

**Living with unpredictability in Multiple Sclerosis**

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## Portfolio Abstract

**Background:** Unpredictability is identified as a major factor in Multiple Sclerosis (MS) and reported to be a “constant companion” for individuals living with MS. It is reported to be a factor of uncertainty, which is indicated to have a biopsychosocial impact on these individuals. However the impact of uncertainty is argued to diminish over time. Whereas, the lived experience of unpredictability is reported to be continual. Furthermore, unpredictability is argued to have a continual psychological effect on individuals with MS. However, unpredictability is an aspect that remains relatively unaddressed in the research. Qualitative research has been highlighted to be fundamental in exploring the individual experience of illness, providing rich detailed descriptions. In addition it has been instrumental in the development of services to meet the needs of these individuals. The significance of unpredictability in MS highlights the need for further exploration of lived experience of this aspect of the illness to support healthcare professionals and the development of services to meet the needs of these individuals.

**Aim:** This study aimed to address the limited research examining unpredictability in MS, to develop a comprehensive understanding of how this aspect affects the lives of individuals with MS.

**Method:** This study employed a qualitative design. Twelve participants were recruited through the MS Society, local advertisements and by a ‘snowballing’ sampling technique. All participants lived in England, had a diagnosis of MS, and were able to provide consent to participate. Individual interviews were conducted (7 face-to-face and 5 telephone interviews) using a semi-structured interview. Interviews were transcribed verbatim and analysed by the researcher using a thematic analysis (TA) approach.

**Results:** Three main themes were derived from the analysis: 1) Challenges to meaning-making; 2) A wide picture of unpredictability; and 3) Surviving unpredictability. Each of the themes generated between two or three sub-themes. The themes told the participant’s story for living with unpredictability.

**Conclusion and recommendations:** Unpredictability was reported to be a key factor of living with MS, yet it was challenging and difficult to understand. Participants described the wide reaching impact of unpredictability influencing them personally and socially. Pragmatic and psychological approaches were employed by participants to deal with unpredictability.

The findings offer insight into the individual's experience of living with unpredictability. It is argued the findings represent individuals who have reached a stage of acceptance with their illness and therefore may offer health professionals guidance around how to support individuals who have not been able to come to terms with the unpredictability of their illness. Furthermore, the findings highlight the wide reaching impact of unpredictability emphasising the importance of the family team. These findings may offer health professionals guidance around providing family education and support to help develop a cohesive network of support for the individual and the family experiencing the effects of unpredictability in MS.

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## **Statement of Contribution**

Hannah Wilkinson was responsible for the design of this project, applying for ethical approval, reviewing the relevant literature, recruitment of participants, data collection, transcription of five of the interviews, analysis and writing up the research.

Dr Roshan das Nair provided supervision and guidance throughout the research process. He was also responsible for independently coding the transcripts, reviewing themes, and reviewing the thematic map that was derived from the analysis.

The MS Society provided the means to advertise the study, on their website and through local MS Society Newsletters. In addition local therapy centres and participants helped to advertise for recruitment to the study.

A transcription service transcribed seven interviews.

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## **SYSTEMATIC LITERATURE REVIEW**

**The Psychological impact of living with an unpredictable illness: A meta-synthesis of qualitative research literature in Multiple Sclerosis<sup>1</sup>**

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## **Abstract**

**Background:** Multiple Sclerosis is characterised by an unpredictable nature, and this is reported to be the largest challenge for individuals. Chronic illness literature highlights the psychological impact of unpredictability however there is a paucity of research examining this concept in Multiple Sclerosis.

**Objectives:** This review aims to systematically explore the psychological impact of unpredictability in Multiple Sclerosis.

**Methods:** A meta-synthesis was conducted. A total of six studies (with 59 participants) were reviewed and critically appraised. Themes of psychological impact of unpredictability were extracted and synthesised.

**Results:** A preliminary model of unpredictability of MS was developed highlighting the different psychological impact of diagnosis, remission and relapse.

**Conclusions:** The psychological impact of unpredictability alters through diagnosis, remission and relapse. Further research is required to explore the experience of unpredictability in Multiple Sclerosis.

**Keywords:** Multiple Sclerosis, psychological impact, unpredictability, systematic review, qualitative

**Key Points:** This qualitative systematic literature review explored the psychological impact of unpredictability in Multiple Sclerosis (MS). This highlighter the changes experienced in the psychological impact of unpredictability through the course of MS. A preliminary model of unpredictability was developed to demonstrate this. Further research is required to explore unpredictability in MS

## **Introduction**

The National Institute for Health and Clinical Excellence [NICE] (NICE 2003) defines Multiple Sclerosis (MS) as a disease of the central nervous system, affecting the brain and the spinal cord, with no known cure. Individuals experience irregular relapses and a downward progression of the illness; and the unknown eventual level of functional impairment and disruptions in daily functioning contribute to the perception of it being a highly unpredictable illness (Mullins et al. 2001; P. W. Thomas et al. 2006).

Research has emphasised the impact of MS, highlighting the emotional and physical effects on the individuals, family and friends (e.g. Aronson 1997; Cheung & Hocking 2004; Mutch 2010). A standardised measure of the impact of MS identifies nine psychological effects: feeling unwell, sleep problems, fatigue, MS-related worries, anxiety, irritability, concentration problems, lowered self-confidence, and depression (Hobart et al. 2001). All these effects lead to functional deficits and reduced quality of life. The UK Department of Health [DoH] (DoH 1992) has highlighted the importance of exploring the lived experience of people with a chronic illness to enable services to provide a good quality of life. Consequently, interest in qualitative studies exploring the lived experience of MS and those who care for people with MS has grown (e.g. Shevil & Finlayson 2006; Malcomson et al. 2008; Olsson et al. 2008; Miller 1997; Moriya & Suzuki 2011; Koopman & Schweitzer 1999; Cheung & Hocking 2004; Mutch 2010).

Unpredictability is one of the largest challenges in MS (Malcomson et al. 2008). There is wealth of research exploring the effects of uncertainty and unpredictability in chronic illness (Thorne et al. 2002; McCormick 2002). However, the impact of unpredictability in MS has not been examined.

This review aims to systematically explore the psychological impact of living with unpredictability in MS, drawing upon qualitative research that highlights the impact of unpredictability. Compared to quantitative research, qualitative research enables researchers to get closer to patients' experiences, by exploring not only what is being said but also how it is said. A nuanced understanding of the psychological impact of unpredictability could offer guidance for future research and identify areas of importance to inform services and future practice.

## **Methods**

### **Systematic literature search**

#### *Inclusion/exclusion criteria*

Inclusion and exclusion criteria were defined *a priori*. Papers were considered if they: included participants were individuals with MS (PwMS) and explored their experience of living with MS; were primary research; discussed psychological impact of the unpredictability of MS; and used qualitative methods of data collection and analysis. Papers using mixed-methods were also considered.

Psychological impact was defined as any cognitive, behavioural or affective changes that an individual perceived to result from the unpredictability of their MS. Unpredictability is defined as an inability to foretell the future (McCormick 2002). By definition, unpredictability is a factor of uncertainty (Neville 2003; McCormick 2002). The concepts are theoretically distinguishable; however there is considerable overlap and inconsistencies in the use and definition of these terms in the literature. Therefore, for the purpose of this review 'uncertainty' and 'unpredictability' were treated as synonymous. Unpredictability was defined as

participants' perception of changeableness or uncertainty of their symptoms, diagnosis and relapses. In addition it included unpredictability/uncertainty encountered in day-to-day living with MS.

### **Meta-Synthesis**

A meta-synthesis was conducted from a critical realist epistemological position, acknowledging that data can provide insight into reality with an awareness that environmental factors may have impacted upon the individual's experiences (Harper 2012). It is recognised that reviewed studies are a secondary level interpretation of the primary data collected from participants. Interpretations are influenced by the researchers' own lived experiences, situation and epistemological stance. A meta-synthesis of the secondary level interpretation brings together the methodological and contextual complexities and provides a third level of interpretation along with its own epistemological slant (Zimmer 2006).

To date, there is no consensus regarding the most appropriate method for meta-synthesis. Walsh and Down (2005), however, outlined the generally accepted techniques and stages involved, and these were used to guide the present review.

### *Search terms*

Search terms were developed by the first author (HW) in consultation with the second (RdN) (see Appendix 1). A systematic search was conducted through NHS evidence search engine. AMED, EMBASE, Medline, PsychINFO, British Nursing Index (BNI) and CINAHL electronic bibliographic databases were searched in July 2012. The databases represented the literature from medical, nursing and social science disciplines. Alerts were set up to indicate new relevant studies during the

review period (1 July – 06 December 2012). A separate search was conducted on Google Scholar using three key terms (“qualitative”, “Multiple Sclerosis” and “psychological impact”) on 16 July 2012. The first 100 citations were checked for relevance. Finally, reference lists of all included papers provided an additional search strategy. Each citation was checked for relevance using the title, where relevance was in doubt the abstract was obtained. In cases where the abstract was unavailable or insufficient information was provided to ascertain relevance, the full text was obtained.

### *Appraisal of Studies*

Quality appraisals are widely debated amongst qualitative researchers. There is insufficient evidence to ascertain the most appropriate tool, rigour or added value of quality appraisals (Noyes et al. 2008; Dixon-Woods 2004). The present review considered studies with different methodologies and hence the Critical Appraisal Skill Programme tool [CASP] (CASP 2010) was used as it meets the methodology-neutral appraisal prompts outlined by Dixon-Woods (2004).

The CASP was used to provide criteria to explore and interpret reviewed studies as suggested by Noyes et al. (2008). However, it was not used to discount studies, given that all studies provide information (Sherwood 1997), and it is deemed inappropriate for qualitative reviews to use appraisal tools to make decisions about including or excluding a study. Therefore, any quality issues identified were considered in the synthesis of reviewed studies to reduce the impact and distortion to the interpretation of the study (Dixon-Woods 2004).

All included studies were thoroughly examined by HW, and general characteristics were extracted and tabulated. These included: study aims, sample size, location

of the study, sample composition (including gender and age range), data collection method, data analysis method, and key findings. These were crosschecked by RdN for reliability. Preservation of the original studies was maintained by reproducing original text from included studies (Walsh & Downe 2005).

### *Reciprocal Translation*

Themes relating to the psychological impact of unpredictability were extracted by HW and discussed with RdN. Themes were identified from the results section of included papers to preserve the PwMS' perceptions. Themes were considered across the studies identifying commonalities and dissonance, and were grouped together to develop concepts as shown in Table 3.

### *Synthesis of Translation*

The themes extracted were refined to develop a model of unpredictability in MS. They were refined through a process of returning to the original text to explore the origin of the theme, identifying how the theme relates to unpredictability in each reviewed study, and comparing and contrasting across studies. For instance a theme of perceived loss of control was identified in three reviewed studies. Commonalities and differences between the three papers were explored, enabling an interpretation of the individual's experience of perceived loss of control due to the unpredictable nature of MS.

## **Results**

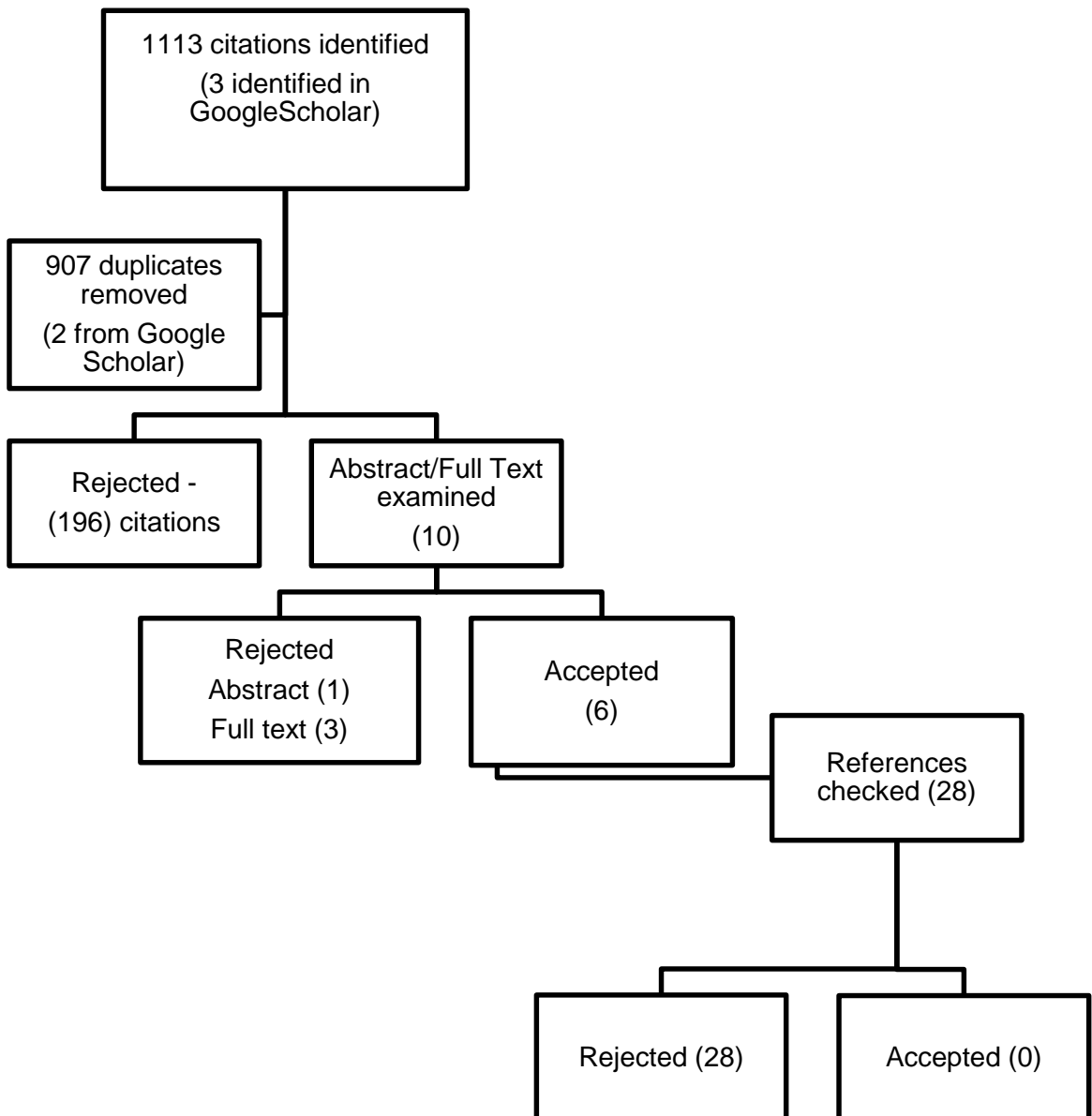
### *Literature search*

A total of 1110 citations were identified from the database search; duplicates were removed leaving 205 citations. Nine citations were deemed relevant in the title



search. Three articles were rejected following the full text search (see Figure 1). An additional three citations from Google Scholar were deemed appropriate, two were identified as duplicates from the database search, and one was obtained in abstract form to ascertain relevance (for list of included citations see Table 1).

**Figure 1:** Flow Chart – Identifying relevant studies



**Table 1:** Summary of studies examined for relevance

Ref	Accepted	Rejected	Notes
Shevil and Finlayson (2006)	✓		
Malcomson et al. (2008)	✓		
Olsson et al. (2008)	✓		
Miller (1997)	✓		
Moriya and Suzuki (2011)	✓		
Koopman and Schweitzer (1999)	✓		
Courts et al. (2004)		✓	Rejected at Full Text Abstract unclear Full text ascertained – no reference to unpredictability
Pinson et al. (2009)		✓	Rejected at Full Text Abstract – unpredictability highlighted Full text ascertained – no indication of psychological effects of unpredictability
Yorkston et al. (2010)		✓	Rejected at Full Text Abstract unclear Full text ascertained – no reference made to unpredictability
Antonak and Livneh (1995)		✓	Rejected at Abstract Not primary research

### *Appraisal of studies*

All reviewed studies provided clear statements of research aims and were deemed appropriate for an enquiry using qualitative methodology.

Credibility checks were reported in four (Malcomson et al. 2008; Miller 1997; Shevil & Finlayson 2006; Moriya & Suzuki 2011) of the six studies and saturation was reported in two studies (Malcomson et al. 2008; Miller 1997). This highlights the rigour and the reliability of the themes identified in these studies. Conversely, a majority of the reviewed studies did not state the consideration of the relationship between researcher and participant, highlighting a potential weakness in qualitative research. Epistemological stances were not stated and hence caution was exercised when extracting themes for synthesis.

### *Comparison of the General Characteristics of the Studies*

Table 2 provides a summary of the general characteristics of the reviewed studies. All studies explored the experience of MS. Four studies focussed on the effects of symptoms of MS (Shevil & Finlayson 2006; Koopman & Schweitzer 1999; Moriya & Suzuki 2011; Miller 1997), however each study provided different aspects of the experience. Reviewed studies spanned a research time period from 1997-2011, sample sizes ranged from 4-17 participants, with one study recruiting female participants only (Olsson et al. 2008). The sample portrayed individuals who have lived with MS for six months to 22 years. Two studies did not report their location (Shevil & Finlayson 2006; Moriya & Suzuki 2011), however, the remaining studies were located in Europe and North America. A majority of the studies did not report

the ethnicity of the participants, therefore it is uncertain how culturally diverse these groups were.

Data were collected through individual interviews, barring one study (Malcomson et al. 2008) which used focus groups. The data analysis methods were not consistent throughout the six studies; two studies utilised thematic analysis (Shevil & Finlayson 2006; Malcomson et al. 2008), three used a phenomenological hermeneutic interpretation approach (Olsson et al. 2008; Miller 1997; Koopman & Schweitzer 1999), and one used a constant comparative method (Moriya & Suzuki 2011). The key findings shown in table 2 represent the findings of the studies in relation to their research aims. The themes identify the effects of MS on the individual, highlighting the range of effects from affective to physical symptoms, and finally to the meanings applied by PwMS to enable successful coping. The key overarching theme identified was the effect of MS on individual's daily life.

**Table 2:** General Characteristics of review studies

<b>Authors</b>	<b>Year</b>	<b>Aims</b>	<b>Location</b>	<b>Sample Size</b>	<b>Sample Composition</b>	<b>Data Collection Method</b>	<b>Data Analysis Method</b>	<b>Key Findings</b>
Shevil and Finlayson	2006	Explore the impact of cognitive changes in individuals with MS in different life roles	Not stated	4	3 females 1 male Age range: 46-60 TSD: 10-27 years Diagnosis of MS, self-reported cognitive changes, 1 full-time worker, 1 part-time worker, 1 parent and 1 retired individual. Ethnicity: White All married	3 in-depth interviews Cognitive Experience form (self-report) Perceived deficits questionnaire (self-report)	Thematic analysis	Cognitive changes have significant impact on the individuals function in daily life, ability to maintain desired roles, and perceive their quality of life.
Malcomson et al.	2008	Explore personal	Ireland	13	9 females 4 males	Focus Groups	Thematic analysis	7 key themes: learning something is wrong;

		accounts and experience of Individuals with MS who felt able to cope Use information to advise others in coping techniques and strategies to maximise well-being and quality of life			Age range: 40-67 years TSD:6-30 years 6 RRMS 6 SPMS 1 PPMS Ethnicity: not reported			getting a name; lack of professional support; unchanging family relationships, adjustment to employment and social life; challenges; successful coping via proactivity, perspective and control; advice for others; and service recommendations.
Olsson et al.	2008	Describe the meaning of women's experiences of living with MS	Sweden	10	Females Age range: 40-59 years Diagnosis of SPMS 9 married 1 cohabiting	Interview	Phenomenological Hermeneutic interpretation	2 main themes: living with an unrecognisable body and trying to maintain power. MS captures the whole body,

					Ethnicity: not reported			resulting in becoming someone who others cannot depend on. Themes of refusing to let MS dictate their lives were apparent.
Miller	1997	Provide a description of the lived experience of people who have relapsing MS	Western New York, USA	10	7 Females 3 Males Age range: 40-59 years TSD: 2-39 years Diagnosed when 24-51 years old 6 employed 1 retired 2 housewives Ethnicity: All Caucasian	Interview	Phenomenological Hermeneutic Interpretation	12 themes identified as essential to relapsing experience of MS: social network, adjustment, coping, hope/hopelessness, control, conflict, relief with diagnosis, uncertainty, loss, fear, getting to know MS and revealing and concealing.

Moriya and Suzuki	2011	Explore the experiences depending on disease severity.	Not stated	17	<p>4 Males</p> <p>13 Females</p> <p>Age Range: 20-59 years</p> <p>Average TSD: 5.9 years (SD=3.9)</p> <p>10 Employed</p> <p>7 Unemployed</p> <p>12 Married</p> <p>5 Single</p> <p>Ethnicity: not reported</p>	Semi-Structured Interviews	Constant comparison method	<p>Mildly impaired participants were able to live a normal life post-diagnosis if adjustments were made. Uncertainty was experienced in terms of treatment efficacy.</p> <p>Moderately impaired participants self-identities fluctuated depending upon their symptoms.</p> <p>Severely impaired participants experienced giving up on coping with their problems and developing new strategies. They experienced a shift in</p>
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								mentality to a new life as a disabled person.
Koopman and Schweitzer	1999	Explore the individual's experience of having symptoms for a period of time and then receiving a diagnosis.	Not stated	5	3 Females 2 Males Age range: 29-40 years Time from symptom to diagnosis: 6 months to 22 years Ethnicity: not reported	Interview	Phenomenological Hermeneutic Interpretation	4 themes: whispered beginnings, echoes of silence, the spoken words, and recreating voice.

*TSD: Time since diagnosis; RRMS: Relapsing Remitting MS; SPMS: Secondary Progressive MS; PPMS: Primary Progressive MS*

### *Reciprocal translation*

Themes identifying the psychological impact of unpredictability were extracted from the reviewed studies. Cognitive, behavioural and affective impacts were identified. The main psychological impacts identified were perceived loss, isolation/withdrawal, and emotional distress. Sub-themes were identified within these constructs. A summary of the themes are outlined in table 3.

**Table 3:** Summary of the themes of psychological effects of unpredictability

		Shevil and Finlayson (2006)	Malcomson et al. (2008)	Olsson et al. (2008)	Miller (1997)	Moriya and Suzuki (2011)	Koopman and Schweitzer (1999)
	<b>Themes</b> Sub themes						
<b>Cognitive</b>	<b>Perceived Loss</b>	+	-	+	+	+	+
	Control	+	-	+	+	-	-
	Independence	+	-	-	+	-	-
	Purpose	-	-	-	-	+	-
	Self confidence	-	-	+	-	-	-
<b>Behavioural</b>	<b>Isolation/Withdrawal</b>	+	-	+	-	-	+
<b>Affective</b>	<b>Emotional Distress</b>	+	+	+	+	+	+
	Anxiety	-	+	-	-	+	+
	Fear	-	+	+	+	-	-
	Anger/Frustration	+	-	-	-	-	-

+ present; - absent

A perception of loss was identified in five of the six papers. Three papers identified loss of control due to the unpredictable nature of their symptoms (Olsson et al. 2008; Shevil & Finlayson 2006; Miller 1997).

Unpredictable cognitive changes were described as a rollercoaster ride of temporal unpredictability, whereby the timing of an inevitable event is unknown (Neville 2003):

“it’s like you are on top of a hill and you know it is going to drop down” (Shevil & Finlayson 2006)

The rollercoaster ride led participants to feel that they were losing control (Shevil & Finlayson 2006). Unpredictable physical symptoms resulted in feeling no longer being in charge of their body, causing changes to their daily functioning (Olsson et al. 2008). They could no longer trust their body and were unable to know if they could complete plans that were important to them (Olsson et al. 2008). One participant highlighted the most disturbing aspect of their MS as the unpredictable seizures, causing a sense of loss of control, resulting in emotional distress (Miller 1997).

A perceived loss of independence due to the unpredictable symptoms was highlighted (Shevil & Finlayson 2006; Miller 1997). The loss of independence due to cognitive changes resulted in emotional reactions (Shevil & Finlayson 2006). In addition, unpredictable seizures resulted in a loss of independence, broken, like a “dripping faucet” (Miller 1997).

Those who experienced moderately severe MS perceived a loss of purpose due to their unclear future (Moriya & Suzuki 2011).

“If I had to try hard in order to get better, I would have a purpose. But just because I try hard, it doesn’t mean I’ll get better. I don’t know what my goal should be.” (Moriya & Suzuki 2011)

Finally, a sense of loss of self-confidence in one’s own ability was identified due to the unpredictable physical effects (Olsson et al. 2008).

“You get insecure in yourself many times...I try...Can I manage this...will I have enough strength to walk that distance...insecure...insecure...I have become in many ways.” (Olsson et al. 2008)

A behavioural impact of perceived social isolation was reported in three studies (Shevil & Finlayson 2006; Olsson et al. 2008; Koopman & Schweitzer 1999). A sense of loneliness was perceived prior to diagnosis; the unpredictable symptoms and the uncertain process of diagnosis left participants lonely in their wait for responses to their investigations (Koopman & Schweitzer 1999). The sense of unpredictability and unanswered questions resulted in ‘being left wondering alone’ (Olsson et al. 2008).

Isolation was further exacerbated by the symptoms of MS “(Cognitive changes) kind of closed down the parameters I live” (Shevil & Finlayson 2006). The changes impacted on communication abilities:

“Its understanding the signals I’m getting from other people and a lot of the times I don’t decipher it right.” (Shevil & Finlayson 2006)

Participants removed themselves from these situations, resulting in isolation (Shevil & Finlayson 2006).

Unpredictability created emotional distress, in particular a response of anxiety was noted (Malcomson et al. 2008; Moriya & Suzuki 2011; Koopman & Schweitzer 1999); anger and frustration (Shevil & Finlayson 2006), and fear was also identified (Malcomson et al. 2008; Olsson et al. 2008; Miller 1997). The emotional strains of unpredictable cognitive problems were referred to as a “pain in the neck that drives me nuts” (Shevil & Finlayson 2006).

Anxiety and fear were elicited by the unpredictability of the illness rather than the specific symptoms. A “fear of the unknown” was apparent (Malcomson et al. 2008; Olsson et al. 2008; Miller 1997) at two time points of the individual’s MS journey: diagnosis and relapses. Individuals did not know what their level of function would be when they woke up each morning (Miller 1997). The experience of relapses caused a fear of a loss of independence (Malcomson et al. 2008). Temporal unpredictability created a sense of anxiety waiting for anticipated problems and interruptions of their lives (Malcomson et al. 2008; Moriya & Suzuki 2011; Koopman & Schweitzer 1999).

### *Synthesis of translation*

The cognitive, affective and behavioural impact of unpredictability was apparent throughout the course of MS (See Table 4). Diagnosis, remission and relapse encounter different forms of unpredictability and different responses from patients. Temporal unpredictability, where a patient knows inevitable harm will occur but is unsure when, is identified during periods of remission. Event unpredictability, whereby the patient knows the timing of the event but does not know the extent of

the problems to be encountered, occurs during diagnosis and relapse periods. The response to the different forms of unpredictability results in different cognitive, affective and behavioural responses. During periods of remission individuals experience day-to-day concerns highlighting the impact of the cognitive and behavioural responses. The affective response turns from fear to anxiety, frustration and anger. Periods of diagnosis and relapse impact heavily upon the affective responses resulting in the perceived sense of loneliness. Cognitive and affective impacts do not stand alone. Perceived loss of control and independence were identified to be related to the affective responses that individuals experiences.

Dissonance was identified between the individual's perception of avoidance and the narrative of their behaviours. Narratives indicate that parameters of their current life had altered and hence they may be unable to complete this task. Avoidance was noted in those who experienced moderately severe MS and hence may indicate a mechanism of adapting to daily unpredictability.

**Table 4:** Model of the psychological impact of unpredictability in MS

<b>Stage</b>	<b>Cognitive</b>	<b>Affective</b>	<b>Behavioural</b>
<b>Diagnosis</b> Event unpredictability	I'm not in control and I don't know what's happening to me <i>(immediate losses)</i>	Fear	Inhibition and withdrawal  Sense of loneliness
<b>Remission</b> Temporal unpredictability	I don't know when things will get worse <i>(loss of control)</i>  Can I do this task? <i>(self-confidence)</i>  I can't do what I used to <i>(loss of purpose and independence)</i>	Anxiety   Anxiety   Frustration/anger	Avoidance   Avoidance   Desistance/'give up' (behavioural deactivation)
<b>Relapse</b> Event unpredictability	I'm not in control and I don't know how bad it will be <i>(immediate losses)</i>	Fear	Inhibition and withdrawal

## Discussion

Unpredictability is a major challenge to PwMS (Malcomson et al. 2008), yet there is a paucity of research exploring the experience of unpredictability in MS. The present review provides a preliminary model explaining the psychological impact of unpredictability over the course of an individual's journey with MS.



In chronic illnesses unpredictability is related to prognosis, when symptoms will occur or if they will experience a relapse (Mishel & Braden 1988). The present review supports this claim. The psychological impact of unpredictability is continuous yet the impact is dependent upon the current experience (diagnosis, remission, or relapse). The *event unpredictability* of diagnosis and relapse creates affective responses that render the individual perceiving a sense of loneliness. The *temporal unpredictability* of remission causes constant reappraisal of the self, impacting on cognitive, affective and behavioural responses. The identification of different forms of unpredictability and the different psychological responses support claims of Monat et al. (1972). Event unpredictability creates an increased level of affective arousal whereas temporal unpredictability leads to avoidance. An avoidant response develops as a form of cognitive coping (Monat et al. 1972). Continual changes in functional ability threaten an individual's identity. Avoidance of situations that challenge one's identity may serve as a form of coping, reducing the reappraisals to ability and identity. The narratives surrounding the avoidant behaviour indicate that this label is used as a protective factor for their identity and beliefs around their abilities, yet within the narratives dissonance occurs indicating the awareness of their functional abilities which do not meet their beliefs.

The present review was unable to reliably distinguish between unpredictability and uncertainty due to a lack of consensus in the definition. Uncertainty is reported to diminish over time as individuals become accustomed to the changes in their symptoms. The adjustment to the uncertainty, accepting their new identity and limitations, causes fear to subside (Miller 1997; Charmaz 1995). Miller (1997) reported that participants did not express strong negative feelings or a sense of loss of control due to uncertainty. However, the unpredictability creates continual

distress to PwMS (Miller 1997). Mishel (1990) stated that when uncertainty escalates, such as in a relapse, it exceeds tolerance levels and shifts the individual to a new way of life. Uncertainty can be viewed as a positive concept creating the opportunity to view life differently. The present review does not reflect patients having a positive attitude towards unpredictability and thus may indicate a difference between unpredictability and uncertainty. Event unpredictability of a relapse creates fear, which subsides during remission, mirroring the description of uncertainty (Mishel 1990); however, the temporal unpredictability maintains the affective response of anxiety. The individual's focus shifts from long term goals to day-to-day matters (Neville 2003). The discrepancy noted by Miller (1997) highlights the importance of distinguishing between these concepts and exploring them individually.

Research exploring event and temporal unpredictability could further inform services and future practice about coping and adjustment to MS. Furthermore, daily fluctuations and continual psychological distress of remission periods highlight the need for further research to explore the experience of unpredictability during these periods.

The present review is limited by the lack of research on the psychological impact of unpredictability. Reviewed studies only included samples from Europe and North America, therefore generalisation of the results should be cautiously done. In addition, meta-synthesis can be conducted across methodologies, but careful attention must be paid to the complexities of methodological assumptions and epistemological stances underpinning primary studies. The present review examined studies that were methodologically different, however, without

knowledge of the epistemological stances of the studies it is likely that some content from the primary studies may have been lost (Zimmer 2006).

In conclusion, the unpredictability of MS is a challenge that needs to be addressed in order to provide appropriate services, and clinicians need to be mindful of this. Further research into the psychological impact of unpredictability in MS, such as longitudinal studies exploring the impact through an individual's journey, could provide further insight and aid tailoring of services to an individual in specific times of need.

## Appendix

### Appendix 1: Search terms used for database searches

1. "\*Multiple Sclerosis"
2. Qualitative\* OR "lived experience" OR "patient perspective" OR experience
3. Psycholog\* OR "psychological impact" OR "psychosocial aspects of illness" OR "psychological adaptation" OR "attitude to illness" OR "disease progression" OR "anxiet\*" OR "depress\*" OR "coping" OR "cogniti\*" OR "behaviou\*" OR "emotio\*" OR adjustment"
4. Psycholog\* OR "psychological impact" OR adjustment OR coping OR anxiety OR depression OR emotion\*
5. unpredict\* OR uncertain\*
6. 4 AND 5
7. 6 OR 3
8. 1 AND 2 AND 7

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## **JOURNAL PAPER**

Living With Unpredictability in Multiple Sclerosis<sup>4</sup>

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## **Abstract**

This article explores the participants' experiences of living with an unpredictable illness, Multiple Sclerosis (MS). Four men and eight women were interviewed, who had lived with MS for at least four years. Analysis of the semistructured interviews followed a thematic analysis approach. Participants reported unpredictability to be a key factor of living with MS, yet it was challenging and difficult to understand. Participants described the wide reaching impact of unpredictability influencing them personally and socially. Pragmatic and psychological approaches were employed by participants to deal with unpredictability. Finally clinical implications of the findings are proposed, highlighting the impact of unpredictability across the family and the use of psychological techniques individuals use to aid understanding of living with an unpredictable illness.

## **Keywords**

lived experience; illness and disease, chronic; multiple sclerosis; research, qualitative; uncertainty

Multiple Sclerosis (MS) is a disease of the central nervous system, affecting the brain and the spinal cord (National Institute for Health and Clinical Excellence [NICE], 2003). It affects around 100 000 people in the UK, and has no known cure (Multiple Sclerosis Society, 2008). Individuals with MS experience irregular relapses alongside a downward progression of their illness and functional abilities. The unknown eventual level of functional impairment and disruptions to daily functioning contribute to the perceptions of this illness being highly unpredictable (Mullins et al., 2001; Thomas, Thomas, Hillier, Galvin, & Baker, 2006).

The three typical patterns of MS (Relapsing-Remitting MS [RRMS]; Secondary progressive MS [SPMS]; and Primary progressive MS [PPMS]) indicate the frequency and length of remission periods an individual might experience. An individual's illness pathway, however, is unique, each taking a different route and telling a different story (Barrett, 1995; Langgartner, Langgartner & Drlicek, 2005). Therefore, there is heterogeneity even within the three different presentations of MS. The unpredictable nature of MS is one of the major challenges (Malcomson, Lowe-Strong, & Dunwoody, 2008), and a common factor, impinging on quality of life, ability to adjust, and psychological distress (Mullins et al., 2001) [for further discussion on Multiple Sclerosis see Extended Introduction: Multiple Sclerosis].

Adjustment and coping has been a focal point in the MS literature (e.g. Dennison, Moss-Morris, & Chalder, 2009; Dennison, Yardley, Devereux, & Moss-Morris, 2010; Pakenham, 1999). Lazarus and Folkman's (1984) stress-coping model is prominent in the field of psychosocial adjustment to chronic illness. According to this model, adjustment is influenced by the individual's evaluation and appraisal of the stressors and the subsequent coping strategies that they employ to manage these demands. The Shifting Perspectives Model of illness proposed that individuals shift between placing wellness

and illness in the foreground, and appraising their experiences based on their current perspective is argued to be effective in accounting for the coping strategies employed by individuals with MS (Dennison et al., 2010). Mullins et al., (2001) reported that greater levels of illness uncertainty resulted in higher levels of psychological distress. These authors concluded that uncertainty plays an important role in the process of adjustment [for further discussion around these models see Extended Introduction: Theories of coping].

Examining the lived experience of chronic illness is reported to be instrumental in achieving an acceptable quality of life (Department of Health, 1992). The MS literature demonstrates a growing interest in qualitative studies exploring the lived experience of MS (Moriya & Suzuki, 2011; Mutch, 2010; Vick, 2013). Living with a chronic and serious illness is reported to be like “the loss of the destination map” that had previously guided the individual (Frank, 1995, p.1). Cognitive and trauma theories indicate that the most difficult events are those that are negative, fail to make sense, and result in turmoil and doubt for the individual (Pakenham, 2008). The ability to understand these events is a significant feature in the adjustment to illness (Pakenham, 2008; Taylor, 1983). It is argued to be beneficial to understand a situation, allowing greater resources and a more active approach to developing coping strategies (Pakenham, Sofronoff, & Samios, 2004). Furthermore, insights into an individual’s management and coping could provide a model for health professionals to support individuals to adapt to living with their illness (Sobel, Lorig and Hobbs, 2002) [for further discussion on the importance of the lived experience see Extended Introduction: Importance of lived experience].

The psychological effects of MS have been widely reported, and have mainly focused on anxiety, depression and anger (e.g. Mohr & Cox, 2001). Uncertainty and unpredictability are argued to exacerbate negative experiences and psychological distress

(Malcomson et al., 2008; Mullins et al., 2001). In particular, they are reported to contribute to high levels of anxiety (Mohr & Cox, 2001). An unpredictable illness, with a downward progression, is reported to affect all aspects of life. The source of control shifts towards the body, which is directly affected by the unpredictable aspects of the illness, in turn this is reported to impact on: decisions, the ability to stick to times, dependence on others, and changes within the home and social aspects of life (Haahr, Kirkevold, Hall, & Ostergaard, 2011). The “crisis” of a relapse exacerbates the impact of MS (Kalb, 2007) but the psychological impact of MS is continual throughout an individual’s illness. A preliminary model has been proposed identifying the cognitive, behavioral and affective impact of the different stages of MS: diagnosis, relapse, and remission (Wilkinson & das Nair, 2013) [for further discussion on the effects of uncertainty and unpredictability see Extended Introduction: Uncertainty and unpredictability section].

Despite the impact of unpredictability in MS there is a paucity of literature pertaining to the lived experience of unpredictability in MS. However “unpredictability” is a term that poses certain challenges to define, and there is a significant overlap and inconsistency in the use of the terms “unpredictability” and “uncertainty” in the literature (McCormick, 2002; Wilkinson & das Nair, 2013). By definition, unpredictability is associated with the inability to foretell the future (McCormick, 2002). It is argued to contribute to uncertainty (McCormick, 2002; Mishel & Braden, 1988; Neville, 2003), the cognitive state when an individual is unable to determine the meaning of illness related events (Mishel, 1988). Considering these definitions, the concepts are theoretically distinguishable: uncertainty is the inability to make sense of illness related events, whereas unpredictability is a state when an individual is faced with the unknown. Yet the interchangeable use of these terms in the literature poses difficulties in separating and enabling a review of the evidence base for unpredictability [for further discussion on the



literature pertaining to uncertainty and unpredictability see Extended Introduction: Uncertainty and Unpredictability section].

In summary, MS being an unpredictable illness is a challenge faced by many individuals and their families. Unpredictability contributes to the adverse psychological impact of MS. The literature to-date does not provide a consistent view of unpredictability due to the difficulties in distinguishing between uncertainty and unpredictability. However, we argue that as unpredictability is suggested to be a common challenge for individuals with MS, it is believed that health care professionals need to be aware of the context in which these individuals understand this aspect of their illness (Benner & Wrubel, 1989), and how it affects their lives and those around them, in order to deliver care that supports these individuals throughout the rollercoaster ride of MS [for further discussion of rationale and study aims see Extended Introduction: Rationale and research aims]. Examining the lived experience of these individuals' understanding of unpredictability might further enable the development of health care services to meet their needs.

### *Study Aims*

This study aims to examine how individuals with MS understand living with the prominent challenge of unpredictability.

## **Method**

### *Design*

A qualitative study design was used, from a contextual critical realist position, to explore how individuals with MS understand living with an unpredictable illness [for further discussion of ontology and epistemology, and researcher's epistemological position see Extended Methodology: Research design]. This design was used to ensure that participant's ideographic meaning of experiences was acknowledged alongside the

impact of the broader social contexts these meanings relate to. Data were collected using individual interviews, either through a face-to-face or a telephone interview, to enable participation from a wide geographic location and to ensure we included those with more severe functional limitations (e.g., poor mobility) [for critical discussion of data collection methods see Extended Methodology: Research design].

### *Development of Study*

This study was designed in collaboration with the MS Society Research Network, who reviewed and evaluated the research proposal. They identified the research topic as being important and meriting further exploration [For further discussion of methodology refinements see Extended Methodology: Research design].

### *Preparation for Data Collection*

A semistructured interview schedule and a demographics and MS experience questionnaire were developed through collaborative meetings with both authors (HRW and RdN) [See appendix B and C for semi-structured interview and MS experience and demographics interview]. The interview schedule addressed factors such as: what it is like to live with an unpredictable illness; how they feel about it; how it affects their relationships and those around them. A pilot study of the procedure, interview schedule and demographics and MS experience questionnaire were conducted. Refinements were made based on reflections from the primary researcher (HRW) and the participant.

### *Procedure*

Participants were provided with written information (electronically or via the post) and an opportunity to ask questions about the study with a researcher (HRW) [see appendix D: Participant Information Sheet]. Participants who lived within the locality of Nottingham, Lincoln or Hull were offered the opportunity to take part in an individual face-to-face or individual telephone interview. Their choice was confirmed on the consent form [see

appendix E: Participant Consent form]. Participants outside these recruitment locations were invited to participate in a telephone interview. Informed consent was taken prior to conducting interviews; telephone interviews were arranged once signed consent forms had been received via the post.

All participants were informed of the research question prior to the interview ‘What is it like to live with an unpredictable illness?’ to allow them time to consider this aspect of their illness. The demographics and MS experience questionnaire was completed and consent clarified prior to commencing the interview. Participants were informed that interviews were recorded for later transcription and analysis.

A semistructured interview was used to guide and open dialogue about living with an unpredictable illness. The interview schedule was used throughout data collection, although the emphasis was shaped by the individual’s personal experiences. Probes were used to encourage more detailed descriptions and reflective statements were used to clarify descriptions if they were unclear.

Participants were offered the opportunity to de-brief following the interview. If any issues or concerns arose from the interviews, these were dealt with sensitively by the interviewer (HRW) and participants were sign-posted to the appropriate service [for further discussion of research procedure see Extended Methodology: Procedure section].

### *Strategies for Sampling*

Participants were recruited through the “Get Involved in Research” webpage (2012) on the MS Society website, local MS Society branches, advertisements in local therapy centers, and word of mouth from other participants [see appendix F: advert for recruitment]. The recruitment process was in line with the requirements of the MS Society [for further discussion of sampling and recruitment see Extended Methodology: Procedure].

Five participants were recruited through the MS Society website, three participants were recruited from local therapy centers, and four participants were recruited by word of mouth from other participants. A further three individuals showed interest from the MS Society website but did not continue to participate; these individuals did not provide a reason. All participants that took part in the interviews identified themselves as diagnosed with MS, spoke English and were able to consent to take part.

### *Participants*

Twelve participants, all living in England, took part. Table 5 describes the sample's characteristics [for further discussion on rationale for number of participants see Extended Methodology: Procedure section].

Table 5: Summary demographics [see appendix G for further participant demographics]

Gender	Age (in years)	Ethnicity	Diagnosis	Relationship status	Employment status	Age when diagnosed (in years)	Time since diagnosis (in years)
Men: 4 Women: 8	Range: 27 – 64 Mean age: 47.3	11 White British 1 Mixed: White Asian	PPMS: 2 RRMS: 7 SPMS: 2 Unknown: 1	Single: 4 Married: 7 Widowed: 1	F/T: 2 Retired: 4 Unemployed: 4 Other:2	Range: 17-58 Mean Age: 36.83	Range: 4 -35

PPMS, Primary Progressive Multiple Sclerosis; RRMS, Relapsing-remitting Multiple Sclerosis; SPMS, Secondary Progressive Multiple Sclerosis; F/T, full time employment

### *Interviews*

Seven interviews were conducted face-to-face in the participant's home and five interviews were conducted over the telephone. Interviews were conducted at a location and time of each participant's choice.

Interviews lasted approximately one hour, and all interviews were audio-recorded for later transcription verbatim by first author (HRW) or a transcription service [for further discussion on transcription see Extended Methodology: Procedure section].

### *Data Analysis*

Decisions were made *a priori* to analysis. A semantic, inductive analysis approach was taken to remain close to the data. Data were analyzed within a contextual critical realist framework. Themes were identified, analyzed and reported using Thematic analysis (Braun & Clarke, 2006). The analysis was conducted using the six phase guideline outlined by Braun and Clarke (2006). Guidelines were applied flexibly, enabling the movement back and forth between the phases (Braun & Clarke, 2006). Main themes were determined by whether the pattern told something meaningful and was important to answering the research question. They were not necessarily the most common themes (Braun & Clarke, 2006; Buetow, 2010). Themes that were identified as not relevant to the research question were excluded [for further discussion on qualitative approaches and rationale for Thematic analysis see Extended Methodology: Data analysis sections].

Authors familiarized themselves with the data, reading and re-reading transcriptions. Initial codes and ideas were noted in the margin. These were collated into themes and sub-themes [See appendix H and I for examples of analysis]. Finally, a thematic map was generated incorporating the themes and sub-themes [See appendix J and K for early thematic map and final thematic map]. The overall narrative and the specifics of each theme were refined through ongoing analysis. Clear definitions and names were generated for each theme.

### *Quality Assurance*

This study employed techniques to ensure quality in analysis. A degree of validity was sought through: a) Researcher triangulation, both authors (HRW and RdN) independently coded transcripts and themes were compared, b) an audit trail of the analysis was maintained to provide a transparent pathway for coding and theme development, c) Verbatim quotations from participants were included to enable the reader to assess credibility of the analysis, and d) a reflective diary was maintained by the first author (HRW) to allow reflection of the interviewer impact on the research throughout all stages. This was utilized to ensure individual themes were not under- or over-represented [See appendix L for excerpts from reflective diary; for further discussion on establishing quality see Extended Methodology: Data analysis, establishing quality].

### *Ethical Considerations*

Ethical approval was obtained from the University of Lincoln's Ethics Committee [See appendix M and N for ethical approval documents]. All participants were informed of their voluntary participation, their right to decline and withdraw from the study, until the start of data analysis. Informed written consent was obtained. Participant identification numbers were used throughout and identifiable details were removed to preserve anonymity and a confidentiality agreement was signed by the employed transcription services [See appendix O for confidentiality agreement; for further discussion of ethical considerations see Extended Methodology: Procedure, ethical considerations].

### **Findings**

Thematic analysis delineated over 1000 initial codes within the data. These were organized into three main themes and seven sub-themes, as shown in Table 6. It is beyond the scope of the current article to address all the themes identified in detail. The

following sections focus on the main themes and provide a summary of the sub-themes to highlight the specific issues raised by the participants in this study regarding living with the unpredictable illness, MS [for further discussion of the themes see Extended Results: Themes and sub-themes].

Table 6: Themes and Sub-themes

Theme	Sub-themes
Challenges to meaning-making	Difficulties of understanding and articulating unpredictability
	How people understand & articulate unpredictability
A wide picture of unpredictability	Self
	Others
Surviving Unpredictability	Psychological
	Pragmatic

### *Challenges to meaning-making*

Aspects of unpredictability were acknowledged and discussed by all participants in one way or another. However, “unpredictability” was not reported to be an aspect directly experienced by some<sup>1</sup> participants. These participants reported that they did not have an unpredictable illness, but they also demonstrated a difficulty in articulating and identifying with unpredictability in their illness. This was highlighted by one participant, who stated, “It’s the unpredictability of it, it’s cos I don’t know what the unpredictability is” (P1, p62<sup>2</sup>). Difficulty in articulating unpredictability was further emphasized when one participant reported, “mine isn’t unpredictable. . . . Days are all the same” (P4, p221), contradicting an earlier statement of “mine [MS] is very unpredictable” (P4, p17). This theme, therefore, attempts to capture the ubiquity of two related concepts: (a) Difficulties of understanding and articulating unpredictability, and (b) How people understand and articulate unpredictability.

*Difficulties of understanding and articulating unpredictability.* Participants identified unpredictability as pervasive and invisible, contributing to the difficulty in understanding and articulating it. Despite participants having different MS diagnoses and experiences of relapses, some aspects of unpredictability were pervasive. For instance, participants were unable to predict symptom flare-ups. They reported “Everything is unpredictable” (P1, p64) and this hindered their distinction between MS and unpredictability. One participant described their constant reminder of unpredictability explaining that they experience it, “on a daily basis, like a, it’s like a relapse, you are not out of it but you are in it. . . . Even on an hourly basis” (P3, p54-58). Participants explained that despite having periods of remission they still experienced “flare-ups”, MS as a whole was unpredictable, it was a constant factor in their life, and to distinguish between “living with unpredictability” and “living with MS” was difficult.

MS was described as an invisible illness. Individuals experienced neurological pain, such as pins and needles. Participants acknowledged that to others they might look well, “they just see me as ok yeh, they have no idea” (P2, p138), but the unpredictability of symptoms posed a challenge for others to understand:

I mean to look at me there is nowt matter with me and yet they’ll see me today and I might be skipping down that street with my granddaughter, three days time they look at me and see me in a wheelchair and think what. (P5, p285)

This was elaborated by another participant who stated, “you might be ok again the next day and that’s quite hard for other people, who don’t know MS to visualize” (P6, p134). The invisible nature of some unpredictable symptoms also made it difficult for people with MS to understand:



It's a pain that is not actually there, so that's what makes it a bit more difficult for me, it's not there so why take a tablet for it, although the tablet is proven to work why am I going to take a tablet something that's not real, it's a neurological pain, don't be ridiculous. (P2, p234)

*How people understand and articulate unpredictability.* Participants employed two main strategies to talk about unpredictability: (a) bringing the abstract into the realm of the concrete and (b) by making comparisons in terms of time, people and conditions.

(a) Participants demonstrated a wide use of biological discourses as a means to articulate and understand unpredictability. In particular, examples of symptom fluctuations were used to articulate the participant's unpredictability. One participant reported: "it still was a pain getting your legs out [of the bath] because they don't move, you can get your legs to you, but they don't move, and sometimes they do; it's very odd, very very odd" (P4, p193).

Participants also used physiological explanations to help understand the nature of their unpredictable symptoms. One participant explained the changes they experienced following a relapse, "but when I didn't [get better], I thought 'well ok, that's now gone,' whatever, you know myelin sheaths or whatever, they've gone" (P6, p34), demonstrating a means for her to understand and accept the unpredictable body changes experienced. It appeared that explaining unpredictability through biological discourse provided a participant with a concrete understanding for what happens in his body when things go wrong:

I think it's a question of, in your mind you know what you're going to do and you think you'll be able to do it, but then for some reason, like you're probably aware

with MS, in terms of, it's the lack of the message getting through from the brain or spinal cord, to parts of the body you want to do something, isn't it. (P12, p30)

In these instances, resorting to concrete biological matter (e.g., myelin sheaths) or imagery (e.g., messages being transmitted) allowed the abstract concept of unpredictability to be understood and voiced.

(b) Comparisons also helped participants articulate their comprehension of unpredictability. Participants identified changes within themselves across the time, acknowledging that each day is different: "I suppose it is because, you know, one day you'll be OK and you can do things, then the next day you can't" (P6, p134). Participants used time comparisons to indicate the changes they had experienced through their illness; these were to be used to highlight how they had never envisaged their life to end up like this:

I realize that prior to being 34-35 when I was diagnosed with it, if somebody had said to me we'll go up to pub and have a drink and call at supermarket and get some cigs I could just do that, that wouldn't be a problem but now it is so much planning. (P1, p22)

Another participant used time comparisons to demonstrate the restrictions that unpredictability had placed on their work life:

I'm not, I'm just not the same person. I can't be, I can't jump into every single role, not that you would expect to at my level because that would just be irrational, but potentially I could have done every single job in the school, you know. (P9, p192)

Participants also used comparisons to articulate a battle they had between themselves and MS. One participant explained, “It [MS] can take what it wants, when it wants” (P5, p169). Some participants personified MS, “It’s like there is a little person just in my head, just taking what they want. . . . That doesn’t sound very logical, psychological, though does it? MS is a person sort of thing” (P5, p165-169). The MS “person” was playing a game with them, stealing parts of them when it wanted. This personification of MS created a visual concept to do battle with, “when I find him I’ll kick their heads in, if my legs are working” (P5, p173). Another participant referred to MS like their conscience, “the MS is always there and it is saying, well if you go out, you know you’ve got to be back by a certain time” (P7, p554). The personification of MS allowed participants to legitimize their battle with MS and its unpredictability, providing a visual image of MS to battle against.

The comparisons within the self were further articulated through the use of a struggle between the body and the mind. One participant articulated his unpredictability as “I’ve got an active brain but inactive body” (P12, p52). This participant described the illness to highlight how he was: “well mentally I’m fully mental, if that’s the right way of putting it, [but] my body is in decline” (P12, p18). This distinction between an active mind and inactive body was prominent in many of the participants’ narratives. Participants utilized this comparison to explain how unpredictability affects their daily activities:

The plan for that hour and a quarter, err, it can work alright in your head and think, yeh I’ll do this, and I’ll do this and I’ll do that, and then it can all go wrong and it’s the unpredictability of it. (P1, p126)

Participants made comparisons between individuals and others to demonstrate their unpredictability. Comparisons were made in particular to other illnesses and what the participants classed as 'normal'. This emphasized how they were different to other people because of their unpredictable illness. One participant highlighted the difference of what is normal to her and her family, stating that it was "quite strange for them, I mean it must be to just all of a sudden know it's just normal for their Nanna to just all of a sudden need to go in a wheelchair or need a walking stick" (P5, p45). Some participants made comparisons between "normal" people and themselves to highlight how their lifestyle had altered to accommodate their unpredictable illness: "like once, normal people wouldn't think 'yeah the shop's crowded, how hot is it? Are them blowers on to overheat you?' . . . But me, I have to think about the lot" (P5, p81). Positive comparisons to others were also used by participants: "I don't know, I don't suppose anybody's got control over life, their life in a way, because you never know what's going to happen" (P6, p190), normalizing the participant's feeling of loss of control from the unpredictability by comparing it to other individuals who do not have MS.

Participants also used comparisons to other illnesses to help their understanding of MS and their symptoms. For some, this was used to aid acceptance of their illness, one participant, when discussing the unpredictable fatigue of the illness stated: "some people would like to be able to go out just for one hour" (P2, p70). This highlighted how the participant acknowledged the benefits of their unpredictable "well" periods which allowed for daily activities to continue, whereas others illnesses may not have "well" periods. This was elaborated by another participant: "if it was arthritis and I was in pain all the time I might not be able to [go out]..." (P4, p199). Whereas some participants used it to articulate their frustration with the unpredictability of their illness:

I mean I once turned round and I said to someone, “I would have rather had cancer” and they said, “That’s not nice,” and I went, “Yeah but at least I could have fought it”, I said, “this I’ve got no chance.” (P5, p245)

For many participants cancer was viewed as a more “acceptable” illness with a more predictable course and causation, it represented something that could be fought. MS however represented an unpredictable illness that could attack any part without warning and against this they felt they had no chance to beat MS.

*A wide picture of unpredictability.*

Participants demonstrated the negative and positive impact of unpredictability on their lives and others around them. One participant described the wide reach of unpredictability: “there was more at risk erm, than just me, it was affecting my family and, and wider” (P3, p9). This theme is separated into (a) self, and (b) others.

*Self.* Participants identified wide reaching effects of unpredictability on their lives, they described feeling that “you sort of are grounded” (P5, p81). They discussed losses in their lives, impacting upon their self-perception and the fear and frustration that was borne out of the unpredictability of their illness.

All participants identified with losses created by the unpredictability, for instance a loss of identity, family role and independence.

Some participants described feeling a loss of identity through the loss of the unique things that made them who they were:

I’ve got three things [cooking, teaching and acting] that are mine and that’s [cooking] one of them, you know. And sometimes you just want to keep it on yourself. . . . So the three things that I’m really, that I really feel, you know, I’ve

got and are unique to me and I can do them well, have all been taken away. (P9, p58)

Participants discussed the difficulties of maintaining their roles within the family when they suffer an unpredictable illness. One participant described their loss of role as a mother, when bed-bound by one of her relapses:

Like a tug, I wasn't well and like aunt or friends would say oh I'll take Mark<sup>3</sup> out of the way, it was that I couldn't, I couldn't physically look after him; husband was at work, there was just us two, because I couldn't do it. (P3, p96)

Others found that the unpredictability did not necessarily mean a loss of role but rather a change in role, essentially leaving them holding a different place in the family:

Yes, you have to think about the children and add me into that mix as well because I have to be, you know, treated as a child also, you know, there are certain things that I can be left alone for, and there are certain things that I have to be treated as a child for. (P11, p281)

Independence and control was important to some participants, with one stating: "Well you need to control your life, don't you, as much as you can" (P12, p198), however they acknowledged that the unpredictability of their illness at times created a level of dependency on others. This loss impacted on their self-perception, dependency was seen as debilitating:

But I love being independent, I cope really well in new situations and changing situations. So that's a real strength for me. . . . So to be dependent on anybody on

anything, I find really difficult, really quite difficult. . . . It makes you feel, it makes you feel disabled. (P9, p112-116)

Unpredictability of MS was described by one participant as “takes a bit of everything” (P5, p281). They found that the unpredictability had an impact on their ability to continue hobbies, social life and for some participants, employment (collectively known as extended activities of daily living [EADL]).

Some participants discussed the loss of their EADL, yet a sense of resilience was demonstrated by participants, continuing activities as and when they could. For all participants, employment roles had to change to accommodate the unpredictability of their illness:

Either this job, I’m going to get this job and it’s going to work out because it’s not going to have the same demands and I am going to survive for five years or six years, or I’m going to say, right, yes that’s it now, you know, I’m going to do a part time job that earns me twenty thousand a year, thanks very much, you know. (P9, p216)

For some, employment was the only activity they did which enabled them to continue to feel they were providing for their family. Many experienced career changes to accommodate their unpredictable illness: “... I [now] came to work for my dad because it is flexible” (P2, p194).

A positive outlook was adopted by some participants, acknowledging that their achievements would not be taken away from them even if they could not achieve these now: “Like I said, if it happened, like years ago before I’d qualified, then it would be horrible, but like nobody can ever take those [qualifications] away from me” (P10, p377).

Unpredictability caused disruption in all participants' hobbies and social life, and spontaneity was curbed:

Yeah because spontaneous as in getting up and going away for the weekend, and just waiting till last minute to make plans is a bit different. . . . I don't know I feel boring at times because the things that I would naturally be doing I can't do it.  
(P2, p280-306)

This participant felt unable to make plans unsure of how they would be later on. This hindered their participation on social activities leaving them feeling "boring" and bored.

Participants' self-perception was affected, they described feelings of being inadequate, small, delicate, silly, and lame. One participant explained they felt "like a failure, like you've failed and you know you failed because it's never going to go" (P2, p332). Furthermore, participants demonstrated their concern about how they were viewed by others: "I am body conscious. Yes, I hate to be thought of as, 'oh look at that old woman with a stick'. I think no I am not" (P6, p10).

A number of participants described the loss of confidence in social situations. One participant described how the unpredictability has affected their outgoing personality, struggling to keep up in social situations:

Yeah in conversation in company and I lose, I lose I just lose interest, I lose track of the conversation and it is hard to be upfront, you know sharp, and in with it I mean when you're well and you're feeling up to it, I've always been very social person, but erm now most of the time I'm, I think oh dear me. (P1, p52)

The illness and how they felt about themselves both had an impact on how people's lives changed in their family and social circles. The awareness of the impact of



unpredictability on the participants' contributed to their fear and frustration. Participants expressed fear about the future. Ironically despite the predictability of the downward progression of their illness over time, as one participant stated: "all you know with MS is, over a period of time you're going to get worse" (P11, p329), participants, were left worrying about the route it would take: "I know it is all going to be unpredictable, but I just don't know where it is going to go" (P1, p62). This left them contemplating the "what ifs" (P2, p6) of life.

Participants' fear of the impact of their unpredictability of the illness caused concerns around their safety. Some acknowledged the security offered by their own homes, created a "security blanket" (P5, p105), one participant described: "Like if my energy is low . . . I know I'm alright, I'm safe in my flat erm because there is all the cords and everything so I know I'm safe here" (P5, p41). Other participants displayed frustration continuing or returning to live at home with their parents as a precaution in case they experience unpredictable flare-ups, one participant described:

Just needing them or knowing that they are there . . . cos that is enough to know like my mum is at the end of the phone that is enough [ . . . ] yeh, that was quite hard [moving back home] [ . . . ] it is like going back in life [ . . . ] not good [made me feel] . . . no not good just angry, really annoyed. (P2, p180)

Participants also discussed the unpredictability of their medication, with an unknown success creating a sense of apprehension:

I thought do you know my arms gone it might be like this permanent . . . erm because I'd had my steroids at this point and my arm wasn't coming back. It took a good six weeks before the steroids kicked in and my arms came back, and I was

thinking right this is permanent now, am I going to get my arm back, are the steroids going to work? (P5, p257)

Participants' expressed their frustrations around others' perceptions of their unpredictable symptoms. One described:

I fell in the alleyway, and five people walked past me because they thought I was drunk, [ . . . ] everybody was like thinking I was drunk [ . . . ] like even if I go out at night time [ . . . ] I have my stick with me most of the time but . . . people are looking at me and judging me [ . . . ] it is yes [frustrating]. (P7, p62)

*Others.* Participants acknowledged that the unpredictability had a wide impact, affecting their family and friends. Relationships were tested but many survived with team work and flexibility. Social roles had changed: "I used to be the prominent one who used to do things and now I've had to sit, sit myself back and he is now, he's in charge you know, he, he tells me sit" (P3, p78). The role changes sometimes disrupted the whole family:

Your whole relationships skewed. . . . Mother-in-law moves in, time of stress, wife sick, erm child is maybe aware of what is happening, and grandma is in, grandma is doing things differently the way mother and dad do you know, house rules change and it, it affects the whole family you know. (P3, p46)

Many identified these role changes as difficult to manage, but they also demonstrated their acceptance of the role changes, relationships were referred to as "teams":

Yeah we work, we cook, while when aunt and uncle come tomorrow, I'll cook hopefully . . . and then Bill will set the table, and then I'll come and talk to them

and Bill will go to the kitchen, he will finish off and he will do the . . . fetching things through to the table and clearing it and things. (P3, p86)

The distinct roles that once might have played out in the families had now changed, and to allow the participants a sense of purpose, relationships had developed into teams, working together flexibly to accommodate the unpredictable effects of MS. Relationships were reported to have strengthened for many, yet in terms of friendships, participants identified that relationships would only survive if friends understood MS and the unpredictability of it. Participants described a learning process of saying “no” to activities, but this was reported to be difficult: “Letting people down so emotionally you are, you know you feel you are, not doing what you should be doing, yeah” (P3, p64).

The impact of these changes was discussed in relation to the impact to lifestyles and activities of those around the participants. One participant acknowledged that they encourage their partner to continue their interests as long as they could, “It’s like Bert you know he says oh ‘is it alright if I go [hobby<sup>4</sup>]?’ and I say ‘go now Bert while I can [look after myself], you might not be able to go later on’” (P4, p17). There was a keen awareness of the flexibility that is required, the increased dependence on others was acknowledged, and the effect this had on their family was noted. A sense of “do it whilst you still can” was adopted by participants and filtered out to those around them, acknowledging that everything is time limited, until their dependence grows and affects other people’s lives as well.

### *Surviving Unpredictability*

Despite many participants expressing a negative perception of their self, and a failure to beat MS, this theme identifies the fighting spirit of the participants; it relates to the ways

in which participants demonstrated their ability to survive unpredictability. We identified two such strategies: (a) psychological, and (b) pragmatic.

*Psychological.* This sub-theme represents the psycho-educational and psychological aspects such as learning about their body and MS, their perspective on life, denial and acceptance of MS. Some participants spoke about the difficulty coming to terms with unpredictability: “I’ve still not accepted that [unpredictability] yet, to this day, er, why things can go wrong and they shouldn’t be, they shouldn’t be going wrong” (P1, p28). Others demonstrated their learning about their illness and their body to aid the acceptance of the unpredictable illness, and understand and listen to their body’s commands:

I just ignore things because say if I was out and I think oh it’s time to go, there was once a time I would have completely ignored it and I’d suffer for days, whereas now I give in to it. (P2, p74)

Some participants accepted unpredictability as it became part of their life: “at one time, I used to think about it quite a lot of the times of the day, just thinking what’s going to happen, whereas now I don’t think I do that” (P2, p214). In learning about their body and symptoms, participants could start to pre-empt some of their symptoms, although they might occur unpredictably, there was a proportion of predictability. Once participants were aware of their limits, they learnt to work within them:

I mean once you’ve, if I sort of say, “Yeah I’m going to go shopping.” And soon as you get in there and it’s too packed you turn around and you have to come back ‘cause there’s no way you’re going to manage it. (P5, p85)

In learning about their body, MS and their own limitations, participants reported how their perspective on life had changed. Participants discussed how they accepted that they could only do what they could. This was articulated by one participant who stated a number of times, “I’d want to do what I can do while I can do it” (P4, p184). Participants reported trying to look at things positively and how living with an unpredictable illness had changed their outlook on life:

I don’t know it probably sounds silly but when I could, couldn’t physically walk at all for a long time, now just walking up the stairs I would probably just smile a little bit and think I couldn’t do that one day, whereas now I can so, I don’t know, in a way I see it as a good thing as it has made me appreciate things whereas before I probably took, took everything for granted, and I don’t think I do that now. (P2, p80)

Participants demonstrated an understanding that simply fighting MS can make things worse, and by working “with” (discussed below) unpredictability in their lives, they are able to fight it more effectively: “erm then from there I sort of went forward and learnt, ‘yeah OK I can, I can live with this’ and the more I stopped pushing and fighting, the more easier it, my body became to live with” (P5, p253). Some participants spoke about how they learnt to laugh at their unpredictable symptoms, “At one point my arm would go sort of, “whey”, a bit like the old Carry On films, there’s a bloke on there used to go, “whey”. And, you know, we have a laugh about that because it’s funny” (P6, p244).

*Pragmatic.* Participants had pragmatic methods of dealing with the unpredictability that they encountered. They discussed how planning was a major factor, yet preparation was the key to success: “. . . but then again I’ll have my walking stick with me . . . Erm, so you sort of plan but you make sure your prepared” (P5, p69).

Distinguishing between having a plan of what they will do but being prepared for all eventualities. They also discussed the adjustments made in their lives to accommodate the unpredictability of their illness. Adjustments ranged from practical decisions about the house and their environment, to size of family and employment. One participant explained: “And I realized then that this illness affected Bill [husband], the things he wanted to do and our life, and I decided to seriously to limit my family because of that,” (P3, p9).

## **Discussion**

In this article, we describe three core themes relating to understanding living with an unpredictable illness, and tell their story of living with an unpredictable illness. The first theme underscored the key difficulties of identifying, articulating and understanding unpredictability. The invisible and pervasive features of unpredictability contributed to these difficulties. Our findings suggested that the pervasive nature demonstrated a challenge for individuals to distinguish between MS and its progression, and unpredictability. The invisibility of the unpredictable symptoms proved difficult for individuals to make sense of it for themselves and articulate to others [for further discussion of the findings see Extended Discussion: summary of the findings].

Despite the challenges of identifying unpredictability, all participants acknowledged this feature in their illness, although it was not explicitly spoken about by all. Our findings suggest that biological discourses and comparisons were used to develop participants’ understanding and enabled them to share their experiences. Leeder (1990) argued that individuals struggle to unify body and self when illness focuses our attention on the body. Our findings support Leeder’s (1990) claim, the mind and the body were not seen as being unified. The battle between mind and body echoed the findings from previous chronic illness lived experience literature (e.g. Olsson, Lexell, & Söderberg,

2008; Toombs, 1992). A further battle between self and MS was reported. This highlighted the fighting spirit of the participants, an aspect that has been identified in previous research (e.g. Dennison, Yardley, Devereux, & Moss-Morris, 2010; Malcomson, Lowe-Strong, & Dunwoody, 2008; Reynolds & Prior, 2003). The personification of MS provided a visual object for participants to battle against. Participants spoke about MS as someone playing games with them, taking parts away when they pleased and possibly returning them at a later date. This provided insight into how they understood and articulated their unpredictable illness. Externalizing the problem from themselves is a similar technique to that used in narrative therapy (A. Morgan, 2000). Separating the problem from the individual can be a method for coping and maintaining self-esteem.

In line with previous literature (e.g. Barrett, 1995; Dennison, Moss-Morris, & Chalder, 2009; Dennison, Yardley, Devereux, & Moss-Morris, 2010; Edmons, Vivat, Burman, Silber, & Higginson, 2007) our findings demonstrated the wider picture and reach of unpredictability. Unpredictability of MS impacts the individual and their wider family and friends. The unpredictable nature left participants experiencing losses, which paralleled findings from previous MS literature around the impact of relapses (Kalb, 2007), these losses are associated with a grieving process that individuals experience. The a sense of fear and frustration in the participants created by the unpredictability, again paralleled the findings from previous MS lived experience literature (Dennison et al., 2010). Our findings suggested that the impact of the unpredictable nature of the illness contributed to a change in self-perception. In some participants this resulted in a lack of confidence, which was echoed in the development of participants' negative self-perception resulting from their unpredictable illness.

Roles and relationships were altered and tested by the continual unpredictable changes of the illness. Positive changes to relationships were identified, and flexibility and team-work aided the success of these relationships.

The final theme demonstrated how the participants lived with unpredictability. “Surviving unpredictability” demonstrated the adjustment and coping mechanisms that individuals utilized. Our sub-themes paralleled the coping strategies identified in the previous literature (e.g. Lazarus & Folkman, 1984): problem-focused (pragmatic) and emotion-focused (psychological). Participants demonstrated a shift from denial to acceptance, a shift in their coping strategies to a more effective coping strategy (Dennison et al., 2009). The perspectives of the participants altered, with participants demonstrating a ‘get on with it’ attitude. They also acknowledged a change in their appreciation; appreciating functions that had returned following relapses, and what they were still able to achieve on a day-to-day basis. Participants acknowledged that the unpredictability was not at the forefront of their minds anymore, where once it dominated their thoughts. Their acceptance of their illness and an acute understanding of their body enabled them to better plan their EADL. While planning was acknowledged by many participants to be a major factor of their life, being prepared was crucial to successful survival of unpredictability. The awareness that even the best laid plans can go wrong ensured that participants were able to accommodate the unpredictability that they encountered. This indicates how participants adjusted to living with unpredictability. The shift in their perspective fits well with the Shifting Perspectives model of illness (Paterson, 2001), which posits that individuals shift their perspective between having illness or wellness in the foreground. Patterson argues that a sense of wellbeing is sustained while the illness perspective is held in the background. Acceptance did not, however, come easily to participants and there was a continual shift between the



acceptance and denial [for further discussions of the findings in relation to previous research see Extended Discussion].

As one of the first studies to focus on the construct of unpredictability it has highlighted its continual effect. Participants described their perception of how this aspect of their illness impacted on themselves and those around them throughout their illness. Toombs (1992) noted, uncertainty is an ever present threat. The present findings identified unpredictability to be a continual threat. The appraisals of threats are reported to be the most important type of appraisals and consistently relate to worse adjustment (Dennison et al., 2009). Participants described a process whereby they learnt about their body and MS, shifting from denial of MS to acceptance, and with this, developing a different perspective on life. Despite participants holding negative self-perceptions, their fighting spirit lived on. They made adjustments that allowed them to battle effectively with MS and continue to live with unpredictability. In addition the participants acknowledged the wider effects of unpredictability, impacting on their family and the decisions made within a family to accommodate the unpredictability of their illness.

### *Limitations*

Although unpredictability was acknowledged by participants as part of their illness, it cannot be identified as a separate construct to living with MS. It can be argued that as MS was identified as unpredictable the difficulty in distinguishing between these ideas was not possible. The difficulties some participants faced in articulating this might point to this challenge of distinguishing unpredictability from MS and its symptoms.

Literature indicates that support from a group impacts on adjustment and acceptance of an individual's illness. Dennison et al., (2010) reported that those who are willing to attend support groups are more willing to accept and explore their illness. With this in mind the results presented in this article represent a sample of self-selected

individuals and hence by virtue of their willingness to participate in the research indicates their willingness to explore their illness. Therefore, these findings may represent individuals who are at a stage of acceptance, and does not account for those who are unable to accept their unpredictable illness [for further discussion of strengths and limitations of this study see Extended Discussion: strengths and weaknesses].

### *Recommendations and Clinical Implications*

The findings might provide useful insight into the experiences of living with an unpredictable illness, acknowledging the wide reaching consequences and the strategies used by individuals living with unpredictability. Given that the sample of the present study might consist of individuals who are at a stage of acceptance and exploration of their illness healthcare professionals might find these findings useful in supporting individuals who are struggling to come to terms with their unpredictable illness. The use of analogies to articulate and describe unpredictability of MS may be useful in therapeutic work with individuals adjusting to the unpredictability of their illness, externalizing MS to develop an understanding for the changes they experience.

This article highlighted the impact on families, participants described changes within the family developing cohesive networks to manage the ever changing nature of their abilities, it can be hypothesized that engagement of family members, increasing their understanding and addressing issues related to unpredictability of MS may improve outcomes for individuals adjustment and coping with MS [for further discussion of clinical implications see Extended Discussion: clinical implications].

Future research should aim to further explore living with an unpredictable illness in those who do not engage in social support groups, to further develop the story around living with unpredictability [for further suggestions of future research see Extended Discussion: future research].

## **Conclusion**

In conclusion, unpredictability was a key factor of living with MS for each of the participants. They found it challenging to articulate and understand unpredictability but were able to do so by using biological language and making comparisons. The impact of living with an unpredictable illness has wide-reaching consequences, which affect individuals both personally and socially. People with MS do however use psychological and pragmatic approaches to deal with unpredictability.

## **Notes**

<sup>1</sup> General ‘quantifiers’ are used for descriptive purposes and do not relate to specific frequencies or ‘significance’ of endorsements. Frequency and prevalence alone did not quantify saliency of themes. The researchers’ judgment in relation to extracts capturing meaning or patterned responses defined the saliency of themes (Braun & Clarke, 2006).

<sup>2</sup> Each quote is labeled with a Participant number (P) and a paragraph number (p) that identifies where in the interview the extract is from.

<sup>3</sup> Pseudonyms are used throughout the article to maintain participant anonymity.

<sup>4</sup> Identifiable information has been removed to maintain participant anonymity.

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**EXTENDED PAPER**

## EXTENDED INTRODUCTION

This section expands on the journal paper, providing an overview of the relevant literature, and forming the rationale for the current study and the research aim.

### **Multiple Sclerosis.**

Multiple Sclerosis (MS) is defined in the National Institute for Health and Clinical Excellence guidelines [NICE] (2003) as a disease of the central nervous system, affecting the brain and the spinal cord. Symptoms are caused by a process of demyelination, where the fatty material that insulates the nerves (myelin sheaths) in the central nervous system are destroyed (Lezak, 1995). The myelin sheaths enhance the transmission of messages, and are found in the white matter of the brain. In MS the immune system mistakes the myelin sheaths as a foreign body that it needs to fight off (like a virus), resulting in the myelin being stripped from the nerves, fully or partially (Multiple Sclerosis Society, 2008). The destruction of the myelin sheaths causes the nerve transmissions to be disrupted from and to the brain, resulting in delayed reactions and uncoordinated responses (Lezak, 1995). The sites where the myelin is damaged are known as plaques or lesions, and appear as hardened areas or scars. Scar tissue replaces the damaged myelin sheaths and contributes to the difficulties for nerve transmissions. The term 'multiple sclerosis' literally refers to many scars (Multiple Sclerosis International Federation [MSIF], 2013).

**Aetiology and prevalence.** MS is reported to affect around 100, 000 people in the UK, with roughly three times as many women being diagnosed than men. The causes of MS are largely unknown, however it is considered that MS occurs due to a combination of environmental and genetic factors (Multiple Sclerosis Society, 2008). To date there is no known cure, but it is suggested that individuals can help manage and cope with their symptoms through the use of medication and other methods (e.g. exercise).

**Diagnosis and disease course.** MS can present as confusing and individuals often experience transient symptoms. In the early stages of MS, symptoms appear vague and can often be attributed to other common disorders

such as a stroke or brain tumours (Rao, Huber, & Bornstein, 1992). This can make MS difficult to diagnose and it is often reached after a process of exclusion of other disorders (McDonald et al., 2001). Traditionally individuals had to experience two attacks before receiving a diagnosis of MS, however the development of the 'McDonald guidelines' shifted the reliance from clinical presentation alone to considering a probable diagnosis after one attack if supported by diagnostic radiological and laboratory evidence of lesions (McDonald et al., 2001). Since the development of these guidelines there have been subsequent revisions to adapt to the ever developing medical resources and technologies (Polman et al., 2011).

MS is typically characterised by unpredictable episodes of relapses and remissions. A combination of demyelination in different areas and residual lessening of response times in areas where the myelin sheaths have already suffered damage generally results in the severe symptoms of an acute relapse which typically resolve leaving the individual with a decline in functioning (Lezak, 1995).

Onset typically occurs in early adult life, there are three common patterns of MS:

1. *Relapsing-Remitting MS (RRMS)* is the most common pattern, affecting around 80% of individuals at onset. An individual can experience periods of good health (remission) of months to years, followed by periods of relapses.
2. *Secondary progressive MS (SPMS)* around 50% of individuals who experience RRMS progress to SPMS. Individuals experience fewer and shorter periods of remission and symptoms gradually become worse (NICE, 2003).
3. *Primary progressive MS (PPMS)* indicates that an individual's symptoms will develop and progressively worsen over time. These individuals typically do not experience the periods of relapses and remission like those with RRMS. This pattern occurs in around 10-15% of individuals at onset.

**Symptoms and consequences of MS.** There are a wide array of symptoms that an individual can experience in MS, which are dependent on the location of the lesions in the central nervous system (Lezak, 1995). Symptoms can fluctuate rapidly and vary between individuals, yet despite the seemingly random nature there appears to be particular symptom patterns (Lezak, 1995). Typically



individuals experience fatigue and double vision (diplopia), yet as the illness progresses symptoms begin to vary in severity and type (Mullins et al., 2001). Typical symptoms reported in MS include: fatigue, motor disturbances such as weakness of muscle groups or paralysis of a limb, sensations such as pins and needles, numbness or pain, cognitive deficits, bladder and bowel dysfunctions, visual disturbances and disturbances in speech and swallowing (Miller, 1997). Many of these symptoms are noted to be difficult to describe and articulate due to the transient or invisible nature of MS (MSIF, 2013).

Cognitive dysfunction is reported to be a significant problem, however the symptom profile and severity of deficits in MS is heterogeneous (Mohr & Cox, 2001). The deficits are dependent upon the location of the lesions, resulting in a range of symptoms being reported. The most common problems reported are processing speed, attention and concentration (Brassington & Marsh, 1998). The cognitive deficits experienced during a relapse may not be permanent and the individual may return to their previous level of functioning (Foong et al., 1998).

Alongside the neuropsychological effects of MS, individuals may encounter psychological symptoms. Emotional distress is reported to be more prevalent in MS than other chronic illnesses (Gulick, 2001; Miller, 1997). Anxiety and loneliness are reported to be common (Gulick, 1989), yet depression is argued to be the most common and debilitating (Mohr & Cox, 2001). The high prevalence of depression in MS is suggested to have multiple aetiologies (Mohr & Cox, 2001). Uncertainty and unpredictability of the illness symptoms and course are reported to contribute to an individual's emotional distress (Gulick, 2001), alongside the impact of deterioration of physical and cognitive functional ability. In addition, it is speculated that depression maybe a complication associated with MS, as well as a symptom resulting from the MS specific immune dysregulation (Mohr & Cox, 2001).

### **Uncertainty and unpredictability**

**Chronic illness literature.** Literature highlights the uncertain and unpredictable course that many individuals with chronic illnesses endure (e.g. Burry, 1982; Haahr, Kirkevold, Hall, & Ostergaard, 2011; Whittemore & Dixon, 2008). Antecedents to uncertainty include familiarity, severity of and, information about the illness, social support, age, marriage status, employment and education

(Mishel, 1999). Unlike acute illnesses uncertainty is reported to be a constant factor within chronic illnesses (Mishel, 1999), filtering into more areas of the individual's life impacting on daily routines and activities (Cohen, 1993a; Weitz, 1989).

Unpredictability is described as inability to foretell the future (McCormick, 2002), and it is a factor that contributes to uncertainty (McCormick, 2002; Mishel & Braden, 1988; Neville, 2003). Uncertainty is defined as the cognitive state when an individual is unable to determine the meaning of illness related events (Mishel, 1988). The unpredictable course, inconsistent symptoms and continual concerns regarding recurrence or exacerbations of a chronic illness fosters a sense of uncertainty and fear. It is suggested that these factors typically result in individuals voluntarily restricting their lives, however unpredictability can span lengthy periods of time or have a narrower time frame consisting of 'good' days and 'bad' days, to intermittent 'good' spells and 'bad' spells within a day (Charmaz, 1983). Understandably these factors impact upon the individual and those around them.

Amongst the wealth of chronic illness literature, uncertainty and unpredictability appear to be prominent features, affecting the emotional distress, quality of life and adjustment and coping with their illness (e.g. Bailey et al., 2009; Gulick, 2001; Miller, 1997; Mohr & Cox, 2001; Reynolds & Prior, 2003), and in some cases it is argued to be a major problem in comparison to depression, pain and fatigue (Bailey et al., 2009; Malcomson et al., 2008). Despite unpredictability being a factor that appears within this literature there has been only one paper identified through the authors search which examines unpredictability as a separate factor (Haahr et al., 2011).

**MS literature.** An individual's illness pathway is unique, individuals with MS have differing experiences resulting in each person telling a different story (Barrett, 1995; Langgartner, Langgartner & Drlicek, 2005). In common with other chronic illnesses, MS is characterised by an unpredictable nature, impinging on the individual's quality of life, ability to adjust, and psychological distress (Mullins et al., 2001).

Individuals with MS are faced with irregular relapses, lack of a cure and a downward illness progression. The inability to foretell the future creates an unpredictable situation (McCormick, 2002). This alongside the perception of ambiguity around the diagnosis and a lack of information about these factors

contribute to the uncertainty of MS (Mishel & Braden, 1988). An individual's perception of MS as a highly unpredictable and uncertain illness is further impacted by an unknown eventual level of functional impairment and disruptions to their education, employment, family relationships, sexual functioning, and daily activities (Mullins et al., 2001; Thomas, Thomas, Hillier, Galvin, & Baker, 2006).

Despite unpredictability and uncertainty being theoretically distinguishable these terms often are used inconsistently in the literature. The terms often appear enmeshed. The review of the literature in the following section primarily focuses on uncertainty due to the dominance of this construct.

**Effects of uncertainty and unpredictability.** Unpredictability and uncertainty are argued to be the major challenges that individuals with MS encounter (Malcomson et al., 2008; Miller, 1997), threatening the individual's sense of well-being and psychological health (Rao et al., 1992; Reynolds & Prior, 2003).

Relapses and exacerbation result in an unpredictable onset of new symptoms or significantly worsening of existing symptoms. The level of uncertainty is heightened as a result, these episodes are considered as "crises" (Kalb, 2007). Individuals commonly experience grief, anxiety, anger and guilt.

An association between uncertainty and psychological distress, after controlling for demographic and illness parameters, was reported in MS (Mullins et al., 2001). Uncertainty is described as a "constant companion" (Mishel, 1999, p.269) in MS, and this factor along with the unpredictability of the illness course was argued to contribute to a level of emotional distress that was higher in comparison to other chronic illnesses (Gulick, 2001; Miller, 1997). These findings were supported by reports of uncertainty and unpredictability in MS exacerbating negative experiences for individuals (Malcomson et al., 2008). Furthermore the uncertain future of living with MS has been positively correlated with fatalistic coping (Miller, 1997). The lived experience of MS is reported to be primarily one of uncertainty and learning to cope with the unpredictability, whereby individuals learn to cope knowing that the future is unpredictable and they are unable to control it (Miller, 1997).

Uncertainty and unpredictability have been identified as affecting individual's ability to cope and adjust. Schüssler (1992) concluded that individuals

who do not accept their illness or perceive it to be uncontrollable are likely to use emotional coping strategies, whereas those who accept and believe that they can influence their illness tend to use problem-solving strategies, which are argued to be more effective than strategies that focus on changing one's emotional reaction, emotion-based coping strategies (Miller, 1997). Individuals facing a future of unpredictable symptoms and uncertainty, that interferes with their ability to function and accomplish major life roles, are argued to cope successfully when they are able to redefine themselves in terms of self, control and independence. Furthermore, thinking creatively and flexibly about their control and independence is argued to make this transition easier (Kalb, 2007).

Hanna's (1996) precursor framework helped identify the positive aspects that individuals with MS can experience (Pinson, Ottens, Fisher, & Kirkpatrick Pinson, 2009). These authors reported that knowledge about the illness reduces the fear of the disease course and possible outcomes. This supported Miller's (1997) argument that uncertainty diminishes over time as individuals become accustomed to exacerbations and learn that symptoms are temporary and not permanently disabling. Miller (1997) argued that continuous uncertainty and unpredictability lead individuals to reappraise these aspects as less threatening, shifting towards the perspective of uncertainty offering opportunities to be healthy rather than ill (Miller, 1997). Furthermore individuals are suggested to develop a sense of control through knowledge (Pinson et al., 2009). This knowledge is argued to counteract the unpredictability of their illness, aiding their ability to deal with the unpredictable symptoms (Lee & Poole, 2005; Pinson et al., 2009; Reynolds & Prior, 2003). In addition hope is argued to provide a means for dealing with uncertainty (Miller, 1997). Finally, lived experience literature has identified the importance of a good support network to enable adjustment and coping to uncertainty (Miller, 1997; Pinson et al., 2009).

**Psychological effects of unpredictability.** Interest has grown in qualitative studies exploring the lived experience of MS both for the individual and their carers (e.g. Cheung & Hocking, 2004; Koopman & Schweitzer, 1999; Malcomson et al., 2008; Miller, 1997; Moriya & Suzuki, 2011; Mutch, 2010; Olsson, Lexell, & Söderberg, 2008; Shevil & Finlayson, 2006; Vick, 2013). Despite a wealth of literature examining the impact of uncertainty in chronic illness (e.g. McCormick,

2002; Thorne et al., 2002), unpredictability has not received the same interest, and often impacted by the overlap and inconsistencies in the use of terminology of uncertainty and unpredictability. One study was identified within the chronic illness literature to examine the construct of unpredictability, but to date none were found within the MS literature. Despite these difficulties within definitions of the two constructs, a meta-synthesis examined six studies that identified unpredictability in MS and psychological impact (see Wilkinson & das Nair, 2013 for full review). The authors concluded that cognitive, affective and behavioural impacts of unpredictability were apparent throughout the course of MS, and a preliminary model was proposed. The impact of the factors were dependent upon the stage in the disease course, with different forms of unpredictability identified (temporal and event unpredictability), during diagnosis, remission and relapse. Different psychological responses were provoked when unpredictability shifted from event unpredictability; where the timing of the event is known but the eventual extent remains unknown, which invoked a sense of loneliness; to temporal unpredictability; where there is knowledge of the inevitable harm but it is unknown when this will occur, impacting upon the cognitive, behavioural and affective responses.

### **Theories of coping**

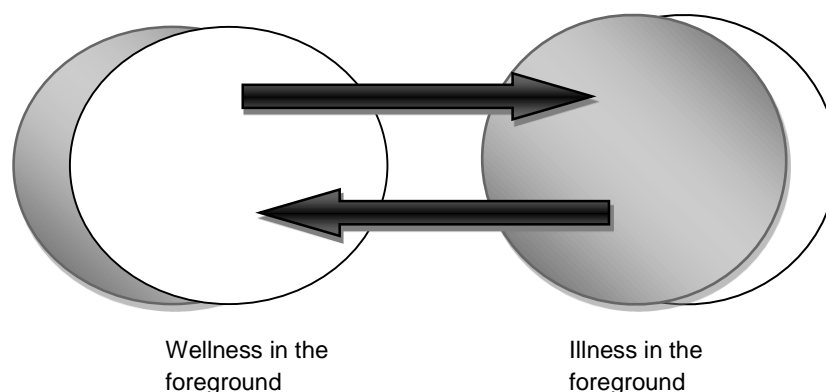
Coping and adjusting to MS appears to be prominent within the MS literature. Although uncertainty has not been the major focus in numerous coping and adjustment studies, the coping mechanisms and adjustment to uncertainty in MS is typically referred to. It is therefore believed that in order to provide a detailed account of the literature that guided the development of this study a summary of the prominent coping and adjustment models that have been discussed in the literature should be outlined.

Lazarus and Folkman's (1984) stress and coping model has been prominent model in the adjustment and coping literature for chronic illness and MS (Lee & McCormick, 2002; Pakenham, 1999). This model broadly classifies the mechanisms of coping in two categories: emotion-focussed and problem-focussed. Emotion-focussed strategies aim to reduce emotional distress caused by the stressful situation and problem-focussed strategies are targeted to alter the

source of stress (Dennison et al., 2009). Literature indicates that the choice of coping style is associated with levels of depression, distress, anxiety, quality of life, relationship satisfaction and social adjustment. It is argued some emotion focussed strategies are related to negative adjustment outcomes (Dennison et al., 2009).

The Shifting Perspectives Models (Paterson, 2001) was developed to explain the coping with chronic illness. This model differs from Lazarus and Folkman's (1984) model due to the demonstration of coping as an on-going and continually shifting process. The experience of chronic illness is depicted as ever changing the perspectives about the illness which enable individuals to make sense of their experiences (Paterson, 2001). The model proposes that individuals measure their wellness by comparing their experience to what they know and understand about their illness and visa-versa (Paterson, 2001). This author describes perspectives to represent beliefs, perceptions, expectations, attitudes and experience about what it means to be an individual with a chronic illness in a certain context. An individual's perspective of chronic illness is argued to determine how they will respond to the illness, themselves, their carers and the situations affected by their illness. The model posits that there are overlapping circles whereby illness or wellness takes the foreground (see figure 2).

**Figure 2: Shifting perspectives model (adapted from Paterson, 2001)**



When an individual holds the illness perspective in the foreground, it is assumed that they can become absorbed by their illness experience, finding it difficult to attend to others. It is argued that holding this perspective in the foreground can be a protective factor. It is assumed that at times of diagnosis or relapse individuals are forced to focus on their illness, learning about their experience and reflecting and coming to terms with their illness (Paterson, 2001).

In contrast placing the wellness perspective in the foreground is suggested to include the appraisal of the illness as an opportunity for change. Individuals revise their self-identity to include what is possible and normal. This perspective assumes that the self is the identity rather than the body being the source of control. It is argued that this perspective allows the individual to focus on the emotional, spiritual and social aspects of their life, resulting in appreciation for life (Paterson, 2001). A threat to the control of an individual is suggested to shift an individual from holding the wellness perspective in the foreground to allow the illness perspective prominence. A shift back to wellness in the foreground is argued to be a gradual process (Paterson, 2001).

### **Importance of lived experience**

Despite the potential limitations of unstructured interviews to examine certain concepts (Mullins et al., 2001), qualitative methodologies have been highlighted as fundamental to explore the individual's experience (Dennison et al., 2009; Rao et al., 1992), particularly following the acknowledgement of the potential biases within structured interviews and rating scales (Rao et al., 1992). Qualitative methodologies have increased in popularity in recent years, highlighting the importance of acknowledging the participant's experience.

A serious illness is described as the "loss of the 'destination and map' that had previously guided the ill person's life" (Frank, 1995, p.1). Negative events that fail to make sense and throw an individual's life in to turmoil and doubt are identified as the most difficult events in cognitive and trauma theories (Pakenham, 2008). Making sense of these events is argued to be a prominent feature in the illness adjustment process (Pakenham, 2008; Taylor, 1983). Research suggests that an ability to make sense of a situation is beneficial and can allow greater resources and a more active approach in developing coping strategies (Pakenham et al., 2004).

Literature examining the lived experience has been highlighted as instrumental in developing services to meet the needs of people living with chronic illnesses to achieve an acceptable quality of life (Department of Health [DoH], 1992). It is suggested that healthcare professionals need to understand the context in which individuals understand their illness (Benner & Wrubel, 1989), furthermore

insights into an individual's management and coping is argued to provide a model for health professionals to support other individuals who are struggling to adapt to living with an illness (Sobel et al., 2002).

### **Rationale for present study**

A review of the current literature highlights the biopsychosocial impact of MS upon the individuals and their carers. The literature indicates that from the point of onset, through diagnosis, and living with MS, individuals experience uncertainty and unpredictability, and this has been highlighted as a dominant factor in the lived experience literature.

Previous literature has focussed on the construct of uncertainty (e.g. Mullins et al., 2001). Unpredictability has been acknowledged to be a major factor in living with MS, yet there is limited research focussing on this aspect alone. A recent meta synthesis, highlighted the psychological impact of unpredictability through the course of the illness (Wilkinson & das Nair, 2013). One study was identified examining unpredictability in Parkinson's Disease, highlighting the importance of examining the lived experience of unpredictability that is continual (Haahr et al., 2011), unlike the concept of uncertainty which is argued to diminish over time (Miller, 1997).

The current guidance on developing services to meet client's needs have increased the interest in the 'lived experience' research. This highlights the use of qualitative measures to demonstrate these experiences. The present study was designed to address the limited research examining unpredictability in MS, to develop a comprehensive understanding of how this aspect affects the lives of individuals with MS. It is hoped that this study will provide the foundations for further research in this area and help develop services to meet the needs of these individuals.

### **Research Aim**

The overall aim of the present study was to address the paucity of research examining living with an unpredictable illness, to provide a comprehensive understanding of this aspect in MS.



## EXTENDED METHODOLOGY

This section expands on the journal article. It opens by considering the epistemological underpinnings for the study and continues by providing a critical examination and rationale for the methodology. The research procedure is described, offering a critical reflection upon the method of analysis used (Thematic Analysis [TA]). Finally this section provides the researcher's statement of perspective for the present study.

### Research Design

**Ontology and epistemology.** The framework for qualitative research relies on the ontological and epistemological positions of the researcher (Braun & Clarke, 2013). Ontology is the study of being, or the nature of reality (Braun & Clarke, 2013) and epistemology is the theory of knowledge, how we know things or believe them to be true (Barker, Pistrang, & Elliott, 2002). It is argued that it is important for researchers to consider their position prior to starting research as this can direct and determine the type of knowledge generated and the theoretical models and methodological frameworks used (Braun & Clarke, 2013).

Ontology ranges along a continuum, from realism, where reality is entirely independent of human ways of knowing about it, to relativism where reality depends entirely on human interpretation. Realism assumes that a knowable world can be achieved through appropriate research, and a 'truth is out there' (Braun & Clarke, 2013). It has been referred to as 'a correspondence theory of truth' (Madill, Jordan, & Shirley, 2000). What we know is assumed to mirror truthfully what there is. In contrast, relativism argues that there are multiple constructed realities, what is 'real' and 'true' differs across times and contexts (Braun & Clarke, 2013). Between these two positions lies the critical realist position, which argues that there is a real and knowable world, however this is 'behind' the subjective and socially located knowledge of the researcher (Madill et al., 2000). This position is argued to underpin a number of different qualitative approaches, including TA (Braun & Clarke, 2013).

Epistemology is concerned with the nature of knowledge, addressing the question of what is possible to know. Ontology and epistemology are argued to be similar in terms of their use of the realist-relativist continuum. Distinctions between

epistemological positions are based upon whether reality is discovered or created through the process of research. A realist epistemological stance assumes the 'truth' is possible to obtain, whereas a relativist epistemological stance assumes knowledge is based upon perceptions and thus no single absolute truth is possible (Braun & Clarke, 2013). Within the continuum there are a number of variants (Harper, 2012). A brief outline of positivism, constructionism and contextualism is provided, as these are argued to be prominent in psychology (Braun & Clarke, 2013).

Positivism assumes a straightforward relationship between the world and our perception of it. The truth can be discovered through the appropriate application of scientific measures. Postpositivism is argued to be a less pure version of the positivist stance (Braun & Clarke, 2013). From this position researchers seek the truth, yet acknowledge that they are influenced by their contexts and in turn influence the research. Therefore findings are facts of truth but subject to theoretical influence (Guba & Lincoln, 2005). Researchers from this position aim to achieve the truth through controlling or removing the subjective influences on knowledge production as much as they are able to (Braun & Clarke, 2013).

Constructionism argues that what we know is not a true reflection of the world. Our knowledge of the world and ourselves are constructed through discourses and various systems. This position assumes that knowledge is a product of how we come to understand it (Braun & Clarke, 2013).

Finally, contextualism is argued to be akin to critical realism, assuming knowledge emerges from contexts reflecting the researchers position and findings are provisional and situated in the context (Madill et al., 2000). Yet it seeks the truth acknowledging that a truth may not be found through one single method but a truth can be found in a certain context (Braun & Clarke, 2013).

**Researcher's epistemological position.** The present study was conducted from a contextual critical realist position. This position is committed to an ontological realists stance where a differentiated, structured, layered and independent of mind, reality exists; and a epistemological position of relativism whereby beliefs are socially produced and potentially fallible, yet it argues that in principle it is possible to provide justifiable grounds to have a preference of one

theory over another (Patomaki & Wight, 2000). From this perspective it is assumed that there is a real world, but there can be no *a priori* assumption that scientific endeavour could come to an end and the real world can be fully reflected (Harper, 2012; Howitt, 2010; Patomaki & Wight, 2000). It was acknowledged that each participant could develop their own meanings shaped by their circumstances, background, personality, experience and expectations. In addition it was acknowledged that the wider social context may also impinge on their meanings (Borrell, 2008). Analysis was data driven, yet the researcher was mindful of the possible limitations for researcher bias affecting analysis (Braun & Clarke, 2006, p.81).

**Rational for qualitative methodology.** Qualitative approaches are reported to enable understanding of experience and processes (Thompson & Harper, 2012). They are argued to be fundamental in exploring individual's experiences (Dennison et al., 2010; Rao et al., 1992). Qualitative research aims to describe the experiences, exploring the quality and texture rather than identify cause and effect relationships and making predictions (Willig, 2008). In recent years there has been a focus on quality and outcome rather than the number of people receiving a service (Thompson & Harper, 2012). This highlights the importance of the participant's 'voice' and experience. Interest in qualitative research was acknowledged by The Department of Health [DoH], highlighting the instrumental nature of the lived experience in people with a chronic illness achieving an acceptable quality of life (DoH, 1992). Further to this Sobel, Lorig and Hobbs (2002) indicated that insights into an individual's management and coping can provide a model for health professionals to support other individuals who may be struggling to adapt to living with the illness. The interest has been continued resulting in calls for qualitative research expertise (e.g. DoH, 2010).

The aim of the present research was to examine individuals' experiences of living with an unpredictable illness, MS. Therefore a qualitative design was considered appropriate for this research based upon the literature supporting qualitative studies in exploring lived experiences (Dennison et al., 2010; Rao et al., 1992; Willig, 2008). In addition qualitative methodologies are considered appropriate when there is little previous existing knowledge in the subject area, thus due to the paucity of existing knowledge of living with an unpredictable illness,

MS, a qualitative methodology was considered the most appropriate method to adopt (Barker et al., 2002).

**Methodology considerations.** Given that a qualitative design was deemed appropriate for the present study, consideration regarding the most appropriate means to collect data was required. The epistemological stance of the researcher is important to consider ensuring the data collection technique fits. Numerous methods were identified as in keeping with the epistemological stance of the researcher (Frith & Gleeson, 2012). A critical evaluation of interview methods is outlined below, providing the rationale for the methodology used in the present study.

**Rational for individual interviews.** Interviews can be conducted from different epistemological stances, thus a focus on how the social structure of the interview is understood, is important (Frith & Gleeson, 2012). Qualitative interviews allow face-to-face contact between researcher and participant. They are typically viewed as the ideal way to collect interview data, the 'gold standard' (Novick, 2008). The use of telephone, e-mail and online interviews are increasingly used as an extension of traditional face-to-face methods (Sturges & Hanrahan, 2004). Interviews are argued to be an appropriate method for experience-type research questions, providing rich and detailed data about the individuals' experiences and perspectives (Braun & Clarke, 2013). A semi-structured interview approach allows flexibility. Open ended questions provide the participant the platform to add other information that might not have been considered and any interesting links can be followed up by the researcher. The rich and detailed data provided from interviews often means that smaller samples sizes are required to obtain adequate data (Braun & Clarke, 2013). Despite interviews allowing a flexible approach, individual interviews as opposed to focus groups are argued to allow the researcher control over the data produced. The researcher is able to guide the interview and it is suggested that this can increase the likelihood of generating useful data (Braun & Clarke, 2013).

Despite the paucity of literature supporting the use of telephone interviews in qualitative research, there are a number of reported advantages for the use of

this method: it offers decreases in cost and travel, allows participation from a large geographical area, inclusion of individuals who are more severely functionally impaired (such as poor mobility) and enhanced interviewer safety (Novick, 2008). Telephone interviews are argued to be a 'versatile' data collection method (E. C. J. Carr & Worth, 2001), providing rich, detailed high quality data (Chapple, 1999; Kavanaugh & Ayres, 1998; Sturges & Hanrahan, 2004; Sweet, 2002). Telephone interviews are typically assumed to provide inferior data compared to face-to-face interviews (Novick, 2008), however evidence suggests that data provided by this method is rich, and comparable to data from face-to-face interviews (Sturges & Hanrahan, 2004). Furthermore, despite arguments that telephone interviews need to be kept short in comparison to face-to-face interviews (Chapple, 1999; Sturges & Hanrahan, 2004; Sweet, 2002), McCoyd and Kerson (2006) reported the use of telephone interviews for 1.5-2 hours with little participant fatigue.

**Limitations of individual interviews.** This method however is without its limitations. Individual interviews are time consuming in comparison for example to focus groups. Collecting data from individual participants undoubtedly impacts upon the data collection period. Despite the argument for individual interviews requiring smaller sample sizes, it is argued that data represents a restricted sample and therefore may not provide the breadth of information in comparison to a survey study (Braun & Clarke, 2013). Furthermore individual interviews are argued to potentially create power imbalances. The relationship between researcher and participant is suggested to be typically seen as a hierarchical relationship, whereby the researcher is in control of the interview. Participants may perceive the researcher as an expert, and it is suggested that this has the potential to disrupt the shared experience (Braun & Clarke, 2013). However, Russell (1999) argued that a shift in power dynamics is not inherent within the interview, but is developed between the researcher and the participant during the interview.

Furthermore there are additional limitations to telephone interview methods. Considerable attention has focussed on the absence of visual cues in telephone interviews (Garbett & McCormack, 2001). It is argued that participants are less likely to disclose sensitive information and communicate emotions when visual cues are absent (Groves, 1990; Henson, Cannell, & Roth, 1978; Moum, 1998). The absence of visual cues is argued to effect the informal communication and

contextual information, development of rapport and cause misinterpretations of responses (Chapple, 1999; Sturges & Hanrahan, 2004; Sweet, 2002). However, Novick (2008) argues that there is little evidence to support these claims.

**Rational for focus groups.** Focus groups are a form of group interviewing, the distinction between group interviewing and focus groups is based upon the emphasis on the interaction within the group during discussions of the research topic (D. L. Morgan, 1997). Focus groups are suggested to be an appropriate methodology when research aims to draw upon participant's attitudes, feelings, beliefs and experience (Gibbs, 1997). This author argued that it is not feasible to access these with individual interviews, indicating that although they may be partially independent of group or social settings, a group setting is more likely to reveal these via the interaction of the focus group. Focus groups offer the opportunity to elicit a multitude of views and emotional processes, however from a researchers point of view this approach does not offer as much control over the data collection as individual interviews (Gibbs, 1997).

Kitzinger (1994, 1995) suggested that the interaction between participants highlights each individual's view of the world, language they use and their values and beliefs about the topic. In addition the interaction can offer the potential for individuals to ask questions, discuss, re-evaluate and consider their understanding of their experience (Gibbs, 1997).

**Limitation of focus groups.** It is suggested that focus groups can be difficult to organise, for instance a representative sample may not be available due to a group nature discouraging certain individuals participating (Gibbs, 1997). In relation to the current target population individuals may have communication problems and hence discouraged from participating in a group situation.

The researcher is argued to have less control of data produced (D. L. Morgan, 1988). Their role is to keep participants focussed on the research topic whilst having little control over the interaction (Gibbs, 1997). Furthermore data resembles the participant's understanding, thoughts and feelings within a very specific context and culture, therefore identifying a clear individual message that could be generalised may be difficult (Gibbs, 1997). In addition group dynamics

have been suggested to limit the disclosure of controversial information (Kaplowitz & Hoehn, 2001).

**Photo methods.** Photo methodologies were explored, to compliment individual interviews. Photo methods were originally used in public health to assess health needs (Wang & Burris, 1997). It was suggested that photos encouraged participants to become co-researchers, having a level of control upon their representations of the research (Wiersma, 2011). It was hypothesised that the abstract concept of unpredictability may be difficult to discuss and hence the use of a photo methodology was considered, to aid the individual to actively think about the effects of unpredictability and present their understanding within the research.

**Service user input.** The MS Society Research Network provided consultation around aspects of the methodology and interview schedule. These were subsequently refined according to the feedback provided, ensuring the study was sensitively designed to meet the needs of the participants while maintaining scientific rigor

Invaluable feedback in regards to a proposed photo methodology was received. Feedback highlighted that the limited mobility of some participants alongside high levels of fatigue may result in added pressure of a time scale to provide pictures for the study. This indicated a potential limitation of this method of data collection for the present study, limiting participation to those who are more physically able. Qualitative information suggested that data collection would best suit an interview methodology to enable participants with a wide range of functional abilities to participate. This was supported by data collected from the questionnaire given to research network members (see appendix P).

To enable recruitment from a wide geographic location and across functional abilities, without impacting on the research budget both face-to-face and telephone interviews were considered. Alternative methods such as e-mail, on-line and methods (e.g. skype interviews) were considered however, they were thought to also encounter restrictions in a similar manner to the previously considered photo-methods, for this sample.

**Rational for integrated methods.** Combining methods within qualitative research is suggested to develop a more comprehensive understanding of the phenomena (Lambert & Loiselle, 2008). Focus groups and individual interviews are argued to not substitute each other (Kaplowitz & Hoehn, 2001), and have both been used alongside each other in studies (e.g. Lambert & Loiselle, 2008). These authors highlighted that when combining methods the ontological and epistemological issues are considered when triangulating.

The present study was concerned with living with an unpredictable illness, an integrated approach was considered appropriate enabling the exploration of individual's account of these experiences within different circumstances: individual and contextual.

**Methodology used in the study.** Although the present study offered an integrated approach to data collection, the focus group option was not utilised by participants. A limited number of participants provided a feedback around their choice to opt for an individual interview, explaining that group situations presented challenges to those who had difficulty in speaking, or maintaining concentration. Individual interviews offered less distraction and were deemed less intrusive in terms of voicing their opinions about the abstract concept of unpredictability. Participants were happy to take part in either face-to-face interviews or telephone interviews.

## **Procedure**

The following section elaborates on the procedure outlined in the journal article and provides a rationale for the number of participants and analysis used (see appendix Q for procedure flow diagram).

**Rational for number of participants.** Consensus theory indicates that small samples can provide complete and accurate information, assuming that the sample constitutes a degree of expertise in the domain in question (Romney, Batchelder, & Weller, 1986). Guest, Bunce, and Johnson (2006) argued that saturation in TA could be reached after the analysis of 12 interviews, based upon the assumption that interviews were conducted with a degree of structure and



participant homogeneity (a similarity of experiences with respect to the research domain). It is argued that saturation invokes a model of qualitative research that is more experiential and positivist, indicating that data can provide a complete and truthful picture of the subject of study (Braun & Clarke, 2013), and this is not wholly in line with the critical realist position of the author. Despite this, evidence of the appropriate sample size is supported by the claims of Braun and Clarke (2013), who argue that small to moderate samples are appropriate for studies of experiences using interviews and TA. These authors suggest small sample sizes should include six to ten interviews and moderate studies include 10-20 interviews. The sample size applied to the present study (10-40) participants allowed for the study to meet the moderate study sample size, whilst allowing for a larger sample if focus groups were to be utilised. The sample used in the present study met the criteria for both Braun and Clarke (2006) and Guest et al., (2006).

**Sampling and recruitment.** Sampling in qualitative studies is typically purposive, with an aim of generating insight into the topic of interest (Braun & Clarke, 2013). The focus for recruitment was defined by the inclusion criteria. Participants were included if they had a diagnosis of MS, could speak English and consented to participate in the research.

Participants were recruited through the “Get Involved in Research” webpage (2012) on the MS Society website, local MS Society branches, advertisements in local therapy centres (see appendix F for advert for recruitment) and ‘snowballing’ (participants were encouraged to inform other individuals about the research). The recruitment process was in line with the requirements of the MS Society. Researchers were aware that the recruitment process may not reach those individuals who are ‘hidden’ or hard to engage (i.e. those who do not seek support through social groups). Whilst the advantages of recruiting from the ‘hidden’ sample, to generate better knowledge and ‘give voice’ to the marginalized population were acknowledged, the reality of accessing and engaging this population was recognised as difficult. In order to account for this it was argued that ongoing reflexive analysis of the researchers role and interpretations was vital (Braun & Clarke, 2013).

Five participants were recruited through the MS Society website, three participants were recruited from local therapy centres and four participants were

recruited by through the 'snowballing' sampling technique. A further three individuals showed interest from the MS Society website however they did not continue to take part; these individuals did not provide a reason.

**Preparation for data collection.** To ensure that an interview schedule targets the information required to meet the research aims, a method of piloting is recommended (Braun & Clarke, 2013). This study employed this procedure; one interview was conducted to ensure the information deemed pertinent to answering the research question was collected. Furthermore it allowed the researcher time to reflect upon the logistics and environment of the interviews, allowing for the refinement of the interview process (see Extended paper Critical reflection section for researcher's reflections). However, Charmaz (2002) stated that interview schedules are not fixed and can evolve across data collection, therefore the interview schedule was reviewed regularly throughout the data collection period.

**Demographic interview.** A demographic interview was designed to collect relevant demographic information for the participants including their diagnosis, age when diagnosed, last relapse and frequency of relapses (see appendix C and G for demographic and MS experience interview and participant demographics).

**Semi-structured interview schedule.** A semi-structured interview was used to guide and open dialogue about living with an unpredictable illness (see Appendix B for semi-structure interview schedule). The interview schedule was used throughout data collection. However, individual's personal experiences shaped the interview, to help capture the range and diversity of participant's response from their own experiences. The researcher aimed to use open-ended questions to encourage participants to provide in-depth and detailed responses, discussing the aspects that were important to them (Braun & Clarke, 2013). Probes were used to encourage more detailed descriptions and reflective statements were used to clarify descriptions if they were unclear. Researchers play a role in co-construction of meaning with the participant, although it is aimed to be minimised, this role needs to be reflected upon, examining the practices and values that may have shaped the data produced.

Participants were offered the opportunity to de-brief following the interview. If any issues arose from the interviews participants were sign-posted to the appropriate services.

**Interviews.** Interviews were conducted between October 2012 and April 2013, by the primary researcher. Each interview last approximately one hour. Seven interviews were conducted face-to-face and five conducted over the telephone. The pilot interview was also included in the data. Only one local participant opted to participate in a telephone interview, due to difficulties between researcher and participant availability. Brief notes were taken in interviews to prompt the researcher to return to clarify any points of ask participant to elaborate further. Following each interview field notes were taken, and a reflective diary was maintained after each interview, transcription and during analysis.

**Transcription.** All interviews were audio-recorded. However due to time limitations only five interviews were transcribed by the researcher. The remaining seven interviews were transcribed by a transcription service. All interviews were transcribed verbatim, and checked for accuracy against the original audio-recording by the primary researcher. This assisted the researcher's familiarisation with the data for data analysis.

**Ethical considerations and approval.** This study gained approval/favourable opinion from the University of Lincoln's School of Psychology Ethical Committee on 6<sup>th</sup> September 2012 (Further amendments were approved via email on 12<sup>th</sup> September 2012 [See appendix M & N for ethics approvals]). The study followed British Psychological Society Ethical Guidelines (Francis, 2009) and was conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki, 2008 (World Medical Association, 2008); the principles of Good Clinical Practice (European Medicines Agency, 2002), and the Department of Health Research Governance Framework for Health and Social Care (DoH, 2005).

Ethical considerations were given to:

1. Participant information and Informed Consent

- a. Providing the participant with information to allow informed choices regarding their participation. Participant information sheet were sent either via post or via email (depending upon the participants choice) to all interested recruits (see Appendix D for Participant information sheet).
  - b. All participants had an opportunity to ask clarify any concerns they had in an introductory telephone call.
  - c. A signed consent form was required by each participant to allow participation. Each participant was provided with a copy of their consent form (see Appendix E for Participant consent form).
2. Participant withdrawal
- a. Participants were informed about their right to withdraw and notified that they were able to withdraw data, without providing a reason, up until the start of data analysis (April 2013).
3. Adverse events
- a. It was not expected that participants would experience adverse events from their participation; however in the event that this occurred, the researcher was able to provide contact details for the appropriate support services. In addition the researcher was able to access supervision if an adverse event occurred.
4. Risk for researcher
- a. The researcher adhered to the lone worker protocol when conducting interviews within the individual's home. A contact person was appointed, they were informed of all appointments, names, participant contact details, start time for appointment and estimated end time. A procedure was agreed and adhered to regarding the appointments. Confidential information held by the named contact person was destroyed after the researcher had returned from the visit.
  - b. If any incidents occurred they were to be reported through the University reporting system.
5. Confidentiality

- a. Participant's confidentiality was maintained by the use of participant identification numbers, pseudonyms and omitting all identifiable information.
  - b. The employed transcription service signed a confidentiality agreement prior to receiving audio recordings (see Appendix O for signed confidentiality agreement).
6. Data protection
- a. In accordance with the Data Protection Act, all data was kept secure in a locked filing cabinet at the University of Lincoln.
  - b. Electronic data was stored on an encrypted password protected memory stick
7. Participants were offered a summary of the results in accordance with the British Psychological Society (BPS) recommendations (Francis, 2009).

Participants were advised to contact the Chair of the University of Lincoln, School of Psychology Ethics board (Patrick Bourke – [pbourke@lincoln.ac.uk](mailto:pbourke@lincoln.ac.uk)) for further advice and approval if there were any concerns regarding the ethics of this study or the researcher.

## Data Analysis

**Qualitative approaches.** There are numerous qualitative approaches, and like quantitative approaches there are different methods that are suited to answer different kinds of research questions (Harper, 2012). The epistemological stance of the researcher also bears importance on the decision of a data analysis method. However, it does not indicate the use of a specific analysis method. Some methods can be used from different epistemological stances (Harper, 2012). It is argued that some versions of TA, Interpretative Phenomenological Analysis (IPA), and Grounded Theory (GT) are underpinned by a critical realist position (Braun & Clarke, 2013). A summary of these approaches are provided.

TA identifies and analyses patterns (themes) of meaning in a data set (Braun & Clarke, 2006). It has been viewed as a foundational procedure in other qualitative approaches (Boyatzis, 1998). However Braun and Clarke (2006) argue that it is a valid method in its own right, and only recently has been recognised as

a distinctive method with a clear set of procedures (Braun & Clarke, 2006). These authors argue that TA is a flexible approach, providing rich, detailed and complex accounts of data.

TA has been criticised because it does not have an associated epistemological position. However Braun and Clarke (2006) argue that is applicable to almost any type of research question and data type if the researcher clearly states their epistemological position at the outset.

Themes can be identified from an inductive (bottom-up) approach, where themes are strongly linked to the data, or from a theoretical (top-down) approach where analysis is theoretically driven (Braun & Clarke, 2013). Despite the relative prevalence of themes within data, the saliency of a theme is not determined by its frequency within the data set (Braun & Clarke, 2006). Themes can contain semantic (manifest) or latent content. Semantic content refers to data that is obvious at surface level, whereas latent content refers to underlying ideas, assumptions or conceptualisations within the data (Joffe, 2012). TA can offer a rich description of the data set or it can provide an in depth account of one aspect of the data, however when using this approach in an under-researched area it is suggested that an account of the entire data set is more useful (Braun & Clarke, 2006). Braun and Clarke (2006) offer detailed guidelines of how to conduct TA [See Extended Methodology: TA Procedure], however it is acknowledged that this is not a solely linear process and movement between the stages may need to occur.

IPA has a psychological interest in how people make sense of their experiences (Larkin & Thompson, 2012). Like TA it describes patterns within the data, however it is theoretically bounded (Braun & Clarke, 2006). IPA has an interpretative phenomenological epistemology. It is interested in understanding the person's relatedness to the world through the meaning they make. A focus is given to the individual's meaning of the experience, and the significance it has for that individual. (Larkin & Thompson, 2012). However, in an IPA study the researcher aims to make sense of individual's reported experiences, interpreting the participant's interpretations (Howitt, 2010).

GT is a systematic yet flexible and inductive approach. There are different versions of GT (Charmaz, 2002), however this approach focuses on systematically facilitating the development of a theory through the application of saturating data

(Willig, 2008). The theory building process involves constant checking between different aspects of the analysis. Data is analysed on an ongoing basis, to guide the collection of further data (Howitt, 2010). This approach is argued to be best suited to research questions about influencing factors and social processes that underpin a particular phenomena (Braun & Clarke, 2013). The focus on social processes allows GT to examine how social structures, situations and relationships, influence patterns of behaviour, interactions and interpretations (Tweed & Charmaz, 2012).

The present study aimed to explore in detail the individual's experiences of living with unpredictability and identify patterns reported by the participants. This study did not aim to generate a theory of their experiences therefore GT was not considered an appropriate approach for this study. However, studies exploring experiences are suggested to be appropriate for IPA and TA (Braun & Clarke, 2013). The following section examines both these approaches in relation to the present study and provides a rationale for the use of TA.

**Rational for TA.** TA is a method that identifies the most salient themes and patterns of meaning across a dataset in relation to the research question (Braun & Clarke, 2006). Despite IPA also examining patterns in the data, it concentrates on how people make sense of their lived experience and is theoretically bound (Braun & Clarke, 2006). This approach focuses on how people perceive and talk about the objects and events (phenomenology) and the process of understanding how the participant makes sense of their experience, is achieved through the researcher's interpretation.

IPA recognises the significance of the events for the participant, producing an ideographic level of analysis (focusing on the particular rather than the general) (Smith, Flowers, & Larkin, 2009). The person is part of the context, and due to this assumption it is described as a contextualist approach (Larkin, Watts, & Clifton, 2006). This can cause the role of social-cultural context to be unclear (Braun & Clarke, 2013). IPA is based upon the assumption that individuals are self-reflective and self-interpretative, reflecting upon the experiences that they have. However, it is acknowledged that a researcher is unable to directly access the participant's world and hence a dual interpretative process is used, known as double hermeneutic. Due to the dual focus on the individual and themes across cases,

IPA is argued to demonstrate a lack of depth and substance in comparison to TA (Braun & Clarke, 2013). Furthermore, both IPA and TA recognise the influential role of the researcher. Yet this plays a less central role in TA, in particular a semantic level of analysis aims to remain close to the data. Frith and Gleeson (2012) suggest that IPA and Inductive TA [ITA] (based within the data) are very similar in the analysis stages, both approaches begin with the individual and remain close to the data as long as possible. However ITA takes words at face value and looks for themes across the data whereas IPA aims to work out what the participant means.

Both IPA and TA are argued to be accessible approaches (Braun & Clarke, 2013). However these authors argue that IPA is a wholesale approach to research, providing a methodology rather than an analytic method. Whereas, TA offers flexibility, it provides a method for analysis, but does not prescribe data collection, theoretical positions, epistemological or ontological frameworks. This flexibility of TA is suggested to be one of its main strengths (Braun & Clarke, 2013). However, the flexibility has also been described as indicating a method that lacks substance unlike more the theoretically driven approach of IPA (Braun & Clarke, 2013).

TA was the chosen approach for the present study due to the aims and the epistemological stance of the researcher. Although IPA could be argued to be an appropriate approach for the present study, TA was utilised due to the paucity of research in the area of MS and unpredictability, this approach was believed to enable the researcher to remain close to the data, having a less influential role in interpretation than IPA.

***A priori decisions.*** TA was carried out from a contextualist, critical realist epistemological stance, following Braun and Clarke's (2006) guide. A number of *a priori* decisions are required prior to the use of TA. Firstly how the analysis is approached, 'bottom-up' (inductive) where themes are strongly linked to the data or 'top-down' (theoretical) whereby themes are driven by theoretical interest. Secondly, researchers need to consider what constitutes a theme, Braun and Clarke (2006) argue that saliency of a theme is not solely dependent upon the frequency and prevalence of themes. Finally, the level of analysis needs to be considered. 'Semantic' level (manifest) refers to what is explicit in the data, obvious at surface level (Boyatzis, 1998). Whereas, a 'latent' level identifies underlying



ideas, assumptions and conceptualisations, and theorises what might be shaping the data (Braun & Clarke, 2006).

This study adopted an inductive, 'bottom-up' approach. It aimed to ensure that analysis remained firmly grounded in the data (Braun & Clarke, 2013). Furthermore, it is argued that a 'top-down' approach is at risk of ignoring the naturalistically occurring themes (Joffe, 2012). Participant's experiences were 'voiced' as accurately and comprehensively as possible, providing flexibility for unforeseen themes to emerge and shape the direction of the study. However, it was acknowledged that researchers have an active role in identifying themes and selecting those of interest to disseminate to readers, and as such this analysis can never be free from the researcher's theoretical and epistemological view point (Braun & Clarke, 2006). Secondly, Braun and Clarke (2006) argued that saliency of a theme is not dependent upon quantifiable measures. In the present study a theme constituted of something important in relation to the research question. Saliency of a theme was not dependent upon the data appearing in all or even most of the data sets (Braun & Clarke, 2006; Buetow, 2010). Data that was deemed to be important in answering what is it like to live with an unpredictable illness constituted a theme. Data that was identified as not relevant to answering the research question was excluded. Finally, a semantic level of analysis was selected for the present study to ensure that analysis remain grounded within the data.

**TA procedure.** Analysis of the data followed the six-phase guideline outlined by Braun and Clarke (2006). This was used as a guide and applied flexibly, enabling the movement back and forth between the phases (Braun & Clarke, 2006). Stages were returned to and transcripts and codes were checked to ensure the accuracy of the analysis throughout the process. The authors six phases are outlined below:

1. Familiarising yourself with the data:

The data was transcribed, read and re-read noting down initial ideas. The researcher transcribed five interviews and the remaining seven were transcribed by a transcription service. Transcription process allowed the researcher to become familiar and immersed in the data. Initial ideas and

patterns and meanings were created. For the other interviews, the researcher spent time checking the transcription, also allowing time to become familiar with the data and start the process of immersion.

2. Generating initial codes:

Each transcript was systematically analysed, line-by-line. Initial codes were assigned representing features of the data that were important in answering the research question (see Appendix H for example of initial coding). The researcher consulted their supervisor during this stage and the supervisor independently transcribed the interviews (see Extended paper section: Establishing Quality).

3. Searching for themes:

Initial codes were collated into potential themes. It was decided *a priori* that data that was important in relation to the research question constituted a theme (Braun & Clarke, 2006). All codes were separated on to pieces of paper and organised into theme piles. This enabled links to be made between codes and themes, identifying main themes and sub-themes (see Appendix I for example of themes and sub-themes generation).

4. Reviewing themes:

Transcripts were revisited to ensure that the initial themes were accurate representations of the coded extracts. Secondly, themes were checked in relation to the entire data set. Once the data was checked a thematic 'map' of the analysis was generated to demonstrate the conceptualisation of the data and the relationship between them. These processes led some themes to be further broken down and, or collapsed. Revisions of the thematic map were produced (see Appendix J and K for thematic maps).

5. Defining and naming themes:

Themes were refined and named, ensuring that the essence of the theme was captured.

6. Producing the report:

Themes and clear and compelling examples were extracted addressing the research aims, to demonstrate the analysis process in the write-up.

**Establishing quality.** Unlike quantitative research there are no absolute criteria for judging whether a piece of qualitative research is good (Braun & Clarke,

2013). Quantitative methods for establishing quality are not deemed appropriate. However, there is a general consensus that researchers need to demonstrate the credibility of their studies (Creswell & Miller, 2000). Qualitative researchers are recommended to make their epistemological position clear at the outset of their research in order to conduct and present their research in a way that is consistent with their position. It is argued that measures of quality vary greatly across epistemological positions (Madill et al., 2000). Methods and criteria have been developed specific to qualitative research (Braun & Clarke, 2013). Yet, it is argued that these methods for judging quality can limit the freedom and hinder the methodological development (Elliott, Fischer, & Rennie, 1999; Reicher, 2000). Methods such as member checking, audit trails and triangulation are commonly utilised in qualitative research. The following sections explore the methods available and provide a critical discussion around their potential use in the present study.

Braun and Clarke (2006) proposed a 15-point checklist for good TA. The present study adhered to these markers as part of establishing the quality of the analysis. In addition when establishing quality in TA it is argued that the aspiration is to balance being faithful to the data with being systematic in one's approach (Joffe, 2012). Good quality TA demonstrates a balanced view of the data and its meaning, without attaching too much importance on the frequency of codes taken out of context (Joffe, 2012). Thick and rich descriptions of the participant, setting and themes allow the reader to judge and make their own decision about the applicability of the findings to other settings (Creswell & Miller, 2000). These authors also noted that thick and rich descriptions can enhance the reader's sense of connection with the participants. The present study aimed to provide thick and rich descriptions of the study, participants and data, whilst maintaining confidentiality. Data provided in the write-up aimed to contain extensive direct quotes to allow the readers to assess validity of the themes. However, it was acknowledged that in practice there is a limitation of space, which may impact on this study (Joffe, 2012).

A transparent audit trail demonstrating the process of data collection through to write-up was produced. Braun and Clarke's (2006) six-stage TA procedure was followed, and supplemented by a research diary following the research process from formation to completion. It is acknowledged that

researchers bring their own background, perceptions and interests to the research, and whilst researchers aim to remain close to the data it is important to be mindful and reflect upon the effect of the researchers pre-existing assumptions (Krefting, 1991). It is argued that a researcher is not a separate entity and therefore needs to be analysed as part of the research (Krefting, 1991). A researcher should continuously reflect upon their own characteristics examining how they influence data gathering and analysis. In order to remain reflective, the researcher maintained a reflective component of the research diary, whereby the researcher's reflections were noted (see Appendix L for excerpts from reflective diary). These reflections aided the researcher, making them aware of their biases and allowing alterations to their data collection or analysis to enhance the credibility (Krefting, 1991).

The present study employed a method of triangulation. This is a method to enhance quality of research based upon the idea of convergence of multiple perspectives. Data was assessed against one another to cross check data and interpretation (Krefting, 1991). Four methods of triangulation are proposed: data methods triangulation, data source triangulation, theoretical triangulation and investigator triangulation. It can be argued that the present study employed theoretical triangulation and investigator triangulation. Data was independently coded by the researcher and supervisor. The themes and codes were cross-checked for credibility, this also ensured that the researchers perspective was understood by others (Boyatzis, 1998; Yardley, 2009). The researcher and supervisor held analysis meetings whereby data was discussed and competing interpretations and explanations for the data were considered, re-visiting themes and amending them as required.

Finally, member checking is a method that is commonly employed by researchers, whereby participants check that data accurately portrays their viewpoint (Krefting, 1991). This method of credibility checking was not employed in the present study. It can be argued that member checking indicates that there is a fixed truth of reality that the researcher accounts for and is confirmed by the participant, and this viewpoint is in conflict with the epistemological stance of the researcher. In addition, it was acknowledged that participant's experiences of living with unpredictability may change during the period between participating and

analysis. Finally from a practical point of view it was important to consider the time and practical implications of conducting member checking.

**Researcher's statement of perspective.** Elliott, Fischer, and Rennie (1999) proposed that a researcher's statement of perspective can aid the reader to interpret and understand the analysis, orientating them to the research and the researcher conducting it.

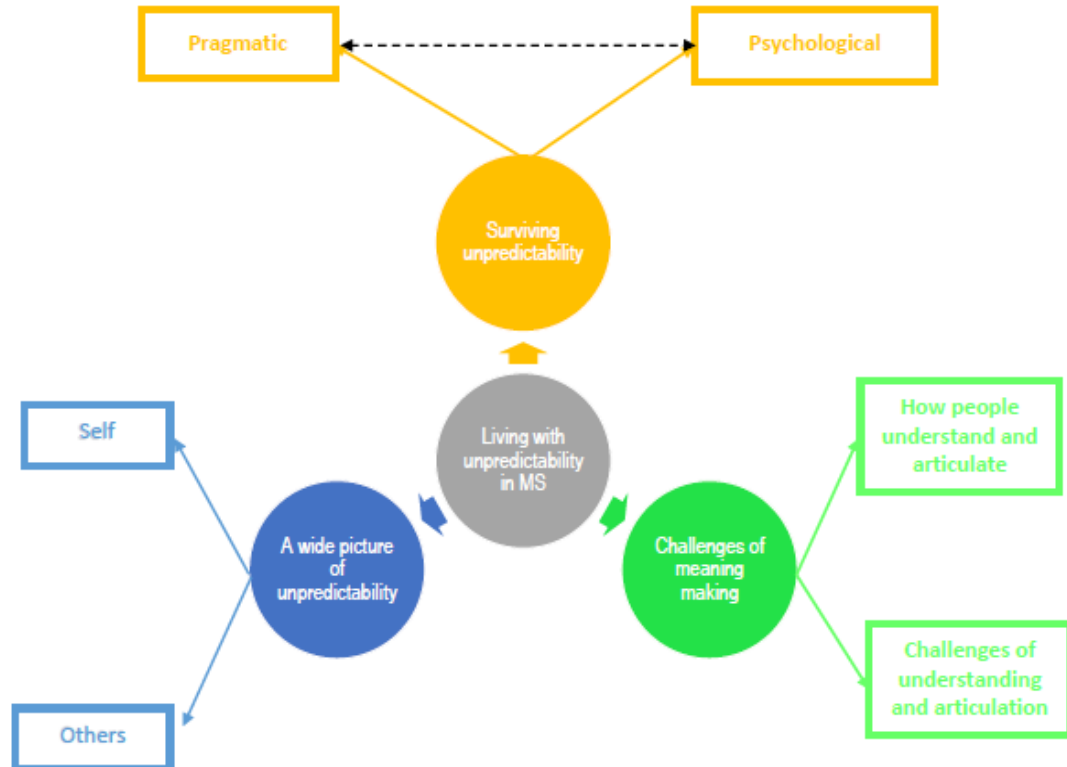
I am a Trainee Clinical Psychologist who has developed an interest in the impact of long-term conditions through my assistant posts in Clinical Neuropsychology services. Through my experience I have been struck by the resilience of individuals who face a future of unpredictability.

This research was conducted as partial fulfilment of the course requirements. I entered into the research with the assumption that living with an unpredictable illness can hinder an individual's quality of life, and an awareness of the prevalence of psychological distress caused by MS. During the research I too fell ill and subsequently have to live with an element of uncertainty as a result of my illness. Therefore I am aware that although I entered this research with my own assumptions, my further personal experience may impact upon my analysis of the data. In order to counteract this I have utilised my reflective journal and sought supervision when required.

## EXTENDED RESULTS

This section elaborates upon the themes and sub themes described in the journal article. A thematic map illustrates the interaction between the main themes and sub-themes in relation to the research aim (See figure 3).

**Figure 3: Thematic Map of Themes and sub-themes [See appendix K for full thematic map]**



To ensure the quality of the research, extracts from the interviews are provided to demonstrate and support the findings. As themes are not wholly independent, there are instances where quotes are used to illustrate several themes.

### Themes and sub-themes

Participants described their experience of living with an unpredictable illness. Three main themes were identified describing the process of living with unpredictability:

1. **“Challenges to meaning-making”**: the challenges that participants found when discussing unpredictability and the methods used to demonstrate unpredictability in their lives;

2. **“A wide picture of unpredictability”**: the wide reaching impact of unpredictability filtering into all aspects of the individual’s life and those around them; and finally

3. **“Surviving unpredictability”**: the methods participants use to live with unpredictability.

**Challenges to meaning-making.** This theme attempts to capture the challenges that participants experienced in talking about ‘unpredictability’. Despite participants acknowledging unpredictability in their illness and day-to-day life, some reported that they did not have an unpredictable illness, yet identified unpredictable aspects of their illness. This theme delineates the ‘difficulties of articulating and understanding unpredictability’ and ‘how people understand and articulate unpredictability’.

***Difficulties of understanding and articulating unpredictability.*** Participants acknowledged that unpredictability was “pervasive” and “invisible”. These aspects appeared to hinder the participant’s ability to understand and articulate unpredictability.

Unpredictability was described as a constant aspect in the participant’s life, one participant reported:

Yeh you are constantly being reminded of it by your symptoms so when you think you are forgetting it all of a sudden you’ll get a pain or tingling or whatever, or your vision will go funny, so you are always being reminded of it. (P2, p326<sup>5</sup>)

All participants acknowledged that “everything is unpredictable” (P1, p64), and this resulted in some participants struggling to separate ‘living with unpredictability’ from ‘living with MS’. Furthermore, unpredictability appeared to produce a sense of a continual wait for the next “crisis”. Many participants portrayed unpredictability through the use of abstract concepts: “it just means like... I don’t know you’re up

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<sup>5</sup> Each quote is labelled with a participant number (P), and a paragraph number (p) that identifies where in the interview the extract comes from.

in the air kind of thing, you don't know you are just floating and waiting type thing” (P2, p326). The lack of concrete understanding of unpredictability challenged participants in their articulation of this aspect of their illness. For many participants the difficulties of understanding and articulating it were further compounded by the invisible nature of the illness:

I suppose it is a health issue but I don't sort of think of it like that, but it is, I know. But you can't see what's wrong with somebody who's got MS, it's all inside not working properly. And some days it works wonderfully and other days it doesn't. (P8, p42)

Many participants acknowledged this difficulty in explaining and understanding the unpredictable and invisible symptoms both to themselves and to other people.

***How people understand and articulate unpredictability.*** For many of the participants the difficulty of identifying with and articulating unpredictability was managed through the use of 'biological discourse' and 'comparisons'.

Some participants used biological language as a mechanism to explain their experiences of unpredictability and the invisible symptoms:

Like you're probably aware with MS, in terms of, it's the lack of the message getting through from the brain or spinal cord, to parts of the body you want to do something, isn't it? . . . And so while your brain has thought that that has happened, when you try to pick up say that jug of milk, the brain has thought, yes you've passed that message on, you're going to do it, and in fact your fingers haven't got that message. (P12, p30)

The previously viewed abstract concept of unpredictability was brought into the realms of concrete explanations. The factual description provided a rationale for the participant, an explanation for their inability to accomplish a simple task that once was done subconsciously. For some participants the comfort of a biological concrete explanation provided a sense of predictability to their symptoms and developed their understanding:



I mean some people are quite lucky and they've just got scarring at maybe the base so it's just the legs, and not the top half but I've got scar, I've got scarring all the way down in three major places. One at the back of my neck, one half way down my spine and one on the base of my spine which doesn't help whatsoever 'cause that means my eyesight's gone before now, my arms gone, my legs gone. (P5, p157)

The symptoms of MS were reported to be a major factor in unpredictability and contributed to the difficulties in distinguishing between 'living with unpredictability' and 'living with MS'. However, many participants tended to articulate their experiences of unpredictability through their symptoms:

I go to the gym twice a week, and walking to the gym and my foot got caught on one of the slabs and I nearly tripped up. I thought, oh there you go, I nearly did it again. But that's sometimes because my feet don't want to pick themselves up, they don't want to walk myself along. But I've got to, every day I've got to, I've got to always look down at the floor to see where my feet are going and watch out for things to trip over because I don't want to do it again. And I've got to do that every day, every time I go out, because that unpredictability is always there. (P7, p250)

Participants articulated and demonstrated their understanding of their unpredictable illness through the use of 'comparisons' within the self and between self and others. The comparisons helped participants comprehend their unpredictable illness. Time comparisons demonstrated the participant's reflection and consideration of unpredictability. They illustrated the changes experienced by participants across long and short periods of time, and highlighted the current impact of unpredictability in comparison to their life prior to MS. Some participants who had lived with MS for long periods of time, acknowledged the changes in the unpredictability across their illness. Unpredictability at one stage allowed time to forget:

When I didn't feel fettered with... I mean in between attacks I used to go 3, 4 years, sometimes I've had two attacks in a year but not usually, I usually

went 3, 4 years, which gave you a long spell in between, time to forget all about MS. . . . It wasn't in my face, it wasn't like every day, like it is now. . . . Because I forgot about the MS, I didn't think about the unpredictability. . . . (P3, p27)

For this participant periods of wellness allowed time to forget however, as their illness changed so did the unpredictability, becoming a constant challenge that is forever in their mind.

Participants reported experiencing a battle with MS, with some participants describing MS and its unpredictability as a person, creating an identity for the illness and an explanation to their unpredictable symptoms:

It's just going to take me, whether I like it or not. Erm, it can take whatever it wants, when it wants. . . . Well they can well it can yeah. Well, yeah it probably is, in my head it is someone who can do that. . . . Yeah, whenever they want, yeah. "Just we'll take that, today. We'll take that, today." It's like there's a little person just in my head just taking what they want. . . . MS is a person sort of thing. . . . but yeah they can take whatever they want when they want and it's not nice to think that someone can take that when they want. . . . When I find him I'll kick their heads in, if my legs are working. (P5, p173)

Despite the sense of a losing battle against the "MS person", who had control and made all the decisions, this participants demonstrated their ability to maintain a sense of humour towards the unpredictability. Other participants likened their "MS person" to their parents constantly telling them what to do:

Like because I want to start going out at night time, the MS is always there and it's saying, well if you go out, you know you've got to be back by a certain time. I feel like I've got my mum or my dad in my ear hole, you know, it's always there. (P7, p554)

This analogy further demonstrated participants' acknowledgement of the level of control the unpredictable illness had on their lives. The personification of MS

allowed the participants to visualise a controlling person, creating a level of understanding of their unpredictable symptoms. In addition it provided the participants a person to fight against or become frustrated with, and legitimised their feelings towards MS and its unpredictability.

Comparisons and distinctions between mind and body were discussed by participants. Many participants reported their mind remaining well but their body deteriorating, "So it's, well mentally I'm fully mental, if that's the right way of putting it, my body is in decline" (P12, p18). Some participants demonstrated a fighting spirit, focussing on maintaining their active mind, "We go out once a week for a quiz, which I quite enjoy, because then you can keep your brain going" (P8, p108) this was further elaborated by another participant:

I want to do things, in terms of, the mother-in-law takes the Daily Mail and within there, there is a Sudoku Magazine, well a freebee every day. And I actively do that and do the crosswords, to try and make sure that my brain's still active. And I've always mentally thought about things anyway but it's probably, it has been more because I can't do it physically, so I've got to do things mentally. (P12, p122)

Whereas, other participants focussed on the lost battle with their body, one participant reported: "Yes, my mind's saying carry on but my body's saying I can't. So that's really difficult to take in, it's really difficult to accept it. But you have to do it because your body just won't carry on" (P7, p148).

Participants tended to compare themselves to other people without MS and those who had other illnesses. Many participants identified the "non-MS" population as "normal", comparing their current state to the "normal" population: "It's doing every day, I'll use the word, chores, activities, in terms of the normal person who just goes, it will take me five minutes to do it, in ten minutes I'll do it" (P12, p48). A sense of separation and difference from the "normal" population was encountered. Yet some participants used these comparisons to highlight how the similarities between themselves and the "normal" population, normalising their experience: "I don't know, I don't suppose anybody's got control over life, their life in a way, because you never know what's going to happen" (P6, p190). This was

further highlighted by another participant who described the difference in thought patterns of younger people in comparison to older people. They normalised their concerns they had about their health and how well they were functioning by explaining this is a normal aging process: “but then, I mean when you’re younger you don’t think about things like that, when you, when you’re older you think well people get, die of different things, you could have a stroke, there’s always tragedies aren’t there” (P3, p76).

Participants described living with MS and the unpredictability it provides in comparison to other illnesses. Many participants compared their illness to other terminal illnesses, such as cancer. Some participants used these comparisons to highlight the positive aspect of their unpredictable illness, however other participants used them to demonstrate a lost battle with MS, unable to fight it, as there is no cure unlike other serious illnesses: “Once, what I mean, once you’ve been diagnosed with something, like cancer, you can fight that but when you’ve got MS you can’t fight it” (P5, p9). However, other participants acknowledged the similarity in their unpredictable illness and other illnesses. The changes demanded and the life adjustments required were part of living any illness: “yeah there has, same as any illness there’s got to be adjustment” (p4, p129).

**A wide picture of unpredictability.** A wide reaching impact of unpredictability was demonstrated by the participants affecting all aspects of their personal and social life. This theme captured: ‘self’ the wide reaching impact of unpredictability on the individual’s life including the losses, impact to self-perception and the fear and frustration demonstrated across many aspects of their lives; and ‘others’ impact of the unpredictability demonstrating the impact on family dynamics and relationship changes

**Self.** Participants identified with the wide reaching impact of unpredictability on many aspects of their lives. All participants identified with losses that they had encountered in their roles, identity, independence and control, they demonstrated a fear of the future and frustrations of the impact of unpredictability. Some participants demonstrated how the impact of the unpredictable illness affect their self-perception.

Loss was a prominent result of unpredictability in MS described by participants. Despite many participants reporting a struggle to maintain independence, control, roles and identity, all participants acknowledged that certain losses were inevitable: “You lose your independence, to a point. I mean you can’t be in control of some things but you can be in control of others” (P5, p173).

Participant’s acknowledged a loss of identities and roles at times through the unpredictable nature of their illness. However a determination to maintain these roles and identities when they were well, or adapt roles to account for their unpredictable illness was demonstrated by many participants. One participant described:

We [son] always used to do as much as we could. . . . I used to say when I was over an attack it was like new life, it was like oh you know, it was just so wonderful that new life of, getting over an attack, and I’m running round and I’ve got the energy and I’ve got, I’ve got the confidence and I go and do things. . . (P3, p74)

A “boom and bust” scenario was depicted by some participants, at times they were able to fulfil roles and identities whilst at other times they had to take a back step, allowing others to step in. Participants appeared to place prominence in their loss of control and independence. Many participants described themselves as independent people and the dependence that they now had upon others, took part of them away. Learning to rely on others was hard to accept and achieve:

It is, it is cause I was a very independent person, I mean I’ve never, I’d do everything myself, erm to a point where now I have to rely on others it’s, it is sort of took some of my independence away, but if I can I will try and alter things that my independence is back to me, somewhere along the lines erm even if it is just a little bit of it but I’ll try. (P5, p29)

Again this quote demonstrated the participants fighting spirit. Despite reporting their losses, participants acknowledged that they became inventive to maintain a sense of independence and control. However, participants recognised that finding

alternative ways to maintain independence and control was harder as their disease progressed.

Participants demonstrated how the impact of unpredictability affected their self-perception. For many the acknowledgement of the impact of unpredictability on the individual appeared to contribute to a negative self-perception: “It makes me feel like I’m really small. I’m trying how best to describe it really. I’m trying to think of the word, you just, I don’t know, it just makes you feel so silly, you know, so stupid” (P7, p 26).

Whilst other participants acknowledged positive aspects of the unpredictability of their illness, developing positive attributes: “Proud really . . . yeh it does, I can take on anything, throw it at me and I can deal with it, bit of a . . . I don’t know . . . an achievement if anything” (P2, p150).

Many participants reported a loss of confidence resulting from their loss of abilities. For some this affected their ability to interact socially, whereas others tried to maintain an outward confidence whilst struggling with an inward loss of confidence:

It [being reliant on others] makes you feel, it makes you feel disabled, you know, or makes you feel that other people see you as disabled, which is just sort of frustrating and annoying. How does it make me feel about me in myself? There is a sense of value and there is, it does knock your confidence, although I try and bulldozer through both of those, and I’m generally successful, well outwardly successful. Inwardly I’m not, of course, obviously, inwardly I haven’t got the confidence or the belief in myself that I can do stuff (P9, p116).

The impact of their illness was identified as having an impact on how others perceived them, and thus impacted upon the relationships and roles within the family.

Unpredictability was reported to impact on their hobbies, employment and social lives (collectively known as extended activities of daily

living [EADL]) of the participants. Some participants described how their employment had been curtailed by the unpredictability of their illness:

I was physically retired from my last role because a risk assessment was done a year after my diagnosis. . . . Because my working environment was walking around data centres, where you have six foot drops, like on these tiles, and if a tile was to give way or a tile was missing and I felt a bit dizzy, obviously they would be responsible for me. The only way of them managing their risk, would be to employ somebody else to work with me. . . . And it's not a highly paid individual would be required, but an individual would be required. And that basically meant that they had to medically discharge me because of that risk, that I was deemed unsafe to be working in the working environment. (P11, p21)

Whereas, other participants described how career decisions and changes had to be made to account for the unpredictability. Many participants described how they tried to maintain their work levels, but found changes had to be made:

I'm not sure even the job I'm applying for at the moment, which is slightly less, in terms of finance that I'm earning now, but not much, I'm not even sure that I'm capable of doing that really. I'm just, the reason why I'm going for it is because it doesn't involve [job]. So therefore I won't have the physical exertion. But apart from that, it's about the same level, sort of strategic thinking and planning and organisation and human resources and all of those sorts of things are about the same level. But I'm not sure whether I can do it or not, whereas, you know, five years ago, say seven years ago, eight years ago, it wouldn't even have occurred to me that I couldn't do it. (P9, p129-130)

Participants acknowledged that the changes they made in their EADL were not permanent, the unpredictability of their illness would continue to affect them and this created a sense of anxiety that they were on a downward spiral in their ability:

But certainly, I mean I think I've got to the stage where I know I need to change my life because this is unmanageable, what I'm doing is totally unmanageable. And so, therefore, I just need to scale back and that's all there is to it. My fear is, is that I'll scale back, you know, and then I'll think to myself, oh no I can't cope with this either, so I'll scale back some more, do you know what I mean? (P9, p238)

Many participants reported a loss of ability to continue with their hobbies and interests. For some this was identified as contributing to a loss of identity: "so the three things that I'm really, that I really feel, you know, I've got and are unique to me and I can do them well, have all been taken away" (P9, p64). For others, the inability to maintain their previous lifestyle left participants bored, and feeling boring:

I don't know I feel boring at times because the things that I would naturally be doing I can't do it, so my hobbies are a bit non-existent anymore, even though I'll still go and watch football because I still like football, but I can't play it. (P2, p306)

Some participants reflected upon how the nature of unpredictability impacted on their social life, experiencing times of feeling well and times of relapses. The long periods of wellness allowed "time to forget", plans were made and participants started to live "a new life" (P3, p74). However, as the unpredictability "came to fruition" (P3, p78), the effects caught up with them:

I've got MS, I was working but you know erm so you'd planned to do things and then when you're not feeling well all these things come in on you and you think why on earth did I do that, you know why was I so silly to, to plan so you stretch yourself, but you don't erm you don't think about, I should have somebody, something that says now just hold on a bit you know, just take it steady, but you don't you just do things automatically don't you. (P3, p19)



Participants acknowledged how difficult it was to remain mindful about their unpredictable symptoms and the impact of these, during “well periods”. Furthermore, learning to say “no” was also reported to be difficult. Many participants described curtailing their social lives, becoming rather last minute, never spontaneous and always on the proviso that they cannot promise to fulfil any plans:

Say to your friends, like don't promise anything, you know, suddenly if I'm fatigued or something, I obviously can't do it. And I should always say like, I'll try to do it but I can't promise. (P10, p129)

Some of the younger participants discussed a feeling of taking a back step, unable to join in and grow up with their friends like they used to:

Erm yeh such as like the time when I come in, I get tired really quick, so like while everyone else is out and, I mean I was 21 at the time and I'm [current age] now, like over them years as people have been carrying on I've like stepped back a little bit cos I've like had to. (P2, p68)

Many participants discussed their fear of the future. Ironically, the predictability of their illness getting worse caused fear within the participants, unsure how their illness would affect them in the future, “I know it is all going to be unpredictable, but I just don't know where it is going to go” (P1, p62) and how they would be able to cope with the changes that they would experience. Whilst all participants considered the “what ifs”, some highlighted how their fear of the future was not akin to how they had been brought up:

My mum used to say there's no point worrying about it, if you can do something about it do it, but if not there is no point in worrying, and that was what I was brought up with you know so . . . (P3, p76)

The impact of unpredictability caused many participants to seek safety. Some talked about the aspects that made them feel safe; finding security in their surroundings and those around them. For some participants the knowledge of

being safe was comforting and provided a reason for them to remain close to home:

Well I'm fine as long as I'm where I am, and that's the thing when you've got everything to hand what you know, if you went on a cruise and things like that where I'm not very bothered about at all, it'd be completely strange, wouldn't it. (P4, p107)

Yet other participants found their need for safety resulted in making changes which were frustrating: ". . . it's like going back in life [ . . . ] not good just angry, really annoyed" (P2, p180). Some participants reported that the unpredictability made them more dependent upon their family: ". . . like just having to move back in with your parents, after like living on your own really for almost ten years" (P10, p20).

A sense of apprehension was acknowledged in participants' discussions about their medication. Many reported fears about their medication and the long term effects, which typically had an unknown rate of success for each individual:

It's like the thought of injecting, I couldn't do it, I couldn't and I was like, I'm not, I'm not, I'm not . . . and I'd take them off the subject, thinking no you are not getting me to do it and after about the third time I thought, ahh I'm going to have just say I can't do it. . . . Erm so, I mean there's another thing that bugs me, what happens with taking the steroids, it can give you diabetes, if I get diabetes then I have to take it. What will I do injecting myself? And it, it petrifies me because diabetes runs in my family, you've got a chance of getting it from the steroids and I'm just petrified of. (P5, p113)

Although participants identified that their medication was one area that they could maintain a sense of control over, many described this as a learning process developing from their frustration in the prescription of numerous types of medication:

I was on hundreds and hundreds of tablets and it was like a guinea pig, to a point where they'd just push me one tablet too far and I was just sat

comatosed in a chair and I was thinking this isn't a life. So literally I said, "No, I'm stop taking them all." And I did, apart from the ones I knew I, I had to cut down on. (P5, p113)

Some participants expressed their concerns around other people's perception of them when their unpredictable symptoms flare up resulting in the participant having to rely on the use of aids: "Yes, I hate to be thought of as, oh look at that old woman with a stick. I think no I am not" (P6, p10). Whereas other participants describe how they had accepted other people looking at them but were frustrated by other people's perceptions of them:

To look at me there's nowt matter with me and yet they'll see me today and I might be skipping down that street with my granddaughter. Three days time they look at me and see me in a wheelchair and think what, or with a walking stick . . . and they, they look at me weird erm but I sort of I've accepted that now. Yeah people look at you, sod them . . . I don't care what they think no more [ . . . ] Yeah it is angry [makes me feel], I'm more angry at other people thinking that now . . . Erm more angry that yeah this illness, most of it is invisible erm and that people look and they sort of look at you and think well . . . (P5, p285)

For other participants, their concerns centred around how their unpredictable illness distinguished them from other "able-bodied" people, resulting in fear that they would not be able to find a partner who could accept their illness:

But for somebody of the opposite sex, that doesn't mean that. They probably think, oh god, she's got a stick, she can't walk very fast, she can't walk very far. It's going to, it's not going to work in our relationship, you know. And I'm finding it hard at the moment to move on from that. Because like my ex-partner, he couldn't take it, that I'd got MS. (P7, p324)

**Others.** The impact of unpredictability was reported to be wider than the individual. Participants described the impact it had on the lives of those around them. MS was described as an illness for the individual and their family, "the whole family I always say that MS isn't just for the person" (P3, p11).

Family dynamics were affected, many participants typically reported the loss of their roles alongside family role changes, where family members became part of a “team”, supporting and helping them when required. Despite acknowledging the flexibility in roles participants reported a change in the dynamics of the relationship:

He’s [husband] now my carer. . . . But now he, he looks after me and sees to the house, he does the shopping, he does the cleaning, I can’t get down on my... On my hands and knees I, have a job to get up, even cleaning that harth, I can see it needs cleaning. . . . But now I have to erm I have to ask him, I have to, I, I seem to be erm, can you have leaders in relationships like that, I used to be the prominent one who used to do things and now I’ve had to sit, sit myself back and he is now, he’s in charge you know he, he tells me sit there, do that. (P3, p78)

At times participant’s reported feeling like they had received too much support, but acknowledged the difficulty in achieving the right balance:

I want to try and do, yes. We should be doing things together rather than him doing everything because he thinks I can’t do it. . . . I do what I can do and he over helps sometimes, but then again I shouldn’t complain, as most women would say. (P8, p262-268)

For some participants the change in roles and ability to complete family chores resulted in the elevated importance of their employment to maintain their purpose within the family:

Yes, painting and decorating, stuff like that, yes I can’t do any of that, which is why I forced myself to do a job that is at this level. Because I know that I’m bringing in a salary. . . . I kind of feel like that’s my contribution, do you know what I mean? That’s my bit that sort of says, look I’m doing this for you and for the family, you know. So at least I’m doing that, even if I can’t cut the grass. (P9, p316)

Participants acknowledged the benefits of the support they received from their family and friends, demonstrating their awareness of the strength of these relationships. Some participants acknowledged positive changes in relationships, and an increased sense of cohesion within families:

Yeah, and it, it's had positive aspects of that as well you know it's made relationships stronger in some cases erm, and friendships, you know, you know you know which friends you can, you can call on and and friends who you can open up to, because of it yeah, so I think, I think it has a positive effect as well. (P3, p106)

However, one participant recognised that their unpredictable illness had influenced their partner's strengths and contributed towards tensions in the relationship:

My wife is completely and totally and utterly supportive and I have no issue with that. In fact, in many ways, it plays into her strengths. She almost needs me, she always needs to want to look after me, do you know what I mean? She almost needs that, it's part of her personality. But, unfortunately, it gives her an excuse for us not to do stuff, which has been the bane of our relationship. (P9, p72)

The impact of unpredictability on the family was reported as a constant effect. Some participants acknowledged how unpredictability of their illness had caused those around them to alter their lifestyle and activities, "he's had to deal with all that, to knock back over time, sort out his relationships at work and things and so it's not only person erm who has MS that has to deal with that" (P3, p11). Participants appreciated the sacrifices of those around them. However some participants demonstrated an awareness of the potential impact that their illness will have on their family as their MS progresses. These participants were keen for family members to maintain their activities for as long as possible.

**Surviving unpredictability.** Despite the negative effects and struggles that participants acknowledged with unpredictability, a fighting spirit was identified in all participants at times. Participants demonstrated their ability to live with an unpredictable illness through 'Psychological' and 'Pragmatic' methods.

**Psychological.** Participants demonstrated the fluctuations between their acceptance and denial of unpredictability. Many participants expressed their anger towards unpredictability. One participant described their anger, however they acknowledged that being angry indicated not being able to cope: "because the alternative is, as I say, to not cope and to get depressed, to be upset, to be angry" (P6, p218).

Other participants discussed how they like to appear to be coping in front of others, in order to hide and protect them from their troubles due to the unpredictability:

Yes I suppose, I don't like to admit, I don't like to admit I've got anything wrong with me. I mean I can't help that that is just how I am. My husband is very good and he tries to help and he helps, and I know I shouldn't push him away when he's trying to help, but just let me do it. Don't let me feel like a cripple, is one of my, you know, don't make me into a cripple before I become one, or I won't say I'll give up, it would be too easy to just give in and not do anything. (P8, p258)

Despite demonstrating aspects of denial towards unpredictability participants fluctuated between acceptance and denial. Many participants demonstrated acceptance of the illness and unpredictability, "but then at the end of the day, I can't do things I used to do, so I've got to live my life the way I am now" (P7, p164). Acceptance of the unpredictability was directly stated by a number of participants. However the process of 'learning about their body and MS', and 'altering their perspective on life' provided the means to come to terms with the unpredictability. Participants reported that learning about their MS and how their body is affected allowed them to understand and be able to adjust or resolve issues when they arise, providing a level of predictability:

Yeah, you sort of work it out, you sort of, as as the doctors say, you know your own body, and you basically, you've got to learn what your body is responding to, erm whether it be the heat, whether it be the cold, whether it, what's affecting it so you can avoid it, or when you're getting them symptoms move away from it and do something positive that will take that away. (P5, p225)

Furthermore, the battle between the individual and MS appeared to remain prominent in living with unpredictability. However, the nature of this battle appeared to be altered from simply fighting it, as demonstrated in the earlier comparisons, to a process of working with it. Participants learnt to find alternative ways to live with unpredictability without the direct battle:

Yeah because you're not pushing, you're not fighting it no more. Where the more you're fighting, the more I was pushing my body past the fatigue level the more my body felt worse 'cause my MS was kicking in. Where when I wasn't fighting it and I wasn't pushing, I was learning to relax and not stress as much my MS wasn't as bad so I felt better. So it was a case I was pushing it to a point where my MS got worse and then I realised, yeah the more you relax with it the more it doesn't hurt, just live with that and see if you can cope with it and that's what I did. Slowly, but surely it took a good while to do it, but I did it, and now I know what's what. (P5, p257)

A stoic perspective of life was described by many participants, "but basically, there's nothing you can do about it, so you have to kind of grab yourself by the lapels and shake yourself and say, come on, you know, get on with it" (P6, p26). They acknowledged this was their life and they had to "get on with it". Although all participants adopted this attitude some individuals reported how difficult it was to apply, "yeh it is quite hard because I don't know, I do think what would it have been like, but I don't know, but it doesn't stop you thinking" (P2, p202).

Participants appeared to adopt a new sense of achievement living with unpredictability. Their altered perspective, led them to appreciate different aspects

of their life. It enabled participants to identify the positives that they had achieved and accomplished whilst living with unpredictability:

Yeh because someone said to me at the time that I would probably never walk again and I was like, “just watch me”, I really went the opposite way and thought no, obviously I go and purposefully walk again cos I couldn’t control it but in my mind I was going to walk again and, yeh so it’s like been an achievement from the start. (P2, p154)

**Pragmatic.** Pragmatic adjustments were reported by many participants. Some did not want to identify themselves as disabled, seeing this as a further loss of independence. However, environmental changes were made to allow the participants to prolong their independence:

That’s it really my legs, I’ve always got a balance problem anyway, you just have to watch what you are doing, you really have to watch what you are doing just can’t get up and just switch the telly on, so everything is done automatically, everything is done for me now do you know I have all the remotes and central heating, fire, I’ve got my own thing for the fire so everything is just done to help me. When we, we had to move from a house to a bungalow, everything is done, we’ve thought about it and it’s all done. (P4, p35)

Many participants acknowledged that the adjustments would be continual, in some cases they were making adjustments and being prepared. Although many participants reported concerns about using some of the aids, other participants acknowledged the benefit of having them available when they were required:

I find it difficult to walk up the stairs, so I’ve got a stair lift. Because I’ve got a wheelchair and I live down steps to our front door, our local authority has, are in the middle of providing me a chair lift outside of our front door, so that I can get to the road level. So I don’t need it full time but when I do need it it’s here. (P11, p47)



Treatment and exercise regimes were reported by participants to help manage their illness and reduce the unpredictable symptoms. One participant explained that by ensuring they are doing everything they can to fight the unpredictability they are content, “Yes and sort of like if my symptoms do worsen, at least I’m doing everything I can like physically as well” (P10, p193). This demonstrated their effective means of battling *with* unpredictability.

All participants acknowledged that the unpredictability of their illness curtailed a sense of spontaneity resulting in activities and events requiring planning. Planning was prominent in all participants’ interviews “. . . sort of planning ahead, you have to plan all the time everything has to be planned” (P5, p65). One participant explained that planning was good, however plans could still go wrong and therefore preparation was the key to their success “No, but then again I’ll have my walking stick with me. . . . So you sort of plan but you make sure you’re prepared” (P5, p73). For many participants the necessity to plan was a major change in their life, some participants acknowledged that this aspect of unpredictability enabled them to feel like they were using their skills gained in employment to aid their survival with unpredictability:

I suppose it’s one way of using a project manager’s brain I suppose. . . . I think yes it does for me because it’s like thinking things through days or weeks before things happen was part of my job. And having to do that now, but also take a little readiness that I might need to change at a moment’s notice because of my condition also on board, helps as well. (P11, p99)

Finally, for some participants the unpredictable aspect of their illness affected the family plans, sometimes resulting in their children feeling disappointed. One participant explained that part of their preparation was to protect their children from disappointment:

Yes, I think they would feel they are missing out but they, only it affects or they’re missing out if they know something’s planned to go to, missing out. If it’s brought up to them as a surprise a day or so beforehand, then all of a sudden on Friday you can’t go because, then yes they’d be, we’re missing out. (P11, p217)

## EXTENDED DISCUSSION

This section elaborates on the discussion provided in the journal article. A summary of the results are provided and considered in context to the relevant literature, and the strengths and limitations of study are discussed. This section will conclude by discussing the clinical implications of the study and suggestions for future research.

### Summary of findings

This study examined the participant's experiences of living with an unpredictable illness. Thematic analysis of 12 interviews generated three themes: Challenges of meaning-making; A wide picture of unpredictability; and Surviving unpredictability.

The first theme 'Challenges to meaning-making' refers to how the participants articulated and understood unpredictability in their illness. This was reflected in finer details through the generation of two sub-themes: 'Difficulties of understanding and articulating unpredictability' and 'How people articulate and understand unpredictability'.

'Difficulties of understanding and articulating unpredictability' referred to the pervasiveness and invisibility of unpredictability which challenged the participant's ability to understand and discuss unpredictability as a separate construct from the illness. Unpredictability was identified as an abstract concept, 'How people understand and articulate unpredictability' referred to the biological discourses and the comparisons that participants used to articulate and demonstrate their understanding of unpredictability. Typically the methods provided a concrete explanation and understanding of the abstract concept of unpredictability. Symptoms and physiological theories were salient methods used to discuss unpredictability in concrete terms. Many participants understood their experiences of unpredictability through comparisons. Comparisons within the self across time emphasised the changes experienced due to the unpredictability. Participants typically compared their current self with the self before MS. Some participants used time comparisons to articulate and emphasise the unpredictability they encountered across both long and shorter periods of time. Comparisons between the self and MS, and the mind and the body were used to demonstrate the

participants understanding of why they experienced unpredictable symptoms. These comparisons were typically referred to as ongoing battles. MS was personified by a number of participants, creating a visual aspect to unpredictability that individuals could battle with and target their frustrations towards. Distinctions between the self and the “non-MS” population were reported, participants typically referred to “non-MS” population as “normal”. They identified the differences and similarities between living with an unpredictable illness and living a “normal” life. In addition the unpredictability of MS was understood and articulated through comparisons to other illnesses. Some participants highlighted the positive aspects of having an unpredictable illness in comparison to other terminal illnesses, however other participants articulated the difficulty having an unpredictable illness that they were unable to fight or determine the progression of, in comparison to other illnesses. Whilst some participants acknowledged that their unpredictable illness was similar to other illness in regards to requiring adjustment.

The second theme ‘A wide picture of unpredictability’ referred to the effects of unpredictability filtering into all aspects of the individual’s life and their wider environment. This theme was further defined through the two sub-themes that were generated: ‘Self’, and ‘others’. ‘Self’ referred to the effects of unpredictability that directly impacted on the participant. Participants’ reported losses were prominent throughout the interviews, identifying a number of individual and personal losses. Participants reported the impact of unpredictability reducing their abilities, altering their family roles and identity. Participants discussed their self-perception and for many participants their self-perception was effected by the impact of unpredictability on their lives. Some participants demonstrated a negative self-perception whilst other participants focussed on the positive aspects of having an unpredictable illness, forcing them to accomplish and manage situations.

Many participants discussed the impact of unpredictability on their personal life, curtailing many aspects of hobbies, employment and altering their social lives. Furthermore participants expressed their fear and frustration of the effects of unpredictability. Participants identified frustration with their increased need for safety; a fear of the future, unknown medication success, fears and frustrations of other’s perception of their unpredictable symptoms. ‘Others’ referred to the wide reaching impact of unpredictability on the participants’ family. Participants reported

the unpredictability infiltrated the family roles, lifestyles and activities, and affected relationships. The changes were reported to signify both positive and negative changes for the participants and their families.

'Surviving unpredictability' referred to the participant's reports of dealing with unpredictability. This theme was elaborated in finer detail through the generation of two sub-themes: 'Psychological' and 'Pragmatic'. 'Psychological' referred to the participant's descriptions of psycho-educational and psychological aspects of surviving with unpredictability. Although participants reported accepting unpredictability, fluctuations between denial and acceptance were reported. A process of learning about the body and their MS allowed participants to develop a sense of understanding and methods to resolve or alleviate unpredictable symptoms. Many participants demonstrated a change in their perspective, looking for positive aspects of their life, altering priorities and making stoic remarks. 'Pragmatic' referred to the practical methods that participant's employed to live with their unpredictable illness. Participants discussed the environmental changes and the adjustments they had made to deal with their disabilities. Planning and preparation were reported to be key methods to maintain their activities despite their unpredictable illness.

The themes generated tell a story of living with an unpredictable illness, with each theme playing a part in the process. Participants demonstrated the importance of being able to understand and articulate their unpredictability. This in turn allowed participants to acknowledge the wider effects. Finally successful living with unpredictability required the participants to make adjustments both psychologically and pragmatically. All participants identified unpredictability as a constant factor in their lives, continually impacting on them and those around them.

### **Findings in relation to previous research**

The present findings demonstrate how participants live with unpredictability, highlighting the continual process of adaptation for the individuals depending upon their current circumstances. This resonates with the assertion that individuals with MS learn to cope with unpredictability (Miller, 1997).

Unpredictability was identified by participants as a pervasive and constant factor in their lives, echoing Mishel's (1999) perception of uncertainty becoming a

constant companion for individuals with chronic illness. Participants descriptions of the unpredictable symptoms highlighted the continual nature of unpredictability affecting individuals over a wide range of time periods, in particular, participants in the later stages of their illness (typically diagnosed with SPMS), reported rapid, daily and hourly fluctuations in their unpredictability, supporting the accounts of Charmaz (1995) and Webster (1989). Furthermore the disconnection between mind and body resonated with Leeder's (1990) ideas that individuals struggle to unify the mind and the body following the separation during illness, as the focus of attention shifts towards the body. The disconnection and battle to unify them supports the findings of further research (Olsson et al., 2008; Toombs, 1992).

Some participants used a method of personifying their MS, providing a concrete and visual aspect to their unpredictability. It can be argued that the mechanism of personifying MS is similar to the method of externalising the problem in narrative therapy (A. Morgan, 2000). The process of externalising the problem allows an individual to see the problem as separate from them self and this can enable individuals to address the effects of their problem (A. Carr, 1998). In the present study participants created MS as a separate person that they could fight against and consider different ways to manage their "MS person".

Pakenham (2008) and Taylor (1983) argued that ability to make sense of an illness was prominent in the illness adjustment process. Although the present findings support this argument, previous research has indicated that lower disability, disease severity and illness duration were related to the ability to make sense of illness (Pakenham, 2008). The present study demonstrated that all participants had the ability to make sense of the unpredictability despite their illness severity and duration. All participants acknowledged the wider impact and developed methods to live with unpredictability. The participants in the present study represented individuals who had lived with MS between 4 to 35 years and had a range of diagnoses and MS experiences.

The theme 'A wide picture of unpredictability' demonstrated the wide impact upon themselves and their family and friends. These findings echoed the lived experience literature of MS and other chronic illnesses (Burry, 1982; Cohen, 1993a; Haahr, Kirkevold, Hall, & Ostergaard, 2011; Miller, 1997; Pakenham, 2008; Weitz, 1989; Whittemore & Dixon, 2008). The reports of a negative self-perception emphasised by the fears of others' perceptions of their unpredictable illness

supporting previous research (Gordon, Feldman, & Crose, 1998; Webster, 1989). Positive aspects of living with unpredictability mirrored the autobiographical accounts of the lived experience of MS, whereby relationships between family and friends were strengthened by the experience of MS (Brown, 1984; Burnfield, 1985; Lowry, 1984).

Identifying positive aspects to their illness, is likened to the term benefit-finding (Mohr et al., 1999). The positive reinterpretation, identified in the 'Psychological' aspects of 'Surviving unpredictability', demonstrates the 'fighting spirit' of the participants, which has been argued to be associated with the later stages of adjustment to illness (Reynolds & Prior, 2003).

Acceptance is suggested to demonstrate the active integration of illness into their view of the world (Pakenham, 2008), this is argued to be similar to the integration stage of Matson and Brooks' (1977) model for MS adjustment. The range of positive gains identified by participants in the present study mirrors the experiences of growth identified in previous research (Pakenham, 2008). However the findings demonstrated a non-linear process to living with unpredictability through the fluctuations of acceptance and denial. This resonates with the adjustment to chronic illnesses, incorporating both positive and negative aspects, fluctuating over time (Sanders, Donovan, & Dieppe, 2002; Yoshida, 1993). It is suggested that denial and negative attitudes may surface on days where symptoms worsen (Reynolds & Prior, 2003), and thus the fluctuations demonstrated may indicate the good days and bad days identified as common features in chronic illnesses (Charmaz, 1991; Webster, 1989). Furthermore, denial or the perception of an uncontrollable illness is argued to result in individuals employing the less effective emotion-focussed coping strategies (Miller, 1997; Schüssler, 1992). However, it is argued that acceptance and denial are terms that cannot easily be associated with chronic illnesses due to the continual change in the illness experience (Paterson, 2001). Paterson argued that denial may be an effective mechanism used to sustain a sense of wellbeing permitting the individual to live as they desired, and thus not represent an individual's inability to cope. The fluctuation of acceptance and denial may represent the shift in the participant's perspective from a wellness focus to illness becoming the forefront. Previously it has been argued that building a good quality of life in MS requires more than the use of problem-focussed strategies (Reynolds & Prior, 2003). These authors

argued that the psychological stress-coping model required supplementation. The present study demonstrates the use of both problem-focused and emotion-focused strategies used alongside each other and interchangeably, supplemented by the use of shifting perspectives. This suggests that there are a number of mechanisms that individuals can employ to live with unpredictability however the ability to flexibly shift perspectives may aid the process of coping and adjusting to the unpredictability.

It is argued that individuals with chronic illnesses may adopt a stoical stance and portray acceptance of their illness to meet cultural expectations. It is suggested that these individuals perceive displays of emotional distress about their illness as failing (Webster, 1989). This was acknowledged in some participants descriptions in the present study. Participants reported maintaining and adopting a positive “get on with it” attitude in front of others, whilst in their own privacy they were struggling to manage with their ever changing circumstances.

Finally, a number of overlapping themes were identified in living with unpredictability in Parkinson’s disease (Haahr et al., 2011) and MS. A loss of control, the body taking control over the mind, a shift towards dependence and compromise, living with an altered environment and a changed social life were prominent themes identified in Parkinson’s disease and MS both in the present study and Haahr et al., (2011). Thus they may potentially indicate certain common challenges of dealing with unpredictability in other chronic illnesses.

### **Strengths and limitations**

One of the key strengths of the present study is that it is the first study to specifically explore how individuals with MS live with an unpredictable illness. Previous literature has suggested that unpredictability is a major factor in living with MS (Malcomson et al., 2008). However there has been a paucity of research that concentrates on this aspect. This qualitative study met the recommendations of Sobel, Lorig, and Hobbs (2002) and the DoH (2010), providing insight into the participant’s lived experiences, management and coping styles, which can be used to inform healthcare professionals and develop services to meet their needs. Furthermore, TA was considered an ideal method of analysis for the present study allowing in-depth analysis of the participant’s experiences in an area that has not

previously been examined. The inductive, semantic approach allowed the researcher to remain “close” to the data. In addition quality assurance methods were adopted to improve the trustworthiness of the analysis. TA generated three themes that provided a coherent analytic narrative of the nuanced experiences of living with unpredictability in MS. This enabled the examination of the findings in relation to previous research, and will provide suggestions for future research.

There are, however, limitations of the present study. Firstly, the participants represent a self-selected sample. It is argued that individuals who attend support groups are more willing to accept and explore their illness (Dennison et al., 2010). By virtue the participants who chose to participate indicate individuals who are willing to explore and examine their experiences. Therefore the sample of the present study may represent individuals who are at a stage of acceptance of their illness and not account for those who are unable to accept their illness. Whilst this is a limitation of the present study, it was acknowledged by the researcher prior to commencement of the study that it may be difficult to engage with individuals who do not seek support from social groups, and thus reflexive analysis of the researcher’s role and interpretations were continually made in an attempt to acknowledge this shortcoming.

Secondly, it is acknowledged that the terms uncertainty and unpredictability were not used consistently in previous research. However, for participants to distinguish between these terms may have been difficult. Furthermore, despite all participants reporting unpredictability as part of their illness, it cannot be identified as a separate construct from living with MS. Participants’ difficulties distinguishing and articulating unpredictability from the other aspects of the illness may highlight this challenge.

Finally, it is argued that individuals who are ill may adopt defences and self-preservation methods during an interview with a seemingly healthy person (Radley, 1993). Therefore participants may have adopted a positive stance portraying an image of successful coping in line with the perceived cultural expectation (Webster, 1989). Furthermore, a number of the interviews were conducted over the telephone whilst the other interviews were conducted face-to-face. It can be argued that face-to-face interviews offered a different dynamic to the interviews, in comparison to the telephone interviews.



## **Clinical implications**

The findings from the present study may provide a useful insight into the participant's experiences of living with an unpredictable illness. It highlights the wide reaching consequences of unpredictability which affect individuals personally and socially. The present study identifies the use of both psychological and pragmatic strategies to live with unpredictability, supporting the claims of Reynolds and Prior (2003), who argued that the psychological stress-coping model requires supplementation. This can inform health professionals to develop services to support individuals both from a psychological and a pragmatic perspective.

Given that the sample is likely to consist of individuals who are at a point of acceptance and exploration of their illness, these findings may aid health professionals to support the individuals who are unable to come to terms with their illness through understanding and articulating their experiences of unpredictability.

Furthermore, the identification of the difficulties to articulate and understand unpredictability provides insight to the challenges faced by individuals with MS to understand their unpredictable illness. The mechanisms identified in the present study may offer health professionals a level of understanding and a means to approach these topics. Participants' use of externalising MS to aid their understanding is akin to narrative therapy (A. Morgan, 2000). This technique is used to externalise the problem from the individual to enable to individual a sense of control. The interest in using narrative therapy to aid adjustment to chronic illness is growing, furthermore, although there is limited evidence there is literature to support the use of narrative therapy in adjustment to chronic illness for both the individual and the family (Weatherhead & Newby, 2011; Weatherhead, Walther, & Todd, 2013).

The present study also highlights the importance of the family team, therefore it can be hypothesised that engaging families and providing support and education to the family network may improve outcomes for individuals with MS.

Finally, the findings from the present study highlight a number of overlapping themes to previous research in other chronic illnesses (Parkinson's disease). This may potentially highlight a commonality in these experiences and

thus may offer the opportunity to develop services to support individuals across a range of chronic illnesses to live with unpredictability.

### **Future research**

Future research should aim to further explore living with an unpredictable illness in MS in those who do not engage in social support groups, to further develop the story around living with unpredictability. The sample of the present study represents individuals who have lived with MS for at least four years and hence it is argued that they may have had time to come to terms with their illness and grieve for their loss, examination of living with unpredictability from the point of diagnosis may offer insight into the earlier stages of learning to live with the unpredictability.

Finally, the findings of the present study highlight the similarity of living with unpredictability in two chronic illnesses, MS and Parkinson's Disease. Future research should aim to further explore living with unpredictability in other chronic illnesses to develop health professionals understanding of this aspect of chronic illnesses and ensure services meet the needs of individuals who are living with unpredictable chronic illnesses.

## CRITICAL REFLECTION

This section offers a critical reflection on the research process. It opens with critical reflections from the initial stages of research and follows the research process through to the write-up. Excerpts from my reflection diary are used to supplement and demonstrate my reflections along the research process. Finally this section closes with a reflection on my development as a researcher, and the learning points I will incorporate in to my development as a scientist-practitioner.

### Initial stages of the research

**Personal orientation to research.** My rationale to conduct the present study was initiated by my previous experience as an Assistant Psychologist, working with an MS team. Long-term conditions had become an area that I had developed an interest in and I was fascinated by how individuals live a life with a chronic condition. I had met a number of people with a range of MS diagnoses and at different points of their illness progression; however there did not appear to be a common illness pathway.

Through discussions with people who lived with MS, unpredictability was highlighted as major factor. In realising the significance of this characteristic of the illness, I questioned why this factor had not been examined in the literature. Whilst questioning this factor I reflected upon my own assumptions of what it would be like to live with an unpredictable illness. I am a person who likes structure and order, and by my own admission I do not like surprises. Despite my constant desire for structure and continuity, I am aware that there are points in my life that have been unpredictable and in these situations I have been able to respond flexibility. Yet, the knowledge that the whole of my life could alter on a day-to-day basis filled me with a sense of fear. Given my own reflections I became interested in considering how individuals who are faced with an unpredictable life due to illness live with this aspect.

## **Planning and conducting the research**

**A research idea to a research proposal.** In designing the research project I was aware that I needed to transfer the valuable knowledge I had gained through my Masters and my previous research roles. I had experienced the difficulties of conducting research within the NHS and specifically certain sample populations. One of my key learning points from my prior research was the difficulty in recruiting, and the stress and strains that this can place upon a researcher especially given time limitations. Yet more importantly I had become aware of what encouraged people to take part in research. The benefit of having support and guidance in designing the study from individuals who had first-hand experience of the illness I felt was invaluable, producing a study that was meaningful to both participant and researcher. This also ensured that my own assumptions which were clouded by my own experiences could be triangulated with others to ensure that the research aim was a pertinent issue for people with MS and not a factor that I believed was important due to my own assumptions.

Given the nature of the research question a qualitative design was deemed appropriate. I was initially captured by the photo methods design, as I believed it offered a different way to approach the research and an aid to discussing the abstract concept of unpredictability. The feedback provided by the MS Society research network caused me to reflect upon my original methodology decision. I was aware that I struggled in distinguishing what I meant by unpredictability. Furthermore, the literature appeared to struggle to distinguish between uncertainty and unpredictability resulting in a paucity of research considering unpredictability. I questioned whether research examining just unpredictability would have clinical utility. This however, was identified as a meaningful topic for individuals with MS, but the original methodology posed concerns. The practical difficulties of using photo methods, outlined by the MS Society research network, were concerns that I had originally considered; however, I had not understood the extent of the additional work that this would entail for the participant and thus potential limitations this could have on the sample. My limited awareness of the physical and invisible aspects, such as fatigue, of the illness had contributed to my original naive decision making, yet I was grateful for the feedback to allow me to re-consider this aspect, and ensure that the research design accounted for this.

**Epistemological position.** In the past I have typically conducted quantitative research, conducting research as part of larger trials. When coming to design this study, from the start with no pre-set design or question it allowed me to really consider and reflect upon my previous research in relation to my own epistemological stance. I enjoy conducting research and being at the forefront, however the positivist quantitative aspect was not akin to my own position. I began to question my own epistemological stance realising the importance this had upon designing a research project that I was committed to. Through reading the philosophical literature around ontology and epistemology, I was initially confused. However, through peer discussions and teaching it became clearer. I considered my position, realising the critical-realist position was akin to my own thoughts, acknowledging that there may be a truth however, to be able to reflect this would be difficult. I was also aware that the experiences we all can impact upon our perceptions and understanding of the world.

**Decisions that had to be made.** The choice of method of analysis was one that required a lot of consideration. This was my first qualitative research project and therefore all methods were new to me. I was aware that TA was assumed to be a useful method for those who have never done qualitative research before (Braun & Clarke, 2013), however I was keen to consider all types of analysis and ensure that I chose the method that was most appropriate. It was identified that IPA and TA were two methods that I could use, and there were arguments for both [See extended method section for discussion]. However, due to the paucity of research in this area, I was keen to ensure that my analysis remained close to the data to demonstrate the participant's experiences of living with unpredictability. I was aware of the criticisms of TA being perceived as lacking clarity (Braun & Clarke, 2006), however I believed it also offered flexibility and the opportunity to remain close to the data as I had originally hoped.

The ethics process, in comparison to many of my cohort appeared to be a simplistic process. My previous experience of ethical approvals provided much needed guidance. I gained ethical approval at an early stage of the research process and this allowed me valuable extra time for recruitment and data collection.

**Planning the interviews.** In planning my research interviews I conducted a pilot interview. This allowed time to practice my research interview skills and provided feedback upon the interview schedule. The pilot interview allowed me time to reflect upon my position as a researcher:

*<sup>6</sup>Conducting the pilot interview today was difficult. The difference between conducting a clinical interview and a research interview felt miles apart. On reflection this was a driven interview, with prior knowledge about the participant causing me to direct the interview. The connections provided a good rapport and understanding of the client's meaning in conversation. There were some local dialect difficulties that could hinder interpretation of the intended meaning from the participant. At times the interview was leading in terms of questions and became felt more like a clinical interview.*

I became aware of the difference between interview styles and sought supervision and guidance around how to conduct a research interview, to ensure that I did not guide the interview too much. I examined the interview schedule to ensure the aim of the interview was prominent in the interview schedule and this was used as a guide only, and not a rigid assessment. I decided that although I was aware of the negatives of note taking during interviews, I found this very useful to help me to come back to ideas and make sure that nothing was missed. I was conscious that this may have less of an impact over the telephone because there will not be a distraction to the participant however, in the face-to-face interviews I decided that I would let participants know that I may note things down of interest during the interview to return to.

### **Reflections during research**

**Interviews.** Following each interview I reflected upon the interview and the interview dynamics:

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<sup>6</sup> Use of *italics* denotes extracts taken from reflective diary.

*This was a difficult interview to conduct in terms of the different outlook, this threw me in terms of my own assumptions the negative aspects of the illness and not considering the potential positives. . . The participant was a similar age to me and thus I felt that the sacrifices that were made due to MS were really resonant with me and made me think how I would feel from that perspective.*

I considered my context in relation to the participants and how this might have affected them. Interviewing across ages, and locality I was aware of the potential influences that this may have on the interviews and analysis. I became conscious that when I tried to explain my interest in this topic I became embarrassed. I felt it was necessary for the participants to understand my context. I wanted to emphasise their importance in developing our knowledge around the experience however at times I felt that this could sound patronising. I was conscious that I did not want there to be an inherent hierarchy in the dynamics of the researcher and participant relationship. I tried to alleviate this by emphasising my knowledge and experience in this area, and highlight the importance of their first-hand knowledge and experience.

Following the interviews I felt it was necessary to reflect on the difference between telephone interviews and face-to-face interviews. In meeting some participant's face-to-face I found I had a very distinct memory of the interviews, allowing a "*snap shot of what living with unpredictability is really like, creating another layer to the information that I potentially may influence me.*" This was something that concerned me in my analysis. I felt that I had a better sense of the person following a face-to-face interview in comparison to the telephone interviews:

*Interview held over the phone today. I found it difficulties at times with barriers of non-face-to-face contact. It was difficult to develop a rapport with this participant. The participant appeared to be quite confrontational. Is it my assumption that this is due to the method of data collection?*

I conducted the second half of the interviews whilst I was in the early stages of recovery from a serious illness. A number of these interviews were conducted over the telephone. On reflection I had not comprehended the complexity of telephone interviews and the difficulty of maintaining the interview when there is a lack of a visual cue. These interviews were incredibly difficult both in terms of length and emotional impact, discussing aspects that now were very pertinent to me. Interestingly, I noted that I was less directed in these interviews and allowed participants to speak more openly, despite the difficulty of the topics. I found that their positivity and ability to maintain many aspects of their lives very poignant. Although, it could be argued that researcher fatigue may have also affected my performance in these interviews.

**Transcription.** Through the process of designing the study I shifted between the idea of transcribing the interviews myself and having them all transcribed. At the point of the transcription phase I decided that I would transcribe all the interviews, as I wanted to allow time to familiarise myself with the data. Although transcription took a lot longer than I originally anticipated it was a task that I thoroughly enjoyed. Braun and Clarke (2006) indicate that transcription can be the first part of data analysis. In support of this I found it extremely useful aiding the later stages of analysis due to my familiarity with the data.

Unfortunately due to my ill health, I had to make a decision to have the remainder of my interviews transcribed. Physically I was unable to maintain the periods of concentration that were required to transcribe, furthermore time was limited. As I had found the process of transcription highly useful I wanted to ensure that I was as familiar with the rest of the data that I had not transcribed, I therefore ensured that I checked each transcription with the audio recording, again allowing time to familiarise myself with the data. This process however, was not as enjoyable as I had previously found the transcription. Through supervision I discussed my acknowledgement of my feelings. The content of interviews and conducting them had become emotionally taxing. Through supervision I became aware that the interviews discussed an aspect that I had once feared, but I too now had to live with. As I became aware of this I realised the importance of reflection during the analysis stage.



**Analysis.** As this was my first attempt at qualitative research I was overwhelmed by the number of initial codes generated from the interviews. I sought a means to help me organise the amount of data that I had, seeking security in a structure. I considered the use of a computer software package to help the analysis stage, and considered the literature around the use of software packages in TA. On reflection my inclination towards the use of a software package to provide a sense of structure followed my previous qualitative research tendencies having a fixed structure and searching for the right answer, however this was not akin to my epistemological stance. I was able to analyse data in a systematic fashion however, I struggled to approach the data from a different position, applying a fluid and creative lens.

I was aware that my choice to conduct an inductive TA was to help me stay close to the data, however from my epistemological stance I acknowledged that the analysis would not truly mirror the data as no research is conducted within a vacuum. I was entering the analysis stage with my pre-existing knowledge of the literature and furthermore I was entering the analysis with my own experiences of an unpredictable illness. I was conscious that this would undoubtedly result in my attention being focused on some ideas at the expense of others. In attempt to minimise my bias transcripts were coded independently by my research supervisor. Analysis meetings were held to discuss the transcripts and consider our coding, and allowing me to consider alternative explanations, and to discuss our explanations. I found this incredibly helpful, providing a platform to discuss the coding, and allowing me to develop a sense of confidence in the analysis.

**Write-up.** The write-up stage was seen as an extension of the analysis stage, as many decisions were made. I identified a difficulty in trying to capture everything whilst realising the need to tell a story of the results. I was keen to ensure that I accurately represented the participants. Given that I described myself as a 'flowery writer' I felt that this approach would allow me to embrace my style of writing however, my fear of becoming flowery with little substance became a constant source of concern. I engaged in reading a number of articles that had used a TA approach, written for the journal I intended to submit to and reading past

TA theses. However, this was not a wholly successful approach. Initially I noted my anxiety levels increasing 'how on earth can I write like this' kept coming into my mind, yet other times I found this a reassuring process offering ideas of how to approach it and what previous authors had achieved.

*Read a number of TA articles today, this was helpful as I have acknowledged the range in the writing styles, yet still there appears to be a structure that I can possibly use to aid writing the journal article.*

I began to look for the story in my results unlike looking for facts and figures, realising that the narrative needed to be coherent and supported by quotes. The process of choosing quotes to demonstrate ideas was difficult, I was keen to do 'justice' to my participants and not miss out any major factors that they had mentioned. I realised that quotes that had demonstrated the points for me would ultimately have a sense of interpretation from myself. This was further compounded when quotes demonstrated different themes. This caused me to question my analysis. Discussions with my supervisor offered the opportunity to raise this and reflect upon my concerns, furthermore it allowed me to discuss and grow in confidence in my analysis.

I found the thematic map provided me a sense of structure that I previously found in quantitative research, providing a visual cue for the analysis story and a template for the write-up.

Towards the end of the write-up, I was aware of my fading motivation. There was still a desire to do the research justice yet a feeling that time limitations caused me a sense that it was not possible to achieve. Yet on reflection this is a feeling that I often approach at the end of a project, and certainly one I have felt when conducting research within in the NHS in the past. The constant strive for perfection within me can be a blessing yet a curse at the same time, always wanting to do better but never satisfied with the accomplishment that has been made. However, working within an environment where there are time restrictions and evidence is coming more and more pertinent. I am aware my feelings of being time pressured and unable to do my work justice are ones that I have to struggle with, and consider how to ensure that I am able to achieve the best quality in the time provided.

## **Development as researcher**

Prior to conducting this study my research had been limited to quantitative studies. This process of research has been a challenge yet it has allowed me to see the quality and benefits of qualitative research, working in line with my epistemological stance. My affinity to the critical realist position has grown through my clinical training, and I have been able to adopt this position in this research. I have become aware of the importance of reflection upon interpretations of data both within the research setting and the clinical setting.

The findings from the present study created a level of concern for me initially. I felt that there was nothing novel in the findings, however, I have come to realise the benefit of telling this story as part of the wider story of living with an unpredictable chronic illness, and how this can be used as a stepping stone for further research.

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## APPENDICES

### **Appendix A: Journal Manuscript Guidelines**

The Manuscript guidelines for authors for Qualitative Health Research journal are longer than 4 pages, therefore if you would like to refer to these guidelines they can be accessed from

[http://www.sagepub.com/upm-data/36307\\_QHR\\_Manuscript\\_Guidelines\\_SEP\\_2010\\_.pdf](http://www.sagepub.com/upm-data/36307_QHR_Manuscript_Guidelines_SEP_2010_.pdf)

accessed 3/10/2013

**Interview Guide**

**Living With Unpredictability in Multiple Sclerosis**

**Researchers: Hannah Wilkinson, Dr Roshan das Nair**

**TRENT DOCTORATE IN CLINICAL PSYCHOLOGY**

The following questions offer a guide for the semi-structured interview. However the interview was not limited to the guide questions only nor did it follow the questions strictly.

What is life like with an unpredictable illness?

(Prompt) How does it make you feel?

(Prompt) Can you give me an example?

How has living with an unpredictable illness affected you?

What does living with unpredictability mean to you?

How has the unpredictable illness affected other people around you?

(Prompt) In what way?

What has unpredictability done to the relationship?

## Appendix C: MS Experience and Demographics Interview

Participant ID ..... Age..... Male/Female (please delete as appropriate)

Please tick the appropriate response

### Ethnicity

#### White

British

Irish

Other

#### Mixed

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed background  Please state .....

#### Asian or Asian British

Indian

Pakistani

Bangladeshi

Any other Asian background  Please state .....

#### Black or Black British

Caribbean

African

Any other Black background  Please state .....

#### Chinese

Other ethnic group  Please state .....

### Relationship status:

Single

Married

Civil Partnership

Cohabiter

Divorced

Widowed

**Employment Status:**

- Full time employment
- Part time employment
- Voluntary work
- Student
- Home maker
- Retired
- Unemployed
- Other  Please state .....

**Please answer the following questions as accurately as you can**

When was your last relapse? (e.g. 1 year 2 months ago) .....

How often do you experience relapses? .....

What is your current diagnosis?

- Primary Progressive MS
- Relapsing remitting MS
- Secondary progressive MS
- Unknown

When were you diagnosed? (years and months) .....

How did you receive your diagnosis? .....

What age were you when you received your diagnosis? .....

What life accomplishments had you made at the time of diagnosis (e.g. relationships, employment, children etc)?

.....

**Thank you for taking the time to complete this form**

## **Appendix D: Participant Information Sheet**



### **Participant Information Sheet** **Living with unpredictability in Multiple Sclerosis**

You are being invited to take part in a research study. Before you decide whether you would like to take part, it is important that you understand why the research is being done and what it will involve.

Take time to read the following information and talk to friends, relatives or others about the study if you wish. Please feel able to ask us if there is anything that is not clear, or if you would like more information.

#### **What is the purpose of the study?**

The purpose of this study is to explore the experience of unpredictability in people who have Multiple Sclerosis (MS).

#### **Am I eligible to take part?**

You are eligible to take part if you have a diagnosis of MS, and you are able to communicate in English. If you would like more information on these eligibility criteria, please do not hesitate to ask the investigator.

#### **Do I have to take part?**

Taking part in this study is entirely voluntary - it is up to you whether you decide to be involved. If you decide not to take part you will have no further contact with the study this will not affect any care of treatment you receive.

#### **What will happen to me if I take part?**

You will have a telephone introductory meeting, to discuss the project further and to answer any questions you may have, you will also receive an information pack. If you then decide you would like to take part in this study you will be asked to take part in an individual telephone interview. If however you live within the area of Nottingham, Lincoln or Hull you will be offered the opportunity to take part in either an individual interview (face-to-face or over the telephone) or a focus group held in a local venue, to discuss:

**'What is it like to live with an unpredictable illness?'**

The researcher will arrange a suitable time to conduct the interview either over the telephone or in your own home, to discuss what it means to live with an unpredictable illness. The interview will last approximately one hour. If you have opted to take part in the focus group the researcher will contact you to let you know about the time and date of the group (if adequate numbers are achieved – minimum of 4). Focus groups will last approximately 1.5 hours. All interviews and focus group discussions will be audio recorded.

**What happens if I decide not to take part, or I change my mind?**

You may choose not to take part, for which there will be no negative consequences. If you decide at any point that you wish to withdraw from the study you are free to do this. You can withdraw all or part of your data up until two weeks after your final interview with the investigator. However, if you take part in one of the focus group discussions, we will not be able to remove your contributions from this data.

**What are the possible benefits of taking part?**

There are no individual benefits to you, but we hope that an increase in knowledge in this area will help to develop future clinical treatments.

**What are the possible disadvantages of taking part?**

There are no physical risks in taking part in the study. You can withdraw from the study at anytime if you felt that you were unable to continue (see above). You would not have to give a reason.

**What if there is a problem?**

If you have any questions or concerns, you can raise these at any time with any member of the research team. If you feel unable to do so, or wish to make a formal complaint about your treatment in any aspect of the study, you can do this through the University's complaints procedures. Please contact Patrick Bourke ([pbourke@lincoln.ac.uk](mailto:pbourke@lincoln.ac.uk)). Further details are available on the University websites.

**Will my taking part in the study be kept confidential?**

All information which is collected about you during the course of the study will be anonymised and kept strictly confidential. Individual interviews and focus groups will be audio recorded and transcribed professionally. Before transcription the individual employed will sign a confidentiality agreement to ensure full confidentiality.

**What will happen to the results of the study?**

This will be presented both as a thesis for a university doctorate and as paper(s) for publication in a scientific journal. Your individual participation will not be personally identifiable in any way in any report. A summary of the findings will be distributed to the MS society for publication via their newsletter or website.

**Who has reviewed the study?**

The University of Lincoln - School of Psychology Ethics Committee

**Who is organising the study?**

The University of Lincoln.

**What happens now?**

Take some time to read over the contents of this Information Sheet. If you are willing to take part, you will be asked to sign a consent form.

**Thank you for taking the time to read this.**

**Contact Information**

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**Appendix E: Participant Consent form**



**Consent form for Participant  
Living with unpredictability in Multiple Sclerosis**

Participant Identification Number .....

Name of Researcher:.....

**Please tick the boxes if you agree**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that I can withdraw all or part of my data up until two weeks after my interview if I take part in a telephone or face-to-face interview.
4. I understand that if I take part in the focus group I cannot withdraw my data.
5. I understand that all interviews and focus groups will be audio recorded.
6. I understand that all information given by me or about me will be treated as confidential by the research team.
7. I confirm that I understand that the information sent for transcription, will be treated as confidential and a confidentiality agreement will be signed.
8. I agree to take part in (please tick the appropriate box)

a. Telephone interview

b. Face-to-face interview

c. Focus group

9. I understand that if I need to make a complaint I can contact Patrick Bourke ([pbourke@lincoln.ac.uk](mailto:pbourke@lincoln.ac.uk)).

10. I agree to take part in the above study.

Name of Participant

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Researcher

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Contact Information**

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## Appendix F: Advert for recruitment

# Do you have Multiple Sclerosis?

- Are you living with unpredictability on a regular basis?
- Would you like to help develop an understanding of what it is like to live with an unpredictable illness and get involved with research?
- Would you like to discuss this issue either individually or within a group setting?
- Do you have at least 1.5 hours to spare?
- If the answer is yes please contact  
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DClinPsy Course  
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For more information about this research project

## Appendix G: Participant demographics<sup>7,8</sup>

Pt No	Age Range	Gender	Ethnicity	Relationship	Employment	Diagnosis	Age at diagnosis	Time since diagnosis (years)	Frequency of relapses
1	40-49	Male	White - British	Married	Retired	PPMS	32	5-9	Daily
2	20-29	Female	White - British	Single	F/T	RRMS	21	5-9	Not often
3	60-69	Female	White - British	Married	Retired	SPMS	29	35-39	Often
4	60-69	Female	White - British	Married	Retired	PPMS	51	10-14	never
6	40-49	Female	White - British	Married	Other	RRMS	40	5-9	1/year
5	40-49	Female	White - British	Single	Unemployed	RRMS	39	5-9	1.5/yr
8	60-69	Female	White - British	Married	Retired	Unknown	58	0-4	Infrequently
9	50-59	Male	White - British	Married	F/T	RRMS	40	10-14	not often (3-4 months little attacks)
7	30-39	Female	White - British	Single	Unemployed	RRMS	17	25-29	not since started treatment
11	40-49	Male	White - British	Married	Other	RRMS	36	5-9	every few years
10	30-39	Female	Mixed - White and Asian	Single	Unemployed	RRMS	27	5-9	only had 1
12	50-59	Male	White - British	Widower	Unemployed	SPMS	52	5-9	constant

<sup>7</sup> Participant numbers, age ranges and range of time since diagnosis have been provided to ensure participant anonymity

<sup>8</sup> Not all MS experience data has been provided to maintain participant's anonymity

## Appendix H: Example of Initial Coding and initial themes

Transcription – P9	Initial Code	Initial Theme
And I've found that all of that's eroded because I just get really, really tired. So, you know, I forget stuff and it could just be my age of course, but you know, I do in a way that I never used to before, definitely, definitely not.	All eroded [ability to hold stuff in your mind] I get tired, forget stuff It could be my age I never used to do that	Impact – affecting cognitive abilities  Perspective - Can't always blame MS Now vs. then - I'm different
R: And so all of that, you know, you're saying that your memory's not working as well and you get so tired. And when you, you're sort of already identifying things where you're not as good and you're saying that quite a lot. How is that making you feel about yourself when you're identifying all of those things?		
P: It makes me feel, I suppose it makes me feel that I can't be the person that I wanted to be. And as you've probably gathered from talking to me this short while, I'm the sort of person that, you know, I'm a bit of a performer, do you know what I mean? I need to show off a little bit from time to time. And I could do that and I could use that to hide or fill in for areas where I wasn't so good. Whereas now I don't feel that I can, so I feel a lot more vulnerable. And that then makes you feel a little bit inadequate really. It makes you feel a bit of a fraud, as if, you know, in actual fact you've just been fooling yourself all along, you know, you've not been able to do all these things.	I can't be who I want to be  I am a performer, I need to show off  I used it to hide and fill in areas where I wasn't so good  I can't do that now, I'm more vulnerable I feel a little bit inadequate You feel a fraud You've been fooling self	Loss - of who he is  Personality – identity  Loss - Can't protect self  Impact – self perception - vulnerable Impact – self perception Impact – self perception Impact – self perception
And you start saying to yourself, oh well I can't do that, do you know what I mean, it must be me, I must be getting it wrong. And it's only people around me that I know well, both colleagues and, you know, at home, sort of saying, god you could do that easy, god no you'd be brilliant at that, oh no you're fine at that, you know. It's only them saying that, that actually keeps me, keeps you sort of believing. I mean I'm better than I was, you know, two/three years ago. Two/three years ago I was absolutely rock bottom and I was in some really dark places. I'm a lot better now than I was but I still harp to those times and I still think of those times. And I still get that heavy heart beat, sometimes I wake up at 3 O'clock in the morning and my hearts feels like it's going at 140/150. And I've tested my pulse and find.	You've not been able to do all these things I can't do Must be me getting it wrong  Others tell me you could do that easy  Others keeps me believing  I was better than I was 2/3 years ago 2/3 years ago I was rock bottom I was in really dark places I'm better now Still think of those times [bad times] I wake up with heavy heart beat	Impact – self perception Impact – self perception Loss – confidence  Others – support, confidence  Others – support  Time - difference now vs then Time – bad times  Fear

## Appendix I: Excerpt of themes and sub-themes with associated codes<sup>9</sup>

<p><b>A wide picture of unpredictability</b></p> <p><b>Fear and frustration</b></p> <p>Safety – “But it is if you know that, you know, if that happens you’ve got someone around that can be able to pick up the phone, dial an ambulance and get someone here because I’ve injured myself” (p33)</p> <p>“I’m quite happy where I am and I feel safe, I don’t feel safe if I’m not in my house or my surroundings” (p50)</p> <p>“Like my mum and dad I feel safe around them ....., I don’t feel safe if they are not there” (P54)</p> <p>“like if my energy is low erm and my granddaughter is due to come I know I’m alright, I’m safe in my flat erm because there is all the cords and everything so I know I’m safe here.” (p41)</p> <p>“As long as I’m indoors, got the door locked, I think, oh I’m safe now because I’m in my own environment.” (p30)</p> <p><b>Medication</b> - “In the early days they put me on Copaxone and that was every day. And I only did it for about four weeks because it was, why am I doing this? If you’ve got diabetes, you know, you inject yourself because you might die, whereas I was just injecting myself painfully every day and not getting anything out of it.” (p38)</p> <p><b>Future</b> - “I just know that the walking, my walking isn’t as good as it could be but whether it will ever get any better, I don’t know” (p109)</p> <p>“it means we don’t know how you are going to be... Tomorrow, next week... You know, any time in the future.” (p3)</p> <p><b>Loss</b></p> <p><b>Independence</b> - “that independence is the major erm problem now ... trying to fight independence with erm all these other things going on” (p78)</p> <p>“It’s stopping you from living the life that you want to lead and it also, it does make you reliant, it does make you reliant.” (p106)</p> <p><b>Roles:</b> - “I don’t know I feel boring at times because the things that I would naturally be doing I can’t do it,” (p306)</p> <p>“It’s like you’re not doing your job you know ...in not being a wife whose with your husband going everywhere” (p52)</p> <p>“Yes, you have to think about the children and add me into that mix as well because I have to be, you know, treated as a child also, you know, there are certain things that I can be left alone for, and there are certain things that I have to be treated as a child for.” (p281)</p> <p><b>Identity:</b> - “So the three things that I’m really, that I really feel, you know, I’ve got and are unique to me and I can do them well, have all been taken away.” (p64)</p> <p><b>Control:</b> - “That’s another thing that I don’t like about it, you can’t control yourself, you can’t actually control what you can do” (p10)</p> <p>“it can take what it wants when it wants and I have no control” (p157)</p> <p><b>Others perceptions</b> - “Well I don’t want to look a right idiot.” (p40)</p> <p>“That’s another thing, when I’m walking, there are times when I’m walking I’m thinking, anybody behind me is going to think, she’s drunk, because I tend to wobble a bit from side to side a bit.” (p42)</p> <p><b>Negative Self-Perception</b> - “Well I don’t want to look a right idiot.” (p40)</p> <p>“yeah like a failure, like you’ve failed and you know you failed because it’s never going to go” (p332)</p> <p>“Fragile, delicate, stupid, you know, because I’ve forgotten like words and everything, it’s like, almost like learning how to speak again.” (p153)</p> <p>“I just feel really useless and stupid.” (p157)</p>
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<sup>9</sup> Please note each participant transcript was colour coded, each colour denotes a participant

## Challenges of meaning-making

### *Difficulties understanding and articulating*

"I don't know, it's all a muddle, because it is all unpredictable, and well it's in the word it's not, I don't know it's just ... I don't know" (p260)

**Pervasive** - "you've got to, if your condition is unpredictable, you've got to treat your whole life as being unpredictable" (p305)

"the whole lot because the symptoms are just... You know they range from physical ones to like memory and speech, it's just ridiculous how many different symptoms that are, then you think oh it's just everything, do you know what I mean," (p264)

**Invisible** - "But you can't see what's wrong with somebody who's got MS, it's all inside not working properly. And some days it works wonderfully and other days it doesn't." (p42)

### *How people understand and articulate*

**Biological discourse** - "Erm, I mean some people are quite lucky and they've just got scarring at maybe the base so it's just the legs, and not the top half but I've got scar, I've got scarring all the way down in three major places." (p157)

### *Comparisons*

**Mind versus Body** - "Yes, my mind's saying carry on but my body's saying I can't" (p148)

"Yes, my legs were telling me to sit down but I thought, no, I'm going to carry on, I'm having a good time up here" (p242)

"We go out once a week for a quiz, which I quite enjoy, because then you can keep your brain going." (p108)

**MS versus Self** - "It's my favourite, that's my MS, as I said, that's my MS kicking in" (p226)

"So like there's me and my other child, you know, the only benefit is you haven't got to buy a ticket for it on the train. If you go Alton Towers you haven't got to buy a ticket." (p313)

**Between time** - "I realise that prior to being 34 35 when I was diagnosed with it if somebody had said to me we'll go up to pub and have a drink and call at supermarket and get some cigs I could just do that, that wouldn't be a problem but now it is so much planning" (p22)

**MS versus "Normal"** - "But I'm thinking, but I'm not, I'm just a normal person but I look rubbish" (p42)

"it stops you from leading, what I would say would be a normal life, because you can't do that" (p330)

"I know we all spill things and drop things in normal life, but this was part of me thinking I had control of the jug when I hadn't." (p18)

"I have no problem in sleeping but in terms of, because you're lying in bed for that kind of length of time, like even when normal, you have sort of aches and pains when you get out of bed don't you?" (p20)

**MS versus Other illnesses** - "I just think that there's so many worse illnesses than MS. Like a person with cancers and terminal illnesses and stuff, and this is something, it's like you just have to deal with and manage." (p90)

"I mean I once turned round and I said to someone, "I would have rather had cancer" and they said, "That's not nice," and I went, "Yeah but at least I could have fought it," I said, "this I've got no chance" (p245)

### *The Wider impact*

#### *EADL*

##### *Employment:*

"I still want to work so and well nobody would employ me like that, I know they wouldn't cos they, well they can't, you can't just turn up to a job even though you physically look ok, they'll be like why, what's wrong why are you going home" (p194)

"And then so I... I wasn't able to physically do that [work].....but erm it wasn't... I wasn't in an attack but I was suffering the results of attacks by that stage" (p68)

"I was waiting, from day one of telling my line manager, I was waiting for the Health and Safety boys to get the call to say, go and do a risk assessment." (p25)

"And that basically meant that they had to medically discharge me because of that risk" (p21)

##### *Social Life:*

"I used to be really spontaneous and just do random things and I don't do that anymore" (p48)

##### *Hobbies:*

"so my hobbies are a bit non-existent anymore, even though I'll still go and watch football because I still like football, but I can't play it" (p306)

##### *Family roles*

"mother-in-law moves in, time of stress, wife sick, erm child is maybe aware of what is happening ..... and grandma is in, grandma is doing things differently the way mother and dad do you know, house rules change and it, it affects the whole family you know" (p46)

##### *Relationship changes*

"So in sort of friendship wise, I think it's been, it's been quite good. I would say that my relationship with my family has been OK" (p278)

##### *Others' lifestyles/activities*

"It is a bit depressing, not just for me I think, but thinking about how my husband and my children are going to cope with that." (p252)

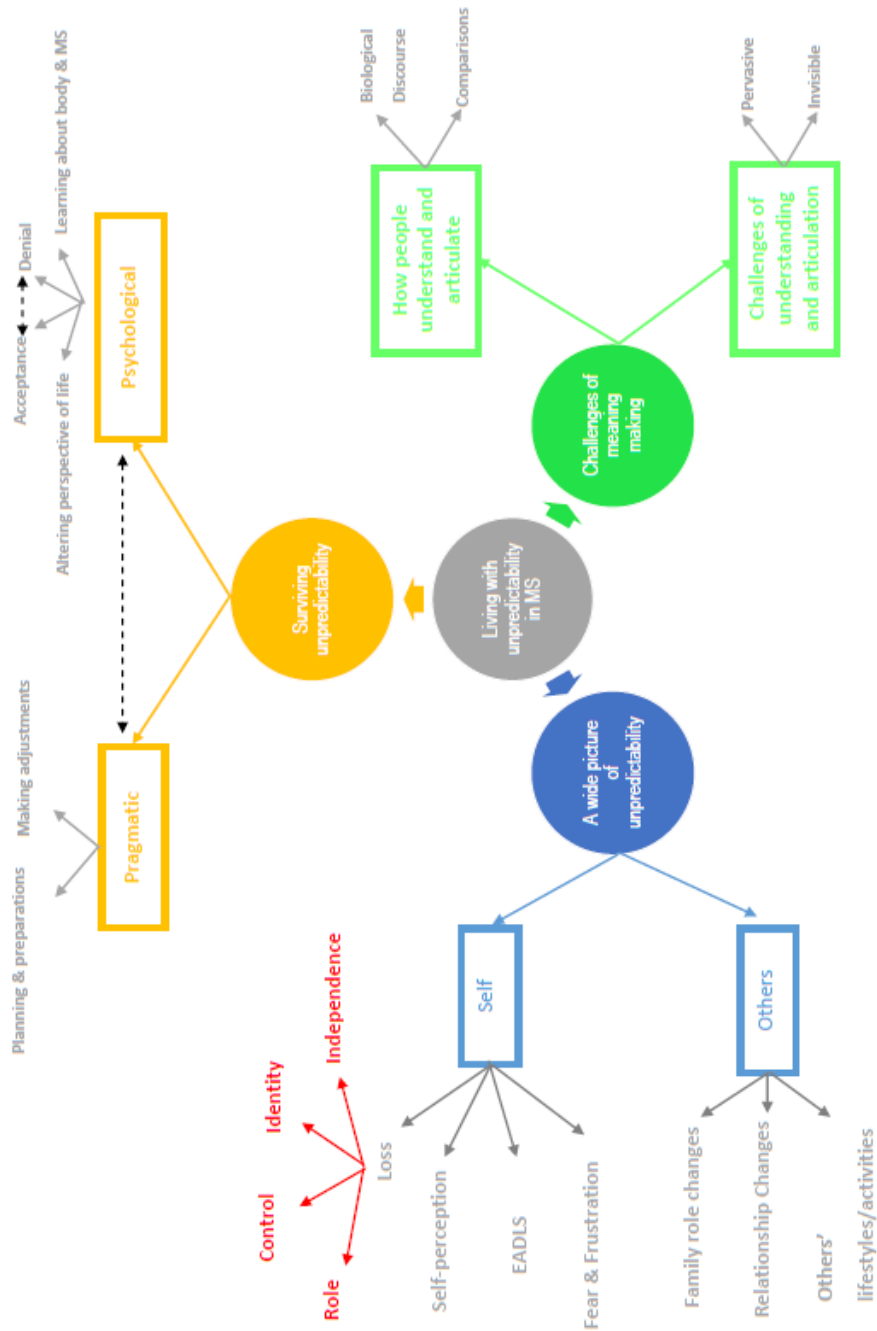
"In a way I'm the one that's alright, I've got people doing things for me. They're the ones that are having to do things and that makes me feel quite sad." (P252)



<p><b>Surviving Unpredictability</b></p> <p><i>Psychological</i></p> <p><i>Acceptance</i></p> <p>"Well I just think, to me it just feels like normality now." (p236)</p> <p>"at one time I used to think about it quite a lot of the times of the day, just thinking what's going to happen, whereas now I don't think I do that" (p214)</p> <p><i>Denial</i></p> <p>"I don't think so.... I try not to think about things too much I was just.... Yeah it was there but I wasn't thinking about it kind of thing because it's being a bit hardened to it.... I think." (p312)</p> <p><i>Learning about body and MS</i></p> <p>"So, you know, it's a gradual learning curve." (p47) "I was slowly becoming accustomed, so I couldn't do certain things." (p41)</p> <p>"We're trying to find where the sweet spot [with medication] is again, is taking a little bit of learning." (p197)</p> <p>"By having to be positive, I have to say to people I have to.... I suppose this happened when I had the relapsing remitting, I had to learn to say no, I'm sorry I can't." (p60)</p> <p><i>Altered Perspective</i></p> <p>"But I suppose you have to just deal with each thing as it comes really and try not to be too, what's the word, try not to think too much that everything's going to go wrong really and just get on with it" (p74)</p> <p>"Well you either cope with it or you just like give up, in my eyes. And I just try and cope with it the best I can and deal with it the best I can and carry on, as I say." (p90)</p> <p>"at one time I used to think about it quite a lot of the times of the day, just thinking what's going to happen, whereas now I don't think I do that" (p214)</p> <p><i>Pragmatic</i></p> <p><i>Planning and preparation</i></p> <p>"So it's, yes just planning things really and letting my friends know that I can't do things" (p121)</p> <p>"So I don't need it full time [chair lift] but when I do need it it's here." (p47)</p> <p>"I realise that prior to being 34, 35 when I was diagnosed with it if somebody had said to me we'll go up to pub and have a drink and call at supermarket and get some cigs I could just do that, that wouldn't be a problem but now it is so much planning" (p22)</p> <p>"No, but then again I'll have my walking stick with me blah, blah, blah. Erm so you sort of plan but you make sure you're prepared" (p69)</p> <p>"you can to a point, because say I wanted to go with my grandchildren to Scunthorpe for the day, I would literally make sure I don't do nothing for about 3 days beforehand, just so that my body has got enough energy and everything in order to do it but you have to sort of plan the three days ahead in order to do that one activity" (p5)</p> <p><i>Making adjustments</i></p> <p>"But exercise for me has gone from like, oh yes I enjoy sport, football team. . . . Joined all that, did all that, now it's become my life blood, you know." (p254)</p> <p>"we moved to the bungalow 5 1/2 years ago, when the stairs and too much it was, I was going up on hands and knees .... and may be falling down sometimes" (p35)</p>	
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# Appendix K: Thematic Map – Final version



## Appendix L: Excerpts from Reflective Diary

PT02	23.11.12	<p>This was a really interesting and insightful interview. It provided a different outlook on the MS course, however the experiences to date have been very different. This was a difficult interview to conduct in terms of the different outlook – this threw me in terms of my own assumptions of the awfulness of the illness and not considering the potential positives. At times it felt as if what was said was said because it felt right rather than being the truth – like there is a facade to keep up and protect others from the real MS – this was made apparent through the narrative however, there were times where when the questions were worded in such a way the facade dropped and the true feeling and what this meant to her was apparent. Through the narrative of the sacrifices made and the changes made to her life it maybe that there is the underlying meaning to this person – however caution must be taken when analysing this – as with this in mind this might cause my own interpretation of how that would feel to be implemented. The participant was a similar age to myself and thus I felt that the sacrifices that were made due to MS were really resonant with me and made me think how I would feel from that perspective.</p> <p>Again I felt as though I led the interview too much, yet this was different in comparison to the first interview whereby I felt this time that I had not understanding of where this person was coming from – with no understanding of their MS experience.</p> <p>Safety – control adjustment to unpredictability? The need for safety and that sense of control appears to be large part of this participant's existence. Safety in her surroundings and those that she feels comfortable around and is able to protect in a fashion.</p>
	26.11.12	<p>Post-traumatic growth in terms of identifying positives of unpredictability?</p>
	Transcription	
	29.11.12	<p>Lost – unpredictability of the whole process. Uncertainty from medical profession, to the actual illness – who knows. 'Dropped in the ocean like a little fish' – Lost – powerful analogies used.</p>
	Transcription	
	17.12.12	<p>Control of changing doctors, consultants, doctors (seen in a number of interviews) what is the impact of this on managing and the sense of control this provides pts.</p>
	Transcription	<p>Indication that change has occurred without much knowledge but the ability to discuss this has shed light on changes? Is this part of the process – the age of the pt and life stage they are at currently, i.e. no dependants or relationship. Or is it part of the adjustment</p>
		<p>phase whereby they are not yet at the stage to consider the different life and thus remain in a denial stage.</p> <p>Separation between individuals with MS and others – if not got it you will never know (also seen in other interview in terms of why me vs them)</p> <p>Unpredictability of symptoms – difficult to explain but fat dr can know what talking about does this remove that frustration of the unpredictable symptoms as it fits medically??</p> <p>Sense of I will take it so others don't have to (Seen in Pt06)</p>
Pt03	30.11.12	<p>Again the positive attitude struck me. There was a long history of MS, become part of this participant's way of life, incorporated and dealt with. The affect on the wider family and the constraints it placed on plans for future, although at times it felt as if considering these were hard and highlighted aspects that were unable to part of her life the narrative posed it as not so bad and 'character building'. Unpredictability changed through the life course. Adjustments to life been made in more recent times however previously it appeared that relapses were seen as a setback.</p>
	24.1.13	<p>Done at a time when personally I am struggling medically – the comments made a large impact on me. I noticed the times when the participant laughed – considering the purpose to this behaviour. There was an underlying tone of anger, upset, disappointment in herself – in terms of how it has affected those around her and that this is continual "it's mum...it's mum" was a point that struck a chord in terms of how her illness has caused others to view her. The positive ending – was not as positive as the narrative may suggest, it was cast in all the negatives of the illness, yet felt like her way of putting a positive spin on things otherwise she may also go down the route of other MS sufferers that she discussed. Her husband becoming her carer – this felt a very important role change and one that did not feel comfortable with her. Although I have noted the sombre undertones of this interview I am aware that my interpretations maybe skewed by my own personal feelings at the time and hence the negative aspects feel very in line with my current feelings.</p>
	Transcription	

## Appendix M: Ethics Approval Letter



Lincoln, 06-9-2012

Dear Hannah Wilkinson,

The Ethics Committee of the School of Psychology would like to inform you that your project exploring "how individuals with MS, understand living with an unpredictable illness, by considering the question 'what is it like to live with an unpredictable illness?' is:

approved

approved subject to the following conditions:

- (1) Specify what confidential information should be destroyed.
- (2) Say which committee approved this work (i.e. School of Psychology)
- (3) State any concerns - contact Chair of the ethics committee i.e. [pbourke@lincoln.ac.uk](mailto:pbourke@lincoln.ac.uk)

invited for resubmission, taking into account the following issues:

is rejected. An appeal can be made to the Faculty Ethics Committee against this decision ([cawalker@lincoln.ac.uk](mailto:cawalker@lincoln.ac.uk)).

is referred to the Faculty Ethics Committee. You will automatically be contacted by the chair of the Faculty Ethics Committee about further procedures.

Could you address each of the issues raised by changing all relevant documentation, and by formulating a reply to each of the numbered issues in a separate document or e-mail? I may be able to approve after your reply by chair's action; if I have any doubts I will need to refer your application back to the School's Ethics Committee.

Yours sincerely,

Patrick Bourke, PhD

Chair of the Ethics Committee  
School of Psychology  
University of Lincoln  
Brayford Campus  
Lincoln LN6 7TS  
United Kingdom  
telephone: +44 (0)1522 886140  
fax: +44 (0)1522 886026  
e-mail: [pbourke@lincoln.ac.uk](mailto:pbourke@lincoln.ac.uk)

## Appendix N: Ethics approval – e-mail trails for amendments

### Re: ethics application

Patrick Bourke

In response to the message from Patrick Bourke, 12/09/2012

To:

Hannah R Wilkinson (11236362)

You replied on 22/09/2012 20:25.

Hi Hannah,

The good news is that your application has been approved. I did this shortly after receiving your additional changes. I apologise if you did not receive it. I attach it again.

Good luck with your research,

Patrick

Patrick Bourke PhD

Senior Lecturer,

School of Psychology,

University of Lincoln.

<http://patrickbourke.blogs.lincoln.ac.uk/>

-----Original Message-----

From: Hannah R Wilkinson (11236362)

Sent: Tue 18/09/2012 21:25

To: Patrick Bourke

Subject: RE: ethics application

Dear Patrick

I have made all the amendments as requested and sent these to you last week, can you confirm that you have received these? If this is the case will I receive a letter confirming my ethics approval. I am recruiting via the MS Society and they have requested a copy of the approval letter and hence I am enquiring after this. I understand that you will be very busy with ethics approvals at this time however I just wanted to confirm the process.

Thank you

Best Wishes

Hannah Wilkinson

Trainee Clinical Psychologist

University of Lincoln

Trent Doctorate of Clinical Psychology

E-mail: [11236362@students.lincoln.ac.uk](mailto:11236362@students.lincoln.ac.uk)

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[Patrick Bourke](#)

To:

[Hannah R Wilkinson \(11236362\)](#)

*Inbox*

19 September 2012 10:52

Hi Hannah,

Patrick Bourke PhD

Senior Lecturer,  
School of Psychology,  
University of Lincoln.  
<http://patrickbourke.blogs.lincoln.ac.uk/>

-----Original Message-----

From: Hannah R Wilkinson (11236362)  
Sent: Tue 18/09/2012 21:25  
To: Patrick Bourke  
Subject: RE: ethics application

Dear Patrick

I have made all the amendments as requested and sent these to you last week, can you confirm that you have received these? If this is the case will I receive a letter confirming my ethics approval. I am recruiting via the MS Society and they have requested a copy of the approval letter and hence I am enquiring after this. I understand that you will be very busy with ethics approvals at this time however I just wanted to confirm the process.

Thank you

Best Wishes  
Hannah Wilkinson  
Trainee Clinical Psychologist  
University of Lincoln  
Trent Doctorate of Clinical Psychology  
E-mail: [11236362@students.lincoln.ac.uk](mailto:11236362@students.lincoln.ac.uk)

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[Patrick Bourke](#)

To:

[Hannah R Wilkinson \(11236362\)](#)

*Inbox*

12 September 2012 10:15

You replied on 18/09/2012 21:25.

Hi Hannah,

This all looks good except that the participants should have some written information as to who to specifically contact should they want to complain. That person is me. So please add my email as a contact as well as your own on the informed consent form - you should also give each participant a copy of this to take away.

Can you please confirm these changes.

All the best,

Patrick

Patrick Bourke PhD  
Senior Lecturer,  
School of Psychology,  
University of Lincoln.  
<http://patrickbourke.blogs.lincoln.ac.uk/>

-----Original Message-----

From: Hannah R Wilkinson (11236362)  
Sent: Fri 07/09/2012 15:08  
To: Patrick Bourke  
Subject: RE: ethics application

Dear Patrick

I have made all amendments requested, see below for a summary of the amendments. I have also attached the relevant documents

1. Confidential information to be destroyed

Amended in:

- Proposal - page 21, Section: Risks for Researcher
- Application form - page 3 Question 9, section: Risks for Researcher

When the researcher is working in accordance with the Lone worker protocol, a named person will hold the participant name and contact details. These will be destroyed once the researcher has alerted the named person regarding their safety following this visit.

All data will be kept in accordance with the ICH/GCP guidelines (EMA, 2002) and the Data Protection Act (1998), audio files, transcriptions and notes will be retained for at least 7 years at the University of Lincoln. Research Tutors and administration staff at the University of Lincoln will be the custodian for this data.

2. Committee that approved this study

Amended in:

- Proposal - page 19, Section: Ethical Committee and Regulatory Approvals
- Application form: page 3, question 9, additional section Ethical Committee and Regulatory Approvals
- Participant Information Sheet - Version 3 (see amendment and proposal)

The committee that has approved this study has been amended to read the University of Lincoln, School of Psychology Ethics board.

3. Concerns regarding the study

Amended in:

- Proposal - page 19, Section: Ethical Committee and Regulatory Approvals
- Application form: page 3, question 9, additional section Ethical Committee and Regulatory Approvals

If there are any concerns the researcher will contact the Chair of the ethical board - Patrick Bourke, for guidance and approval.

Please do not hesitate to contact me for further clarification, if required

Thank you

Best Wishes

Hannah Wilkinson

Trainee Clinical Psychologist

University of Lincoln

Trent Doctorate of Clinical Psychology

E-mail: 11236362@students.lincoln.ac.uk



## Appendix O: Signed Confidentiality Form – Transcription Service<sup>10</sup>



### Data Protection Act 1998 Confidentiality Agreement for Transcribers

This Agreement is made as of 24/4/13 (Date), by and between the University of Lincoln, with principal offices at Brayford Pool, Lincoln LN6 7TS (the University) and \_\_\_\_\_ with principal offices at \_\_\_\_\_ (the Transcriber).

The Transcriber has been appointed by the University of Lincoln to transcribe audiotapes/audio files and documentation resulting from research undertaken by \_\_\_\_\_ which will involve the disclosure to the Transcriber of personal data held by the University. Accordingly the Transcriber is required to deal with any such information in accordance with the terms of this Agreement and the Data Protection Act 1998.

The Transcriber undertakes to respect and preserve the confidentiality of personal data. Accordingly, for an indefinite period after the date of this Agreement the Contractor shall:

- maintain the personal data in strict confidence and shall not disclose any of the personal data to any third party;
- restrict access to employees, agents or sub-contractors who need such access for the purposes of the contract (and then only if the employee, agent or subcontractor is bound by conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request);
- ensure that its employees, agents or sub-contractors are aware of and comply with the Data Protection Act 1998; and
- not authorise any sub-contractor to have access to the personal data without obtaining the University's prior written consent to the appointment of such sub-contractor and entering into a written agreement with the subcontractor including conditions of confidentiality no less strict than those set out in this agreement, which the Transcriber shall enforce at the University's request.

The Transcriber agrees to indemnify and keep indemnified and defend at its own expense the University against all costs, claims, damages or expenses incurred by the University or for which the University may become liable due to any failure by the Transcriber, its employees, agents or sub-contractors to comply with any of its obligations under this Agreement.

For the avoidance of doubt, the confidentiality imposed on the Transcriber by this Agreement shall continue in full force and effect after the expiry or termination of any contract to supply services.

The restrictions contained in this Agreement shall cease to apply to any information which may come into the public domain otherwise than through unauthorised disclosure by the Transcriber.

This Agreement shall be governed by and construed in accordance with the laws of England and the parties hereby submit to the exclusive jurisdiction of the English courts.

Signed for and on behalf of \_\_\_\_\_

Signed: \_\_\_\_\_ Name: \_\_\_\_\_

Title: \_\_\_\_\_ Date: \_\_\_\_\_

Signed for and on behalf of the University of Lincoln

Signed: \_\_\_\_\_ Name: \_\_\_\_\_

Title: ADMIN OFFICER Date: 24.4.13

Version 1, August 2011

<sup>10</sup> Please note all identifying information has been removed to preserve anonymity

## Appendix P: Designing the study - Research Network Questionnaire

### What is it like to live with an unpredictable illness?

Please answer the following questions honestly, I appreciate all feedback. My aim is to design a study that you feel will be a benefit to people who experience an unpredictable illness.

**Please make the response that is most suitable bold**

**1 = not at all**

**5 = very much**

- 1. Do you think the topic area of 'what is it like to live with an unpredictable illness' will be a beneficial topic area to explore?**

1            2            3            4            5

- 2. Do you think it physically possible to use cameras?**

1            2            3            4            5

- 3. Do you think the pictures would be useful:**

- a. To help you talk about the effects of unpredictability in your life**

1            2            3            4            5

- b. To help other people understand what it is like to live with an unpredictable illness**

1            2            3            4            5

- 4. Or, would you prefer to talk to someone about this rather than take pictures?**

1            2            3            4            5

- 5. If this study did use photos would you be interested in taking part?**

1            2            3            4            5

- 6. Should this study be open to all MS sufferers?**

Yes

No

Thank you for taking part, your help is greatly appreciated.

## Appendix Q: Procedure Flow Diagram

