The Lived Experience of Diagnosis Delivery in Motor Neurone Disease: A Sociological-Phenomenological Study

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Abstract

Relatively few previous studies of individuals receiving a diagnosis of Motor Neurone Disease within the UK health care system have employed qualitative approaches to examine the diagnostic journey from a patient perspective. A qualitative sociological study was undertaken, involving interviews with 42 participants diagnosed with MND, to provide insight into their experiences of undergoing testing and receiving a diagnosis. Adopting a sociological-phenomenological perspective, this article examines key themes that emerged from participant accounts surrounding the lived experience of the diagnostic journey. The key themes that emerged were: *The diagnostic quest; living with uncertainty; hearing bad news; communication difficulties; and a reified body of medical interest.*

In general, doctor-patient communication both at pre and post diagnosis was experienced as highly stressful, distressing and profoundly upsetting. Participants reported such distress as being due to the mode of delivery and communication strategies used by health professionals. We therefore suggest that professional training needs to emphasize the importance to health professionals of fostering greater levels of tact, sensitivity and empathy towards patients diagnosed with devastating, life-limiting illnesses such as MND.

Keywords: *Motor Neurone Disease (MND); Diagnosis Delivery; Sociological-Phenomenology; Lived Experience; Patient Perspective*

Introduction

1.1 Motor Neurone Disease (MND) is a neurodegenerative disease of the nervous system, where the motor neurons in the cortex, brainstem and spinal cord gradually diminish in number until lost entirely (Eisen & Krieger 1998). A rapidly progressing disease, it destroys the body's functional capabilities, including coordination, communication and respiration (Casey 2011). Individuals with MND will have been experiencing symptoms for a period of time prior to receiving an official diagnostic label (Clarke et al. 2001). Life expectancy from diagnosis is estimated at between 2–5 years (Holmes 2005). At any one time in the UK it is estimated that 5000 people are living with MND (Clark & O'Brien 2006). This number remains stable due to records showing as many people dying from the condition as being diagnosed with it each year (Robinson & Hunter 1998). As each manifestation of MND occurs slightly differently in each person, there remains no definitive symptom to allow easy diagnosis, and no definitive diagnostic test currently available (Locock et al. 2009).

1.2 Relatively few previous studies of individuals receiving a diagnosis of Motor Neurone Disease within the UK health care system have employed qualitative approaches to examine the diagnostic journey from a patient perspective. The aim of this article, therefore, based on a sociological research project, is to explore the lived experience and life-worlds of MND sufferers, and to analyse key themes that emerged from participant accounts, surrounding the diagnostic journey. The research involved interviews with 42 participants diagnosed with MND, and sought to provide insight into their experiences, including those of undergoing medical testing and receiving a diagnosis. Before proceeding to discuss our key findings in this domain, we provide a brief review of the literature in relation to (i) previous studies of MND; (ii) the theoretical framework of sociological-phenomenology, which we employ to analyse the data. We then portray the research project. First we turn to the sparse extant literature addressing MND.

1.3 Previous research concerning MND has largely focussed on quality of life issues, cause, potential cure, and palliative care, from a positivist perspective, and employing quantitative methods (Cedarbaum et al. 1999, Leigh et al. 2003, Talbot 2009, Taylor et al. 2010). In contrast, there is a relative paucity of research examining the distressing period of diagnosis. Clark and O'Brien (2006) draw attention to considerable gaps in knowledge, and highlight the need for qualitative approaches to reveal the hidden, undisclosed, silent voices of those diagnosed and living with MND. King et al. (2009) note that few formal studies have been undertaken in relation to how individuals live with and negotiate their illness, and make important choices about their on-going care. A qualitative study exploring MND diagnosis from a health care professional perspective has advocated the provision of suitably qualified psychological support to be available during diagnosis (O'Brien et al. 2011). However, there remains a relative dearth of literature in the sociological domain, which focuses upon the actual MND sufferer's perspective. Here we draw upon a sociological-phenomenological framework (Allen-Collinson 2011) to situate our findings.

1.4 Phenomenology is, we consider, well-equipped to provide detailed, perceptive and well-grounded insights into the 'here-and-now, raw reality of the body' (Sinclair 2005: 90), the lived reality of patients with MND and other, analogous diseases. Martinková and Parry (2011) note that phenomenologists look *at* what we normally look *through*; we look *at* our human-ness in order to provide an account of what we are and how we experience a given phenomenon, how it presents itself to consciousness. Adopting a more 'sociologised' form of phenomenology allows us to acknowledge and address the 'structurally, politically and ideologically-influenced, historically-specific, and socially situated nature of human embodiment and experience' (Allen-Collinson & Hockey 2011: 332). Husserlian phenomenology was introduced and applied systematically by Schütz (1967) whose sociological interest was sparked by the Husserlian concept of the life-world (*Lebenswelt*) and intersubjective communities. Schütz (1967) subsequently adapted these insights, and synthesized aspects of Husserl's thinking with Weberian conceptualisations of *Verstehen* and social action, in order to create a sociological-phenomenology. Sociological-phenomenology thus sharpens the focus upon social actors' corporeal embeddedness within cultural and social worlds. In this vein, Csordas' (2002: 244) concept of 'somatic modes of attention' is apposite to sociological-phenomenological health research, given his focus upon the 'culturally elaborated ways of attending to and with one's body in surroundings that include the embodied presence of others'. For the purposes of this paper, Allen-Collinson's (2011: 299) concept of a phenomenologically-inspired sociology is adopted, and for ease of reading we term this 'sociological phenomenology'.

1.5 When the physical body 'goes wrong' it is forcibly brought to consciousness and becomes intimately linked to our internal sense of well-being. The thematic analysis of individuals' narratives of being diagnosed with MND conveys an insightful insider perspective on a highly distressing event in a person's life. Participant voices make a valuable contribution to understanding the process of living through symptom onset, living with the uncertainty of experiencing a debilitating illness without the 'label' of a clinical term, and eventually receiving a devastating and life-changing diagnosis. The aim of our research was to discover individual experiences of the diagnostic process of MND. This article provides qualitative accounts from individuals with MND, within a specific timeframe encompassing their experiences of seeking medical help at illness onset, receiving a clinical diagnosis, and their on-going interactions with health care professionals. First, we portray the research project, before proceeding to present our findings, and then to situate these in a wider discussion.

Research project

2.1 The purpose of the project was to undertake sociological-phenomenological study of the lived experience of MND. Male and female participants of all ages >18 were recruited and invited to comment on a series of events pertaining to the illness timeline. This included talking about: (i) life prior to receiving a formal diagnosis; (ii) the receiving of the actual diagnosis; and (iii) life after diagnosis, and it is upon these themes that we focus in this article. The project was granted ethical approval by the relevant University authorities and adhered to the BSA ethical guidelines. The ethical concerns of the research constitute the focus of a paper in progress. Despite all the careful planning and submitting of applications to ethical committees, it was of course impossible to identify all aspects prior to engaging with the actual data collection, and ethical concerns were inevitably on-going throughout the project and continue to this day, as we make judgments regarding issues of representation and publication.

2.2 Participant recruitment for this study within the UK was greatly assisted by the auspices of the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), funded by the Department of Health as part of the National Institute for Health Research and the UK Clinical Research Network. Through this body, a successful application was lodged to be matched with potential participants from the national data base within the UK. The Motor Neurone Disease Association (MNDA) UK also advertised and promoted the study on its website, at Regional MND conferences, and in smaller branch meetings.

2.3 A semi-structured approach was used to interview a total of 42 participants aged between 42 and 74, all of whom had received a formal clinical diagnosis of MND (see Table 1). Interviews occurred at a time and in a place of the participants choosing.

Table 1: Participant age and gender

	Male	Female
Age		

40–49	2	3
50–59	5	3
60–69	6	2
70+	5	0
Undisclosed	13	3
Total	31	11

So that participants had adequate experience and knowledge of living with their condition and the healthcare systems germane to the condition, it was requested that only those who were six months or more post-diagnosis took part. As the purpose of the study was to be as inclusive as possible, it was decided that the use of e-mail communication, alongside more 'traditional' interviews, would permit the inclusion of a greater number of participants, at various stages of the illness.

2.4 Specific to this research study, and in comparison with other qualitatively designed studies relating to lived experience (Brobäck & Berterö 2003; Kralik et al. 2004; Nordgren et al. 2007), substantive communication difficulties caused by the illness were encountered. The occurrence of dysarthria and dysphonia meant that researching, for example, just 10 people (the above studies range from 6–9 participants) would not allow for adequate levels of data collection depth. This is not necessarily due to the participants not choosing to divulge rich information, but rather that the condition restricts the ability verbally to articulate. Those affected in this way were given the option to be 'interviewed' by email. Also, having only a small number of participants often involves repeat interviewing several times over an extended period in order to gain sufficient data. In our study, the practicality of this was dependent on the health of the individuals taking part. Given the rapid onset and progress of MND, it was anticipated during the study planning stage that in many cases the participant might become too ill to continue participation.

2.5 Issues of gender, ethnicity or age were not considered key variables for the purpose of this particular project, where the main focus on this occasion was to investigate individual experience, regardless of gender and other key sociological variables; therefore participants were not required to disclose this information unless they freely chose to do so during the interview; 64% of participants did divulge age.

2.6 An interview guide was provided for all participants taking part, and comprised eleven questions of an open-ended nature. Thematic analysis was carried out, which included the reading and in-depth re-reading of transcripts, seeking rich narrative accounts describing the participants' experiences of diagnosis delivery and the subsequent support provided by healthcare staff. Salient themes and interpretations of these were discussed with another colleague as a 'critical friend', to aid in the formulation and clarity of shared or unique experiences of the participants.

2.7 In this article, we focus on specific instances relevant to the period around diagnosis, including a short period of time directly prior to diagnosis, the diagnosis delivery, and up to 18 months post diagnosis. It is not within the remit of this particular article to discuss the reactions, thoughts and feelings of friends or health professionals, but rather to focus on the individual experiences of the MND sufferers themselves, to hear their voices. All participants are identified only by gender and age (where disclosed) to protect anonymity. Further to ensure anonymity, any personal details relating to geographical places or work environments have been changed or omitted.

Findings

3.1 Following data analysis, the following first-order themes emerged: *The diagnostic quest; Living with uncertainty; Hearing bad news; Communication difficulties; and A reified body of medical interest.*

Knowing something is wrong - The diagnostic quest

3.2 MND is 'biographically disruptive' (Bury 1982), provoking an assault on personal and felt identity, it leads to an interruption of continuity in a person's day to day life. Respondents commonly reported being aware that something was not 'right' with their physical health prior to seeking help from their General Practitioner (GP) in the first instance. As symptoms develop, and the level of disruption increases, anxiety prevails as it becomes apparent that life cannot continue as previously lived. This understanding of their altered self was commonly reported by describing pivotal moments, for example, the occurrence of accidents, when trying to perform seemingly mundane tasks, easily manageable prior to symptomatic onset. For example:

'I was at my granddaughter's house one day when she asked me if I would have a game with a bat and ball in the garden. I went out willingly. After a few minutes I had to step backwards to hit the ball, there I was lying on my back. I soon realised that if I stepped backwards or sideways I fell over' (Female, 54 years)

And:

'Forgetting everything [the problems recently being experienced with my body] I started to run. The pavement was on a slope. The next thing I knew I was skateboarding on my hands, my head jerking back violently. Having come to a standstill, or bottomstill, I looked up. The post woman [who I wanted to catch to post my granddaughters birthday card] was still there, the palms of my hands were bleeding but I managed to get to my feet and walk the few yards

and give her the card in the envelope' (Female, 54 years)

Yet despite respondents recognising that something 'wasn't right' with their physical body, when they sought help in the form of medical knowledge and treatment, reactions received from GPs during the initial diagnostic quest were noted by many participants as highly unsatisfactory and sometimes unhelpful:

'It was affecting my running so I was quick to ask the doctor what was going wrong. The [first] GP diagnosed 'restless leg syndrome' without an examination, and told me to live with it' (Female, 55 years)

And:

'I mentioned the fact that I fell over if I stepped down with my left foot. He made no comment, perhaps he didn't hear me. I felt very stupid about the whole situation and his non-reaction reinforced my attitude towards myself [that I was making a fuss over nothing]' (Female, 54 years)

3.3 After a further period of time, respondents described a period of increasing realisation and awareness that symptoms were progressively, and in some cases, quite rapidly worsening. This generated a profound 'loss of self' (Charmaz 1983), where individuals found themselves in a position where their life-world was fractured and bodily disruption was impossible to ignore:

'By September I could no longer ignore the deterioration in my speech. My tongue movements were slow affecting not only my speech but my eating' (Female, 59 years)

Yet even at this point, when medical opinion was sought more insistently, there appeared to be difficulties in being taken seriously, and obtaining the necessary referrals required to access more specialised medical knowledge:

'I was seriously beginning to think the worst, although everyone assured me it was probably just my age, or a consequence of too much [fitness] training. Eventually I plucked up the courage to see the doctor who reassured me I was very fit and had nothing to worry about but by all means see a physiotherapist' (Female, 51 years)

Here it appeared, at least in the earlier stages of the illness, that respondents still wished to believe that the abnormalities occurring were a temporary state that could and would be rectified over time, perhaps with the aid of medical intervention and treatment. Such an opinion may have been partially influenced by their faith in the health system, and by GPs who did not at the time communicate any great concern:

'The fact it would have such an impact on my future failed to register with me at the time, after all the doctors now know what it is, so I'll be fine!!' (Male, 46)

This belief was often born out of participants being previously very healthy; leading to disbelief that serious illness could prevail:

'I have eaten well and exercised well most of my life and I couldn't understand why this was happening to me' (Male, 55 years)

This occurred in combination with MND being a largely sporadic illness, therefore providing the individual with no advance warning, no prior family history or narrative map to draw upon as a source of symptom recognition. Due to the often rapid onset and severity of the illness, however, even before clinical diagnosis, the frightening realisation often dawned that a recovery was increasingly unlikely:

'Initially I continued to swim quite a bit but eventually this dwindled away. One day on holiday, I jumped in the pool and found I could not swim and keep my head above water. Although I should have been able to stand up I did not have enough coordination to get into a standing position. Luckily I managed to get to the side of the pool and swimming became another activity lost to me' (Male, 51 years)

3.4 The period of time required for many to get 'taken seriously' by health professionals was a recurrent theme that emerged from data analysis, and meant that often the individual began to question themselves, and their bodies, as well as continuing to live with worsening, untreated, symptoms, constant worry, and a decreased quality of life both physically and mentally:

'I had symptoms for well over a year before anyone medical took me seriously!' (Female, 55 years)

And:

'[It was] Frustrating, originally taking two years to get taken seriously, I was seeing a consultant for a chest problem I had for a few years. Explaining I was having difficulties speaking with words running in to each other. He replied he understood me fine but I said that was because I was speaking slower than normal. It came to a head one afternoon when I mentioned I could read quicker than when in conversation. Passing a text book to me to read he finally took me seriously' (Male, undisclosed age)

3.5 Being on the receiving end of a diagnosis for terminal illness is a highly negative 'epiphany' – not only for the sufferer, but also for significant others: family, friends, and a wider social circle. Participants reported that once the initial presence of physical illness had been detected, there appeared to be reluctance on the part of many doctors fully to disclose the extent of the diagnosis or likely prognosis. Whilst this is of course understandable to some extent if doctors are unsure as to diagnosis/prognosis, again the form of communication selected is salient. One participant recounted a particularly unhelpful and disturbing response from his doctor:

'When we went down there for all the testing, I tried to ask the doctor what he thought was wrong, and he just turned around and walked away' (Male, 59 years)

Such diagnostic liminality was commonly experienced over a prolonged period of time, often many months, and even continued after a significant number of tests:

'They asked me all about my family background, and I said there's no, there's been no history in my family of such things, and then, and then that set the ball rolling with lots of different tests, and then 18 months later I go the diagnosis of having Motor Neurone Disease' (Female, 48 years)

3.6 Given the relatively rare incidence of MND in the population (see Holmes 2005), it is important to acknowledge that medical professionals themselves may be uncertain as to diagnosis and prognosis:

'I went into his room and he had all my notes spread across the table and he went 'you've got something progressive but we don't know what yet' and I was upset, and the more I thought about it, progressive in what way, you know.... I thought maybe in years to come, maybe I'm going to be in a wheelchair or....which was bad enough anyway.' (Female, 48 years)

3.7 In addition to the angst surrounding continued physical deterioration, the lack of diagnosis, even if signalled as tentative, appeared to increase the distress and anxiety already being experienced by patients. Delays in declaring a diagnosis often meant an agonising wait for the individual. Many participants recounted feeling that medical professionals were not willing (rather than being unable) to inform them of a diagnosis:

'The neurologist was not prepared at that time to say what my illness was; he was prepared to state that the illness would dramatically reduce my life expectation' (Male, undisclosed age)

Such delays could engender false hope, and appeared to delay the acceptance of having a serious illness with a shortened lifespan, subsequently providing grounds for intense regret:

'I did the worst thing possible and wasted precious time living life as if I was dreaming, feeling sorry for myself, hoping for a miracle and looking for that impossible miracle' (Male, 51 years)

Liminality and living with uncertainty

3.8 For those interviewed, it was apparent that they wished to know the outcome of the many tests endured, or the possibilities they held, whether or not this meant a poor prognosis in the long term. The felt isolation of undergoing the many tests without the opportunity to discuss or share those experiences and concerns with medical professionals seemed to create a period of intense existential loneliness, and perceived separation from others during this time:

'Even today if I see a machine that looks like an MRI it brings back the awful loneliness I felt in that machine' (Male, 51 years)

3.9 The stress, worry and apprehension of not knowing was highlighted by many to be equally as detrimental to health and well-being as the stress of knowing about and living with a diagnosis of MND. Participants described and identified this period as a time of great frustration:

'I found waiting for results to be the worst thing – in one case it took three weeks for a report to get to my consultant from another consultant who worked in the same building!' (Male, 51 years)

3.10 In some cases, the prospect of such long delays prompted individuals to seek private consultation and diagnosis, usually at significant personal cost. Several respondents admitted to having 'a pretty good idea what might be wrong' prior to the official diagnosis, having invested time and money leading their own research into symptomology. Although when the diagnosis was eventually confirmed, individuals not surprisingly found the acceptance of the actual diagnosis very difficult. Although all of those interviewed spoke about wanting to know the diagnosis, perhaps unsurprisingly, when this was eventually delivered, it was encountered as a frightening and life-changing event, and suicide was even contemplated:

'I was frightened about that [the diagnostic outcome]. There were thoughts of ending it all' (Male, undisclosed age)

3.11 Knowing something was gravely wrong, yet not knowing what this might be, was described as a

'frightening' and 'disorientating' state. This was compounded when the individual was made aware of the lack of life-prolonging or curative treatments available. It emerged from the data that to 'speculate' and to 'know' are two very different feelings that can evoke very different embodied emotions. The complexity of the certainty/uncertainty nexus emerged strongly, for a diagnosis of MND could signal the end of hope; a definitive diagnosis means the end of expectation of recovery. Whilst there is uncertainty, there is hope of a different prognosis. Yet alternatively it also means that confirming patients' fears helps ensure they do not live in false hope, but rather can begin to learn with the reality of their condition and altered life-world, even if this requires medication as a coping mechanism:

'I couldn't survive, psychologically, without my medication. Not because it relieves my pain but because it helps me cope with the reality of my disease' (Female, 59 years)

This paradox of wishing to know, yet at the same time not know the future, was recognised by all respondents. In the earlier stages of the post-diagnostic period this appeared to be felt particularly keenly.

Hearing bad news

3.12 There appears to be disparity in how information communication may be understood differentially by health professionals and patients. According to Cassell et al. (2001), communication for health professionals is about the collecting, exchanging and provision of factual information. This is often undertaken in a 'rational' and time-efficient way, but with minimal consideration as to how this mode of communication may affect the patient psychologically. Above all respondents perceived that it was carried out in a way that avoided too much personal involvement or investment. Even when the diagnosis was known by the health professional, full disclosure and provision of information were not always afforded to the patient, sometimes, it appeared, for somewhat patronising reasons:

'He just said bluntly "I'm sorry my dear, as I suspected, you have Motor Neurone Disease. It's very serious, but you're an intelligent woman and I know you would like to know" I then asked him how serious, was I going to end up in a wheelchair? What was MND? He patted me on the arm, said "Oh you don't need to know any more yet". Then walked off leaving me behind the curtain (cubicle) in bits' (Female, 55 years)

This may have been because the medical professional felt ill-equipped to undertake the 'emotional labour' (Hochschild 1983) required, but nevertheless, the patient was left in a state of intense distress. With a terminal prognosis such as this, there is no emotionally painless way of breaking bad news, but the diagnosis may be not entirely unexpected:

'On being told I had MND I wasn't truly shocked for I had been aware for some time that something was wrong' (Male, undisclosed age)

3.13 Although for most, even with prior awareness that something was seriously wrong, when the diagnostic moment actually arrived, it caused a level of reactionary distress that individuals suggested was uncharacteristic of their usual mode of *Dasein* or 'being-in-the-world', signifying the extraordinary impact and gravity of such a diagnosis:

'When given the diagnosis I acted like any mature adult in his forties and cried my eyes out, thinking why me and generally feeling sorry for myself' (Male, 51 years)

3.14 The day, time and place where the diagnosis was confirmed became, for many involved in this study, a poignant and unforgettable moment in their life, an epiphany etched starkly in memory:

'Eventually after a battery of tests the diagnosis of MND was made. That moment in the consultant's room will stay with me forever. I drove back to school knowing I had to do a parents evening.... What I said to those parents I don't know as that part of the day escapes me' (Female, 51 years)

And:

'It was a lovely day, dry, warm and sunny, the wrong sort of day for such a depressing diagnosis but then what day would be good for that diagnosis! It was also the day after my birthday and since then birthdays have never held the same attraction as invariably my thoughts drift to "that" day' (Male, 51 years)

As Sparks et al. (2007) highlight, the manner in which the physician chooses to approach the delivery of bad news has been found to be salient with regard to the quality and tone of the physician-patient relationship. A declared diagnosis of MND marks the beginning of a particular association between patient and health professional, and the diagnostic moment is where a physician-patient relationship typically becomes first established (Chio & Borasio 2004). Here patient satisfaction and trust in the clinician are often initiated, or, conversely trepidation and dissatisfaction begin to take root. It is therefore important that the physician proceeds with care.

'I found the consultant neurologist off hand and too busy to spend more than two minutes with me [after an hour's wait to see him] and on subsequent visits.... I saw a different person each time, none of whom spent more than a few minutes with me' (Male, 70 years)

3.15 For many participants in this study, the diagnosis was delivered in an outpatient setting, where appointment duration was limited, the clinician highly 'booked', and, most crucially for patients, the time in between visits was several months or more. These findings cohere with other studies investigating conditions of life-limiting potential. In a study relating to cancer diagnosis Loge et al. (1997) found that only 52% of their participants were provided with condition disclosure in the privacy of a physician's office, whilst 48% reported disclosure taking place in the hospital corridor, over the telephone or by letter. In the current study, it transpired that many people would attend an outpatient appointment on their own, as their partner/spouse was at work, or the individual did not wish to 'bother' another family member or friend. However, data analysis revealed that being alone at the diagnostic encounter was highly significant, in particular for those who had either driven themselves to the appointment, and/or were returning to a home they inhabited alone. Had they been aware of the severity of what they were to learn, participants noted that they would certainly have brought someone with them. Given that in preceding consultations the magnitude of their condition had been kept from them, or made light of, when they did actually receive the diagnosis, understandably it was experienced with great shock.

'They knew I was single, they knew that.....but they didn't think, would you like to bring someone with you? Or it would be a good idea to bring someone with you? [...extended pause...] I wish I had been given that option, because it was the worst thing being told that diagnosis' (Female, 48 years)

3.16 It was apparent that many people found it hard to accept their diagnosis initially and it was not uncommon for respondents to have reported seeking a second, third, or in the case of one respondent interviewed, nine opinions:

'When the first doctor ..um.. the neurologist, said I had MND, I saw other guys and one guy..... in fact I saw nine neurologists, I had to pay to go and see them. [...long pause...] I didn't like what they were saying'. (Male, 70 years)

This could be partly attributed to the difficulty individuals had experienced in accepting their condition, but for some it appeared to reflect a lack of confidence in their doctor, based on the way s/he chose to manage their relationship, resulting in the patient finding it difficult to trust the doctor's opinion. Commensurate with this, patients indicated that they were dissatisfied with the communication of their diagnosis where they felt the clinicians lacked the ability to offer emotional support and/or empathy to patients. Moreover, respondents spoke of feeling a lack of satisfaction not only vis-à-vis their initial diagnosis delivery, but subsequent to this, when information that would have enhanced understanding of their condition was not forthcoming. Similar experiences have been reported in studies relating to diabetes, for example, where Kralik et al. (2001) reported participants leaving the room post-diagnosis, feeling frightened and unconfident as to how to understand and manage their illness. In addition, our participants noted the paucity of discussion that surrounded the availability of therapies and palliative care.

'Sorry to sound bitter, but we both feel, in general that since confirmed diagnosis, the NHS [National Health Service] attitude to MND is that it's incurable so, [shrug shoulders], we'll just monitor your deterioration every few months. A bit defeatist and you feel dumped' (Female, 55 years)

3.17 In one case, a request to talk about advanced directives and living wills, which included a wish for 'DNR' (do not resuscitate), was met with a flat refusal. When this particular patient questioned the healthcare professional regarding such reluctance or refusal to talk about future treatment options, he was told 'it was not the right time' to discuss such options, leading the patient to note:

'I strongly support the right of people with MND or any other terminal, harmful condition to have the voluntary ending of life..... Why should someone with religious views or any other view dictate to me how I live or end my life.' (Male, undisclosed age)

3.18 Other respondents revealed that the vast majority of information, choices and details of post-diagnostic care arose from visits made to their general practitioner, rather than from the specialist neurologist consultants, despite these latter usually being more knowledgeable and in a more qualified position to answer specific MND-related questions. Such experience of being 'kept in the dark' was reported as deleterious for patients.

Communication difficulties

3.19 Effective clinician–patient communication has been directly linked to improved patient satisfaction, greater levels of trust, adherence to suggested treatment plans, and subsequently health-related and well-being outcomes (Jahan & Qureishi 2008). Yet there is much evidence to suggest that communication opportunities are unfortunately being thwarted by the use of overly complicated language by clinicians to patients and their families:

'On being told in March 2009 that the diagnosis was Progressive Pseudo Bulbar Palsy it didn't really mean anything to me, at the time I thought maybe I had had a mini stroke or possibly some form of cancer so I was relieved, although the word "pseudo" threw me a bit, no way did I connect palsy to MND' (Male, 74 years)

3.20 Inadequate communication may not of course be deliberate on the part of the clinician; personal attributes can be a factor in interaction problems. As has been noted in the literature, such negative

attributes include: having an authoritarian attitude, lack of empathy, and short temperedness or ignorance (Jahan & Qureishi 2008). In addition, Jahan and Qureishi (2008) suggest that miscommunication is exacerbated when non-verbal communication comes into the interactional play. Eye contact, touch and use of 'territories of the self' (Goffman 1972) all fall into this category. If negative aspects of these components are combined in a single consultation, it may leave the patient feeling inferior, anxious, and unable to voice their views, concerns or ask questions. In turn, this can leave a person feeling ill-informed about her/his condition and prognosis, 'floundering in an abyss' regarding treatment selection and availability of choices. Overall, this leads to an experience of 'thrownness' and 'unhomelike' (Heidegger 1962) in phenomenological terms, a lack of control and autonomy vis-à-vis their own illness, and feeling a lack of support from the medical experts. A respondent reflected on her experience of having insider knowledge, yet at the same time being on the receiving end of a negative patient experience:

'I honestly think that had I not been a NHS employee at diagnosis enabling me to access all the relevant departments with ease and also having insider knowledge of how the system SHOULD work, then I think I would have become very depressed, possibly suicidal' (Female, undisclosed age)

3.21 Not only was a lack of information reported prior to, and at the diagnostic phase, but similarly, many participants highlighted the lack of information from health practitioners post-diagnosis. Jahan and Qureishi (2008) suggest that priority should be attributed to communication surrounding the enhancement of physical comfort, emotional support, and the alleviation of fears and anxiety. However, the gap between the ideal and real emerged as salient. Maguire and Pitceathly (2002) have discussed how doctors may often provide information in ways that patients find difficult to understand, and even ignore what patients actually wish to know.

'Once the diagnosis is available then the neurologist should explain fully how quickly the patient could lose certain of his or her faculties – i.e. mobility, speech, eating, drinking, control of saliva, use of fingers and hands..... My neurologist just said that my expectancy of life would be greatly reduced' (Male, 59 years)

In addition, participants found that health professionals spent little time ascertaining whether patients had understood the information delivered, a dimension highlighted as highly salient by other researchers (e.g. Silverman et al. 1998). Many respondents reported feeling dissatisfied with the explanations provided, the help offered, or the time it took to receive any of the assistance they sought and/or were entitled to. This coheres with study findings relating to the diagnostic deliveries of other serious conditions, for example, leukaemia, multiple sclerosis and chronic psoriasis (Kralik et al. 2001). A few felt that what was forthcoming was far too little, and, in some cases, proffered far too late:

'[I found it devastating] to find out in such a bad way, no information, no advice. Funnily enough, 18 months after diagnosis, the NHS sent me to a 'Stress Diagnosis Counsellor' to help me. My first words were 'where were you 18 months ago when I really needed you?'" (Female, 55 years)

Others felt that the responsibility of finding out about the condition landed squarely on their shoulders, being presented with little or no information about the condition, and experiencing a sense of abandonment by the medical professionals:

'It was hard [hearing the diagnosis]. I was there by myself, I knew nothing about MND. I came home and thought, what's that? So I got on the computer and all the medical books and thought what the hell..... I felt as though I was just left to die' (Male, 70 years)

Some were given contact information for the Motor Neurone Disease Association, a UK not-for-profit charitable organisation, highly praised by all those interviewed during this research. However, such information provision was sporadic and did not appear to be standard practice, but dependent on the health practitioner. Participants also reported feeling abandoned post-diagnosis, left to deal with the condition on their own, once a medical diagnosis had been delivered:

'On the plus side it is good to have a diagnosis when you know there is something wrong but you don't know what it is. On the negative side, there is no cure for MND so the knowledge of the continuing deterioration and progressive disability is depressing and debilitating. There is a tendency for professionals to give a diagnosis and then walk away from the problem leaving you to deal with it' (Male, 64 years)

3.22 It may be, to some extent, that health professionals were seeking to protect themselves from emotional encounters, to retain a presentation of self (Goffman 1959) as the 'responsible' and 'strong' practitioner, a form of detached professional concern that serves as a means to keep intact and maintain their own emotional survival. Self-preservation methods have been identified as including: attending to physical ailments and symptoms only, switching the topic of conversation if psychological or difficult social issues arise during discussion, and 'jolly' patients along so that the opportunity to stray from the direct physical matter is reduced (Maguire & Pitceathly 2002). All of these techniques can, however, be experienced as highly detrimental to a patient's sense of well-being.

A body of medical interest

3.23 As previously noted, MND is not a common medical occurrence; and one that health professionals in

general may seldom, if ever, encounter in an entire career. Unfortunately, as respondents noted, their 'rarity value' could also deleteriously affect their experience of receiving care of a dignified, sensitive and respectful nature:

'Many medical professionals can be tactless, unfortunately I am an interesting case and so they relish in examining me and providing more of an "insight" into my condition' (Male, 51 years)

When the health professional seems blinkered to the needs of the patient, the patient is at risk of being objectified and observed by others through an inhuman gaze (Merleau-Ponty 1962):

'I felt like I was [used as] a prop so that she could give a demonstration lesson to the nurse' (Female, 54 years)

Individuals then find themselves viewed no longer as a person with social agency, who is accepted, respected and understood by others in the interactional order (Goffman 1972), but as reified and other, a 'thing' to be observed and studied as a rare case:

'She [the physiotherapist I had been referred to] became quite excited and fetched a colleague to observe with her. I gathered that I displayed a rare but classic gait which was in the text books. In other words I was a freak! To appreciate what a shock this was, you have to realise that I had always [until very recently] had a slim figure, good posture and confidence in my physical appearance' (Female, 54 years)

Understandably, being on the receiving end of such harsh, undignified and tactless treatment was endured at great personal cost to the individual's subjectivity, sense of personal pride and self-confidence.

Discussion

4.1 It is recognised that participants in this study were self-selecting in that they chose to respond to a request for participation, and therefore the opinions expressed may not be representative of MND sufferers in general. There were, however, many common and salient threads among participant responses, clustered under the themes reported above. Participants reflected during interviews on their expectations that the diagnosis would be delivered by health professionals displaying sensitivity, respect, compassion and human warmth. In reality, what emerged during this research, were narratives of doctor-patient communication experienced as highly stressful, distressing and profoundly upsetting. The results of this study therefore highlight the need for improvements in practice in various areas.

4.2 Health professionals should be encouraged to acknowledge that although their patients may possess only a layperson's knowledge of bio-medicine, on many dimensions they have expert knowledge in relation to their own bodies. Data analysis revealed that despite 'knowing something was wrong', respondents struggled to get themselves taken seriously by health professionals, and found it frustrating trying to demonstrate to others that their bodies were not behaving as expected. The personal discovery of having an incurable illness, the onset of a rapidly unfolding chronic illness, that has been described as effectively a death sentence, (Goldstein & Leigh 1999) can often emerge as a shock to the individual. There is the discovery that not everything can be repaired or replaced, that instead of returning to health there is only greater ill health and disablement to endure. The healthy body is one of 'transparency' (Carel 2011), one which we take for granted in our healthy state and which denotes normal function. Provided everything is functioning as we expect, our body usually remains in the background and recessive, as noted in Leder's (1990) phenomenologically-based account. Although there are times where we do notice the health of our body, for example when we have a sore throat, Heidegger (1962) notes that this is the only time when the body moves from the background to the foreground of our attention, our intentionality is then directed to our body-self. Carel (2011) similarly argues from a phenomenological perspective that when our body is functioning in the way to which we have become accustomed, and expect, our attention is deflected outwards, away from our body, and instead concentrates on our intentional goal or action. When early biological markers are experienced by patients and then brought to the attention of medical practitioners, it is important that due consideration is seen to be paid to their significance, so that key illness indicators are identified early on in the illness, allowing faster referrals to be made to access specialist neurological services. The patient thus needs to be viewed as someone who holds a form of expert bodily knowledge about their own corporeality; knowledge that needs to be taken seriously and into account by health professionals.

4.3 The issue of non-disclosure presented as a strong theme throughout the respondent narratives. Where a health professional chose not to discuss the possible causal factors of ill health, this led to respondents feeling 'frightened', 'disorientated', in a liminal state, and 'hoping for a miracle'. Being provided with only partial disclosure, and awareness that they had an illness which would 'dramatically reduce life expectancy' left the individual feeling 'hopelessly lost'. This, participants highlighted, was highly psychologically damaging, when advised of the 'label' of the illness, yet not knowing the deeper implications, this led to 'stress', 'worry', and 'apprehension'.

4.4 The psychological well-being of an individual is a key element in the lived-body experience of health and illness. For if one element of the mind-body nexus changes, it inevitably affects the other as the two are fundamentally interlinked. As Allen-Collinson and Hockey (2011) note, in theorisations of the 'lived body', the mind and body are inextricably linked and form an on-going, fluid and dynamic partnership. Thus, health professionals need to acknowledge the role of emotional health as fundamental to a felt sense of well-being. An undercurrent running strongly through participant responses was the sentiment

that physiological health concerns appeared to take precedence over psychological health in the biomedical professional milieu, including throughout the diagnostic journey. There emerged little evidence that the psychological and emotional well-being of the patient was addressed during the diagnostic phase. Rather, this appeared to be reported as an afterthought, with one respondent recalling a wait of 18 months for an appointment with a stress diagnosis counsellor. In 'Living with uncertainty' individuals described feeling 'lonely', 'frightened' and 'lost' during prolonged periods of diagnostic testing. In the subsequent theme, 'Hearing bad news', this was compounded when respondents reported the distress of being left psychologically unsupported and 'in bits' after the diagnosis was presented, perceiving the consultant to be 'off hand', eventuating in an overall experience of feeling abandoned and 'dumped'.

4.5 Once the illness has been diagnosed, the patients experienced difficulties in regard to their on-going relationship with the health professional. In contrast to finding it difficult to attract attention toward a malfunctioning body during the pre-diagnostic period, 'A body of medical interest' demonstrated how respondents reported their dissatisfaction at being objectified, 'othered' and generally used by various health professionals, including as a means of teaching others about MND, in a manner that appeared to accord them little dignity and empathy. Participants reported that whereas previously their body appeared of minimal concern to health professionals, any manifestation of 'interesting' or 'exotic' illness radically changed this perception. Patients were poked, prodded, examined, objectified and observed by others, and compared to text book accounts. This resonates with Leder's (1990) phenomenological observation that in times of illness the body takes on an 'alien' appearance and feel, becoming an object of fascination for others, but for the individual 'owner', the body no longer appears in a way that expresses personal wishes in terms of identity and personality. The occurrence of 'social dys-appearance' (Leder 1990), where the ill self becomes noticed, but as an 'inhuman' object, links to Merleau-Pontian (1962) conceptualisation of being cast under an inhuman gaze, leading to the self becoming subject to an objectifying gaze under the scrutiny of medical professionals. Further, when the incidence of MND is identified, although there is consensus that it is a rare occurrence, patients do not wish to become objects of an 'excited' gaze, where the health professional brings in other colleagues to 'observe' the spectacle, for example, of a 'classic but rare gait'. This kind of unwanted attention risks undermining the dignity and self-esteem of the diagnosed individual, leading to the perception of becoming a 'freak' and a medical specimen for others.

Conclusions

5.1 In this article, we have highlighted some of the key themes that emerged from our qualitative research investigating patients' experiences around the diagnostic period in relation to MND. Specific recommendations for those seeking to improve the illness experience of persons progressing through the neurodegenerative illness pathway, and emergent from our findings, include the need for health professionals to seek to understand the patient's point of view, from their life-world. Such patient-centring includes providing full disclosure in an honest yet empathetic manner, should the participant indicate their wish for this, throughout the period of diagnostic testing. Most of our participants highlighted this as a central and fundamental need. The patient's wish to receive (or not) information about her/his condition needs to be respected. This includes frank and open discussion of what illnesses are being tested for, and therefore what is being ruled out, given that a definitive single test for MND does not exist at present. By providing full disclosure of the outcomes of testing and diagnostic processes (if the patient wishes to know these) it may influence the building of a greater level of therapeutic alliance and trust between the patient and health professional throughout the diagnostic period, in addition to enhancing longer-term care. In tandem with the need for diagnostic clarity, attention needs to be paid to the on-going psychological health of the individual, with provision of support so that an individual may be better prepared to accept the intense shock of receiving a diagnosis of a severely debilitating and life-limiting chronic illness. 'Chronic sorrow' (see Olshansky 1962) is a state of being-in-the-world that is commonly linked to those living with life-threatening conditions. Developing MND means learning to live with irremovable loss as a constant reality, mourning for those losses and accepting life in the present. Chronic sadness is a distinct type of sadness, viewed as a 'normal' reaction to a condition involving significant losses. The decline in emotional state is left to develop after the initial trigger becomes unmentionable (such as a diagnosis of a terminal illness). The lack of acknowledgement by others of the situation keeps it below the surface where the individual sufferer is left to manage emotionally by themselves; this could be considered at a detriment to the individual's psychological health and well-being.

5.2 By addressing some of the issues around what patients perceive as the unsatisfactory mode of delivery of diagnoses and subsequent care provision, the current research aims to highlight areas for further study that could identify improved training strategies for health professionals. Previous research has acknowledged that giving a diagnosis of MND is challenging, with many patients reporting highly negative feelings about the poor communication skills of physicians (O'Brien et al. 2011). Professional training could therefore emphasize the importance to health professionals of fostering greater levels of tact, sensitivity, empathy, warmth and compassion, and thus improving the diagnostic and treatment experience of patients diagnosed with MND and analogous devastating, life-limiting illnesses. Other recommendations have also advocated the provision of suitably qualified psychological support to be available during diagnosis (O'Brien et al. 2011). If this were to be incorporated into standard practice, it might help to make a significant difference for individuals who arrive to face the diagnosis on their own without the social support of a family member or friend.

5.3 In conclusion, by achieving the recognition of more holistic need, the distressing, lonely and stressful experience of the illness pathway to a diagnosis of MND, recounted so vividly by participants in this study, may be ameliorated. This may lead to greater development and enhancement of coping mechanisms, increased levels of dialogue between doctor and patient, increasing the opportunity for more satisfactory experiences in relation to the diagnosis pathway. In general, the majority of

respondents in this study did want to assist in the education of health professionals in learning more about MND, recognising that greater familiarity with the disease might well enhance someone else's diagnostic experience.

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