid deterioration and life expectancy of only 2-5 years beyond diagnosis (Mehta et al., 2017). There is no known cure for MND and current treatments have been shown to increase survival by an average of only a few months (Mehta et al., 2017). Around 10% of MND cases are familial with a genetic component, while 90% are sporadic with unknown aetiology (Mehta et al., 2017). In Australia, there is an estimated incidence

of 2/100 000 cases of MND, with a 1:1.5 ratio of female to male, and median onset around 60-62 years of age (Talman et al., 2016).

MND causes a loss of motor neurons in the brainstem, spinal cord, and motor cortex leading to muscle weakness and wasting (Mitchell, 2007). Typical clinical presentations involve dysphagia and dysarthria from bulbar onset, upper limb weakness from cervical onset, and lower limb weakness from lumbar onset (Mitchell, 2007). The progression leads to loss of function of respiratory muscles and death is generally caused by respiratory failure (Ceriana et al., 2017). The complexities and severity of symptoms requires integrated health services including nursing, allied health, neurology, respiratory, palliative care and psychological support (Talman et al., 2016). Multi-disciplinary MND specific services have shown a survival advantage (Talman et al., 2016).

Background

The pre-diagnostic phase can be a great time of uncertainty for people with MND as they search for answers to their troubling symptoms and deteriorating health. This idea is evident in the preparative waiting theory (Giske et al., 2007), where being in the diagnostic phase means “to be in a process of continually attempting to make sense of one’s situation” (p.87). Anxiety may result as the waiting time for diagnosis is extended and uncertainty rises. Distress arises from uncertainty about the future, and a lack of control over the process, timing, and impact of a diagnosis (Mistry et al., 2013). Illness uncertainty has also been associated with increased levels of depression, decreased quality of life, and fatigue (Bailey et al., 2009).

Giving bad news with such a poor prognosis as MND is recognised as one of the most difficult tasks health professionals face (Porensky et al., 2016). Reliable and accurate information about the diagnosis, treatment options and possible outcomes often helps better equip patients to make informed decisions and feel greater control (Warnock et al., 2017). The way that bad news is delivered can influence how a person and their loved ones are able to move past the diagnosis and learn to live with the disease (Aoun et al., 2015). A negative diagnosis experience may have negative impacts on later patient-health professional relationships, which can obstruct access to potentially beneficial health

services (O'Brien et al., 2011). While several guidelines exist on breaking bad news, these tend to focus on the diagnosis experience as a single pre-planned event as opposed to being part of a journey involving multiple interactions with health professionals (Warnock et al., 2017). There is increasing recognition that this narrower view of giving bad news may be enhanced by engaging with patients and families in a range of patient focused activities that support decision making and adaption to implications of their diagnosis (Warnock et al., 2017).

The diagnosis period is a critical time that can impact a person's journey as they attempt to navigate a myriad of physical and emotional changes. It is essential that health professionals attempt to provide patients with appropriate support in a compassionate and sensitive manner that will enhance their diagnosis experience and promote better outcomes. Therefore, understanding current diagnosis experiences of individuals with MND can help guide health professionals in tailoring future care delivery. Limited research exists on the diagnosis experience of MND. Those papers that do explore this area have reported on satisfaction with delivery of the diagnosis (Aoun et al., 2015; Hugel et al., 2006; Johnston et al., 1996; McCluskey et al., 2004; O'Brien et al., 2011), coping with the diagnosis (Hugel et al., 2010), and the emotional impacts of the diagnosis (Bolmsjo, 2001; Locock et al., 2009; Mistry et al., 2013). Two of these studies recruited from the same neuroscience centre (Hugel et al., 2006; Hugel et al., 2010), meaning that findings are likely impacted by the policy and practice of a single institution. Three studies included carer participants, thereby reflecting the viewpoints of carers in their results (Locock et al., 2009; McCluskey et al., 2004; O'Brien et al., 2011). Additionally, two studies used a quantitative approach to understand the experience (Aoun et al., 2015; McCluskey et al., 2004). There is a need, therefore, to take a qualitative approach within Australia, to understand the depth and scope of the diagnosis experience of those diagnosed with MND.

Methods

Aim

This study aimed to explore the diagnosis experiences of those living with MND, and how these experiences have impacted their lives.

Design

Qualitative description is a method that provides a rich, yet straight forward description of participant's experiences using similar language to that provided by the participant (Neergaard, 2009). The method is a distinct method of naturalistic inquiry and holds overtones of other qualitative methods, such as ethnography or phenomenology (Sullivan-Bolyai, 2005). It seeks understanding of complex experiences, and to depict the viewpoints of those who have had the experience using qualatative analysis method (Sandelowski, 2000). Data can be obtained from multiple sources where commonalities and differences within the data can be analysed, leading to themes that hold true to the data which can be examined according to what is already known (Sandelowski, 2000).

Sample and Setting

Participants were English speaking adults with a formal diagnosis of MND, without cognitive impairment that would impair their capacity to consent or participate in the study. Carers were invited to be present during the interview for support if the person with MND so wished. One participant chose to have their carer present for the interview.

Recruitment was achieved through advertisements in social and print media. Key stakeholders, such as disease specific organisations and University research groups, were enlisted to disseminate the advertisements. Invitations were also sent to support group coordinators and MND clinics across Sydney and the Illawarra region for distribution to members. Potential participants were asked to contact the researcher for further information about the study and to arrange a mutually convenient interview time.

Data Collection

Semi-structured interviews were conducted by a single interviewer who is a Registered Nurse (SR). Four interviews were conducted in participants' homes; one was conducted via skype; and one via several emails between the participant and interviewer. In this instance, the participant answered the interview questions directly and responses were expanded on in subsequent emails. This flexibility

in the means of conducting the interviews was deemed necessary to facilitate inclusion and participation of this complex group.

During the interviews, the researcher aimed to build rapport and trust with participants to facilitate exploration of their diagnosis experiences through open and direct questions, allowing for detailed narratives and stories about these experiences (Given et al., 2008). Interview questions were developed from a review of the literature and consultations with experts in chronic disease and MND. Given the likely small sample size and potential vulnerability of the participants no pilot interviews were conducted. However, the questions and interview techniques were reviewed after the first few interviews by the interviewer and experts in qualitative research (LH & MS). Further interviews did not reveal any new information indicating saturation had been achieved (Clarke et al., 2014).

Interviews were audio-recorded and transcribed verbatim by a professional transcription company. The interviewer recorded field notes about each interview. Interviews were conducted until data saturation was achieved.

Data analysis

Thematic analysis, as described by Clarke et al. (2014), was undertaken through data immersion, leading to the development of codes capturing key analytical ideas. Similarity of patterns among these codes led to the emergence of themes, where a thematic map was developed and used for detailed analysis of each theme leading to final definitions and names. This process was a useful method in identifying patterns in relation to people's experiences and gaining meaning through understanding (Clarke et al., 2017).

Ethical Considerations

Considering the sensitive nature of researching a population with a life-limiting disease, ethical consideration was focused on maintaining the dignity of participants and preventing harm (Cascio, 2018; Mullany, 2010). Participants were given as much time as they required during difficult discussions without pressure to continue if they became distressed (Mullany, 2010). Having

experience caring for people with MND as a Registered Nurse, the interviewer was able to provide professional support and details of appropriate support services if required. Approval to conduct the study was received from the Human Research Ethics Committee at the University of Wollongong prior to recruitment and data collection. Each participant was given a pseudonym in reports and publications to preserve their anonymity.

Results

Due to the relative low prevalence and high severity of MND, which precluded some interested individuals from participating, recruitment was challenging. Despite this, the six participants were drawn from South Eastern New South Wales. As demonstrated in Table 1, 4 (66%) participants were diagnosed 6 months or less before the interview. There was an equal ratio of women to men (50%). Table 1 also provides participants' pseudonyms to allow the reader to connect with their stories.

Four themes emerged from the data, namely barriers to early diagnosis increase uncertainty, being treated as a person, regaining self and control, and support.

Table 4.1 Participant demographics

Pseudonym	Gender	Age Range	Marital Status	Time since diagnosis
Cheryl	F	50-60	Divorced	1 month
Bert	M	60-70	Married	2 years
John	M	30-40	Defacto	6 months
Cassie	F	30-40	Married	4 years
Barbara	F	70-80	Married	6 months
Craig	M	60-70	Divorced	3 months

Barriers to early diagnosis increase uncertainty

The period between symptom onset and formal diagnosis was a time of great uncertainty for all participants. "You felt like you've been thrown in a black hole and left there.... devastated and terrified because I know the outcome" (Barbara).

Perceptions of not having concerns taken seriously, not communicating suspicions of MND, breaks in continuity of care, and failure to follow up were identified as barriers to early diagnosis and sources of stress. Three participants strongly suspected MND as a cause for their symptoms very early and immediately sought investigations to confirm. Craig, who had suspected he had MND after researching his symptoms, described being referred to a neurologist “to ease my mind”. While Cassie’s initial concerns of MND were dismissed altogether by her General Practitioner (GP);

“He said you’re over exaggerating, remember you are only like three weeks post baby, come back, it’s carpal tunnel. I said well, it’s not. I was a bit cheesed off. So, as I walked out the door, I actually said to him you don’t think it’s MND and he replied oh no, ha ha, and I was very cross.”

For some participants, diagnosis involved months or even years of investigations with a range of different specialists. Craig described;

“The neurologist did some tests and said I didn’t have it and referred me to an ear nose and throat specialist who found nothing wrong. I also had an MRI to check for stroke.... As my voice became worse I was referred to Drwho confirmed I did in fact have MND. He referred me back to the first neurologist who sheepishly confirmed the diagnosis.”

Cheryl’s experience highlighted delays in diagnosis resulting from breaks in continuity of care, and lack of knowledge on the part of her GP.

“His report came back that I had anterior horn cell disorder. I asked the (GP) what it was, and she said I don’t know anything about it.... The neurologist that did the nerve conductive study had a full patient load or something and he wasn't taking any new patients. So (the GP) sent me to see another neurologist.”

The protracted waiting caused a significant psychological toll. In the two years it took for his diagnosis, Craig described feeling “severely depressed with fear and panic attacks” as he continued to search for answers to his symptoms. In contrast, timely diagnostic testing and open communication

by neurologists led to faster diagnosis and reduction of uncertainty about the meaning of their symptoms. This was clearly illustrated by John's experience.

"I'm kind of a bit of a no bullshit type of person, so I just asked him straight out if it's really bad. He said yep. He thought it was MND.... He was very open with it.... I'm very lucky it was only a month for me.... If a doctor is able to say we've fast tracked X, Y and Z test, that would be very assuring."

Being treated like a person

Being treated like a person encapsulates the idea of being valued, cared about, and being thought of as a person rather than a diagnosis. Cassie described her anger about her treatment by a neurologist;

"I was like hey, hang on a minute, you don't know where I'm at, you haven't even screened me like a human...I really felt I was treated like a number."

Whereas John praised his neurologist, describing the value of "being cared about. Knowing that a health professional cares about you and not just there to put you through the office or diagnosis."

The ability of health providers to show a genuine interest in knowing the person and speaking openly and honestly created greater rapport and trust.

"I think he was very diplomatic.... he handled the whole situation very well.... I think that's been one of the best parts about the whole situation, is how good he was." (John)

"He was like great.... laid back, engaging, had a laugh, talked about every day stuff.... He also pulled up all the assessments, turned the screen around.... Spoke to you like a human." (Cassie)

When participants had negative experiences with health professionals, they described negative emotions and disengagement. In contrast to her current provider, Cassie recalled a negative experience with a previous neurologist stating that if she continued to see him "I think it would be very tense. I would probably dread every appointment." Similarly, Cheryl described how upset she became when her neurologist's office repeatedly forgot to send her referrals for other appointments,

and after one of the specialists agreed to making an appointment without a referral she went in and; “he didn’t know why I was there. They still had not gotten the referral. I had to explain.” This left her feeling “like I wasn’t even important.”

A strong relationship with health professionals encouraged participants to maintain regular contact and engage with clinicians and services as they felt comfortable and not threatened. “So now to go to him it’s like well, just to catch up. It’s not a stressful experience.” (Cassie)

Regaining self and control of life

In addition to the relationships with health professionals, participants spoke about the work that they themselves had to do in their lives. Regaining self and control of life describes the participant’s ability to move past the initial shock of the diagnosis and find a way to regain control over their life and learn to live with MND. While participants differed in their methods of regaining control, those who were able to achieve this demonstrated practical and positive attitudes toward living with MND.

Several participants discussed remaining normal for as long as possible and not being changed by the disease. Bert and Barbara both spoke of how they were “determined to keep going as long as I can” with daily activities. Others, however, focussed on the psychological impact. John recalled advice where he was told “that you should never let an experience change who you are, or what you are. I’ve been very conscious to make sure that I am who I was before being diagnosed.” Similarly, Cassie explained how, “we don’t really dwell on it, we just get on.... I think I’m very blessed, like my mood has never fallen. I have melt downs.... But I say they’re probably quarterly.... So yeah you just have to laugh.”

For some, this shift in attitude toward life post MND diagnosis meant they were able to find some good from the diagnosis by reassessing what is important to them in life.

“I might not have changed, but the way I perceive things is also very different. Work is a chore, and there’s far more important things. I believe that there’s a lot of good

things that have come out of this as well.... who my friends are, how much closer I am with my family, that's one of the most important things." (John)

For two participants, however, the psychological impact of the MND diagnosis was overwhelming. Craig explained'

"I work from home now and avoid social contact because I am so embarrassed about my voice.... I am on antidepressants and have 4 (large) glasses of wine each night to ease the horror.... I am shattered to pieces to put it mildly."

Cheryl also struggled to regain control over her life and expressed the impact that MND had, resulting in uncertainty and fear about her future. "I love my job. I can't work now. I can't stand for a long time. I can't walk far distances. Yeah, life sucks.... I hope I'll be alright."

Support

Those participants who were able to move past the diagnosis and regain some control over their life described having high levels of support from family and friends. These family and friends provided emotional support, practical support such as researching doctors and services, and physical support with activities of daily living or transport.

"It's very important for people who have just been diagnosed that their family and friends kind of congregate around them and give as much support as possible. I think that's very important." (John)

Cassie recalls drawing on her mother to help find a new neurologist; "So I said to mum I don't want to have to go through this conversation that we're having today again and again. I said can you go and find someone who you think that I might like, you know the type of person."

Cassie and Craig both described being committed Christians who drew support from their religious affiliations and faith in God. Cassie recalled telling her neurologist, "I'm a committed Christian so I just said to him, is that all you have to say? I mean I'm fine, I have a hope in heaven, I just need to go and sort my family out." In the same way, Craig explained "I go to church.... and a bible study group.

I receive enormous support and prayers mostly from the younger people.” Despite this support however, he also described feeling anxious and severely depressed.

The two participants not able to move past their diagnosis both described a lack of support from family. Craig was estranged from his wife, children and grandchildren since before his diagnosis.

“On the few occasions (my wife and I) do get together we get on very well, but she has made it clear that she wants to move on. I think she is truly shocked by my MND diagnosis. The girl and my eldest son have three children whom I don’t see as my children don’t want me around them.”

Cheryl described how she lives “with a girlfriend and her husband. They've been very good to me. But she doesn't want to be my carer. My daughter is [overseas]. ... She's got multiple sclerosis. What a f**ked up gene pool we've got.”

There was a mixed reaction to the amount of information and formal support each participant sought from health professionals. Participants highlighted the need for timely information and referrals to support services.

“Have a pack ready, so when they’re having a lucid moment they can read where to go.” (Cheryl)

“Be more upfront with information about MND and about the help you can get. Most people don’t know anything when they’re first diagnosed.... Even if they had given me something like this (holds up pamphlet).” (Barbara)

Craig and Cassie chose not to participate in formal support associations for different reasons. While Cassie gained support from her connections with friends and family, Craig saw support groups and services as a negative reminder of his prognosis.

“It made me feel like a dead man walking. I delete the MND newsletters after making sure that there is no mention of a new development or research advance.” (Craig)

Cheryl highlighted distance to travel to a support groups as a barrier.

“I don’t want to go to [distant suburb] (to attend) those newly diagnosed with MND seminars...It’s too far.”

Discussion

Receiving a diagnosis of MND, is a difficult and complex process the experience of which, has significant and lifelong implications. Delivering such a diagnosis requires skills and an understanding of the impact of such news. Through understanding people’s experiences, health professionals can be better equipped to provide person centred care to individuals affected by MND. Being included and valued in the search for answers to symptoms was highlighted by participants as an important part of their diagnosis experience. By providing timely and accurate information about prognosis, treatment options, and possible outcomes, individuals can be empowered to be informed decision makers, with feelings of control and hope despite poor prognosis (Campbell et al., 2010; Draper et al., 2013; Warnock et al., 2017). Indeed, being able to maintain control over as many aspects of their life as possible was an important part of participants holding on to themselves as a person, rather than as a disease. This empowerment has also been shown to help in building trust and engagement with health professionals and health services (Campbell et al., 2010), which was clearly demonstrated throughout the narrative of this study.

The time between symptom onset and diagnosis was identified as the period with the greatest level of uncertainty, with minimal support from health professionals. During this time participants identified a gap in links to appropriate support services and limited resources, such as literature on MND, as negative aspects of their diagnosis experience. Lack of MND information, its prognosis, treatment, clinical research, and services appears to be an ongoing issue (Baxter et al., 2017). Although high quality services and literature exist, lack of referral and distance to such services were highlighted as barriers to access. This would, however, be a fairly simple strategy to improve the experience. With the rapid growth in internet-based health resources perhaps health professionals could direct individuals to reputable online resources that could fill this gap, which may be particularly beneficial to rural patients.

The time during the diagnosis period was described by participants as a period of great uncertainty where they felt anxious and, for some, unsupported. Illness uncertainty is a well-established notion, which has been linked to decreased quality of life, anxiety and stress as patients seek to find answers to their changing situation (Bailey et al., 2009). By decreasing the length of time to diagnosis, anxiety and stress related to uncertainty of deteriorating health may be reduced (Giske et al., 2007). Barriers to a caring diagnosis experience such as disregard of patients concerns, and inappropriate referrals were highlighted in both this and previous studies (Hugel et al., 2006; O'Brien et al., 2011). In addition, breaks in continuity of care with lack of follow up, and failure to communicate suspicions were also identified as barriers. The findings suggest that open and inclusive communication, that addresses both the patient's and the health professional's concerns and suspicions, may be beneficial in reducing barriers to diagnosis. It also highlights the importance for follow up of previous reports when a patient changes health care provider.

Strong support from family was identified as an important part of being able to integrate their diagnosis into their lives and to regain control over their lives. Individuals who lacked family support described higher levels of anxiety and feelings of isolation. This idea is reflected in the family systems theory (Milberg et al., 2014), which suggests family and friends are potential protective factors in coping with MND. Family systems theory aims to understand the importance of support within families as an emotional unit and their impact on patients ability to cope (Draper et al., 2013). Palliative care research also suggests that a lack of family support is a factor in identifying patients at risk of not coping (Milberg et al., 2014). With this in mind, health professionals may identify lack of family support as a potential barrier to enabling individuals to manage their diagnosis, which may require interventions.

Limitations

While data saturation was achieved in the small sample size, the limited pool of potential participants was a challenge in the recruitment of participants. Additionally, an in-depth exploration of the experiences of two participant's was challenging because of communication difficulties due to

dysphonia. Exploration of alternate communication methods may have enhanced communication and is a consideration for future research.

This study provided a qualitative snapshot of participants' feelings and experiences at a particular point in time. Research that takes a longitudinal perspective or which is conducted at the time of diagnosis may provide different insights. A strength of this study, however, was that participants were drawn from a broad geographical area and had been treated by, and received a diagnosis from, various health care professionals and services. Therefore, findings are not an evaluation of a single service or group of health professionals.

Conclusion

This study has identified a number of important issues affecting the diagnosis experience of people with MND, which can help guide health professionals in their delivery of care. The period leading up to formal diagnosis is a time of great uncertainty where participants felt unsupported and increasingly anxious with protracted waiting time to diagnosis. This supports the need for timely diagnosis and the provision of support during the diagnosis phase. By actively including patients in their diagnosis process through open and inclusive communication, which focuses on the individual as a person, health professionals may potentially enhance the diagnosis experience of MND. It also gives the health provider an opportunity to assess a patient's varying needs based on their individual circumstances and direct them to appropriate services and educational tools.

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