



AUTHOR(S):

TITLE:

YEAR:

Publisher citation:

OpenAIR citation:

Publisher copyright statement:

This is the _____ version of an article originally published by _____
in _____
(ISSN _____; eISSN _____).

OpenAIR takedown statement:

Section 6 of the "Repository policy for OpenAIR @ RGU" (available from <http://www.rgu.ac.uk/staff-and-current-students/library/library-policies/repository-policies>) provides guidance on the criteria under which RGU will consider withdrawing material from OpenAIR. If you believe that this item is subject to any of these criteria, or for any other reason should not be held on OpenAIR, then please contact openair-help@rgu.ac.uk with the details of the item and the nature of your complaint.

This publication is distributed under a CC _____ license.

Structured Abstract

Aim: to explore the lived experience of the meaning of being diagnosed with Multiple Sclerosis on the individual's sense of self.

Background. The time of leading up to and immediately following the diagnosis of Multiple Sclerosis has been identified as a time period shrouded by uncertainty and one where individuals have a heightened desire to seek accurate information and support. The diagnosis brings changes to the way one views the self which has consequences for biographical construction.

Design: A hermeneutic phenomenological study.

Methods: In-depth qualitative interviews were conducted with 10 people recently diagnosed with multiple sclerosis. The data were analyzed using interpretative phenomenological analysis.

Findings: This paper presents the three master themes: the 'Road to diagnosis', 'The liminal self' and 'Learning to live with Multiple Sclerosis'. The diagnosis of Multiple Sclerosis may be conceptualized as a 'threshold moment' where the individual's sense of self is disrupted from the former taken-for-granted way of being and propose a framework which articulates the transition.

Conclusion: The findings highlight the need for health care professionals to develop interventions to better support people affected by a new diagnosis of Multiple Sclerosis. The conceptual framework which has been developed from the data and presented in

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

this paper, provides a new way of understanding the impact of the diagnosis on the individual's sense of self when affected by a new diagnosis of Multiple Sclerosis. This framework can guide health care professionals in the provision of supportive care around the time of diagnosis.

Summary box

What does this paper contribute to the wider global clinical community?

- The findings will help to inform the global **clinical** community to further develop understanding about how to better support people who are newly diagnosed with Multiple Sclerosis.
- The conceptual framework offers the global **clinical** community a way of understanding the lived experience of people newly diagnosed with MS.
- This conceptualization could be used to inform the development of interventions to better support people newly diagnosed with MS.

Keywords: Multiple Sclerosis, diagnosis, biography, liminality, sense of self, nursing, psychosocial nursing, qualitative research, phenomenology

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

INTRODUCTION

The prevalence of chronic illness is increasing worldwide (World Health Organisation, 2014).

Within the UK, people with chronic conditions place considerable demands upon the health service, with 60% of hospital bed days and 80% of GP consultations being attributed to long term conditions, this amounts to 70% of the health service budget being spent on long term conditions (NHS England, 2014). Over the past decade one of the key challenges facing health care professionals in the UK is configuring services to provide care that is responsive to the changing needs of people with complex long term conditions including MS, to enable them to be able to self-manage their condition and stay at home (Scottish Government, 2009). Currently much of the guidance for services providing care for people with chronic conditions is focussed on an aging population, as chronic illness is often associated with getting older. Multiple Sclerosis (MS) affects a significantly younger population it is therefore imperative that we understand the lived experiences of those with MS in order to consider how to better meet their health care needs.

Multiple Sclerosis (MS) is a chronic degenerative neurological condition for which there is no cure. The condition may present as a series of small and often seemingly mild and insignificant symptoms. However, it may also present as a dramatic loss of function such as paralysis of the legs. Depending on the nature of onset of the disease, diagnosis may be a slow process involving a culmination of linking together signs and symptoms or it may be relatively quick in the case of dramatic loss of function. At its onset, MS usually affects young people between the ages of 20-40 and is three times more common in women than men (Mackenzie *et al.* 2013). The incidence of MS peaks at about 30 years of age, with prevalence at its highest around 50 years of age (Koch-Henriksen & Soelberg Sørensen, 2010). Receiving a diagnosis of a chronic condition is widely acknowledged as a significant life event which may result in stress for the individual and

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

their family (Bury, 1982, Newby, 1996). This study seeks to understanding of the biographical impact of newly diagnosed MS on the individual and how this impacts on how the person manages the transition to living with MS.

BACKGROUND

The time of leading up to and immediately following the diagnosis of MS has been identified as a time period when individuals have a heightened desire to seek accurate information and support (Heesen, et al. 2003, Hepworth, et al. 2002, Johnson, 2003, Kralik, Brown, & Koch, 2001). Many people engage in active information seeking and arrive at a self-diagnosis of MS before it is confirmed by a physician. This stage is described as pre-diagnostic limbo and is a stage which is common in other chronic conditions with symptoms which may be described as 'non-specific' (Dickson, et al. 2008).

The reactions to a diagnosis of a chronic illness may result in a number of emotional responses including fear or relief (Bury, 1982, Corbin, 2003). Similarly, individuals' reactions to being diagnosed with MS vary. For many this may provoke feelings of fear, anxiety, despair and depression (Koopman & Schweitzer, 1999) or uncertainty (Mishel & Braden, 1988). This may be due to common misunderstandings and stereotypical representations of people with MS which includes the perception of the wheelchair bound, dependent person (Koopman & Schweitzer, 1999). Whilst this may become the reality for some individuals with MS, it affects only around 10% of people with the condition (MS Trust, 2005). A number of studies highlight the prevalence of psychological distress in relation to dealing with the diagnosis of MS (Dilorenzo et al., 2008, Lexell, et al. 2011).

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Previous studies which have explored the experience of being diagnosed with MS have highlighted being diagnosed with this chronic condition poses a challenge to the individuals sense of identity and as such, contributes to a reconstruction of identity (Mozo-Dutton, et al., 2012, Toombs, 1995). A changing conceptualisation of the self is a theme which has been identified across a number of chronic conditions (Koch, et al. 2004, Sanderson, et al. 2011, van Gennip et al., 2013). Bury (1982) and Charmaz (1983) are two influential theorists whose work has gone on to influence the study and interpretation of biographical research. Within the context of the experience of living with MS, a number of studies have highlighted the implications of the diagnosis for the person's sense of self (Gagliardi, 2003, Mozo-Dutton et al., 2012, Toombs, 1995).

There has been a number of studies that have explored the impact of a diagnosis of MS involving participants who have had the condition for many years (Johnston, 2003, Mozo-Dutton, et al. 2012). This poses limitations on the findings of such studies as participants have to rely on their memory of being diagnosed with MS, and with the passage of time, diagnostic procedures and attitudes to giving patients information may have significantly changed.

Much of the literature to date has focussed on the experiences of people with middle to advanced MS (Harrison et al., 2004, Esmail et al., 2010, O'Connor, et al. 2008). This paper provides insights into the unique experience of those who have been recently diagnosed with MS and proposed a conceptual framework for understanding the impact this experience has on the individual's sense of self.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

The liminal self was first conceptualised by the anthropologist van Gennep (1960), whose seminal text on 'rites of passage' defined three periods of liminality. Van Gennep (1960) classified the phases of liminality as, pre-liminal (rites of separation), liminal (rites of transition) and post-liminal (rites of reincorporation). Liminality has been used as a conceptual framework to explore the rites of passage through transition to MS (Barrett, 1995), as well as other illnesses such as cancer (Blows et al., 2012, Navon & Amira, 2004). However this has mainly been used as a framework to explore and describe the processes of transitioning, rather than deep exploration of the conceptualisation of the self in illness. The concept of liminality may be useful in helping to understand this period where individuals feel in limbo, as they have some symptoms, maybe even some information or a diagnosis, but the full picture of what this means for them is yet to emerge. This paper explores the lived experience of people newly diagnosed with MS and considers the relevance of the liminal self as a conceptual framework for understanding the lived experience of being newly diagnosed with MS.

METHODS

Design

This qualitative study was underpinned by interpretative phenomenological analysis (IPA) which has its roots in philosophical phenomenology with the hermeneutic circle being central to the approach (Smith et al., 2009). The process of hermeneutic phenomenology requires interpretation of the meaning of the experience or situation so that one can integrate the new experience as part of a new and emerging life-world, a situation referred to by Gadamer as the 'fusion of horizons' (Gadamer, 1976). The task of the researcher is

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

to understand the life-world of the participant as it is interpreted from their own horizon or vantage point. Within IPA the interpretative inquiry is grounded in the narratives of the individual's lived experiences, therefore research questions are exploratory in nature as opposed to explanatory (Smith et al., 2009).

People with MS (~~PWMS~~) who had been diagnosed within the previous six months were recruited to the study from a Neurology Clinic in the UK. Six months was chosen so that the experience of being newly diagnosed was still fresh. Participants were over the age of 18 and able to provide informed consent. Participants were also invited to nominate a support person to participate and the findings of this part of the study are reported elsewhere (XXXXXXXX, 2015). Participants were contacted to arrange a suitable time for interview and were interviewed within 6 months of being diagnosed with MS and again between 6-12 months following the initial interview. One participant was not contactable at the follow up interview.

Data collection

In-depth semi-structured interviews conducted in the participants' homes allowed the participant and researcher to engage in focussed dialogue where the participant recounted their life story as a narrative construction of their experience (Darlston-Jones, 2007). As this was part of a larger study which also explored the views of support persons, the participants were given the choice to be interviewed together or separately. Five participant pairs were interviewed together and the remaining participants were interviewed individually.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

A flexible interview guide covering the main topic areas was developed to inform the interview and allow the flow of conversation to be directed by the participant. To commence the interview, participants were encouraged to tell their story by beginning to recount the events leading up to diagnosis. For example the participants were asked, 'Can you tell me a bit about your journey to being diagnosed with MS?' or 'What things stick in your mind about the time leading up to diagnosis?' These open questions helped to frame the interview and encouraged the participants to talk openly. Other areas covered included what the participants knew about MS prior to diagnosis, how they felt at the time of being given the diagnosis, and what had happened since the diagnosis.

All interviews were digitally recorded and transcribed verbatim. The content of the interviews was discussed between all authors during research **team meetings, supervision sessions**. The narrative transcripts provided the basis for data analysis.

Ethical considerations

Ethical approval for this study was granted by the relevant ethics committees and approval to proceed was given. Potential participants were assured that the information they provided would be treated as confidential, and that they reserved the right to refuse to participate in the study. Participants were also reminded of right to withdraw from the study at any time, without any negative impact on their care. Pseudonyms were given for all participants.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Analysis

The data were analysed using the seven step process outlined in the Interpretative Phenomenological Analysis (IPA) process (Smith, et al. 2009) (see Table ~~One~~ ~~Two~~). In IPA, the process of extracting themes is placed firmly *in vivo* so that it maintains an idiographic ontology, often with painstaking analysis of cases (Smith & Osborn, 2008). Smith & Osborn (2008) suggest that themes from each interview may be set aside and each new data set started from scratch to allow the researcher to be open to new themes as they present in the data. The *in vivo* themes were then integrated into groupings of similar themes to develop the master themes. To be classified as a master theme, the theme occurred in at least half of all of the participants' interviews.

The first author conducted the data collection and the majority of the data analysis however steps were taken to ensure credibility checks were integrated throughout and that the study adhered to the guidelines for qualitative research by Elliott et al. (1999). Four transcripts were independently analysed by the second and third authors. This allowed comparison of more than one qualitative perspective at research team meetings. In addition to this formal credibility check, accounts from the support person (XXXXXX, 2014, xxxxxx, 2015) provided a different qualitative perspective allowing triangulation of data with the person with MS's accounts. Whilst experiences were from different perspectives, key events and experiences could be verified and understood from the different participant's viewpoints.

RESULTS

Description of participants

Of the ten participants with MS, there were eight women and two men. ~~(see Table One).~~

The participants were aged between 25 and 45 years. At the first interview the time since being diagnosed ranged between 2 weeks to seven months ~~(one participant interview delayed due to availability)~~ and follow up interviews were conducted between 6-12 months later.

Three main themes emerged from the data: *'road to diagnosis'*, *'the liminal self'* and *'learning to live with MS: an uncertain future'*. It is worth noting that whilst each of these themes has a number of sub-themes which were grouped together into one major theme, all had a cross cutting theme of the 'impact on the self'.

Road to diagnosis

Regardless of the timescale, there was a period of time for all participants where symptoms were experienced prior to a confirmed diagnosis of MS and this is reflected as journey towards the moment of diagnosis. Each individual described in great detail the events that led up to being diagnosed, along with the details of the diagnostic consultation itself. When asked to describe the events leading up to being diagnosed with MS, participants described different experiences in terms of the impact of symptoms and levels of engagement with health care services. For some participants this time period extended over many years, from a first episode of symptoms which had not been given a conclusive diagnosis, to other participants who had been diagnosed within a few weeks of their first episode of symptoms. Some referred to events from a number of years ago that the recent

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

diagnosis had brought back into focus. This was perhaps most powerfully presented by Janice, who had previously experienced symptoms over 20 years ago:

It all started 20-odd years ago. I had, it was when I was a student, I had an episode of pins and needles going down my left hand side of my body and when I was bending my neck and it persisted for three months. So it was only this year, at the end of January we were going out for a walk... and I felt pins and needles on my right hand side, so that took me right back to 20- odd years ago. (Janice)

Recognising symptoms which require further investigation was commonly alluded to in the interviews, and is characteristic of the road to diagnosis of MS with some participants suspecting '*this is something serious*' (Steven). The embodied experience of physical symptoms described as 'Knowing one's body: knowing one's self' reflects the interrelated nature of the experience of abnormal bodily symptoms amongst the participants and their sense of self. The "pre-liminal" phase characterised by the "rites of separation" helps to conceptualise the lived experience where the symptoms of MS are experienced but the cause is not yet known but some disruption to the sense of self has begun.

Being diagnosed with MS was a defining moment in the individual's life where they are given a name for the cause of their symptoms. How individuals reacted to being told they had MS was influenced by the meaning and significance the diagnosis had for them. For some the diagnosis came as a relief, with fear of a brain tumour being a worse scenario, or it was described in negative terms such as '*being blown away*' (Lorna); for others the

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

diagnosis legitimised their quest for medical help as they had begun to worry that the symptoms were *'all in their mind'* (Billy).

The metaphor of crossing the threshold emerged from participants' accounts describing the experience of being given a diagnosis of MS, where one moves from 'not knowing' to 'knowing' the cause of the symptoms which have been experienced. The irreversible nature of crossing the threshold was described by one participant in the following statement:

There's nothing else I can do is there? Can't turn back time. I often say that, you know, I wish I could go back to last year. You know, when I was fine and taking the dog out through [the] Park and the nice summer days and you can't go back to that. (Sheila)

The "threshold" conceptualises the experience of being diagnosed as a pivotal moment in the transition from person with symptoms to person with MS.

The Liminal Self

All participants reported a sense of disruption to their perception of their self and described a period of negotiating the new perception of their self into their biography, how this interrupts or disrupts their sense of self, resulting in a liminal state of being. The disrupted self relates to the individuals' notion of their sense of self, their 'taken for granted self' being thrown into disarray, and their 'self' being a disrupted person by being diagnosed with MS. Previous conceptions of the self that participants had constructed (biographies) were now challenged, and new narratives of the self emerged. These new

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

biographies now included the 'self' as a 'self with MS'. The participants mainly described the impact on their sense of self as a disruptive element, one where they had been living a life relatively secure in their sense of who they were, and how this related to the world around them. The diagnosis of MS usurped this understanding and caused them to question certain aspects of their biography. The following account clearly articulates the impact having MS had for this participant:

I don't think I'll ever be the same person I was kind of thing. You get stuff that you wouldn't have thought anything about before. I mean MS I didn't know what it was and you've now got all that experience. I mean I still try and be me kind of thing at the end of it but you still come across things that you never had before and find I can't always do the same amount I used to do. (Julia)

Here Julia described how having MS changed her sense of self and acknowledged the irreversible nature of this change due to her experience and new found knowledge of MS. There was also a real sense of this change in sense of self being unwelcome, as Julia struggled to maintain her former sense of self. In her account Julia said she would '*still try and be me*' which suggests a sense of fluidity to her sense of self congruent with a liminal self. Another participant captured the changing biographical narrative she constructed about herself reflecting on her previous notions of self with the new self with MS as part of that self:

You sort of think of yourself as invincible and I have worked, had a family, I'm always active, I do tons of things and so you see that a wee bit of superwoman quality in yourself, I think we all do. And seeing that maybe there's another angle to that now is that every

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

time I think... when I'm looking at myself I think well also there's a bit now that's added on that's got MS onto it, so that's another facet of my personality or being me now. (Eileen)

Being able to maintain specific roles seemed to be important to the participants in this study and was related to the roles and relationships they valued in the context of their own lives. The roles included social, familial, and employed roles. The sub-theme of 'the self as mother' emerged from the data from the participants who were mothers but there were no participants in this study who were fathers. For the participants who were mothers, their role as mother appeared strongly linked to their identity and where MS impinged on their perceived ability to perform the mothering role this was described in a negative way:

Because I think it's very hard for any child who has been with a parent who's been able to do everything, taking them everywhere and I probably did too much for him, if that's possible, but to find that your mother can't really take you anywhere, or do as much with you I think that's probably quite hard to accept. (Lynne)

For those participants who were mothers with MS, the experience of having MS posed a threat to their identity of self as mother. For the participants of this study the sense of self being disrupted and a strong sense of being between two selves was particularly apparent. The liminal self conceptualises the lived experience of biographical disruption where the person's sense of self is in transition, betwixt and between the old self and new self.

Learning to live with MS: an uncertain future

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

MS impacted on the daily life of all the participants with MS, to a lesser or greater degree, depending on many factors such as the actual or perceived severity of symptoms. For some of the participants this meant having to make small concessions to their activities and for others the impact meant significant lifestyle changes were necessary. There was a sense that re-assessing their lifestyle choices may have been an on-going process as the course of the condition progressed. The "post-liminal" phase helps to understand the experience of those transitioning to living with MS it conceptualises the reincorporation of the sense of self transforming the self as a person with MS. However, this experience is subject to on-going uncertainty and as such is never quite stable. Thus, a sense of not knowing what the future holds was evident when making such adjustments to living. For Julia, like most of the participants, the symptom of fatigue meant that she had no idea from day to day how she would feel and quite literally had to lay down to MS:

... Like sometimes I have to say, you know, I actually can't do this because I'm tired. I don't think he always realises why I come in and I go to my bed, but I literally need to go to my bed even if it's just for a wee while, just for a rest. I think there's been times he doesn't really get that. (Julia)

This quote also illustrates the difficulty for the support person in accommodating the changes in the person. Whilst fatigue was a symptom common to all the participants with MS in this study, other symptom patterns were more individual, which is a feature of MS. The narratives discussed in this theme illustrate the profound impact the symptoms of MS had on the participants' daily lives in respect of their physical functioning, as well as the threat of further deteriorating functional capacity through being disabled.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Uncertainty also appeared to be a strand which transcended the whole experience of being a person with MS and was described by Janice:

You don't know what's going to happen. There could be nothing for the next X amount of years or there could be something next week, you don't know. So I think it would just be take it as it comes. (Janice)

The overwhelming sense of uncertainty of life typified the relationship between the individual with MS and their inability to look to the future with certainty. The future seemed filled with possibilities and threats to one's ability, so taking each day as it presented itself was one way of being able to cope. A further aspect to this was that participants found the concept of life filled with uncertainty difficult to understand.

Negotiating health care became part of the participants' experience of learning to live with MS. Some participants described difficulties in accessing health care for MS-related support. For others, once the diagnosis was confirmed, it opened up a range of supportive services, including health care and insurance claims. Being able to access specialist support services and information was seen as a positive aspect to having a confirmed diagnosis, as illustrated by this participant's account:

It is a relief to have a diagnosis... ...if you get that then the whole support services and information opens up to you. (Eileen)

The participants' accounts also illustrated that MS overshadowed their daily lives in their wider social and work related networks, resulting in a degree of social isolation. Becoming

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

socially isolated from daily life and activities was captured in a number of the participant interviews. For one woman, who was the most physically disabled of the participants, her symptoms of MS meant that she was not as able to travel around, even short trips to the shops or hairdresser became major events and she lost contact with most of her friends. For another, isolation came about through changing her work pattern to working at home, losing the social contact that being in the workplace brings. The participants also highlighted certain legal restrictions that are imposed as a result of being diagnosed with MS that may impact on the experience of isolation, such as the impact of having the driving licence temporarily revoked. The data suggest the experience of living with MS appears to be bound to the experiencing of restrictions imposed in one's life and a feeling of uncertainty over the course of the condition.

In summary, these data highlight the impact of biographical disruption precipitated by the diagnosis of MS, instigating a liminal state of being in the world. The findings of this study therefore extend the understanding of the relevance of liminality to the individual's sense of self when diagnosed with MS. The interviews with people who were newly diagnosed, or within six months of diagnosis with MS were used to inform the development of the conceptual framework, *'The liminal self in people with MS'* (see Figure 1). As such the framework can be said to be grounded in the data. The conceptual framework illustrates

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

how the diagnosis of MS may affect the individuals' 'taken for granted' biographical narrative, or sense of self, and as such extends current understanding of this lived experience.

The framework uses the conceptualisation of the theory of liminal self to articulate the lived experience of the person developing and being diagnosed with MS and how it impacts on their sense of self. The "*Preliminal self*" conceptualises the lived experience prior to diagnosis where symptoms of MS are experienced but the cause is not yet known. The "*Threshold concept*" is a useful metaphor attributed to the point of being diagnosed, as such this moment represents an epistemological shift from not knowing to knowing one has MS. As the data suggest, the experience of being diagnosed is a pivotal moment in the transition from person with symptoms to person with MS. The "*Liminal self in MS*" conceptualises the lived experience of biographical disruption where the person's sense of self is in transition, betwixt and between the old self and new self. As such this represents an ontological shift in the individual's concept of self. The "*Post-liminal self in MS*" conceptualises the reincorporation of the sense of self transforming the self as a person with MS, where the diagnosis is part of one's self concept but one is not defined by it. This experience is subject to on-going uncertainty and as such is never quite stable.

DISCUSSION

The presence of physical symptoms prompted the participants in this study to seek help from medical services. In this part of the participant journey, there was, as yet, no label for the symptoms, simply an awareness of something not being quite right and the possibility that it might be 'something serious' and as such the sense of self may be rendered

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

fragile as the symptoms may pose a threat to the person's existence, and way of being-in-the-world. These findings support earlier work by Johnson (2003), who discovered that, even prior to the confirmation of diagnosis, people begin to raise suspicions and worry over what might be the cause of their symptoms, with some considering MS as a possible diagnosis.

Thorne (1993) identified the diagnostic event as particularly significant for people with chronic illness, as not only were they given a name for the cause of their symptoms, but the diagnosis gave a signal as to what the future may hold. This paper extends current understanding to illustrate the meaning participants attributed to the condition itself and how this influenced the transition of the individual's sense of self. The findings and interpretation presented in this paper are supported by previous studies which have explored the experience of being diagnosed with MS, which have highlighted being given a name for the condition as contributing to a reconstruction of identity (Mozo-Dutton, et al. 2012, Toombs, 1995). In his seminal paper Turner (1964) used the metaphor of a threshold to explain the preliminal self as the separation from the old self begins and the person stands at the threshold between their previous way of structuring their identity, which has become invalid as the individual is faced with new characteristics to be incorporated into the self (Turner, 1964). The findings of this paper extend current understanding of the liminal self in the study of chronic conditions by conceptualising the moment of diagnosis as a threshold concept within the context of liminality. The diagnosis process and event may thus be understood as a rite of passage into a new community where one's identity is bound by the social norms and culture that have been built around the diagnosis. The diagnostic event also represents the demarcation whereby the individual moves from a

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

place of familiarity, the old self, to somewhere beyond, which is unfamiliar, unknown and uncertain. This bears similarities to Kelly's (2010) notion of game playing, without knowing the rules of the game, being a person with MS without really knowing what that means for the self. The transition to being a 'self with MS' is overshadowed with uncertainty as the participants struggled to make meaning for the sense of self, with MS thus suggesting a more chaotic interpretation of the experience as suggested by Kralik, et al. (2006).

The current study has highlighted the fluid state of the sense of self, leaving the individual 'betwixt and between', neither well nor ill (Turner, 1964, p46). This feeling of being neither the pre-diagnosis self nor the new self affected by MS was also described by the participants in the current study. Being neither their 'old self' nor a 'new self' was similarly described by Dickson, et al. (2008) in their study of people with chronic fatigue syndrome, with 'identity crisis' one of the main themes.

How the participants experienced living day to day life with MS and how this became part of their new identity and way of being in the world, supported an ontological shift in their sense of self. In the post-liminal phase, biographical reconstruction is an ongoing process that evolves following the period of instability. Several authors have explored the connection between embodied experience and the self in relation to biography (Finlay, 2003, Williams, 2000). In relation to the person with MS, Finlay (2003) explored the dynamic relations between body-self-world in her phenomenological study of 'Ann', a woman with advanced MS. The embodied experience of the symptoms of MS were inextricably intertwined with the sense of self and being-in-the-world and bear relevance to the uncertain future described by the participants in this study.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

The findings in this study highlight that uncertainty was not experienced as a universal phenomenon, rather it is a subjective and socially constructed experience which is often uncomfortable and leads individuals to try to adopt certain ways of coping to minimise their discomfort in the uncertain state. Additionally, the experience of uncertainty by an individual is not a constant state; rather it is a state that fluctuates depending on the context of the condition and the person experiencing it. The experience of uncertainty has been identified as an important concept in the study of a number of chronic illnesses including MS (Charmaz, 2002, Grytten & Måseide, 2005, Johnson, 2003, Kralik et al., 2001, Mishel, 1988, 1990, Mozo-Dutton et al., 2012) which suggests the concept of the liminal self may have relevance to other chronic conditions. In keeping with the findings from previous studies, the findings support uncertainty as an on-going feature of the lived experience with the prevailing threat of relapse (Grytten & Måseide, 2005, Johnson, 2003). However, the current study draws attention to the experience of the individual whose symptoms of MS may not be considered as particularly intrusive. This has implications for nursing and other health care professionals involved in supporting people affected by MS at this time. It is important to recognise the distress that the uncertainty may create regardless of symptoms.

The findings from this study have informed the development of a conceptual framework which brings together a number of theories which were implicit in the data, including biographical disruption (Bury, 1982, Charmaz, 1983), uncertainty theory (Mishel, 1988), transition theory (Kralik 2002), rites of passage (van Gennep, 1960) and threshold concepts (Turner, 1964). Figure 1 shows the relationship between the sub-themes

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

The findings present the lived experience of early symptoms which represent the preliminary phase which is discussed under the theme 'road to diagnosis'. This phase suggests the beginnings of a separation from the individual's conceptualisation of their taken-for-granted pre-symptomatic self and is proposed as the 'preliminal self with MS'.

The concept of the liminal self in MS raises two significant implications. First, the conceptual framework may serve to inform the provision of support for people who are newly diagnosed, by providing insight into the experience of the liminal self and the psychosocial impact of the diagnosis. We found the current experiences of support privileges the experience of physical symptoms over the psycho-social impact of MS. The findings of this study show that being diagnosed with MS is the threshold where individuals begin the process of considering the implications posed by living with the condition. In the initial stages of the liminal self, individuals are often in emotional upset and struggling to make sense of what this means for their own sense of self. It is therefore implied that healthcare professionals supporting those newly diagnosed with MS should consider the provision of support around the time of diagnosis rather than waiting for physical symptoms. The conceptual framework offers health care professionals a context for understanding the person at the individual level and how the diagnosis of MS is understood.

Second, this study presents the conceptual framework as an emerging framework for further research into the study of individuals faced with life changing diagnoses. Further longitudinal research to where individuals with MS were followed through acute exacerbations of their condition would also provide greater insight into the on-going biographical impact of this condition.

Limitations of this study

The findings of this study have been drawn from in-depth qualitative interviews with 10 people with MS in Scotland. This offers a unique perspective from participants within the Scottish context. As such the findings are not intended to be generalisable beyond this setting, however they may have relevance to others in similar settings.

The timescale of the study allowed for one follow up interview with each participant at six to twelve months after the initial interview. This provided some longitudinal data which highlighted early impact of the diagnosis of MS on the sense of self for the person with MS and their support person. Kralik, et al. (2006) suggest longitudinal studies are required to capture the full biographical transition experience. A longer timescale may have allowed for deeper exploration and understanding of the biographical impact as it is possible that the post-liminal self will be subject to further threshold moments due to relapses of MS. With these limitations in mind the conceptual framework is presented as an emergent framework which requires further testing.

CONCLUSION

The aim of this study was to explore the experiences of the person newly diagnosed with MS, to develop an understanding of the lived experience and in particular the impact on the individual's sense of self and how individuals affected manage the transition to living with MS. The interpretive approach allowed the participants to reflect upon their lived experience and construct narratives around that experience. These narratives helped to communicate the meaning of the experience for the individual's biographical narrative.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

This study provides an in-depth understanding of the experience of being diagnosed with MS and the subsequent impact on the patient's biographical narrative, which contributes to current understanding on the experience of people with MS. This paper articulates the experiences the liminal self in the person newly diagnosed with MS and offers a preliminary conceptual framework as a way of understanding that experience for health care professionals. The provision of high quality care that is sensitive to the needs of the person is of particular importance for individuals with a new diagnosis. The framework presented can inform health care professionals about nature and needs for supportive care around the time of diagnosis. The conceptual framework offers the potential for further research to enhance the care of people with MS and may have relevance for other long term conditions.

RELEVANCE TO CLINICAL PRACTICE

The above findings provide practitioners with:

- A new way of understanding the impact of the diagnosis on the individual's sense of self when affected by a new diagnosis of Multiple Sclerosis.
- A framework which can guide health care professionals in the provision of supportive care around the time of diagnosis.
- Evidence to inform the need for the development of interventions to better support people affected by a new diagnosis of Multiple Sclerosis.

Acknowledgments

The authors would like to thank all participants in the study for giving their time and sharing their experiences. The authors would also wish to extend thanks to the staff of the neurology unit who helped recruit the participants for to the study. This study was conducted in part fulfilment of the award of Doctor of Philosophy (Ph.D.) for the first author (XXXXX, 2014).

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

REFERENCES

- Barrett, J. (1995) Multiple Sclerosis. the experience of a disease. *Women's Studies International Forum*, 18(2), 159–171. doi:[http://dx.doi.org/10.1016/0277-5395\(95\)80052-Q](http://dx.doi.org/10.1016/0277-5395(95)80052-Q)
- Blows, E., Bird, L., Seymour, J., & Cox, K. (2012) Liminality as a framework for understanding the experience of cancer survivorship: a literature review. *Journal of Advanced Nursing*, 68(10), 2155–64. doi:10.1111/j.1365-2648.2012.05995.x
- Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167–183.
- Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of health & illness*, 5(2), 168–95.
- Charmaz, K. (2002) Stories and Silences: Disclosures and Self in Chronic Illness. *Qualitative Inquiry*, 8(3), 302–328. doi:10.1177/107780040200800307
- Corbin, J. M. (2003) The Body in Health and Illness. *Qualitative Health Research*, 13(2), 256–267. doi:10.1177/1049732302239603
- Darlston-Jones, D. (2007) Making the connections: the relationship between epistemology and research methods. *The Australian Community Psychologist*, 19(1), 19–27.
- Dickson, A, Knussen, C., & Flowers, P. (2007) Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & Health*, 22(7), 851–867.
doi:10.1080/14768320600976224
- Dickson, A, Knussen, C., & Flowers, P. (2008) ‘That was my old life, it’s almost like a past-life now’: Identity crisis, loss and adjustment amongst people living with

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Chronic Fatigue Syndrome. *Psychology & Health*, 23(4), 459–476.

doi:10.1080/08870440701757393

Dilorenzo, T., Becker-Feigeles, J., Halper, A., & Picone, M. (2008). A qualitative investigation of adaptation in older individuals with multiple sclerosis. *Disability & Rehabilitation*, 30(15), 1088–1097. doi:10.1080/09638280701464256

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999) Evolving guidelines for publication of qualitative research studies in psychology and related fields. *The British Journal Of Clinical Psychology / The British Psychological Society*, 38 (Pt 3), 215–229.

Esmail, S., Huang, J., Lee, I., & Maruska, T. (2010) Couple's Experiences When Men are Diagnosed with Multiple Sclerosis in the Context of Their Sexual Relationship. *Sexuality and Disability*, 28(1), 15–27. doi:10.1007/s11195-009-9144-x

Finlay, L. (2003). The intertwining of body, self and world: A phenomenological study of living with recently-diagnosed multiple sclerosis. *Journal of Phenomenological Psychology*, 34(2), 157–178. doi:10.1163/156916203322847128

Gadamer, H. (1976) *Philosophical Hermeneutics*. Berkeley, CA: University of California Press.

Gagliardi, B. A. (2003) The experience of sexuality for individuals living with multiple sclerosis. *Journal of Clinical Nursing*, 12(4), 571–578. doi:10.1046/j.1365-2702.2003.00739.x

Grytten, N., & Måseide, P. (2005) 'What is expressed is not always what is felt': coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illness*, 1(3), 231–243. doi:10.1179/174239505X56012

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Harrison, T., Stuifbergen, A., Adachi, E., & Becker, H. (2004) Marriage, impairment, and acceptance in persons with multiple sclerosis. *Western journal of nursing research*, 26(3), 266–85, discussion 286–92. doi:10.1177/0193945903260188

Heesen, C., Kolbeck, J., Gold, S. M., Schulz, H., & Schulz, K. H. (2003) Delivering the diagnosis of MS--results of a survey among patients and neurologists. *Acta neurologica Scandinavica*, 107(5), 363–8.

Hepworth, M., Harrison, J., & James, N. (2002) *The Information Needs of People With Multiple Sclerosis (MS)* Retrieved from: <https://dspace.lboro.ac.uk/dspace-jspui/bitstream/2134/3722/1/Information%20needs%20of%20people%20with%20Multiple%20Sclerosis.pdf> accessed: 5th October 2015

Johnson, J. (2003). On receiving the diagnosis of multiple sclerosis : managing the transition. *Multiple Sclerosis*, 9(1), 82–88. doi:10.1191/1352458503ms856oa

Kelly, A. (2010) Lost the feel for the game: meanings of onset and diagnosis of AIDS dementia for significant others. *Qualitative Health Research*, 20(4), 531–40. doi:10.1177/1049732309360537

Koch, T, Jenkin, P., & Kralik, D. (2004) Chronic illness self-management: locating the 'self'. *Journal of Advanced Nursing*, 48(5), 484–92. doi:10.1111/j.1365-2648.2004.03237.x

Koch-Henriksen & Soelberg Sørensen, (2010) The changing demographic pattern of multiple sclerosis epidemiology. *Lancet Neurol.* 9: 520–32

Koopman, W., & Schweitzer, A. (1999). The Journey to Multiple Sclerosis: A Qualitative Study. *Journal of Neuroscience Nursing.*, 31(1), 17.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Kralik, D. (2002) The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39(2), 146–54.

Kralik, D., Brown, M., & Koch, T. (2001) Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing*, 33(5), 594–602.

doi:10.1046/j.1365-2648.2001.01704.x

Kralik, D., Visentin, K., & Van Loon, A. (2006) Transition: a literature review. *Journal of Advanced Nursing*, 55(3), 320–9. doi:10.1111/j.1365-2648.2006.03899.x

Lexell, E. M., Iwarsson, S., & Lund, M. L. (2011) Occupational adaptation in people with multiple sclerosis. *OTJR: Occupation, Participation & Health*, 31(3), 127–134.

Mackenzie, I.S., Morant, S.V., Bloomfield, G.A., MacDonald, T.M., O'Riordan, J. (2013) Incidence and prevalence of multiple sclerosis in the UK 1990 – 2010: a descriptive study in the General Practice Research Database. *Journal of Neurology, Neurosurgery & Psychiatry*, 0: 1-9 doi: 10.1136/jnnp-2013-305450.x

Mishel, M. H. (1988) Uncertainty in illness. *Image: Journal of Nursing Scholarship*, 20(4), 225–232.

Mishel, M. H. (1990) Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship*, 22(4), 256–262.

Mishel, M. H., & Braden, C. J. (1988) Finding meaning: antecedents of uncertainty in illness. *Nursing Research*, 37(2), 98.

Mozo-Dutton, L., Boot, J., & Simpson, J. (2012) MS and me: Exploring the impact of multiple sclerosis on perceptions of self. *Disability Rehabilitation*. 34(14):1208-17. doi: 10.3109/09638288.2011.638032.

MS Trust. (2005). Key Facts about MS. Letchworth Garden City: MS Trust. Retrieved from <http://www.ms-trust.org.uk/information/keyfacts.jsp>

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Navon, L., & Amira, M. (2004) Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Social science & medicine* (1982), 58(11), 2337–47. doi:10.1016/j.socscimed.2003.08.029

<https://www.nice.org.uk/guidance/cg186> Date accessed: 5th October 2015

Newby, N. M. (1996) Chronic illness and the family life-cycle. *Journal of Advanced Nursing*, 23(4), 786–791. doi:10.1111/j.1365-2648.1996.tb00052.x

NHS England (2014) *Five Year Forward View*. Available at: <https://www.england.nhs.uk/ourwork/futurehhs/> (accessed 23rd August 2016)

O’connor, E. J., McCabe, M. P., & Firth, L. (2008) The impact of neurological illness on marital relationships. *Journal of sex & marital therapy*, 34(2), 115–32. doi:10.1080/00926230701636189

Sanderson, T., Calnan, M., Morris, M., Richards, P., & Hewlett, S. (2011) Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociology of health & illness*, 33(4), 618–33. doi:10.1111/j.1467-9566.2010.01305.x

Scottish Government. (2009). *Improving health and wellbeing of people with long term conditions in Scotland: a national action plan* (Vol. 23).

Smith, J. A., Flowers, P., & Larkin, M. (2009) *Interpretative Phenomenological Analysis. Theory, method and research*. London: SAGE Publications.

Smith, J. A., & Osborn, M. (2008) Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology A practical guide to research methods* (Vol. 7, pp. 53–80). London: Sage Publications.

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

XXXXXXXX, K. (2014) *A phenomenological exploration of the biographical impact of newly diagnosed MS on the individual and their support person*. Unpublished PhD thesis, Edinburgh Napier University.

xxxxxxxxxxxxxxxxxxxxxxxx (2015) The experiences of support persons of people newly diagnosed with Multiple Sclerosis: An interpretative phenomenological study. *Journal of Advanced Nursing*. (Early View) DOI: 10.1111/jan.12758

Thorne, S. (1993) *Negotiating Health Care: The social context of chronic illness*. London: Sage.

Toombs, S. K. (1995) Sufficient unto the day. A life with Multiple Sclerosis. In S. K. Toombs, D. Barnard, & R. Carson (Eds.), *Chronic Illness. From Experience to Policy*. (pp. 3–23). Indiana: Indiana University Press.

Turner, V. (1964) Betwixt and Between: The liminal period in Rites de Passage. *The Proceedings of the American Ethnological Society* (pp. 4–20).

Van Gennep, A. (1960) *The Rites of Passage*. Chicago: University of Chicago Press.

Van Gennip, I.E., Pasman, H.R.W., Oosterveld-Vlug, M.G., Willems, D.L., Onwuteaka-Philipsen, B.D. (2013) The development of a model of dignity in illness based on qualitative interviews with seriously ill patients. *International Journal of Nursing Studies*. 50: 1080-1089.

World Health Organisation. (2014) *GLOBAL STATUS REPORT on noncommunicable diseases 2014*. WHO, Geneva.

Williams, S. (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*, 22(1), 40–67. doi:10.1111/1467-9566.00191

Words: 7747

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

Pseudonym	Age	Gender
Julia	25	F
Billy	35	M
Ruth	42	F
Steven	36	M
Sheila	34	F
Janice	42	F
Lynne	49	F
Lorna	40	F
Eileen	45	F
Nancy	44	F

Table One: Participant demographics-REMOVE TABLE

Key steps in Interpretative Phenomenological Analysis (Smith, Flowers & Larkin, 2009)
1. Reading & re-reading
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases
7. Writing up

Table OneTwo: Key steps in IPA process

THE LIMINAL SELF IN MULTIPLE SCLEROSIS

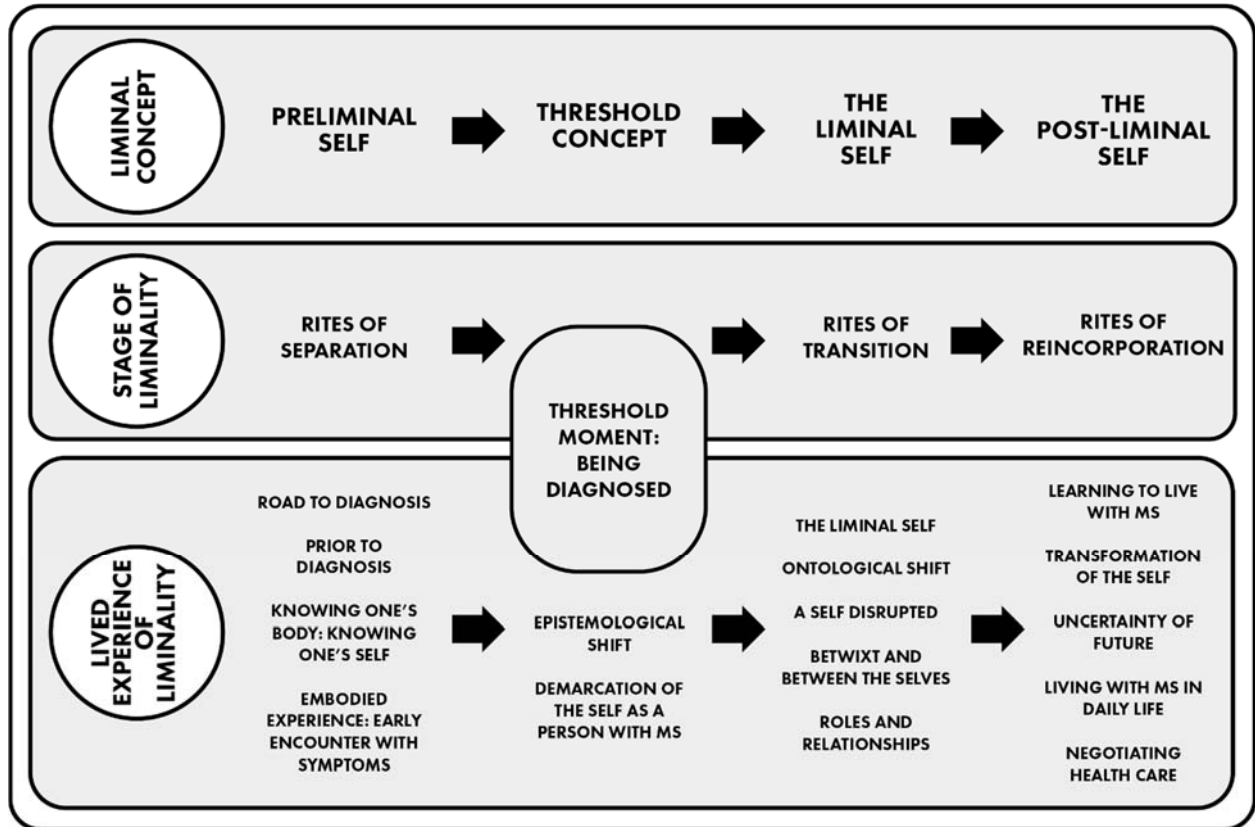


Figure One: The liminal self in people with MS