THE UNIVERSITY OF HULL

Multiple Sclerosis: Living the Reality and Experiences of Hope

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by

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I would like to dedicate this project to my sister; Hope.

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Part One:

Are we getting it right? Experiences of living with Multiple Sclerosis:

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Overview

This thesis is divided into three parts: a meta-synthesis of qualitative research, an empirical report and appendices.

Part one is a descriptive meta-synthesis reviewing the contribution of phenomenologically informed qualitative literature regarding the lived experience of Multiple Sclerosis (MS). The meta-synthesis aimed to provide insights for healthcare professionals working in person centred MS services, in addition to reviewing literature relating to the empirical paper. Individuals living with MS have diverse healthcare needs and person centred care offers a holistic approach to meeting these needs. Six broad themes regarding the lived experience of MS were identified following synthesis of findings from seven qualitative studies. Deficits in person centred care are highlighted and implications for future service provision are discussed.

Part two is an empirical study investigating a deficit in person centred care highlighted in the meta-synthesis: the concept of hope. The study examines the subjective experience of hope by exploring what generates, diminishes, or maintains hope for individuals living with Relapsing-remitting MS (RRMS) who confront relapses and remission of MS symptoms over time. Six individuals were interviewed and interpretative phenomenological analysis (IPA) was used to identify themes from their narrative accounts of hope. The study considers the importance of family systems and relationships in the experience of hope in RRMS, in addition to exploring illness experiences which result in losing hope. Clinical implications are discussed including the role of hope-fostering interventions for individuals living with RRMS adopted from the Recovery Model currently operating in mental health services.

Part three consists of appendices relating to the research, including a reflective statement discussing the process of research from conception to results.

Part One

Are we getting it right? Experiences of living with Multiple Sclerosis:

A qualitative meta-synthesis

Are we getting it right? Experiences of living with Multiple Sclerosis: A qualitative meta-synthesis

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Abstract

Purpose. This qualitative meta-synthesis aimed to provide a descriptive, meta-understanding of the lived experience of Multiple Sclerosis (MS) to facilitate person centred interactions in MS services.

Methods. Descriptive meta-synthesis was used to synthesise findings from single phenomenologically informed qualitative studies identified through systematic searching of electronic databases and relevant journals.

Results. Seven studies were synthesised and six interrelated themes were identified including (i) the Diagnostic Experience (pre-diagnostic phase, investigation phase, reactions to diagnosis), (ii) Barriers to Stable Adjustment, (iii) Shifting Systems (family, social life, employment), (iv) Resiliently Accepting MS Over Time (v) the World of MS, and (vi) From Me to You: Guidance for Healthcare Professionals.

Conclusion. Deficits in emotional and psychosocial support were identified at diagnosis and throughout the lived experience of MS. Stigma appears to be a barrier to engaging in support services depending on the visibility or invisibility of disability associated with MS. Implications for person centred approaches to diagnosis, support, and family systems are discussed.

Keywords: Multiple Sclerosis, qualitative, meta-synthesis, person centred care, lived experience

Introduction

Multiple Sclerosis (MS) is a complex, chronic and highly variable disorder of the central nervous system (CNS), and the most common cause of neurological disability in young adults (Compston & Coles, 2008). Benign, frequently remitting, or progressive forms of MS, characterised by various unpredictable neurological symptoms, affect approximately 100,000 individuals in the UK alone (MS Trust, 2011). Following diagnosis, individuals embark on a journey of continual adjustment (Malcomson, Lowe-Strong & Dunwoody, 2009), and many confront an uncertain future of increasing disability and distress (MS Trust, 2011).

Individuals living with MS access a range of multidisciplinary healthcare services over prolonged periods (National Institute of Health and Clinical Excellence; NICE, 2003). Since MS is experienced idiosyncratically, routine interactions with healthcare professionals are crucial in meeting individual healthcare needs. Traditionally, the biomedical model has dominated MS service delivery by focussing on adherence to, and management of, symptom alleviation using disease modifying therapies (DMT). However, the Department of Health (DH) in the UK has recommended a cultural shift from traditional MS service delivery towards person centred care (DH, 2004; 2005). The person centred care approach acknowledge individuals as unique human beings who create personal meanings of illness, embedded within a systemic context of general health, wellbeing, relationships, culture, and society (Smith & Hoppe, 1991). Individuals are considered collaborative partners in identifying individual needs during healthcare interactions.

The International Alliance of Patient Organisations (IAOP), a global alliance of patient organisations representing all nationalities across all illness areas, and non- profit organisations in the US (e.g. the Institute of Medicine. the Picker Institute), have been

conducting research promoting person-centred healthcare since the 1970s (NICE, 2012). In the UK, person centred care was recommended in the National Health Service (NHS) Improvement Plan (DH, 2004), and is a Quality Requirement stated in the National Service Framework (NSF) for long term conditions, including MS (DH, 2005). A person centred service for individuals living with MS should consist of a holistic, integrated, interdisciplinary approach to care planning, reviews and service delivery (DH, 2005).

Successful person centred care relies on collaborative partnership during healthcare interactions. Healthcare professionals need to recognise the expertise arising from unique experiences of illness. However, exploration of personal illness experiences to inform what is important to individuals when receiving healthcare remains a deficit within the NHS (Leatherman & Sutherland, 2008). In MS, individuals have reported deficits in information provision, support, inappropriate attitudes and divergent perceptions of healthcare needs during interactions with healthcare professionals (Kersten, George, McLellan, Smith & Mullee, 2000). However, the value of individual illness experiences in informing commissioning decisions and shaping healthcare delivery, has been recognised recently in the UK (NICE, 2012). NHS Services are attempting to refocus attention away from those delivering services towards key aspects individuals identify as important.

In 2010, a scoping study of patient experience literature was conducted by the Royal College of Nursing (RCN) Research Institute, aiming to inform the work of the Patient Experiences Guidance Group (Staniszewska et al., 2010). Following synthesis of a complex evidence base, a Generic Patient Experience Framework identified the lived experience as a significant dimension of patient experience (Staniszewska et al., 2010). The lived experience is a common focus of qualitative research studies. Since 1994, a

significant number of qualitative studies have focussed on long term management of health conditions, including MS (Finfgeld, 2003). However, qualitative research studies remain isolated from clinical practice (Sandelowski, Docherty & Emden, 1997; Sherwood, 1999), despite being regarded as essential in developing evidence-based practice and effective person centered interventions (Sandelowski & Barroso, 2007), and in shaping health care policy (Finfgeld, 2003).

The lived experience of MS is idiosyncratic and uncertain. The causes and prognosis of MS remain undetermined in research, limiting knowledge required to live with MS. This poses a dilemma for individuals living with MS and healthcare professionals when meeting personal needs. Personal needs may shift according to emerging MS symptoms and wider systemic factors associated with healthcare services. Therefore, it is essential healthcare professionals have knowledge of the lived experience of MS to assist in person centred care interactions.

To date, there appears a paucity of research examining the contribution of published qualitative research regarding the lived experience of MS. Therefore, the current review aimed to conduct a meta-synthesis of qualitative research to provide a comprehensive and descriptive meta-understanding for healthcare professionals. The focus of the current meta-synthesis was to answer the research question 'What is the lived experience of individuals living with MS as described or interpreted using phenomenological methods of qualitative inquiry?' The question aimed to be broad enough to capture the phenomenon of interest, and sufficiently focussed to enhance meaningfulness of findings for healthcare professionals in person centred MS services.

Method of Meta-synthesis

Methods of synthesising single qualitative studies have been grouped under the term meta-synthesis defined as '…the bringing together and breaking down of findings,

examining findings, discovering essential features and in some way combining phenomena into a transformed whole…' (Schreiber, Crooks & Stern, 1997; pp. 314). The main aim of meta-synthesis is the generation of new and integrative findings that go beyond the content of original studies (Finfgeld, 2003).

Epistemological Issues

Synthesis of studies using varying qualitative methods informed by different epistemological positions and theoretical structures is a contentious issue in meta-synthesis (see Appendix A for discussion). However, inclusion or exclusion of varying qualitative methods used in studies in a meta-synthesis is dependent on the review's focus. The current review's focus was to synthesise qualitative research investigating the lived experience of MS. Focus on experience as lived, and describing this experience as a phenomenon of interest, is fundamental to phenomenological research (Finlay, 2009). In addition, small samples typically used in phenomenological research allow detailed examination of the lived experience (Walshe & Downe, 2005). Therefore, the current meta-synthesis included single studies using phenomenological informed methodology.

Descriptive Meta-synthesis

Findings from single phenomenologically informed studies were synthesised using a descriptive meta-synthesis. Descriptive meta-synthesis aims to look broadly at phenomena (for examples see Barroso & Powell-Cope, 2000; Salter, Hellings, Foley & Teasell, 2008), resulting in a comprehensive analysis of phenomena (Schreiber et al., 1997). In accordance with the descriptive intent, findings are generally not deconstructed; unaltered texts of research findings provide data for translation across studies (Schreiber et al., 1997). In the current review, data were identified as all text

labelled as results or findings in study reports, including results or findings in abstracts if different from the text (Thomas & Harden, 2008).

Procedure

Based on previously published descriptions of process (Schreiber et al., 1997), the present meta-synthesis comprised 3 steps: (i) identifying published papers for inclusion, (ii) quality appraisal and data extraction, and (iii) summarizing and synthesis.

Identifying published papers for inclusion

Search Criteria

To enhance generalizability of findings, systematic sampling of studies was conducted across disciplines (Finfgeld, 2003). Searching occurred across four electronic computer databases (PsychINFO, CINAHL, Web of Science, SCOPUS) using the following search terms examined in the title, abstract, topic or keywords of articles:

(i)   Multiple Sclerosis OR MS

        AND

(ii)   (lived AND experience) OR (subjective AND experience) OR perspective*
        OR view* OR insight* OR meaning* OR experience*

The truncation symbol (*) was used to generate alternative endings to search terms in all electronic databases. Domains of research (e.g. health science, Medline coverage, social science) and specific research areas (e.g. psychology, nursing, neuroscience, neurology), were limited depending on the database. In addition, four journals relating to the focus of the review were searched (Qualitative Health Research, Multiple Sclerosis, Multiple Sclerosis and Related Disorders and Multiple Sclerosis International).

Inclusion/ Exclusion Criteria

An inclusion and exclusion criteria was imposed on selection of articles at this stage:

Inclusion criteria

(i) Articles had to be published in peer reviewed journals due to prior assessment of quality (Finfgeld, 2003).

(ii) Articles had to written in English.

(iii) Articles must have used adult participants over the age of 18 diagnosed with MS. No upper age limit was stipulated as MS is a lifelong condition, experienced across the lifespan.

(iv) Articles must have been published between 1995 and 2012. The year 1995 was selected as Disease Modifying Therapies (DMT's) were introduced in the treatment of MS in this year (Jacobs et al., 1996).

(v) Articles must detail an attempt to explore the lived experience of MS in the title and/or abstract.

Exclusion criteria

(i) Articles using quantitative methodology and/ or mixed methodology.

(ii) Articles using samples of individuals under the age of 18.

(iii) Articles exploring the experiences of carers, family members, spouses, or healthcare professionals.

(iv) Articles which were systematic, literature, book reviews or case studies.

(v) Articles focussing on specific aspects of MS.

A total of 2073 articles were identified using search terms (Figure 1). Article titles were examined for further screening using inclusion/ exclusion criteria, and abstracts viewed if unable to ascertain the study's focus from the title. After implementation of inclusion/

exclusion criteria, 42 articles were retrieved for further examination. Fifteen duplicates were removed and the remaining 27 articles were screened using two core selection criteria (Finfgeld, 2003):

(i)   Information should be provided about the use of accepted qualitative methods.

(ii)   Findings should be supported by raw data.

In addition, upon full-text reading, three further exclusion criteria were applied:

(i)   Articles were excluded if they used a sample prior to 1995.

(ii)   Articles were excluded if funded by pharmaceutical companies. The review focussed on individuals' experiences of living with MS, and not their experiences of pharmaceutical products.

(iii) Articles were excluded if they used qualitative methodology informed by a different epistemological position than phenomenology.

Justifications for Excluded articles

Upon further examination of full-text articles, 20 articles were excluded. Eleven articles focused on specific aspects of the lived experience of MS including aging (Dilorenzo, Becker-Feigeles, Halper & Picone, 2008; Finlayson, Van Denend & DalMonte, 2005; Ploughman et al., 2012), social experience (Fong, Finlayson & Peacock, 2006), diagnosis (Koopman & Schweitzer, 1999), race and gender (Loveland, 1999), lifestyle balance (Matuska & Erickson, 2008), symptom severity (Moriya & Suzuki, 2011), wellbeing (Olsson, Skär & Söderberg, 2010), coping (Pinson, Ottens & Fisher, 2009), and quality of life (QOL; Reynolds & Prior, 2003; Somerset, Sharp & Campbell, 2002).

Three studies were excluded as they employed quantitative methodology to extract themes including likert scales (Mohr et al., 1999) and questionnaires (Pakenham, 2007;

2008). One study was excluded as no method of data analysis was provided (Courts, Buchanan & Werstlein, 2004), and one study was excluded following no information regarding qualitative methodology (Russell, White & White, 2006). One study was excluded as it used a sample obtained prior to 1995 (Quinn, Barton & Magilvy, 1995). One study used a specific model imposed on data analysis (Gagliardi, Frederickson & Shanley, 2002), and another study used carers as a source of information (Edmonds, Vivat, Burman, Silber & Higginson, 2007).

Hand-searching

References sections of the seven remaining articles were hand-searched. Following hand-searching, two articles were identified but were excluded upon closer examination as both focussed on specific aspects of MS. One article focused on incontinence management (Koch & Kelley, 1999a), and the other study focused on diagnosis (Fawcett & Lucas, 2006).

Expert Author Contact

Three authors (L. Dennison; LD, C.H. Irvine; CHI, and V. Wright-St Clair; VWS-C) were contacted. One author (CHI) no longer conducted research in MS and the other authors (LD, VWS-C), provided two additional studies of interest. However, both were excluded upon closer examination. One study was an unpublished master's thesis (Wright-St Clair, 1996), and the other focussed on psychological interventions in MS (Dennison, Moss-Morris, Yardley, Kirby & Chalder, 2013).

Final Studies included in the Review

Seven articles remained for inclusion in the review including Barker-Collo, Cartwright & Read (2006); Dennison, Yardley, Devereux & Moss-Morris (2011); Irvine, Davidson,

Hoy & Lowe-Strong (2009); Malcomson, Lowe-Strong & Dunwoody (2008); Miller

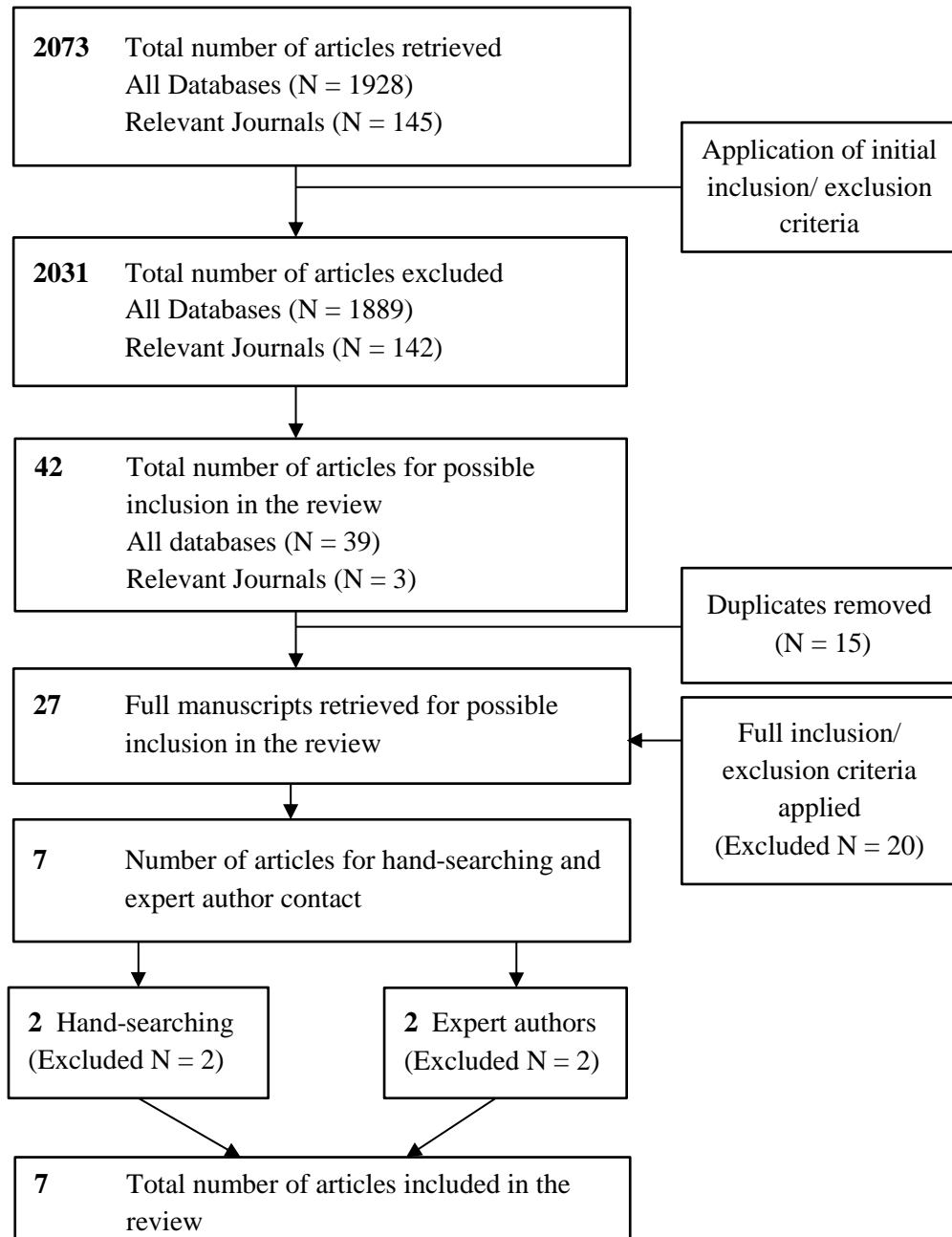(1997); Olsson, Lexell & Söderberg (2008); and Wright-St Clair (2003).

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┌─────────────────────────────────────┐
│ 2073   Total number of articles      │
│        retrieved                     │
│        All Databases (N = 1928)      │
│        Relevant Journals (N = 145)   │
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         ▼                    │ exclusion criteria   │
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│ 2031   Total number of      │
│        articles excluded    │
│        All Databases        │
│        (N = 1889)           │
│        Relevant Journals    │
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│ 42     Total number of      │
│        articles for         │
│        possible inclusion   │
│        in the review        │
│        All databases        │
│        (N = 39)             │
│        Relevant Journals    │
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│ 27     Full manuscripts     │ ┌─────────────────────┐
│        retrieved for        │←│ Full inclusion/      │
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│ 7      Number of articles   │
│        for hand-searching   │
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│ 7      Total number of      │
│        articles included    │
│        in the review        │
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Figure 1. Flow chart depicting stages of the systematic search of studies included in the

meta-synthesis.

Quality Assessment

Quality assessment of qualitative research using generic checklists remains controversial since agreement regarding quality is difficult to achieve (Murphy, Dingwall, Greatbatch, Parker & Watson, 1998). However, robust quality markers are crucial in establishing meta-synthesis as an accepted method of reviewing and synthesising qualitative research (Walshe & Downe, 2005).

Murphy et al. (1998) identified the importance of credibility and relevance when evaluating qualitative research. Mays and Pope (2000) expanded on Murphy et al. (1998) by posing seven questions to consider when assessing and evaluating the quality of single studies (see Appendix B).This quality assessment tool allows the rater to efficiently identify aspects of quality during reading and it can be easily replicated. Studies were not excluded on the basis of the quality in the current meta-synthesis. Quality assessment functioned to identify areas of strengths and weaknesses (Table 1), and was rated independently by two researchers (CB, KB) using Mays and Pope (2000) criteria. Independent ratings were combined to identify areas of discrepancy.

Credibility

All studies provided adequate descriptions of sampling strategies and data collection methods. All studies fulfilled the criteria of auditability; data analysis procedures were adequately described and studies provided raw data to support interpretations made by the researcher. However, a discrepancy emerged regarding the auditability of Miller's (1997) study investigating the lived experience of RRMS. Although Miller's (1997) study provided raw data, it was limited compared to other studies reviewed. Reflexivity and attending to negative cases were identified as areas of weakness across independent ratings of quality. Only three studies (Irvine et al., 2009; Miller, 1997; Olsson et al., 2008) attempted to capture the influence of the researcher in the research process, and

three studies provided evidence of attending to contradictory data and capturing
negative cases (Dennison et al., 2011; Miller, 1997; Olsson et al., 2008). Evidence of
fair dealing regarding the exploration of alternative and plausible explanations from a
range of perspectives was identified in all studies.

Relevance

Evidence of transferability was identified in all studies. Information was provided about
participants, settings, and context, enabling the reader to determine relevance of
findings. Six studies provided evidence of analytic generalisability. A broader context
and suggestions for future research were discussed in relation to findings. No evidence
of analytic generalisability was identified in Wright-St Clair's (2003) study.

Table 1. Results of the quality assessment.

| Study | Credibility | | | | Relevance | | |
	Data Collection	Auditability	Reflexivity	Negative Cases	Fair Dealing	Transferability	Analytic Generalizability
Barker-Collo et al. (2006)	+	+			+	+	+
Dennison et al. (2011)	+	+		+	+	+	+
Irvine et al. (2009)	+	+	+		+	+	+
Malcomson et al. (2008)	+	+		+	+	+	+
Miller (1997)	+	+	+	+	+	+	+
Olsson et al. (2008)	+	+	+		+	+	+
Wright-St Clair (2003)	+	+			+	+	

Data Extraction

Description of Studies

Studies included in the review used sample sizes ranging from 8 to 30 with a total of 103 participants (21 males; 72 females) from all seven studies. From the studies which provided diagnostic data, 40 participants were diagnosed with relapsing-remitting MS (RRMS), 18 with primary progressive MS (PPMS), and 18 with secondary progressive MS (SPMS). Two studies (Irvine et al., 2009; Wright-St Clair, 2003) did not provide specific diagnostic categories accounting for 24 individuals who had been diagnosed with MS. Age of participants ranged from 27 to 72 years and three studies were conducted in the UK, two in New Zealand, one in the US and one in Sweden. Articles had been published between 1997 and 2011. Four studies used semi-structured interviews to collect data conducted in a variety of settings including participants' homes, over the telephone, in local hospitals, MS support groups, or in MS Clinics. Data were collected in two studies using focus groups, and one study used a focus group and semi-structured interviews. Phenomenological informed approaches to data analysis included thematic analysis, interpretative phenomenological analysis, hermeneutic phenomenology, symbolic interactionism, and one study used thematic analysis and aspects of grounded theory (Table 2).

Table 2. Features of studies included for analysis.

Author (Year) Country	*n*	Participants	Setting and format for data collection	Data analysis styles reported
Barker-Collo et al. (2006) New Zealand	16	5 Males, 11 females; aged 27 to 72 years (M = 56.19 years); years of education 9 to 17years (M = 12.25 years); 12 married, 1 single, 3 widowed; 8 diagnosed with RRMS, 8 diagnosed with PPMS; average of 6 years of problems prior to diagnosis	Semi-structured interviews lasting between 1 to 2 hours. Participants were interviewed in their own homes.	Thematic Analysis (Bowling, 1997)
Dennison et al. (2011) UK	30	73.3% female 22, 26.7% males 8; 90% White British; 36.7% aged 40-49; 33.3% aged 50-59; all participants had at least Secondary Education; 63.3% married; 18 diagnosed with RRMS; 4 diagnosed with PPMS; 8 diagnosed with SPMS; all participants had been diagnosed in the last 8 years; average time	Semi-structured interviews conducted over the telephone by post graduate health research student under the supervision of the researchers lasting approximately 45 minutes	Inductive Thematic Analysis (Braun & Clarke, 2006) Aspects of Grounded Theory (Charmaz, 2006)

		since diagnosis 3.8years, range 2 months to 8 years (SD = 2.1 years); 15 were fully ambulatory, 12 limited ambulatory requiring mobility aids, 3 in wheelchairs		
Irvine et al. (2009) UK	8	1 male, 7 females; aged 36 to 63 years (M = 49 years); years since diagnosis ranged from 5 to 20 years (M = 12.8 years); years in education ranged from 10 to 19 years (M = 13.4 years); 7 unemployed, 1 retired; 6 married, 1 separated, 1 divorced; 5 had 2 children, 1 had 3 children, 2 had no children	Semi-structured focus group interview occurring at local branch of MS Society	Interpretative Phenomenological Analysis (Smith & Osborn, 2004)
Malcomson et al. (2008) UK	13	9 females, 4 males; aged 40 to 67 years (M = 54 years); time since diagnosis ranged from 6 to 30 years (M = 17 years); 6 diagnosed with RRMS. 6 diagnosed with PPMS, 1 diagnosed with SPMS; 8 were ambulant plus mobility	Two focus groups lasting 1.5 hours	Thematic Analysis (Braun & Clarke, 2006)

		aids, 3 were independently mobile, 2 were wheelchair users		
Miller (1997) USA	10	7 females, 3 males; aged 40-59 years; all participants living with RRMS between 2 to 39 years; diagnosed between the ages of 24 to 51 years; 6 employed, 1 retired, 2 housewives, 1 child minder; all White; 8 married with children	Semi- structured interviews occurred at two local MS Clinics	Colazzi Method of Hermeneutic Phenomenology Interpretation (Colazzi, 1978)
Olsson et al. (2008) (Sweden)	10	10 females all diagnosed with SPMS; ages ranged from 43 to 59 years (Md = 49 years); length of symptoms ranged between 9 to 39 years (Md = 23 years); time since diagnosis ranged from 5 to 29 years (Md = 18.5 years); 9 married, 1 cohabiting; 8 receiving disability pension, 2 in part-time work; all participants required mobility aids	Narrative approach interviews (Mishler, 1986; Sandelowski, 1991) conducted over the telephone either in participants own home or at a local rehabilitation hospital. Interviews lasted between 40 to 60 minutes	Phenomenological Hermeneutic Interpretation (Lindseth & Norberg, 2004; Ricoeur, 1976)

Wright-St Clair (2003) New Zealand	16	6 females recruited for focus group used to generate agenda of topics to explore in interviews	Phase 1: Focus group	Symbolic Interactionalism (Blumer, 1969)
		10 females purposively sampled from 30 participants selecting across age, years since diagnosis, living situation, occupational profile	Phase 2: semi-structured interviews lasting 2 hours	

Table 3. Process of meta-synthesis.

Identified Theme	Identified Subtheme	Examples of supporting themes from primary studies
The Diagnostic Experience	Pre-diagnostic phase	Pre-diagnostic stage (Barker-Collo et al., 2006); Something is wrong (distress, uncertainty and fear; Malcomson et al., 2009)
	Investigation phase	Feeling overwhelmed, The black picture (Dennison et al., 2011); Changing outlook/perceptions of adjustment and changes in self-identity and concept (Irvine et al.,

		2009); Something is wrong (distress, uncertainty and fear; Malcomson et al., 2008)
	Reactions to diagnosis	The diagnostic experience, Reactions to diagnosis, Living with MS (Barker-Collo et al., 2006); The Black Picture, Abandoned at diagnosis (Dennison et al., 2011); Reactions to being diagnosed/impact of being diagnosed with MS, Changing outlook/perceptions of adjustment and changes in self-identity and concept (Irvine et al., 2009); Getting a name (prolonged; unsupportive and unhelpful; feelings; Malcomson et al., 2008); Hope and hopelessness, Revealing/concealing, Relief at diagnosis (Miller, 1997)
Barriers to Stable Adjustment		Feeling overwhelmed, Good days, bad days, Critical incidents, Intolerable intrusions, Precarious adjustment (Dennison et al., 2011); Reactions to being diagnosed/impact of being diagnosed with MS, Changing outlook/perceptions of adjustment and changes in self-identity and concept (Irvine et al., 2009); Consequences to lifestyle (major challenges; stress; unpredictability; fear; Malcomson et al., 2008); Getting to know MS, Coping, Control, Loss, Uncertainty, Fear, Adjustment (Miller, 1997); An unrecognisable body: being directed by the ill body (Olsson et al., 2008); MS as an aggressor, MS as a guest (Wright-St Clair, 2003)
	Family	

Shifting Systems		Living with MS (Barker-Collo et al., 2006); Relationships and dependency (Irvine et al., 2009); Consequences to lifestyle (interpersonal; unchanging family relationships Malcomson et al., 2008); Social network, Revealing/ Concealing, Conflict (Miller, 1997); An unrecognisable body: having the will but finding it troublesome to perform, An unrecognisable body: a feeling of being perceived as different, Trying to maintain power: having the strength to fight. Trying to maintain power: seeing possibilities in life (Olsson et al., 2008)
	Social Life	Living with MS (Barker-Collo et al., 2006); Managing others responses, Learning to accept help, Adapting social and leisure activities (Dennison et al., 2011); Reactions to being diagnosed/impact of being diagnosed with MS, Social activity (Irvine et al., 2009); Consequences to lifestyle (social adjustments; Malcomson et al., 2008); An unrecognisable body: Being directed by the ill body (Olsson et al., 2008)
	Employment	Social activity (Irvine et al., 2008); Consequences to lifestyle (changing employment circumstances; Malcomson et al., 2008); Conflict (Miller, 1997); An unrecognisable body: being directed by the ill body, Trying to maintain power: having the strength to fight (Olsson et al., 2008)

Resiliently	Living with MS (Barker-Collo et al., 2006); Managing symptoms, Good management,
Accepting MS	Adapting social and leisure activities, A process that takes time, Stages, Being Positive, Don't
Over Time	dwell, Focus on can, not can't, Not giving in, Keeping a normal life, Doing something
	valuable, Arming self with information (Dennison et al., 2011); Social activity, Changing
	outlook/perceptions of adjustment and changes in self-identity and concept, Attitude and
	relationships with others (Irvine et al., 2009); Getting on with day to day life (proactivity;
	perspective; control via self-management; acknowledge feelings; use it or lose it; social
	interaction; stress management; information is empowering) , Advice for others with MS
	(self-management and perspective; Malcomson et al., 2008); Coping, Getting to know MS,
	Adjustment, Hope and Hopelessness, Control, Uncertainty, Social Network (Miller, 1997);
	Trying to maintain power: seeing possibilities in life, Trying to maintain power: having the
	strength to fight, An unrecognisable body: being directed by the ill body (Olsson et al., 2008);
	MS as a saviour, MS as a partner, MS as an adversary (Wright-St Clair, 2003)
The World of MS	Living with MS (Barker-Collo et al., 2006); Helpful interactions, Having help at hand,
	Having support, Joining or avoiding the cripple club, The spectre of what might happen, Not
	relating, Experiencing and avoiding stigma (Dennison et al., 2011); Reactions to being

	diagnosed/impact of being diagnosed with MS, Social activity, Attitude and reactions of others (Irvine et al., 2009); Getting on with day to day life (social interaction), Advice for others with MS (self-management and perspective; Malcomson et al., 2008); Social network, Coping, Uncertainty, Getting to know MS, Revealing/ concealing (Miller, 1997); An unrecognisable body: having the will but finding it troublesome to perform, An unrecognisable body: a feeling of being perceived as different, Trying to maintain power: having the strength to fight, Trying to maintain power: seeing possibilities in life (Olsson et al., 2008)
From Me to You: Guidance for Health Professionals	The diagnostic experience, Reactions at diagnosis (Barker-Collo et al., 2006); Attitude and reactions of others (Irvine et al., 2009); Advice for others with MS (self-management and perspective), Advice for health professionals (personal needs; guidance and information; expert patient and peer support), Getting a name (prolonged, unsupportive and unhelpful; feelings), Getting help (lack of social support; Malcomson et al., 2008); Hope and hopelessness, Relief at Diagnosis, Conflict, Getting to know MS (Miller, 1997); Trying to maintain power: having the strength to fight, Trying to maintain power: seeking answers to unpredictability (Olsson et al., 2008)

Results

Synthesis of Identified Themes

Findings from the seven studies included in the meta-synthesis were synthesised using a descriptive meta-synthesis method. Six themes emerged regarding the lived experience of MS, supported by themes (Table 3) and raw data from primary studies in the form of quotes:

(i)   The Diagnostic Experience (pre-diagnostic phase, investigation phase, reactions to diagnosis)

(ii)   Barriers to Stable Adjustment

(iii)   Shifting Systems (family, social life, employment)

(iv)   Resiliently Accepting MS Over Time

(v)   The World of MS

(vi)   From Me to You: Guidance for Health Professionals

The Diagnostic Experience

Three distinct phases regarding the diagnostic experience emerged within findings; the pre-diagnostic phase (Barker-Collo et al., 2006; Malcomson et al. 2008), the investigation phase (Dennison et al., 2010; Irvine et al., 2009; Malcomson et al, 2008), and reactions to diagnosis (Barker-Collo et al., 2006; Dennison et al., 2010; Irvine et al., 2009; Malcomson et al., 2008; Miller 1997).

Subtheme: The Pre-Diagnostic Phase

Noticing various physical changes intruding on daily life preceded seeking help (Malcomson et al., 2008). Physical changes appeared unrelated until reaching a specific threshold, prompting individuals into connecting them into a coherent yet unlabelled problem:

'I had been having these weird symptoms for some time….I began to realise that these things may have been connected.' (Barker-Collo et al., 2006; p. 437)

Realisation of an unlabelled problem was associated with anxiety, confusion, panic, fear and a tendency to think the worse (Barker-Collo et al., 2006; Dennison et al., 2011; Irvine et al., 2009; Malcomson et al., 2008).

Subtheme: The Investigation Phase

Emotional changes motivated individuals into actively seeking explanations for the unlabelled problem. Seeking explanations was accompanied by overwhelming feelings of distress, anxiety, uncertainty, fear of the unknown and impending doom (Barker-Collo et al., 2006; Dennison et al., 2011; Irvine et al., 2009; Malcomson et al., 2008 Miller, 1997):

'I thought: My god what's wrong with me?' (Barker-Collo et al., 2006; p. 437)

At this stage, individuals expressed feeling abandoned by professionals. This related to difficulties in defining symptoms, being given incorrect diagnoses, or by professionals concealing diagnoses of MS (Barker-Collo et al., 2006; Miller, 1997):

'I don't think I actually got told: "You have MS." It was more like, well, you don't have any of these other things that it could be, so the only thing else is MS.' (Barker-Collo et al., 2006; p. 437)

Others passively waited for news or were forced to actively pursue investigation results:

'I phoned the hospital and said that I had been waiting nearly a year for my results!' (Malcomson et al., 2008; p. 666)

Subtheme: Reactions to Diagnosis

Mixed emotional reactions were experienced within an atmosphere of *'doom and*

gloom' (Miller, 1997; p. 298) and hopelessness around the time of diagnosis (Barker-Collo et al., 2006; Dennison et al., 2011; Miller, 1997). Individuals who experienced prolonged periods of symptoms, or who had been given numerous labels, reacted with relief associated with rejecting private fears of terminal illness (Irvine et al., 2009; Miller, 1997). Relief was also associated with a sense of closure, helping individuals to move forward and survive:

'I was delighted because I knew what it was, it wasn't a life threatening illness and I could get on and battle with it.' (Malcomson et al., 2008; p. 666)

Others suspicious of MS were unsurprised, and some looked upon diagnosis with a sense of hope (Irvine et al., 2009; Malcomson et al., 2008). Conversely, powerful negative emotional reactions were overwhelming reported. Shock and fear of the unknown induced a deluge of emotion, forcing individuals to confront the life changing news (Barker-Collo et al., 2006; Malcomson et al., 2008):

'I felt mostly scared….I mean, you hear the words multiple sclerosis and they tell you what that might mean, but you really don't know.' (Barker-Collo et al., 2006; p. 438)

Diagnosis also diminished feelings of self-worth, self-esteem and attractiveness. One female described how she felt she was '*not the girl he* [husband] *married anymore'* (Irvine et al., 2009; p. 602), and another individual described how diagnosis '*robs you of your confidence'* (Irvine et al., 2008; p. 602):

'*You have fears in your mind, your self-esteem goes completely; you feel less attractive.' (*Malcomson et al., 2008; p. 666)

Individuals described not knowing how and when to reveal the diagnosis to significant others, resulting in prolonged concealment. Concealment was conceptualised as denial which was maintained within immediate systems around individuals (Miller, 1997).

Barriers to Stable Adjustment

The adjustment period varied among individuals. Adjusting to the uncertain experience of MS was challenging, conceptualised in one article as:

'*It is always there and it can crop up at any time…you are just conscious of it, being in the background….it can sneak in the back door.*' (Wright-St Clair, 2003; p. 50)

Although individuals achieved an acceptable quality of life, the experience of good and bad days meant quality of life fluctuated and depended on the presence or absence of symptoms (Dennison et al., 2011; Malcomson et al., 2008; Miller, 1997):

'*You catch them on one of their off days, things would look different*' (Irvine et al., 2009; p. 604).

Uncertainty associated with the potential for future catastrophe became a frightening expectation and interrupted living with MS:

'*Uncertainty yes, that's difficult to manage as you can't plan ahead. That's the big one because you don't know how you will feel.*' (Malcomson et al., 2008; p. 668).

Future related threats were perceived as intolerable and individuals doubted their perceived ability to cope with threats in reality e.g. losing the ability to walk, drive or live independently (Dennison et al., 2011). However, individuals who had encountered threats in reality coped and adapted which contributed to positive adjustment. Fear associated with anticipating loss of physical abilities and future relapses, was a barrier to successful adjustment (Miller, 1997; Olsson et al., 2008; Wright-St Clair, 2003). Anticipating the possibility of future relapse created a sense of powerlessness and difficulty in keeping relapses in perspective:

'*That's a fear; will I be able to make it?* (Malcomson et al., 2008; p. 886)

Significant fears included the overwhelming threat of accepting a wheelchair ('*I was scared, the wheelchair was beckoning';* Malcomson et al., 2008; p. 668)*,* of increasing dependency, and the dread of feeling unable to trust the declining body (Dennison et al., 2011; Irvine et al., 2009; Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008). These fears led to insecurity:

'*You get insecure in yourself many times . . . I try. . . Can I manage this . . . will I have enough strength to walk that distance. . . '.* (Olsson et al., 2008; p. 421)

Shifting Systems

The impact of MS moved beyond boundaries surrounding the individual. Significant systems were implicated in the adjustment process by accommodating changes brought about by the intrusion of MS. Three distinct systems were discussed including the family system, social life and employment.

Subtheme: Family

A supportive family system was crucial to living with MS. Although some individuals described MS having no impact on family life (Malcomson et al., 2008), MS was generally considered an intrusive family member which demanded adaptation (Barker-Collo et al., 2006; Irvine et al., 2009; Miller, 1997; Olsson et al., 2008). Partners provided the most physical, emotional and financial support. Those individuals divorced or single received help from intergenerational family members e.g. children or parents (Irvine et al., 2009; Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008). The family system empowered individuals to continue in their family role, especially those with children:

'*The children have been my reason to struggle…'* (Olsson et al., 2008; p. 423)

A lack of support was a significant concern despite individuals facing a dilemma of needing support but feeling conflicted about accepting support (Irvine et al., 2009; Miller, 1997; Olsson et al., 2008). Accepting support enabled individuals to take a larger role in life (Irvine et al., 2009; Miller, 1997), but also induced feelings of guilt and failure of being unable to participate actively in family life:

'*It's hard for the children when I feel like this….Yes it's….Mum does not feel right, Mum cannot walk,…Mum cannot….manage….It feels like a failure in a way.*' (Olsson et al., 2008; p. 421)

Fear of being a burden and dependent on others to meet basic needs, yet wanting to meet personal needs independently, was a contentious issue between individuals and caregivers (Irvine et al., 2009; Miller, 1997; Olsson et al., 2008). Individuals described needing to engage in completing everyday tasks despite caregivers finding it difficult to witness loved ones struggle (Irvine et al., 2009; Olsson et al., 2008):

'*This is my problem with my husband. He's too helpful and I'm afraid with his help I'm going to lose what I can do.*' (Miller, 1997; p. 297)

Barriers to engaging in everyday tasks imposed by caregivers resulted in feelings of resentment, tension, and concealment. Although support from caregivers was appreciated, some individuals felt their caregivers were *'killing them with kindness'* (Irvine et al., 2009; p. 603).

Subtheme: Social Life

A concerted effort was required to adapt behaviour and communication to continue engaging in social life (Dennison et al., 2011; Malcomson et al., 2008). New boundaries were created around social life regarding the impact of physical difficulties associated with MS:

'My social life? I don't know, it has been affected, of course it has . . . MS means things do change.' (Malcomson et al., 2008; p. 667)

Effortful planning of activities helped to accommodate physical limitations such as bladder and bowel problems and fatigue (Malcomson et al., 2008; Olsson et al., 2008). Crowded public places were avoided and individuals described needing to apologise to others if their difficulties were exposed in public (Irvine et al., 2009). Aspects of the physical environment were exploited to accommodate physical limitations such as using a trolley to maintain stability in supermarkets (Irvine et al., 2009).

Coping strategies such as having a sense of humour, pacing and knowing personal limitations assisted in engaging in social life (Malcomson et al., 2008). However, social life was accompanied by isolation, being ignored, and loneliness:

'It can feel really lonely to be stuck with this disease. I sometimes feel that I am alone in the world.' (Barker-Collo et al., 2006; p. 440)

In addition, individuals perceived being viewed and communicated to differently despite feeling like the same person on the inside:

'They [people] *don't know how to address you'* (Olsson et al., 2008; p. 422)

Subtheme: Employment

Employment was important in enabling individuals to make a contribution to society, in maintaining a sense of purpose and direction to daily life, and for financial reasons:

'My job is so important to me . . . If you take away your job you take away your life. I compromise and work part time.' (Malcomson et al., 2008; p. 668)

Working for as long as possible was desirable and even when physical limitations impacted on employment, individuals attempted to compromise by adapting e.g. going

part-time and/ or using assistive workplace devices (Malcomson et al., 2008). Decisions to leave employment were motivated by the impact of physical limitations and fatigue on other valued priorities in life (Irvine et al., 2009):

'*I gave up work five years ago because I wanted to have a life.*' (Malcomson et al., 2008; p. 668)

Employers were generally described as understanding however, some individuals described fighting employers to remain in the workplace, and some felt ostracised by the world of work (Irvine et al., 2009; Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008).

Resiliently Accepting MS Over Time

Learning to live with, and accept MS was a unique process which took time (Dennison et al., 2011; Irvine et al., 2009; Miller, 1997). Time facilitated acceptance and experience of still being able to accomplish within society (Irvine et al., 2009). Shifting priorities and values encouraged a deeper appreciation of life, and a living for today attitude indicated a shift in the perception of time itself (Barker-Collo et al., 2006; Irvine et al., 2009; Olsson et al., 2008):

'*You have to get into a different mind-set, take every day at a time.*' (Malcomson et al., 2008; p. 669)

'*You suddenly notice that the grass is green whereas you didn't have time before.*' (Irvine et al., 2009; p. 604)

Over time, an inner strength was discovered assisting in sustaining a stubborn fighting spirit and a proactive, positive mental attitude towards MS (Dennison et al., 2011; Irvine et al., 2009 Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008; Wright-St Clair, 2003):

'*You can't give into it....You have to fight it kicking and screaming, don't give in.*'
(Malcomson et al., 2008; p. 669)

A proactive positive mental attitude influenced perceptions of self-managing MS by
enabling individuals to access research, alternative avenues of support, and appropriate
and positive information (Malcomson et al., 2008). Proactivity appeared to empower
individuals to actively change aspects of MS management e.g. changing GP's, engaging
in befriending services, and accessing various sources of information:

'*I learnt from the library, woman's magazines and so on. I met another MS sufferer at
hospital and between the two of us we worked it out together.*' (Malcomson et al., 2008;
p. 669)

Feeling empowered to self-manage facilitated the development of practical coping
strategies such as planning and structuring daily tasks, keeping mentally and physically
active, being realistic, pacing, and listening to the body (Dennison et al., 2011; Irvine et
al., 2009; Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008). In addition,
accepting good and bad days facilitated a sense of control over the illness experience.
Overcoming barriers was associated with maintaining a sense of hope (Miller, 1997;
Olsson et al., 2008). Hope was associated with not deteriorating and the ability to
control MS using medical interventions and alternative treatments (Olsson et al., 2008).
Future hopes included accessing appropriate palliative care (Olsson et al., 2008) and
although hope for a cure was expressed, this was acknowledged as an unrealistic
expectation:

'*There's always hope but you need to be realistic.*' (Malcomson et al., 2008; p. 670)

Spirituality, faith in God, humour, avoidance of attributing blame to others and of
grieving for things outside one's control, compensated feelings of depression and

uncertainty (Irvine et al., 2009; Miller, 1997), in addition to being open and honest about feelings:

'*I think the emotional side of MS is different from the medical side, people with MS need to talk about their fears.*' (Malcomson et al., 2008; p. 669)

The World of MS

Recently diagnosed individuals, those minimally impaired, the young, or those in the early stages of MS felt overwhelmed when attending MS support groups (Dennison et al., 2011; Irvine et al., 2009; Miller, 1997). Avoidance and distancing from MS support groups functioned to protect individuals from threatening reminders of disability (Dennison et al., 2011; Miller, 1997). Threatening reminders such as witnessing decline in others with MS, seeing wheelchairs, and information about mobility aids, was unhelpful in dealing with the practical and emotional aspects of MS (Dennison et al., 2011). Fear accompanied threatening reminders maintained by encountering negative MS stereotypes:

'*It frightened me. And again it brought up the spectre of what would happen if it all went, if it all progressed and I ended up having to use this or having to do that. What would life be like?*' (Dennison et al., 2011; p.483)

However, engaging positively with the MS world facilitated acceptance through the advantages of increased social support, mutual sharing of experiences with understanding others, the accessibility of superior and different perspectives and confrontation and dismissal of worries (Dennison et al., 2011; Irvine et al., 2009; Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008):

'*Everybody understands and everybody knows*' (Irvine et al., 2009; p. 602).

For some, MS support groups provided a sense of belonging but not for those who displayed no outward visible signs of MS. Some individuals refused to become too involved with MS groups to maintain a normal life and to delay shifting towards a life based around MS (Dennison et al., 2011). Perceived stigma associated with MS was reduced by attending MS support groups although noticing disability provoked distancing from a perceived undesirable group (Dennison et al., 2011).

Stigma extended beyond MS support groups and manifested as symbols of disability revealing difference to the world. The outside world was described as lacking understanding about MS (Irvine et al., 2008; Miller, 1997), with public perceptions of MS as a contagious disease still lingering:

'*People can be really weird about these things, worried that they could catch it or something*' (Barker-Collo et al., 2006; p. 439)

This led to individuals concealing MS which was easy for those with less visible signs, yet those who appeared healthy were perceived as illegitimately using the sick role (Barker-Collo et al., 2006; Miller, 1997). Stigma associated with visible signs of MS including mobility aids was managed using reframing e.g. reframing a walking stick as a hiking stick (Dennison et al., 2011; Irvine et al., 2009). However, stigma associated with walking aids discouraged individuals from using them. Avoiding the use of walking aids resulted in others perceiving individuals as drunk (Irvine et al., 2009), and increased fatigue which impacted on valued activities and relationships:

'*If you take a stick out, people look at you and think you're disabled and some people have a problem with that. I grapple with that sometimes, I actually won't take a stick out unless I really, really have to.*' (Dennison et al., 2011; p. 484)

Accepting the use of aids was a significant event but one which permitted possibility by allowing individuals to conserve energy to use in valued activities (Dennison et al., 2011; Olsson et al., 2008).

From me to you: Guidance for Healthcare Professionals

Individuals living with MS were keen to offer advice to healthcare professionals regarding neglected needs identified through their personal experiences (Barker-Collo et al., 2006; Irvine et al., 2009; Malcomson et al., 2008; Miller, 1997). Posing the question of what might be helpful was appreciated:

'*This is good what you're doing today, you see, people don't ask.*' (Malcomson et al., 2008; p. 671)

The diagnostic experience was identified as emotionally frustrating, disempowering, prolonged and lacking in reassurance (Barker-Collo et al., 2006; Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008). The conversation imparting the diagnosis was remembered as a significant and emotional event, highlighting the long-term impact of this conversation:

'*I was left to stew basically.*' (Malcomson et al., 2008; p. 667).

Powerlessness was associated with an overly medical diagnostic approach to diagnosis lacking in sensitivity, empathy and understanding. This led to lasting negative impressions of GPs and neurologists and feelings of isolation and abandonment from the medical team (Barker-Collo et al., 2006; Malcomson et al., 2008).

The emotional impact of MS was regarded as an unaddressed need. Many described how GPs focussed on physical aspects of MS with minimal information offered to understand how to cope with MS (Malcomson et al., 2008). Offering counselling to assist in adjusting and accepting MS was suggested, although individuals were sensitive

to inferences around the word counselling and its association with mental illness (Malcomson et al., 2008). Therefore the label of emotional support appeared as important as the provision of support:

'*I don't think they should call it counselling because that scares people off.*' (Malcomson et al., 2008; p. 670)

Individuals requested emotional support is delivered by someone who lives with MS to facilitate empathy often lacking during healthcare interactions. In addition, one individual suggested *'group work was great'* (Malcomson et al., 2008; p. 671):

'*You cannot describe it* [meeting others with MS]. . . . *It's like heaven in some way to meet others with the same* [experience of illness]. *You can recognize yourself all the time and things* (Olsson et al., 2008; p. 423)

A lack of psychosocial support was identified leading to dissatisfaction with healthcare professionals and services, and maintenance of worry (Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008). Individuals discussed having an easier life if they felt understood by professionals and how seeing a specialist helped to imagine a brighter future (Miller, 1997; Olsson et al., 2008). Professionals projecting a sense of hope was important in addition to honesty, sincerity, and meeting individual needs holistically to avoid being left with unanswered questions (Miller, 1997; Olsson et al., 2008).

Provision of information was identified as important in maintaining autonomy, to aid in adjustment, in explaining MS, and in coping with fatigue and depression (Barker-Collo et al., 2006; Malcomson et al., 2008; Miller, 1997; Olsson et al., 2008):

'*I think it would have been useful to have been given some written-down information from the specialist, but he was such a busy guy.*' (Barker-Collo et al., 2006; p. 437)

Individuals requested information and guidance on exercise, alternative therapies, and the need for an access point for information (Barker-Collo et al., 2006; Malcomson et al., 2008; Miller, 1997). Information functioned to dismiss worries if it was realistic, tailored to the individual using a variety of formats and provided at the right time (Barker-Collo et al., 2006; Malcomson et al., 2008).

Discussion

The current descriptive meta-synthesis aimed to provide a comprehensive, meta-understanding of the experience of living with MS to facilitate person centred healthcare interactions in MS services. By examining and integrating findings from qualitative studies using phenomenological informed methods, common themes emerged, despite MS being a highly variable and idiosyncratically experienced illness. Themes reported in the current meta-synthesis have major implications on person centred MS services.

The provision of emotional and psychosocial support was identified as an unmet need especially at diagnosis, highlighting deficits in person centred care provision. Barriers to providing person centred care at diagnosis may be associated with diagnostic approaches. Guidelines in the UK recommend diagnoses of MS be delivered by neurologists or experienced specialists in MS (NICE, 2003). Historically, this group of professionals have adopted a biomedical diagnostic approach, emphasising physical treatment needs rather than emotional and psychosocial needs (Johnson, 2003; White, White & Russell, 2007). In addition, misunderstandings may arise from the use of medical language typically used in biomedical approaches, therefore reducing the likelihood of establishing good rapport to facilitate future person centred care interactions (White et al., 2007).

An alternative to biomedical diagnostic approaches is the Person Centred Integrative Diagnosis model (PID; cited in Salloum & Mezzich, 2010). This model regards

diagnosis as an interactive and formulatory process, involving partnerships between clinicians, patients, families and communities, to contextualise ill health and positive health needs (Salloum & Mezzich, 2010). However, implementing the PID model in MS services may be problematic as biomedical approaches dominate MS healthcare and research. Therefore, person centred care may represent a paradigmatic shift in which services may resist or require time to accommodate and implement change (Salloum & Mezzich, 2010).

Economic barriers may influence the feasibility of adopting person centred care in MS services, particularly in countries providing government funded healthcare services (e.g. NHS in the UK). Despite increased demand for healthcare services in the UK, the impact of national and global economic recessions means monetary resources are dwindling. Costs associated with advances in medical treatment for MS could increase the economic burden on services in the future. In addition, time may be a barrier to facilitating person centred care, especially in high demand services, as person centred care requires time to explore diverse needs.

Reducing economic barriers to person centred care implicates the role of multidisciplinary services in meeting personal needs holistically. Effective communication and direct referral systems to specialist mental health services could provide avenues of emotional and psychosocial support. However, when counselling was mentioned in the current meta-synthesis, the label 'counselling' raised concerns regarding its association with mental illness. Applying additional labels to individuals living with MS, who are already aware of not meeting social norms, can have negative consequences, especially on identity (Quicke & Winter, 1994; Telford, Kralik & Koch, 2006). Labelling support positively e.g. support to facilitate coping and building on

resilience, in addition to providing information to make informed decisions, may influence decisions to engage.

The process of re-labelling support raises the impact of stigma in the experience of living with MS. Stigma is experienced within social contexts, arising from negative social interactions with others who perceive individuals as deviating from socially desirable norms (Joachim & Acorn, 2000). Stigmatising attributes such as visible signs of disability associated with MS are harder to conceal, increasing the likelihood of experiencing stigma. Stigma also appeared to influence engagement in support services. Research suggests increasing support from trusted and selected others e.g. MS peers, helps to manage stigma, reduces distress, depression, and anxiety, and improves self-efficacy by experiencing a sense of belonging to a group sharing similar attributes (Goffman, 1963; Joachim & Acorn, 2000; Lincoln et al., 2011). Therefore, for individuals with visible signs of MS, approaching and engaging in support groups may facilitate management of stigma. In addition, visible signs of MS may be associated with progression and as MS progresses, individuals may need increased support.

However, the impact of MS can also be invisible. Findings from the current meta-synthesis associate the invisibility of MS (e.g. those minimally impaired) with avoidance and distancing from engaging in support groups. These strategies may allow individuals to normalise perceived stigmatised attributes (Becker, 1981). Individuals who display no visible signs of MS, who are minimally impaired, or who have good mental health may not benefit from MS support groups, where individuals are confronted with visible threats of future disability (Messmer Uccelli, Mancuso Mohr, Battaglia, Zagami, & Mohr, 2004). Person centred care could provide individualised approaches to support including the management of stigma, despite stigma being a part of the experience of living with MS.

The current meta-synthesis implicates the role of systems in facilitating or impeding adjustment to MS. Responsive, supportive, hopeful, and understanding healthcare professionals, families, and employers, facilitated a resilient and enduring capacity to adapt and cope with MS. Family were a major source of support however, as MS progresses over time, the burden of care on families increases. Caregivers are at risk of physical, psychological, social and financial difficulties (Kouzoupis, Paparrigopoulos, Soldatos & Papadimitriou, 2010).

Individuals are placed at the centre of care using a person centred approach which potentially neglects systemic factors. However, individual needs exist within a systemic context thus allowing a person centred approach to identify individual and systemic needs. Research implicates the role of psychologically informed therapies to address the systemic impact of MS. Providing individualised cognitive behavioural therapy (CBT) for individuals living with MS with comorbid depression or anxiety has been found to have a systemic impact (Moss-Morris et al., 2009; Thomas, Thomas, Hillier, Galvin & Baker, 2006). Problem focussed time limited therapy has had positive outcomes for individuals and families living with MS in addition to systemic family therapy and couple therapy (Bogosian, Moss-Morris, Yardley & Dennison, 2009; Campbell & Patterson, 1995).

Limitations

The method of qualitative meta-synthesis remains ill-defined. In addition, assessing the quality of studies included in a meta-synthesis remains controversial. Methodological limitations and controversy associated with assessing quality limits the ability to replicate meta-syntheses. However, the current meta-synthesis minimised these limitations by conducting a broad, systematic search of literature to avoid exclusion of potentially valuable data, by explicitly stating inclusion/ exclusion criteria, and by

reporting and comparing quality rated independently by two researchers. Individuals living with MS may best assess the credibility of interpretations in the current meta-synthesis, but a peer-review of analysis was not undertaken. In addition, individuals participating in primary studies were able to answer questions posed in an interviews and therefore, may represent a group of individuals with no significant cognitive impairments associated with MS.

Future Research

Future research could identify barriers and facilitators of person centred care cross culturally, in countries providing private or government funded healthcare systems. Identifying barriers and/ or facilitators from different healthcare systems implementing person centred care may help in reducing economic factors or improving the efficiency of services. Future research could also identify barriers and/ or facilitators to engaging in MS support groups. Although the current meta-synthesis contextualised stigma as a barrier to engagement, the impact of visible and invisible signs of MS and engagement in support remains unclear. Qualitative research methods could explore the experience of stigma in those experiencing visible or invisible signs of MS.

In addition, future research needs to identify effective and person centred emotional and psychosocial interventions which attempt to reduce stigma and the impact of future-related threats, especially at diagnosis. Lastly, healthcare professionals projecting a sense of hope for the future was important (Miller, 1997; Olsson et al., 2008; Solari et al., 2007; White, et al., 2007). Future research could explore the experience of hope for individuals to identify why projecting a sense of hope is important in living with MS.

Clinical Implications

Findings from the current meta-synthesis were derived from 'bottom up' individual experiences, not 'top down' bureaucratic guidance or service protocols. Therefore, the

findings detail an attempt to capture what individuals identify as important. In practice, the current meta-synthesis could provide healthcare professionals with awareness of specific needs during healthcare interactions.

Service gaps have been identified through the process of meta-synthesis, including emotional and psychosocial support, and the need for effective communication and efficient referral systems for multidisciplinary services. A shift from biomedical approaches in MS services supports recommendations regarding person centred care, and changing diagnostic approaches may reduce the negative emotional impact of an MS diagnosis. Positive experiences of services, including healthcare professionals projecting a sense of hope for the future, may function to provide a foundation of rapport needed for future engagement.

Meeting individual needs using tailored support or care plans may facilitate reducing the impact of stigma in MS, in addition to helping individuals access support when they are ready and according to their stage of MS. Clinical implications acknowledged in the current meta-synthesis would assist in the revision of clinical guidance regarding the management of MS in adults in the UK (National Institute of Health and Clinical Excellence; NICE Final Scope, 2012).

Conclusions

In conclusion, the current meta-synthesis has contributed a descriptive, meta-understanding regarding the experience of living with MS. By identifying themes, this meta-synthesis has identified barriers and facilitators in the provision of person centred care and neglected needs in MS. These findings can be used to facilitate person centred care to meet individual needs holistically whilst being able to attend to issues of difference and diversity. Responsive, understanding, and hopeful communication and interaction between individuals living with MS and healthcare professionals ultimately

maintains dignity and respect. Therefore, person centred care is an important approach, identifying and maintaining what is important for individuals living with MS as human beings, and not what is important for the illness they embody.

Declarations of Interest

The authors report no declarations of interest.

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Part Two

A Qualitative Study of Experiences of Hope in Relapsing-Remitting Multiple Sclerosis

A Qualitative Study of Experiences of Hope in Relapsing-Remitting Multiple Sclerosis

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Abstract

Purpose. This qualitative study aimed to explore the experience and meaning of hope for individuals living with Relapsing-remitting Multiple Sclerosis (RRMS).

Methods. Semi-structured interviews were used to obtain narrative accounts from six individuals living with RRMS and data was analysed using Interpretative Phenomenological Analysis (IPA).

Results. Participants identified similar themes regarding the experience of hope in RRMS. Four superordinate themes and 11 subthemes were identified: (i) Ingredients of Being Hopeful (Subthemes: hopeful foundations; personal resources, catalyst of hope), (ii) Hopelessly Disconnected (Subthemes: the punishment of diagnosis, cruel relapses, menacing reminders) versus Hopefully Connected (Subtheme: you can't hope on your own), (iii) the Goldilocks Zone of Hope (Subthemes: staying just right, great expectations), and (iv) Hoping and Coping (Subthemes: taking the long view, valuable anchors versus releasing the shackles).

Conclusion. Findings suggest the experience of hope for individuals living with RRMS develops early in life, is generated and maintained individually and systemically, and can be temporarily lost when confronting existentially disconnecting illness experiences. The implications of hope and relationships are discussed regarding MS services and healthcare professionals.

Keywords: Multiple Sclerosis, hope, adjustment, qualitative, lived experience, coping

Introduction

Relapsing-remitting Multiple Sclerosis (RRMS) is a chronic, lifelong and neurodegenerative disease of the central nervous system (CNS), characterised by unpredictable relapsing and remitting patterns of neurological symptoms (Lublin & Reingold, 1997). In the UK, RRMS affects 85% of 100,000 individuals diagnosed with MS (MS Trust, 2011), and is a common cause of neurological disability affecting young adults (Compston & Cole, 2008).

Following diagnosis, individuals confront an uncertain future of relapses, increasing disability, and distress (MS Trust, 2011). During periods of relapse, pre-existing symptoms are exacerbated and/ or new MS symptoms emerge causing new disabilities (Thomas, Thomas, Hillier, Galvin & Baker, 2006). Although pharmacological interventions (e.g. steroids, disease modifying therapies; DMT) aim to reduce relapse severity and frequency, no cure exists for RRMS (Thomas et al., 2006). In addition, pharmacological interventions do not change accumulated disabilities, and have dubious effects on long term outcomes (Compston & Cole, 2008).

Onset of RRMS occurs between the ages of 20 and 40, impacting on the most productive years of life (Halper, 2010). Over time, individuals negotiate contrasting perspectives of relapse and remission of physical symptoms whilst confronting changing perceptions of the self, relationships and roles, threats of dependency and disability, and limited options for controlling the uncertain illness experience. Unsurprisingly, comorbid mental health difficulties, including depression and anxiety, are prevalent in MS (Chwastick et al., 2002; Noy, et al., 1995; Sadovnik et al., 1996).

However, positive adjustment to RRMS, conceptualised as fostering a positive outlook on life in spite of MS (Marks & Millard, 1990), can be a realistic goal and appears to be motivated by psychological factors rather than physical aspects of MS (Irvine,

Davidson, Hoy & Lowe-Strong, 2009; Malcomson, Lowe-Strong & Dunwoody, 2008). Since options for physically managing RRMS are limited, psychological factors facilitating positive adjustment are crucial and require further investigation.

The universally and subjectively valued phenomenon of hope (Parse, 1999; Seligman, 2005) was recently identified as a beneficial cognitive related adjustment factor in a review of psychosocial correlates of adjustment in MS (Dennison, Moss-Morris & Chalder, 2009). A focus of positive psychology, hope has been conceptualised as a fulfilling cognitive, emotional, and motivationally based belief or expectation regarding the future, incompatible with anxiety and depression, and a human strength and buffer against illness (Peterson & Seligman, 2004; Sheldon & King, 2001).

A conclusive, all-encompassing definition of hope currently eludes research (see Appendix C for a discussion of hope). However, two dominant research discourses defining hope exist. In psychology, the definition of goal directed hope defines hope as a positive goal-related motivational state, activated and utilised in creating agency in finding pathways to achieve personally significant goals (Snyder, 2000; 2002). In contrast, definitions of generalised hope define hope as a multidimensional life force and a complex state of being (Dufault & Martacchio, 1985; Miller, 2007).

Using definitions of goal directed hope or generalised hope in research typically influences choice of research methodology. Quantitative research uses quantifiable measures of hope to establish relationships between hope and variables of interest and/ or to identify hope as a precursor to effective intervention (Farran, Herth & Popovich, 1995). In MS, quantitative investigations of hope have reported conflicting evidence regarding the role of hope and depression. Low hope and hopelessness were associated with depression in MS (Hickey & Greene, 1989; Patten & Metz, 2001), yet hope was found to neither mediate nor moderate a relationship between disability and depression

in another study (Lynch, Kroencke & Denney, 2001). Higher perceived levels of social support and self-esteem have been positively correlated with hope in MS (Foote, Piazza, Holcombe, Paul & Daffin, 1990). In addition, hope was an indicator of emotional wellbeing in a study examining the relationship among illness uncertainty, stress, and coping in MS (Wineman, Schwetz, Goodkin & Rudick, 1996).

Quantifiable hope measures have been criticized for a reductionist focus on specific aspects of hope e.g. goal achievement, whereas multidimensional concepts of hope regard hope as more than achieving goals (Scioli, Rici, Nyugen & Scioli, 2011). Investigations into multidimensional aspects of hope typically employ qualitative methodology to explore hope as an experience. The experience of hope has been investigated in chronic illness populations such as chronic obstructive pulmonary disease (COPD; Milne, Moyle & Cook, 2010), cancer (Little & Sayers, 2004), neurological conditions including stroke (Arnaert, Filteau & Sourial, 2006) and spinal cord injury (Smith & Sparks, 2005), and degenerative illnesses such as dementia (Wolverson-Radbourne, Moniz-Cook & Clarke, 2010). An enduring capacity to experience hope was reported in these studies in spite of chronic illness. A qualitative investigation of hope in MS identified hope as a resource used to defy and challenge MS, in addition to facilitating a sense of purpose in life, and engaging in certainty regarding the present and future (Soundy et al., 2012).

Living in uncertainty regarding the threat and experience of relapses in RRMS may limit an individual's ability to achieve specific goal-directed hopes. Therefore, the experience of hope in RRMS may not be accessible through quantifiable hope measures. In contrast, deeper insights into multidimensional aspects of generalised hope can be gained using qualitative methodology. Hope has been previously investigated qualitatively in MS (Soundy et al., 2012). However, participants in Soundy et al.'s

(2012) study were involved in a goal directed MS rehabilitation programme implicating an experiential dominance of goal-directed hope. In addition, there appears a paucity of qualitative research investigating the experience of hope in RRMS, despite a theme of hope and hopelessness reported in a rich and detailed qualitative investigation into the lived experience of RRMS (Miller, 1997).

Therefore, the current study aimed to explore and make sense of the lived experience of hope for individuals living with RRMS using the qualitative method of Interpretative Phenomenological Analysis (IPA; Smith, Jarman & Osborn, 1999; Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009). The current study explicitly positions itself within the generalised hope discourse to facilitate exploration of multidimensional aspects of the hope experience (Dufault & Martacchio, 1985; Miller, 2007). Specifically, the current study aimed to use IPA to explore how hope is experienced, generated, maintained, or diminished, and if hope changes over time in response to relapses.

Method

Design

A qualitative methodological design using IPA (Smith et al., 1999; Smith & Osborn, 2003; Smith et al., 2009) was used to investigate, explore and make sense of the experience of hope for individuals living with RRMS using semi-structured interviews. The method of IPA has been specifically developed for qualitative psychological research and is useful for exploring complex or ambiguous concepts such as hope. Other methods of qualitative inquiry including Grounded Theory, Content Analysis and Discursive Analysis were examined for appropriateness prior to the selection of IPA (see Appendix D for discussion).

Participants

Between September 2012 and February 2013, purposive sampling techniques obtained a homogenous sample of nine participants living in the same geographical area, and who attended the same MS Nurse-led Clinic in the north of England. No upper age limit was stipulated which potentially eliminates exploration of specific challenges associated with RRMS and the experience of hope confronting individuals across the lifespan in greater depth e.g. ageing and hope. However, RRMS is a lifelong condition and both hope and RRMS are experienced across the lifespan. Upon initial verbal contact, two participants were unreachable, and one participant declined to participate. The final sample consisted of six participants; four females and two males (Table 1).

All participants had completed >17 years of education except one. Two participants were married, two were single, and two were cohabiting. Three participants had no dependents, two had three dependents, and one had two dependents. No particular religious orientations were disclosed. Three participants were employed, one was a student, and two were unemployed. All participants cited family and friends as current coping strategies, in addition to involvement in MS charities, listening to, and playing music, reading and exercise. To further situate and contextualise the sample (Elliot, Fisher & Rennie, 1999), participants rated their perceived level of social support, hope, and mood on a subjective scale of 1 (poor) to 10 (good; see Table 1 for details).

Ethics

Ethical approval was granted on May 12th, 2012 from the Proportionate Review Sub-committee of the National Research Ethics Service (NRES) Committee South West-Central Bristol, UK; part of the National Health Service (NHS) Health Research Authority (Research Ethics Committee; REC reference number 12/SW/0167).

Table 1. Participant demographic information.

Participant Pseudonym	Age Range	Years Diagnosed	Social support (1-10)	Mood (1-10)	Hope (1-10)
Rachael	40-49	12	10	8	8
Claire	20-29	3	10	9.5	9.5
John	20-29	1	8	7	9
Jackie	20-29	5	10	10	9.5
Kelly	30-39	3	10	8	6
Matthew	30-39	2	10	10	5.5

Procedure

MS nurses approached participants during MS Nurse led clinics if they fulfilled the following inclusion criteria:

(i)   Diagnosed with RRMS.

(ii)   Over the age of 18.

(iii)   English as a first language.

(iv)   Had capacity to consent.

MS Nurses assessed criteria (i) and (iv) to maintain confidentiality and made initial contact with participants by providing them with a leaflet detailing aims of the study, (Appendix E) and a Participant Information Sheet (PIS; Appendix F). Interested participants were requested to consent to share contact details with the researcher. Subsequently, the researcher contacted participants to arrange a face to face meeting in their home.

Ethical and research issues were discussed during the face to face meeting prior to obtaining informed consent (Appendix G) including right to withdraw, confidentiality, anonymity, protection from harm, use of participant data including quotes from interviews, and data storage issues. If participants consented, they were assigned a pseudonym, were asked to provide demographic information (Appendix H), and to rate their perceived level of hope, mood and social support prior to conducting semi-structured interviews.

A semi-structured interview schedule (Appendix I) of open-ended questions and prompts guided exploration of participants' experiences of hope whilst living with RRMS. Development of the interview schedule involved the researcher asking people attending an MS support group and an MS nurse for their opinions about the wording and order of questions. Interviews lasted between 30 minutes and 3 hours and were audio recorded. Questions were asked flexibly to facilitate participants in providing a detailed account using their own words. Participants were enabled to set the parameters of the topic to ensure the researcher did not impose their understanding of the phenomenon onto participants' narrative.

Data Analysis

The iterative, inductive and idiographic method of analysis (Smith et al., 2009) was adopted. First, audio recorded interviews were transcribed verbatim followed by immersion in data via continual and detailed reading of individual transcripts. During reading, the left hand margin was used to note initial ideas and specific points to inform reflexive engagement with the data. During re-reading, the right hand margin was used to note emerging themes by mapping interrelations and connections. These themes were clustered prior to returning to the transcript to ensure analysis was grounded in the data. This process was repeated for each transcript. Following analysis of individual

transcripts, themes across cases were observed leading to the development of superordinate themes and subthemes representative of all participants' experiences. Themes were not selected due to prevalence but in relation to richness of participants' accounts to maintain adherence to the IPA approach (see Appendix J for an example of IPA analysis).

Researcher Reflexivity

Researcher characteristics potentially influencing the interpretation of findings include being of female gender and sharing a similar life stage to participants. These may have impacted on how participants chose to share their experiences, and how the researcher understood and interpreted their experiences. The researcher also has prior experience of illness and hope and these experience potential influence the interpretation of findings. In addition, the researcher's personal approach to interviewing included being hopeful which may have influenced how participants chose to discuss their experiences of hope.

Validity and Quality

Assessing the validity and quality of analysis in IPA is highly debated as the use of easy to use quality checklists can be too simplistic and prescriptive, potentially missing the subtleties of qualitative research (Smith et al., 2009). The current study selected Yardley's (2000) principles of quality in IPA to assess validity and quality. This assessment tool was selected as it offers a variety of ways to establish validity and quality by assuming a pluralistic stance and can be applied to qualitative research irrespective of orientation (Smith et al., 2009). Socio-cultural and systemic implications were considered at each stage of the research process to ensure sensitivity to context. Attentiveness to participants during data collection and analysis ensured commitment to the research process. Rigour was ensured through the use of appropriate sampling

strategies, interview quality, and idiographic analysis procedures. Transparency was established through clear research stages, in addition to explicitly recording the researcher's assumptions about the topic prior to conducting the research. These were reflected on during supervisory contact. Coherence was ensured by establishing theoretical connections between assumptions and the research process using self-awareness and reflexivity to reduce researcher bias. In addition, credibility checks of themes and interpretations were conducted via a peer IPA research group. Four researchers with IPA experience checked individual transcripts and validated themes to ensure interpretations were grounded in the data.

Results

Themes and Subthemes

Four superordinate themes and 11 subthemes emerged from the data following analysis (Table 2).

Table 2. Superordinate themes and subthemes regarding participants' experiences of hope in RRMS following IPA analysis.

Superordinate Theme	Subthemes
Ingredients of being hopeful	Hopeful Foundations
	Personal Resources
	Catalyst of Hope
Hopelessly Disconnected Vs. Hopefully Connected	Punishment of Diagnosis
	Cruel Relapses
	Menacing Reminders
	You Can't Hope on Your Own
The Goldilocks Zone of Hope	Staying Just Right
	Great Expectations
Hoping and Coping	Taking the Long View
	Valuable Anchors Vs. Releasing the Shackles

Theme 1 (Ingredients of Being Hopeful) captured participants' experience of developing in hopeful systems (Subtheme: Hopeful Foundations), which appeared to facilitate the development of independent resources needed for hope (Subtheme: Personal Resources). However, hope required a significant activating event to become a conscious aspect of life (Subtheme: Catalyst of Hope). Theme 2 (Hopelessly Disconnected Versus. Hopefully Connected) captured participants' experience of disconnecting from hope at diagnosis (Subtheme: Punishment of Diagnosis), during relapses (Subtheme: Cruel Relapses), and when encountering reminders of loss or future restrictions (Subtheme: Menacing Reminders). Reconnecting to hope was facilitated by connections with loved ones, friends, MS peers, professionals, and research (Subtheme:

You Can't Hope on Your Own). Theme 3 (The Goldilocks Zone of Hope) reflected participants hopes to stay just right in spite of uncertainty (Subtheme: Staying Just Right), and the difficulties of having too much hope (Subtheme: Great Expectations). Theme 4 (Hoping and Coping) related to coping strategies used by participants including revising world views and perspectives (Subtheme: Taking the Long View), the pleasure of engaging in the normalities of life (Subtheme: Valuable Anchors), yet also feeling motivated to do extraordinary things (Subtheme: Versus Releasing the Shackles).

Definitions of Hope

Participants were asked to define hope to establish a common understanding. Defining hope as a positive, future orientated mental outlook predominated:

'It's [hope] *kind of like a positive thing almost…. Trying to see things from a….positive outlook and thinking….I'm hopeful that this is going to happen….and if you've got that feeling inside, you then you've got a hope there haven't you?'* (Jackie, Lines 9-12)

Hope was associated with maintaining rationality and happiness, and with ambition, passion, and determination to change a hopeless situation and defined as a place of assurance, a longing feeling and a driving force:

'….this might sound a little bit Hollywood, but it's [hope] *the driving force kind of thing….'* (John, Lines 15-16)

Theme 1: Ingredients of Being Hopeful

Subtheme: Hopeful Foundations

The ability to engage independently in the experience of hope required a foundation constructed as part of being raised in hopeful family systems. Hope was taught at a young age by hopeful parents who provided emotional nourishment to their children:

'It's [hope] *what's fed into you emotionally from your parents….'* (Rachael, Line 94)

Parents were experienced as hopeful role models who used their personal hope to help others. John described the impact of his parents and their occupations, and how this motivated him to do the same:

'….My mum….she was very sort of…. providing something for people and my dad… The fact that he's made such an impact, and similar with my mum, I suppose that's why I feel like I need to as well because they both did.' (John, Lines 228-236)

Hope was discussed as a physical resource, with qualities of a physical object which could be given to others. Parents gave children their hope during development and upon reaching adulthood, the legacy of hope continued. Once in adulthood, participants used hope independently from their hopeful foundations to make autonomous life choices:

'….you get to live with people who are hopeful or negative or positive….and then you make your own adult choices….' (Rachael, Lines 95-96)

Also in adulthood, hope appeared to have developed into an unconscious and automatic process:

'I don't know that I need to be told to be hopeful….I think I have been told as a young child….and this is the result. I am most certainly glass half full not glass half empty….' (Rachael, Lines 25-27)

Subtheme: Personal Resources

Hopeful foundations facilitated the development of personal resources including hopefulness, optimism, humour, and positive world views. Being hopeful was a constant presence and a way of being in the world. Hope was not solely related to the experience of living with RRMS, although being hopeful aided in discovering an inner strength:

'I think a lot of people when they're ill….you find this inner strength from somewhere… I think that's the hope bit….' (Jackie, Lines 28-31)

Hope enabled Matthew to remind himself of his past physical strength prior to receiving a diagnosis of RRMS:

'My nickname at work was Weeble….they could knock me around….but I'd never fall down.' (Matthew, Lines 101-105)

Through the process of being hopeful, Matthew was able to hold onto a representation of being physically strong in the past despite physical strength being diminished in the present. Although his physical strength was diminished, Matthew was able to continue to feel strong in spite of RRMS. In addition, reminding themselves of coping and moving on from previous negative experiences facilitated a hopeful confidence in coping with RRMS:

'When I started University in [place]*, I got attacked….it just became something else that I got over just like I feel this will as well. This might just take a bit longer.'* (John, Lines 111-117)

Subtheme: Catalyst of Hope

For hope to emerge as a conscious aspect of life, participants expressed needing to experience hopelessness. Hopelessness was experienced as a void of despair yet hope provided an anchor point within the void. When experiencing hopelessness, Claire conceptualised the capacity to hope at its most productive. Kelly described how hope is embodied in everyone but only recognised when something challenges the individual. She also described how hope needed something negative to hope against to create a sense of hopeful motion towards something different:

'I think it [hope] *needs a negative thing for you to hope back against….and for someone to think there is hope to carry on and get through the other side.'* (Kelly, Lines 601-602)

Theme 2: Hopelessly Disconnected Vs. Hopefully Connected

Subtheme: Punishment of Diagnosis

The diagnostic process generated the first connection to RRMS and at this point, participants experienced a void of hope. Making sense of why they had been diagnosed was difficult. Matthew directed his frustrations at being diagnosed towards a higher power by disregarding an existence of a God. His frustrations related to a sense of injustice that the diagnosis had not been given to someone who he perceived deserved it:

'Is there such a thing as God? I don't think so because he would have given it to a drug dealer wouldn't he? That's how I look at it.' (Matthew, Lines 557-558)

Diagnosis was referred to as a form of punishment which led participants to reason about what they might have done wrong. Jackie described her experience of diagnosis as feeling ganged up on, and Kelly questioned the value of hope as she experienced diagnosis as a punishment for unknown past sins:

'It's like what hope is there if they've done this to me? What have I done to deserve this? Have I done something wrong? Is there a reason why he's done it to me?' (Kelly, Lines 320-321)

Both John and Kelly metaphorically described diagnosis as a form of criminal punishment:

'When I was first diagnosed I did kind of sort of take it as a bit of a death sentence….' (John, Lines 289-290)

'I thought I'd really done something wrong to be given this because at the time it felt like a life sentence....' (Kelly, Lines 335-336)

Metaphors regarding diagnosis as a life or death sentence illustrate notions of being a prisoner of RRMS and living life without freedom. The source of the punishment was not directly alluded to by participants, yet their words evoked a sense of an omnipotent, invisible, and opportunistic nemesis, rendering them powerless to protect themselves. Without a physical presence to project and externalise their anger and frustrations, participants were left with internal fears of the unknown and a tendency to think the worst. Disconnections from the present moment at diagnosis manifested as emotional reactions of shock, minimisation and denial. In addition, John described losing faith in his body, and the terror which accompanies a future of losing physical abilities:

'There's a band called Metallic....they have a song called One and on the video… there's a person ....he's in a war and he loses his arms and his legs and.... he can only move his head, and I remember thinking not just losing your limbs but I thought....getting to a stage when you would lose simple bodily functions would be the most terrifying thing ever, and then when this happened to me, I thought "Oh my god, my biggest fear ever is actually happening"....' (John, Lines 293-300)

John also described RRMS as an unknown quantity with the ability to frighten others:

'....I feel like in my life with MS it's a lot like Pandora's Box really. I feel once it's opened....it's going to scare people.' (John, Lines 766-767)[2]

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[2] Pandora's Box is an artifact in Greek Mythology taken from the myth of Pandora's creation in Hesiod's Works and Days (West, trans. 1988, p. 39). The box, given to Pandora, contained all the evils of the world. Interestingly, hope is the last thing to emerge from the box according to the myth of Pandora. In modern day, the phrase "to open Pandora's box" means to carry out an action or endure a situation in which the consequences can be severe.

Subtheme: Cruel Relapses

Participants felt diminished, switched off and less of a person during a relapse. Relapses were accompanied by a void of hope especially if there was no sign of the relapse abating:

'....when I was relapsing all the time I mean it [hope] *didn't help….'* (Claire, Lines 742-743)

During a relapse, a macabre atmosphere of blackness appeared to envelop participants whose thoughts turned to their own mortality:

'....Facing you own mortality….it's not good, no….it does not make you feel good. Its black, that's how I describe. Its pure black and those thoughts are there all the time….' (Rachael, Lines 49-53)

Claire discussed how her thoughts turn to euthanasia during a relapse as a way of attempting to make her partner's life easier. Thoughts about permanently disconnecting from life were associated with Claire's partner witnessing her humiliation associated with RRMS symptoms, her reduced independence, and the need to rely on her partner to provide care:

'...When I was really bad like all these horrible things that happened, really humiliating horrible things….I was crying my eyes out and I just said to him [partner] *"if this gets worse….then I'll go to Switzerland"….'* (Claire, Lines 103-105)

During periods of relapse, individuals described a sense of being vulnerably disconnected from their present life. Both Claire and Kelly described feelings of vulnerability during a relapse reminded them of existing in a different and incongruent life stage:

'You know at 22, apparently not potty trained, not being able to walk anywhere or do anything and it was just…. complete crap….' (Claire, Lines 437-438)

'….it was a struggle getting from here to the door to answer it….I was shuffling and I was like an old woman that's the only way I can describe it….' (Kelly, Lines 264-266)

Matthew described hoping to improve during a relapse despite facing loss. Through Matthew's words, relapses bear resemblance to an opportunistic thief robbing him of parts of himself:

'….you're hoping you're going to get better….before the relapse….I'll have problems all the time but then the relapse will take something else away from me….' (Matthew, Lines 486-488)

Participants described the experience of waiting for relapses to resolve and the fear of being left in the relapse state forever:

'Some relapses, you'll get to a point where if it stays like it is for a while you just think it's never going to get better. So you're just waiting and waiting and thinking is this it now? Am I stuck like this forever?' (Kelly, Lines 236-237)

Subtheme: Menacing Reminders

Being reminded of what had been lost to RRMS evoked feelings of anger and loss of hope. Matthew described his anger at being reminded of loss when thinking about an interaction with a lifeguard at a local swimming pool:

'….I went to watch them [children] *and this bloke came up to me and said "Why don't you get in the pool Mr* [participant's name]*"….I says….I can't walk right he said "Oh, we've got a crane". Piss off. You what? You aren't going to frigging crane me into the frigging water….'* (Matthew, Lines 325-328)

Claire discussed feeling angry when witnessing television programmes depicting individuals wilfully giving up abilities she has lost without choice:

'....there was like a 40, 50 stone woman on it [television programme] *who was saying "Well, I know I'm giving up my mobility." It's like you're wilfully giving that up and yet there are so many people who don't have a choice….it makes me so angry that people take that for granted….'* (Claire, Lines 133-137)

Hopelessness was associated with attending MS conferences and MS support groups which involved connecting with others in advanced stages of MS. Visibly witnessing decline in others resulted in participants confronting reminders of future possibilities, including dying from RRMS. Rachael described how she avoids attending MS conferences and reflects how such conferences invite introspection:

'....I don't know that I would particularly want to do the big MS conferences. That would make me feel quite hopeless….. I think I notice that people were dying, weren't that far from being dead and they were going there to try and find something to stop them dying in the next year and I found that very difficult. That's not something [pause] *I would feel very quiet after that.'* (Rachael, Lines 170-175)

When attending MS Support Groups, Matthew described how witnessing others in progressive states of decline resulted in him wanting to avoid and distance seeing this in reality. Contemplating possibilities of fulfilling future normative life roles were questioned by John, who felt RRMS would intrude on his ability to become a father and his ability to care for another human being:

'I do wonder how I could be a father now…. I wouldn't be able to do sort of father things because I feel like I'm too involved in getting through my own stuff rather than helping somebody else' (John, Lines 687-690)

Having knowledge of damage caused by RRMS appeared to serve as an internal reminder. Embodiment of internal reminders created difficulties in distancing the self from the illness, and from the continual threat of future damage. Reduced hopefulness was associated with the threat of internal damage resulting in loss of a physical ability needed to engage in valued activities e.g. playing the guitar:

'....I've seen the little lesions that I've got on my spinal cord and....obviously some of them haven't disappeared....but if I like....lost the ability to use my hand completely I don't think I would be as hopeful....' (John, Lines 261-264)

In addition, the initial decision to commit to taking medication was a life changing moment. Medication became a constant and everyday reminder of the illness as a physical object accepted into the body.

Subtheme: You can't hope on your own

A life without family was a life without hope. Through his words, Matthew imagined other individuals living with RRMS without a family and loathed this possibility:

'I'd hate to think of someone whose got MS who has no family because if I didn't have no family, well, I wouldn't have no hope.' (Matthew, Lines 26-27)

Claire described the only long term possibility in diminishing hope would be the loss of her partner and by recognising this could become a reality, she acknowledged keeping hope alive through her partner as a risky strategy.

'The only thing long term that would completely diminish hope would be him [partner] *not being there which is like a risky thing because we are finite. We kind of have a used by date....'* (Claire, Lines 383-385)

Having a loving connection between Claire and her partner allowed her to imagine how she might live alone with RRMS. Living alone with RRMS was linked to nihilism and

meaninglessness. Partners appeared to function as a fuel of hope, keeping hope alive during the difficult times and assisting in buffering the effect of bad news. There appeared to be no reason for participants to give up hope completely as long as there was a physical connection, regardless of quality, between them and their partner:

'Even if he [partner] *was in a coma, even if he was in a persistent vegetative state, there's still something to hope for because he's not gone, he's there….'* (Claire, Lines 403-404)

Partners and family helped to maintain participants hope to improve and this was facilitated by the need to avoid becoming a burden on their loved ones. Ultimately, family was a reason to hope and a reason to not give up hoping. Sustaining connections with friends was also important in maintaining hope but friends had to provide a friendship which existed before the onset of RRMS. Friendships which remained unchanged helped to sustain a connection to the past and prevented participants feeling different:

'….My Friends….I always said when I got diagnosed don't treat me any different just because I've got MS….I don't want you treating me any different to what you ever did and they haven't done.' (Jackie, Lines 40-44)

Having positive feedback regarding their ability to cope with RRMS via connections with others living with MS, assisted in generating hope and in preventing becoming lost in RRMS especially on a bad day:

'A lot of people have said to me how well I'm coping with it [RRMS]*…and even when it's a particular bad day when I'm thinking that I'm not coping with it just the fact that somebody says "Oh yeah, wow", then that definitely generates it* [hope]*….'* (John, Lines, 194-197)

In addition, individuals described sustaining connections with professionals helped to imagine a positive future in which new treatments would become available quickly:

'....I mean the nurses and Doctors are brilliant, so there's hope with them that they're going to make sure everything's available to me....' (Kelly, Lines 534-535)

Staying connected to research investigating MS helped to create a focus of hope by allowing participants to hold in mind a future orientated perspective regarding the development of treatments:

'The fact that I know all the research that's going on, and I know of the amazing results they've had, it gives me something to focus on, and even in the awful times I can think well I know what they can do.' (Claire, Lines 255-257)

Research created a hopeful expectation for something better and a need to hope less by knowing more. Hope sustained through connecting with research enabled John to hope for parts of his body to be restored in the future:

'I'm quite hopeful.... by the time I'm....35 or 40 they'll have something concrete....even if it is a sort of stem cell procedure that repairs your spinal cord maybe.' (John, Lines 23-25)

Theme 3: The Goldilocks Zone of Hope

Subtheme: Staying Just Right

A major hope for participants was to remain just right for as a long as possible without deteriorating. The hope to stay just right appeared to mitigate the effects of uncertainty associated with RRMS by maintaining certainty in the present. Both Claire and Jackie describe their hope to not get worse whilst questioning how realistic this hope will be in the future:

'My complete hope which I have to hold onto because I don't know if it's realistic or not but the ultimate hope would be that I don't get worse....' (Claire, Lines 118-120)

'I'm hopeful that my condition doesn't get....worse.....I know things are going to get worse but I'm hopeful that they won't progress too quickly so that I can just get on with life....' (Jackie, Lines 50-56)

For Matthew, his hope to stay just right related to avoiding major relapses:

'....hopefully not going to get them big major relapses like I had before when I was bedbound because that was horrible....' (Matthew, Lines 236-238)

In addition, hoping to stay just right facilitated participants to imagine a future in which they would avoid becoming a burden on loved ones:

'....I would hope that I don't get worse because I wouldn't want to be a burden....' (Claire, Lines 93-94)

'I hope more than anything that I don't get worse and I....don't turn [partner's name] *into* [carer]*... because he's my husband, and I know it's like in sickness and in health but he's my husband and I would never want people, and people already do label him as a carer and I hate it's a horrible word, it's a horrible everything because well husbands and wives care for each other but nobody else calls them a carer....'* (Claire, Lines 108-112)

To facilitate a hope to stay just right, participants engaged in various coping strategies related to controlling and balancing the uncertain experience of RRMS. John describes how having another relapse in the future could damage his hope since he has changed aspects of his lifestyle to avoid relapsing:

'....I think that [relapse] *could damage my hope quite significantly. I keep thinking that if I do have another relapse it won't be as bad as the first one because I'm doing so much....but yeah, if suddenly it was worse then I'd be thinking well why have I been eating this ridiculous food for a year if hasn't actually made a difference?'* (John, Lines 646-651)

Controlling and balancing the uncertain experience of RRMS was facilitated by attuning to body sensations and symptoms. By listening to feedback from their bodies, participants accessed medication quickly to alleviate symptoms which enabled them to return to feeling just right:

'If I have a relapse based on past experience and it's a proper relapse and not an infection I can realistically hope that the steroids will work again....' (Claire, Lines 276-278)

Staying just right also involved participants monitoring aspects of their environment and emotional states which may impact on RRMS symptoms:

'....if say I feel more tired and sluggish on an morning now or whenever, then I probably know it's something to do with my temperature, so that's good to know. It means I don't get as down as before because before, I would just think "Oh, this is useless", whereas now it's like well, I am wearing a lot of layers or well, you know I have been in a hot shower or, I have been in a really warm bed.' (Claire, Lines 753-757)

'If I've had a really, really stressful time, then I'll bear it in mind....you kind of look for key performance indicators....' (Claire, Lines 788-790)

Although experiencing symptoms and relapses provoked a loss of hope, knowing that relapses resolve in time and participants could return to feeling just right helped to retain hope:

'Yeah, symptoms at times make you lose hope but I'm at that stage now where I keep hoping and hoping and I know it will get better….' (Kelly, Lines 468-469)

'….You can feel yourself getting better and it's like ok well, I know that's not permanent then….' (Claire, Lines, 779-780)

Subtheme: Great Expectations

Participants described the consequences of having too much hope. Too much hope appeared to lead to upset and disappointment. Matthew described the absence of being guaranteed an outcome whilst hoping and compared having too much hope with hoping to win the lottery:

Matthew: *'…. I think the more hope you have the more upsets you can have. You know what I mean?'* (Lines 41-43)

Researcher: *'Can you tell me more about that?'* (Line 44)

Matthew: *'Well some people go round "I hope I get six numbers on the lottery at weekend" but…if you don't get they're going to be upset….you hope you win something but you're not guaranteed…. so I think having hope is a good thing but it's also a bad thing as well because you know you'll have let downs.'* (Lines 44-47)

Matthew's description of the lottery links to the experience of RRMS. Being diagnosed with RRMS is similar to a lottery since it can affect anyone but unlike the lottery, there is no potential of winning. Therefore, hoping whilst living with RRMS is taking a chance. Claire also described anxiety associated with hoping too much for a cure or to

stay just right. Too much hope potentially places a curse on the hope becoming a
reality. Therefore, Claire described needing to have a balance of hope:

'It's [hope] *like anxiously wanting to make sure you have the perfect level of wanting
something to happen….'* (Claire, Lines 20-21)

Participants discussed not wanting to rely on hope too much to avoid disappointing
themselves and others. Hope was used as an excuse in some instances to inform others
that something they were hoping for was not completely reliable. Claire questioned the
value of hope when discussing the difficulties of hoping too much. However, the
alternative of not hoping was unbearable for Claire who described a cycle of negative
and destructive emotions, and a life living as Miss Havisham[3]:

*'….It's like well what good does hoping actually do? But I have to keep hoping that
because otherwise then what will I become? Just some angry twisted Miss Havisham
type character….'* (Claire, Lines 169-171)

Avoiding the need to hope too much resulted in individuals taking a lighter approach
that permitted keeping things in perspective. Using hope rationally allowed individuals
to maintain a realistic sense of hope whilst avoiding disappointment and feeling let
down by their own personal uses of hope.

Theme 4: Hoping and Coping

Subtheme: Taking the long view

Over time individuals discussed developing an alternative perspective regarding life
with RRMS. Different perspectives were facilitated by discovering and maintaining
hope over time and hope appeared to facilitate engaging in a spiritual outlook on life.

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[3] Miss Havisham is a character in Charles Dickens' (1861/2004) novel Great Expectations. In the novel
she is depicted as a wealthy spinster, living in a ruined mansion, who has not seen the sunlight for years.
She is said to look like a cross between a waxwork and a skeleton with moving eyes.

Kelly described how she engaged in a *'silent little prayer of hope every day'* (Line 84), which enabled her to imagine staying well and helped to limit the impact of RRMS on her life:

'It's hope that you say a silent little prayer of hope every day….the hope is always there hoping that I'm going to stay healthy I'm going to stay fine and it's not going to affect my life.' (Kelly, Lines 83-87)

Kelly's prayer appeared to anchor her to the present. She described how her prayer became a habitual, unconscious and omnipresent process beginning in the dark, early days of RRMS and continuing as the process of hope proved itself to her over time. Individuals also discussed a deeper appreciation of life:

'….you just think life's this short…I might have this illness but I'm still here and I'm going to appreciate everything because, you know, you never know what's around the corner….' (Jackie, Lines 214-216)

Time itself appeared to facilitate acceptance of RRMS by experiencing recovery from relapses. Time was also associated with hope. Over time, individuals discussed how hope became more important as the acts and processes of hoping were reinforced by positive outcomes. Rachael described how an increased understanding of RRMS assisted in being able to hold a different perspective on improvement and having conviction she will be able to adapt to emerging disabilities if they occur:

'….I understand what happens with the disease….that is me being ill. That is not where I am going to be left….I know I will improve from there and if I am left with issues then life will adapt to compensate for those.' (Rachael, Lines 53-56)

Time also facilitated taking a different perspective on actively engaging with RRMS rather than being a passive recipient of its consequences. Kelly described how over time she has begun to engage in combat with RRMS using positive thinking as a weapon:

'Positive thinking that's the only way you can fight it is with your mind….' (Kelly, Line 362)

Subtheme: Valuable Anchors

Staying engaged in familiar everyday tasks was valued by participants. Valued tasks of daily living facilitated a connection to the normalities of life in addition to anchoring participants to the present. Participants described that at all costs doing nothing must be avoided. For Rachael, her daily routine was a comfort, helping her to feel normal especially during periods of relapse. In addition, completing parts of her daily routine allowed her to experience a sense of accomplishment:

'….routine is deeply comforting, yeah, just pottering round, cleaning the worktops, putting the washing on, all of those things make you feel normal and you think well actually I've contributed as well….' (Rachael, Lines 134-136)

Participants described feeling uncomfortable when accepting help. If help was accepted, participants described feeling motivated to improve in order to repay the debt. In addition, being in control of things which can be controlled outside of RRMS was comforting:

'….I'm a massive control freak but MS you can't control at all so like I control my diet rigidly generally because I can control it. I control like our expenses because I can….' (Claire, Lines 449-451)

Participants also discussed the importance of maintaining parts of their life which existed before RRMS. It appeared important for participants to continue working and using personal talents:

'....I leave my mark on the world because I drive round and say I made those blinds, I made those curtains that feels nice. It's important to me to work, it's important also to be artistic....' (Rachael, Lines 80-82)

Subtheme: Versus. Releasing the Shackles

As a result of living with RRMS, participants expressed an increased sense of boundless ambition. Participants appeared to rebel against restrictions imposed on their life by RRMS and no longer wished to deal with the trivialities of life. Claire described how time spent living with RRMS had increased her sense of hoping for more ambitious things, and how she does not foresee a limit to this ambition:

'I think like the longer it's gone on I've hoped for more ambitious things I've had more ambitious targets....it's like well what's the limit?' (Claire, Lines 642-650)

A sense of urgency accompanied changing unhappy aspects of life associated with time spent living with RRMS. In contrast to using everyday tasks as comforts and anchors, individuals also expressed feeling motivated to do extraordinary things including setting ambitious challenges, targets, and personal goals. Jackie described how she is driven to help others by completing challenges for charity and how over time, she feels more inclined to take risks. Raising money for charity revealed additional benefits for Jackie who described the process of reciprocity associated with helping others:

'....raising money for stuff whether it be the MS Society or whether it be you know other charities....doing something for yourself but yet helping others while doing it; everyone's happy....' (Jackie, Lines 285-288)

Discussion

In the current study, use of semi-structured interviews facilitated individuals living with RRMS to provide a detailed account of their experiences of hope. Multidimensional aspects of hope were described, supporting use of qualitative research methods e.g. IPA, in investigating generalised hope as a complex state of being, consisting of multiple dimensions (Dufault & Martacchio, 1985; Miller, 2007).

Findings from the current study suggest hope develops early in life, is generated and maintained individually using positive coping strategies and perspectives, and systemically by establishing and sustaining connections with hopeful others. In addition, hope can be temporarily lost when confronting existentially disconnecting illness experiences.

Relationships appeared important in the experience of hope for individuals living with RRMS. This supports previous findings implicating the importance of significant others in the experience of hope (Aspinwall & Leaf, 2002; Scioli et al., 2011; Scioli, MacNeil, Partridge, Tinker, & Hawkins, 2012). The development of hope for individuals living with RRMS in the current study appeared to be influenced by early relational experiences of hopeful caregivers. Attachment theory suggests establishing secure attachment relationships with primary caregivers early in life is a sufficient but not necessary condition for the development of trust in others which facilitates hope (Bowlby, 1969; Dunkel & Sefcek, 2009; Erikson, 1950). However, attachment theory is one way of conceptualising and understanding individual's responses in the current study. Establishing secure attachments in early life are not necessary or sufficient conditions for the development, presence or absence of hope. In addition, development of a future orientation, a prerequisite for hope, appears to develop between 0-2 years during the process of separation-individuation (Jacoby, 1993 Mahler, 1968). Through

the process of separation-individuation, infants acquire the ability to form internal representations of significant others. These representations allow infants to develop knowledge regarding the existence of significant others despite them not being physically visible; also known object permanence (Piaget, 1954). Hope could be conceptualised as a form of object permanence allowing individuals to hold internal representations of hoped objects, despite the object not being physically visible.

In the current study, the family system appeared important in generating and maintaining hope. Interestingly, family members appeared to function as secure bases for hope when lost by the individuals e.g. at diagnosis, or during relapse. Systems theory suggests biological systems, such as families, attempt to maintain stability during change by adapting to internal and external feedback occurring within or outside the system (Mingers, 2004). Hope appeared to be maintained by accommodating deficits of hope in one part of the family system by generating hope in another part. During periods of hopelessness, hope appeared to be anchored externally in significant others (Bernardo, 2010), associated with interdependency needed to endure periods of relapse. However, as the individual moves into remission, their independence and autonomy is likely to increase, shifting external anchoring of hope to internally within the individual (Bernardo, 2010).

Loss of hope accompanied periods of relapse and appeared to be associated with existential concerns of mortality and disconnecting from life. According to terror management theory (TMT; Greenberg, Koole & Pyszczynski, 2004), conflict between knowledge of the inevitability of death, and the biological drive for self-preservation creates existential anxiety. Existential anxiety can be resolved by creating meaning (Greenberg et al., 2004) and paradoxically, reminders of mortality increase the salience of living a meaningful life (King, Hicks & Abdelkhalik, 2009). In addition, higher

levels of hope have been positively correlated with a strong sense of life being meaningful (Varahrami, Arnau, Rosen & Mascaro, 2010). In the current study, meaning appeared to be created by developing alternative perspectives of life, spirituality, valuing family and the normalities of life, in addition to actively changing lifestyle to avoid relapsing. Interestingly, thoughts about euthanasia were used as a way of controlling death and its meaning in life during relapse.

In the current study, diagnosis was associated with an absence of hope and perceived as a form of punishment, shattering individuals' assumptions regarding a just and fair world. Belief in a just world suggests an individual becomes a victim of injustice when they experience an unwarranted event e.g. being diagnosed with an illness when they have not engaged in behaviours associated with increased risk of the illness (Hafer & Begue, 2005; Lerner, 1980). This sense of injustice appeared to be a barrier for hope at diagnosis and was accompanied by negative emotional and cognitive reactions. Shock, anger, frustration, powerlessness, fear of the unknown, catastrophising, minimisation, and denial, were experienced at diagnosis. These reactions share attributes of the initial stages of the grief, supporting previous research suggesting the stages of grief are experienced following a diagnosis of MS (Koopman & Schweitzer, 1999). Experiencing grief reactions at diagnosis could also account for feelings of injustice regarding loss of a previously lived life.

Distancing and avoidant coping strategies were used by individuals in the current study to manage hopelessness when confronting reminders of loss and/ or future related threats. These strategies have been conceptualised as emotion focused coping which appear to increase during periods of distress (Jean, Paul & Beatty, 1999), and are associated with poorer adjustment in MS (Pakenham, 1999).

McCabe, McKern & McDonald (2004) reported individuals living with MS are more likely to use detachment styles of coping, and less likely to use problem focused coping (e.g. seeking social support, focusing on the positives). Interestingly, McCabe et al. (2004) discussed when a distressing situation or threat is encountered in real time, individuals tend to use emotion focused coping regardless of illness. Therefore, the use of emotion focused coping in the current study appeared to function as an adaptive response, protecting individuals at the point of confronting distressing reminders or future related threats.

Problem focused coping was used by individuals in the current study and these appeared to be facilitated by hope, time and experience of RRMS. However, engaging in problem focused coping appeared to be dependent on the hope of preventing deterioration. Hope for consistency in spite of the inconsistent nature of RRMS, could be conceptualised as an unrealistic hope. Unrealistic hope arises when individuals use hope to defy medical prognosis. By defying medical prognosis, individuals may neglect the illness experience resulting in diminished treatment adherence and poor lifestyle choices. Yet individuals in the current study questioned how realistic a hope to stay the same was. This supports previous research findings suggesting a high degree of accuracy and realism regarding hope and chronic illness (Folkman, 2010). Furthermore, individuals in the current study were aware of the benefits in balancing hope, facilitating engagement in realistic hopes.

Limitations

Limitations of the current study include sampling bias as individuals who were hopeful may have been attracted to participate. This potentially neglects individuals lacking in hope which could have been valuable in gaining further understanding of the hope experience. This limitation is supported by subjective ratings provided by participants that suggested a high level of perceived hope across the sample. In addition, in adhering

to the principle of obtaining a homogenous sample in the process of IPA, difference and diversity was neglected. Cross-cultural experiences of hope were not explored in the current study. Individuals living with RRMS were not asked to check the validity and credibility of themes. Although the researcher attempted to validate themes using external sources (e.g. peer IPA research group, research supervision, reflective diary), the individuals providing their experiences would be best suited to assess the validity and credibility of themes. Lastly, although the researcher attempted to limit the impact of subjectivity, total researcher objectivity is unachievable resulting in the researcher's subjectivity playing a role within the research process.

Future Research

A strength of the current study was the use of qualitative methodology which attempted to gain deeper insights into the experience of hope for individuals living with RRMS. These deeper insights provide a foundation for future quantitative research to establish objective cause and effects relationships between the roles of family systems in the experience of hope. In addition, future research could address barriers and facilitators of hope at diagnosis, during relapse, and what facilitates regaining hope following periods of hopelessness. Furthermore, future research could examine factors associated with the development of hope early in life to establish relationships between hope and the processes of attachment, separation-individuation, and the development of object permanence.

Clinical Implications

Findings from the current study are potentially applicable to other conditions which follow a relapsing-remitting trajectory such as chronic pain, rheumatoid arthritis, migraine, herpes, in addition to mental health conditions such as depression, bi-polar disorder, schizophrenia and psychosis, and addictions. The recovery model (Shepherd,

Boardman & Slade, 2008), a currently emerging globally accepted approach to mental health services, has identified hope as a central tenet in recovery from serious mental health conditions (Shepherd et al., 2008).

Research examining hope fostering interventions associated with the recovery model have focused on interventions aimed at relationships between individuals accessing services, healthcare professionals, families and peers. Hope fostering interventions associated with healthcare professionals include providing emotional support, taking a caring, understanding, cooperative and unconditionally accepting approach, working from the individuals' frame of reference, holding and communicating hope and focusing on positive strengths (Darlington & Bland, 1999; Kirkpatrick et al. 1995; Kirkpatrick, Landeen, Woodside & Byrne, 2001; McCann, 2002). Establishing social networks, and meeting others with experience of the illness-wellness transition were identified as hope fostering interventions, in addition to exploring individuals' philosophy on life, identifying future hopes, and experiencing success (Darlington & Bland, 1999; McCann, 2002).

The recovery model has not been translated to MS services. However, person centred care approaches to MS service provision is a Quality Requirement stated in the National Service Framework (NSF) for long term conditions including MS in the UK (Department of Health; DH, 2005). Person centred care practices may facilitate providing hope fostering interventions individually and systemically.

Conclusion

In conclusion, individuals living with RRMS experience hope independently and systemically. Hope functions as an enduring coping resource facilitated by early and continued experiences of hopeful others, helping individuals to endure existentially challenging, and hopeless experiences. If hope is lost by the individual, the family

system adapts by holding, generating, and maintaining hope. Hope does not diminish in

quality once acquired; it is cared for by others depending on the needs of the individual

living with RRMS.

Declarations of Interests

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Part Three

Appendices

Appendix A

Reflections on Methods of Meta-synthesis and Phenomenology

The synthesis of qualitative research is a complex, contested and highly debated area (Thomas & Harden, 2008). Methods of synthesis are less well developed, and the ability to generalise beyond the original context of qualitative investigations has been criticised (Sandelowski & Barroso, 2007).

There is less debate regarding the synthesis of quantitative research (e.g. systematic literature reviews; meta-analysis). Such methods use robust protocols and defined statistical analysis techniques to compare findings, and improve certainty in cause and effect conclusions (Walshe & Downe, 2005). However, John (1992) criticised the rhetorical power of numbers, and the epistemic authority of science and statistics as a dogmatic approach to combining scientific knowledge. This approach appears to marginalise qualitative research from policy makers and clinicians, limiting its influence on practice (Evans, 2002; Silverman, 1997).

Yet there is growing recognition in the value of synthesising qualitative research to inform healthcare policy and knowledge, and as a method of disseminating qualitative studies to wider audiences (Finfgeld, 2003; Jones, 2004), whilst preserving context and complexity (Thomas & Harden, 2008). In addition, Estabrooks, Field & Morse (1994) suggested qualitative synthesis offers a method of achieving a higher level of abstraction than single studies, thus enhancing generalisability.

Descriptive meta-synthesis

There are various methods available to synthesis qualitative research studies (e.g. Dixon-Woods et al., 2006; Harden & Thomas, 2005; Noblit & Hare, 1988; Paterson, Thorne, Canam, & Jillings, 2001; Thomas & Harden, 2008). Descriptive meta-synthesis

involves the synthesis of qualitative findings resulting in a comprehensive analysis of phenomena (Schreiber, Crooks & Stern, 1997). This method was selected based on the focus of the meta-synthesis. The researcher wanted to review the contribution of qualitative research investigating the lived experience of Multiple Sclerosis (MS). Descriptive meta-synthesis aims to look broadly at phenomenon rather than focussing on analysis of a single concept. Therefore, using this method of meta-synthesis permitted examining the lived experience of MS.

Rationale for selecting studies using phenomenological approaches

When single studies using various qualitative methodologies are combined, they can produce misinterpretations (Esterbrooks et al., 1994). Some researchers recommend excluding studies using various qualitative methods from different epistemological perspectives (Jenson & Allen, 1996). Others acknowledge the common interpretative position of all qualitative methods, and synthesis across multiple perspectives may serve as an opportunity to enrich understanding (Finfgeld, 2003; Sandelowski, Docherty & Emden, 1997).

The current meta-synthesis chose to synthesise studies using phenomenological approaches only to remain affiliated with the review's focus. Phenomenology is concerned with the study of experience according to an individuals lived world (Finlay, 2009). Phenomenology assumes knowledge is acquired through experience and that individuals can communicate their thoughts, beliefs, and knowledge about their relationship to the phenomenon. In phenomenology, experience is viewed as uniquely embodied yet complexly intertwined with the world. Experience can be explicitly accessed through words, or implicitly masked in perceptual or sensory experiences. Phenomenological methods avoid taken for granted ways of being in the world by

moving away from assumptions, and describing and reflecting on the essence of the phenomenon of interest (Smith, Flowers & Larkin, 2009).

Studies in the meta-synthesis used a variety of phenomenological approaches. One study (Irvine, Davidson, Hoy & Lowe-Strong, 2009), used interpretative phenomenological analysis (IPA; Smith et al. 2009) which is underpinned by phenomenology. Two studies (Miller, 1997; Olsson, Lexell & Söderberg, 2008) used hermeneutic phenomenology (Lindseth & Norberg, 2004; Ricoeur, 1976) which attempts to understand the meaning of a phenomenon by shifting between the text as a whole and its parts. Another study (Wright-St Clair, 2003) used symbolic interactionism (Blumer, 1969) which attempts to interpret the day to day dynamic relationship between an individual and the symbolic meaning of a phenomenon. Finally, three studies (Barker-Collo, Cartwright & Read, 2006; Dennison, Yardley, Devereux & Moss-Morris; 2011; Malcomson, Lowe-Strong & Dunwoody, 2008) used thematic analysis (Braun & Clarke, 2006). Thematic analysis is a qualitative method which transcends methodological boundaries (Boyatzis, 1998).

One study used aspects of grounded theory alongside thematic analysis (Dennison et al., 2011). The researcher did not consider grounded theory to be affiliated with phenomenology as it attempts to discover features of an experience to generate theory, and is allied with positivist epistemology. However, in Dennison et al. (2011) study, thematic analysis was used primarily to discover the essence of individuals experiences, which informed the findings used in the meta-synthesis.

References for Appendix A: Reflections on Methods of Meta-synthesis and Phenomenology

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Appendix B

Meta-Synthesis Quality Assessment

Mays and Pope (2000) Criteria for assessing quality in qualitative research:

Credibility

(i)   Were the explanations of sampling strategies and data collection methods provided? (Data Collection)

(ii)   Was the method of data analysis described and enough data displayed to allow the reader to determine whether interpretations were made by the researcher are supported by raw data (Auditability)?

(iii)   Did the authors acknowledge the influence of the research process and the presence of the researcher in the role of prior biases, assumptions and experiences on the collected data (Reflexivity)?

(iv)   Has appropriate attention been given to contradictory data? Are negative cases taken into account? (Negative Cases)

(v)   Did the authors explore alternative, plausible explanations for the data collected and incorporate a range of different perspectives (Fair dealing)?

Relevance

(vi)   Did the authors provide information regarding participants, settings, and context so that the reader might be able to determine the relevance of findings to other settings (Transferability)?

(vii)   Did the authors discuss the finding within a broader context, propose generalisation of findings and/ or suggest a direction for future research (Analytic Generalisation)?

Independent Quality Assessments

Researcher KB

Study	Credibility				Relevance		
	Data Collection	Auditability	Reflexivity	Negative Cases	Fair Dealing	Transferability	Analytic Generalizability
Barker-Collo et al. (2006)	+	+			+	+	+
Dennison et al. (2011)	+	+		+	+	+	+
Irvine et al. (2009)	+	+	+		+	+	+
Malcomson et al. (2008)	+	+		+	+	+	+
Miller (1997)	+		+	+	+	+	+
Olsson et al. (2008)	+	+	+		+	+	+
Wright-St Clair (2003)	+	+			+	+	

Researcher CB

Study	Credibility				Relevance		
	Data Collection	Auditability	Reflexivity	Negative Cases	Fair Dealing	Transferability	Analytic Generalizability
Barker-Collo et al. (2006)	+	+			+	+	+
Dennison et al. (2011)	+	+		+	+	+	+
Irvine et al. (2009)	+	+	+		+	+	+
Malcomson et al. (2008)	+	+		+	+	+	+
Miller (1997)	+	+	+	+	+	+	+
Olsson et al. (2008)	+	+	+		+	+	+
Wright-St Clair (2003)	+	+			+	+	

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    320.7226.50

Appendix C

The Elusive Nature of Hope: Considerations and reflections on defining hope

Hope has been described as a basic human need and response, identified cross culturally as a universally and subjectively valued phenomenon (Hammer, Mogensen & Hall, 2009; Herth & Cutcliffe, 2002; Parse, 1999; Seligman, 2005). All individuals irrespective of race, gender, socio-economic status or religious orientation possess the capacity to hope, generating a fundamental phenomenon of interest. The concept of hope has been explored within numerous research disciplines including psychology, nursing, medicine, philosophy and theology (Scioli, Ricci, Nyugen & Scioli, 2011).

Despite the wide research base, hope remains an elusive and difficult concept to define, partly due to the use of hope in language (Eliott & Olver, 2002). In speech, hope can be used as a noun, verb and/or adjective depending on the intentions of the speaker. Hope can also refer to the present, the future, the past, a state, an amount, or possession which can be subjectively held (Ballard, Green, McCaa, & Logsdon, 1997; Cutcliffe, 1996; Owen, 1989).

Hope is not static and can be used in many different ways. As a noun, hope appears to have properties of an object, and as a verb becomes personalised and active (Eliott & Olver, 2002). The development of language as socially constructed cannot be ignored since the use of hope in the English language ultimately influences the way hope is defined and researched (Potter & Wetherell, 1987). However, hope appears universal. Universal hope has been defined as a general belief in the future, a defence against despair, and a safeguard for the human being (Dufault & Martocchio, 1985; Marcel, 1965). Universal hope highlights the existence of hope cross-culturally, independent of language barriers.

Expressing hope also varies. Hope can be expressed as a feeling, in thinking, and whilst behaving or relating (Averill, Catlin, & Chon, 1990) In addition, hope can function as a state or a trait (Averill et al., 1990). State hope refers to the use of hope in specific situations, fluctuating over time and in response to various events (Averill et al., 1990). Trait hope has been conceptualised as an attitude or approach to life, fluctuating less in response to life events (Averill et al., 1990).

The absence of a unified definition potentially limits clinical applications of hope (Farran, Herth & Popvich, 1995). However, one must question why this is the case in current research. One could infer an absence of a unified definition of hope reflects hope as a concept defying scientific investigation. However, despite the fragmented definitions of hope, various definitions exist and are outlined below.

Hope in Positive Psychology

Positive psychology has been described as the systematic examination of positive experience (Seligman, 2005) including valued subjective experiences such as hope, positive individual traits, and societal aspirations (Seligman & Csikszentmihalyi, 2000). In 2004, Peterson and Seligman conducted a comprehensive examination of positive psychological constructs resulting in the Character Strengths and Virtues Handbook. Character strengths, including hope, were conceptualised as foundations of the human condition, existing on continuums, and varying between and within individuals. Hope was defined as a fulfilling cognitive, emotional and motivational belief or expectation of the future, incompatible with anxiety and depression (Peterson & Seligman, 2004).

Goal-Directed Hope

Depending on the epistemological positions of research, prior research knowledge influences the research process, the chosen research methodology, and methods of data analysis. Realism has influenced the development of operationalized definitions of hope

to objectively quantify the experience using quantitative measures (Miller, 2007). Goal directed hope definitions exist within this paradigm. Goal directed hope has been defined as a positive goal-related motivational state, activated and used to create agency to find pathways to achieving personal goals (Snyder, 2000; 2002; 2004).

Generalised Hope

Definitions of generalized hope appear allied to nursing research and define hope as a complex state of being consisting of multiple dimensions (Miller, 2007). Using definitions of generalized hope, research is less able to operationalize and quantify the experience. Therefore, research needs to adopt a different epistemological position informing alternative research methodology.

In a meta-synthesis of qualitative nursing research examining the concept of hope in healthy and chronically ill individuals, Hammer, Morgensen and Hall (2009) proposed six dimensions of hope. Dimensions of hope included living in hope (being dimension), hoping for something (doing dimension), hope as a light on the horizon (becoming dimension), hope as a human to human relationship (relational dimension), hope versus hopelessness and despair (dialectical dimension), and hope as weathering the storm (situational and dynamic dimension; Hammer et al., 2009). The 'doing' dimension of hope conceptualised by Hammer et al. (2009) has been associated with goal directed definitions of hope (Snyder, 2000; 2002; 2004). Therefore, goal directed hope and generalised hope are interconnected, not separate and independent definitions (Folkman, 2010).

Hope and Chronic Illness

Farran, Herth and Popvich (1995) defined hope as "….a delicate balance of experiencing the pain of difficult life experiences, sensing an interconnectedness with others, drawing upon one's spiritual or transcendent nature, and maintaining a rational

or mindful approach for responding to these life experiences" (p. 5). This resonates with Marcel's (1965) thinking in that hope is activated when individuals are challenged by difficult and potentially hopeless life experiences (e.g. illness, separation).

Activation of hope in hopeless situations creates an interesting dynamic regarding hope. Commonsense could suggest when faced with a hopeless situation, an individual's capacity to hope could be reduced (Groopman, 2004). This is significant for individuals living with lifelong chronic illnesses. Chronic illnesses interrupt the normative life experience, and require individuals to adjust to an alternative future by accommodating restrictions imposed by the illness. The ability to sustain hope in spite of a restricted and potentially distressing future has been conceptualized as a dialectical dimension of hope (Hammer et al., 2009). Individuals can engage in hope whilst confronting hopelessness and despair (Hammer et al. 2009).

In chronic illness, hope appears to facilitate coping and managing stress over time by allowing individuals to hold conflicting expectations simultaneously e.g. hope and hopelessness (Folkman, 2010). In addition, hope has been implicated in coping with chronic illness, and permits engagement in certainty when facing uncertainty (Farran et al., 1995). Furthermore, the activation of goal directed hope (Snyder, 2000; 2002; 2004) appears to be mediated by an individual's perception of threat associated with costs of not achieving a particular goal, uncertainty, and having adequate internal and external resources (Morse & Doberneck, 1995). An increased frequency in perceiving threats to achieving goals could suggest an increase in goal directed hope, therefore a need to hope more frequently.

Conclusions

Although a conclusive definition of hope currently eludes research, a position within the hope literature must be taken to inform the research process. It appears that positioning

research within goal-directed hope or generalised hope influences the type of methodology chosen. Each definition appears to lend itself to either a quantitative or qualitative approach. The current study has positioned itself within the generalised hope discourse, using qualitative methods to investigate hope as an experience. However, part of this experience may include goal directed hope.

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Appendix D

Rationale for Choosing Interpretative Phenomenological Analysis (IPA):

Reflections on ontology, epistemology and reflexivity

Our experiences of the world as researchers' impacts on the way we choose, act, and decide to research the world. Therefore, the role of our own experiences, assumptions, and world views need to be considered within the research process, specifically our ontological and epistemological positions. There are no correct positions in research, but different positions inform various research approaches yielding different types of knowledge. Therefore, understanding our ontological and epistemological positions facilitates us to clearly and critically assess the process of our research, and our reasons for choosing specific research methods.

Ontology and epistemology

Ontology is concerned with the philosophical study of existence or reality. Ontology attempts to answers questions about what entities are real, or said to be real within the world, and deals with the question of what is there to know. Epistemology is the philosophical study of the theory of knowledge, and deals with questions such as what kind of things are knowable, how can we know it, and whether anything can be known for certain (Colman, 2006).

Realism and relativism

Realism assumes there is a real and objective world independent of the human mind. Realist ontology underpins positivism which assumes objective knowledge about the world can be derived through scientific methods, such as observations and experimentation (Fletcher, 1996). Positivism rejects introspective and intuitive

knowledge by focussing on objective and value neutral knowledge (Fletcher, 1996). Developing hypotheses to test using scientific methods and gathering quantifiable data is a quantitative approach to research, underpinned by realist ontology and positivist epistemology.

In contrast, relativism assumes there is no absolute objective reality, and knowledge of the world is created in the human mind (Fletcher, 1996). Therefore, knowledge and understanding of the world is subjective and relative to an individual's interpretation of their private sensory and perceptual experiences. Qualitative research, which is interested in exploring and understanding rather than explaining and quantifying experience, is more affiliated with relativist ontology.

Ontological and epistemological positions of the current research

The experience of hope is likely to be influenced by individuals' life experiences, social relationships, personal world views, beliefs, perceptions and values. In addition, although there is an assumption in the scientific world that an objective and quantifiable illness of relapsing-remitting multiple sclerosis (RRMS) exists, it is also likely to be experienced differently by individuals. Therefore, although individuals' experiences of hope and RRMS may share some attributes, no two individuals are expected to have similar meanings and interpretations of their experience. This reflects relativist ontology.

The view of the researcher is that research is a way of learning, exploring and understanding individuals' experiences rather than attempting to reduce, quantify, or apply existing theories and/ or hypotheses. The researcher views individuals as experts of their experiential knowledge and rejects the nomothetic approach. The nomothetic approach prevents retrieval of data contributed by individuals and instead combines group data (Lamiell, 1987). The researcher is more allied with idiography which is

concerned with the particular and committed to detailing how a particular phenomenon has been understood from the perspective of particular individuals (Smith, Flowers & Larkin, 2009).

Considering the researcher's position, and a paucity of current research into the area of hope in RRMS, it was decided to adopt an exploratory approach using qualitative methodology underpinned by relativist ontology. Due to the complexity associated with the concept of hope and idiosyncratic nature of RRMS, quantification would most likely reduce the value of individual experiences.

Rationale for choosing Interpretative Phenomenological Analysis (IPA)

The researcher considered alternative qualitative approaches prior to selecting Interpretative Phenomenological Analysis (IPA) as an appropriate methodology. Reasons for and against alternative approaches are detailed below.

Grounded Theory

Grounded theory (Glaser & Strauss, 1967) aims to develop or discover a theory which is "grounded" in data from participants who have experienced the process to provide a framework for future research (Strauss & Corbin, 1998). Using this method, the researcher generates theory based on extensive interviewing inquiring about an experience as a sequential process. Generating theory from data indicates the researcher discovers something which already exists in reality (Willig, 2001). Therefore, the researcher is attempting to directly perceive a phenomenon independently from the individual experiencing the phenomenon, which adheres to positivist epistemology (Charmaz, 2006; Clarke, 2005). The researcher did not intend to generate theory but intended to explore experiences. Therefore grounded theory was deemed inappropriate.

Content Analysis

Content analysis is the systematic examination of pre-existing communication or text

regarding a phenomenon by identifying and developing categories (Pope & Mays, 1995). The aim of content analysis is not to generate theory but to identify categories existing within a phenomenon. Categorising phenomenon could be considered reductionist, and since the researcher wished to examine the experience of hope in RRMS in depth, this method was deemed unsuitable.

Discourse Analysis

Discourse analysis focuses on the role of language in the construction of individual social realities (Willig, 2001). Language and the words individuals use to communicate an experience forms the basis of data. This appears to reject the idea that communicating experience involves more than just language. Individuals living with RRMS may communicate their experience of hope in a variety of ways other than language. This may include non-verbal communication, and the processes occurring during relational interactions such as parallel processes. Therefore, discourse analysis was deemed inappropriate in facilitating the researcher to gain a deeper level of interpretation regarding hope in RRMS.

Interpretative Phenomenological Analysis (IPA)

IPA is an exploratory approach committed to examining how individuals make sense of their experiences without attempting to generate theory or draw conclusions (Smith et al., 2009). IPA is informed by three theoretical perspectives including phenomenology, hermeneutics and idiography. Phenomenology attempts to study experience, what it is like to be a human, and what matters to the individual and their lived world. Phenomenological approaches attempt to get as close to the experience as possible since pure experience is inaccessible. Experiences may be expressed in words or they may contain unconscious elements therefore, a level of interpretation is required to access meanings behind the language. In addition, the hermeneutic influence in IPA is

associated with the researcher engaging in a double hermeneutic whereby the researcher attempts to make sense of an experience, which is also being made sense of by the individual (Smith & Osborn, 2003). IPA is also affiliated with idiography by paying attention to the particular, being committed to detail, and how the experience is understood from the perspective of the individual.

After reviewing the theoretical underpinnings of IPA, the researcher considered that they related well to the area of hope in RRMS. Individuals experiences of hope in RRMS are likely to differ and be influenced by nuances within the world around them. In addition, individual experiences of hope in RRMS are considered by the researcher as important in their own right; generalising this experience was deemed inappropriate. Furthermore, the researcher is aware that experiences such as hope and RRMS are idiosyncratic and personal. Therefore, the idiographic approach suits a person centred approach in attending to individual experience.

Following a review of alternative methods of qualitative approaches for the current study, IPA was selected due to its exploratory nature which would facilitate exploring, making sense, and understanding the experience of hope for individuals living with RRMS.

Reflexivity and Credibility

Reflexivity is essential in enhancing the credibility of findings by acknowledging the role of the researcher's assumptions and experiences in shaping the research process (Mays & Pope, 2000). It would be unwise to assert that absolute researcher objectivity is possible, especially using qualitative methods where the researcher is engaged in making sense of an individual's experience. Therefore, the researcher's own

assumptions, experiences, values, and world views, need to be considered to minimise the impact of imposing these onto the individual's experience.

The researcher kept a reflective diary throughout the research process which functioned to bracket and reflect on personal considerations impacting on the research process. Being a fairly young female, sharing a similar life stage to participants may have impacted on how participants chose to share their experiences, and how the researcher understood and interpreted their experiences. It is possible the researcher's previous experience of illness may have impacted on interpretation. In addition, the researcher is in a position to experience both hope and hopelessness. Therefore, prior experiences of being hopeful or hopeless could have impacted how experiences were interpreted. The researcher considers themselves to be a hopeful individual; therefore, taking a hopeful approach to interviewing may have influenced how participants chose to discuss their hope.

To minimise the impact of having a single interpretation, the researcher engaged in a peer IPA research group which provided alternative reflections on transcripts and themes. Four researchers with experience of IPA were involved in this process to ensure interpretations were grounded in the data. In addition, research supervision was used to reflect on transcripts and themes to further ensure validity.

Research supervision was also used to discuss process issues occurring between the researcher and the data during analysis. Using the reflective diary, the researcher reflected on parallel processes occurring during analysis including losing hope, feeling angry and wanting to distance from the analysis yet also needing to be engaged. Research supervision was used to identify whether these emotional reactions were associated with processes of specific parts of transcripts.

Furthermore, research supervision and the reflective diary were used to understand the researcher's relationship to the research process itself. The researcher developed a dynamic relationship with the research. At times, the research was felt as an enemy; a gremlin sent to confound the researcher, tripping the researcher up, and robbing the researcher of time. However, the research was also felt as a constant and comforting presence. The researcher felt the research was a friend at times, teaching, guiding and leading the researcher deeper into participant's experiences.

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Appendix E

Leaflet for obtaining consent to share participant contact information

The Lived Experience of Hope in Relapsing-Remitting Multiple Sclerosis (Version 2)

Opportunity to participate in a study aiming to understand the experience of hope in people diagnosed with Relapsing-Remitting Multiple Sclerosis.

The study is being conducted by me Charity Blamires (Trainee Clinical Psychologist) as part of my Doctoral Qualification in Clinical Psychology and will involve you taking part in an interview where you will be asked questions about your experience of hope.

If you are interested, please provide your contact details below and I will be in touch with you within two weeks.

Thank you for taking the time to read this information.

_ _

Name:

Contact Details:

Best time to contact:

I _ _ _ _ _ _ _ _ _ _ _ _ _ consent to my contact details being shared with Charity Blamires (researcher).

I understand these details will only be used to contact me to talk about the study.

Signed _ _ _ _ _ _ _ _ _ _ _ _ _ _

Date _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Appendix F

Participant Information Sheet

Participant Information Sheet

You are being invited to take part in a research study which aims to learn something about the meaning and experience of hope for people who are living with Relapsing-Remitting Multiple Sclerosis. Before you decide to take part you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like some more information.

Thank you for taking time to read this information.

The Lived Experience of Hope in Relapsing-remitting Multiple Sclerosis (Version 2)

Hope has been described as a positive resource which helps people living with Relapsing-Remitting Multiple Sclerosis to adjust to their illness. Hope also helps to reduce rates of depression in Multiple Sclerosis and plays a key role in coping with the effects of stress over time. However, there appears to be a lack of research discussing what hope means and how it is experienced for people living with Relapsing-Remitting Multiple Sclerosis. By understanding more about hope, the current study aims to contribute to its effects for people living with Relapsing-Remitting Multiple Sclerosis.

What is the purpose of the study?

This study is looking to understand more about the meaning and experience of hope for people who are living with Relapsing-remitting Multiple Sclerosis. Hope can mean different things for different people; what we hope for may be different and how we use hope can vary from person to person. This study aims to investigate what hope means to people living with Relapsing-remitting Multiple Sclerosis, what people's experiences of hope are, what kind of things people hope for, what helps to foster hope, what hinders hope and if hope changes over time. This study hopes to contribute to the understanding of hope and its effects for people living with Relapsing-remitting Multiple Sclerosis.

Why have I been chosen?

This information has been given to all people who attend Multiple Sclerosis Nurse led clinics in the North Yorkshire region who have been diagnosed with Relapsing-remitting Multiple Sclerosis. We are hoping to recruit around 10 individuals in total.

Do I have to take part?

No, the study is voluntary. If you decide to take part you will be asked to sign a consent form to show you have agreed to take part. You may withdraw from the study up to the point of when the researcher will begin to analyse the information you have provided. This analysis will take place after the interview. Up to this point, you can withdraw at any time, without giving a reason; this will not affect the care you receive. After signing the consent form, you can still change your mind about taking part in the study. If you feel this study will be too distressing you do not have to take part. If at any point during

the study you feel uncomfortable in any way or that it is too much trouble, you can withdraw from the study.

What will happen if I decide to take part?

You will have been asked by your MS Nurse to consent to share your contact details with the researcher and the researcher will have then contacted you to share this information to help you make an informed decision about whether or not to take part. If you agree to take part then you will need to complete and sign a consent form. A meeting will be arranged to discuss this with the researcher and this meeting will allow you to ask any questions about the study and your involvement. This meeting will be arranged at your convenience. After you have signed the consent form, you will be asked to provide some information about yourself including your age, diagnosis, age when diagnosed, years of education, religious orientation, marital status, number of dependents, employment status, nature of employment, perceived level of social support, mood, current level of hope and current coping strategies. Then another meeting will be arranged at your convenience to conduct an interview which will last approximately 60 minutes. The interviews will be conducted by a trainee clinical psychologist and the conversation will be audio recorded. There is no right or wrong answers to any of the questions; we want your experience and opinions about hope.

What are the possible disadvantages and risks of taking part?

The questions require you to think about your experience of hope. If following the study you feel concerned about any of the issues raised you will be able to talk to the researcher to discuss what further action you wish to take. Taking part in this study requires some of your time, which may be inconvenient for you. Although unlikely, if sensitive information is divulged or any emotional distress experienced, the researcher will offer support and help you to access your allocated MS nurse, your GP or mental health services.

What are the possible benefits of taking part?

We cannot promise the study will help you although previous research has found that people can find talking about their hopes to be beneficial. It is hoped that the information we get from this study will help improve the understanding and treatment of Relapsing-Remitting Multiple Sclerosis.

What will happen if I decide I no longer wish to take part?

You may withdraw from the study up to the point of when the researcher will begin to analyse the information you have provided. This analysis will take place after the interview. Up to this point, you can withdraw at any time, without giving a reason; this will not affect the care you receive. After signing the consent form, you can still change your mind about taking part in the study.

What if there is a problem?

If you have concerns about any aspect of the study, you should ask to speak to the researchers who will do their best to answer your questions. You can contact the researcher at the Department of Clinical Psychology and Psychological Therapies at the University of Hull on 07806492108 between the hours of 9:00am and 8:30pm. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from your local MS clinic or online at: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

Will my taking part in this study be kept confidential?

Yes. All personal information collected about you during the course of the study will be kept strictly confidential. Any details that could be used to identify you will not be used in the research. Each person will be recorded and identified by a number or a code. All information which is collected about you during the course of the research will be anonymised. Quotes from the interview are used but the source of these quotes will not be identified. The coded data will be stored securely on University Departmental premises for five years after completion of the study.

What will happen to the results of the study?

Upon completion of the study you will not be contacted again unless you wish to receive the results. The results will be written up and submitted for publication in an academic journal. No details will be included in the write up that could be used to identify individual participants. *You will not be personally identified in any of the results.*

Who is organising and funding the research?

The study is being conducted by the researcher as part of the academic requirement for the qualification of a Doctorate in Clinical Psychology. The research is supported by MS clinics in North Yorkshire and is funded by the Humber NHS Foundation Trust.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by a peer review board at the University of Hull and has undergone proportionate review by the NRES Committee South West-Central Bristol.

Further information and contact details

If you have any queries please do not hesitate to contact Charity Blamires whether or not you decide to take part in this research project. I would like to thank you for taking time to read the information.

Mob: XXXXXXXXXXX (between the hours of 9:00am and 8:30pm)
Address: Department of Clinical Psychology and Psychological Therapies
            University of Hull
            Cottingham Road
            Hull

Charity Blamires
Trainee Clinical Psychologist
Humber NHS Foundation Trust
University of Hull

Appendix G

Consent Form

Participant Pseudonym for this study:

CONSENT FORM

Title of project: The Lived Experience of Hope in Relapsing-Remitting Multiple Sclerosis

Name of researcher: Charity Blamires

	Please initial the box

1. I confirm that I have read and understand the information sheet dated 02/07/2012 (version 3.0), for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw up to the completion of the interview without giving any reason, without any legal rights or care being affected.	☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the NHS Trust, where it is relevant to my taking part in this research. I give Permission for these individuals to have access to my records.	☐
4. I am aware of the potential risks and benefits of taking part.	☐
5. I agree to take part in the above study.	☐
6. I agree to allow the named researcher to contact me using contact details I provide.	☐

Name of participant   Date   Signature

Name of person   Date   Signature
Taking consent

Appendix H

Demographic Information Sheet

Demographic Information

Participant Pseudonym:

Age:

Diagnosis:

Age when diagnosed:

Years of Education:

Religious Orientation:

Marital Status:

Number of Dependents:

Employment Status:

Nature of Employment:

Perceived Level of Social Support:

1	2	3	4	5	6	7	8	9	10
Poor									Good

Perceived Mood:

1	2	3	4	5	6	7	8	9	10
Low									High

Perceived Level of Hope:

1	2	3	4	5	6	7	8	9	10
Hopeless									Hopeful

Current Coping Strategies:

Appendix I

Interview Schedule

(P = Prompt)

<u>Generating a Common Understanding of Hope</u>

1. *Based on your own experiences how would you define hope generally?*
    P How would you explain hope to someone else? What would you say?
    P If we were trying to write a definition for a dictionary, what would you put?
    P What would you want to tell people that hope means?

2. *Can you tell me about your hope for you?*
    P What does hope mean to you?
    P What kinds of things do you hope for?
    P Do you have hope?

<u>Current Life Circumstances</u>

3. *Can you tell me about how hope relates to your life currently?*
    P Where are you in terms of the definition we have just discussed?
    P How hopeful or hopeless do you feel currently?
    P What is it about your life currently which makes you feel hope or a lack of hope in this way?

<u>Generating Hope</u>

4. *What has helped you to generate hope?*
    P If you could identify a source of hope for yourself what would it be?
    P Where do you think you get your hope from?
    P Is there a place you draw hope from?
    P How do other people in your life help you to generate hope?

<u>Loss of Hope</u>

5. *Are there things/situations that cause you to lose hope?*
    P Can you think of a time when your hope felt low?

P When your hope has been low, what kinds of things do you so to help yourself   regain hope?

P Are there things that help you to feel hopeful?

Maintaining Hope

6. *How do you maintain your hope? What helps you to maintain your hope or makes you feel hopeful?*

P How do you stay hopeful?

P What helps you keep hope/hopeful?

P Are there things that help you to feel hopeful?

Changing Nature of Hope

7. *How has your hope changed since you were diagnosed?*

P What effects of being diagnosed do you think had on your sense of hope?

P How do you think your sense of hope has been used to adjust to your diagnosis?

P What effect do drug treatments have on your sense of hope?

8. *How has your hope changed after experiencing relapses?*

P How does your sense of hope change after you have experienced a relapse?

P If you feel your hope is low after a relapse what helps you to increase hope?

P What about relapses prevents you from feeling hopeful?

P What about relapses helps you to feel hopeful?

9. *What does hope mean to you if you look towards the future?*

P Do you feel hope enables you to think differently about the future?

P How does hope help you to think about your future?

10. *Is there anything else you would like to say about hope that you have not discussed already about your hope?*

P Is there anything else that I haven't asked you that you think I should know?

P Or anything else you think is important I should know about hope?

<u>Close of Interview</u>

11. How are you feeling after what you have discussed today?

12. How do you feel the interview went?

Appendix J

Worked Example of Interpretative Phenomenological Analysis (IPA):

Creations of Themes

A section of transcript from one participant follows to illustrate stages of the IPA process in the creation of themes. This excerpt is from an interview with 'Rachael' who was diagnosed with RRMS at the age of 32.

Extract of Transcript

Researcher: *Yeah, at the time when you're ill, when you're in it, that's the time when….*

Rachael: You are too ill. You are too ill to have any emotions about anything. Well, I most certainty have been this year. I, I was so ill it was like (pause), I'd like to say it like having flu, not a cold, flu, but it's isn't because something happens in your head so you are reduced to 10% of what, who I am. So there is no humour. I am not looking to laugh but I am looking to laugh normally, erm, I don't want, I can't communicate. It's too much. That would make me shake [*shakes*], do that, shaking if I had to have a conversation.

Researcher: *Can I ask you what's going on, if you don't mind. If anything in the interview is too distressful to talk about please let me know, but what's going on in your head at that time when you were at that 10%?*

Rachael: Not good things. Facing you own mortality. Erm it's not good no. Its, err, I think what anybody thinks about when, erm, if they had a car crash and they can't walk. Being able to not walk and not lift your arms. But it's what happened in your head as well, (*yeah*), erm, so it's not just

physical things, it does not make you feel good. It's black. That's how I describe it its pure black and those thoughts are there all the time, So yeah, awful in that bit, but I do, I do know and I understand what happens with the disease, or I think I do, (*yeah*) erm, that that is me being ill. That is not where I am going to left (*yeah*) is in that really poorly, erm, place. I know I will improve from there and if I am left with, erm, issues then life will adapt to compensate for those.

Researcher: *Do you think hope plays a role in that from when you become ill do you think hope plays a role in getting out of that getting out of that blackness?*

Rachael: Yes because you could choose at that point to stay in that blackness. I could still be in that blackness couldn't I? I could still be saying, I had another thing 3 weeks ago and I could still be saying "Oh I feel really tired", which I do, "I am just going to lie on the sofa and have everybody run the kids backwards and forwards", erm, but that's just being a pest to other people and I don't like being a pest to other people. Erm, so absolutely not, go out with my friends this afternoon, I have looked forward to it all week the fact that (child's name) is chucking up, I will still go cos' it's what two hours of (pause) laughing. Yeah, I completely download everything from the week with my friend and say ninininnee. There's somebody that we have a problem with, another mum, so we have to talk about her (*right*) who abuses both of our natures and, err, so we talk about her and then the rest of its just having a laugh and then I come home and I feel fab and then that might be pretty much all, you

know, cook tea, lie on the sofa, fall asleep at 9 0' clock and that's ma day

done.

Stage 1 Analysis

Transcripts were continually read and re-read to facilitate engagement and

understanding of the whole text. Audio recording of interview was also listened to

during reading.

Stage 2 Analysis

The left hand margin of transcript was used to note initial ideas, specific points, and to

identify semantic content using descriptive, linguistic and conceptual comments to

inform reflexive engagement with the data.

Initial Comments	Transcript
	Researcher: Yeah, at the time when you're ill when you're in it that's the time when…. Rachael: You are too ill. You are too ill to have any emotions about anything. Well, I most certainty have been this year. I, I was so ill it was like (pause), I'd like to say it like having flu, not a cold, flu, but it's isn't because something happens in your head so you are reduced to 10% of what, who I am. So there is no humour. I am not looking to laugh but I am looking to laugh normally, erm, I don't want, I can't communicate. It's too much. That would make me shake [*shakes*], do that, shaking if I had to have a conversation.
Disconnect from emotion Making sense of symptoms Mind-body links Whole body experience Reduced, diminished self Void of positive emotions Disconnecting from normality Isolation Anxiety	

	Researcher: Can I ask you what's going on, if you don't mind. If anything in the interview is too distressful to talk about please let me know, but what's going on in your head at that time when you were at that 10%?
Existential crisis Questioning mortality Catastrophic loss; disconnect Sudden loss of physical and mental abilities; unease Black void; absence of colour; nothingness; persistence of thought; unable to avoid or appease Knowledge empowering Separates self/ illness Knowledge of recovery; adapting; compensating Impermanence	Rachael: Not good things. Facing you own mortality. Erm, it's not good, no. Its, err, I think what anybody thinks about when, erm, if they had a car crash and they can't walk. Being able to not walk and not lift your arms. But it's what happened in your head as well, (*yeah*), erm, so it's not just physical things, it does not make you feel good. It's black. That's how I describe it its pure black and those thoughts are there all the time, So yeah, awful in that bit, but I do, I do know and I understand what happens with the disease, or I think I do, (*yeah*) erm, that that is me being ill. That is not where I am going to left (*yeah*) is in that really poorly, erm, place. I know I will improve from there and if I am left with, erm, issues then life will adapt to compensate for those.
	Researcher: Do you think hope plays a role in that from when you become ill do you think hope plays a role in getting out of that getting out of that blackness?
	Rachael: Yes because you could choose at that point to stay

Questions self	in that blackness. I could still be in that blackness couldn't
Choice: blackness	I? I could still be saying, I had another thing 3 weeks ago
Specific event of being ill	and I could still be saying "Oh I feel really tired", which I
Burden on others	do, "I am just going to lie on the sofa and have everybody
	run the kids backwards and forwards", erm, but that's just
	being a pest to other people and I don't like being a pest to
Seeking social interaction	other people. Erm, so absolutely not, go out with my friends
Pleasurable activities	this afternoon, I have looked forward to it all week the fact
Carry on regardless	that (child's name) is chucking up, I will still go cos' it's
Valuing things in life	what two hours of (pause) laughing. Yeah, I completely
Positive emotion	download everything from the week with my friend and say
	nininnee. There's somebody that we have a problem with,
Normalities of life; gossip	another mum, so we have to talk about her (*right*) who
Having a confident; trustful	abuses both of our natures and, err, so we talk about her and
relationship	then the rest of its just having a laugh and then I come home
	and I feel fab and then that might be pretty much all, you
Importance of routine	know, cook tea, lie on the sofa, fall asleep at 9 0' clock and
	that's ma day done.

Stage 3 Analysis

The right hand margin of transcripts was used to note emerging themes by mapping interrelations and connections within the transcript. These themes were clustered prior to returning to the transcript to ensure analysis was grounded in the narrative. This process was repeated for each transcript.

Initial Comments	Transcript	Emerging Themes

	Researcher: Yeah, at the time when you're ill when you're in it that's the time when….	
Disconnect from emotion	Rachael: You are too ill. You are too ill to have any emotions about anything. Well, I most certainty have been this year. I, I was so ill it was like (pause), I'd like to say	Disconnections
Making sense of symptoms	it like having flu, not a cold, flu,	
Mind-body links		
Whole body experience	but it's isn't because something	Disconnections
Reduced, diminished self	happens in your head so you are reduced to 10% of what, who I	
Void of positive emotions	am. So there is no humour. I am	Void of hope
Disconnecting from normality	not looking to laugh but I am	
Isolation	looking to laugh normally, erm, I don't want, I can't communicate.	Disconnections
	It's too much. That would make	
Anxiety	me shake [*shakes*], do that, shaking if I had to have a conversation.	
	Researcher: Can I ask you what's going on, if you don't mind. If anything in the interview is too distressful to talk about please let	

	me know, but what's going on in your head at that time when you were at that 10%?	
		Reminders
Existential crisis Questioning mortality	Rachael: Not good things. Facing you own mortality. Erm, it's not good, no. Its, err, I think what anybody thinks about when, erm, if they had a car crash and they	Disconnections Loss
Catastrophic loss; disconnect Sudden loss of physical and mental abilities; unease	can't walk. Being able to not walk and not lift your arms. But it's	
Black void; absence of colour; nothingness; persistence of thought; unable to avoid or appease	what happened in your head as well, (*yeah*), erm, so it's not just physical things, it does not make you feel good. It's black. That's how I describe it its pure black	Void of hope Menacing reminder
Knowledge empowering Separates self/ illness	and those thoughts are there all the time, So yeah, awful in that bit, but I do, I do know and I	Coping Adjustment Coping
Knowledge of recovery; adapting; compensating Impermanence	understand what happens with the disease, or I think I do, (*yeah*) erm, that that is me being ill. That is not where I am going to left	Adjustment
	(*yeah*) is in that really poorly, erm, place. I know I will improve from	Perspective
	there and if I am left with, erm,	

	issues then life will adapt to compensate for those.	
	Researcher: Do you think hope plays a role in that from when you become ill do you think hope plays a role in getting out of that getting out of that blackness?	Hope and Choice
Role of hope: Choice to stay disconnected and in the void (blackness)	Rachael: Yes because you could choose at that point to stay in that blackness. I could still be in that blackness couldn't I? I could still be saying, I had another thing 3 weeks ago and I could still be saying "Oh I feel really tired", which I do, "I am just going to lie on the sofa and have everybody run the kids backwards and forwards", erm, but that's just being a pest to other people and I don't like being a pest to other people. Erm, so absolutely not, go out with my friends this afternoon, I have looked forward to it all week the fact that (child's name)	
Specific event of being ill		
Burden on others		Motivation: Hope and Others
Seeking social interaction		Role of others and hope
Pleasurable activities		
Carry on regardless		
Valuing things in life		Perspective

Positive emotion	is chucking up, I will still go cos' it's what two hours of (pause) laughing. Yeah, I completely download everything from the week with my friend and say ninininnee. There's somebody that we have a problem with, another mum, so we have to talk about her (*right*) who abuses both of our natures and, err, so we talk about her and then the rest of its just having a laugh and then I come home and I feel fab and then that might be pretty much all, you know, cook tea, lie on the sofa, fall asleep at 9 0' clock and that's ma day done.	Normalities of life Connecting to others Importance of valued relationships
Normalities of life; gossip Having a confident; trustful relationship		
Importance of routine		Comforts of normality and routine

Stage 4 Analysis

Quotes from transcripts were identified supporting emerging themes. At this stage, emerging themes were checked and validated by peers in a peer IPA research group and during research supervision to ensure they were grounded in the data.

Emerging Theme	Supporting Quotes
Disconnections (Hopelessly	'You are reduced to 10% of what, who I am.' 'Not good things. Facing you own mortality. Erm, it's not

Disconnected, Menacing Reminders)	good, no.' 'Being able to not walk and not lift your arms. But it's what happened in your head as well, (*yeah*), erm, so it's not just physical things, it does not make you feel good.'
Void of hope (Hopelessly Disconnected)	'So there is no humour. I am not looking to laugh but I am looking to laugh normally….' 'You are too ill to have any emotions about anything.' 'It's black. That's how I describe it its pure black and those thoughts are there all the time, So yeah, awful in that bit….'
Coping/ Adjustment/ Perspective (Hoping and Coping: Taking the Long View)	'I understand what happens with the disease, or I think I do, (*yeah*) erm, that that is me being ill. That is not where I am going to left (*yeah*) is in that really poorly, erm, place. I know I will improve from there and if I am left with, erm, issues then life will adapt to compensate for those.'
Hope and Choice (Hoping and Coping)	'Yes, because you could choose at that point to stay in that blackness. I could still be in that blackness couldn't I?'
Connecting to others (Hopefully Connected: You can't Hope on Your Own)	'I could still be saying "Oh I feel really tired", which I do, "I am just going to lie on the sofa and have everybody run the kids backwards and forwards", erm, but that's just being a pest to other people and I don't like being a pest to other people.' '…..go out with my friends this afternoon, I have looked

	forward to it all week the fact that (child's name) is chucking up; I will still go cos' it's what two hours of (pause) laughing.'
Comfort of Normality and Routine (Hoping and Coping: Valuable Anchors)	'Yeah, I completely download everything from the week with my friend….' '….the rest of its just having a laugh….' 'I come home and I feel fab and then that might be pretty much all, you know, cook tea, lie on the sofa, fall asleep at 9 0' clock and that's ma day done.'

Stage 5 Analysis

Following analysis of individual transcripts, emerging themes across cases were collated facilitating the development of a list of superordinate themes and subthemes. Superordinate themes and subthemes were checked against transcripts to ensure they were grounded in the data. Themes were not selected due to prevalence but in relation to the richness of participants' accounts.

Appendix K

Guidelines for Authors: Disability and Rehabilitation

Disability and Rehabilitation

Instructions for Authors

Disability and Rehabilitation is an international interdisciplinary journal and particularly welcomes contributions from a wide range of professional groups, including medical practitioners, occupational therapists, physiotherapists, speech and language therapists, clinical psychologists and those involved in nursing, education and engineering.

Disability and Rehabilitation is organised into sections: Reviews; Research Papers; Case Studies; Perspectives on Rehabilitation; reports on Rehabilitation in Practice, Education and Training and Correspondence. Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

Submissions and Peer-Review
All submissions should be made online at *Disability and Rehabilitation*'s ScholarOne Manuscripts site: http://mc.manuscriptcentral.com/dandr
Authors are given the option to remain anonymous during the peer-review process. Authors will be able to indicate whether their paper is 'Anonymous' or 'Not Anonymous' during manuscript submission, and should pay particular attention to the below:

Authors who wish to remain anonymous should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the "Main Document" and will be sent to the referees. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.

Authors who wish to be identified should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the "Main Document".

All submissions should include a separate title page that contains contact information for the authors(s).This should be uploaded as a 'Title Page' and will not be sent to referees.
If a paper is deemed to be acceptable for publication pending minor revision, the author(s) names may be disclosed to the referees when the Editor's decision is made, irrespective of whether the authors names(s) were included as part of the original submission. Every effort will be made to keep the author(s) name(s) anonymous, if required, should the paper require extensive revision and further peer-review. If authors wish to remain anonymous throughout the second round of peer-review, they are reminded not to include identifying information in the 'Authors Response' section during the upload of their revised paper. Every paper that is revised and resubmitted must clearly indicate the parts of the manuscript that contain amendments, by highlighting the revised text in a different colour or by using 'Track Changes' (for minor revisions).
Please contact the Editor if you require more information.
Systematic Reviews should be submitted as a 'Review' and Narrative Reviews should be submitted as 'Perspectives in Rehabilitation'. All Systematic Reviews will be automatically submitted for the annual Best Review Paper competition.

Education and Training
This is a new section for the journal. It will publish papers relating to the education and professional training of those working in the field of rehabilitation. Papers are encouraged which develop innovatory approaches to this process and provide multi-disciplinary and international comparisons for those working in the field. Through this new section it is intended to contribute towards the development of education and training within these professional groupings. Papers should be submitted with any tables, figures, or photographs, all of which should be of high

quality suitable for reproduction. Submissions should be in English presented in double line spacing. Submissions should include, where appropriate, a formal statement that ethical consent for the work to be carried out has been given. Photographs of patients should be avoided, but if essential, patients' consent in writing must accompany manuscript. It is not sufficient to mask identity by covering the patients' eyes.

Word Limit

There is no stated word limit to papers submitted to *Disability and Rehabilitation*. It should however be noted that space is at a premium and therefore succinct and well-constructed papers are more likely to be reviewed positively. However, the key to evaluating a paper will be the quality of the work along with the methodology adopted particularly for qualitative studies which do tend to be longer.

Disability and Rehabilitation considers all manuscripts at the Editor's discretion; the Editor's decision is final. Please see below for information on the Journal's Appeal Procedure.

Disability and Rehabilitation considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to *Disability and Rehabilitation*, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which *Disability and Rehabilitation* incurs, and their papers will not be published. Copyright will be transferred to *Disability and Rehabilitation* and Informa UK Ltd., if the paper is accepted.

IMPLICATIONS FOR REHABILITATION

A feature of the Journal is a boxed insert on 'Implications for Rehabilitation'. This box should include between two to four main bullet points drawing out the implications for rehabilitation for your paper.

All papers including reviews, research, rehabilitation in practice, perspectives on rehabilitation, case studies and a new section on education and training for rehabilitation professionals must include this feature. This should be uploaded as a separate document through Manuscript Central as a single side of A4 during submission.

Included below are examples. If you have any questions, please contact the Editor.

Example 1: Leprosy
• Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
• Reconstructive surgery is a technique available to this group.
• In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis
• Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
• People with MS have complex reasons for choosing to exercise or not.
• Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

Example 3: Community Based Rehabilitation
• Community Based Rehabilitation (CBR) is a Western concept that may not readily fit other cultures.
• CBR needs to be 'owned' by those involved and subject to re-interpretation to be effective in other cultures.

Manuscript Preparation

In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type

upon submission. These should be submitted as 'Image' files during submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples).

Structure of Paper
Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (uploaded as separate files); figures with captions (uploaded as separate files).

An introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation; standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section. Extensive tabulations will not be accepted unless their inclusion is essential.

Title Page
A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing the article. The title page should be uploaded separately to the main manuscript and designated as 'title page' on ScholarOne Manuscripts. This will not get sent to referees.

Abstracts
Structured abstracts are required for all papers, and should be submitted as detailed below, following the title page, preceding the main text.
Purpose State the main aims and objectives of the paper.
Method Describe the design and methodological procedures adopted.
Results Present the main results.
Conclusions State the conclusions that have been drawn and their relevance to the study of disability and rehabilitation.
The abstract should not exceed 200 words.

Nomenclature and Units
All abbreviations and units should conform to SI practice. Drugs should be referred to by generic names; trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Copyright Permission
Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than fifty word) extract from the text, from a source which is copyrighted - or owned - by a party other than Informa UK Ltd or the contributor. This applies both to direct reproduction or 'derivative reproduction' - when the contributor has created a new figure or table which derives substantially from a copyrighted source.

Code of Experimental Ethics and Practice
Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

Tables, figures and illustrations
The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written 10.0 SD 2.65. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4 ± and a group all precisely 4.0 years, 4.0. Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or

figure] 1 ...' (not Tab., fig. or Fig). The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript:

Insert table 2 about here[4]

Each table and/or figure must have a title that explains its purpose without reference to the text. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Tables
Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations
Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher. Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

Acknowledgments and Declaration of Interest sections
Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section
Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section
All declarations of interest must be outlined under the subheading 'Declaration of interest'. If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report no declarations of interest.* When submitting a paper via ScholarOne Manuscripts, the 'Declaration of interest' field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission. Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement.

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Mathematics

Click for more information on the presentation of mathematical text.

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[4] For ease of reading, tables and figures were included in the main body of the text.

References[5]

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus. Examples are provided as follows:

Journal article:
[1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. Science 1992;258:1122-9.

Book chapter:
[2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. The pharmacological basis of therapeutics. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings:
[3] Irvin AD, Cunningham MP, Young AS, editors. Advances in the control of Theileriosis. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis:
[4] Mangie ED. A comparative study of the perceptions of illness in NewKingdom Egypt and Mesopotamia of the early first millennium [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet:
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APPEAL PROCEDURE
Disability and Rehabilitation **and** ***Disability and Rehabilitation: Assistive Technology***
The Editors of both Journals will respond to appeals from Authors relating to papers which have been rejected. The Author(s) should email the Editor outlining the concerns and making a case for why their paper should not have been rejected. The Editor will undertake one of two courses of action:

1: The Editor Accepts the Appeal
I. In this case the Editor will secure a further review making available confidentially the relevant information for the reviewer
II. The Editor on receiving the review will either accept the appeal and therefore invite a resubmission for further review; or reject the appeal and no further action will be taken.
III. If an appeal is rejected there will be no further right of appeal within the jurisdiction of the Journal.

2: The Editor does not uphold the Appeal

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[5] For ease of reading, the American Psychological Association (APA) reference style was adopted instead of the Council of Science Editors (CSE) Citation & Sequence format.

I. If the Editor does not accept the appeal and is not prepared to secure further review the decision will be referred to the Editor of the relevant affiliated Journal for independent consideration. In the case of *Disability and Rehabilitation*, the Editor of *Disability and Rehabilitation: Assistive Technology* will be contacted, and if an appeal is not upheld by the Editor of *Disability and Rehabilitation: Assistive Technology*, the Editor of *Disability and Rehabilitation* will be consulted.

II. The Editor will either confirm the decision or recommend that a further review be obtained.

III. Therefore, if both Editors agree that the appeal should not be upheld there will be no further right of appeal within the jurisdiction of the Journal.

Dave Muller, Editor in Chief, ***Disability and Rehabilitation***
Marcia Scherer, Editor, ***Disability and Rehabilitation: Assistive Technology***

Appendix L

**Implications for Rehabilitation: Feature for the journal Disability &
Rehabilitation**

"A feature of the Journal is a boxed insert on 'Implications for Rehabilitation'. This box
should include between two to four main bullet points drawing out the implications for
rehabilitation for your paper. All papers including reviews, research, rehabilitation in
practice, perspectives on rehabilitation, case studies and a new section on education and
training for rehabilitation professionals must include this feature. This should be
uploaded as a separate document through Manuscript Central as a single side of A4
during submission."

**Paper 1: Are we getting it right? Experiences of living with Multiple Sclerosis: A
qualitative meta-synthesis**

(i) Person centred care has been recommended as a healthcare approach to
multiple sclerosis (MS) service provision.

(ii) People living with MS have complex and diverse healthcare needs.

(iii) Person centred care provides an approach in meeting individual MS healthcare
needs holistically.

**Paper 2: A Qualitative Study of Experiences of Hope in Relapsing-Remitting
Multiple Sclerosis**

(i) The concept of hope is associated with positive adjustment in relapsing-
remitting multiple sclerosis (RRMS).

(ii) People living with RRMS have complex reasons for losing hope.

(iii) The role of family and healthcare services are important in encouraging hope
in RRMS.

Appendix M

Reflective statement

Introduction

This reflective statement will attempt to detail what I have learnt about my approach to research. By reflecting on the process of carrying out research from conception to results, I will seek to discover what will help in future research endeavours.

Project Development

During my experience of clinical psychology training, I have been struck by people's ability to overcome adversity when confronting illness. Adversity is part of the human condition, to be endured by most, but so is surviving, to persevere and carry on in spite of life's trials. This urged me to explore research examining positive human strengths facilitating adaptation to adversity. Positive psychology provided a large research base examining positive strengths, including the concept of hope. Reviewing this literature coincided with training in a recovery orientated psychosis service which used the recovery model (Shepherd, Boardman & Slade, 2008). In this model, hope is a central tenet of recovery. This led me to develop questions regarding the role of hope and recovery in lifelong chronic illnesses and illnesses which follow a pattern of recovery and relapse over time.

Returning to the literature, I began exploring lifelong, chronic, and relapsing illnesses and identified relapsing-remitting Multiple Sclerosis (RRMS). Upon closer examination of the RRMS literature, I was struck by the dominance of biomedical research focussed on physical deficits of the illness experience. I was filled with a sense of hopelessness and wondered how this was experienced by people living with RRMS. I was keen to

understand whether hope exists for people living with RRMS and if it does, how is it experienced, where does it come from, what helps to generate and maintain it despite continuous threats of future relapse and disability? These questions were informed by my personal beliefs and knowledge regarding RRMS. Therefore, reflecting on researcher subjectivity began early in the research process.

The Literature Review

Initially, I considered systematically reviewing literature regarding the role of hope in relapsing-remitting conditions. However, there was a lack of coherence regarding relapsing-remitting conditions creating difficulty in defining a review question. At the same time, I was involved in a service users group designed to support the development and learning of clinical psychology trainees. Engaging and listening to people talk about their experiences of services led me to consider how people living with MS experience services.

After returning to the literature exploring MS service provision in the UK, person centred care was identified which appeared to consider the importance of people's experiences and needs. I wondered whether providing a comprehensive account of living with MS may facilitate healthcare professionals and services in identifying person centred needs. I also wondered whether hope would be identified as a need for people living with MS.

Choosing to conduct a meta-synthesis seemed appropriate to the focus of the review. However, reviewing literature debating methods of meta-synthesis, it became clear I needed to be sensitive to synthesising studies using qualitative methods informed by various theoretical underpinnings and epistemology. Keeping the focus of the review in mind helped to select an appropriate meta-synthesis method, in addition to selecting studies using phenomenological informed methods.

Examining similar meta-syntheses helped to develop search terms needed to capture studies for the review. In addition, alternative words were generated and included searching for peoples' views, perspectives, meanings, insights, experiences, lived experiences and subjective experiences of MS. Nursing research dominated published meta-syntheses and qualitative studies examining the lived experience of MS. This reinforced thoughts about the clinical implications of the meta-synthesis in MS services.

Journal Selection

Articles identified during the literature review had been published in the journal Disability and Rehabilitation informing the selection of this journal. In addition, articles published in this journal tend to reach a wide audience as it publishes articles from a range of disciplines including clinical psychology. Since the needs of individuals living with MS are multifaceted and require involvement of many different services, I wanted the research to be received by as many people as possible. This will hopefully enhance the clinical utility of the current research.

Design of the Empirical Study

Exploring and understanding experience as opposed to quantifying experience seemed appropriate for exploring hope in RRMS following a review of the hope literature. Many different definitions of hope exist. Operationalized definitions of hope existed in quantitative research which tended to focus on specific aspects of the hope, reducing and compartmentalising the experience. I also identified a paucity of research examining hope in RRMS. Therefore, an exploratory design using qualitative methods was chosen. Using this design aimed to provide insights which could function as starting points for future quantitative research.

I have learnt from conducting this research that careful consideration of ethical issues during conception and implementation is essential. The skills learnt through clinical

psychology training assisted me in establishing a clear pathway for potentially distressed participants to resolve any potential ethical issues.

The design of the study also involved considering logistical issues such as time management, travelling to locations, and arranging meetings with MS nurses. The logistical process began early which helped in mitigating the effects of potential problems. In addition, I observed a number of MS clinics with the MS nurse which facilitated my understanding of MS service provision and living with MS.

Participants

Establishing a good relationship with the MS nurse was crucial in recruiting participants. Spending time with the MS nurse helped me to notice how well she knew her clients, and the care and attention she paid to their experiences. Through our conversations, it was clear she had an interest in the current research, and had previous research experience. It was also essential she was provided with clear, uncomplicated instructions helping to minimise the time taken to recruit participants. She was also sensitive to selecting people who she thought would be hopeful. This was used to reflect on how this may impact on the research process. Establishing good rapport with the MS nurse, being physically visible in the MS clinic, and providing clear instructions regarding recruitment minimised problems. Interestingly, the smooth recruitment process may reflect interest from people living with RRMS in discussing hope.

I chose to contextualise the sample of participants as much as possible to adhere to sampling procedures regarding IPA (Smith, Flowers & Larkin, 2009), in addition to situating the sample for potential readers (Elliot, Fisher & Rennie, 1999). I chose to obtain demographic information, in addition to obtaining subjective measures of hope, mood, social support, and coping strategies. Upon reflection, I did not need to obtain this information since participants discussed these issues during the interview.

Interviews

The interview process was the most enjoyable part of the research. Interviews were conducted in participants' homes. This provided a comfortable and private location in which participants were able to access facilities and social support quickly if required. It was interesting to reflect on whether participants may have shared different experiences if interviews were conducted in the MS clinic. The MS clinic is primarily associated with their experiences of RRMS. My style of interviewing developed over the course of interviews. During the first interview, I noticed conversations beginning before I had turned the audio recorder on, which could have provided valuable insights into living with RRMS. Therefore, in subsequent interviews, I balanced using conversation with completing paperwork earlier so I was able to record sooner.

Participants discussed a variety of topics reflecting the shifting nature of RRMS in their lives. The interview schedule provided some structure however; I was keen to curiously explore topics brought up by participants. I believe this is what led to a rich description of hope in RRMS but also extended the length of interviews. Metaphors and personal strengths were described by all participants, but I noticed participants changing the subject quickly when asked about hopelessness which could be interpreted as a protective response.

I noticed participants' using the phrase 'you know' when discussing their experiences. I have not experienced RRMS but I have experienced being hopeful and hopeless so I believe empathy was established. I am close in age and in a similar life stage to participants which could have facilitated the relationship. Participants were keen to help me by asking if their answers were helpful, by making me comfortable in their home, and by saying at the end of the interview if there was anything else they could do.

I was acutely aware of imposing my own personal assumptions and knowledge of psychological constructs onto participants' experiences during the interviews. Use of a reflective diary and research supervision was crucial in bracketing this knowledge to facilitate reflective engagement with participants' accounts. In addition, I reflected on the difference between therapeutic interviews and research interviews to maintain a researcher interview stance.

Identifying a saturation point was difficult due to my lack of experience and confidence in using qualitative research methods, in addition to anxiety associated with missing important insights. Reaching data saturation is a subjective matter and something which I reflected on in research supervision. Following the end of the fifth interview, I noticed similar themes, confirmed in the sixth and final interview, which influenced my decision to stop collecting data.

Analysis

Data analysis was challenging and intense, magnified by the length and richness of interviews. Initial stages of analysis involved noting ideas and interests which consumed nearly every sentence. However, intensely engaging in the analysis allowed me to know the data well, facilitating further stages of analysis. I quickly noticed how I became lost in the analysis. I would often practice techniques to keep myself grounded in specific parts of the data included using a reflective diary to note emotional reactions, keeping a chronological log of ideas, themes, and metaphors which popped into my head, and identifying my own conceptions. Research supervision and a peer IPA research group also helped me to take an objective stance on the data. This helped to prevent confirmation bias and to provide external credibility checks ensuring analysis was grounded in the data.

Analysis was not a linear process and I found myself continually shifting between transcripts, initial ideas, themes, and quotes to ensure themes were grounded in the data. There was a fine line between conducting a descriptive and an interpretative analysis and I found myself doing both during analysis. However, returning to the transcripts, using research supervision, a reflective diary, and the peer IPA research group, facilitated a compromise between descriptive and interpretative analyses.

Results: A Reflection

Hope existed as an experience in spite of RRMS and appeared related to significant relationships during development and in adulthood. The results contribute to the debate regarding hope, and hope in the experience of chronic illnesses such as RRMS. I was highly invested in being able to communicate participants' experiences of hope. I feel the results captured both overarching and idiosyncratic facets of the hope experience in RRMS.

Personal Reflections

Although this reflective statement marks the end of my research journey, it also marks the beginning of my experience into the research world. Thinking reflectively about research itself, research has no end. Research is a continuous process, growing exponentially, shifting and transforming based on insights and the kind offer of time by many. Research is dynamic, moving in giant leaps or small steps. Each leap or step builds on the last, gathering momentum and propelling the human race into a changing present and an unlived future of possibilities. Writing this reflective statement was left to very end of the research process; perhaps appropriately, since it marks the end of a three year journey. It has been a journey which has left a permanent mark, creating personal change and growth, and has opened doors to knowledge which were once

previously closed.

References for Appendix M: Reflective Statement

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