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**‘It's the Unknown’ – Understanding Anxiety: From the Perspective of People
with Multiple Sclerosis**

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Abstract

Objective: A qualitative study of PwMS who had clinically significant levels of anxiety was conducted to gain a richer perspective on their experience. The objective was to explore PwMS' experiences of anxiety and their perspectives on causes and outcomes.

Design: Twenty in depth, semi-structured interviews were conducted with PwMS consecutively recruited from the Neurology Department of a NHS University Hospital. Sixteen had a relapsing-remitting course, three had a secondary progressive course and one person had primary progressive MS. Interviews were recorded, transcribed and analysed using inductive thematic analysis.

Results: Although participants thought different factors had initially triggered their anxiety, being given the diagnosis of MS appeared to be the most significant factor for many participants. Difficulties in the workplace and in relationships, particularly related to perceived dependence on others were also important themes. A wide range of emotional responses and negative thinking were associated with anxiety; this suggested the presence of comorbid depression. Participants were able to acknowledge the positive and negative coping strategies that impacted on their anxiety.

Conclusion: This review confirms that anxiety can have many negative implications for PwMS and suggests that early detection and intervention are necessary in order to improve patient wellbeing.

Key words: anxiety, multiple sclerosis, chronic illness, mental health, qualitative

Introduction

Anxiety can be defined as an excessive feeling of unease and worry which individuals find difficult to control, that consequently interferes with their everyday life (American Psychiatric Association, 2000). Worldwide estimates of the proportion of the population who are likely to experience anxiety in their lifetime range between 0.8% and 9% (Kessler, Petukova, Sampson, Zaslavsky, & Wittchen, 2012; Kessler & Wang, 2008). However, for PwMS, anxiety has been found to affect between 15.8% and 57% of the population (Feinstein, O'Connor, Gray, & Feinstein, 1999; Garfield & Lincoln, 2012).

Multiple Sclerosis (MS) is a chronic inflammatory neurological condition of the central nervous system (DeLuca, Genova, Hillary, & Wylie, 2008). Mental health difficulties such as depression and anxiety have been found to be particularly common among PwMS (Janssens et al., 2003). Anxiety symptoms have been found to be amongst the most disabling, impacting overall health and quality of life (Fruhwald, Loffler-Stastka, Eher, Saletu, & Baumhackl, 2001). For PwMS, anxiety may be severe and prolonged due to the individual's concern about the uncertain outcome of future episodes and the potential seriousness of the symptoms (Cecile et al., 2004).

Anxiety among PwMS has been associated with fatigue, younger age of onset (Wood et al., 2013), chronic pain (Kalia & O'Connor, 2005), being female, previous episodes of depression, suicidal thoughts, alcohol abuse, social stressors (Wood et al., 2013) and level of disability (Tsivgoulis et al., 2007). A recent systematic review (Butler, Matcham, & Chalder, 2016) highlighted that anxiety among PwMS is associated with a number of physical, cognitive, social and psychological factors rather than just the

illness itself. The review also drew attention to the high levels of anxiety that exist among PwMS and the need for early intervention and treatment of anxiety throughout the course of MS.

A limited number of qualitative studies have examined the experience of MS. A study exploring the experience of women with MS reported that the physical and emotional aspects of MS were intertwined and the emotional impact of living with a deteriorating and unpredictable condition was emphasized (Blundell Jones, Walsh, & Isaac, 2014). This draws attention to the need for further analysis on emotional experiences related to unpredictability. Other research drew attention to the impact of MS on the self; this impact did not inevitably mean a loss of self but instead a changing self; one capable of dynamism as well as stability (Mozo-Dutton, Simpson, & Boot, 2012). Research examining adjustment in early stage MS reported MS as a distressing and intrusive condition but found that information, support, problem-focused coping, goal adjustment, a positive outlook and a fighting spirit were effective in maintaining an acceptable level of well-being for participants (Dennison, Yardley, Devereux, & Moss-Morris, 2010). These coping strategies however were not examined in relation to anxiety or at later stages of adjustment. Furthermore, recent qualitative research on adjustment reported that some factors identified as influencing adjustment are more difficult to modify (e.g. illness progression and social environment) than others (e.g. emotional reactions, concealing/revealing the condition and perceptions of environment). However, overall the factors that are modifiable are likely to be even more important as the illness progresses and could be incorporated into future interventions (Bogosian, Morgan, Bishop, Day, & Moss-Morris, 2017). These will be important to consider in the context of anxiety for PwMS.

Anxiety has been relatively neglected within the MS literature in comparison to topics

such as depression and cognition despite its clear importance for PwMS (Lobentanz et al., 2004). Specifically there is a deficit of qualitative studies on this topic. Therefore, it would be beneficial for research to examine how anxiety fits into the MS picture independently from depression through qualitative interviews. This study aims to gain a comprehensive understanding of anxiety from the perspective of PwMS, by exploring their views of the factors that influence, determine and impact their anxiety. Implications of such research include suggestions for interventions that could benefit PwMS.

Methods

People with MS were screened for anxiety using the hospital anxiety and depression scale (HADS) by a mental health nurse at a National Health Service (NHS) University hospital in the United Kingdom. Participants were included if they were diagnosed with MS, over 18 years old and were experiencing anxiety. Twenty patients who scored 11 or above on the anxiety sub-scale of the HADS were consecutively recruited from one hundred and twenty consecutively assessed patients. Participants had been diagnosed with MS between two and twenty-seven years previously.

Materials

The HADS was chosen as it was previously found to be a reliable measure of depression and anxiety in a hospital setting (Zigmond & Snaith, 1983) and has been specifically validated for use with PwMS (Honarmand & Feinstein, 2009). The cut-off point of 11 was chosen as this has been reported to be the optimal cut-off point for patients who experience a high probability of experiencing clinically significant anxiety (Zigmond & Snaith, 1983). Within the study, the average anxiety score for participants was 14.15 (S.D. = 2.96). For depression, the average score was 10.2

(S.D.= 4.04). Overall, the average combined distress score for all participants was 23.5 (S.D.= 6.61).

Design

Semi-structured interviews were conducted to explore the nature of anxiety and related concerns that PwMS and anxiety held. The interview schedule devised was based on discussions with clinicians and patients seen in the clinic and focused on the potential sources of anxiety for PwMS. It consisted of eighteen semi-structured questions (see Table 1). The interviews were held over the phone by two postgraduate psychologists who were completing a master's degree in mental health. This was for the convenience of the participants as they were able to do this in their own home without having to travel. The interviews were recorded.

(Insert Table 1: Interview Schedule Questions)

Before the interview, participants were given the opportunity to ask any questions and were told they could withdraw from the study at any time. Semi-structured interviews were conducted using the interview schedule. The interviews lasted between thirty and sixty minutes (mean time=42.16 minutes). All participants were offered a follow-up session after the interview with the MS mental health nurse if they wanted it. This was to ensure that the participants were supported with any undue distress caused by the topics raised.

Each interview was audio-recorded and subsequently transcribed verbatim following the data protection guidelines by the first author (EB). The transcript was then examined against the audio recording to ensure accuracy. Responses were then analysed using the inductive thematic analysis procedure (Braun & Clarke, 2006). For this analysis, the interviews were initially read repeatedly to identify meaningful units

of text relevant to the topic. Secondly, units of text were coded and assigned a descriptive name in Nvivo 10 software by the first author. When possible, these codes reflected participants' vocabulary and were redefined and combined, with new and alternative codes being generated (Glaser & Straus, 2012). Broader themes were identified and organised into a preliminary framework. Written accounts of themes were repeatedly checked against transcripts to ensure they accurately represented the data (Patton, 1990). The same unit of text could be included in more than one category (Tesch, 1990). The data was systematically reviewed to ensure that a name, definition and an exhaustive set of data to support each category was identified. Finally, the categories were grouped into themes and sub themes. Interviewing continued until data saturation was reached and no new themes were being identified.

To increase the robustness of the analysis, every second interview was independently coded by the second author (RT). Thematic coding, identification of themes and construction of the final framework occurred through discussions amongst three of the authors (EB, RT and TC). Areas of disagreements were resolved by consensus. This analysis was conducted in line with published guidelines on qualitative analysis (Elliott, Fischer, & Rennie, 1999).

Findings

Table 2 describes the sample. The majority were women, single, white British, educated to at least A level (final examinations for secondary or pre-university education) and their MS was more likely to have a relapsing remitting course.

(Insert Table 2.)

Inductive thematic analysis led to four main themes from the interviews. The number of participants whose responses featured under each theme is indicated (See Table 3) and a diagram of the themes is illustrated (see Figure 1).

(Insert Table 3: Summary of main themes and subthemes)

(Insert Figure 1: Thematic representation of themes related to anxiety in people with MS)

How it began (the development of anxiety)

Big life events

Fifteen of the participants mentioned the development of anxiety early in life. This was often linked to key events that triggered symptoms. For example, one participant felt that her adoption was likely to have contributed to her current mental state.

‘I was adopted quite young so the loss of mother..’ (P11)

Other stressful life events that formed the basis for other participants’ anxious tendencies were associated with seeing a close family member go through a debilitating sickness. For example, P7’s father was diagnosed with motor-neurone disease and P5’s sister contracted meningitis.

‘I was sixteen when my oldest sister got meningitis and had to have her limbs amputated and that was a pretty horrific ordeal for my whole family. It made me very anxious’ (P5)

It’s part of my personality

Seven of the participants linked anxiety symptoms to their personality. For example, P9 described herself as always feeling like an anxious person.

‘I kind of think of myself as a slightly uptight and anxious person’ (P9)

Four participants suggested that an anxious temperament followed by the diagnosis of MS, magnified their anxiety levels.

‘Obviously it happened before (the diagnosis) but just not as severe’ (P1)

For the remaining participants, their experiences with anxiety began with the diagnosis of MS.

Response to my diagnosis

A diagnosis of MS had a profound effect on the mental state of the participants. P3 recalled the diagnosis as an ‘upsetting’ time that caused ‘a total panic’. P8 too, associated her anxiety to her first appointment with the neurologist, who at first wrongly associated her symptoms with a stroke. Some participants felt a sense of disbelief.

‘I found it quite hard at first to accept the diagnosis and I thought for a long time it could be something else’ (P16)

“ I was quite worried because you know something is wrong but you don't know what it is, you don't know how serious it is and what's going to happen to you”. (P2)

Two of the participants had close family members who had been diagnosed with MS. They felt this intimate knowledge of MS symptoms was likely to have triggered their anxiety when they were diagnosed themselves. The unavailability of treatment and information and lack of predictability of the illness at diagnosis further triggered anxiety for many of the participants.

‘Being told that you have a condition where there is no cure, there is no available treatment, I mean you are on death-row’ (P17)

Getting on with life (impact on life with MS and Anxiety)

MS and anxiety making each other worse

One of the main triggers for anxiety that became apparent during the interviews was the severe physical symptoms that patients had to learn to cope with as the illness progressed.

Pain appeared to be a key factor.

‘Sometimes I cannot get out of bed without a struggle because of the pain of everything due to the MS’ (P14)

P18 had difficulty with hand movements and this impacted on her daily life as a mother of small children.

‘I can’t unscrew medicine bottles so the children have to unscrew their own medicine bottles’

Cognitive difficulties associated with MS such as a difficulty processing thoughts were also found to be an anxiety-provoking factor.

‘The thoughts don’t sort of come out sort of as quick [...] so that brings up a lot of anxiety for me’ (P10)

A relapse or a decline in physical functioning further triggered anxiety as the illness progressed.

‘If my MS is playing up I get anxious’ (P9)

Overall, the uncertainty surrounding the progression and the course of the illness was a major concern.

‘What’s going to happen? Am I going to have another relapse, Will I get worse?’ (P6)

It became apparent throughout the interviews that anxiety could act as a trigger for a relapse or ‘flare-up’. P2 recalled her most recent relapse that occurred 6 years ago; she spoke of the time as being a stressful period in her life, as she had a cancer scare.

‘The massive relapse that I had 6 years ago [...] came about because I thought I had breast cancer [...] and I was stressing so I know for me that it’s stress that makes my MS worse’ (P2)

Work-life struggles

The impact of MS symptoms on work ability was a major contributor to high levels of anxiety. For P3, her anxieties were based around finance, as she had not worked full time in the past few months due to her fatigue. P3 felt that no one would hire her.

‘When there’s someone perfectly fit and able [...] in the same position’ (P3)

P1 experienced anxiety, hiding her MS condition from her company, as she felt disclosing her illness may impact her career prospects adversely. She felt she would be viewed as a ‘liability’. Instead she said she would rather ‘lie and deal with the consequences’. P7 felt a constant anxiety in her work-life regarding how much she could do while simultaneously being under pressure to earn money.

‘I actually wonder what I can handle so that's a bit of a kind of worry because obviously I have to earn money so I have an underlying anxiety around all the work stuff if I am honest’ (P7)

P4’s anxieties concerning work developed due to the lack of support she received and she believed this led to a worsening of her MS symptoms. She spoke of being ‘targeted’ and a ‘burden’ as a result of having MS.

P5 worried that her colleagues would see her MS as a ‘weakness’, therefore she ‘over-compensates’ because she does not ‘want people to know the problems’ she experiences. This feeling of vulnerability due to MS symptoms was prominent throughout the interviews; participants felt that their MS symptoms put them at a disadvantage in the workplace.

Family and friends

Participants worried about the impact their MS would have on those around them, particularly their partners.

‘It has put quite a strain on the marriage actually.... it is sometimes quite difficult for my husband to accept it’ (P16)

P8 was concerned about whether her husband would stay with her due to the difficulties of caring for someone with MS. For other participants, anxiety was linked to whether others would accept their illness. Participants also worried about the loyalty of their friends, as some MS symptoms inhibited their social lives and their participation in activities they once enjoyed. P17 mentioned her dependence on others and how this caused anxiety for her.

“I feel like I have to keep on asking people to do basic things. I cannot even walk out the front door without somebody helping me” (P17).

“I just don’t feel me”

Embarrassment

Eighteen of the participants said that they experienced several other strong emotions as well as anxiety. One of the common themes from participant responses was embarrassment at having MS associated with perceived stigma surrounding the disease.

‘The sense of embarrassment that you get that seems too irrational but you do feel really embarrassed about the whole thing and like what people would think of you’

(P5)

Six participants spoke of a time when they were experiencing a ‘flare up’ and they felt others around them thought they were drunk. This appeared to cause distress, as they

believed many members of the public have a lack of knowledge about MS and its associated symptoms.

Worry

All of the participants conveyed worry about what would happen to them in the future and how they would cope with the uncertainty of the illness. Participants did not feel they were in control of what was happening with their bodies, which often led to a sense of frustration.

‘It's the not knowing that's hard to deal with’ (P16)

Fear

Fearful thoughts about the future triggered anxiety, particularly when severe symptoms were present. Participants were worried about the consequences the illness would have on their lives.

‘One of my worst fears is being in a wheelchair’ (P20)

Loneliness

Many participants had smaller social circles and restricted social lives, which had occurred since their diagnosis was made. The change was attributed to the severity of MS symptoms.

‘I feel terrible about being in a wheelchair... You just feel so isolated really’ (P15)

Sadness

Negative thoughts appeared to be strongly linked to anxiety symptoms for many participants.

‘I tend to go straight to the negative all the time. My default setting is anything I do will turn out disastrous and usually it doesn't’ (P11)

Hopeless thoughts were also consistently mentioned throughout the interviews highlighting the high level of comorbidity.

‘I question the existence of life and all the rest of it. You think of ending your life....

it’s hard to carry on sometimes’ (P17)

Coping

What works

Since the diagnosis of their MS, many participants developed helpful coping strategies to deal with the impact of their illness. One participant believed that a healthy diet was more beneficial than drugs.

‘Diets do more than the drugs to some degree’ (P9)

Many participants said that since their diagnosis of MS, exercise had helped reduce their anxiety levels and had been beneficial for their overall wellbeing. One participant stated that this is something she would like to do daily to reduce anxiety.

‘The immediate thing is I need to be keeping active. At least it’s something that I am

going to be doing everyday’ (P12)

Rest, relaxation and living positively in the moment also appeared to have beneficial effects.

‘I try to stay clear from stress and stressful situations which does help to reduce

anxiety levels’ (P14)

What can make things worse

Unhelpful coping strategies for dealing with MS and anxiety were most often linked to denial and avoidance.

‘It’s like I block it out like a coping mechanism. Maybe I find it too painful to go

there’ (P11)

P4 acknowledged that she might still be in ‘denial’ about having MS as she did not have any visible symptoms.

The consumption of alcohol and cannabis was also frequently mentioned as a coping strategy. However, it has been debated as to whether the positive consequences of smoking cannabis or drinking alcohol outweigh the negative or vice versa. For example, four participants mentioned that cannabis relieved painful MS symptoms and anxiety. However, participants also stated that it was an illegal drug with other potentially harmful effects.

‘I have been smoking weed all my life and now more because of the MS. ... it makes the stabbing and sharp pain in the morning...a dumber pain. It’s not as fierce’ (P20)

Other participants spoke of a ‘glass or two of wine’ after a long stressful day to relieve anxiety.

Discussion

This study provides a unique insight into the experiences of anxiety in the context of MS. The PwMS’ interviews provided vivid and detailed descriptions of their anxiety. Often anxiety was linked to the unpredictability of the illness and the significant impact it had on their daily lives. However, it was also associated with life experiences and personality factors, which are important to account for to gain a full understanding of anxiety in the context of MS. It was clear that a variety of emotional reactions such as worry and embarrassment were all linked and a distinct emotional reaction was uncommon; this is similar to previous research which reported that women struggled emotionally with many aspects of living with MS (Blundell Jones et al., 2014). The stigma associated with MS symptoms was commonly linked to these emotional reactions. Previous research suggested that social stigma may be

experienced through being ignored or conversely overemphasizing the symptoms of MS (Grytten & Maseide, 2006).

Many of the participants reported significant emotional distress and negative thoughts related to their anxiety. This is in line with previous literature that reported anxiety can co-occur with depressive symptoms in 75% of MS patients (Bamer, Amtmann, Ehde, & Johnson, 2008). In a prospective study, depression was the only factor that significantly predicted whether someone was anxious or not, accounting for 46% of variation (Garfield & Lincoln, 2012). A recent systematic review of the literature also highlighted high levels of comorbid anxiety and depression among PwMS (Butler et al., 2016). Greater focus on the co-existence of depression and anxiety amongst PwMS is needed to establish the most appropriate intervention (Bamer et al., 2008).

The severity of anxiety symptoms among PwMS is supported by prior empirical research. A lifetime prevalence of clinically significant anxiety is 18.6% for PwMS in contrast with 5.1% for the general population (Aarsland & Figved, 2007). In this study, level of disability was consistently mentioned as a factor provoking anxiety for participants and is in line with previous research (Aloulou et al., 2011; Askari et al., 2014; Beiske et al., 2008; Butler et al., 2016). However, a lack of correlation between anxiety and disability has been found by some who suggest anxiety is a psychological reaction to the impact of the disease (Sidorenko, Boyko, & Gusev, 2010).

Although some participants reported previous experiences of anxiety, being given a MS diagnosis played a crucial role in the development of anxiety symptoms for some. This echoes previous research that reported anxiety is often prominent at the time of MS diagnosis disclosure, especially for women (Giordano et al., 2011). Interestingly, MS related symptoms often induced anxiety but also anxiety could trigger MS related

symptoms. This relationship has been reported in previous research highlighting the bidirectional effects between depression/anxiety and severity of medical illness (Katon, 2003). Helping the patient to clearly identify the nature of the symptoms may help them to develop more effective coping skills. Further research is warranted to further explore this complex bidirectional relationship.

Many participants reported their MS diagnosis increased their anxiety in the workplace. At work some participants reported that they concealed their illness, some reduced their workload and some overcompensated to avoid being perceived as weak. Research has reported that workplace stress-related interventions are likely to be very valuable for those with a chronic illness such as MS (McGonagle & Barnes-Farrell, 2014). Specifically, interventions using social modeling to enhance self-efficacy may be helpful to prevent identity threat experiences (Bandura, 1994). The MS literature has highlighted that self-efficacy based interventions can also reduce feelings of loneliness and improve overall social functioning (Amtmann et al., 2012; Kalina & Hinojosab, 2016).

Participants were also extremely anxious about how their illness affected their close relationships with partners and friends. A common worry was that partners would leave due to increasing dependence within the relationship as previously reported (Mozo-Dutton et al., 2012). Research has highlighted that individuals in all cultures are likely to strive for norms and values within their own culture (Heine, Lehman, Markus, & Kitayama, 1999). Within western culture, value is typically placed on being an independent, self-contained, autonomous entity (Markus & Kitayama, 1991). This is a possible explanation for why this change in independence can bring up anxiety for PwMS living in western cultures. Future research should explore the loss

of independence in other cultural contexts to investigate the role cultural norms may play in living with MS. However, it is important to note that many PwMS indicated that if they had good social support they felt less of a burden on others and felt they were better at coping. This is in line with previous research on coping which found that the more MS patients perceived their family circle as being available, the more they used problem-focused coping (Rommer, Sühnel, König, & Zettl, 2017; Roy-Bellina, Moitrelle, Camu, & Gely-Nargeot, 2009).

Accounts from this study highlight the significant need for psychological interventions for PwMS. The comorbidity of anxiety and depression highlights the need for interventions that target both anxiety and depression together as higher levels of depression are linked to poorer response of anxiety symptoms to CBT (Martinsen, Olsen, Tonset, Nyland, & Aarre, 1998). Trans-diagnostic or ‘unified’ treatments have been proposed for PwMS (McEvoy, Nathan, & Norton, 2009) as they use the same underlying treatment principles across mental health difficulties, without changing the protocol to suit specific diagnoses (Chorpita, Taylor, Francis, Moffitt, & Austin, 2004). In trans-diagnostic treatments the common maintaining processes of psychological difficulties are targeted within the one protocol. One of the most widely supported approaches of these types of interventions is broad-spectrum trans-diagnostic CBT (TD-CBT) (Barlow, 2000). This applies core CBT-based treatment principles and techniques such as graded exposure and cognitive restructuring to target the common processes underlying anxiety and depression. A systematic review of existing literature on these types of treatments for depression and anxiety in adults found large and significant reductions in both anxiety and depression, and moderate improvements in quality of life (Newby, McKinnon, Kuyken, Gilbody, & Dalgleish,

2015).

A Working Conceptual Model of Anxiety for PwMS based on Beck's model of emotional disorders has been proposed (Butler et al., 2016). The model assumes that anxiety can be triggered by critical events, which may include developing the disease, fear of disability or other life stressors. Subsequently, avoidance coping, anxiety, low mood or stress and unhelpful thinking maintain the symptoms. Despite PwMS stating clearly that they thought psychological interventions were important, research has reported that 52% of patients with clinically significant anxiety were not receiving any type of psychotherapy nor medication for anxiety (Aarsland & Figved, 2007). Greater access to psychological services for PwMS is therefore necessary.

However, the psychological intervention, whether it be focused specifically on anxiety or transdiagnostic issues, should address the individual concerns of the patient. This can be done by carrying out a detailed assessment focusing on their specific preoccupations. An individualized formulation can then be shared with the patient and collaboratively a way forward can be agreed. From a pharmacological perspective, serotonin reuptake inhibitors have been recognised as first-line treatment in depression comorbid with a spectrum of anxiety difficulties. Short-acting benzodiazepines (BZDs) have also been considered as an important 'bridging strategy' to target an acute anxiety component (Coplan, Aaronson, Panthangi, & Kim, 2015).

Shortcomings of this qualitative study need to be acknowledged. The method of data collection by telephone may have impacted participant responses. This method may restrict the ability to develop rapport. However, research has indicated that telephone interviews can be effective in qualitative research (Sturges & Hanrahan, 2004) and participants can be more willing to share sensitive information (Novick, 2008). The

detailed descriptions and the length of the interviews indicate that our telephone interviews provided rich and trustworthy data. Furthermore, it is important to consider that interviewer characteristics can impact participant responses. However, response bias appeared to be minimal as interviewees spoke honestly, demonstrated by their willingness to share stories they may have found embarrassing and were open about their emotional responses.

A higher proportion of women were interviewed compared to men. However, a study based on the largest, most ethnically representative survey of the U.S. population to date found that women were more likely than men to meet criteria for all anxiety disorders examined, with the exception of Social Anxiety Disorder (SAD) (McLean, Asnaani, Litz, & Hoffmann, 2011). It has also been suggested that a gender ratio approaching 4:1 of female to male diagnosis exists in MS (Orton et al., 2006). It is important therefore to consider this when interpreting results. Although the sample was recruited consecutively, thereby not introducing a selection bias, the sample was selected from a group of patients who were anxious. Further qualitative studies should focus on those who are coping as well as those who are not. In addition the majority of the participants were those with relapsing remitting MS. It would be interesting to explore in more depth the views of those with primary progressive MS. Although only three of our sample had progressive MS this reflects the prevalence rates in the population (Minderhoud, van der Hoeven, & Prange, 1988)

Data from qualitative research can be understood and interpreted in numerous ways. Taking this into consideration, the findings should be regarded as evocative thought-provoking themes rather than definitive facts. Recall bias may also influence responses provided. Research has highlighted a tendency for people to recreate

autobiographical memories in order to form a coherent, favourable view of their self in the moment (Wilson & Ross, 2003). It is also important to consider that question 2, 4 and 9 of the interview schedule may have been responsible for particular responses however we felt they were important questions to consider in the context of the research question.

In conclusion, the insights gained from this research may be of particular interest to clinicians involved in designing, developing or delivering interventions for anxiety among PwMS. This is the first qualitative study, to the author's knowledge, explicitly examining anxiety in the context of MS and draws attention to the need for clinicians to consider the significant impact anxiety has on PwMS. The richness of the data draws attention to the specific impact anxiety has on PwMS and how this should be considered for each individual, especially in its development and role in everyday life. The findings also highlight the possible role of wider sociopolitical norms in living with MS, such as the value placed on independence in western society. One can imagine that living with the worry of a relapse is bound to be anxiety provoking. As to whether a relapse intensifies the anxiety is debatable and needs to be explored further. In an extensive study examining mental health issues it was concluded that clinicians should evaluate all MS subjects for anxiety difficulties as they represent a treatable cause of disability in MS (Korostil & Feinstein, 2007). This study supports those findings and the value of providing psychological interventions within a model of stepped care including prevention, brief interventions and psychological and/or pharmacological treatment for those in most need. The specific contents of the interventions should address the specific concerns of the patients. This can be done by carrying out a detailed assessment focusing on the specific concerns of the patients. An individualized formulation can then be shared with the patient

and collaboratively a way forward can be agreed. Future research should focus on what approaches work best for PwMS and at what stage.

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Tables

Table 1: Interview Schedule Questions

Interview Schedule Questions
1.Before you were diagnosed with MS did you experience excessive anxiety or worry?
2. If yes what form did it take? Was it a generalized anxiety or anxiety due to being in a social situation or did you experience panic attacks or anxiety due to a specific phobia or anxiety due to a traumatic event?
3. Can you tell me about when you began to experience excessive anxiety or worry?
4. Do you think that there was a certain trigger that caused you to become worried or anxious?
5.For how long would you say you would experience these anxieties for? Or is it on going?
6.What do you feel anxious about? Currently do you have specific anxieties?
7.Can you describe what takes place physically when you become anxious?
8.Can you now describe the thought process that occurs when you are feeling anxious?
9.Do you experience anxieties about having MS and the uncertainty of the illness?
10.Do you have an MS attack directly after experiencing anxiety or vice versa?

11.Do you have a disability as a result of having MS and if so do you have any embarrassment about having a disability, or any of the aids that play a part in your life now?
13.Do you experience anxiety about your social and work life and how MS will have an impact on this?
14.Do you experience anxiety about having to be dependent on others?
15. Do you experience anxiety about the future?
16. How are you able to cope with such anxiety? - Do you have any specific coping strategies to deal with the anxiety?
17. Do you find it helpful seeing the mental health nurse and discussing your anxieties?

Table 2. Describes the sample

Gender	18 females, 2 males
Age	26-67 years (M= 41.75, S.D. = 10.98)
Ethnicity	60% 'White British', 10% 'White Other', 10% 'Black British', 10% 'Black Caribbean', 5% 'West African' & 5% 'Indian'
Education	60% University level, 35% A-Levels, 5% GCSE level,
Marital status	40% married/living with a partner, 60%

	single
Type of MS	80% had a relapsing-remitting course, 15% had a secondary progressive course, 5% had primary progressive MS.

Table 3: Summary of main themes and subthemes

Theme and Sub-themes	Number of participants
1. How it began (the development of anxiety)	
Big life events	8
It's part of my personality	7
Response to my diagnosis	14
2. Getting on with life (with MS and Anxiety)	
MS and anxiety making each other worse	20
Work-life struggles	20
Family and Friends	19
3. "I just don't feel me" (in response to MS and anxiety)	
Embarrassment	18
Worry	20
Fear	2
Loneliness	6
Sadness	12

4. Coping	
What works	19
What makes things worse	15

Figure 1: Thematic representation of themes related to anxiety in people with MS