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The Psychological Processes of Adaptation and Hope in Patients with Multiple Sclerosis: A Thematic Synthesis

Andy Soundy[1*], Carolyn Roskell[1], Tracey Elder[1], Johnny Collett[2], Helen Dawes[2]

[1]Department of Physiotherapy, School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Edgbaston, Birmingham, UK
[2]Department of Sport and Health Sciences, Faculty of Health and Life Sciences at Oxford Brookes, University, Oxford, UK
Email: [*]A.A.Soundy@bham.ac.uk

Abstract

Purpose: The purpose of the current research was to review the lived experiences of patients with multiple sclerosis (MS) in order to extrapolate the psychological process of adaptation. Methods: A thematic synthesis was undertaken within 3 phases: systematic search for literature, critical appraisal of included studies and synthesis of research. Results: A total of 47 studies were included in this review, this included 1146 (812 females, 265 males, and 69 unknown) unique patients with MS (aggregated mean age: 49.3 years [30/47 studies], aggregated time with illness: 12.3 years [28/47 studies]). The critical appraisal of research illustrated that the design of the studies and the reference to reflexivity in studies were not well considered. The synthesis was able to identify a primary response of psychological adaptation as well as distinct coping strategies. A model of emotion, hope, and adjustment was identified. Conclusion: Simple processes of adaptation for people with MS can be considered by clinicians and utilised to promote mental well-being in patients. Clinicians and researchers also need to be aware of the important psychological needs of patients during interactions. Discussion and clinical implications are provided.

Keywords

Qualitative, Meta-Synthesis, Adaptation, Hope, Neurology, and Multiple Sclerosis

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[*]Corresponding author.

1. Introduction

Multiple sclerosis (MS) is a disease affecting the brain and spinal cord which is typically defined within different descriptors that identify the state and course of the illness [1]. It is characterised by an unpredictable course, but often leads to substantial disability [2]. Approximately 2.1 million people in the world are affected [3], within the United Kingdom this represents around 0.3% of the population. MS has a higher incidence in women than men, with a peak onset between the ages of 40 - 50 years [4]. MS is reported to have a considerable impact on an individual's quality of life, ability to continue life roles, the ability to work and/or undertake leisure activities [3]. MS is costly for society and the patients, their carers and families. For instance, in the UK, half yearly costs for patients with MS have been estimated as £8397 [5], these figures are similar to other westernised countries, for instance annual costs in the US are $30,601 per patient [2].

Patients with MS experience periods of anxiety, fear and uncertainty, which can lead to hopelessness, depression and feelings of abandonment [6]. Perceptions of stress, fear, and uncertainty exert a negative impact on a patient's meaningful activities (work, social activities) and interactions [7]. This, in turn, is likely to have a significant impact on the patient's quality of life. For instance, the perceived ability to cope [8] and experience of depression [6] are negatively associated with quality of life for patients with MS. This evidence suggests that emotions are likely associated with adjustment, hope and the ability to cope. Thus, there is evidence that MS has a severe and negative impact on a patient's quality of life and mental well-being[1]. Indeed, in patients with MS, psychological constructs are considered a better predictor of adjustment than illness related factors, for instance remission status or the severity of symptoms [6].

Despite the negative impact of the illness, it is possible for patients to positively influence their mental well-being. For instance, patient's perceptions of control over their life or, those patients who are able to positively reappraise their own situation can experience better adjustment [9]. Evidence to support such conclusions is generated from quantitative studies that utilise specific inventories [10]. Such quantitative studies are valuable in identifying the strength and direction of relationship between psychological concepts but less able to consider the processes involved, the different ways that the concepts may be defined, or have the ability to be theory generating through the process of synthesis.

Recent evidence from other chronic and palliative conditions has demonstrated how concepts such as coping, adaptation and hope can be understood through reviewing qualitative studies based on patient's experience of illness [11]. Indeed a recent psychological model developed from a qualitative synthesis of research has been able to identify a process of psychological adaptation and hope enablement for patients with motor neurone disease [12]. The model reflects a well-established framework of adaptation [13] that considers two broad outcomes including a coping or succumbing response to the illness experience. Expressions relating to the expression of hope and adaptation lie at the centre of the model. However, they are not well considered. For instance, the spectrum of responses relating to adaptation e.g., those found in classic stage and phase models of adjustment [14] are missing, as is the spectrum of expressions relating to hope [11]. Further, the model does not consider the coping processes identified within existing literature on coping, for instance from a taxonomy of coping strategies [15] [16]. Neither does the model consider many of the psychological processes involved in self-management [17], or, alternatively the importance of the person as an active agent in the illness as a part of the self-regulatory literature [18]. The proposed model has other weaknesses, for instance, the common sense model of illness has identified the dual cognitive and emotional processes that occur simultaneously as a response to the threat of illness [19] [20]. Further to this, evidence has identified a strong affinity between emotional regulation and coping [16]. Indeed, emotions are considered an important part of self-management processes [17] as well as a factor that influences a patient's coping response [21] [22]. Thus, although difficult to establish [23], being able to establish the psychological processes of adaptation and the expression of hope is valuable for research for patients with MS.

To the best of the author's knowledge only one qualitative review [24] has been conducted considering the experiences of patients with MS. This narrative review only included 15 articles and primarily considers interaction with health care professionals rather than processes of adaptation. Past the need for a qualitative review, there is also need for further understanding around the expression of hope identified within a recent model of hope enablement [12], in particular how the processes of psychological adaptation (including adjustment and

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[1]Mental well-being is defined as a sense of satisfaction, optimism and purpose in life, a sense of mastery, control, belonging, as well as the perception of social support [12].

coping related responses) integrate with this expression. Further to this, it is possible that this understanding could be applied more generally and consideration for concepts identified above, could identify and contribute to a theory on this topic.

Given the above rationale, the purpose of this review is to illustrate the processes of psychological adaptation following events that relate to MS (MSRE; multiple sclerosis related event); which include symptoms of MS which impact on the individual's mental well-being both pre and post diagnosis). This will be undertaken by considering three major points: 1) that psychological adaptation occurs before a coping or succumbing response to illness, but includes aspects of an emotional response, acceptance and is contained and relates to the expression of hope as identified in a recent model for individuals with motor neurone disease [12]; 2) that the idea of psychological adaptation is related to the ability to accept, reject or defy what has happened which is important for patients with MS [25] and 3) the dichotomy of hope from hope to no hope [11] can be expressed by patients about how they their expectations, wants or desires in the future, with hope in possibility as a central factor that is needed as part of this expression [26].

2. Methods

A position as a "subtle realist" [12] was selected for the purpose of this review. With this in mind, the review is focused on the generalizable experiences detailed in the included studies with an aim of developing a theory or model which may have a broad application to all individuals with MS, as well as other patients who suffer with chronic and palliative conditions. A thematic synthesis [27] was undertaken in three stages: 1) search strategy; 2) appraisal of literature; 3) synthesis technique.

2.1. Electronic Search

The primary author undertook an electronic search of the following databases was undertaken, from inception until January 2015; PubMed, Medline, CINHAL, and PsychInfo. The key words used in the database included; Experience OR Hope OR Adjustment OR Coping OR expectation AND qualitative OR mixed methods AND Multiple Sclerosis. Secondary search methods included; Electronic searches of Google Scholar and Sciencedirect were undertaken for the first 500 hits generated. Citation chasing of included articles was conducted. Finally, the author's personal library of literature was accessed to aid the identification and search process.

2.2. Eligibility Criteria

The primary author determined by two authors (AS, TE) and moderated by a third (CR). An article was included when it satisfied the following eligibility criteria, considered within the domains of the "SPIDER" tool [28]:

S—Sample
The focus of the sample is on individuals diagnosed with MS.

PI—Phenomenon of Interest
Articles were selected if they considered the patient's experience and expressions associated with hope, coping or adjustment. Verbatim experiences and expressions were required to be reported within articles. Further to this experience and perceptions from others (health care professionals, carers, family or friends) which focused on the patient experience were included. Articles were included where there was at least one paragraph within the result section of the article that fitted these criteria.

D—Design
Any type of qualitative design was considered including phenomenology, grounded theory, or ethnography. Mixed methods studies and case studies were included where a clear qualitative section could be utilised for the purposes of a synthesis. Articles were excluded if they were reflective pieces, quantitative research, reviews, books, theses, or conference proceedings. Internet sources were excluded if they were not presented in a traditional article form with a methods section that could be critically evaluated.

E—Evaluation
Articles were required to use the following type of evaluation method: field notes, diaries of any kind, interviews or focus groups. Articles were also required that could document experiences, views, or attitudes from users. Only articles published in English were included.

R—Result Type
To be included, articles had to contain qualitative results including observations, as well as interviews that il-

lustrate verbal and nonverbal interactions.

2.3. Data Extraction

A pre-determined form was used to extract demographic details from included studies by the primary author. This form identified the following; sample size, gender, age, diagnosis, geographical location, setting of data collection, sampling method undertaken, analysis type, aim of study, and information on the interview schedule, duration of interviews and the type of analysis used by the study.

2.4. Critical Appraisal

An initial screening tool assessing the quality of the studies was used [29]. Following this, a modified 13 item critical appraisal tool developed from the 32 item Consolidated Criteria for Report Qualitative Research form (COREQ) [30] was used to assess the methodological quality of included articles. The reduced item version was used as the other 19 items identified within the COREQ, don't appear to be sensitive to identifying methodological weaknesses from studies [12] [31]-[33]. The traditional three domains were retained and included: domain 1, research team and reflexivity (5 items); domain 2, study design (5 items); domain 3, study analysis (3 items). See Supplementary file A for full item breakdown.

2.5. Data Analysis and Qualitative Meta-Synthesis

A framework analysis [34] [35] was undertaken and developed from previous research based on a recent model on illness adaptation [12] as well as previous understanding from literature which considered the expression of hope and adaptation in neurological research [11] [25] [26] [32] [36] [37]. The framework had 5 themes including; 1) individual losses and the levels of hope, 2) adaptive responses, 3) expression of emotion and agency, 4) cognitive responses which (re)enable or disable hope, autonomy and perceived control. The framework was tested against the first 20 articles, which allowed the framework items to be reorganised (changing, adding and adapting themes, sub-themes, codes and units) on 4 occasions. This was followed by a reduction phase, which looked to define each unit and consider how it was associated with other cognitive and emotional expressions and identify how many studies supported each code (vote counting) [38]. The reduced and simplified framework split cognitive responses which reflective psychological adaptation and hope from coping related responses. Thus, other than acceptance and denial related spectrum of responses, coping was defined by previously identified groups of coping strategies/labels [15] [16]. The most frequent association between codes were identified and presented in the results including: a) a spectrum of hope related responses (from no hope to concrete hope) [11]; b) a spectrum of adjustment related response (an inability to accept to positive embracement); and c) events of emotional expression, with consideration to the circumplex model of affect [39] because affect is considered the heart of emotional states [40] and clearly linked to the emotions described within the initial analysis.

The review used previous knowledge from different models and theories from inception of the review through to completion of analysis. This was undertaken to utilise the highest application of theory [41]. The purpose of this is to identify a generalizable model and process in line with the methodological orientation taken for the review, but not to claim it as "the truth" [42], rather an identification of a process that could exist and that is able to challenge and further current models and views of psychological adaptation. An audit trail of the synthesis can be obtained from the primary author.

3. Results

3.1. Demographics

A total of 841 hits were identified from the search processes with a total of 47 articles [25] [43]-[87] meeting the eligibility criteria. A total of 1146 (812 females, 265 males, and 69 unknown) unique patients were included in this review. The diagnosis and type of MS for each individual included 59 patients with primary progressive, 148 with secondary progressive, 149 with relapsing remitting, 2 with Benign and 801 unknown. The aggregated mean age (across 30/47 studies) was 49.3 years. The aggregated mean time of living with the illness post diagnosis (across 28 studies/47 studies) was 12.3 years. Studies were most frequently conducted in the UK (n = 12), USA (n = 11), Sweden (n = 8), Canada (n = 6), and Australia (n = 4). The primary setting of data collection was the patient's home (n = 22), a MS charity community location (n = 5) or a hospital/rehabilitation clinic (n = 6).

The PRISMA diagram can be seen in **Figure 1** and summary **Table 1** provides details of the included studies.

3.2. Critical Appraisal

All studies were identified as being appropriate to include in the review. Average scores across all studies revealed that the weakest reporting occurred within domain 2 the study design domain (average score 1.3/5). Within this domain details about non-participation of participants, the use of a pilot interview or construction of interview guides, the use of field notes, as well as consideration of data saturation were often not reported or considered. The average score for domain 1 was 1.4/5, within this domain the interviewer characteristics and consideration to bias and assumptions of the interviewer, as well as participants knowledge of the interviewer very rarely considered. Finally, the highest scoring domain was domain 3 scoring 1.4/3. However, consideration to the structure of the analysis using an audit trail or coding tree were most often not considered by the included studies. See Supplementary file A for complete summary scores.
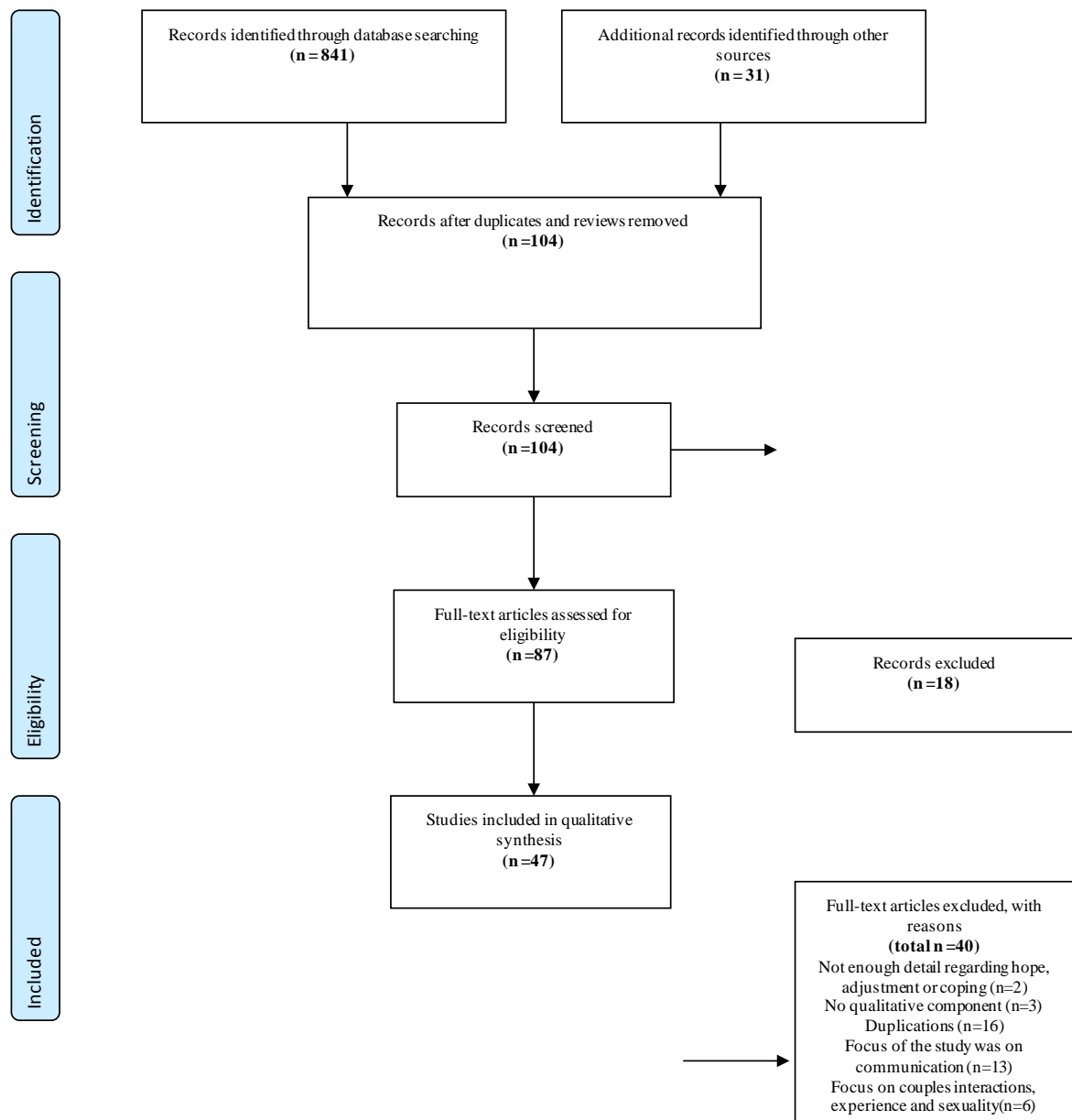

Figure 1. A PRISMA diagram for the study.

Table 1. The study characteristics of included studies.

Study	Qualitative method (methodology given if identified)	Participants	Sampling and setting	Data collection, study aims and analysis
1) Ahlström (2007)	Semi-structured interviews	15 (?♂) patients with MS Sub-types No type break down Mean age: 51 years Age range: 29 - 60 years Mean time with illness: not given Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) severe disease or injury; b) aged between 18-64; c) had received personal assistance in their daily lives; d) marked intellectual functional impairment and aphasia were excluded Setting: Two interviews in the patients home Study geographical location: Sweden	Data collection tool: semi-structured interview guide. Interview 1 considered falling ill, problems in daily living and family situation. Interview 2 repeated this and also included integrity, autonomy, participation in the events of daily living. Study Aim: "The aim of the study is twofold: i) to describe the losses of persons severely afflicted with chronic illness and who therefore, may experience chronic sorrow; and ii) to identify meaningful underlying patterns related to these losses in the form of chronic sorrow through an abductive approach to analysis." (page 77) Average interview time: not given Interview time range: not given Analysis: abductive approach (both inductive and deductive).
2) Barker-Collo *et al.* (2006)	Semi-structured interviews	16 (5♂) patients with MS Sub-types 8 PP 8 RR Mean age: 56 years Age range: 27 - 72 years Mean time with illness: 6 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) received diagnosis of Ms either <5 years ago or >15 years ago, b) Setting: Participants homes Study geographical location: New Zealand	Data collection tool: Questions identified: 1) events leading to diagnosis and what happened following the events 2) what impact multiple sclerosis had on their lives Study Aim: "explore participants' pre-diagnosistic and diagnosis experiences as well as the implications of living with the disease" (page 436) Average interview time: not given Interview time range: 1 - 2 hours Analysis: Thematic analysis
3) Boeije (2002)	Case study	1 (1♂) patients with MS Sub-type Not given Mean age: not given Age range: not given Mean time with illness: not given Mean time until diagnosis: not given	Sampling: purposive Eligibility: (a) diagnosis with MS Setting: not given Study geographical location: Holland	Data collection tool: Consider the experience of multiple sclerosis Study Aim: Consider the experience of multiple sclerosis Average interview time: Interview time range: Analysis: Constant comparison approach
4) Boland *et al.* (2012)	IPA	7 (3♂) patients with MS Sub-types: 3 PP 3 RR 1 SP Mean age: not given. Median: 53 years Age range: 35 - 70 years Mean time with illness: not given. Median = 10 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) diagnosed with MS for >2 years, b) speak English, c) have a significant other who would participate in interviews, d) previously worked with the primary author, e) were experiencing emotional or social crisis. Setting: not clear. Study geographical location: New Zealand	Data collection tool: semi-structured interview guide. Questions considered the patients coping approach, whether these had changed over time, o = and how coping may change in the future. Study Aim: "to gain a more in-depth understanding of how couples cope as a dyad when one of them has MS" (page 1368) Average interview time: not given Interview time range: not given Analysis: IPA
5) Boys and Mac Millian (2005)	Phenomenological approach	12 (5♂) patients with MS Sub-types: Not given Mean age: not given Age range: 8 - 18 years Mean time with illness: not given. Mean time until diagnosis: not given	Sampling: purposive Eligibility: (a) children aged between 1 and 18 years diagnosed with MS Setting: not given Study geographical location: Canada	Data collection tool: semi-structured interview guide. Guide focused on the patients thoughts and feelings about MS, what effect MS has had on their lifestyle, future relationships and stress and their ability to cope and advice they would give to others. Study Aim: Consider the experiences of children and adolescents who have MS Average interview time: not given Interview time range: not given Analysis: narrative analysis

Continued

6) Courts *et al.* (2004)	Focus group design	13 (3♂) patients with MS Sub-types not given Mean age: 46.9 years 47.3 years for women. 45.7 years for men. Age range: 1.5 - 15 years for women. 28 - 59 years for men. Mean time with illness: 5.8 years 5.6 years for women, 6.9 years for men. Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) had a diagnosis of MS, b) attended the MS society community location. Setting: MS society community location Study geographical location: United states of America	Data collection tool: Focus groups. A period of uninterrupted time was given to each participation about their experiences of having MS. This was combined with comments from others which followed. Study Aim: "investigate the concerns and problems or lived experience of a group of men and a group of women with MS" (page 43) Average interview time: not given. Interview time range: 1.5 - 2 hours Analysis: not clear.
7) Dennison *et al.* (2010)	Telephone interview	30 (8♂) patients with MS Sub-types 18 RR 4 PP 8 SP Mean age: not given. Age range: not given. "36.7% in 40's, 33.3% in 50's" Mean time with illness: 3.8 years. Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) diagnosis of MS for >8 years, b) could be recruited from MS society website and NHS MS services. Setting: Telephone interviews Study geographical location: United Kingdom	Data collection tool: Telephone interview considering a series of open ended questions. Considered: (a) thoughts and feelings when first diagnosed and at present Study Aim: "in depth investigation into the process of adjusting to early stage MS." (page 480) Average interview time: 45 minutes Interview time range: not given. Analysis: inductive thematic analysis
8) Dilorenzo *et al.* (2008)	Telephone interview	13 (4♂) patients with MS Sub-types Not given Mean age: 68.3 years Age range: 62 - 75 years Mean time with illness: 22.5 years. 8 - 42 years Mean time until diagnosis:	Sampling: purposive Eligibility: a) 60 years and older, b) English speaking, c) diagnosed for >5 years Setting: Telephone interviews Study geographical location: United states of America	Data collection tool: Open questions to the consider the experience and impact of living with MS and the factors which relate to adaptation. Study Aim: "identify psychosocial and/or physical characteristics reported to be related to adaptation in older individuals with MS Average interview time: not given. Interview time range: 60 - 90 minutes Analysis: software with thematic approach.
9) Dyck and Jongbloed (2000)	Semi-structured interviews	54 (0♂) patients with MS Sub-types Not given Mean age: not given Age range: 25 - 49 years Mean time with illness: not given Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) individuals with MS, b) attendance of the MS society locally. Setting: Patients home Study geographical location: Canada	Data collection tool: semi-structured interviews. Considered; a) work experiences, b) illness management strategies, c) income issues, d) housing and personal relationships. Study Aim: "take account of both the individual and societal dimensions of employment, by investigating the everyday work experiences of women diagnosed with MS and the contextual framing of such experience" (page 339) Average interview time: not given. Interview time range: 1 - 2 hours Analysis: Constant comparison methods
10) Edmonds *et al.* (2007)	Semi-structured interviews	32 (13♂) patients with MS Sub-types: SP 21 PP 6 RR 3 Other 2 Mean age: not given. Median: 55 years Age range: 18 - 79 years Mean time with illness: not given. Median 14.5 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: (a) individuals with Ms Setting: Patients home and rehabilitation unit where they attended for treatment Study geographical location: United Kingdom	Data collection tool: Open ended question considering the most important things about living with MS. Study Aim: "As little is known about the needs and experiences of people severely affected by progressive or RRMS, we used a qualitative approach to investigate these issues" (page 102) Average interview time: not given. Interview time range: 30-60 minutes Analysis:

Continued

11) Finlayson (2004)	Phenomenological approach	27 (4♂) patients with MS Sub-types Not given Mean age: 62 years Age range: 55 - 82 years Mean time with illness: 20 years Mean time until diagnosis: 22 years	Sampling: purposive Eligibility: a) 55 years if older, b) diagnosed with MS for at least 15 years, c) speak English, d) access to a private location for interview. Setting: Patients homes Study geographical location: United States of America	Data collection tool: semi structured interviews Study Aim: "exploratory study focused on describing the health concerns and service needs of older adults with MS… developing an understanding of living and aging with MS" (page, 56) Average interview time: 107 minutes Interview time range: not given Analysis: thematic analysis accompanied with software
12) Finlayson *et al.* (2005) * same sample – excluded for totals	Mixed method	27 (4♂) patients with MS Sub-types Not given Mean age: 62 years Age range: 55 - 82 years Mean time with illness: 22 years Mean time until diagnosis: 20 years	Sampling: purposive Eligibility: a) 55 years if older, b) diagnosed with MS for at least 15 years, c) speak English, d) access to a private location for interview. Setting: Patients homes Study geographical location: United States of America	Data collection tool: Semi-structured interview guide which focused on the participants perspective of aging. Study Aim: "For this reason, the authors set out to identify what people who are ageing with MS describe as the positive and negative aspects of living with the disease" (pages 117 - 118) Average interview time: 107 minutes Interview time range: Analysis: content analysis
13) Fallahi-Khoshknab *et al.* (2014)	"naturalistic paradigm"	25 (7♂) patients with MS Sub-types Not given Mean age: not given Age range: 20 - 55 years Mean time with illness: 10 years. Range 4 - 20 years. Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) having MS for at least or more than 1 year, b) no hearing or speaking impairments, c), awareness of phenomenon that was being considered, d) no other pathological condition Setting: not given. Study geographical location: Iran	Data collection tool: semi-structured interview. Questions considered thoughts and feelings following diagnosis Study Aim: "to elicit the experience of patients faced with an MS diagnosis and to explore its dimensions." (page 276) Average interview time: 45 - 75 minutes. Interview time range: not known. Analysis: unclear.
14) Fong *et al.* (2006) * same sample— excluded for totals	In-depth interviews	27 (4♂) patients with MS Sub-types Not given Mean age: 62 years Age range: 55 - 82 years Mean time with illness: 22 years Mean time until diagnosis: 20 years	Sampling: purposive Eligibility: a) 55 years if older, b) diagnosed with MS for at least 15 years, c) speak English, d) access to a private location for interview. Setting: Patients homes Study geographical location: United States of America	Data collection tool: Semi-structured interview guide which focused on the participant's perspective of aging. Study Aim: "explore the social experiences of those aging with multiple sclerosis from their own perspective." (page 696) Average interview time: 107 minutes Interview time range: Analysis: content analysis
15) Gagliardi *et al.* (2002)	Naturalistic case study method	18 (9♂) patients with MS Sub-types Not given Mean age: not given Age range: 27 - 61 years Mean time with illness: not given Mean time until diagnosis: not given	Sampling: purposive Eligibility: (a) a diagnosis of MS Setting: in person or telephone interviews Study geographical location: United States of America	Data collection tool: guided conversations using an in depth interview Study Aim: Consider what it is like to live with MS by analysing based on the Roy mode of adaptation Average interview time: Interview time range: Analysis: Roy adaptation rules for research
16) Gaskill *et al.* (2011)	Mixed methods	16 (5♂) patients with MS Sub-types Not given Mean age: 54 years Age range: 21 -64 years Mean time with illness: 15 years. Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) endorse suicide ideation, b) attended MS centre hospital, c) clinician diagnosis of MS, Setting: unclear. Study geographical location: United States of America	Data collection tool: Open ended questions considered the context, meaning and function of suicide ideation, as well as association of suicide ideation with time of day, symptoms and family problems Study Aim: explore meanings of suicide ideation for individuals with MS Average interview time: Interview time range: 40 - 60 minutes Analysis: General thematic analysis

Continued

17) Hainsworth (1994)	Structured interviews	10 (1♂) patients with MS Sub-types Not given Mean age: 42.8 years Age range: 28 - 55 years Mean time with illness: 4 years Mean time until diagnosis: not given	Sampling: Convenience Eligibility: (a) a diagnosis of MS Setting: patients home Study geographical location: United States of America	Data collection tool: Burke Chronic Sorrow Interview Schedule. The questionnaire uses 16 question to determine the intensity, occurrence, when it can occur and what can influence it Study Aim: To examine the experiences of chronic sorrow in patients with MS Average interview time: not given. Interview time range: 60 - 90 minutes Analysis: content analysis
18) Hunt *et al.* (2013)	Phenomenological approach	5(2♂) patients with MS Sub-types Not given Mean age: not given. Age range: 40 - 65 years Mean time with illness: not given. Range = 1 - 30 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) living with MS, b) engaged with visual art work Setting: Private room in physiotherapy clinic Study geographical location: United Kingdom	Data collection tool: semi-structured interview guide. Study Aim: "This qualitative study explored the meanings of leisure-based art- making for people living with multiple sclerosis" (page 2) Average interview time: 1 hour Interview time range: not given. Analysis: IPA
19) Irvine *et al.* (2009)	Semi-structured focus group	8 (1♂) patients with MS Sub-types Not given Mean age: 49 years Age range: 36 - 63 years Mean time with illness: 12.8 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) 18 years and older, b) diagnosed with MS for at least 5 years, c) willing and able to participate in a focus group Setting: MS charity location Study geographical location: United Kingdom	Data collection tool: A semi structured interview guide. Focused on views about how MS affects individual's day to day lives, the patient's values and how they see themselves. Study Aim: "this study explored individuals' subjective experiences of coping with the changes associated with MS and the adjustments required in relation to self and identity" (page, 601) Average interview time: Interview time range: Analysis: IPA
20) Lsaksson *et al.* (2007)	Mixed methods	38 (12♂) patients with MS Sub-types RR 26 SP 9 PP 3 Mean age: 40.5 years Age range: 20 - 62 years Mean time with illness: 5 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: (a) clinically defined or laboratory supported diagnosis of MS Setting: Patient's homes or room at a hospital Study geographical location: Sweden	Data collection tool: semi-structured interview Burke Chronic sorrow inventory. Focused on the patients concerns of chronic sorrow. Study Aim: "The overall aim of this study was to explore the presence and meaning of chronic sorrow in 61 persons with MS" (page, 316) Average interview time: not given Interview time range: not given Analysis: latent content analysis
21) Isaksson and Ahlström (2008) * same sample—excluded for totals	Descriptive with semi-structured interviews	38 (12♂) patients with MS Sub-types RR 26 SP 9 PP 3 Mean age: 40.5 years Age range: 20 - 62 years Mean time with illness: 5 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: (a) clinically defined or laboratory supported diagnosis of MS Setting: Patient's homes or room at a hospital Study geographical location: Sweden	Data collection tool: semi-structured interview Burke Chronic sorrow inventory. Focused on the patients concerns of chronic sorrow. Study Aim: "the goals of this study were to describe the method patients with MS use to mange choric sorrow and to apply these management methods to the theoretical model of chronic sorrow" (page, 181) Average interview time: Interview time range: Analysis: latent content analysis
22) Kirkpatrick Pinson *et al.* (2009)	Semi-structured interviews	10 (0♂) patients with MS Sub-types Not given Mean age: 56.4 years Age range: 46 - 68 years Mean time with illness: 17.4 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) clinical diagnosis for at least 8 years, b) a diagnosis of progressive-relapsing, secondary progressive, or primary progressive type of multiple sclerosis, c) no major depression currently, d) self or physician assessment of successful coping. Setting: at participants home or convenient locations Study geographical location: United States of America	Data collection tool: semi structured interview tool. Arranged around the precursors to coping. Study Aim: "report findings on how the precursors described above are expressed in women who are coping effectively with MS." (page 184) Average interview time: not given Interview time range: not given Analysis: thematic analysis

Continued

23) Koch & Kelly (1999)	Action research	8 (0♂) patients with MS Sub-types Not given Mean age: not given Age range: 38 -75 years Mean time with illness: not given Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) a diagnosis of MS, b) incontinence Setting: not given Study geographical location: United Kingdom	Data collection tool: focus groups discussing aspects around the aims. Study Aim: "identify strategies for successfully managing urinary incontinence and what is important for the women who live with it" (page 15) Average interview time: not given Interview time range: not given Analysis: not given
24) Koch *et al.* (2001)	Action research	4 (0♂) patients with MS Sub-types Not given Mean age: not given Age range: not given Mean time with illness: not given Mean time until diagnosis: not given	Sampling: purposive Eligibility: (a) a diagnosis of MS Setting: MS community centre Study geographical location: Australia	Data collection tool: focus group schedule. Consideration to question around experiences, perceptions and strategies associated with urinary incontinence. Study Aim: "address a noticeable absence in the research literature about MS related urinary incontinence by providing an understanding of how men and women perceived and articulate the implications of this problem" (page 16 - 17) Average interview time: 2 hours Interview time range: not given Analysis: not given
25) Malcomson *et al.* (2008)	Focus groups	13 (4♂) patients with MS Sub types 6 RR 6 SP 1 PP Mean age: 54 years Age range: 40 - 67 Mean time with illness: 17.2 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) diagnosis of MS, b) self-belief that they were coping with the illness Setting: not clear (likely MS community centre) Study geographical location: United kingdom	Data collection tool: focus groups Study Aim: "the primary aim of this study was to explore personal accounts and experiences of individuals with MS who felt able to cope with the disease in day-to-day life" (page, 663) Average interview time: 90 mins Interview time range: not given. Analysis: thematic analysis
26) Lexell *et al.* (2009)	Grounded theory	10 (4♂) patients with MS Sub types 8 SP 2 RR Mean age: 53 years Age range: 41 - 67 years Mean time with illness: 17 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: (a) 'moderate' limitations in occupational performance, (b) ability to take part in the interview, (3) no disease influencing occupational performance. Setting: Patients homes Study geographical location: Sweden	Data collection tool: semi-structure interview considering experiences and occupations currently engaged in and if change had occurred over time. Study Aim: "gain an enhanced under-standing of how people with MS_ experience their engagement in occupations." (page, 773) Average interview time: 82 mins Interview time range: 32 - 133 mins Analysis: constant comparison method
27) McLaughlin and Zeeberg (1993)	Ethnography	Denmark 51 (20♂) patients with MS Sub-types Not given Mean age: 40.8 Age range: 22 - 58 years Mean time with illness: 11 years. Range 3 - 18 years. Mean time until diagnosis: not given USA 35 (17♂) patients with MS Sub-types Not given Mean age: 42.4 years Age range: 19 - 65 years Mean time with illness: not given Mean time until diagnosis: not given	Sampling: purposive Eligibility: (a) patients with MS Setting: Patient's homes or workplace Study geographical location: Denmark	Data collection tool: semi-structured interview schedule and structured interview schedule (self-care behaviour for MS inventory). Study Aim: "compares the extent of self-care behaviours of groups with MS in Denmark and in the United States" (page, 318) Average interview time: Interview time range: 1 - 5 hours Analysis: quantitative content analysis

Continued

28) Miller (1997)	Phenomenological	10 (3♂) patients with MS Sub-types Not given Mean age: not given Age range: 40 - 59 years Mean time with illness: not given. Range: 2 - 39 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) willing and able to relate their experience b) diagnosed for greater than one year, c) with a disability score which indicated normal functioning, d) no cognitive deficits Setting: Clinic for MS patients Study geographical location: United States of America	Data collection tool: semi-structured interview guide considering experience of othe patient. Study Aim: "patients need to be asked about their lived experience of MS so that we as health care professionals can address concerns and improve their quality of life" (page, 296) Average interview time: not given Interview time range: not given. Analysis: thematic analysis
29) Mozo-Dutton *et al.* (2012)	IPA	12(4♂) patients with MS Sub-types RR 3 SP 5 PP 1 B 1 Unknown 2 Mean age: 46 years Age range: 34 - 71 years Mean time with illness: 14 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) diagnosis of MS, b) aged over 18 years, c) able to consent to take part Setting: Patient's home or "where they felt most comfortable" Study geographical location: United Kingdom	Data collection tool: Semi structured interview guide questions focus on self pre and post illness as well as future view of self. Bio-psychosocial and practical implications of impact explored. Study Aim: "search explicitly addressing the experience of self among people living with MS remains an important priority. This qualitative study aims to address this gap and build on previous literature, by conducting an in-depth exploration of personal perceptions of self and the perceived impact of MS on " (page, 1209-1210) Average interview time: not given. Interview time range: 40 - 75 mins Analysis: IPA
30) Norton and Chelvanayagam (2010)	Internet Survey	150 (36♂) patients with MS Sub-types RR 56 SP 47 PP 26 Don't know 26 Mean age: not given. Median 50 years Age range: 19 - 73 years Mean time with illness: Mean time until diagnosis:	Sampling: purposive Eligibility: (a) member of MS society UK Setting: Patients home via a computer Study geographical location: United kingdom	Data collection tool: open questions. Study Aim: "Many people wrote at length about the bowel problems that they experience. This survey aimed to explore the issue in more detail in order to describe the impact bowel dysfunction has on the lives of people with MS, and to identify interventions that MS Society members find helpful that may warrant further investigation." (page 2) Average interview time: not applicable Interview time range: not applicable Analysis: content analysis not clear.
31) O'Connor *et al.* (2005)	Mixed methods	62 (22♂) patients with MS Sub-types Not given Mean age: 46 years Age range: 19 - 65 Mean time with illness: 12 years. Range 1 - 43 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) diagnosis of MS, b) attending a hospital, c) aged between 18 - 65 years, Setting: Hospital Study geographical location: United Kingdom	Data collection tool: semi-structured interview to consider experiences of MS and employment. Study Aim: "identify factors that impact on work retention in patients with MS." (page 892) Average interview time: not given Interview time range: not given Analysis: not given
32) Olsson *et al.* (2008)	Phenomenological	10 (0♂) patients with MS Sub-types 10 SP Mean age: 49 years Age range: 43 - 59 years Mean time with illness: 18.5 years. Range 2 - 29 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: a) had a diagnosis of MS, b) attended a rehabilitation hospital for MS. Setting: rehabilitation centre Study geographical location: Sweden	Data collection tool: Telephone interview schedule Study Aim: " Average interview time: not given Interview time range: 40 - 60 mins Analysis: Phenomenological hermeneutic interpretation
33) Olsson *et al.* (2010)	Phenomenological	15 (0♂) patients with MS Sub type SP 15 Mean age: not given. Median 54 years Age range: 35 - 70 years Mean time with illness: not given. Median 24 years. Range 7 - 34 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) female, b) diagnosis of secondary progressive MS Setting: Patients home Study geographical location: Sweden	Data collection tool: Telephone interview schedule Study Aim: "describe meanings of feeling well for women with MS." (page, 2) Average interview time: not given Interview time range: 40 - 60 mins Analysis: Phenomenological hermeneutic interpretation

Continued

34) Olsson *et al.* (2011) * same sample— excluded for totals	Phenomenological	15 (0♂) patients with MS Sub type SP 15 Mean age: not given. Median 54 years Age range: 35 - 70 years Mean time with illness: not given. Median 24 years. Range 7 - 34 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) female, b) diagnosis of secondary progressive MS Setting: Patients home Study geographical location: Sweden	Data collection tool: Telephone interview schedule Study Aim: "elucidate meanings of being received and met by others as experienced by women with MS" (page 2) Average interview time: not given Interview time range: 40 - 60 mins Analysis: Phenomenological hermeneutic interpretation
35) Pakeman (2008)	Mixed methods	145 (25*♂) patients with MS Sub-type Not given. Mean age: 49 years Age range: 21 - 80 years Mean time with illness: not given Mean time until diagnosis: not given *numbers estimated	Sampling: purposive Eligibility: a) Member of MS society, b) diagnosis of MS Setting: home Study geographical location: Australia	Data collection tool: Postal survey. If patients indicated they could make sense of the MS one open ended question about how individual make sense of their MS. Study Aim: "this report presents qualitative and quantitative data on sense making collected from a larger study designed to examine coping processes in adaptation to MS and caregiving" (page 96) Average interview time: not applicable Interview time range: not applicable. Analysis: quantitative content analysis
36) Ploughman *et al.* (2012)	Semi structured interviews	18 (4♂) patients with MS Sub-types RR 3 PP 2 SP 10 B 1 Unknown 2 Mean age: 66.5 years Age range: 56 - 80 years Mean time with illness: 33.5 years. Range 20 - 50 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) diagnosis of MS, b) aged over 55 years, c) had MS for at least 20 years, c) patients who lived over 1.5 hours from researcher group Setting: home (not identified implied) Study geographical location: Canada	Data collection tool: semi-structured interview. Focused on experience, interactions, relationships, typical day and strategies to deal with Ms Study Aim: "describe the factors influencing health aging from the perspective of the older person with MS" (page, 27) Average interview time: not known. Interview time range: 60 - 80 minutes Analysis: thematic and INVIVO computer software
37) Prunty *et al.* (2008)	Focus groups	20 (0♂) patients with MS Sub types RR 12 PP 2 SP 2 Unknown 4 Mean age: 32 years Age range: 20 - 40 years Mean time with illness: 6.5 years. Mean time until diagnosis: not given.	Sampling: purposive Eligibility: (a) member of the MS society Setting: not identified. MS community locaitonlikely. Study geographical location: Australia	Data collection tool: focus groups Study Aim: "document the main themes and concerns for women with MS considering motherhood" (page 701) Average interview time: 60 mins Interview time range: not given. Analysis: thematic analysis
38) Reynolds and Prior (2003)	Phenomenological	27 (0♂) patients with MS Sub-types not given Mean age: not given. Median 48. Age range: 32 - 75 years Mean time with illness: not given. Median 14 years. Range 2 - 37 years Mean time until diagnosis: not given.	Sampling: purposive Eligibility: (a) lived with a diagnosis of MS for more than 5 years Setting: Patients, home, at clinic and by telephone Study geographical location: United Kingdom	Data collection tool: semi-structured interview guide Study Aim: "we explore women's strategies for achieving an acceptable quality of life" (page, 1228) Average interview time: not given Interview time range: not given. Analysis: thematic analysis
39) Robinson (1990)	Narrative	50 (?♂) patients with MS Mean age: not given Age range: not given Mean time with illness: not given Mean time until diagnosis: not given.	Sampling: purposive Eligibility: (a) diagnosis with Ms Setting: home Study geographical location: United Kingdom	Data collection tool: Written life stories from people with Ms Study Aim: "people were enjoined to write their life stories including anything in their lives—events, experiences or feelings which was important to them." (page, 1177) Average interview time: not given Interview time range: not given Analysis: narrative analysis

Continued

40) Schneider and Young (2010)	Phenomenology	7 (0♂) patients with MS Sub-type PP 3 RR 4 Mean age: 50.4 years Age range: 41 - 55 years Mean time with illness: 6.1 years Mean time until diagnosis: not given.	Sampling: snowball Eligibility: a) females between 40 - 55 years of age who had been formally diagnosed with either PP or RR multiple sclerosis, b) diagnosis had been in place for a minimum of two years Setting: Patients home and telephone Study geographical location: Canada	Data collection tool: semi-structured interview schedule. Considering physical activity, coping stressors and quality of life. Study Aim: "examine the specific coping strategies they used when managing their MS, in relation to their participation in physical activity" (Page, 3) Average interview time: not given. Interview time range: 19 - 53 mins Analysis: Thematic analysis
41) Somerset *et al.* (2002)	Phenomenology	16 (8♂) patients with MS Sub-types Not given Mean age: 46.1 years Age range: 31 - 72 years Mean time with illness: 12.1 years. Range 1 - 30 Mean time until diagnosis: not given.	Sampling: Maximum variation sampling Eligibility: a) individuals who had MS, b) individuals who attended a day centre. Setting: MS day centre Study geographical location: United Kingdom	Data collection tool: semi-structured interview schedule focused on experiences. Study Aim: "establish the elements of life that were important for the participants. These experiences were then shaped into a broad picture that went some way to elucidate and to expand issues that are common to many people with MS, to suggest how they link together and to highlight possible opportunities for intervention and participation that might improve quality of life. (Page 152) Average interview time: Interview time range: 60 - 90 mins Analysis: thematic analysis
42) Soundy *et al.* (2012)	Phenomenology	11 (4♂) patients with MS sub-types SP 6 RR 5 Mean age: 54.5 years Age range: 42 - 69 years Mean time with illness: 17.0 years Mean time until diagnosis: not given	Sampling: purposive Eligibility: a) individuals who had MS, b) individuals who were part of a larger study. Setting: MS community centre or Rehabilitation centre Study geographical location: United Kingdom	Data collection tool: semi-structured interviews focusing on 5 sections relating to hope, control, the MS, information and interaction. Study Aim: "analyse patient's expression of hope and consider how these expressions fall within the paradox of chronic illness." (Page 345) Average interview time: not given Interview time range: not given. Analysis: thematic with apriori concepts
43) Thorne *et al.* (2004)	Interpretative	12 (2♂) patients with MS Sub-types Not given Mean age: not given Age range: 33 - 54 years Mean time with illness: not given Mean time until diagnosis: not given.	Sampling: purposive Eligibility: (a) Patients with MS who have been diagnosed for at least 5 years Setting: Patients home or "convenient location" Study geographical location: Canada	Data collection tool: Study Aim: "we posed the question How do persons with MS describe and explain helpful and unhelpful communications in their health care?" (Page 8) Average interview time: not given Interview time range: 1 - 2 hours each Analysis: thematic analysis with INVIVO software
44) Thannhauser (2009)	Grounded theory	4 (1♂) patients with MS Sub-types Not given Mean age: not given Age range: 14 - 21 years Mean time with illness: not given Mean time until diagnosis: not given.	Sampling: Convenience and discriminatory Eligibility: (a) diagnosed with MS before the age of 18 years. Setting: Patient's home Study geographical location: Canada	Data collection tool: semi-structured interview with 10 open questions and one focus group. Focused on the role of the peer relationship. Study Aim: "the following benefits: a) increasing understanding of the experiences of individuals with pediatric MS, b) guiding future research in this area, and c) guiding the development of programs, interventions, and services for children and adolescents with pediatric MS" (Page, 2) Average interview time: 1 hour Interview time range: not given Analysis: Grounded theory
45) Riessman (2003)	Case study	2 (2♂) patients with MS Sub-types Not given Mean age: 40.5 Age range: not given. Mean time with illness: not given Mean time until diagnosis: not given.	Sampling: purposive Eligibility: (a) had a diagnosis of MS Setting: University setting Study geographical location: United States of America	Data collection tool: In-depth interviews. Masculinity in the face of illness is explored. Study Aim: analysis of life history interview Average interview time: Interview time range: Analysis: narrative analysis

Continued

46) Isaksson and Ahlström (2006)	Phenomenology	61 (22♂) patients with MS Sub-types Not given Mean age: 42 years Age range: 20 - 70 years Mean time with illness: not given. Median 4 years. Range 1 - 15 years Mean time until diagnosis: not given.	Sampling: Purposive Eligibility: (a) Patients diagnosed with MS for a period of at least 6 months Setting: Patients home or secluded room in hospital Study geographical location: Sweden	Data collection tool: Semi-structured interview with open questions. Focus on patients experiences pre and post diagnosis with MS Study Aim: "to describe patients' conceptions of MS before they were diagnosed as well as their illness experiences connected with the initial symptoms and diagnosis" (page 229) Average interview time: not given Interview time range: not given. Analysis: content analysis
47) Wollin *et al.* (2006)	Phenomenology	13 (?♂) patients with MS Sub-types Not given Mean age: not given Age range: 23 - 55 years Mean time with illness: not given. Mean time until diagnosis: not given.	Sampling: not given Eligibility: a) Patients diagnosed with MS, b) over 18 years old, c) able to speak English, d) able to give consent Setting: Patients home Study geographical location: Australia	Data collection tool: Semi-structured interview with open questions. Focus on patient's experiences with MS, focus on finances, future, social support coping, and quality of life were made. Study Aim: "aimed to explore the needs of people with Ms and gain insight into their views on what services and support are required" (page 20) Average interview time: not given Interview time range: 1 to 2 hours. Analysis: content analysis

Note: B = Benign MS, PP = primary progressive, SP = secondary progressive, RR = relapsing remitting, MS = multiple sclerosis, IPA = Interpretive phenomenological analysis, mins = minutes.

3.3. Synthesis

3.3.1. Basic Thematic Table

Supplementary file B provides a full thematic summary of results including meaning of codes, vote counting to consider code representativeness, meaning units and association between units. Within each theme, only codes with support from at least 5/47 studies (approximately 10% of studies) were included. Within the text, the number of studies supporting each code is provided in brackets (xx/47 studies). Verbatim quotes are identified within the supplementary file.

3.3.2. The Application of Thematic Findings to a Psychological Process of Adaptation

A primary response of adaptation was identified relating to the expression of emotions, hope and adaptation. These responses were identified within a model of emotion adjustment and hope (MEAH). In addition to this, different strategies used for coping were identified.

The primary response of adaptation

An initial cognitive response representing adaptation to a MSRE was identified. The response included emotional responses and responses relating to hope and adjustment.

Emotional Responses to the MSRE

Emotional experiences were documented, most often with a negative or unpleasant connotation; they were likely associated together with each other and a succumbing response. The generation of two general types of unpleasant emotions included: shock (12/47), panic fear or being scared (19/47), anxiety (11/47), worry and concern for oneself and others (7/47), anger (15/47), and frustration (18/47).

The clearest association to psychological concepts identified with all these emotions appears to be the acknowledgement of their situation, including the meaning for their lives and future. In addition to this, shock, anger, and frustration were likely linked to an inability to accept. Notably shock created an inability to comprehend and take on-board what was happening, most often at diagnosis, but also as changes from the MSRE impacts the patient's life. Thus, shock and panic, combined with devastation (below) were likely associated with an inability to cope and possibly hopelessness. Anger and frustration were likely associated with defiance, denial and resistance. A less clear relationship to hoping is acknowledged. The emotions fear, anger, frustration, anxiety and pain may be linked with acceptance as a reaction to the greater recognition of impact the illness, symptoms and uncertainty may have on their lives. Fear, psychological pain and anxiety were likely linked with chronic sorrow and a feeling of losing hope or hopelessness.

There were experiences of unpleasant deactivated emotions following an MSRE these being upset

(14/47), sadness (12/47), depression (12/47), pessimism (7/47), being overwhelmed or devastated (9/47), guilt (6/47), embarrassment and shame (5/47) and fatigue (16/47). Being upset, sadness, depression, pessimism and fatigue were likely associated with chronic sorrow and a patient's resignation to their own situation. It was more evident that these emotions were also linked with an inability to defy or cope, as well as feeling of losing hope or feeling hopeless about their situation. The effects of being isolated from others and receiving less social support could generate these feelings. Being overwhelmed was likely associated with stronger feelings associated with the inability to cope and accept, as well as, with a feeling of losing hope and hopelessness. However, it could also be associated with the acknowledgement, acceptance or resignation of one's situation. Fatigue was likely associated with acknowledgement, acceptance and resignation. It may or may not be associated with a feeling of hopelessness, as it could be linked with a defiant attitude, anger and frustration.

Finally, pleasant deactivated responses included relief (16/47), joy and positivity (5/47). Relief was most often reported following the diagnosis, thus, it was linked with acknowledgement and acceptance. It may be associated with hope in a cure or possibility, although, relief could be associated with losing hope when understanding the implications of the diagnosis. Joy and positivity appeared to have a direct link to acceptance and positive integration and embracement of one's situation. It also linked to hope in possibility.

A spectrum of adjustment related responses

The spectrum of responses is presented as a dichotomy from positive embracement to an inability to accept the MSRE and denial of it.

Some people with MS were able to identify a positive embracement (10/47) of the MSRE which identified the importance of the patient taking responsibility for changing their situation, whilst being able to use, or make the most of it. In addition to this the MS was seen as something that is non-devaluing to the point where patients can express the positive experiences of life with MS. It was a post acceptance expression or sub-type of acceptance. Acceptance (19/47) demonstrated a recognition that; the MSRE could be incorporated into the patients' lives (acceptance was defined by the patient and represented the difficulties or losses they perceive, related to the MSRE), that there was a reduced need to defeat or deny it, they could feel less unpleasant emotions and in the words of the patients they were able to "come to terms with it". It is noted that acceptance can be viewed as a coping strategy. Finally, people with MS expressed resignation (aka chronic sorrow) (12/47) to the MSRE. It could illustrate a detached documentary of the illness with a focus on what has been lost and illustrated a sub-type of acceptance.

The most basic recognition of adaptation was identified as an acknowledgement of a MSRE (10/47) which was identified as the middle of the spectrum of adaptation. For instance, pre-diagnosis this could be an acknowledgement that something serious was wrong, or identified post-diagnosis, as having an awareness of what the diagnosis was (e.g., a label given during diagnosis) and that it was a serious illness (often providing relief that it was not more serious). Acknowledgement of the MSRE in both instances could be reflected as a process, which developed across time through learning by speaking to others and searching for information, as well as having experiences of the MSRE.

Many responses from patients' included the difficulty to acknowledge or accept (11/47) and integrate the MS related event into their lives. The inability to accept related to; a) not wanting to accept the perceived threat that the illness represented, b) the perception that acknowledging it would limit their self-expression and emotions, thoughts, or feelings that had been created, c) the implication and potential change that could result from the MSRE and their own ability to engage in meaningful activities (like their job, hobbies, social interactions or leisure pursuits) and the resultant influence of self worth this change may have, and finally d) a misunderstanding or inability to comprehend the information given to them by others (e.g., by health care professionals at diagnosis). Finally, at the end of the spectrum, people with MS could express the inability to accept the MSRE and instead expressed denial related responses (14/47). Denial was observed pre-diagnosis with patients attributing MSRE to other more natural causes that could be recovered from. Often patients could acknowledge that something was wrong but would not undertake health-seeking behaviour to understand the problem further. The lack of recognition of how serious the problem was, could lead to diagnostic delays. Post diagnosis denial was identified with patients concealing their diagnosis in the belief that they could be cured. Denial was used as a coping strategy because for some patients acknowledging the MSRE and what was happening was considered too much to handle. Denial may also have been used as a tactic to allow separation from the illness and/or avoid of being stereotyped by the illness. Some patients did not accept what had happened, but acknowledged one day they would have to, thus, the diagnosis was dealt with when the patient perceived this as a requirement.

Hope related spectrum of responses

This spectrum of responses reflected the dichotomy of hope (11, 88) in that responses ranged from concrete hope to no hope and an inability to cope. Hope in possibility and uncertainty were represented as responses that existed each side of the middle of this spectrum.

Hopes were expressed for changes that could be perceived as positive for the patients (15/47). Particularised hopes were expressed and included the following; hope for a cure, for improvement, for "normality" in their lives, or just to cope. People with MS could hope for a cure, a reason for this could be that they presumed MS could be cured and that they were unaware that it was a lifelong condition. Patients could express hope as a wish or within their imagination that they could be better, or they could hope that the disease would go away, the latter could be associated with the uncertain trajectory of the prognosis of any one patient. Hope for a cure was linked to medical advances and for those who had religious faith in God, to heal. Patients would hope that the disease would not progress but also that they would be able to cope and adapt to the changes and challenges.

The hope in possibility (10/47) represented a willingness to accept that the hope expressed may not occur and expressed against their own situation which was viewed more positively e.g., pre-diagnosis that they didn't have MS or post diagnosis that they had a remitting or form of MS which is slow in progress. Hope in possibility represented a positive view of the unknown future, which could not be determined with certainty. Whilst some patient's could express hope in possibility, others expressed their vulnerability to the uncertainty (27/47) of outcomes and their prognosis. The unknown speed and magnitude of change were important aspects of the MS that were perceived as important to the concept of uncertainty and each patient in their future lives. Uncertainty created unpleasant emotions and impacted the patient's sense of control and ability to make choices.

Finally, some individuals experienced and expressed the loss of hope and hopelessness about their situation (14/47). Hopelessness was underpinned by the perceived limited value in trying to make changes because of the pre-determined future and outcome of having MS it was also reflected and more present in patients whose experience of symptoms were at a point where no value in living life was experienced or could be seen in the future. Related to this, patients could express an inability to cope (6/47) with the event, their situation or circumstance. This was directly related to a result of the change brought about by the MSRE and impact of that change on their life (which could be considered as not worth living). The inability to cope was also identified as part of patients perceiving a pre-determined future (14/47). The pre-determined future was illustrated by patients who focused on the outlook that was to come, the loss of joy in living and the perceived lack of control, ability to care for themselves and dependency on others as well as inability to see close others following their own death. The inability to cope was considered as part of the symptoms worsening and the experience of permanent disability towards a point where they no longer wished to live.

The model of emotion, adjustment and hope (MEAH)

The model represents the combination of an emotional response, the ability to integrate and adjust to what has happened and identifies the expression of a patient's hope as defined above. It is considered or represented as a sphere or cube due to its components. The emotional responses to illness represent one axis; whist hope and adjustment represent another axis (see **Figure 2**). The emotional responses to illness illustrate reactions, which can be explained or considered using the circumplex model of affect (39). The responses relating to the concept of hope are represented on a continuum between hopelessness for ones situation and concrete hope for ones situation (11). The expression not identified within the hope spectrum from the current results (perhaps lost in analysis within an overlapping theme like hopelessness) was that some patients may see no need to hope for change to the MSRE [88] since this is the middle of the spectrum it is important to note. The adjustment related axis reflects components of the traditional stage model of adjustment [89]. The components of the stage model are rearranged to reflect the cognitive elements of the stage models from denial to positive (re)integration. **Figure 2** provides a visual of this model and components.

Primary Routes Identified within the MEAH

It is possible that within the MEAH (viewed as a sphere or cube) a typical response could be identified. These responses could quite easily be grouped by responses that illustrate an ability or potential to cope or a potential to succumb to the MSRE with all three aspects being identified.

Coping Strategies associated with the coping or succumbing response

A summary of the higher order family of codes for coping strategies was identified (15, 16). The family of codes are presented within those coping strategies that primarily facilitated coping or those codes that hinder the coping process.
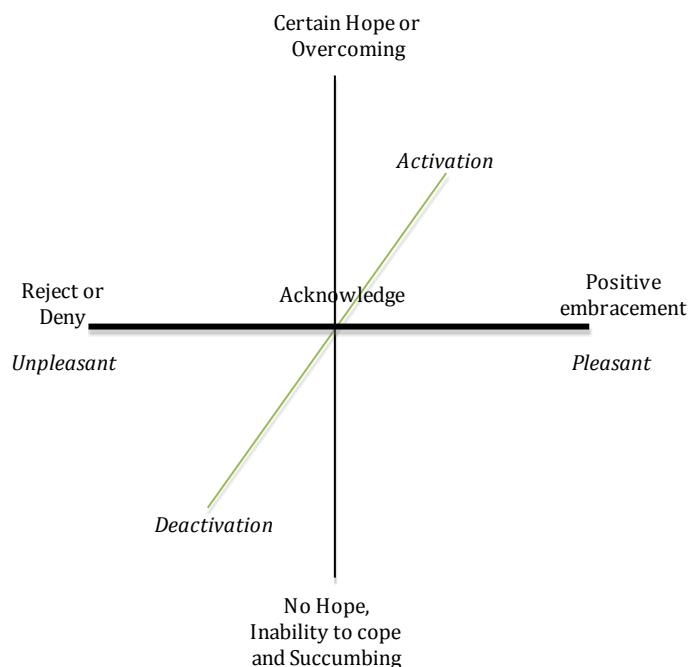
Certain Hope or
Overcoming

Activation

Reject or
Deny

Acknowledge

Positive
embracement

Unpleasant

Pleasant

Deactivation

No Hope,
Inability to cope
and Succumbing

Figure 2. The emotional and cognitive responses to the MS related disease or event.

Coping strategies that facilitated coping

The primary 'families' of codes that enabled and supported the coping processes were; problem solving with 5 codes, self-reliance with 3 codes, support seeking with 3 codes and 2 codes were associated with information seeking and accommodation.

The coping family entitled self-reliance included the following 4 codes: 1) The ability to resist and be resilient against the illness event (21/47). This required patients to be brave, battle or fight against what was happening, to have determination and endure the process and the adversity it brought. This fighting spirit was essential for patients who wanted to continue to engage in meaningful activities and interactions. 2) The need to realise the choice and responsibility to take action (29/47). This response often occurred as a counter action to the uncertainty experienced or the uncontrollability about the MSRE and/or advice given by professionals. It was regarded as a point at which self-regulation begins and people were able to feel more in control of their own situation. 3) Experiencing independence, being able to assume a role in life and have value (27/47). Part of this strategy meant being able to accommodate the effects of the MRSE by working with others. This strategy could be problematic when others made the person with MS feel too dependent, worthless or not valued, it also required acceptance of help from the person with MS. 4) Maintaining dignity and integrity of living was identified as important for people with MS (12/47). It was important for patients, especially at more advanced stages of MS, to feel respected as a person, as others (health care professionals, family, or friends) are required to have access to more private and personal aspects of the person's life, for instance toileting could be experienced as an intrusion. In addition, individuals wanted to be treated as a whole person and not feel stigmatised or devalued because of their MS.

The coping family entitled problem solving included the following 5 codes: 1) Focusing on activities that still could be done (22/47). This was achieved by pacing and planning activities that were achievable according to the restrictions the MSRE imposed on the person. This strategy could be affected by the uncertainty and variability of the MS symptoms. 2) Accessing a healthier life (16/47). This included accessing and engaging in healthy behaviours (e.g., changing diet, exercise), accessing alternative therapies or medicines (e.g., experimental drugs). 3) Adapting to access meaningful activities (20/47). This was achieved by using mobility devices (e.g., wheelchair, hoists) or other devices (e.g., urine pads or home alteration) that enabled the person with MS to continue activities, roles and valued interactions. 4) Continuing as normal (17/20). This was achieved by attempting to defy the MS symptoms and retain activities and interactions that were previously undertaken. 5) Al-

tering engagement in activities (14/47). This was identified as ways of engaging in public that accommodated the MS symptoms; these including utilising rest periods, restricting activities or undertaking activities in different ways.

The coping family entitled support seeking included the following 3 codes: 1) Being able to express emotions or feel listened to (12/47). This allowed patients to feel able to express honest experiences of the illness and feel valued by others. 2) Spiritual influences (10/47). This included structured or unstructured engagement in spiritual activities (e.g., church attendance or praying at home) which allowed the person to feel uplifted, supported as well as enabled acceptance of their situation and buffered the experience that the disease was in control. 3) Doing something for others (11/47). This included people with MS obtaining value and feeling a sense of purpose from giving or doing something for others.

The coping family entitled information seeking included the following 2 codes: 1) Upwards and downwards social comparison (18/47). Individuals could give examples of peers that inspire them. However, some patients did not want to make comparison because comparisons were seen as threatening or did not want to be associated with groups of peers because of being seen and defined by that group and the perceived limitation or stigmatised qualities of it. 2) Searching for information about the illness and possible cures (21/47). This was defined by a need to understand the MS further and following diagnosis this could be focused on searching for possible treatments and cures.

The coping family entitled accommodation included the following 2 codes: 1) Reappraising, reframing, rationalising and/or benefit finding (27/47). This code was defined through being able to reconsider how they view their situation, identify the value that their life has now, and/or identify the benefit within it. For instance, more importance and value could be placed on family relationships, seeing the value in using a wheelchair rather than the negative aspects of having one and identifying the ways in which others are helped by their own actions. 2) Living positively and making the most of each day (19/47). This theme was defined by the need to value and utilise the time they had left and appreciate what was possible.

Coping strategies that hindered coping

The primary 'families' of codes that primarily hindered the coping process included helplessness with 3 codes, and social isolation, submission and escape with 1 code.

The coping family entitled helplessness included 3 codes: 1) the perceived loss of control in life and over the disease symptoms (17/47). This was defined by the inability to exercise control over their body, activities, relationships, interactions and existence. The perceived loss of control could lead to a perceived inability to cope and suicide ideation. 2) The sense of powerlessness or being helpless (10/47). This was represented by the inability to act or influence the disease related processes. Powerlessness was identified following diagnosis and could be severely influenced by interactions with health care professionals. 3) A pre-determined future (14/47). This was defined by patients who recognised a point in the future where life would no longer be worth living, they could identify what the future would be like and that there would be a point in time when they couldn't cope and life was not worth living.

The coping family entitled social isolation included 1 code: 1) the experience of activity restriction and isolation (26/47). This was informed by the loss of, and having to give up meaningful interactions and activities. These losses had a negative impact on mental well-being and could lead to suicide ideation.

The coping family entitled submission included 1 code: 1) the loss of choice, freedom and dependency on others (25/47). This was defined by the need to rely on others and a loss of freedom, choice, dignity and respect this could bring. These losses affected a person's sense of self-esteem and self-worth.

The coping family entitled submission included 1 code: 1) having a break from the illness (9/47). This was defined by not revealing the diagnosis, not talking to others about the MS and not thinking about it or making plans in the future to accommodate it.

4. Discussion

The current review has been able to illustrate a broad psychological process associated with MS and MSREs. The process has been able to link together emotions, adjustment and hope to identify how a primary response to adaptation may occur. The current findings illustrate the importance of the concepts of acknowledgement and hope in possibility in enabling a positive expression from a patient. The current findings also illustrate the importance and value in certain groups of coping strategies for people with MS.

4.1. The Psychological Processes of Adaptation in MS

Previous literature [9] [13] [14] [90] has been able to build evidence for the importance of the different psychological components identified in a patient's response to the MSRE. For instance, the following findings from a previous review [9] support a coping response in identifying that; hope has been associated with less depression, being positive and optimistic is associated with better mental well being, and also that positive adjustment is aided by coping strategies such as benefit finding, positive re-appraisal, and seeking social support.

The psychological processes identified from the current results have been able to integrate and synthesise previous theory [91]-[93], psychological models [12]-[14] [19] [90] [94] and processes [16] [17] that consider psychological adaptation to chronic illness. The MEAH provides a simplified and integrated process that is usable for clinicians, and researchers, enabling access to understanding and measuring the patient's expressions and experiences of adaptation. It also identifies certain coping strategies which exist in the spectrum of adjustment and hope and distinguishes them from the taxonomy of coping strategies previously identified [15]. Given the findings it is quite possible that the responses to adaptation and the utilisation of specific coping strategies lead an individual to a period of coping or succumbing, which supports a previous model [12].

4.2. Capturing an Emotional and Cognitive Response to an Illness

Emotions have been identified as important in the coping [17] [95] and self-management [17] response to illness. Further to this, feeling positive [9] or feeling depressed [90] can have a significant impact on a patient's mental well-being. Thus being able to capture such emotions is important to interventional-based research. The MEAH has provided a simple way of capturing and illustrating expressions made by patients that relate to adjustment, hope and emotions, as well as identifying central psychological factors from the current findings that influence the patient's adaptation. Importantly, the different psychological factors are constructed in a simple way which could be captured using a simple checklist. It is also noted that spectrums of hope and adjustment can be found within the 13 common illness narratives expressed by patients with MS [96] and thus a simple checklist developed to represent the MEAH within this review may help the understanding of how hope, adjustment and narratives vary in response to illness.

4.3. The Different Use of Coping Strategies and the Importance of Self-Reliant Strategies

Planning and positive re-appraisal have previously been identified as the most frequently used coping strategies in people with MS [97] and are likely linked with protection against psychopathology [98]. Although risk factors like avoidance and suppression can have a stronger negative association with psychopathology [98]. The use of problem solving coping strategies within the following families of coping was less for newly diagnosed patients with MS compared to healthy control. These included problem solving, support seeking, and accommodation [97]. Thus, based on the current results it may be that the family of coping strategies around self-reliance is more prominent immediately following diagnosis before the use of problem solving, support seeking and accommodation is possible. It may also be that following change or exacerbation from MSRE that self-reliance is also identified as more prominent in its utilisation. Further to this, the ability for the individual to be self-reliant may be marked by a point (the decision to regulate behaviour) where individuals can identify the importance and realise the need of self-regulatory behaviour [99] and thus begin behaviour self-regulation [100] following a MSRE.

4.4. Towards a Theory of Psychological Adjustment Needs (TPAN)

A theory is proposed which identifies particular psychological needs that are required to overcome an event, trauma or disease and symptoms. These needs include; a) independence, choice and dignity, b) an expression of defiance and resilience c) realising choice and gaining a perception of control, d) hope in the possibility of seeing positive aspects of one's future. Finally, e) the ability to acknowledge what has happened and what it means to the individual.

First, independence, choice and dignity are clearly represented as fundamental aspects of living that patients want to retain; this is supported by previous research in individuals with neurological illnesses e.g., [32] [33] and may be more prominent as the illness progresses or towards the end of life [12]. Research has identified that dependency can be linked with feelings of being powerless or feeling ineffective at tasks [101]. Also when pa-

tients are dependent on others, negative feelings can be generated from non-friendly interactions [102]. Results from the current review illustrate that there is a point where life may be perceived as not worth living, this point was directly associated with independence and dignity. Health care professionals are called to help patients self-manage and empower them with knowledge [103], as this aids their independence directly. This is achieved by providing choice for the patient [104] and respecting their identity and privacy [105]. It is worth noting however, that within the dignity driven care paradigm, researchers [106] have suggested the need to balance the provision of respect, the support for autonomy, and preference for the patient with the need not to abdicate professional responsibility.

Second, the need to defy one's circumstances is a central psychological factor, which influences the proposed processes of adaptation. The ability to defy is reliant on important psychological constructs including courage [17], motivation or agency [107], resilience [108] and determination [32]. Further to this, the importance of will power and self-control as a central role of self-regulation has been identified previously [109], although both aspects can be vulnerable to depletion [18].

Third, the perception of control is regarded as a crucial dimension that relates to adaptation [93] and that can influence a patient's ability to access coping resources and strategies [21] [110]. It is a factor which moderates the relationship between coping and adjustment [23] as well as a key factor identified within the common-sense model of illness threat [20]. A perception of reduced controllability can promote a great use of escape-based coping strategies [97]. Thus, the perception of higher levels of controllability is likely associated with a coping rather than succumbing response to a disease related event.

Fourthly, the hope in possibility protects an individual from the effects of uncertainty, because this type of hope embodies some level of uncertainty [26], but is accepting to what might not be rather than being associated with worry and fear of possible outcomes. Possibility allows a patient openness to change and a willingness to accept what happens in the future [11]. Indeed, being able to consider positive aspects of one's future is possible for individuals who are dying [111]. It has been identified that both the perception of control and being more optimistic (in this case seeing possibility) is associated with individuals having more self-determined motivation (less need for external pressure and a greater sense of purpose) leading to higher levels of mental well-being [94].

Finally, the ability to acknowledge an event related to illness prevents and protects against denial related responses or a response that is not able to accept what has happened. Some form of acceptance or related variant of acknowledgement, positive embracement, or resignation (chronic sorrow) likely protects patients against succumbing to the effects of the illness [12]. Put in another way, without this, patients will only have access to a very limited number of negative illness narratives without acknowledgement [11] [96].

4.5. Implications

Several implications are given: 1) The MEAH illustrates that a patient's adaptation to MS could be easily captured and used within research and clinical environments. 2) The different elements of psychological adaptation and coping strategies play an important role in maintaining mental well-being in patients with MS. 3) Being able to recognise the importance of the elements within the TPAN will likely influence the mental well-being and quality of life of patients with MS [3]. It is very likely that both of the above implications can be applied to other neurological patient groups and groups of patients with chronic and palliative illnesses.

4.6. Limitations

The effect of financial limitations and cognitive decline are not considered within the analysis. Sub-analysis considering the variation in the different forms of MS was also not possible; also the sample used in the analysis was predominantly female. The ability of each article to cover all the themes may restrict the analysis, alternatively the ability of the author to extract all meaning identified in articles is also restricted. Emotions were generated by an understanding of the circumplex model of affect with no consideration to other models or views. The influences of biological changes such as cognitive problems or brain atrophy are not identified, nor are consideration to the influence of culture addressed. Studies contained patients with different age groups that may have impacted on the results, however, given the focus on generalisable processes, the impact of this may be limited. The psychosocial factors that influence the processes of adaptation are not considered. For instance, some of the following factors likely impact on the adaptation processes, these include; personality [23], social

support [32] or the effects of isolation [112].

4.7. Conclusion

The key psychological processes involved in adaptation for patients with MS have been identified within the current review. The results illustrate the importance of understanding the emotional and cognitive processes involved in adaptation. Health care professionals, researchers and patients may benefit from considering the proposed model and theory when assessing and promoting psychological adaptation in patients with MS.

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Only the primary author has contributed to the intellectual property of this manuscript.

Declaration of Interest

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