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The Psycho-Social Impact of Impairments: The Case of Motor Neurone Disease

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Introduction

There is currently a great deal of debate within both disability studies and medical sociology with regard to what Carol Thomas (2012) has termed *The Disability Question*. At the heart of this question is whether the emphasis of research on disability should be placed on the impact that a particular impairment has on an individual, which Thomas has termed “impairment effects”, or on how societal organisation and cultural values act to exclude people with an impairment, which Thomas and others have termed “disablism”. Medical sociology has traditionally been dominated by the former, whilst in disability studies attention has been placed on the latter. More recently in disability studies, the emerging Critical Disability Studies approach has added a third element to this debate with a focus on the discourses that surround impairment and the cultural values that reproduce these discourses. Here the emphasis is placed on critiquing how these affect people with impairment, a concept that is also known as “ableism” (Goodley 2012; Chouinard 1997).

In this chapter, we use data drawn from a project on living with Motor Neurone Disease (MND) funded by Motor Neurone Disease Scotland to explore the relative merits of these approaches and examine their applicability to an impairment group that straddles the boundaries of chronic illness, terminal illness and impairment. The aim of our study was to document the experiences and perceptions of people with MND and their partners about what it was like living with the condition. We sought to explore what they thought was important in their day to day life, including the management of the symptoms associated with MND and their temporal nature, the services they received and the service providers. We also wanted to investigate how

people felt that having the condition changed their social relationships with family, peers and professionals, and on their ability to participate in the mainstream.

To date there has been little research from within disability studies on people with MND or on the experiences of those with degenerative disabilities and terminal conditions in general (Scambler 2005, 2011). From medical sociology, Simon Williams has argued that disability studies has simplified the disability problem to such an extent that it only applied to those without a chronic illness and that it has ignored the needs of those with chronic and or progressive conditions (Williams, 1999, 812). With chronic or progressive conditions, people's needs, their experiences and their perceptions may be different to those with a so-called static condition, and if disability studies is to attempt to include all disabled people then this knowledge gap needs to be filled.

Thomas has attempted to answer her own query, and to meet these critiques from medical sociology, by developing a two-pronged solution to the disability question through modifying the social model of disability into what she terms the social relational model of disability (1999, 2007). Disability is, she argues:

... a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being. (Thomas, 1999: 3)

Further she suggests that some disability theorists have misread the original UPIAS definition which stated that disability was something imposed "on top of impairments" and makes the case that some of the restrictions experienced by people with an impairment are not social in origin. These restrictions are not disabilities but are the result of what she calls "impairment effects", which she defines as non-socially imposed restrictions. Thomas accepts that impairments are not irrelevant and that their effects combine with disablement. She concludes that disability research must engage with both (1999; p137).

Alongside this, Thomas has called for an exploration of what she terms the psycho-emotional dimensions of disability, by which she means the consequence of living

with an impairment in a society that does not easily accommodate people who are different, or who have different needs. If the social model is about the oppression people face on the outside (attitudes and physical barriers), the psycho-emotional dimension refers to oppression on the inside. As Thomas says:

‘... it is about being made to feel of lesser value, worthless, unattractive, or disgusting as well it about ‘outside’ matters such as being turned down for a job because one is ‘disabled’ (Thomas, 2004: 38)

Thomas theorises that this form of oppression, because it becomes internalised, affects what people can be, who they believe they are, and so affects what they can do. Donna Reeve (2012) has further developed this concept, which she sees as being triggered by stigma and latent oppression in society. Psycho-emotional disablism is both absorbed from outside and is learned through a loss of opportunities, experiences (such as being stared at) or the absence of experience, for example not getting a job or being prevented from forming a relationship.

Thomas argues that to answer the disability question we need an approach that allows for the incorporation of both a sociology of impairment and impairment effect, and a sociology of disablement, to use her distinction. She argues that this will enable the development of an understanding of both the social oppression experienced by people with an impairment, and the embodied experience of living with an impairment. Both ideas developed from within medical sociology as well as those from disability studies are needed.

In this chapter we critically reflect on the ideas of Thomas, Reeves and others concerning the concept of impairment effects and psycho-emotional disablism, and argue that whilst these writers have explored how disablism has produced psycho emotional impacts, they have failed to explore how impairment itself can have a similar effect, disabling people in private spaces and in their private lives. MND is a very brutal and severe condition, and the lived reality of its impact on those with the disease and their families cannot be explained without a full engagement with the condition. We begin with a brief description of the condition and then move on to discuss how medical sociology has examined MND.

Motor Neurone Disease

Describing the symptoms associated with a condition and discussing how these symptoms affect individuals is something that is not usually 'done' in disability studies, particularly in the UK where the body has disappeared from much theoretical work. With some exceptions (for example Shakespeare et al 2009), the visceral experience of impairments, of what it is actually like to live with an impaired body is generally bracketed in favour of structural factors. Even in approaches from within critical disability studies which claim to focus on embodiment lived experience is absent with emphasis instead is on the cultural production of the disabled body (Vehmas and Watson 2014). However, such approaches only give partial accounts of what it is like to be a disabled person or to live with a chronic condition (Shakespeare and Watson 2010).

MND, sometimes called Amyotrophic Lateral Sclerosis (ALS) is a term applied to cover a range of different neurodegenerative syndromes all of which share a common neuropathology, in particular the progressive degeneration of motor neurones. It is a progressive, terminal condition that in the UK affects approximately 1 in 50,000 people: at any one time there are roughly 3,000 people with the condition (Forbes et al 2007). Incidence increases sharply as people age, reaching a peak in the seventh decade, although the incidence in the very elderly is uncertain and it is less common in people under 50 (Ibid). Although the condition is very rare, the impact it has on the population is much larger with one report suggesting that for every person affected by MND another 14 close family or friends are affected (MND Association of Victoria, 2008).

MND affects motor neurones which undergo progressive degeneration and die. There are four common forms of onset:

- Primary Lateral Sclerosis (PLS),
- Progressive Muscular Atrophy (PMA)
- Amyotrophic Lateral Sclerosis (ALS)
- Bulbar Palsy

The symptoms people experience vary according to the mode of onset. Bulbar onset affects breathing and eating whilst PLS, PMA and ALS predominantly affect the upper and lower limbs and walking and movement, termed spinal onset. Most people experience a combination of both spinal and bulbar symptoms.

MND initially causes motor weakness, often beginning with fairly minor symptoms like a drop foot (increasing the risk of tripping) or slurred speech. New symptoms emerge every few weeks or months, and the physical decline in some cases can be very rapid. Normally, within a matter of months of diagnosis adults with MND experience extensive motor weakness across their whole body to the extent that they can no longer turn in bed, cough, breath, eat, talk, walk or hold themselves upright in a chair. In addition to the soreness associated with not being able to move position, muscle spasms can cause sharp pain. It is consequently a very distressing condition, although there is a great deal of variety, both in the symptoms people experience and in the speed of progression. The historian Tony Judt (2011: 15) described his own experience of the condition as "progressive imprisonment without parole". MND can also affect cognitive skills and mental health, although there is some debate as to whether this is a consequence of the use of oxygen to ease breathing difficulties and the drugs to fight spasms and pain, which can leave individuals in an 'altered state', or the condition itself.

Death usually results from respiratory failure, and generally occurs within 18 months of diagnosis. Although the disease has a quick progression, many people with MND are not given a prognosis at diagnosis. Some people do not survive 6 months after diagnosis, while others can survive for up to 5 years.

The Sociology of MND

While disability studies has to a large extent ignored conditions such as MND, the same is also to an extent true of medical sociology. Much of the previous research on MND has focused on the medical aspects associated with the condition, such as how the disease progresses and how the disease can best be managed. In their recently published systematic review of qualitative research with people with MND, Sakellariou et al (2013) emphasized that we only have limited knowledge of how people live their lives with MND. However, there have been a few studies which

have sought to explore how MND is experienced from the perspective of those with the condition and their family and carers. A series of relatively small scale studies in England by Brown (2003), Hugel et al (2006), Hughes et al (2005) and Brown et al (2008) have documented the lived experience of those with MND and the care and support that those with the condition and their carers receive.

All of these studies describe the emotional trauma associated with MND and how living with the condition produces uncertainty. As a consequence, people prefer to live in the “here and now” rather than think about the future (Sakellariou et al 2013). Brown (2003) documents what she calls the ‘existential shock’ of the diagnosis and the impact that has on both those with MND and on their families and their friends. Hughes et al (2005) comment on how the rapid physical deterioration associated with the condition affects the emotional and physical well-being of both the individual with the condition and their family and how these two combine and make coping with the condition very difficult. As the condition progresses people start to lose touch with their friends and stop their usual social activities (Brott et al 2007). However there is evidence to suggest that people with MND continue to want to be in control of their lives and to be involved in decisions about their care and support and about their opportunities (King et al 2009). People want to be enabled to be in charge and to maintain their sense of self and self-identity.

Problems in the delivery of care and support are also often highlighted. In the UK the shift to primary care as the main deliverer of support, whilst welcome in some areas, can create difficulty for people with MND. For example, although General Practitioners (GPs) will invariably be involved in the care of MND patients, often they have little or no prior experience of working with people with MND and may lack adequate knowledge of this rare condition (Oppenheimer 1993, Robinson & Hunter 1998, Van Teijlingen et al 2001, Brown et al, 2005). A general practice with 10,000 patients is likely only to encounter a case of MND every two to three years (Shaw 1999) and an individual GP can expect to see one patient in their career (Levy 2000). The provision of good care and support is critical during the early and late stages of the condition (Sakellariou et al 2013).

Methods

The data presented here are drawn from a three year project that aimed to assess what it was like to live with MND in Scotland. We adopted a two pronged approach, running a series of focus groups with those who had recently cared for a partner, parent or other who had died. We spoke to 22 people in this stage of the study, the purpose of which was to sensitise us to the key issues faced by those with MND and their families. In the second stage of the study we interviewed people from across Scotland with the condition. In all we recruited 43 people to act as our key informants (around 400 people live with MND in Scotland currently so this is a sizeable proportion). We interviewed each key informant and their family members up to 4 times over the course of the study. By adopting this longitudinal approach to the research, we were able to document how their views and experiences changed over time. According to our extensive review of the literature, this longitudinal strategy has not previously been used to explore the impact of MND on people and their families. Ours was also the largest study in terms of the number of voices heard that we can find globally.

All those we spoke to were interviewed in their own homes, and we documented their experiences as the disease progressed. Most of the interviews were joint interviews with their husband, wife or (adult) child, and in a number of cases where the participant had little or no spoken communication the partner answered most of the questions. However, we were careful to ensure that the person with MND was included in the interview and all questions were directed to him or her. Some participants communicated through pen and paper or used equipment such as a light reader. No one was excluded because they faced barriers to communication: interviews just took longer to accommodate their needs. All interviews were taped and transcribed. The informants and their family members were active participants in the research process shaping both the content and the direction of the research as they identified practices, events and processes that were important to them.

The interviews were analysed using standard qualitative methods and an inductive comparative analysis of the data was carried out (Silverman, 2010). The transcripts were read and coded and themes and topics of particular importance to individual participants were identified. The categories evolved as more and more transcripts were analysed. By using this coding system we were able to identify patterns,

breaking the data down into manageable units and regrouping this data as emergent themes (Atkinson, 1992). We now turn to a discussion of these themes.

Living with Motor Neurone Disease

Impairment effects

The effect of MND, and how its intersection with and affect on day to day life, was the most common theme running through all of the interviews and was the single most important issue for all those we spoke to. One of the most difficult aspects, and the most commonly discussed topic for people with MND and their families, was the fast progression and rapid decline that was often associated with the condition. This, coupled with a lack of prognosis, unsettled individuals and generated a sense of the future being uncertain. This often meant that many people were unable to move beyond their impairment, it overwhelmed everything, all they did and all they were.

Several participants described how unpredictable their life had become, and how in the absence of a timeline or a prognosis they could not anticipate what would happen to them, or plan for the future. Despite not being given a prediction of how their condition would progress by medical practitioners, and also being advised by them and by other health and social care workers not to seek out alternative information, many had gone to websites, used web-based discussion groups or had accessed other sources of information: all were aware of the approximate eighteen month average life expectancy post diagnosis that is commonly quoted. Imminent and inevitable death was for many the only certainty: uncertainty was confined to the speed of progression and the pattern of decline. The uncertainty associated with the condition, coupled with its rapid progression and the fact that it is terminal, left many people feeling abandoned. There was no time for people to ‘get used’ to this information and to undergo what Williams (1984) terms ‘narrative reconstruction’. So one family member told us,

‘and she helped me fill in the form [for Disability Living Allowance] and [the Finance Advisor] said ... “I’m not asking you to lie, but I’m asking you to fill

in the form for the worst case scenario”, and like three months later it *was* the worst case scenario.’

(Jenny, talking about her mother Kate).

The fast progression prevented people being able to assimilate and normalise their impairment and to create a new identity: people had no time to get ‘used’ to living with an impairment and its consequences. In this way the body was more significant than social barriers.

The limitations resulting from MND often made it impossible for people to carry out what previously had been key activities or identifiers in their lives:

‘He had been a wood carver and had painted and he was just giving it all up. And I would ask “Why are you not doing it?” and he would say “Because I can’t hold things”’

(Grace, talking about her husband Ron).

It was not just Ron’s inability to carry out a practised task, but the inability to perform at his normal level and to produce quality craftsmanship that caused him to stop working with wood. Similarly Patsy, a knitter and wool spinner, had stopped knitting as she became more aware of her failing skill and speed, and was no longer able to operate at the level she had previously.

This reaction was not just confined to tasks, it affected whole swathes of people’s lives, with many giving up activities that had once defined them. For example, Rachel talked about the loss of anticipation:

‘You know there are things that you are never going to do again that you miss... I mean sometimes you are watching the television and a nice programme is on and somebody is there and they are down the beach? And they’re walking in the water, and I think “I’ll never do that again...” “I’ll never swim in the sea again...” There’s all that... You know? People going out for a walk? We used to love going for walk when we were on holiday we just used to walk – never do that again, it’ll never happen. That’s what I’m

saying, there's all that... Everything is tainted by it, every single aspect of your life is tainted by this disease – no' just the mobility, everything of it, everything about it. God forgive me, I say to Rick “See if I had cancer? At least I'd be able to get about...”

(Rachel).

The terminal nature of MND was also central to this. For example, a number of people commented on the futility of hope, or of maintaining a positive attitude, or of fighting the progression of the condition. This hopelessness was also highlighted by Rachel, who said:

‘There's always an element of hope with cancer you know, for us, it's nothing’

(Rachel).

Challenging impairment effects

A minority of our respondents took a different perspective and were more able to live a life beyond their impairment effects. For people in this group, their very extensive levels of impairment did not appear to overwhelm them in the same way as others. This was achieved in a number of ways. For some, the only way to face the challenges presented by living with MND was to avoid any discussion of the condition at all and to bracket the impairment and its effects:

‘... her approach was, right from the very first day after she was diagnosed, was to just get on with life and not go over it or to even talk about it to me. She just simply blanked it out. That was her way of dealing with it’

(Brian, talking about his wife Eilidh)

Some people railed against their impairment effects and tried to continue as they had done previously:

‘... you know when your fingers go ... he couldn't fasten buttons and he would say “No! I'll do it myself.” He would get on with it and even if it took him 10-15 minutes, he would be determined.’

(Vicky, talking about her husband Cameron).

The refusal to talk about the condition featured in many narratives. Whilst it was a way of managing life with MND, it was also a way of people ensuring that who they were did not become lost, so that they could maintain their identity and their social role:

‘I’d like to talk to someone to ball my eyes out or whatever, but I can’t ask for it. So I never talk about it. I’d never say, that’s my arms going or you know my hands are getting weaker ... because you’re always on the verge of tears, it sits there all the time. Who wants to know it’s getting worse? I can’t let [family] see me upset, they can’t see it get to me. Because I’m the Mammy, they feed off me’

(Emma).

From these quotes, it may be argued that the participants were under some social pressure to minimise the impairment effects, even if it was self-imposed. This avoidance of support sometimes extended to a rejection of some assistive technologies. Many described the presence of equipment like hoists, hospital beds, reclining chairs, commodes and so on as an intrusion into their lives, and actively resisted the use of equipment or adaptations that they felt interfered with their independence. Some rejected equipment designed to extend life because it took away an element of control:

‘He was trying to get used to his breathing machine, Craig was thinking I have to breathe when I want to breathe. Not when it tells me to breathe.’

(Julie, talking about her husband Craig).

Many people used comedy, and a very dark humour to deny the inevitability of MND.

‘... and I suppose one final laugh, well we probably shouldn’t laugh at it but last year at Christmas time we knew it was a matter of days, Kate’s ... um ... brother bought her a calendar for 2010 as a Christmas present which was

extremely ill advised but we could see the funny side of it ... [Kate said]
“what the hell do you think we are going to do with that? “
(Calum, talking about his mother-in-law Kate).

In other cases, humour was used to show how relationships were still central. For example, two people we interviewed used an electronic speech board to communicate, and in both cases their teenage children had switched off their parent’s machine when they were getting told off or were being asked about homework. In telling these stories, the parents found great humour and pointed to the normality of their relationship with their respective 13 year old children. But we argue that maintaining this normalcy was at the cost of acknowledging the corporeal experience.

Disablement and disablism

As discussed, social model theory has helped the concept of disablism to emerge as social barriers are highlighted. Within our research, examples of direct disablism were rare. This may be both because many of the informants were older and that very rapidly their level of impairment meant they were unable to access the mainstream, and thus simply did not experience barriers. Where people did access the mainstream, it appears that they tended to modify their lives and only to go to accessible environments: disablism may have shaped their choices, but they did not talk about this. For example people went to different restaurants than they may have done previously, or they changed their normal shopping habits, which may explain why we did not hear very many stories about access issues. Also, many had already retired or were in their final years at work, and only a few participants talked either about a desire to be in work, or complained about being forced to retire. Some even commented about how understanding their employer had been, and how they or their partner had received more than the minimum entitlement to sick pay. This is not to say that disablism was absent, or that it did not effect people’s wellbeing, as we discuss below.

However, disablism was encountered in other areas, coming to the fore particularly around access to support services, for example around the entitlement to live as part of a couple. In one case, we were told how a couple had to fight for their right to an

accessible route into their first floor flat, and how for a period the husband had to give his wife fireman's lifts in order to get home:

Martin: 'When [Joanne] 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...'

Jo: 'And what reason did they give?'

Martin: '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.'

Many couples were required to move from their first floor bedrooms to smaller, often single occupancy downstairs rooms because local authorities preferred to build wet rooms than to provide stair lifts. Others talked about the issue of shared beds, and the difficulties they had in getting funding from the local authority to buy a double bed that would meet their needs. Some Scottish local authorities apply a five year rule to the provision of adaptations, only funding work if they believe that the benefits will last for more than five years. This ruling discriminates against anyone diagnosed with MND, and several people reported being turned down because they were considered an 'invalid use of budgets'.

'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, talking about her brother Laurence).

The provision of appropriate and accessible toilets was also a major concern.. Whilst these policies are clearly unjust, they could, as Bury(2010; 175) has argued, be driven by a desire to control the financial implications of managing health problems in the community, rather than arising from disablism. Nevertheless and whatever its origin

this denial of service clearly had effects on their psycho-emotional well-being but these were perhaps more indirect than direct (Reeves 2012). It is to a discussion of psycho-emotional disablism that this chapter now turns.

MND and psycho-emotional dimensions

People with MND and their families faced a wide range of psycho-emotional disablism and its effect and potential to harm was considerably more detrimental and disruptive to the lives of those with MND than direct disablism. In the rare occasions where people described such disablism, it was the potential ‘embarrassment’ that people commented on rather than the denial of the actual opportunity:

‘I did go to another restaurant between Christmas and New Year with a group of friends but I forgot that there was three steps going up to it. And whilst there is a hand rail, the hand rail stops short... So, I got up the first two steps ok and then I had to get the other boys to give me a hand up the third step which was... it was quite embarrassing you know. I am still at the stage... I mean, I know that it is daft a lot of the times but I do still... I don’t know how to say this – I am still quite self-conscious about... eh... being able to do things and being self sufficient basically.’

(Andrew).

Whilst the cause of this discrimination is structural in origin it is not the actual discriminatory act (the absence of a full handrail) that is the problem, it is the felt effect this has on his identity. As Thomas would put it (2007) it is more a barrier to being than a barrier to doing.

The impact of MND on interactions with others either on a formal or informal basis, particularly with non-family members, was a major concern for many of our informants. For some, the fear of meeting people and of their reaction to them was so overwhelming that they withdrew from almost all social contact. Rachel for example described how ‘embarrassed’ she felt when going out in public:

Rachel: ‘I fell embarrassed at neighbours seeing me. Embarrassed at friends seeing me. Crazy! Why should I? But I do.’

Jo: 'Because of their reaction to you?'

Rachel; 'No! they've been great, it's me. I'm embarrassed.'

Jo: 'But if it was them ...'

Rachel: 'I'd be there, with them! But the shoe is on my foot and I'm embarrassed to have this illness. I'd rather die tomorrow than have to deal with this. You have to mentally adjust all the time, it's too much.'

Rachel had stopped leaving the house because she did not want people to see her. Here, and in many other cases, the stigma that caused this disability was, to use Scambler's terms, 'felt' rather than 'enacted' (1986). Although many people used the term "stigma" to describe their position, few attributed this to any specific episode or to any particular action.

For many of our respondents, it was not the physical or the built environment that excluded people and nor was it the attitudes of others. It was more a fear of exposure or of being the centre of attention:

'... if some friends maybe come in and they're just sitting in the chair and maybe I have been in the living room and I make my way through... When I come in and I see them all looking like this... Do you know? And I want to say "Don't... Don't do that... You're making me feel... Don't look at the way I'm walking... I know I'm walking and I'm always getting worse but you're sitting and going like ... this is drawing attention to me..." I would never say to them, I would never say to them... But I do feel... and then I start to feel embarrassed... But all they're doing is... "Oh God, look at him walking..." That's what they are obviously thinking but to me I don't like them staring ... they're no' staring... But the looking and I get embarrassed about that...'

(Tim).

People felt that they stood out because of their impairment and became the centre of attention out of a fear that was driven in part by the different ways that they now needed to do activities. For example, people told us how they no longer ate out in restaurants because of the way that they had adapted their eating practices.

In the above examples, we have documented three elements of the disability experience as postulated by Thomas. There was for our informants a fourth element, which we have called psycho-emotional impairment effects: we have coined this term to explain aspects of living with MND which are distinct from either the effects of the impairment or the different experiences of disablement.

Psycho-emotional impairment effects

One of the most profound themes to emerge from our analysis of the data was about fear. Living with MND generated a level of fear that prevented many people from actually doing or being. This fear was represented in a range of ways. People were scared of the future; of how impaired the condition would actually make them; of how much they would suffer; and in particular, of how they would die. People were very aware that MND was a terminal condition with a poor prognosis, as Marie said:

And God forgive me I used to say to Stephen [husband] “Do you know Stephen it would be better if I had cancer...” and I know I don’t mean ... but there is always a certain element of, for people with cancer ... because there is treatments and there is this and there is that. It’s everywhere...

There was an almost universal fear of not being able to breath and suffocating. However this fear was not just confined to the end of life. Many participants talked about how MND affected their breathing and swallowing, expressing an acute fear about being unable to get a breath, being unable to cough, and being unable to stop choking. Such coughing or choking fits were common, and each time they occurred they reminded people of the terminal nature of their condition and the precarious nature of their existence. For example, for Betty the fear of choking became so real that it prevented her from doing anything, as her husband Robert told us:

‘and one of the strange feature of this was that we had to avoid any sort of emotional situations because physically, if Betty was to cry it would probably have choked her ... if she was to burst into tears it could’ve possibly have killed her ...’

Here there is an interplay between fear, impairment effects, psycho-emotional disablism and disability. All these combine to reinforce each other. Betty had to avoid emotionally exposing herself to the reality of her situation, to the experience of having MND because to be upset could trigger a choking fit severe enough to cause death.

Conclusion

In this conclusion we reflect on how these data and the analyses presented here can help in answering the disability question posited at the start of this chapter. For Thomas, disability is a socially constructed barrier to being which has a psycho-emotional element (2004; 43). The evidence from this study suggests that disability can be an impairment related barrier too, as the psycho-emotional dimensions of living with such limiting impairments create, in and of themselves, a barrier to being. Because of the severity of impairment, many participants lived in fear of the final stages of the condition: they feared being trapped, in pain, unable to move, unable to speak, choking for breath. This was worse than the idea of dying. For many of those we spoke to, living with MND became all embracing. As Brown and Addington-Hall describe, they were forced ‘to turn inward, to face death in an increasingly difficult day-to-day life’ (2008: 211). In the case of MND, it would appear separating out this fear, the cause of this fear, and the experience of this fear, and disaggregating it into one of Thomas’s three categories is impossible, as Shakespeare has argued in relation to MS (2013, 24). Scambler and Newton (2010;103) have argued that with some impairments the social oppression can become secondary to the biological effects of the condition.

Our participants understood their impairments stopped them ‘doing’. They also understood their impairments as a barrier to ‘being’, as they hid from society and stopped activities. Here they were not responding to ablism: they did not consider themselves inferior to other people and did not recount stories to suggest that others thought of them in this way, nor did they think that disabled people were inferior. But they did think they were inferior to themselves as they had been, to the preserved echo of an identity of someone pre-MND.

Thomas connects her ideas to a Social Relational Theory of disability which allows a bridge to be built between those ‘socially identified as impaired and those deemed non-impaired or ‘normal’’ (Thomas, 2004: 41). Here Thomas draws a hypothetical line between all people. In the case of MND, though, this line has to be drawn between the person’s history of life without impairment, their present life with impairment and their future lives of more severe impairment.

The progressive nature of MND and the severity of symptoms impacted on our respondents’ stories, meaning that the body could not be ignored or even conceptually sidelined. As a prognosis was lacking, so the body became the evidence base, the primary indicator of how much time was left. To paraphrase Charmaz (201;19) ‘The vicissitudes of MND can make meanings fragile, not only of illness but of self, situations and relationships’.

Our research shows that “barriers to being” are impacted directly by impairment effects, though the fear of social situations exacerbated this and further limited our participants’ desire to be in social spaces or situations. Impairments have a psycho-emotional impact. In addition to the challenge of progressing symptoms and facing end of life, many participants also spoke of there being an emotional element directly connected to the biomedical state of the body. The fear of choking for example caused distress which would not be captured by the notion of psycho-emotional disablism. It is difficult to entirely distinguish between the psycho-emotional impairment effects (triggered by the body) and psycho-emotional dimensions (triggered by disablism) (Watson 2012; Shakespeare 2014) Avoiding a scrutiny of the psycho-emotional impact of the physical, biological and psychological elements of their impairment brackets these experiences entirely from the gaze of disability studies.

What we are proposing is an additional element to Thomas’ original conceptualisation, one that incorporates the psycho-emotional effect of the impairment and a focus on limitations in private spaces (see figure 1). This will allow us to analyse the data more fully and to ensure that we produce a picture that will incorporate or include all of their lives. Potentially, it also supports the development of interventions that can help at all of these levels, including counselling. Sian Vasey (1992) in her defence of the social model argues that there is nothing that the disabled

people's movement can do for people in distress or in pain and that it is therefore not worth including these private areas of life. This enormously reduces the issues which the disability movement can mobilise around and disability studies explore.

Following Watson and Shakespeare (2002) and Shakespeare (2006), we argue that disability studies must re-visit the experience of impairment in order fully to represent the complexity and heterogeneity of the experience of disability. If we take this more extensive approach, pressure can then be placed on services to help people at this level. Without such help, many of those with long term chronic conditions will not be able to take part in society, no matter how accessible or welcoming that society is. Our approach is novel because we are articulating the importance of the psycho-emotional impacts of impairment, as a concept distinct from psycho-emotional disablism.

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