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Abstract

Aim. This study explores the experience of the diagnosis of Multiple Sclerosis for the support person and identifies the impact on their lives.

Background. At the time of diagnosis the support person may not be readily identified in a traditional caring role, however the diagnosis itself brings with it the possibility of changes to the roles within the relationship and possible consequences for biographical construction.

Design. A hermeneutic phenomenological study.

Methods. A convenience sample of nine support persons was interviewed between December 2008 and March 2010. The data were analysed using interpretative phenomenological analysis.

Findings

The participants in this study were often not readily identifiable as "carers" however the diagnosis of Multiple Sclerosis implied a shift towards a caring role at some point in the future. The uncertainty surrounding the nature and progression of the condition left this identity hanging, incomplete and as such contributed to a liminal way of being.

Conclusions This paper reveals that biographical disruption is not limited to the person diagnosed with Multiple Sclerosis but that the support person also undergoes a transition to their sense of self to that of *anticipatory carer*. The findings provide insight into the biographical and emotional impact of Multiple Sclerosis on the support persons early in the development of the condition.

Keywords (max 10): Nursing, Psychosocial nursing, Multiple Sclerosis; Biography; Sense of self; Carers; Liminality; Phenomenology; Qualitative research

Summary statement

Why is this research needed?

- It is important to further develop understanding about how support persons of people who are newly diagnosed with Multiple Sclerosis experience the condition.
- Previous research has focused on individuals in a “hands on” caring role which does not capture the experience of those supporting the person who is newly diagnosed with a chronic condition.

What are the key findings?

(bullet point removed)

- A *shared journey*: the experience of being diagnosed with Multiple Sclerosis (MS) by the support person was from a different perspective; that of concerned observer, not quite apart, yet not quite the same.

- The *anticipatory carer* captures the interpretation of the support persons’ accounts that described their anticipation of a change in the nature of the relationship between themselves and the person with MS and to their sense of self, from partner or parent, to that of carer.

- The *need for support* of the support persons is evident as they did not want to share their worries with the person with MS for fear of adding a burden. The emotional impact of being the support person was also highlighted through feeling isolated.

How should the findings be used to influence practice and/or research?

- The anticipatory carer provides a way of understanding the lived experience of the support persons of people newly diagnosed with MS. This conceptualization provides knowledge for health professionals on how to understand this experience and thus be better able to provide support.

- The theory of liminality could be further developed to provide a framework for support for the anticipatory carer.
- Further research is required to explore the utility of liminality as a framework for understanding the experience of the anticipatory carer.

INTRODUCTION

Multiple Sclerosis (MS) is a complex and unpredictable degenerative neurological condition which commonly presents in young adults in their 20s and 30s and is more common in women than in men. It is estimated that more than 2,000,000 people around the world have MS and it is more common in populations further away from the equator (Wu & Alvarez, 2011). Within the United Kingdom (UK) MS affects more than 100,000 people, with Scotland having the highest incidence of MS worldwide (MS Trust, 2014). The MS International Federation map of MS shows the worldwide incidence and spread of MS (Figure 1).

Being diagnosed with a chronic condition is a significant life event which may result in a change in the way individuals perceive their “self” (Bury, 1982; Newby, 1996). The wider impact of the condition on those close to the person with MS has been associated with significant impact on psychological and emotional wellbeing (Ray & Street, 2007). Despite the fact that physical care may not be required for the person in the early stages of living with MS, the need for support within close relationships has been highlighted as an important factor in influencing a positive transition to living with MS (Harrison et al., 2004; Gagliardi, 2003).

Background

The term ‘carer’ has been defined almost exclusively in terms of physical activities required to help an individual with a particular disability or condition, with much of the literature relating to carer roles referring to those with physical caring duties, such as providing personal care, and administration and monitoring of medications (Eriksson & Svedlund, 2006; Ferrell et al, 1993; Murray et al., 2002; Nolan & Grant, 1989; Persson et al 1998). In addition, much of the literature is related to older individuals where chronic illness is often interpreted as an inevitable consequence of the aging process (Adamson & Donovan, 2005; Ray, 2006). This term ‘carer’ does not fit well with the support person of the newly diagnosed person with MS, as the support person may not be actively engaged in traditional caring duties, nor may they identify themselves as ‘carers’. To avoid confusion, in relation to the possibility of people not identifying themselves as ‘carers’, the term ‘support person’ has been used to refer to those close to the person with MS, however, when reviewing the literature it is acknowledged that a variety of terms have been used including carer, relative, and partner.

The experience of chronic illness within a coupled or parental relationship has been researched within the context of a number of conditions, with the experience of couples affected by stroke (Burton, 2000; Eriksson & Svedlund, 2006; Pringle, 2011) and cancer (Badr & Taylor, 2008; Belcher et al., 2011; Fergus, 2011; Navon & Amira, 2004; Zunkel, 2002) being among those most commonly researched. Previous studies in MS have identified couple relationships as an important social context within which the psychological process of learning to live with MS is managed (Esmail et al, 2010; Harrison, Stuifbergen, Adachi, & Becker, 2004; O’Connor et al, 2008; Pakenham, 2008; Starks et al, 2010). Themes from this body of literature suggest that the chronic conditions may significantly affect the experience of psychological adjustment to living with the condition for both partners (Burton, 2000; Belcher, et al., 2011; Fergus, 2011; Navon & Armina, 2004).

The need for psychological support for the support person has been highlighted in several studies (O’Connor et al., 2008; Pakenham, 2001; Pakenham, 1998) with Pakenham (2001) highlighting a correlation between a lack of social support and psychological distress. Cheung and Hocking (2004) conceptualised the experience of the support person as “caring as worrying”, with worries about their own health, their relationship, and lack of support, indicating an internalisation of the process which may cause psychological distress. It should be acknowledged that the participants in this study all provided at least one hour of hands-on care per day to the person with MS, therefore the findings may not be so relevant to the support person of the person in the early stages of living with MS.

The context of the coupled relationship and type of MS is also important, as Starks et al. (2010) highlight responses to the demands and stressors of MS, which they identified as being “in-sync” and “out-of-synch” (p 196) with each other. The authors identified the characteristics which indicated which category a couple would fall into, with “in-sync” couples having a relapsing-remitting type of MS, which was relatively stable, allowing both partners to maintain their social roles and identity, and a collaborative problem solving style. The characteristics of out-of-sync couples include rapid progression of MS, having to give up work early, oppositional styles of responding to the increased demands and stress of MS, and struggles with parenting adolescent children and increased caring demands for the support person. Several studies have drawn attention to the impact of MS on the sexual relationships of couples, with some participants having a positive outlook despite their symptoms of MS and others experiencing psychological distress when they could no longer participate in sexual intercourse due to the impact of their MS on the relationship (Gagliardi, 2003; Harrison et al., 2004; Esmail, et al., 2010). Koch et al. (2002) suggest there is a close link between the individual’s construction of sexuality and the shift in identity and perceptions of the self.

A qualitative study involving a focus group with twelve spousal carers of people with MS found that the spouses of people with MS struggled to maintain their identity in the face of changes to their role from partner to caregiver within the relationship (Courts et al., 2005). The impact of MS related symptoms and disability have been found to cause a degree of disruption within the couple relationship in people with MS (Gagliardi, 2003; Harrison et al., 2004; Koch et al., 2002; Kralik et al., 2003). While some have focused on the experiences of the person with MS (Koch et al., 2004; Kralik et al., 2003), Harrison et al. (2004) explored the impact of MS-related disability on marital relationships. Harrison et al’s (2004) findings imply that the quality and stability of the marital relationship influences the person with MS’s ability to accept their disability, suggesting that being in a stable relationship may have therapeutic effects for some people with MS.

Bury’s (1982) work on biographical disruption and Charmaz’s (1983) on loss of self has contributed significantly to current understanding of the impact of chronic illness on the sense of self. Bury (1982) defines biographical disruption as having three aspects to it; “taken-for-granted assumptions and behaviours”, “fundamental re-thinking of self-concept” and “response to disruption and mobilisation of resources”. The theoretical framework for this study has been underpinned by Bury’s theory of biographical disruption. The majority of studies focusing on biographical disruption do so from the perspective of the person with the condition with little consideration having been given to the experience of the support person. Where studies have explored the experiences of the carer, the majority have been conducted with participants who have a clearly defined carer role, therefore little is known about the impact of MS on the support person in the early months of learning to live with the condition. This paper seeks to explore this aspect of the lived experience in order to articulate this aspect of the support person's journey and to identify any support needs. The finding presented here are part of a wider study where the experiences of the person with MS were also explored (XXXXX, 2014). This paper presents the findings from the research question, "What is the impact of the diagnosis of MS on the support person?"

THE STUDY

Aim

The aim of the study was to explore the impact of the diagnosis of MS on the support person.

Design

This qualitative study was underpinned by interpretative phenomenological analysis (IPA) which is a relatively recent development in qualitative research (Smith et al., 2009). IPA has its roots in philosophical phenomenology with the hermeneutic circle being central to the approach, (Smith et al., 2009) The epistemology of IPA is grounded in interpretative inquiry of the narratives of the individual's lived experiences, therefore research questions should be focused on understandings of experiences and as such be exploratory in nature as opposed to explanatory (Smith et al., 2009). In this sense IPA is idiographic as the individual experience and the meaning of that experience is of paramount importance (Smith and Osborn, 2008). Smith, et al. (2009) discuss the congruence of IPA and social constructionism as the approach seeks to uncover the lived experiences of the individual and make explicit the meaning they construct related to the experience within their own social context (Smith & Osborn, 2008).

Sampling and recruitment

People newly diagnosed with MS were recruited to the study from a Neurology Clinic in one health board in the UK. Qualitative research demands that participants are representative of the sample (Barbour, 2008). Therefore the support persons were nominated for participation by the person newly diagnosed with MS who agreed to participate in the wider study. This form of convenience sampling ensured that participants met the criteria of having experience of someone close who had been diagnosed with MS. Each participate was contacted individually and provided with information about the study prior to agreeing to participate.

Description of participants

Data collection took place between December 2008 and March 2010. Data presented here are drawn from the nine support persons nominated by the persons with MS to participate in this study. Participants were interviewed between two weeks and six months of the persons with MS being diagnosed. Follow up interviews were conducted between six to twelve months following the initial interview. Whilst saturation is not a key feature of IPA, the second interviews allowed the researcher to return to the field to follow up on initial themes from the first interviews, thus adding depth to the themes (Barbour, 2008). One participant and their support person were not contactable at the follow up interview.

Data collection

In-depth semi-structured interviews were conducted in the participants' homes. Participants were given the choice to be interviewed together or separately. As part of the wider study the experiences of the person with MS were also explored and are reported elsewhere (XXXXX, 2014). Five participant pairs were interviewed together and the remaining participants were interviewed individually. When asking participants' preference in interviewing, those who opted for joint interviews did so by stressing they “had no secrets” and that the MS had affected them both, so it was appropriate to be interviewed together. This is similar to Morris' (2001) experience when interviewing couples affected by cancer, who found that antagonism may arise in individual interviews as the “spectre of secrets” (p 555) is raised by the potential non-disclosure of interview discussions.

The semi-structured interviews allowed for active engagement of the participant and researcher in focused dialogue where the participant recounted their life story as a narrative construction of their experience (Darlston-Jones, 2007). An interview guide which covered the main topics of interest was used to guide the interviews but also allowed a degree of flexibility for the participant to direct the flow of the conversation with only occasional input from the researcher to ensure that the key topics were addressed. 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 the time leading 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. All interviews were recorded on a digital recorder and transcribed verbatim.

Ethical considerations

Ethical approval for this study was granted by the relevant ethics committees and approval to proceed was given. Potential participants were provided with written information about the study and offered the opportunity to participate. 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 loved one’s care. Written consent was obtained prior to the first interview and verbal consent was gained prior to the follow up interview. Pseudonyms were given to each participant to protect anonymity.

The possible therapeutic value of research interviews has been well documented in the literature (Elmir et al., 2011; Holloway & Freshwater, 2007). Holloway & Freshwater (2007) suggest storytelling in the qualitative interview may also help participants to develop resilience: as they recount their experiences they develop new understandings. Details of additional support post interviews were available to participants but were not required.

Data analysis

The analysis process followed Smith, Flowers and Larkin's (2009) seven steps (see Table One). IPA has been used in a number of biographical studies researching in chronic illness (Dickson et al., 2008a; Dickson et al., 2008b; Dickson et al., 2011). A defining feature of IPA is the idiographic nature of the analysis process. IPA advocates analysing each participant's account, respecting the individual nature of that account before moving on to the next case. This approach to analysis is particularly suited to the study of identify as the triple layer analysis focuses on descriptive noting, linguistic noting and conceptual noting.

[INSERT TABLE ONE]

During the analysis the first author made notes on different types of comments on each transcript including descriptive comments and asked interrogative questions of the data such as: "what is it like to experience this situation from the participant's viewpoint?", "what is the person really saying here?", "what is the real issue, the meaning in this extract?". During the linguistic analysis phase, how participants talked about the condition and the self is the focus of the analysis (Smith et al., 2009). For example, the use of the personal pronoun (I or you) in interview transcripts when participants were describing the impact of MS on the self was particularly relevant to assess the use of distancing language, or considering the emphasis placed on experiences described through the use of repetition and metaphors (Smith et al., 2009).

The conceptual analysis involved developing *in vivo* themes which offered a conceptualisation of the meaning in the data. Further interpretative analysis of the themes allowed these to be integrated into three major themes. To be classified as a major theme, the theme occurred in at least half of all of the participants' interviews and was therefore presenting as a pattern across the cases (Smith Flowers & Larkin, 2009).

Rigour

The first author conducted the data collection and the majority of the data analysis whoever 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. This was complemented by ongoing discussion of the emerging themes between the authors. In addition to this formal credibility check, accounts from the person with MS (XXXXX, 2014) provided a different qualitative perspective allowing triangulation of data with the support person's accounts, to assess the credibility of the data.

FINDINGS

Of the nine participants, there were five women and four men, aged between 25 and 80 years. Six of the participants were partners of the person with MS and there were three who were mothers of the person with MS. Three key themes were identified: “a shared journey”, “the anticipatory carer” and “the need for support”. The themes are illustrated by the quotes taken from the participant interviews.

A shared journey

The description of the experience of supporting the person being diagnosed was described by the participants as a journey. To a certain extent, the support person's journey echoed that of the person with MS, yet the experience was from a different perspective; that of concerned observer, not quite apart, yet not quite the same. Of great significance to many, were concerns about the cause of the symptoms, or finding out the definitive diagnosis. For the support persons, this journey was often an emotional one, where they sat alongside the person with MS, sharing some of their anxieties, worries and concerns:

> “Up until the actual diagnosis both of us were sitting there knowing, or individually thinking that there was something else more wrong with Ruth.” (Brian)

The sense of concern for the person with MS was common and supports the shared element of the experience, yet Brian's description of them “individually thinking” illustrates the individual aspect of the experience which is shared but not the same. The sense of frustration was also acknowledged as a shared experience, as illustrated in the following account:

> "But as far as the doctors were concerned, as Lorna said, it was frustrating I know for her and it was frustrating for me that it went on for a couple of months, not knowing why she was going for an MRI and what they were looking for." (Nic)

The emotional impact of the experience is strong and the participants often stressed their shared sense of frustration. Terms such as scary, worried, fearful, and angry were commonplace in the data. Often the support persons were left out from key consultations with medical and nursing staff as discussions focused on the person with MS. The support persons did not appear to have any identifiable source of support around this time.

Feelings of anger and guilt were also common. Jean's experience was complicated by her son's previous mental health problems, as his symptoms had been attributed either to being psychosomatic or a possible side effect of medication. Allowing his symptoms to be attributed to this was a source of frustration and guilt for his mother:

> "I am quite angry at myself for accepting that it was just the tablets but because it coincided with the blips of Billy taking his tablets that allowed me to accept that it could have been the medication. So I am angry at myself and the health service because they are qualified, I am not." (Jean)

The data from the support persons suggest being diagnosed is a shared experience with the person with MS, and that this is an emotionally troublesome experience. This was evident with participants drawing on instances they experienced alongside the person with MS.

The anticipatory carer

The anticipatory carer captures the interpretation of the support persons' accounts that described their anticipation of a change in the nature of the relationship between themselves and the person with MS, from partner or parent, to that of carer. All of the support persons reported a slight change in the relationship, whereby they had taken on certain chores that had previously been the domain of the person with MS. The data were rich in narratives that expressed an anticipation of being a carer at some point in the future.

> "I have had to think about it from the point of view that I may, at some point, be in a position of being a central carer in Lorna's life and that initially was a big mental shift. But then I had to think about well yes, but Lorna does what she can for herself now, so she's not there yet and she may never be there and if she is we'll support her to do as much as she can for herself." (Nic)

The "big mental shift", described by Nic, suggests a degree of cognitive dissonance with the potential change of role and subsequent impact on her identity. The sense of uncertainty in the participant narratives suggest that even though there is the prospect of becoming a carer, it may never happen, therefore the conceptualisation of the "anticipatory carer" suggests a liminal state of being.

Anticipating having to make significant changes to living and lifestyle arrangements was also prevalent in the support person narratives. For some, this included considering moving house to accommodate future physical impairment:

> "Initially we kind of had this... not panic, but we kind of thought oh maybe we should move flat and go to somewhere at ground level and you know, on the basis that we have to prepare. And then you kind of calm down a bit and you think well wait a minute, we're fine! Fine, we don't need to do that now." (Nic)

This reaction was fairly typical of the support persons' initial thoughts about MS, however once the initial anxieties subsided, more realistic thoughts took place. One of the participants however, put the diagnosis of MS into perspective by explaining that as they had lived with the symptoms of MS for some time prior to receiving a confirmed diagnosis, there was no need to make rash decisions:

> "Our whole world's not going to revolve around the fact that Billy has got MS, we're going to accept it and get on with it and deal with it. We have actually dealt with it for three years to be honest this is actually nothing new, it now just has a name." (Jean)

Anticipating the impact of MS was commonplace and taking steps to minimise these became part of the role of the support person, almost like a buffering role. Taking each day as it comes was a sentiment shared by many of the support persons. The anticipation of change as an inevitable consequence of MS is strong in the data. This supports the need for accurate information and support for the support person as they too adapt to living life with MS.

The "anticipatory carer" theme has highlighted the impact of being diagnosed with MS on the role of the support person as they anticipated a shift in their identity from partner or parent to carer. The findings presented here suggest this is not an easy transition; rather the person's sense of self is disrupted from the taken-for-granted roles in their established relationship to an incomplete transition to "anticipatory carer".

Need for support

The previous themes have alluded to the need for support for the support persons, however during the course of the research interviews it became clear that these interviews were, for some, the only time they were able to speak openly about how the diagnosis of MS had impacted upon them. The emotional impact of being the support person was also highlighted as many of the support persons alluded to feeling isolated or not having anyone to listen to their worries. This suggests an emotional burden of care for the anticipatory carer, which highlighted the *need for support* of the support persons as they also shared the experience of learning to live with MS. Not wanting to share their worries with the person with MS for fear of adding a burden was voiced by many of the participants:

> "If you're in the capacity as I am as a support person for Lorna, having somebody to go to and talk to about it independently of the person that you're with or that you're supporting is quite important to have. Somebody who is outside that, so you can be honest about how you feel without feeling guilty and without certainly burdening the person who has the diagnosis." (Nic)

The need for individual support, focused on the experiences of the support person so they can express their feelings honestly, is clear. Participants described having to shield their own feelings about MS to maintain a façade of coping, "being strong" for the person with MS. Not being a burden and "just wanting to speak to someone" were common phrases used by the support persons, which further supported the interpretation of the anticipatory carer role as one which requires support. For one of the support persons interviewed, the research interview itself appeared to have a therapeutic value for her:

> "I am glad I have spoken to somebody, I feel better myself that I have spoken to somebody." (Judy)

The research interview allowed this participant to speak freely about her feelings without fear of upsetting or burdening her partner. Up until this point she had not had this opportunity. As well as needing support, the data demonstrate the need for the support persons to be adequately informed about MS to be able to support their loved one. The support persons were often asked lots of questions about MS as the persons with MS struggled with the diagnosis:

> "He kept asking me these questions at the beginning and I couldn't help him… I had to make him phone the doctor to go and see the nurse but he was asking me all these questions and I says I don't know. So one day… I says to him I want you to phone that MS nurse and get an appointment, I had to be quite firm because I was getting bombarded with all these questions and I couldn't help him." (Judy)

This account highlights a feeling of being helpless, as the support person could not respond to questions about MS. These data suggest it is necessary for the support persons to be informed, so that they are better able to support the person with MS. These findings articulate the need for support for the support persons both on an emotional level and for practical information and support about MS. There appeared to be a complete absence of support available which is focused on the needs of the support person as descriptions of support available were notable by their complete absence in the data.

DISCUSSION

The findings suggest a disruption to the support person's taken-for-granted identity, from that of partner/parent to anticipatory carer. Few studies have focused on the shared experience of support persons, or as they are more commonly referred to in the literature, "carers" or "significant others" (Cheung & Hocking, 2004; Kelly, 2010; Murray et al. 2002; Nolan & Grant, 1988). The support persons of people with newly diagnosed MS are often not yet in "hands-on" caring roles; however the term anticipatory carer articulates the recognition of a potential change to their role within the established relationship. The uncertainty that clouds this experience, along with a lack of information and support, means that the support persons are often learning the rules of engagement as they go along. These findings are similar to earlier work relating to the support persons of people with early onset of dementia (Kelly, 2010). Drawing on Bourdieu's theory of habitus (Bourdieu, 1984), Kelly likened the altered state of personhood as like learning to play a new game where the rules are unknown and the game players are unprepared.

The experience of the support persons drew attention to the "shared journey", where their experience as concerned observer, not quite apart from, yet not quite the same as the person with MS. While the support person's experience differed from the person with MS in that they did not have an embodied experience, the knowledge of their loved one experiencing unexplained symptoms caused worry in most cases. This finding is also reflected in a qualitative study of carers of people with chronic illness (Cheung & Hocking, 2004). Cheung and Hocking (2004) described the emotional impact on the carers as "caring as worrying" whereby carers worried about their partners, their relationship and their future. Previous studies in MS have identified couple relationships as important “social context within which the psychological aspects of chronic illness are managed” (Harrison et al., 2004, p267). Harrison et al.’s (2004) longitudinal study over six years explored the impact of MS-related disability on marital relationships. Their findings suggest that partner roles can be important in marriages, and when they are unexpectedly changed due to disability, the relationship may be threatened. The findings presented in this paper suggest the changing context of the relationship is particularly relevant for the support persons as the impact of early symptoms including fatigue, caused a major stress between couples. This suggests that the need for accurate information regarding the nature of MS is required to support the support persons at this early stage of being with the person with MS.

As the support persons faced the prospect of becoming a carer, the nature of MS did not allow for them to determine when this would happen, if at all. This potential change in role signifies the beginning of the “anticipatory carer” identity which may precipitate additional lifestyle adjustments. The conceptualisation of lived experience as the “anticipatory carer” helps to explain the impact of the experience on the individual’s sense of self, where previous conceptualisations of the self within the relationship are no longer valid, yet the new identity is not yet fully defined. This is reflected by Courts et al., (2005) who found that the spouses of people with MS struggled to maintain their identity in the face of changes to their role within the relationship. Whilst previous studies have articulated this issue in relation to carers who have a direct “hands on” caring role (Eriksson & Svedlund, 2006; Ferrell et al., 1993; Murray et al., 2002), the present study highlights the impact on the identity of the support person where they do not have a clear role as direct care giver. The “anticipatory carer” therefore contributes to our understanding of the experience of the support person of those newly diagnosed with MS. The incomplete transition of the support person’s identity from partner or parent to carer can be likened to the concept of liminality which refers to a stage where participants "stand 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). This stage of liminality is often referred to as “betwixt and between” where the sense of self has become unbalanced and is ambiguous (Barrett

1995; Turner, 1964). Turner (1964) suggests this phase is a transitional phase where the person is in a “state of progressive movement” to “becoming” a new self (Turner, 1964, p46). The anticipatory carer alludes to a liminal way of being as individuals begin to process the information and begin to attribute meanings for the self as being the support person of the person with MS.

The support persons’ experience gave a strong sense of isolation with some reporting that the interview itself had been therapeutic as they had no-one outside the relationship to talk to about how they felt about the experience of MS. Not wanting to be a burden to the person with MS, and “just wanting to speak to someone” were common phrases used by the support persons which further supported the interpretation of the anticipatory carer role as one which requires support which is currently not readily available. Carer burden is widely discussed in chronic illness literature but this mainly focused on carers who are engaged in physical caring duties rather than in the early stages of learning to live with a chronic condition (O’Connor et al., 2008; Pakenham, 2007; Pakenham, 1998). It is possible that carer burden, in relation to the emotional burden that is carried, is overlooked. The findings from this study provide insights into what it is like to provide support to someone newly diagnosed with MS, in the absence of external support to fulfil that role. It has been suggested that there may be a link between the perceived levels of carer burden and satisfaction with caring, and perceived quality of life (Bogosian, Moss-Morris, Yardley, & Dennison, 2009). The consequences of this are of relevance for health care professionals who are involved in supporting individuals who may face being in a caring role.

Limitations

The findings of this study have been drawn from in-depth qualitative interviews with nine support persons of people with MS in one area of the UK. As such the findings are not intended to be generalisable beyond this setting; however they may have relevance to others in similar settings.

Five of the interviews were conducted with the person with MS present. The focus of the interviews also related to the person with MS's experience of being diagnosed. It is possible that the support person's experience was more marginalized in these interviews than in the individual interviews. However the joint interviews allowed for a shared experience to be discussed and as such added depth to the understanding of the experience.

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. A longitudinal study to explore the ongoing impact of MS as the condition develops would help to illustrate the changing nature of the carer role.

CONCLUSION

This paper articulates the experiences of the support person as the "anticipatory carer", a concept where the person understands the significance of the diagnosis yet, is unable to transition to the role of carer and is unsure of what the future holds. This study has drawn from the concept of liminality as a useful construct for understanding the support person experience. As well as highlighting the impact of the diagnosis on the individual's sense of self, this paper has also highlighted the emotional impact and isolated nature of the experience of being the support person of the person newly diagnosed with MS. The paper highlights current lack of available support for this group of people and as such identifies the urgent need for the provision of timely and accessible support. Such support will improve the experience not only for the support persons but also for those with MS as the support persons will be better equipped to provide the support expected of them in their close relationships.

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