



Qualitative Analysis on the Impact of Fatigue on Individuals Diagnosed with Multiple Sclerosis

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ABSTRACT

The following research explores the impact of fatigue on Individuals diagnosed with Multiple Sclerosis; building on the research by Olsson et al (2003), but alternatively offers a comparative approach; incorporating both men and women rather than focusing solely on one gender. Existing literature frequently centres upon quantitative methodologies, focusing on prevalence rates and statistics; thus the research employs a qualitative methodology to gain a more in depth understanding of individual experiences of fatigue and Multiple Sclerosis. Six semi-structured, ethnographic interviews were conducted; subsequently being transcribed and analysed through use of a thematic analysis based on Braun and Clarke's (2006) principles. Three themes were uncovered: identity change, stigmatism and emotional consequences; with analysis showing the significant association between such themes and fatigue. These are supported with ample evidence, allowing a comprehensive insight into individual experiences. Furthermore, identity change and stigmatism were generally exposed to be gendered.

KEY WORDS:	FATIGUE	MULTIPLE SCLEROSIS	QUALITATIVE	THEMATIC ANALYSIS	GENDER
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Introduction

Background to Multiple Sclerosis

Multiple Sclerosis (MS) is a common, chronic neurological disorder where inflammation and demyelination occur in the white matter of the central nervous system (Gilden, 2005). Substantially more women are diagnosed with the disorder (Coyle et al, 2004), and it is believed to affect around one in a thousand people, with over a million estimated sufferers worldwide (Sadovnick and Ebers, 1993). Generally diagnosis occurs amid the ages of twenty and forty; making MS the most common yet disabling illness affecting young adults (Reynolds, 2003).

Predominantly, MS is characterised as episodic with full remission separated by erratic relapses (Mitchell et al, 2005); whereby approximately eighty-five per cent of sufferers present a relapsing-remitting course (Dennison et al, 2010). It is suggested that only a minority of individuals with the disorder have a progressive course from the onset (Goodkin, 1998).

The disorder is accompanied by varying unpredictable, unpleasant and potentially disabling symptoms including fatigue, lack of co-ordination, sexual problems, cognitive and visual impairments (Hunyi and Nanayakkara, 2001). Thus, MS has a profound impact on multiple life domains, including social activities, intimate relationships, family life and employment (Dennison et al, 2010). While many appear to adjust successfully to MS and the challenges it presents (Antonak and Livneh, 1995), it is evident that a vast amount of individuals suffer high levels of psycho-social problems, such as psychological distress and impaired quality of life (Janssens et al, 2003).

Although evidence has suggested a genetic influence on disease susceptibility, and unconfirmed work has proposed that a viral infection may be significant in the aetiology of the disease, the exact cause of MS remains unknown (Noseworthy, 1999). There is no known cure for MS, with alleviation of symptoms forming the cornerstone of care (Branas et al, 2000).

Fatigue

Fatigue is an exceedingly common, yet poorly understood and defined symptom associated with numerous chronic and disabling illnesses (Sheean et al, 1997., Flachenecker et al, 2002). It is considered as a state of exhaustion dissimilar from physical weakness or depressed mood; associated with low positive affect, neurological impairment, psychological distress and a sense of loss of control over your environment (Krupp, 2003). Furthermore, it is evident that fatigue can have profound effects on an individual's quality of life, often leading to anxiety, depression and disturbed motor function (Krupp et al, 2010).

Fatigue is a recurrent and disabling symptom amongst sufferers of MS, frequently having significant effects on their everyday functioning. It is believed to consume sufferer's lives with an overwhelming sense of physical exhaustion (Comi et al, 2001). The exact cause and relationship between MS and fatigue as a symptom is unknown; with its medical characteristics remaining poorly understood (Krupp et al, 1988).

Using a fatigue impact scale on a sample of eighty-five individuals with MS, Frisk et al (1994) found that fifty-five per cent reported fatigue as one of their worst symptoms; furthermore, fourteen per cent recorded it as their worst. Thus demonstrating fatigue is a prevalent and severe problem in individuals diagnosed with MS. However, Comi et al (2001) argued that fatigue can frequently relate to motor disturbances and mood

disorders; hence it is challenging to determine if the fatigue they experience is a characteristic of these or a direct result of MS.

Fatigue as a symptom of MS has been the focus of special interest due to the considerable impact it has on a sufferer's quality of life (de Castro et al, 2000); thus the research attempts to explore individual experience of MS and fatigue and the ways in which it impacts on their daily functioning.

Identity change

Individuals suffering with a chronic illness and fatigue frequently find their identity to be at risk (Reynolds and Vivat, 2010); whereby sufferers are forced to repeatedly adapt as they experience new losses (Charmaz, 1995). Chronic illness and symptoms of fatigue can lead to extensive social consequences, including unemployment, a limited social life and family problems; subsequently having a significant impact on their identity, often leading to withdrawal from their social life.

Chronic illness was explored by Charmaz (1983), finding it was repeatedly associated with a 'loss of self', or a 'diminished self'. Asbring (2001) demonstrated the role of chronic illness and fatigue in identity loss, principally with regards to work and social life. She stated that participants occasionally defined their new identity in terms of otherness; hence showing failure to unite both the earlier and new found self. Contrastingly, Scrambler and Hopkins (1986) argued that individuals with chronic illness work to evade acquiring 'spoiled identities', and thus attempt to maintain their identity and self. It is suggested that failure to reconcile the existing social identity with the new social identity primarily results in such damage to an individual's identity and sense of self (Adams et al, 1997).

Individuals have been found to feel as though they have been cast into 'narrative suspense'; contemplating potential futures and formulating new plans (Mattingly, 1998). Conversely, Dickenson et al (2008) found that sufferers of chronic fatigue syndrome (CFS) were unable to anticipate future plans; fixating on feelings of worthlessness, insignificance and failure. Thus we can see a clear distinction of identity crisis and identity change after diagnosis amongst individuals.

Although, positive consequences following identity change have been observed, as evidenced by Asbring (2001) who discovered approximately half of the sample had experienced positive aspects of identity change; predominantly increased self-respect and personal integrity. Furthermore, she argued the illness and fatigue provided participants with increased time for reflection on their lives, often resulting in re-evaluation and change in attitudes and habits; some creating a more favourable identity than the one prior to diagnosis. Subsequently, limitations associated with chronic illness can lead to positive growth in individuals with regards to a new 'true' self (Arroll and Howard, 2013). Additionally, individuals were exposed to frequently embrace the illness, perceiving it as an opportunity to expand and learn in contrast to being a victim of illness (Kralik, 2002).

It is evident that experiences of chronic illness and fatigue vary across genders (Thorne et al, 1997); thus it can be assumed that identity change is experienced differently according to the sufferer's gender. Exploration of chronic illness and fatigue through use of a qualitative methodology revealed a clear dichotomy between men and women's experience of the illness and the ways in which they were treated by medical professionals (Clarke, 1999).

An extensive repertoire of coping strategies is essential for an individual affected by MS and fatigue, in order to construct a life of greater quality. Managing the impact of such a disabling illness has on the self and identity is a daily challenge for many, as research reveals MS has a particularly pernicious effect on well-being in comparison with other disabling illnesses (Rao, Huber and Bornstein, 1992).

In addition, coping strategies are found to vary across genders. Women are professed as being able to cope better due to stereotypical expectations of females as passive and adaptive (Coppock et al, 1995), contrasted to men whereby symptoms are seen to threaten their masculinity (Seidler, 1998). Additionally, Williams (2000) found women were able to effectively incorporate the condition, symptoms and treatment regimens into both their personal and social identities; hence showing adaption to living with the condition. Men, contrastingly, attempted to separate their condition from their personal and social identities; consequently it was not seen to be an integral part of their identity. Similarly, Charmaz (1994) found men attempted to conceal their condition, particularly when in a public setting.

Although apparent that identity change is experienced in a variety of ways across genders, Clarke (1999) concluded that whilst patients explained the causes of chronic illness and fatigue in gender appropriate ways, they did not experience the symptoms in accordance to their gender. Furthermore, existing research assumes that all men experience identical identity change, as with women, thus ignoring how experiences of MS and fatigue may differ from one individual to another. Through use of two male illness narratives, Reissman (2003) effectively demonstrated contrasting versions of masculinities; hence individual differences must be considered. Hence an individualistic approach, considering independent thinking and experience is essential; this is commonly ignored in social-cognitive approaches, where emphasis is on illness cognitions and models of cognitive coping, therefore failing to deal with the complexity of identity change.

Stigmatisation

Chronic illness and fatigue is commonly accompanied by stigmatism; whereby the individual is often seen to be less than a whole person, of less value than others and not as well functioning (Asbring and Narvanen, 2002). Stigma is defined by Goffman (1963) as a differentness that is undesired, and that due to the undesired attribute the individual will experience stigmatism.

Employing a qualitative methodology, Grytten and Maseide (2006) successfully looked at stigma experienced by fourteen patients with MS, discovering that a copious amount reported stigmatism in social relationships; particularly the issue of being isolated or ignored. Conversely, they also found evidence of overemphasis and support in social relationships. Hence, it is crucial to look at stigmatism from an individual perspective.

Stigmatism within MS and fatigue can lead to negative consequences (Jacoby et al, 2005), as many struggle to manage stigma within social networks (Grytten and Maseide, 2006). The stigmas attached to MS along with associated symptoms are often perceived as a burden by the sufferer (Halper, 2007).

Ample research reveals that stigmatism is experienced differently across genders. Prout (1989) found that ill health in males was stigmatised, being perceived as a form of weakness or incompetence. Contrastingly, females were not stigmatised for their illness; thus stigmatising effects of illness were found to be gendered.

Extensive avoidance strategies are essential in order to cope with the negative consequences of stigmatism; particularly by applying protective disclosure. Grytton and Maseide (2005) interviewed fourteen individuals diagnosed with MS and their relatives, investigating how coping was used as impression management of the body, thus to counteract stigma and illegitimacy. They found protective disclosure could be effectively applied, whereby individuals purposefully conceal their illness to influence social judgement and hence to avoid stigmatism. Such strategy prevented deprivation of social belonging, particularly with regard to work. Additional evidence of patients being able to intervene in the management of stigmatism positively is extant (Becker, 1981), where development of an adequate social support system and coping mechanisms enable individuals to adapt to their illness, and in turn avoid stigmatism.

Due to the widespread impacts that stigmatism can have with relation to MS and fatigue, this report will explore individual narratives and accounts of experiences of stigma; including both positive and negative consequences as a direct result. Furthermore, an understanding of how individuals cope with stigma is essential for nurses aiming to deliver individualised, comprehensive patient care (Joachim and Acorn, 2000).

Emotional consequences

It is proposed that MS and fatigue as a symptom can impose a severely deleterious emotional impact on individuals; particularly as a result of functional loss and progression of symptoms (Devins and Sealand, 1987).

An abundance of research highlights the prevalence of depression as a direct result of MS (Anderson and Gookin, 1996., Thompson, 1996); whereby approximately fifty per cent diagnosed develop depressive symptoms (Sadovnick et al, 1991., Feinstein, 2011). However, it must be considered that point-prevalence data generally consists of a small sample that is not necessarily representative, incorporating differing assessment measures across studies; thus results commonly vary tremendously (Minden and Schiffer, 1991).

Depression rates among MS sufferers are significantly higher than other chronic illnesses and neurological disorders (Minden et al, 1987); hence we must consider depression as a result of MS specific disorder processes. Although, it is essential to remember that such high rates of depression may be the result of depressive symptoms confounding with those of MS, including fatigue, loss of concentration and changes in sleep (Mohr and Cox, 2001).

Existing empirical research into the relationship between MS, fatigue and depression generally incorporates a quantitative methodology (Johnson et al, 1996., Sanchez et al, 2003), ignoring individual experiences; thus the research employs qualitative methods to gain a more in-depth understanding into the domain.

Anxiety and anger are other emotional consequence associated with MS and fatigue as a symptom; however, there is limited existing empirical research. Prevalence rates of anxiety across MS sufferers exceed those of the general population; unsurprisingly due to the uncertainty and perceived threat of the disorder (Wineman et al, 1996). Occurrence of anxiety following diagnosis of MS is generally lower than rates of depression; Noy, et al (1995) were the only researchers to find a higher prevalence rate for anxiety than the rate of depression in a sample, finding ninety per cent suffered anxiety in comparison to just fifty per cent with depression.

Although a lack of literature exploring the relationship between MS, fatigue and anger exists, an association has been noted, suggesting it generates increased anger (Minden, 1992). It is advocated that anger may be an appropriate response following the frustrations of having MS and related symptoms, particularly when individuals experience new physical limitations (Mohr and Cox, 2001).

Associated frustrations and anger infrequently result in negative consequences, but can be problematic if causing distress to the individual, or if anger is displaced onto others (Mohr and Cox, 2001); thus experiences of anger must be considered. Furthermore, research into the area gives way to similar methodological issues as studies into depression with regards to small sample sizes and inconsistent assessment measures.

Negative emotional consequences are commonly observed following diagnosis of MS; particularly associated with uncertainty, progression of the disorder and related symptoms, including fatigue. However, over time positive changes can be observed in terms of individual outlook and values. Furthermore, psychological challenges and functional difficulties, including uncertainty and depression, can be seen to be ameliorated to some extent with time; particularly due to an increased appreciation for life (Irvine et al, 2009).

Due to the vast negative emotional consequences following diagnosis of MS and as a direct result of fatigue, the research will aim to explore individual experiences; thus to help build on the limited empirical research that exists into the topic area. In turn, offering support for nurses who require specialised knowledge in order to provide adequate support to patients (Isaksson and Ahlstrom, 2006).

Methodology

A qualitative methodology was carried out, involving narrative life stories via semi-structured ethnographic interviews on six participants with MS, three male and three female; hence gaining a personal insight into the participant's lives and the impact that MS fatigue has on them.

Method rationale

A qualitative methodology was employed to allow ample insight into individual experience (Frost, 2011). Since the 1980's, qualitative methods have become progressively prevalent in psychology, being described as a rich and deep methodology (Bryman, 1988). Smith (1995) defined it as a phenomenological approach where the emphasis is on attempting to understand the psychological conceptions of participants.

An advantage of qualitative research is that it follows an ethos for equality, where the researcher assumes a learning role, conducting research among participants rather than on them. It enables examination of issues from the participant's perspective (Johnson et al, 2004), hence research is more personal.

The research was not testing a hypothesis, looking for casual explanations or aiming to make any predictions from the analysis, so a qualitative methodology was logical to perceive participants worlds. A quantitative methodology would simply prove or disprove a hypothesis solely based on numerical data, thus it would not generate the same level of understanding (Runciman, 2002). Furthermore, Field and Morse (1985) argued that qualitative methods should be adopted when there is 'little known about a domain', which is relevant for this study.

Rationale for data collection

Interviews are a fundamental method of data collection within qualitative research; helping to explore people's experiences of illness (Pennebaker, 2000). The research employed semi-structured, open-ended interviews; thus took the form of a free-flowing conversation where participants were not asked the same questions (Latham and Finnegan, 1993). This methodology is praised for its inclusion of open-ended questions, whilst allowing the researcher to maintain a level of control on a given topic (Rapley, 2001).

Ethnographic interviews have become increasingly more common as a data collection method in qualitative research (Aronson, 1992); described as a method involving immersion in a setting and attempting to reflect on the context from the perspective of the interviewee (Coolican, 2004). Hence, the interview is conducted in a place that the participant is most comfortable. The research comprises of ethnographic interviews in the participants homes, thus allowing for maximum comfort.

Furthermore, a narrative design will be used in order to gain an increased understanding of the impact MS fatigue has on individuals. This method has been used successfully on women with MS by Olsson et al (2005), giving a broad understanding of how fatigue impacted upon their lives; hence the research builds on their findings, illustrating personal life stories and experiences. Reissman (2003) proclaimed that comparison and examination of narrative accounts disclose contrasting meanings and interpretive complexity of how illness is experienced; thus this design was relevant in the research.

Participant recruitment

Purposive sampling is defined as a random selection of sampling units within the segment of the population with the most information on the characteristic of interest (Guarte and Barrios, 2007). As the study required six participants with MS, three male and three female, a purposive sampling method was logical.

Initially, participants were approached and asked to partake in the research with an invitation, included in the information sheet (Appendix 2); hence were able to gain a full understanding of the aims and processes of the research. Following verbal consent, participants were given a consent form (Appendix 3), informing them of their right to withdraw and ensuring them that no harm would come of them during the interview process. Interviews were based around a brief topic guide (Appendix 4), allowing a natural flow of conversation whilst avoiding a rigid set of questions and were recorded using a Dictaphone; therefore allowing them to be transcribed later for analysis (Appendix 1). Finally, participants were de-briefed (Appendix 5); further ensuring their right to withdraw and thanking them for participating.

Six participants were interviewed, three male and three female, ranging from twenty-five to fifty years old; therefore offering a comparative perspective. This is crucial as existing research focuses solely on the effects of MS fatigue in relation to one gender, particularly women (Olsson et al, 2005). Each interview lasted between fifty and ninety minutes; hence detailed life stories were able to be obtained. All participants were given pseudonyms for the purpose of anonymity; they are summarised in Table 1.

Table 1: Summary of participants

Name	Age	Initial diagnosis	Marital status	Employment	Mobility
Susie	43	24 years	Married	Part-time retail assistant	Increasing mobility problems
Jenny	27	6 years	Single	Health care assistant	Good mobility
Linda	50	21 years	Married	Unemployed for 13 years due to severity of symptoms	Uses a wheelchair
John	35	8 years	Married	Transport manager	Generally good mobility
David	44	11 years	Married	Early retirement from teaching	Walks with a stick
Paul	25	7 years	Single	Admin assistant	Increasing mobility symptoms

Rationale for Thematic analysis

A thematic analysis was conducted in order to analyse the transcribed interviews. Braun and Clarke (2006) define it as a method for analysing and identifying themes within a data set, focusing on identifying and analysing patterns of behaviour (Aronson, 1994., Roulston, 2001).

Within qualitative methodology, it is a common process of encoding data (Boyatzis, 1998); often exposing multiple themes within a narrative. A theme is described as capturing important information within a data set in relation to the research question; subsequently producing some level of meaning or patterned response from it (Braun and Clark, 2006).

While thematic analysis is widely used within psychology as a qualitative analytic method, it is rarely acknowledged (Braun and Clarke, 2006); often being criticised for its 'anything goes' nature, as many consider this poses a disadvantage (Antaki et al, 2002).

Braun and Clarke (2006) proposed a six phase process when conducting a thematic analysis; this was successfully followed and incorporated into the research. The initial phase was to familiarise with all aspects of the data, including transcribing the interviews. Phase two required the production of initial codes using the transcripts, where interesting aspects of the data were identified. After initial coding, phase three sought to place these codes into potential themes, before being reviewed in phase four then named and defined in phase five. A detailed analysis was conducted for each theme, before finally the concluding analysis was derived in phase six. The research discusses each theme in-depth, providing adequate evidence and support from existing literature.

Ethical Considerations

The British Psychological Society (2009) adheres by a code of ethics which all psychological research is required to comply with. The application for Ethics Approval Form (AFEA) (Appendix 6) demonstrates that the research abided by all ethical considerations. The research required participants to discuss personal events for approximately fifty to ninety minutes, thus potential invasion of privacy may have occurred. As all the participants had MS and experienced fatigue as a symptom, personal and traumatic experiences were exposed; however prior to the interview participants were advised that they did not have to disclose information they felt uncomfortable talking about. Following the interviews, participants were de-briefed, making sure that no discomfort or harm had been experienced.

Analysis and Discussion

Identity change

Generally, MS occurs in the prime of life and is highly unpredictable; thus it is probable that individuals will suffer a strong psychological effect, changing values and beliefs and how they see themselves (Irvine et al, 2009); in turn leading to a change in identity. Analysis of the transcripts revealed that five of the six participants had undergone a degree of identity change with regards to MS and particularly fatigue, some are demonstrated below:

Susie: transcript 1, line 385-388

'Yeah I have changed; I can't do the things I used to. You know I was always a gym bunny and loved going for walks and things like that you know and now I can't because of my legs'.

Linda: transcript 3, line 410-414

'I can't do anything for myself now...I can hardly walk anymore, I can't cook or clean...the fatigue just means I have to rest and sit all the time'.

Paul: transcript 6, line 450-456

'I can't play football or do anything active anymore like I've always done, so yeah of course my identity's changed...I just feel like a completely different person since I last relapsed...I'm just always knackered'.

A mutual complaint was how tiredness due to the fatigue associated with MS, in turn leading to identity change. Change was particularly related to the loss of ability to take part in their normal life prior to diagnosis of MS; hence supporting the notion of a diminished self (Charmaz, 1983).

Findings were consistent with Williams (2000), as Linda incorporated MS, fatigue and treatment regimens into her identity, hence she was able to adapt to living with MS:

Linda: transcript 3, line 423-427

'My life revolves around it now, every afternoon I have to lie down because of the fatigue so I try to get as much done in the morning...I guess you just get used to it'.

Conversely, Susie did not see MS and fatigue to be integral in her identity:

Susie: transcript 1, line 396-399

'Of course it's affected what I can do, but I don't let it define me in anyway, like even if I'm tired or not feeling great I won't let it stop me doing what I want to do'.

Thus Susie chooses to make the MS and symptom of fatigue a lesser part of her life as possible; subsequently not incorporating it into her identity. It is evident that Susie avoids acquiring a 'spoiled identity' and instead chooses to maintain her initial identity prior to diagnosis; hence offering support for Scrambler and Hopkins (1986). Williams found this was generally the case with males, as they separated their illness and identity. This is apparent in both John and David:

John: transcript 4, line 384-385

'...I won't let it stop me from stuff I've always loved doing'.

David: transcript 5, line 173-175

'I try as much as I can to get on with my normal life before (MS)...but some things you just can't do anymore'.

Both John and David fail to unite the new found self with the earlier self, suggesting it to be a separate entity. This is not the case for Paul who challenges Williams as he incorporates his new found illness into his existing identity:

Paul: transcript 6, line 471-473

'Because of it (MS) I've had to change who I am I guess. My hobbies and that are different and I have different friends, it just kinda becomes part of you'.

Paul has united MS, fatigue and his identity thus has experienced identity change. By reconciling the prior and new identity Paul avoided damaging or losing his identity, as predicted successfully by Adams et al (1997).

Ample research shows both positive and negative consequences following identity change due to MS and fatigue as a symptom; as individuals commonly feel worthless and less of a person. In transcript three, Linda describes how due to her decreased mobility, identity change has been experienced negatively:

Linda: transcript 3, line 613-616

'I hate who I am now, I just feel you know worthless, like I'm annoying...you see I have poor mobility, it stops me from being me...or doing anything'.

Linda demonstrates how identity change as a direct result of MS can be experienced negatively. Furthermore, John reveals how the symptom of fatigue can have the same negative effect to identity:

John: transcript 4, line 489-491

'to be honest it's the tiredness that's changed me...fatigue hits me every day, making me feel useless...since it (diagnosis of MS) I'm just not me'.

Thus we are able to conclude that both MS and fatigue as a symptom can have an extensive effect on one's identity negatively. Contrastingly, positive consequences following diagnosis and identity change can be observed within a number of the transcripts:

Susie: transcript 1, line 812-815

'It's made me appreciate life a lot more, so now when I feel alright I always make the most of it, like do stuff I enjoy that I can't do when I'm having one of my bad days'.

John: transcript 4, line 736-739

'I used to have a lot of bad habits...didn't appreciate things as much...I like who I am more now'.

Susie and John mirror Asbrings (2001) findings as they experienced positive identity change; including increased appreciation and a re-evaluation of their lives resulting in positive change. Hence we can conclude that MS and fatigue can result in both negative and positive consequences with regards to identity change.

Existing research proposes that experiences of illness and symptoms of fatigue vary across genders (Thorne et al, 1997); however the research failed to offer full support for such a claim with regards to identity change. The transcripts suggested higher complexity than a simple gender divide; thus it is important that we study them from an individual perspective. Current literature fails to do so, assuming the different genders experience identical identity change.

Stigmatisation

MS and symptoms of fatigue are commonly accompanied by stigma in a social context. The transcripts revealed that stigmatisation was experienced by three of the six interviewees as a direct result of their illness and fatigue, as evidenced below:

Linda: transcript 3, line 101-105

'I applied to study as a student nurse but was rejected straight away due to me having MS. They said I wouldn't be up to it, you know because of the fatigue that comes with it. They just assumed I couldn't do it, they wouldn't even interview me'.

Paul: transcript 6, line 250-254

'I told my friends when I was diagnosed and ever since I've been like excluded and isolated from the group. Its like they don't see me in the same way just because of the MS'.

David: transcript 5, line 157-162

'People just see me as incompetent, like I can't do anything anymore...I get tired a lot so they just assume I can't do stuff'.

It is apparent that diagnosis of MS and symptoms of fatigue can lead to ample stigmatisation and unfair treatment. Hence, their undesired attribute has led to stigmatisation, as proposed by Goffman (1963). The examples also support Prout's (1989) findings with regards to males being stigmatised, as the MS is perceived as a form of weakness or incompetence in both Paul and David. No stigma was experienced by John however:

John: transcript 4, line 403-405

'It's never made anyone stigmatise against me no, if anything it's just made everyone fuss over me.'

Prout also concluded that females were not stigmatised for their illness, which is not the case for Linda, however both Susie and Jenny experienced no stigmatisation:

Susie: transcript 1, line 560-562

'No I've never had anyone stigmatise against me or be negative towards it (MS).'

Jenny: transcript 2, line 472-473

'Everyone's been great actually; I've just had loads of support'.

Thus it is ostensible that diagnosis of MS doesn't always result in stigmatisation and that often stigmatisation is gendered. When individuals do suffer stigmatisation, however, such experiences can lead to negative consequences, including questioning their self-worth and isolation as indicated by Paul:

Paul: transcript 6, line 270-273

'It makes me feel like less of a person, you know makes you think like you're just a burden to everyone, like obviously I can't do the things I used to...I feel left out a lot'.

Paul mirrors Asbring and Narvanen's (2002) claims that suffering from a chronic illness can lead to an individual being seen as less than a whole person. Furthermore, Paul offers support for Grytton and Maseide's (2006) study, showing isolation to be the result of stigmatism within social relationships.

Although stigmatism received for having MS can have negative effects, it is palpable that many have discovered ways in which to avoid stigma through coping strategies and concealing their illness:

Susie: transcript 1, line 438-440

'I don't tell anyone I even have it, I don't want them to just see me as someone with MS'.

Paul: transcript 6, line 368-372

'I just put on a happy face; I don't let anyone know I'm in pain or nothing...I don't want to be treated differently just because of the MS'.

Hence supporting Grytton and Maseide's (2005) study, finding that sufferers were able to purposefully conceal their illness to influence social judgment and avoid stigma.

Stigmatism can have copious negative and positive consequences with relation to MS and fatigue as evidenced in the transcripts; thus is an important area for future research. Although offering support for a gender difference with regards to experiences of stigmatism, it is essential to remember the study uses a small sample using a qualitative methodology; hence cannot be accepted as objective truth.

Emotional consequences

MS and fatigue as a symptom constantly produces negative emotional consequences, including depression, anxiety and anger.

Chwastiak et al (2002) advocated that existing literature shows a high prevalence rate for depression among individuals with MS; research suggesting fifty per cent suffering with the disorder experience depressive symptoms (Feinstein, 2011). The transcripts exceed this with five out of the six going through a stage of depression; some are evidenced below:

Susie: transcript 1, line 952-957

'When I last relapsed I felt so depressed...I've been put on antidepressants a few times actually'.

Paul: transcript 6, line 613-615

'Sometimes I just won't get out of bed for days 'cos I'm so depressed'.

It is apparent that depression can be experienced as a direct result of the MS along with the progression of the disorder; including symptoms such as fatigue. Furthermore, Chwastiak et al (2002) found those with more advanced MS had significantly more chance of experiencing clinically significant depressive symptoms, in contrast to those affected minimally by the disorder; thus suggesting depression is associated with pattern of illness. In transcript three we learn how this is the case with Linda, who was diagnosed 21 years ago, is in a wheelchair and experiences severe associated symptoms, such as fatigue:

Linda: transcript 3, line 4, 689-698

'I was diagnosed 21 years ago...I've been on anti-depressants now every day for years...I don't think I could manage without them now...I just lie there too exhausted to get up, it makes me feel so down'.

This contrasts to Jenny in transcript 2, who was only diagnosed six years prior to the interview, has a benign course, good mobility, with little disease activity and has minor symptoms of MS and fatigue:

Jenny: transcript 2, line 576-580

'Nope I haven't been what I'd describe as depressed...I've had some awful days, sad days, but I stay happy and positive'.

Linda and Jenny offer support to Chwastiak et al (2002), showing depression to be associated with pattern of illness, as well as showing the length of diagnosis and symptoms of fatigue to be crucial with regards to depression. Hence, it cannot be concluded that the depression experienced is a direct result of the MS alone, rather it is also the result of its confounding symptoms, including fatigue (Mohr and Cox, 2001).

Using a qualitative methodology, the study offers support for a high prevalence of depression among those with MS; hence building on existing quantitative research into the domain, which commonly ignores individual difference. However, as the research only incorporates six participant's experiences of depression, it is essential to remember it is not necessarily representative, thus is not generalizable beyond the data set.

Anxiety as a negative emotional consequence often can be observed following diagnosis; predominantly due to uncertainty and perceived threat (Wineman et al, 1996). This is palpable in several of the transcripts:

Susie: transcript 1, line 405-410

'I'm so terrified and anxious about what's gonna happen next...obviously no one can predict it can they'.

Linda: transcript 3, line 784-786

'I'm deteriorating every day; its scares me what I'll be like in a few years' time'.

Both Susie and Linda experience anxiety with regards to MS; particularly when considering their future disorder course. Furthermore, anxiety is apparent in relation to fatigue as a symptom, as outlined by David:

David: transcript 5, line 768-770

'I'm so tired all the time, just makes you wonder what you might miss out on'.

David noticeably feels anxious about his future with MS due to the symptom of fatigue hindering him in partaking in his normal everyday life. All six of the interviewees hinted

at feelings of anxiety with regards to their illness and fatigue; thus showing a higher prevalence rate for anxiety than depression within this sample, therefore offering support to Noy et al (1995).

Anger as an emotional consequence of MS and fatigue must be considered due to the distress it may cause on the individual or those around them. The participants implied feelings of anger; particularly lamenting things such as *'why me?'* and *'it's not fair that I have it'*.

Although generally negative emotional consequences follow diagnosis, positive consequences can equally be observed:

Jenny: transcript 2, line 856-859

'I don't let it get me down, I just stay as positive as I can...its definatly give me a more positive outlook and general appreciation for life'.

Jenny has undergone positive emotional change, particularly experiencing an increased appreciation for life; hence supporting Irvine et al (2009). Furthermore, they suggested that time can help improve negative consequences of MS and fatigue; this is apparent in Susie who describes a similar increased appreciation for life. Linda, however, challenges these claims, as she tells us she has been on antidepressants for a number of years; hence time has not improved her negative consequences.

The research builds on the existing, limited empirical research into the domain of emotional consequences associated with MS and fatigue as a symptom. It explores the high prevalence rate for such consequences, offering support for positive outlooks ameliorating negative emotional consequences over time. Furthermore, it offers specialised knowledge into the topic area which may be useful for nurses attempting to provide adequate support to patients.

Research limitations

It is essential to remember that participants were recalling their experiences of MS and fatigue retrospectively; hence recall bias may influence individual accounts. It is evident that people have a tendency to reconstruct memories; either to create a more favourable view of themselves (Wilson and Ross, 2003), or to present themselves more positively to the interviewer. Therefore individual narratives should not be considered as objective truths but purely reconstructions of experiences.

Although rich, deep, personal accounts of individual experience of MS and fatigue were able to be obtained, the employment of a qualitative methodology prevents generalisation beyond the sample. Furthermore, the study consisted of just six participants so findings within the data set should not be viewed as conclusive or generalised as the sample is unlikely to be representative.

Additionally, MS varies tremendously from one person to another, making it impossible to make any conclusive remarks with regards to experiences of the illness and associated symptoms.

Reflexive Analysis

Reflexivity is considered by Watt (2007) as an essential and potentially facilitating understanding of the research process and the phenomenon being studied, thus it is important to take a reflective stance towards the research enabling personal critique.

Being able to look inwards at the processes from an outside stance will help to tackle the impossibility of objectivity; this can be difficult when conducting personal research that is full of personal interpretations.

On reflexion, I believe the research could be significantly improved by incorporating multiple interviews; thus to build up more of a rapport and in turn leading to more in-depth information into the topic area. However, due to time constraints and word limits, it was not possible; hence this could be a consideration for future research, along with a larger sample size.

I thoroughly enjoyed having the chance to meet and interview such interesting individuals. My knowledge into MS fatigue and its various impacts has been significantly increased through use of a qualitative methodology; I perhaps would not have learnt as much if I'd employed quantitative methods. This increased awareness has encouraged my interest to work with similar individuals in the future.

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