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'Running out of time:' Exploring the Concept of Waiting for People with Motor Neurone Disease

Jo Ferrie and Phillippa Wiseman

University of Glasgow, Glasgow, United Kingdom of
Great Britain and Northern Ireland

Abstract

Waiting is a part of everyday life. It is often characterised by its banality: its quotidian nature. Time spent waiting can be seen as boring, wasted, and at times painful or distressing, or conversely hopeful or full of potential. The experience of Motor Neurone Disease (MND) reveals a population for whom (limited) time has a significant impact on quality of life. This paper will argue that waiting, for people with MND, exemplifies the relationship between time, power and agency. In so doing we can better conceptualise the manifold ways in which time and waiting are experienced through choosing to wait, enforced waiting and waiting when time is known to be 'running out'. Through a sociological analysis of multiple forms of waiting three key themes emerged that characterised waiting as powerlessness; emotional (as a form of production), and; alternating as an experience between patience and endurance. This paper challenges the passivity, universality and ambivalence ascribed to waiting and instead argues that waiting affects the 'time left' for people with MND. It also offers up a lens through which to view time through the multiple textures and tensions of waiting produced through chronic illness.

Keywords

Waiting, motor neurone disease, power, emotion, time

Introduction

This paper explores waiting in a particular context: having Motor Neurone Disease (MND). This paper forms a prolegomenon to understanding experiences of MND and how this intersects with time and power. This study reveals multiple forms of waiting: waiting and seeing; enforced waiting; and waiting when time is 'running out'. These modes of waiting are experienced within the context of temporalities in conflict. As such, 'waiting' comes to represent 'time-stilling' (Anderson, 2004, see also Bissell, 2007) whilst MND involves the continuous and, frequently, rapid deterioration of the body. A focus on the phenomenological experience of being diagnosed with this terminal condition and the consequences of waiting for (in)appropriate support allows us to reconsider theories of waiting which have often been constructed within a view of time being less limited (Bissell, 2007). As the experience of having MND has not previously featured in discussions on waiting and time and this paper provides the opportunity to view waiting through the lens of MND. Through using MND as a case study we offer up chronic illness as a medium through which to think about the precarity of time and often juxtaposing forms of waiting.

Within modernity, time has been positioned as our enemy, limiting progress and shaping all activity; time constrains and creates possibility in everyday life. Our lives are structured through frameworks of time and often involve periods of waiting characterised as tedious or wasted time. Waiting has been interrogated in the academic literature, often positioned as inevitable, with the wait-er seen as passive and non-productive. Bournes and Mitchell (2002) argue waiting is a 'common human experience' and that everyone's lives involve waiting in some way or another, similarly Bissell

maintains that 'waiting is a universal experience' (Bissell, 2007: 283). Waiting can be experienced in manifold formats, from quotidian forms of waiting such as waiting for the phone to ring or the bath to run (Bissell, 2007), to more exceptional forms such as waiting for the onset of labour (Eri et al., 2010) or infertile couples waiting to adopt a child (Sandelowski et al., 1991). For Fujita (2002) waiting is to be understood in two ways, firstly in terms of 'what is waited for' and secondly 'how we wait'; he argues that 'how we wait' depends on 'what is waited for'. Thus waiting for a kettle to boil is significantly different to waiting for a terminal diagnosis, for example. One is time to be whiled away, whilst the other demands endurance. In this paper we focus on this emerging notion of waiting as endurance or 'raw'.

Waiting has, generally, been overlooked by sociological study (Auyero, 2011; Bissell, 2007 see also Schwartz, 1974). Within work exploring temporality, there has been limited focus on experiential waiting in relation to a terminal diagnosis or chronic illness, a mode of waiting that is not ambivalent, cannot be avoided and must be endured (Sutton et al., 2011). Sutton et al. (2011: 32) refer to this process of forced waiting and endurance as 'raw waiting'.

As waiting becomes recognised as (at times) the experience of endurance, power becomes visible as a force shaping waiting; allowing exploration of why we wait and whether we have a choice in waiting (Fujita, 2002). The body of literature on waiting and temporalities allow us to explore scales of time and scales of waiting. Auyero (2011) and Sutton et al. (2011) bring to the fore the relationship between waiting and power or domination, arguing that having to wait long periods of time can amplify powerlessness and weakness on the part of those who wait. In this sense perhaps waiting is articulated as passive and in relation to waiting with a chronic illness this is particularly salient as whilst participants in this study often felt a lack of control or powerlessness in waiting, they were also able to assert agency in waiting. As Sutton et al. (2011) note, waiting is for the weak, those who have no choice but to wait. The powerful may be able avoid waiting; they have the resources and the potential to end it (Schwartz, 1974). Most people have the ability to avoid ambivalent waiting through technologies that exist to avoid waiting such as kindles, mobile phones, computers and televisions. Raw waiting is of a different sort, much more associated with a kind of structurally enforced powerlessness. If waiting is a product of modernity then raw waiting, or waiting that must be endured without avoidance, is a product of the structural and power inequalities produced through modernity. As Bourdieu writes, modernity has made way for the:

exercise of power over other people's time both on the side of the powerful (adjourning, deferring, delaying, raising false hopes, or conversely, rushing, taking by surprise) and on the side of the 'patient' as they say in the medical universe, one of the sites par excellence of anxious, powerless waiting. (Bourdieu, 2000: 228 cited in Auyero, 2011)

Conversely waiting, boredom and time have been explored in terms of their potentiality, their capacity to create and anticipate as temporal spaces within which social meaning can be created and experienced and has the capacity to challenge notions of waiting as passive. As such waiting has the potential to be seen as agentic and those who wait as active producers of social meaning (Barbalet, 1999).

Emerging from our analysis of waiting are a series of agentic practices that challenge notions of waiting as a passive state. Choosing to seek medical help, receiving a diagnosis and approaching social services for further support punctuates waiting for bad news but critically evidence productivity and activity on the part of those who wait. This paper will explore these

multiple scales of waiting in terms of power, emotionality, and patience and endurance.

Waiting in health and illness

Waiting in relation to health and illness has been given significant attention in the literature. In general these analyses have focused on relatively routine but protracted waiting times in waiting rooms (Akerstrom, 1997), the fear emanating from an unwanted diagnosis and the impacts that these can have on patients (Bishop, 2013), and waiting for a 'serious' diagnosis (Giske and Gjengedal, 2007; Thorne et al., 1999), or transplant (Brown et al., 2006; Yelle et al., 2013). Focusing on waiting rooms generally demonstrates waiting as passive, however some studies (such as Yelle et al., 2013) argue that waiting is not passive but instead is agentic through emotion, for example the experiences of hope or of fear for example.

Hope is central to many studies on waiting in relation to illness and in particular, diagnosis. Yelle et al.'s (2013) study into narratives of waiting for a lung transplant explored how significant periods of waiting affected participants' wellbeing, mental health, and everyday lives as they had to be prepared at any moment to be called in to be transplanted. Patients were partnered with mentors who had 'come through' the process and who gave hope as to what their futures could be like. Critically, the negative experience of waiting was recognised and mitigated through mentoring in this example. Tying in to what Gaspirini writes (1995), waiting for a lung transplant was endured by emphasising the prospect of having functioning lungs at the end. Similarly, Bournes and Mitchell's (2002) study into waiting in critical care discussed hope and anticipating restoration to good health as key to coping in the period of waiting. Ezzy (2000) discussed hope and time in the context of HIV illness narratives and found that positive successes in managing HIV led to increased hopefulness and planning for the future, that the potentiality of long periods of good health restored a sense of identity. Good health is a process that requires effort (though effort does not always result in good health). Hopefulness in waiting, then, is an agentic practice that challenges the assumption of the passive wait-er.

A return to good health is a way of reducing waiting times too. This reinforces normative meanings around health and illness as shorter waiting times for a lung transplant are, of course, desirable and denotes priority. As Zerubavel (1987: 345) argues "The rapidity with which doctors and nurses attend some patients, for example, is usually indicative of their relatively high priority to them as emergencies . . ." the converse being that long and protracted periods of waiting can be understood, by those waiting, as being of low importance or low priority. Within contexts of health and lack of resources, organs for example, having quicker access to those resources and a short wait may denote importance or high priority. Where those are able to pay to wait shorter times then waiting may be felt by those who can't as being of low priority or of low status. Being made to wait, as Zerubavel explains, 'is often regarded as a symbolic display of degradation' (Zerubavel, 1987: 345). This could refer to degradation in terms of status but perhaps could also be understood in terms of physical degradation, degradation of health and of the body. However, Zerubavel (1987) doesn't focus on the fact that protracted periods of waiting can be experienced not as an indication of low status or degradation of the wait-er but as a result of the difficulty in diagnosing particular conditions or perhaps the pressure and constraints placed on medical professionals to rule out other possible conditions and give accurate and reliable diagnoses with haste. As will be seen later, this is particularly salient when it comes to the diagnosis of MND which can often be drawn out, complicated and precarious.

Like Zerubavel (1987), Bissell (2007) describes normative frameworks built around speed, haste and productivity as entrenched in Western individualist understandings of what is good and preferable. Activities undertaken with speed, and in good time, can denote importance, high status, priority and necessity. Certainly Parsons' discussion of 'the sick role' speaks of restoration to health with haste in order to be productive and legitimate (Jutel, 2009). A good patient, according to Parsons' (1951), remains absent while ill so as not to infect others, and rests to ensure a speedy recovery. They do not place undue pressures on the healthcare system, as their recovery becomes their own moral concern. Such a role may indeed work with infectious conditions. Parsons' work has contributed to a culture of patience within healthcare where waiting one's turn is approved of. This approach is less useful with chronic conditions (Nettleton, 2006) or where there is no cure (or return to work), but speedy diagnoses is still key to optimising illness management, and ensuring timely access to necessary services, treatments and support (Jutel, 2009 see also Bell, 2014).

A diagnosis can, at times and in certain circumstances, be understood or experienced as a reward and a relief to the patient, ending one element of waiting. As Jutel (2009: 278) notes, being given a diagnosis 'gives permission to be ill'. Medical professionals have the power to deliver diagnoses and the power to diagnose sets them apart, imbuing them with 'medicine's authority', a form of superiority that makes the patient relatively inferior or powerless (Jutel, 2009, see also Freidson, 1972). The power to deliver diagnoses in a timely fashion is also the potential power to open-up access to other services necessary to manage ill health and chronic conditions, which is instrumental to quality of life.

Similarly, waiting for necessary services can be understood in terms of 'time wasted' and highlights the structural affects of waiting (for example 'normal' waiting for appointments and referrals). Abbott and Carpenter's (2014) study into transition management for young men with Duchenne Muscular Dystrophy (DMD)¹ outlined that often parents would see transition services as 'wasting precious time' as families had to wait for these services. Time was understood by participants and families and constructed as 'precious' by parents who were aware that 'there was not much time left' and was structured by organisations' enforced waiting thereby rendering time waiting as 'wasted' (Abbott and Carpenter, 2014: 1201). Ultimately Abbott and Carpenter (2014) question the efficacy of services that are being mapped onto lives that experience specific or unique scales or frames of time. It will be seen that services built for normative understandings of what the life-course is, or should be, were often incompatible for people with MND and arguably for those with other chronic and life limiting illnesses.

Waiting, Bissell (2007) surmises, results in a juxtaposed feeling of temporalities in conflict; the slowness and frustration of waiting, juxtaposed with the continuously moving, and often 'fast', nature of everyday life. As will be explored through MND, this conflict can have devastating effects when 'time left to live' is 'running out'.

Motor neurone disease

MND is an umbrella term used in the UK to describe a range of conditions that affect the motor neurones in the brain leading to gradual paralysis of the body (Ba'umer et al., 2014). The most common type is Amyotrophic Lateral Sclerosis (ALS). Other more rare types include Primary Lateral Sclerosis (PLS) and Progressive Muscular Atrophy (PMA), though many

people do not receive a more specific diagnosis than MND.

MND is a terminal condition in all cases, and many people reach end of life within two years of diagnosis (Motor Neurone Disease Association (MNDA), 2015), although a small number survive beyond 10 years and for some, then, it shares the characteristics of a chronic condition. Brown (2003) described MND as sitting astride the boundary between chronic and terminal illness with people facing (possibly years of) care strategies and then end of life after an unspecified (but short) amount of time. Around 1 in 50,000 (Hoppitt et al., 2011) people have MND in the global population and there are roughly 5000 people in the UK with the condition today. It is not understood what causes MND though there is thought to be a genetic basis in around 10% of cases (MND Scotland, 2012).

The road to diagnosis is a fairly long and circuitous one involving a series of tests. A person must fail each test (that is, no other explanation for the loss of muscle strength can be identified) before they are diagnosed with MND (MNDA, 2015) and thus waiting for the diagnosis is punctuated by some relief as they discover they haven't had a stroke, they don't have Multiple Sclerosis, they don't have Muscular Dystrophy and so on. However, once they have their diagnosis there is no cure and no treatment.

Muscle weakness or fasciculation in MND is first detected via fairly minor symptoms; small disruptions to daily activities. For example, increased experiences of tripping, tired feet or slurred speech are noticed at first (Gordon, 2013). Symptoms gradually increase in incidence and severity over weeks and months. As paralysis develops, people struggle to cough (Young et al., 2011) breath, eat, talk, walk, sit unaided, turn over in bed and fine motor movement can be affected too (Gordon, 2013). There are broadly speaking two forms: bulbar onset and spinal onset. The disease has a quick progression and although prognosis is discussed at diagnosis, so much variability in presentation makes it difficult to predict how the symptoms will develop (MNDA, 2015).

MND has been conceptualised, academically, in terms of biography and disruption to identity and sense of self (Bury, 2001; Locock et al., 2009). Ferrie and Watson (2015) have looked at the notion of MND as a disability, and Pavey et al. (2013) have looked at phenomenological accounts of receiving a diagnosis of MND. However, MND has not been understood in terms of temporality, waiting and its implications.

Research methods - Recruitment, sample and analysis

The material explored in this paper is taken from a study funded by MND Scotland which aimed to explore the health and social care needs of people with MND and their families in Scotland. Forty people with MND and their families were involved in interviews (roughly 10% of people living in Scotland with MND). MND Scotland wrote to their contact list inviting families to participate. We did not see the contact list, and we did not disclose to MND Scotland which families had contacted us directly for more information. Pseudonyms were used and other identifiers were removed (e.g. location). Interviews occurred between 2010 and 2012 and families were visited between 1 and 4 times. This quasi-longitudinal approach allowed rapport to build and the study to follow the progression of MND. In addition five focus groups with family members who had lost someone who had MND were conducted across Scotland. Featured quotes include whether it derives from the person with MND or their relative to aid clarity. However, we also felt and participants felt that the phenomenological experiences of waiting with MND were pervasive not just for the person with the condition but for their loved ones, carers and family members

and so their narratives provide meaningful parts of that lived experience. Ethical permission was granted by the University of Glasgow's internal review board in 2010.

Phenomenology is a philosophy and research approach that aims to explore the lifeworld of each participant. It is concerned with a thorough engagement with each participant's perspective to gain rich and original insight around a particular shared experience (van Manen, 2007), in this case, of living with MND and as such this data was analysed by examining the phenomenological experiences of those participants. Interviews began with the question 'Tell me how it started' and participants were then given the freedom and space to supply rich phenomenological detail as they discussed aspects of health, social care and the nuances of living life with MND. Waiting was not initially a key theme to emerge within the data until it was looked for, and then it pervaded all interviews, all stages of the condition, and the full range of services and support networks.

The initial discussion in most interviews was around the experience of diagnosis and waiting. The wait between first seeing a GP and receiving a diagnosis of MND did not exceed 24 months. Some informants had difficulty discerning exactly how long they waited before reporting early symptoms to their GP, others were more precise: 13 reported symptoms to their GP immediately, 10 within three months of noticing symptoms, three waited up to six months, three up to 12 months and two just over one year. Advice from others, painful symptoms or restricting symptoms were most likely to trigger an early visit to a GP. It is essential to note, here, that narratives presented reflect the experiences, thoughts and feelings of participants with MND and their families and loved ones. We did not formally interview health or social services for the purposes of this study. As will be seen there were multiple intersecting forms of waiting being experienced by participants and therefore some forms of waiting, such as waiting for a diagnosis, for example, were reflected on by some in retrospect and by others who were involved in waiting at the time of interview, such as waiting for home services. The complexity of these myriad forms of waiting brought to the fore the mosaic experience of time for these participants and their families.

Key findings

We have argued that the diagnosis of MND is not a straightforward process; as there is no 'test' (MNDA, 2015) often it is a diagnosis by omission. The narratives presented in the following section will examine multiple modalities of waiting and shifting temporalities within the journey to diagnosis. This journey was understood by participants as choosing to 'waitand-see', being made to wait or 'time wasted' by medical and social services. The following sections will present the effects of having to wait for care and home adaptations and how services founded on normative ideas of the lifecourse can impose multiplicities of waiting on people with MND.

'Waiting and seeing' and the 'patient' patient

Waiting, as Schweizer (2005) maintains, is universally associated with the negative; the idea that 'nobody likes to wait' may imply that waiting would rarely be chosen. For the most part waiting is understood as something enforced. From waiting for a bus to waiting in prison, it conjures a sense of containment and restraint placed upon you by an external force. Within waiting, Bissell (2007: 285) argues that agency is embodied through the capacity to decide upon how waiting is done. However, choosing to

wait-and-see is a different form of waiting to being made to wait. It is a restriction placed from within rather than from an external force. Rather than an 'empty interval between instants' (Schweizer, 2005: 789) or 'interstitial space' (Gaspirini, 1995) it is the agentic practice in deciding how to continue on or what to do next, if anything. For Gasprini (1995) this is characterised by hope. And as Saybasılı (2011: 361) writes:

'Waiting' disturbs the passage of chronological time, and this particular interruption has potentiality for reevaluation beyond horizons that have been known.

For participants experiencing early onset symptoms of MND, choosing to wait to see the doctor was a process actively chosen. At this stage, participants were in control of waiting. It allowed space for participants to decide that there may be nothing wrong:

I noticed that when I got up in the morning my calf muscles were very tight – as if they had kind of shrunk in the night . . . The first few steps as I stretched out it was "ooh, ooh . . . But having said that I had retired from work of course so I wasn't as active as I was every day so I just assumed . . . "C'mon How old are you?" "You're sixty whatever? You're muscles obviously are not going to be what they were". So, everything had a logical explanation. (Marie)

For Marie, symptoms were initially constructed as being normal bodily signs of ageing and she waited to see her GP. The continuance of minor 'niggles' and 'twitches' over periods of months would convince others to eventually see their GP. In Marie's case this period of waiting lasted for just over a month:

So, I left it about a month or something but then I used to think "Oh, I need to get off my, my feet are . . ." you know how if you have been on your feet all day and they get really, really achy . . . that was in the June, and as I say I left it until about July and then at the beginning of August I thought "This is not going away. I'll need to go and see . . . there's something not right here." So, I went away down to the doctor. (Marie)

Participants chose to wait in order to garner whether there actually was a problem. Waiting to see if there was a problem allowed participants to have control over their own decision-making and, to some extent, it allowed them to have control over when they thought it was 'time' to see a doctor. This is reminiscent of Parsons' (1951) notion of the 'good' fussfree 'patient' Patient. This period of purposeful waiting was integral to participants' sense of hope as it acted as the symbolic and temporal bridge between living everyday lives and beginning the process of waiting to find out what was wrong.

The decision to end the period of 'waiting and seeing' emerged when symptoms began to impact on daily activities:

[I] found taking notes or typing things up on the computer or whatever – this numbness in my right hand was beginning to cause a problem so I went and saw my GP. (Alex)

When waiting became problematic and the experience of corporeal uncertainty emerged, participants then saw it necessary to seek medical advice. Our participants took the decision to participate in a process of waiting of a different sort. For most, the period of 'waiting and seeing' lasted for around three months, while for others it took up to 12 months before going to see a doctor. Choosing to wait offered possibility, it offered the possibility that there was no ill health. This period of waiting had the potential to be temporary, a benign period of wasted time with no truly negative

outcome.

Emotions as agentic practice

Waiting can also be seen as the purposeful act of hoping; as Sutton et al. (2011) wrote, waiting is more than the passing of chronological time, it is a subjective, personal and emotional experience linked critically to hope.

Deciding it was time to see a doctor propelled participants into a more protracted experience of waiting, one which removed agency and control from them. The period of waiting was no longer founded on potential for a benign outcome but increasingly became more distressing as waiting continued, time became stretched and waiting became 'raw'. However this period of enforced waiting, whilst not within participants' control, was still one in which participants could hope, and as Sutton et al. (2011: 31) note that 'it is hope that makes the powerless persevere'. Whilst participants were initially waiting to hear back from their doctors, they were hopeful that through seeing the doctor they would find out nothing was wrong:

K: So, I was saying to my friend. . . I said "I hope I don't have some kind of muscle wasting disease here . . .". God, you know how you just say things? And I never meant it for a minute by the way. Anyway, so I had to go back in a fortnight and then I had these little tiny twitches in my thighs. Twitch twitch . . . you know like your muscle's just kind of twitch twitch. I went back down two weeks later to get the results of the x-ray and the blood test, and she said to me "Well, everything is clear."

JF: That was your GP?

K: My GP. "Everything's clear: your blood tests are clear and your x-rays are clear." I said "Oh, that's great because I was beginning to get a wee bit worried." Kay

This impasse whereupon results were initially good reconfigured the process of waiting into one that was both useful and productive. This was the case for a number of participants who began their long journey to MND diagnosis with reassurance that nothing was wrong. Participants also discussed their doctors' hopes that symptoms of MND could be attributed to more benign forms of illness or condition. Hoping was a co-constructed and inter-subjectively experienced event (Van Gennep, 1960) in which participants still hoped to emerge from the experience without MND but were, simultaneously, no longer a person without MND.

And she put me through a number of tests and then they reckoned that they might need to . . . it might be an allergy . . . So, I had an allergy test – with all this pain in my back and she came back to phone me one evening to say "I may have good news – you may have an allergy – Cinnamon and E121 and . . . that might be causing this problem" and as I later on discovered that she didn't really believe that – it was a . . . a hope. Simon

The temporal space imposed by waiting is filled here by emotion in stark contrast to Fujita's (2002) example of waiting for the kettle to boil. The flood of emotion counters the notion that waiting is passive, or idle.

Temporalities were multiple and layered at these points and crucially in conflict with one another. A week spent waiting for allergy test results or for 'sprained ankles' to rectify was seen as 'reasonable' similarly the potential that symptoms may be age-related sat nicely with normative and everyday understandings of the progression of the life course and 'natural' effects of ageing. Whilst participants engaged in waiting and the process of time-stilling (Anderson, 2004), their condition was progressing and for some people symptoms were emerging weekly. However, as progression

continued then waiting a month or two began to be conceptualised as 'wasted time'. Time spent finding out what was wrong shifted from a fairly leisurely process of discovery to a much more hurried and worried search for an explanation. While one mode of waiting ended another emerged. Emotion triggered an ebb and flow of activities, hopefulness permitted patient waiting and anxiety punctuated and characterised endurance.

'Raw waiting' as endurance

As the diagnostic process continued participants began to feel that time was being wasted and that they were being made to wait too long to find out what was wrong; they simultaneously felt that this was because their symptom development was not being taken seriously and began to feel a sense of powerlessness:

But we had to push and push to get appointments and to get diagnosed because it was just waiting a couple of months and waiting a couple of months and it was too much of a worry, too much of a pressure. So, we just kept phoning up their secretaries and everything. Just push, push, push to get the tests and get the results. (Charlotte, whose husband Tom had MND)

The shift from waiting and seeing and waiting with hope to waiting without choice or knowledge was distressing for participants. As this process seemed to increasingly stretch and protract time, potential for hope simultaneously began to diminish. The process of waiting for a diagnosis, waiting to conduct tests and receive test results had a far-reaching impact on the person with symptoms and their families. Participants described the frustration and distress that their family members were going through as periods of waiting stretched. Crucially participants began to feel that doctors were deliberately delaying the process of diagnosis:

So, I came off the phone and I thought, "My God, if I have to wait another 5/6 months – I don't think I will be able to walk by that time". . . My family and my daughter and that – they are cracking up. So I thought about it and I thought "see to tell you the truth – I don't think that I could wait six months. I'm starting to get a bit panicky now." (Marie)

As Marie shows, not only did extensive delays in waiting to hear back from doctors produce distress for her and her family, it evidences multiplicities of temporal experience as MND continues to progress all the while. Diagnosis is slowed and delayed while MND progresses and the body deteriorates. Participants discussed the difficulty in trying to end the period of waiting by making appointments with their consultants. Challenging enforced waiting required the energy to fight for access:

"Well, my husband was supposed to be seeing them in three months and this is now six months . . ." and [the hospital receptionist] said "Well, the next appointment is in a year." And I thought "Well, that's not good enough. He could be dead in a year." So, she phoned me back (this was the Friday) . . . oh she said "I can get you a private appointment with [the consultant] on Monday morning but it will cost you . . ." (I can't remember how much – stupid money) and I said "Well, that's not good enough. My husband was supposed to have been seen three months ago at that doctor's request. He could be dead in a year and I don't see why we should be in this position . . ." and she phoned me back . . . she then said "Well, I'll phone back to the hospital." And she called me back and she said "Right, you can see [the consultant] on Monday and there is no charge." (Kate, on behalf of her husband Phillip)

Kate and Philip's example allows us to explore the relationship between waiting and power. Enforced waiting or being made to wait illustrates the

structural constraints and complex relations of power manifested in the relationship between those that have the power to enforce waiting and those who endure it. As Sutton et al. (2011) describe, phrases such as 'you snooze, you lose' illustrate these normative temporal frameworks in modernity. Those with the power to end, limit or avoid waiting – do. However within the context of MND and medical institutional structures, for both the patient and doctor, this is not always possible. In some cases, consultants may have the power to end waiting for an appointment and in the case of Kate and her husband Phillip – didn't until directly challenged. Power is associated with speed and efficiency and powerlessness with being made to wait; in this example the participants' powerlessness in the face of a degenerative condition was furthered as it was suggested that the only way that their waiting would end was if they sought private healthcare at a cost. Thus not waiting or a refusal to wait might also necessitate wealth or financial resources. In Kate and Phillip's example the result of having to wait the extra year for a consultation potentially meant that Phillip would not be alive by that point in time. Participants' feelings about waiting and the prospect of time running out as the reality of a negative outcome comes to the fore is in tension with the fact that medical professionals are constrained by the need to provide accurate diagnoses which also take time, resources and planning. At the centre of this tension is the interplay between various agents' experiences of time in conflict within the context of a gaining an accurate and efficient diagnosis.

The experience of enforced waiting for a diagnosis also delayed advice about how to deal with symptoms.

I'd asked [the neurological consultant] when he still thought it wasn't MND, "What should I do? Exercise?" He told me that until we had a clear diagnosis that we should just carry on as normal but now I've wasted a year. (Sharon)

Sharon was looking for ways to alleviate or ameliorate symptoms of MND in the meantime in order to make her period of waiting more bearable, as something that she could assert control over. However she was encouraged to wait, by her consultant, 'as normal' without trying to improve her symptoms in the waiting period. As such she felt that the time waiting was 'time wasted' because it was unproductive and that she passive and unable to assert her agency in waiting.

The effect of this process of diagnosis created a sense of dread for participants as ongoing tests returned negative results and the balance tipped increasingly from hope to despair. After long periods of waiting, for some up to two years, participants received their diagnoses of MND. However, for some the delivery of diagnosis was delayed because their consultants demonstrated distress at having to give a diagnosis of a terminal condition and so rescinded the diagnosis of MND:

M: So, it was a morning appointment so by about two o'clock Claire had got herself in a state worrying about me so she phoned him back . . . So, she said "I am going to phone him up and see what he said to you"

JF: Oh, so she wasn't with you?

M: Oh yes she was with me but she wasn't with me in the room when I was being assessed . . . She was in the waiting room you see . . . So, he got quite upset, the [Consultant], to be fair to him . . . he said "Tell [Mike] not to worry – it is probably not Motor Neurone . . . in fact, I am 90% sure that it is trapped nerves . . ." (Mike)

Mike waited another six months to get a definitive diagnosis of MND: time was stretched even further as a diagnosis was withdrawn. The consultant offered Mike false hope. This suggests that the consultant may have

believed that this period of waiting and hoping was a more desirable state to be in than accepting a diagnosis of MND. Either the consultant was themselves still hopeful and in the 'wait and see' phase, or they needed to take time to be absolutely sure of their diagnosis, or were not always sensitive to the effects of 'raw waiting'. Insensitivity to the endurance experienced by patients may have been unintentional on the consultant's part, but it was nevertheless felt as a destructive force. While MND itself enforced a process of waiting out of doctors' control, structural issues around delayed appointments and poor communication could have minimised periods of distress and of 'raw waiting'.

Waiting and social worth: Social services

The post-diagnosis period saw another shift in how temporality was understood. While the pre-diagnosis period of waiting was focused on gaining a diagnosis, waiting to find out what was wrong through waiting by choice and enforced waiting, the post-diagnostic period saw 'time left' (to live) as incredibly precious (Abbott and Carpenter, 2014). Not only was this time spent trying to reconstruct a sense of self and identity as a person, now with MND, but with diagnosis came the ability to initiate access to services (both care and social) that mediated and managed the 'time left'; participants now had to negotiate MND with a new set of social structures. This final section examines the experience of waiting for social care and services.

From our analysis of the diagnostic process we saw participants employ a 'patience as a virtue' strategy, called upon to challenge rising anxieties and fears as muscle weakness persisted. As symptoms progressed and the home became more inaccessible, the families we spoke to became constrained by the inadequacies of their physical spaces affecting their wellbeing. Professionals like social workers and occupational therapists (OT) became instrumental in aiding participants in this period post-diagnosis providing home adaptations, mobility aids and other equipment. As with diagnosis, participants started off patiently waiting for support, and then endured the absence of action: again waiting became 'raw' (Sutton et al., 2011). Critically, waiting was experienced differently as time post-diagnosis became precious, pressured and finite. Participants and their families were acutely aware of the value of the time left for them:

You know we had thirteen different [professionals] in the house one Friday morning, and I just thought you know . . . time is precious and you need to have time together without all these people.
(Maggie, whose husband Derek had MND)

Linked to this idea of the finitude of time, Kay discussed how time was eroded by waiting for support, and how this impacted on well-being.

Well, they've never ever, never have I phoned and they have phoned back. I can guarantee you that I would need to phone again. So, [the OT] never phoned back of course so the next day, phones again "Oh, she'll be in at lunch time." So I phone back and I phoned back and said "Oh, it's Mrs Campbell, I was just wondering about the stuff you were going to get and nothing has arrived." "Eh, what was it again?" Kay

Kay was not only made to wait for the necessary equipment but she was dismissed or ignored. This kind of perceived banal bureaucratic waiting, in the context of having MND, had detrimental affects on her self-esteem and sense of social value and worth. Further, her corporeal decline was not taken into consideration:

K: Any approaches have come from us to them. She [OT] has never phoned me and said "How are you now? Will I come up and see if there is any other thing

that you are needing?"

JF: So, how long ago was the assessment when she came in here?

K: Oh, last year.

JF: So, everything [in relation to mobility] has changed since then.

K: She's never been back. Absolutely.

Kay

Firstly, Kay becomes exasperated with waiting on top of dealing with muscle weakness. Secondly waiting for resolution became redundant as her body and needs changed. There is a degree of constraint (of time and of money) on OTs to respond urgently to all requests. Waiting is a structural issue as average waiting times come into conflict with the temporal dimensions of MND. OT structures were more suited to static conditions and failed to respond to MND's constant progression. The impact of waiting made Kay, and others feel powerless as their homes became inaccessible. The energy exerted to manage these periods of waiting not only led to feelings of diminished social value and power, in turn, more energy was required to challenge having to wait.

Paul and Rachael fell into a funding gap. The family was considered low priority or non-'emergencies' (Zerubavel, 1987). When a local authority considers major adaptations to a home, they impose a five-year rule on the property to ensure their investment is fully utilised. The five-year rule pertains to the receiver of the adaptation to remain in their home for five years in order for the adaptation to be justified. The five-year rule could be enacted in different ways, one way is to prevent people from moving out of their property into another property that then needs a similar level of adaptation (and another investment) but has been interpreted to mean that the person who requires the adaptation must make five years use of it, and if the person has a terminal illness where end of life may occur before this five years then they may become exempt:

When [Rachel] was first diagnosed . . . em . . . it wasn't good at all. We had a terrible run in with . . . we had wanted a stair lift fitted and they wouldn't do it. Despite being approached by the MSP and everything, they wouldn't do it . . . eh . . .

JF: And what reason did they give?

They didn't think basically . . . and again this 5 year thing came into the equation . . . to cut a long story short they basically didn't think they would get their money's worth out of it.

(Paul, whose wife Rachel had MND)

The old adage that 'time is money' has particular salience in this example (Schweizer, 2008). The fact that adapting Rachel and Paul's home was not seen as 'worth the money' because the family wouldn't get enough use out of it evidences the moral worth placed on time and use/productivity. Not only were they made to wait but they were denied what they needed because their time left was not seen as worth the economic investment. Being made to wait for an accessible bathroom again exacerbated this powerlessness and feelings of low value:

We had to fight, fight for a wet floor shower room to the extent of "Well, you're not entitled" Based on what? I had people say to my face about that. I've also had people say to my face "Well, he's not got cancer so we've not got all of these things in place. I actually said to them, "So you're actually grading life limiting illness now are you?" I said that to them and there was silence. (Nadine, whose brother Laurence had MND)

Both Nadine and Paul argued that they had no power. Accessing their home, and access to hygiene and comfort was not seen as sufficiently worth the investment of social services. Despite receiving a diagnosis of MND, this did not automatically legitimate participants. The diagnosis didn't make them eligible for support without significant difficulty and

once again enforced 'raw waiting' (Sutton et al., 2011). The barriers imposed by professionals' conduct, and bureaucracy, impacted on quality of life left.

Discussion and conclusion

This paper has outlined the multiple modalities and scales of waiting for people with MND. Further, it has sought to examine the ambivalence placed upon 'waiting' and to challenge the passivity ascribed to it. It has critically challenged the notion that waiting is 'dead time', or unproductive time experienced universally. As outlined in this paper, waiting is a universal experience in the sense that everybody waits and the experiences of that waiting are varied and multiple. While not useful to hierarchise scales of waiting, it is important to unpack what waiting means and how it is experienced in different social and corporeal contexts.

Waiting with MND was found to be a distinct and unique experience due to multiple modes of waiting. Like most chronic and terminal illness, MND upset normative assumptions about chronological time in relation to the life course. The temporal nature and progression of the condition itself along with the structural implications of diagnostic delay produces a sort of waiting that challenges the 'modern' preoccupation of waiting as ambivalent or banal. Time stilled and stretched in the face of protracted periods of waiting for a diagnosis in contrast to the rapid, unwitting and disabling progression of symptoms.

This study found that choice played a key role in how waiting was endured and managed. Waiting was initially entered into by choice by the participants. The mode of waiting was understood as 'waiting and seeing' that resulted in hopefulness and potential for a benign outcome. This period was also a period of patience as participants wanted to be seen to be 'good patients' willing to wait.

The often rapid and ongoing progression of symptoms unsettling daily life and events initiated a different sort of waiting – one of endurance. This came into conflict with structural delays imposed upon them by GPs, Consultants and, latterly, social services. Managing waiting was also the exercise of managing anxiety, fear and distress as well as the reality of corporeal degeneration. The production of intense emotion and powerlessness rendered these protracted periods of endured waiting as anything but ambivalent or passive. Doctors' decisions to protract periods of testing without informing participants as to why, and decisions to rescind diagnoses left participants feeling of less social value and worth, of lower status than those who could enforce waiting – waiting became demeaning (Comfort, 2008). Such experiences of powerlessness and being a low priority were echoed post-diagnosis, a period where participants should have been seen as 'legitimate' yet their 'eligibility' was still questioned by social care professionals. Despite time now being prognosed as finite, waiting was still enforced, and endured by participants.

The people with MND who participated experienced different modalities of waiting depending on what was waited for. MND in itself was found to produce powerlessness and distress as it progressed week-by-week, month-by-month however, critically endured raw waiting could have been minimised by less protracted journeys to diagnosis and by appropriate measures taken by social and care services.

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