A qualitative study exploring psychosocial professionals’ perceptions of the acceptability and effectiveness of psychosocial interventions in multiple sclerosis care

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A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Professional Doctorate in Health Psychology

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April 2022

Word count: 32,235

Table of contents

Acknowledgements……………………………………………………………….. 1

Preface..2

Abstract..3

Systematic review...4

1.0 Introduction...6

1.1 Overview of multiple sclerosis 6

1.2 Psychosocial interventions in MS care 8

1.3 A model for organising and providing care 10

1.4 Therapeutic approaches and content 12

1.5 The acceptability of psychosocial interventions 16

1.6 The acceptability of psychosocial interventions in MS care – perceptions of people with MS...16

1.7 The acceptability of psychosocial interventions in MS care - perceptions of healthcare professionals 21

1.8 COVID-19 and interventions for MS care 27

1.9 The Current Research Study 28

2.0 Research Methodology 30

2.1 Research design 30

2.2 Theoretical position 30

2.3 Data collection: Online surveys 31

2.4 Method of data analysis 34

2.5 Survey design...35

2.6 Participants...39

2.6.1 Demographics 39

2.6.2 Participant recruitment...41

2.6.3 Sample size 41

2.7 Procedure 43

2.8 Data analysis 43

2.9 Quality and rigour in qualitative research..45

2.10 Ethical considerations and approval 48
2.10.1 Ethical approval 48
2.10.2 Participant informed consent 48
2.10.3 Participant safety 48
2.10.4 Confidentiality and storage of data 49
3.0 Data analysis – Results 50
3.1 Summary of psychosocial interventions delivered by healthcare professionals 51
3.2 Theme 1: “CBT can be helpful, but thought challenging can have limited use”: CBT and the complexity of MS 52
3.3 Theme 2: “Change isn’t possible” vs Ready to change 57
3.4 Theme 3: “Not trying to be the expert”: Working collaboratively and respectfully 61
3.5 Theme 4: “It helps to know they are not on their own”: The value of support networks 65
3.6 Theme 5: “There is not enough focus or funding for this kind of input”: Systematic barriers 69
4.0 Discussion 73
4.1 “CBT can be helpful, but thought challenging can have limited use”: CBT and the complexity of MS 73
4.2 “Change isn’t possible” vs Ready to change 76
4.3 “Not trying to be the expert”: Working collaboratively and respectfully 77
4.4 “It helps to know they are not on their own”: The value of support networks 78
4.5 “There is not enough focus or funding for this kind of input”: Systematic barriers 80
4.6 The Chronic Care Model for neurological conditions (CCM-NC) 81
4.7 Recommendations for psychosocial interventions in MS care 83
4.8 Strengths, limitations and directions for future research 84
4.9 Conclusion 87
5.0 References 89

6.0 Appendices 112
Appendix A - What is the evidence of effectiveness of psychosocial interventions to increase quality of life in adults with Multiple Sclerosis: A systematic review .. 112
Appendix B – Permission for use of figure 1 138
Appendix C - Reflective chapter 139
Appendix D - Privacy notice 147
Appendix E – Participant information sheet 150
Appendix F – Participant consent form 153
Appendix G – Online survey 154
Appendix H – Demographic survey 157
Appendix I – Participant debrief 159
Appendix J – Invitation letter 160
Appendix K– Examples of initial TA coding 161
Appendix L – Thematic maps 168
Appendix M – Ethics application 170
Appendix N – Ethical approval letter 179

ACKNOWLEDGEMENTS

I would firstly like to thank all the participants who kindly took the time to take part in this study, whom without this research would not have been possible. A special thank you goes to the Multiple Sclerosis (MS) Trust who kindly took the time to support with the recruitment process.

Thank you to my supervisory team, Dr Elizabeth Jenkinson and Dr James Byron-Daniel for their invaluable expertise and guidance. I am extremely grateful for Dr Jenkinson’s continued encouragement and support throughout my thesis, which helped aid my confidence as a qualitative researcher.

I am also thankful to my fellow trainees on the Health Psychology Professional Doctorate, it has been a pleasure being on this doctorate journey with you all. I wish you all the best and hope to cross paths with you in the future.

To my Mum, Dad and sister Melissa, thank you for your continued loving support and encouragement to reach my goals. Mum, I am truly grateful for the huge amounts of time you have given to help look after Chloe and Elliot, so that I can have the time to work on this thesis. Without your support I would not have been able to complete this research. To my partner Ross, thank you for your patience and support in what has been a long journey.

This thesis is dedicated to my daughter Chloe and my son Elliot. You have given me the strength and motivation to push through the difficult times and complete this thesis. I hope that one day this inspires you to live your dreams and achieve your goals.

PREFACE

I commenced the Professional Doctorate in Health Psychology at the University of the West of England in 2017. The doctorate requires the successful completion of five competencies:

1) Professional skills

2) Consultancy

3) Teaching and training

4) Behaviour change interventions

5) Research

To date, I have successfully completed the professional skills, consultancy, teaching and training and behaviour change interventions competencies.

The research competency is divided into two parts, comprising of a systematic review and a thesis. This thesis has therefore been submitted to fulfil the requirements of the research competency. I have successfully completed part one, the systematic review (Appendix A). The review titled, 'What is the evidence of effectiveness of psychosocial interventions to increase quality of life in adults with Multiple Sclerosis: A systematic review', helped to inform the current thesis.

Prior to commencing the professional doctorate and throughout I worked full-time at a health clinic as a psychotherapist. During this time, I have delivered both individual and group psychosocial interventions. This has included working with clients to support them with lifestyle changes, around areas such as substance misuse and eating disorders. I have also delivered interventions to support clients in the management of health conditions such as, fibromyalgia, infertility and at times multiple sclerosis (MS). My experience in this area and networking with other MS healthcare professionals combined with my interest in psychosocial interventions led me to research in this field.

ABSTRACT

Multiple sclerosis (MS) is a chronic autoimmune disease of the central nervous system, affecting more than 2.3 million people worldwide, with over 100,000 people in the UK diagnosed with the condition (NHS, 2021). The symptoms of MS appear in different forms, resulting in physical and psychosocial impacts. Previous research has stressed the need to consider the perspectives of both patients and healthcare professionals (HCPs) in supporting people with MS. Despite this, the perceptions of HCPs in MS psychosocial support are under researched. This study aimed to explore the perceptions of psychosocial HCPs of the acceptability and effectiveness of psychosocial interventions in MS care. In this qualitative study, 32 HCPs currently delivering psychosocial interventions in MS, completed open-ended questions in an online survey. Five themes were identified using thematic analysis; ; 1) "CBT can be helpful, but thought challenging can have limited use": CBT and the complexity of MS, 2) "Change isn't possible" vs Ready to change, 3) "Not trying to be the expert": Working collaboratively and respectfully, 4) "It helps to know they are not on their own": The value of support networks, 5) "There is not enough focus or funding for this kind of input": Systematic barriers. Findings brought into question the effectiveness and acceptability of existing psychosocial interventions in MS care. The main findings showed that despite its common use, CBT was said to be limited due to the cognitive decline in people with MS, resulting in difficulties understanding CBT principles. With the breadth of MS symptoms, a flexible approach should be taken for interventions to be effective, however not all HCPs felt they had the knowledge of how to achieve this. A lack of understanding of psychosocial interventions in MS care was said to be held by both people with MS and other HCPs. Support networks made up of HCPs and family/friends are needed alongside psychosocial interventions to increase the acceptability and effectiveness of these. Psychosocial interventions in MS care were also said to be inadequately resourced and undervalued making it challenging to deliver these effectively. This study has provided valuable insight and knowledge of the perceptions of HCPs of psychosocial interventions in MS care. Findings have implications for health psychology in the design and delivery of psychosocial interventions for people with MS. This includes training and educating HCPs to develop the confidence to deliver effective and acceptable interventions which meet the diverse needs of patients. Organisations are encouraged to review how service capacity is used in order to be more effective and to meet the recommended guidelines set out by NICE (2019, 2016).

Systematic Review - "What is the evidence of effectiveness of psychosocial interventions to increase quality of life in adults with Multiple Sclerosis: A systematic review"

During the period of December 2017 and January 2018 the researcher of the current study carried out a systematic review (Appendix A) which aimed to systematically synthesise the evidence of effectiveness of psychosocial interventions on quality of life (QoL) in adult multiple sclerosis (MS) patients from randomised controlled trials (RCTs) carried out in the area. The review also aimed to critically appraise methodological quality of studies identified and build upon and update existing literature in order to draw conclusions as to how effective psychosocial interventions are for improving QoL in MS. Fifteen studies from the search were eligible for inclusion in the review.

In summary, the review highlighted encouraging results for using psychosocial interventions in improving QoL for individuals with MS. Overall, all studies apart from one cognitive rehabilitation intervention (Lincoln et al, 2002) showed improved QoL post-intervention, although level and duration of improvement differed. The majority of interventions used a group face-to-face approach and some combined this with individual sessions. Psychotherapy interventions were found most beneficial for improving QoL and this improvement was greater over time in those using cognitive-behavioural therapy (CBT) (Cosio et al, 2011; Graziano et al, 2014; Thomas et al, 2014). However, methodological limitations are noted with two studies being rated weak.

Alongside CBT further factors found helpful or suggested from different interventions included a multi-disciplinary team (MDT) approach, providing education on strategies to manage MS and booster sessions to maintain gains. There were mixed results for using mindfulness with benefits seen post-intervention reducing over time in two of the three studies (Carletto, 2017; Simpson, 2017), suggesting only a short-term effect for this intervention. However, authors did propose supplementation of regular booster sessions to maintain gains (Grossman, 2010) and the use of eHealth programs to render interventions more accessible (Carletto, 2017). It may also be helpful to consider merging mindfulness alongside a further intervention type that has longer term benefits.

Five studies referred to costings; the MDT home-based intervention highlights great economic potential by reducing hospital admissions without increasing cost of care (Pozzilli, 2002). However, the nurse-based home intervention was described as possibly too costly for Turkey where the study took place (Akkus & Akdemir, 2011). One education programme stated the intervention would not require additional skills outside of those already used by staff in a neurological setting or additional resources (Ennis, 2006). The FACETS CBT study reported the intervention could be relatively inexpensive to local practices and can be readily incorporated into these (Thomas, 2014). Finally, the professionally guided self-care programme described the intervention as being “low-cost” (O’Hara, 2002). Although there was no report on cost-effectiveness for mindfulness interventions, previous studies have described them as brief and cost-effective (Hofmann, 2010). Studies from many countries have stated MS results in heavy economic burden (Amato, 2002). The use of psychosocial interventions for MS may therefore not only be beneficial for improving QoL, but also economic costs surrounding healthcare support as the condition progresses. It should be noted, information surrounding cost-effectiveness was limited in the current studies highlighting the need for further investigation.

However, despite encouraging results, there are methodological limitations with only 4 studies rated as strong/high-quality. It was unclear if these studies can be generalised to male and female MS patients as well as those from different ethnic groups. It was also uncertain as to how beneficial psychosocial interventions are for individuals with severe MS. Further studies were recommended to ascertain effectiveness of psychosocial interventions in improving QoL for these population groups. The review also suggested that it may be beneficial for future research to expand upon the review by including non RCT studies, as well as future studies including further information on intervention adherence. The cost-effectiveness of using psychosocial interventions for MS remained unclear, highlighting the need for further investigation of this. Despite this, evidence from the review did provide health-care providers with considerations as to what may be beneficial when looking to develop the care for individuals with MS.

Although my thesis does not stem *directly* from the results of my systematic review, it remains grounded within the field of psychosocial interventions for multiple sclerosis care. The systematic review provided an awareness of the types of psychosocial interventions that are available for people with MS and how effective these are with regards to addressing QoL. However, studies showed methodological flaws and the acceptability of these interventions alongside how they work in practise were not considered. The perceptions of HCPs on psychosocial interventions in MS care were not explored in the systematic review. These limitations informed the current study.

1.0 INTRODUCTION

1.1 Overview of Multiple Sclerosis

Multiple Sclerosis (MS) is a chronic autoimmune disease of the central nervous system and the most common disabling neurological disease to affect young adults (Rejdak et al, 2010). According to the National Multiple Sclerosis Society (2020) it affects more than 2.3 million people worldwide, with over 100,000 people in the UK diagnosed with the condition (NHS, 2021). Symptoms commonly manifest between the ages of 20 and 40 years (Rejdak et al, 2010) and its prevalence is 2 to 3 times more amongst women than men (NHS, 2018). There has also been shown to be a significant 1.7-fold increased risk of all-cause mortality in patients with MS compared to the general population (Jick et al, 2014).

The symptoms of MS appear in different forms and are usually progressive. Symptoms include fatigue, pain, numbness, loss of balance, stiffness, tremors, bladders problems, bowel trouble, vision problems, cognitive problems difficulties with speech and swallowing, sleep issues, sexual issues and hearing problems (MS Trust, 2018; MS Society, 2021). The most widespread and impactful consequence of MS is said to be poor mobility which may result in significant disability (Baird et al, 2018). The different forms of MS fall under three main categories: relapsing-remitting (RR) MS which is the first stage most people will be diagnosed with. People with RR MS experience distinct relapses of symptoms lasting at least 24 hours. Some relapses are mild, however some are more severe, with the individual experiencing full or partial recovery (MS Society, 2021). Secondary-progressive (SP) MS for many people comes after RR MS and describes the transition from relapse into a steady progression of symptoms. Individuals have fewer or no relapses, although their disability increases (MS Trust, 2020). Primary-progressive (PP) MS describes symptoms that are progressive from the onset and gradually worsen rather than distinct relapses (MS Trust, 2020).

Due to its progressive nature, coping with MS is ongoing and individuals are confronted with emotional and social challenges (Eklund & MacDonald, 1991). Alongside the physical symptoms, most people with MS have psychological symptoms which can begin at any stage of the disease (Glanz et al, 2007; Amato et al, 2012). Previous research has shown mental health comorbidity in MS is associated with disability, social harms, increased somatic symptoms, diminished treatment adherence and reduction in quality of life (QoL) in people with MS (Chwastiak & Ehde, 2007; Chiaravalloti & Deluca, 2008). Compared to the general population, people with MS have been shown to have lower QoL (Gedik et al, 2015, Sue Ryder, 2019), this is also significantly lower than individuals with other chronic diseases such as inflammatory bowel disease and rheumatoid arthritis (Ruddick et al, 1992). This diminished level of QoL may be the result of impaired functioning in daily living and the detrimental effect upon their family relationships, social dynamics and employment (Gil-Gonzàlez et al, 2020). The main determinants of health-related quality of life (HRQoL) amongst people with MS, have been reported as being fatigue and depression, with fatigue having a prevalence rate of over 90% and depression around 50% (Biernacki et al, 2019). Previous research amongst people with MS has cited fatigue as being one of the most disabling symptoms of MS, with it having a significant impact on physical and cognitive function (Roberts, 2017). QoL can also be affected by disease factors such as MS type, disability level and individual factors such as age, education, social support or employment (Gil-Gonzàlez et al, 2020).

People with MS often have complex needs which require support from a variety of community services, resulting in financial costs for patients, families of the patients and the community. Costs can include home-care, loss of earnings for the patient and caregiver and expensive medical treatment (Whetten-Goldstein et al, 1998; Parkin et al, 2000). Working life becomes a source of worry and anxiety for people with MS. Not long after diagnosis, almost half of those who leave their employment due to their MS condition will do so within the first three years of being diagnosed (Messmer Uccelli et al, 2009). Simmons et al (2010) explored the longitudinal changes in employment and the importance of symptom management amongst people with MS in Australia. Two self-report surveys were performed 4 years apart. A total of 1,135 participants responded to the first survey, 1,329 to the second and 667 to both. The surveys highlighted that of those employed the most common reason for leaving their job was due to MS symptoms. These symptoms included fatigue (69.5%), mobility problems (43.8%), difficulty with cognition (36.7%), balance of dizziness (36.7%) and heat sensitivity (30%).

Although research into reducing the number and severity of relapses through pharmacological interventions has made advancements, there remains no cure for MS (Clarke & Coote, 2015). However, considerable evidence suggests that the use of psychosocial interventions for people with MS can help to improve many of the most common symptoms including fatigue, pain, depression, anxiety and stress (Turner & Knowles, 2020). Furthermore, recent research has described people with neurological conditions as being let down by the health and care systems, with mortality rates increasing, patchy access to services and a lack of direction and coordination in healthcare services to improve things for people with neurological conditions (Sue Ryder, 2019). There is, therefore, a need for research to continue into the development and evaluation of these essential psychosocial interventions that aim to reduce MS symptoms and improve the QoL for people living with MS. A critical and detailed stance on the considerable evidence for psychosocial interventions and the need for further research in this field will now be explored.

1.2 Psychosocial interventions for MS care

Psychosocial interventions are non-pharmacological interventions that address social, psychological, personal, relational and vocational factors (Turton, 2014). As well as psychological interventions, this also includes health education and social support (Forsman et al, 2011). These interventions can be delivered using both individual and group approaches. The National Institute of Clinical Excellence (NICE) highlights the need for psychosocial management to be included in the routine care of people with MS. This should allow for individuals with MS to be able to express their thoughts, feelings and any concerns. There should also be a tailored approach which is responsive to an individual's changing needs, including relapses, deteriorating symptoms and progression (NICE, 2016; NICE, 2019). The importance of individualised needs within MS treatment is also highlighted in an article by Giovannoni and Rhoades (2012), on the current approaches to treatment selection for people with MS. The article aimed to explore the factors that should be evaluated in the selection of therapy for people with MS. The article highlighted that in order to be able to meet the specific needs of individuals, treatment needed to be individualised. This individualised treatment would also change if needed during the duration of the disease due to symptoms and relapses. Given the high-risk that people with MS have of developing cognitive difficulties and/or emotional dysfunctions, it is recommended that interventions should be delivered earlier in diagnosis as a preventative rehabilitation approach (Hung & Yarmak, 2016).

The delivery of MS care is typically carried out by a specialized multidisciplinary team (MDT) to provide care for all facets of the disease (Gallien et al, 2014; Roberts et al, 2017). It is suggested that the team should be made up of a professional clinical network who have an expertise in managing MS (NICE, 2019). This includes GPs, neurologists and specialist nurses. Other professional support which should be involved according to the individual's needs include physiotherapists, occupational health, speech and language therapists, psychologists, social care, dietitians and continence specialists (NICE 2016). A MDT approach which integrates patient-care and rehabilitation activities is needed to increase the efficacy of therapy, provide improved overall patient satisfaction and improve the QoL for people with MS (Sorensen et al, 2019). However, multidisciplinary working can be complex and has its challenges. Staff and stakeholders can have differing views and attitudes towards the best ways to bring about a good outcome and what this outcome is made up of (Firth-Cozens, 2001). Jaglal et al (2014) carried out a qualitative study aimed at understanding the existing health and community service needs and gaps in neurological care. Semi-structured interviews were conducted with 180 participants, of whom included HCP's, community-based non-health care professionals and policy makers. Data analysis was an iterative constant comparative process involving descriptive and interpretive analyses. Participant interviews revealed negative views surrounding neurological conditions from the general public, employers, in schools and healthcare providers. This negativity has been particularly related to behavioural disturbances and has led to delays in diagnosis and treatment, less support from providers and patients being unaware of support services which they can access or not seeking them out.

A literature review by Xyrichis and Lowton (2008) identified two themes from a thematic analysis of 10 qualitative studies. These themes were team structure and team processes, both of which highlighted factors that can hinder MDT working in primary and community care. The theme of team structure was made up of three sub-themes. Firstly, team premises, which was seen as being important for facilitating communication. Teams which were made up of team members being based in different locations resulted in less integration and therefore limit team effectiveness. Secondly, the team size and composition showed that larger teams seemed to not function as well as smaller teams due to lower levels of participation. Evidence for this has been found by Rutherford and McArthur (2004) who further state that the status of team members also has implications for effective team working, as individuals may hold back from providing input towards decision-making. Stability was also highlighted as an influencing factor for effective team working, with those that had been working together longer and made up of more full-time staff being found to be more effective. The third sub-theme focused on organisational support, and the crucial part it plays in effective teamworking. This included encouragement of innovation and support to implement change, without this team members can be left feeling discouraged and powerless (Cashman et al, 2004).

The second main theme of team processes was again made up of three sub-themes. The first focused on the need for regular team meetings to increase innovation levels (Borrill et al, 2000), a breakdown of professional barriers (Rutherford and McArthur, 2004), enhanced communication (Hanafin & Cowley, 2003) and improved interpersonal relations (Xyrichis & Lowton, 2008). The second sub-theme was clear team goals which was spoken as being a key factor for team effectiveness (Borrill et al, 2000), team functioning (Cashman et al, 2004) and clarity of each professionals' role. Professional conflict and ineffective teamwork can occur when there is a lack of understanding one another's professional role (Xyrichis & Lowton, 2008). The final sub-theme raised the importance of audit which can help to evaluate the team's effectiveness (West & Markiewicz, 2004). However, despite the beneficial suggestions which are made by the Xyrichis & Lowton (2008) review, the quality of the studies included are not made clear.

Overall, MDTs are thought to be the best way of working for patients and the HCPs involved. However, in order for HCPs to work effectively together there needs to be constant attention, recognition and adjustment (Firth-Cozens, 2001).

1.3 A model for organising and providing care

The chronic care model for neurological conditions (CCM-NC) (Jaglal et al,2014) was developed to address the factors that are specific to providing quality multi-disciplinary care for those with neurological conditions. The model originated after expanding and modifying the chronic care model (CCM) (Wagner, 1996) and the expanded chronic care model (expanded CCM) (Barr et al, 2003). The CCM has been widely used to inform service delivery across a diversity of healthcare settings and chronic condition specific contexts (Harris et al, 2017). The CCM-NC was devised after semi-structured interviews were conducted with 180 participants, of whom included HCP's, community-based non-health care professionals and policy makers. Data analysis was an iterative constant comparative process involving descriptive and interpretive analyses. There were two aims of carrying out the interviews. Firstly, to gain an understanding of the existing health and community service needs, including gaps in care. Secondly, to develop a model which may help improve the quality of care, health and well-being for people with neurological conditions. As seen in Figure 1, the CCM-NC is made up of three components; socioeconomic and political context, community integration and health system.

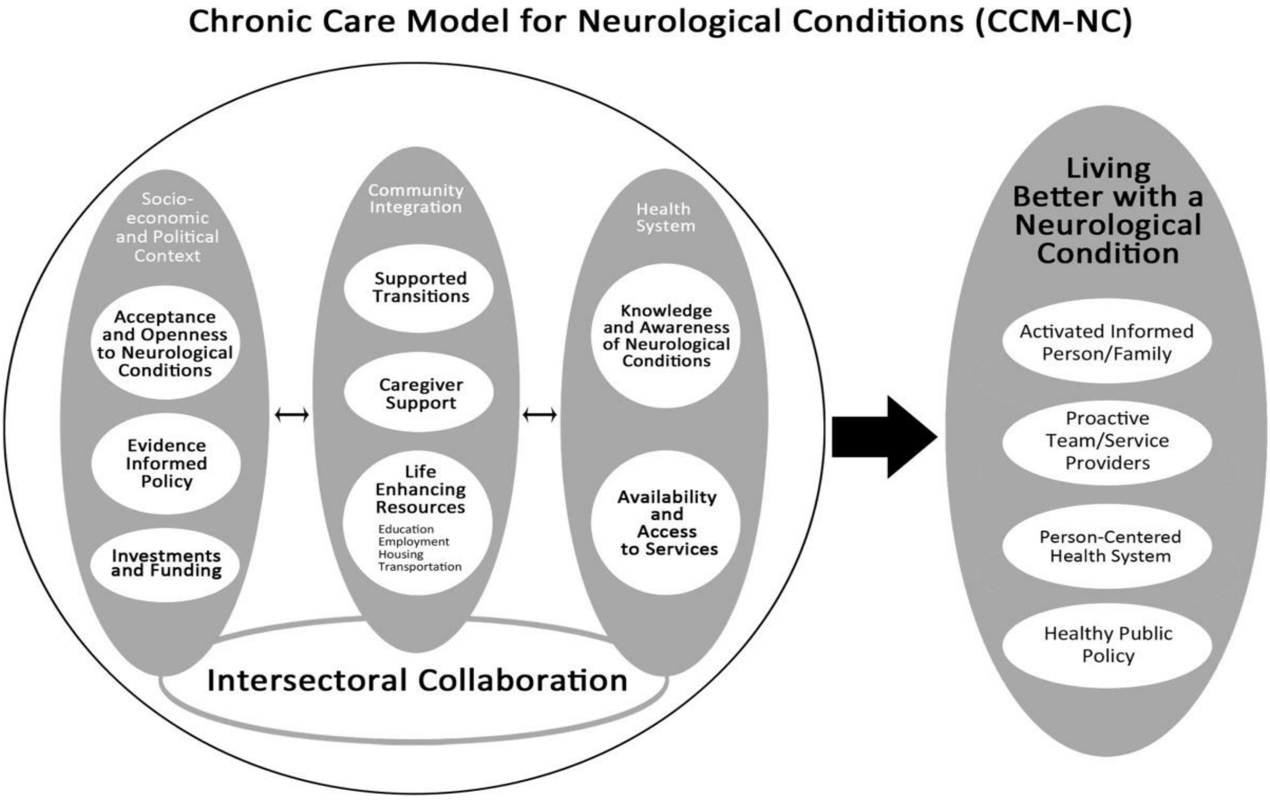


Figure 1: The Chronic Care Model for Neurological Conditions (CCM-NC) (Jaglal et al, 2014) with permission in Appendix B

The overall aim of the CCM-NC is to have an activated informed person/family, a proactive team of service providers, a person-centred health system and a healthy public policy in order to improve the well-being of people with a neurological condition. To achieve this, the CCM-NC speaks of an intersectoral collaboration between the socio-economic political context, community and health system.

Although the CCM-NC addresses the factors that are specific to providing quality multi-disciplinary care for those with neurological conditions, there are some challenges and limitations identified by the creators of the model. The main limitation which Jaglal et al (2014) identify was that people with neurological conditions were not interviewed to inform its development. Next steps would therefore include validating the model with people with neurological conditions. The developers of the CCM-NC, also identify the challenges that may come with prioritising the various model components in different countries due to differences in health and social care systems.

Having discussed the different components that underpin the health system needed for people with neurological conditions, the ways in which MS services can be delivered will now be discussed.

1.4 Therapeutic approaches and content

A wide range of approaches to psychosocial interventions have been evidenced as being applied in MS care. A meta-review of 30 systematic reviews exploring psychosocial adjustment to MS diagnosis identified six approaches that were used when designing interventions; CBT, mindfulness, acceptance and commitment therapy, psychoeducation and supportive counselling/psychotherapy (Topcu et al, 2020). Interventions were delivered in several different formats, including groups, one-to-one, telephone, internet and information booklets. These interventions were found to be effective in improving QoL, coping, self-management, depression, anxiety, fatigue, knowledge gain and job-satisfaction. The review also highlighted that it is important to develop interventions around the specific symptoms that play an important role in adjusting to MS, such as fatigue. Evidence for this can be seen in qualitative studies showing the positive effect of interventions addressing fatigue (Thomas et al, 2015; Khan et al, 2014). However, it was not clear in the meta-review by Topcu et al (2020) how effective these interventions were in improving an individual’s adjustment to MS. Due to the interventions in the studies being administered to mixed groups of people with MS, it was also unclear as to how effective these were for those newly diagnosed.

The use of cognitive behavioural therapy (CBT) is a common therapeutic approach, used as a framework for psychosocial interventions in MS care (Ehde et al, 2019). CBT was originally used as a method for treating emotional disorders, however it has become increasingly common in supporting people with chronic illness to help symptom management and improve psychological outcomes such as depression and quality of life (Ehde & Jensen, 2004). CBT uses a collaborative approach to help patients identify and change problematic thoughts, feelings and behaviours (Davies, 2021). CBT has been recommended by NICE (2009) guidelines for the treatment of depression in chronic physical health problems and for the management of chronic primary pain (NICE, 2021).

When considering which factors should be included in the delivery of a psychosocial intervention for MS care Borghi et al (2018) used mixed-methods to analyse transcripts of intervention sessions made up of 41 patients. The study focused on group-based CBT and how these promote change for people with MS. Participants were recruited from an MS Clinic Centre of a large hospital in Italy. From the data, the researchers put forward several suggestions to consider in the delivery of MS group interventions. These included ensuring that those delivering group interventions are aware of resistance and openness to change coexisting in the change process. It was also suggested that a group intervention should be a minimum of 3 sessions focusing on promoting identity redefinition, a sense of coherence and self-efficacy whilst also including follow-up sessions once the group was completed. Results from a scoping review of 10 studies, found that interventions showing significant effects were a minimum of six weeks in length with one weekly session of 50 minutes, which should be led by a trained interventionist (Asano et al, 2014). With the nature of MS meaning that symptoms cannot be pre-determined, it leads to individuals having to readjust with each new symptom or change in function they experience. Therefore, the goal of interventions is said to not be one of acceptance but rather one of self-management and learning to adapt (Fraser et al, 2013). To aid adaption, Kalb & Reitman (2012) suggest disease-related education, treatment of emotional and/or cognitive problems, support for family members, support for those remaining employed and for the transition out of this if it is necessary to do so.

The use of mindfulness-based interventions (MBIs) is becoming more popular and frequently used for psychosocial issues (Burgess et al, 2017). Mindfulness is the awareness and acceptance that develops by paying attention non-judgmentally to things in the present moment (Carletto et al, 2020). Participation in mindfulness has been shown to help those with chronic diseases to cope better with symptoms and improve well-being, QoL and enhanced health outcomes (Merkes, 2010). Mindfulness has also been shown to help improve pain interference (Senders et al, 2018) and acceptance by encouraging patients to perceive their physical and psychological symptoms differently (Crowe et al, 2016; Barwick et al, 2020).

A mixed-methods study by Bogosian et al (2016) explored treatment mechanisms in an MBI to decrease distress for people with progressive MS. The study analysed quantitative data from a pilot randomised control trial of 40 participants and a qualitative structured interview with 15 participants who completed the intervention. Data was analysed using deductive thematic analysis. The findings suggested that mindfulness may benefit those with a chronic progressive condition, by helping them gain more control over their emotions and daily challenges. However, mechanisms such as acceptance and self-compassion were found to be more challenging for participants to engage with and more time was needed for these to develop. Findings also showed that the success of mindfulness interventions was dependent upon group dynamics. Previous evidence has shown the effectiveness of integrating CBT and mindfulness interventions for people with MS in improving QoL and reducing psychological problems, including anxiety, stress and depression (Sabagh Kermani et al, 2020). However, to fully benefit from a mindfulness intervention, suggestions that a movement component such as yoga (Grossman et al, 2010) or walking meditation (Tavee et al, 2011) may be necessary to have an improved effect on fatigue and functional physical health QoL. Although, as highlighted by Spitzer and Pakenham (2016), by not including movement exercises in an intervention it enables all participants including those with mobility difficulties to participate in all aspects of the intervention. The importance of considering individual factors has been suggested to avoid causing potential psychological harm to the participant. A recommended exclusion criterion put forward for MBIs includes severe depression, severe social anxiety, recent bereavement, divorce or other personal crisis. Baer et al (2019) proposed that these conditions are likely to interfere with an individual’s ability to participate and get the full benefit from the intervention, however this is not the case for everyone and is subject to clinical judgement.

The evidence for group interventions providing individuals with MS with benefits for their mental wellbeing, can be seen in a quantitative quasi-experimental study by Rafiee et al (2020). The study aimed to determine the effectiveness of positive group psychotherapy on reducing the psychological symptoms and improving QoL in women with MS. Thirty women were selected through opportunity sampling from patients of the MS Society in Iran. Participants were placed into 2 groups, for which the experimental group received an intervention consisting of 8 positive group psychotherapy sessions. Two weeks following the intervention, both groups completed the Depression Anxiety Stress Scale (DASS) and Multiple Sclerosis Impact Scale-29 (MSIS) questionnaires. Results showed that the group intervention reduced psychological symptoms and improved QoL in women with MS. Further findings from the study also showed that feeling part of a group, being supported and experiencing positive and enjoyable events can also satisfy personal needs and improve the QoL in women with MS. A similar study was carried out by Leclaire et al (2018) exploring the feasibility and acceptability of a positive psychology group intervention for people with

MS. Eleven participants completed 5 weeks of the intervention and each week completed a positive psychology exercise. Patient reported outcome measures, including measures of positive affect, optimism, depression, anxiety, and HRQOL were completed at baseline and after 5 weeks. Results from the measures showed the intervention to be feasible and acceptable, with MS patients demonstrating a reduced level of fatigue and depression. However, the limitations of the study highlighted that there was a high rate of decline to participate in the intervention, for which the study researchers suggested that weekly visits to an MS centre to attend the intervention may not be feasible for many of those with MS. It was put forward that alternatives such as virtual group interventions should be considered. As with the previous study by Rafiee at al (2020), all participants in the study intervention were female and so it is unclear in both studies as to whether the group intervention would be similarly acceptable to male individuals with MS.

The use of a one-to-one approach is also commonly used for MS interventions. A randomised control trial by das Nair et al (2016) aimed to compare individual and group interventions for psychological adjustment in people with MS. Twenty-one participants were recruited and allocated to an individual (n=11) or group intervention (n=10). Both interventions were delivered over six sessions and in accordance with a structured group manual for which adaptations were made to suit the individual format. Results from the study found that the individual intervention had better attendance rates, with 88% of sessions attended compared to 55% of group sessions attended. This lower attendance rate of group interventions is consistent with previous literature (Holmes et al, 2012). As attendance rates impact the effectiveness of interventions the reason for non-attendance needs to be determined. Hypotheses put forward for higher individual intervention adherence has included the ability to focus on specific topics in individual sessions and so people may feel that they get more out of them instead of groups, people may also feel more obliged to attend individual sessions as the focus of the therapy is on them. However, it was also highlighted that individual sessions are easier to rearrange if the client/patient is unable to attend unlike group sessions. There was no statistically significant difference between group and individual interventions. However, on all outcome measures the scores were better for individual interventions, including those at the 4-month outcome assessment, with effect sizes ranging from 0.29 to 0.86. Findings from a previous review have also suggested that individual interventions may be more effective in the short-term, however longer-term changes are comparable (Firth, 2014).

1.5 The acceptability of psychosocial interventions

In addition to considering intervention approach and delivery, acceptability should be considered in the design, evaluation and implementation of healthcare interventions (Sekhon et al, 2017). However, acceptability is a concept that is not clearly defined and is under-theorised in research (Sekhon et al, 2018). For the purposes of the current research the definition will refer to a combination of that put forward by Ayala et al (2011) and Sekhon et al (2017). These definitions describe acceptability as a construct that determines how well an intervention is considered by people delivering or receiving a healthcare intervention, to be appropriate and meets the needs of the target population and organizational setting. The acceptability of interventions is dependent upon both the perspectives of those delivering the interventions and those receiving them (Diepeveen et al, 2013; Ayala & Elder, 2011). If an intervention is perceived as being acceptable by the client/patient the level of treatment adherence and improved outcomes increases (Hommel et al, 2013). From the HCP's perspective if the intervention is felt to have low acceptability, this may mean that the delivery of the intervention is not as intended and as a result impact the effectiveness of the intervention (Sekhon et al, 2017).

1.6 The acceptability of psychosocial interventions in MS care – perceptions of people with MS

Further evidence for the use of CBT in chronic physical health problems as recommended by NICE (2009) has been confirmed in a qualitative study by Gotterberg et al (2016). The study explored individual face-to-face CBT aimed at alleviating depressive symptoms. Twelve people with MS who received 15-20 individual face-to-face CBT sessions were interviewed to gain an understanding of their experiences of the intervention. Data was analysed using qualitative content analysis and highlighted two main themes; 'CBT as a demanding process' and 'Confronting everyday life after CBT with self-knowledge and well-being'. Data showed that participants felt the intervention helped them to acquire strategies to aid the management of their feelings, including depression, anxiety and any negatives thoughts. Further evidence of the benefit of CBT alleviating depression symptoms in people with MS can be seen in a systematic review and meta-analysis, in which it was also highlighted that CBT may also improve disease-specific QoL (Hind et al, 2014).

Alongside improving psychological symptoms, the use of cognitive reconstructing techniques has also been shown to reduce pain for people with disability-related chronic pain, including MS (Ehde & Jensen, 2014). However, some clients/patients in the Gotterberg et al (2016) study disengaged from the CBT intervention at an early stage due to difficulties in understanding how feelings, reactions and acceptance of MS can relate to one another. The guidance of the therapist was found to be important in facilitating this understanding and being able to sort out events and thoughts, due to their fatigue levels and cognitive impairment, which has also been found in a previous qualitative study (Hind et al, 2010). Some also found the time and energy required to engage in CBT and complete the in-between session homework challenging. Support from family and work was therefore seen as being necessary to help prioritise CBT alongside daily life responsibilities. The study also highlighted that by the therapists having existing knowledge of MS and working collaboratively as an MDT may help to facilitate participation in CBT. There are however limitations to the Gotterberg et al study (2016). Researchers highlighted that as participants were actively recruited and offered CBT at no financial cost, this may impact the transferability. There was also a short period of time since some participants had been diagnosed with MS, therefore for these individuals it may be that they were in a crisis reaction rather than depression.

A systematic review of 106 studies exploring the QoL of adults with MS, has also reinforced the need for social support alongside interventions (Gil-Gonzalez, 2020). Roberts (2017) stated in a report on MS and holistic management, that due to cognitive dysfunction, clients/patients may need additional support to remember appointments, medication and information from discussions. A quantitative study by Kever et al (2021) assessed social support in individuals recently diagnosed with MS (n=185) and in an independent validation sample (n=62). Participants completed a neurobehavioral evaluation including measures of mental health, fatigue, QoL, cognition and motor function. In both sample groups higher social support was associated with better mental health, QoL, subjective cognitive function and less fatigue. Ratajska et al (2020) have also found higher levels of social support being associated with better mood and QoL

The peer support that takes place in groups is said to be a key element in health promotion when supporting people with chronic diseases (Embuldeniya et al, 2013). For example, the positive psychological benefits of being part of a group intervention were evidenced in a qualitative study which aimed to explore the perceptions of people with MS of a community-based group exercise programme (Clarke & Coote, 2015). In the study, data was gathered via focus groups from 14 participants who had participated in a randomised controlled trial of community-based exercise interventions. Thematic analysis of the data revealed that participants felt part of a team and more motivated to attend the group sessions and complete exercises at home, knowing they did not want to let others in the team down. Participants also spoke positively of gaining advice from others in a similar situation to them and feeling a sense of empowerment. However, participants spoke of the difficulties in adhering to the exercises once the programme had finished. The positive psychological benefits of group interventions have been further evidenced in qualitative interview studies, where individuals with MS have reported that experience sharing, being accepted in a group and companionship are of high value (Learmouth et al, 2013; Aubrey & Demain, 2012). The use of a group approach may also help to challenge dysfunctional automatic thoughts and beliefs and therefore help an individual move onto a different thought process regarding their condition. (Thorn & Kuhajda, 2006).

Although studies have shown a positive response from people with MS who have participated in group interventions, it has been acknowledged that being able to meet individual needs is a challenge in this setting and so therefore conflicts with the guidelines set out by NICE (2019) (Plow et al, 2009). A qualitative study by Lahelle et al (2019) explored group dynamics in a group-based, individualised physiotherapy intervention for people with MS. The sample of participants included 40 patients with MS and 6 physiotherapists with expertise in neurological physiotherapy. Data from a mixture of 13 group recorded sessions and 13 individual interviews was analysed using Malterud's (2012) method for systematic text condensation. The analysis found that when individualization was unable to be applied to group sessions, due to a widely varying level of functionality, the patients expressed disengagement and there was deterioration within the group. Lahelle at el (2019) concluded that rather than holding the traditional viewpoint of seeing individual and group-based interventions as being separate from one another (Everett, 2010; Jones & Kulnik, 2018), that using an integrated approach of the two interventions should be considered. Plow et al (2009) also put forward the view of a combined approach of the two therapeutic methods, with the suggestion that participants benefit more physically from individual rehabilitation sessions and more mentally from group-based interventions. This approach of mixing interventions is also recommended by das Nair et al (2016).

Despite the many positive outcomes which can be fostered by group interventions, studies into chronic disease interventions have suggested that groups can also have negative outcomes. In a qualitative study by Palant & Himmel (2019), the negative effects of social support for patients with inflammatory bowel disease (IBD) were explored. Open-ended interviews were conducted with 42 patients with IBD and the data were analysed using grounded theory. The findings suggest that although social support, including support groups, can be a positive resource in chronic disease, this may also promote a negative experience for patients. Participants spoke of experiencing levels of anxiety and discomfort when listening to others in the group talk about the possible health problems that they may experience in the future when they were hoping to get better. Participants felt that by talking extensively about the symptoms meant they were focused on the negative aspects of the disease. Individuals within group interventions can at times compare experiences as to who has been more successful in coping with their condition. Participants spoke of feeling anxiety and frustration when they met other patients who were feeling better compared to them. It led them to question their condition and ask why they weren't feeling better, some felt they could never feel as well off and have left group interventions.

A qualitative synthesis by Embuldeniya et al (2013) aimed to explore the perceived impact and experience of participating in peer support interventions for individuals with a chronic disease. Synthesis of 25 included studies showed that despite the positive experiences from being in a group, participants can also experience feelings of isolation, due to perceiving others in the group as having dissimilar lifestyles or personalities. Sharing amongst the group can also generate a competitive culture of "whose condition was worse". The sense of connection amongst the group was also evidenced as dependent upon the intersubjective relationships within peer groups. The synthesis suggested that when developing and implementing peer support interventions the potential negative impacts need to be considered.

A qualitative study by Van Heest et al (2017) exploring the impact of a one-to-one fatigue management course also highlighted the benefit of using a one-to-one approach for individuals with a chronic condition. Forty-nine participants with chronic conditions and fatigue took part in the fatigue management course. Data was gathered using measures for fatigue, QoL and self-efficacy at pretest-posttest follow-up. Positive results from the study showed a significant reduction in fatigue and increases in self-efficacy and QoL. The researchers stated that using a one-to-one approach allowed more time to be spent on modules relevant to the client's/patient's situation, rather than having to follow the standardised course material. The client-centred approach also helped to provide a comfortable environment to share private information and set goals, which was said to have likely contributed to the effectiveness of using a one-to-one approach. The use of homework and discussions helped to promote interaction and encouraged participants to apply what they had learnt to their own situation. However, the researchers did highlight that a one-to-one approach cannot match the strengths of a group approach. It was suggested that this lack of peer support may be the reasoning for the participants in the study showing no significant improvement in social well-being.

Methley et al (2017) highlighted the importance of the interaction between clients/patients and HCPs. In this qualitative study the perspectives of 24 people with MS and 34 HCPs of UK healthcare MS services were explored. Semi-structured interviews were conducted and analysed using constant comparative analysis. Data analysis identified three themes; access to primary and secondary care, interpersonal interactions and continuity of care. All of these were concluded by the authors to be central to positive experiences of healthcare. The need for HCPs to have adequate knowledge of potential MS symptoms in order to assess people with MS correctly for services was also highlighted. Suggestions for the increase of specialist knowledge included further training or education, collaboration between specialist services to increase access to knowledge on MS and training those practitioners with special interests, such as pharmacists to help improve access to knowledge on symptom management. The study by Methley et al (2017) also highlighted a person-centred approach and relational continuity can help to improve the experiences of people with MS, helping them to feel more understood whilst also developing trust. This therapeutic relationship also has the benefit of improving the experiences of HCPs to be able to holistically appraise client/patient symptoms and progression. MS can bring about a number of anxieties, implementing relational continuity can also help provide psychological reassurance (Davies et al, 2015). It is poor interactions such as a lack of empathy, respect and listening skills which impacts the person-centeredness of care.

The impact of positive personal interactions in reducing anxiety and providing reassurance, is also evident in service users' experiences of contacting NHS patient medicines helpline services (Williams et al, 2020). Semi-structured interviews were carried out over the telephone with 40 users of patient medicines helpline services. Inductive reflexive thematic analysis of these interviews highlighted positive personal qualities including good listening and communication skills, being compassionate, calm, knowledgeable and working with the client/patient to create their plan of needs. A lack of these qualities can cause harm to the intervention and result in a sustained psychological deterioration (Baer, 2019). There are limitations to the Methley et al (2017) study which researchers have highlighted. With data being collected through one-off interviews, it may be beneficial to complete multiple longitudinal interviews to investigate changing experiences over time with the fluctuating and progressive nature of MS. The low response rates from GPs, although not unusual, influenced recruitment of people with MS through primary care. Researchers also highlighted that people with MS using primary care may have a better recollection of their last care consultation or experience more care due to comorbidities, than individuals recruited from community samples whose MS was long term and more stable.

1.7 The acceptability of psychosocial interventions in MS care - perceptions of healthcare professionals

When considering the acceptability and effectiveness of psychosocial interventions, it is important for us to consider the perceptions of healthcare professionals (HCPs) as the success of future MS interventions relies on their engagement and expertise. Previous literature on patients' experiences of healthcare has suggested that this is unsatisfactory (Methley et al, 2017). Therefore, by combining the perspectives of professionals and patients, a better understanding can be attained of how to meet patients' unmet needs and optimise their care (Golla, 2011). The important role of HCP's perspectives in the shaping of interventions to ensure that they are feasible, acceptable and appropriate has also been shown in healthcare research including; palliative care for people with severe dementia (Midtbust et al, 2018), inpatient diabetes care (Burr et al, 2020), the delivery of telehealth (MacNeill et al, 2014), NHS patient medicines helpline services (NHS, 2020) and end of life care (Sleeman et al, 2015). Evidence has also shown that staff and patient experiences are interlinked (Cornwell, 2014). NHS organisations which have high levels of staff engagement, where they are involved in decision-making, provide better quality care including lower mortality rates, better patient experience and lower rates of staff sickness absence (Ham, 2014). Despite their important role, the view of HCPs on the acceptability and effectiveness of psychosocial interventions for MS sufferers has been found to be under researched thus far.

A qualitative study by Ytterberg et al (2017) explored the experiences of three psychotherapists after conducting individual face-to-face CBT aimed at alleviating depressive symptoms in people with MS for which data was gathered using semi-structured interviews. Content analysis of the interviews highlighted two themes, the first being 'trusting their expertise as a psychotherapist while lacking MS specific knowledge' and the second theme identified as 'the process of exploring the participants' readiness for CBT with modifications of content and delivery'. Theme one spoke of understanding the complexity of living with MS. Within this theme, psychotherapists stated that some people with MS appeared to not have accepted their diagnosis. Therefore, these individuals were unable to make connections between their fatigue, cognitive difficulties, their need for support and the lightening of burdens in everyday life. The analysis of the interviews showed that psychotherapists saw a decrease in depressive symptoms and improvement in mental wellbeing when using CBT. They also spoke of how by working with people with MS, the therapists themselves learnt how problems with acceptance and managing the demands of everyday life contributed to depressive symptoms. A lack of general knowledge of MS was felt amongst the psychotherapists. They particularly felt a lack of knowledge of the impact of MS on the individual they were treating. The feeling of having a lack of knowledge and confidence in managing the needs of people with MS, particularly the mental health needs, has also been spoken of by GPs and practice and specialist nurses (Methley et al, 2017). A lack of basic knowledge and awareness around neurological conditions and principles of self-management is also cited by HCPs existing research (Jaglal et al, 2014).

The second theme highlighted that the psychotherapists felt it may be beneficial to not commence CBT too soon after an individual has been diagnosed with MS. It was found to be difficult to deliver change-orientated therapy when patients had been recently diagnosed and were facing uncertainty. Psychotherapists felt that this may have affected patient motivation to engage with CBT, highlighting that some individuals need time to come to terms with their diagnosis before looking at everyday life obstacles. Despite CBT being a collaborative process (Kazantzis et al 2013; Luong et al, 2020), the lack of MS knowledge amongst the psychotherapists meant that they were unsure of the goals which could be set around behavioural activation. The researchers of the study highlighted the importance of having MS specific knowledge to be able to adapt behavioural activities and at times the cognitive component of CBT to meet individual needs. An example of this need could be seen from the psychotherapists identifying that problems with memory, concentration and getting started with tasks made homework activities challenging. Homework is a fundamental part of CBT functioning and is also cited as one of the main reasons for CBT failing (Tang & Kreindler, 2017).

Psychotherapists also spoke of late cancellations from their patients which they felt was due to a lack of motivation. Again, the need for different forms of CBT was put forward as a solution to reduce this. It was felt by psychotherapists that where CBT is offered to patients instead of sought after, there may be lower levels of motivation and a feeling that it's too much work. Furthermore, it was suggested by psychotherapists in the study that having a charge for the therapy may encourage motivation. From the study the perceptions and experiences of psychotherapists can be seen as needing to be considered to help gain an awareness of the ways that CBT may need to be adapted for people with MS. Psychotherapists also spoke of the difficulties in gauging improvement for those people with MS whose original depression was mild, this primarily took the form of a change in self-perception. However, as highlighted by the authors of the study, a limitation was that the perspectives of only three psychotherapists were used, which researchers state was due to the small number of people with MS engaging with the intervention being researched. This may limit the resonance and transferability of these qualitative findings (Tracy, 2010).

A study carried out in Rome and Milan using a mixed-methods approach, examined patient and HCPs' experiences of a home-based palliative approach for adults with severe MS (Giovannetti et al, 2018). Semi-structured individual interviews were conducted with 12 patients and 15 informal caregivers. Two focus group meetings were conducted with patient referring physicians, made up of 4 participants in each group and one focus group was conducted with home-based palliative approach staff made up of 9 participants. However, the physician focus groups provided little experiential data. Three themes were generated from the patient and carer interviews and staff from the home-based approach; expectations, met and unmet needs and barriers. From the data analysis, the researchers concluded that the home-based intervention was effective in reducing patient symptoms and feelings of isolation amongst patients and caregivers. However, it was felt that duration needed increasing to be delivered over a longer term, although the study did not state the length of time the current intervention was delivered for. Researchers also identified the need for greater resource to be invested into increasing human resource capacity (Jaglal et al, 2014) and building a functioning team, which had been described as under-responsive with competing priorities

(Giovannetti et al, 2018). This lack of resources has been evidenced in further literature as creating a barrier in the delivery of interventions by HCPs in care settings (Toomey et al, 2020). The data also showed a lack of availability of services and rehabilitation input. However, the study highlighted in its’ limitations that at one venue the referring physician focus group was not held and that not all team members attended the HCP focus group. Some important aspects of the team’s experience may therefore not have been identified.

Following on from the study by Giovannetti et al (2018), the availability of MS services was discussed in a study by Wilkinson et al (2018). MS specialists were asked to complete an electronic questionnaire where they were asked to rate on a scale of 1-10 how well they felt their service met six of the NICE quality statements. Results from the questionnaire revealed that most of the 57 HCPs who participated felt that that the support they were offering at diagnosis was above average. The small number of professionals that deemed their service to be extremely poor, stated that this was due to being unable to provide adequate or at times any support to people with MS. Some also stated that their capacity to be able to provide support was being taken over by the clinical aspects. Another concern raised was the lack of referrals being made to services, which was suggested as being the result of poor joined-up working. 83.6% of the questionnaire responses spoke of providing a responsive assessment within their service. However, it was difficult for services to carry out the comprehensive annual review which aims to discuss the patient’s symptoms, wellbeing, care needs and the impact their MS has on daily activities. It was recognised that with the rising number of people with MS, there is an increase in demand upon services and MS nurses have caseloads which are above a sustainable level. Therefore, there is a need to address how service capacity is used in order to be more effective with the limitation in resources. Methley et al (2017) recommend that to help meet with MS NICE guidelines and to make for a more positive healthcare experience there needs to be more timely access to services and relational continuity of care is needed.

The challenges faced within MS services can also be seen in a qualitative study by Golla et al, 2012), exploring the views of HCPs to assess their perceptions of the unmet needs of those severely affected by MS. Thirteen physicians, 7 nurses and 3 social workers all of whom specialise in MS participated in the study. Participants either gave an expert interview or took part in a focus group. All transcripts of interviews and focus groups were coded using thematic analysis. These views were then compared to those of patients highlighted in a previous study by the authors (Galushko et al, 2014). Although the study aimed to assess the unmet needs of people with MS, HCPs also voiced the unmet needs they experience whilst working in MS care. The researchers highlight the importance of considering these unmet needs of HCPs working in MS care, as it is in doing so that support for people with MS will be successful. Results from the study showed that HCPs identified more unmet needs for patients than the patients themselves. These unmet needs were identified in four categories. Firstly, support from family/friends for which HCP's referred to, support to access healthcare services, support in managing everyday life, emotional support, support in maintaining biographical continuity and the needs of relatives. The second theme looked at healthcare services where HCP's spoke of competence, treatment options, doctor-patient interaction, time, information, coordination of care and financing services. The third theme explored managing everyday life and included self-care, housekeeping, children, finances and living. The final theme identified was maintaining biographical continuity, where HCP's spoke of work, meaning/identity, social acceptance and relationships.

Findings in the Golla et al (2012) study suggest that the unmet needs of HCPs caring for clients/patients with MS showed HCPs often feeling overstrained in their day-to-day work. HCPs spoke of being unable to arrange adequate care due to external strains and not having enough time for clients/patients, which was particularly highlighted amongst social workers and nurses. The complexity of MS, its progression and diagnosis were said by HCPs to be a challenge and an area which brought about difficulties in their work within MS care. Despite the knowledge that MS is incurable, pressure was felt, particularly from physicians whose aim is to cure. Once progression with the disease occurred, physicians viewed this as a personal defeat. There are however some limitations to be mindful of with the study by Golla et al (2011). The researchers spoke of difficulties with recruiting HCPs which resulted in a smaller number of participants to take part in focus groups and interviews, therefore weakening the strength of the findings. Those being interviewed also spoke of not knowing where most patients who were highly physically affected by MS were living, they were described as vanishing unseen, and so their unmet needs may not have been completely addressed in the study.

Evidence of concerns from HCPs are also shown in a quantitative study exploring HCPs responses to MS and motor neurone disease (MND) (Carter et al, 1998). A short self-administered questionnaire was completed by 317 HCPs, including nurses (44%), physiotherapists (19%) and GPs (14%). The questionnaire used a Likert-type scale to elicit HCPs perceptions of their ability to manage patients with MS and MND. Open-ended questions were also used to identity the reasons why HCPs were or were not able to convey hope and what they found were the most challenging management issues in caring for people with MS and MND. In this study the progressive nature of MS symptoms was the main concern of HCPs and its unpredictable course which created problems with planning for care. HCPs also spoke of how the changes in cognition and personality can result in patients becoming difficult or demanding. In particular HCPs have raised concerns around the mental health difficulties that can arise for people with MS, especially around times of relapse. Both practice nurses and specialist nurses spoke of their lack of training around mental health. However, despite this, lengthy delays and a decreased access to mental health services has left them working outside of their remit (Methley et al, 2017).

A qualitative study by Peters et al (2019) explored the perspectives and experiences of HCPs on the training and delivery for a MS fatigue self-management program. The study used individual semi-structured interviews at two points after delivering the intervention. Six female HCPs made up of occupational therapists and physiotherapists participated in the first interview and 5 in the second. Data analysis highlighted two themes. The first theme was ‘reciprocity’, which showed how HCPs reciprocated the program they were trained to deliver as an active participant rather than the expert. They instead shared ideas and experiences, gave and received information and problem solved together as a group. This created a more inclusive environment and HCPs stated that they felt a feeling of personal reward and an expansion upon how they would usually practice. Using this approach was also said to create less pressure on HCPs to have to know everything about MS, as it instead allowed patients to share their expertise on MS and symptom management. Those professionals who recognise the benefits of interventions support the patients and add value to the health service. The second theme, ‘enhancements’, suggested ways to enhance future intervention training and delivery of the program. HCPs stated that they liked the non-didactic approach to learning and that having the training delivered as a group encouraged individuals to draw upon their own and their peer’s knowledge and expertise. Participants stated that having a mix of expertise and healthcare backgrounds in the group was important in their learning and that this should be considered in all future training. However, it was highlighted that participants did not feel comfortable once they had finished the training to contact one another for support, a formal provision set up by the facilitators of the training was therefore suggested.

The need for the intervention to be available outside of the main centres was spoken of. This would allow people with MS in more rural areas to be able to attend without having to travel long distances which can be extremely fatiguing for some.

Further evidence of interventions in MS needing to be more available outside of rural areas has been cited in a report by Mynors et al (2016), which showed provision of MS specialist nursing being relatively well provided for in some areas and in others it was inadequate. Jaglal et al (2014) also spoke of the difference in neurological community-based services with those in rural areas lacking. Further findings from the Peters et al (2019) study found that some HCPs also found difficulties in the group when needing to address individual needs which may be more sensitive, such as mental health, incontinence or the need for accessing specialized equipment. However, researchers of this study did highlight limitations regarding the small sample size and that those HCPs in the study had volunteered to train as facilitators for the intervention and were therefore more likely to be motivated to learn a new approach. Although, this does raise the consideration of only training those HCPs who demonstrate an openness to patient-centred care.

1.8 COVID-19 and interventions for MS care

At the time of the current study the World Health Organization (WHO) recognised coronavirus (COVID-19) as a global health emergency. COVID-19 poses additional challenges in managing MS, including serious health concerns for people with MS and their medication potentially increasing their risk of acquiring COVID-19 (Maghazi et al, 2020). During the time of this pandemic, research has shown an impact upon the psychological state of people with RRMS, with anxiety levels elevated and lower QoL scores. With anxiety being a known psychological outcome of MS, this has also been shown to exacerbate the severity of the disease (Artemiadis et al, 2011). The main concern of people with RRMS was not being able to go to hospital as they would usually (Stojanov et al, 2020). This was due to people with MS belonging to the vulnerable proportion of the population, they were therefore advised to keep away from the hospital or outpatient clinics so as to minimise their risk of COVID-19 infection (Bonavita et al, 2020). During the pandemic delivery of rehabilitative therapy and homecare services was disrupted, which was said to potentially have negative consequences for MS outcomes and health-related QoL (Moss et al, 2020). In order to continue to be able to provide support to people with MS during this time, some services have been providing online and telephone support. This is reflected in the findings of this research.

1.9 The Current Research Study

This research aims to explore and understand the perceptions of psychosocial HCPs on the acceptability and effectiveness of psychosocial interventions in MS care. The study will therefore inform the design of future interventions delivered by MS health services, and training for healthcare professionals. For the purposes of this research, psychosocial HCPs are defined as HCPs who deliver a psychosocial intervention, have professional qualifications and who are a member of a professional body, some of which included the Health and Care Professions Council (HCPC), The Nursing and Midwifery Council (NMC), The United Kingdom Multiple Sclerosis Specialist Nurse Association (UKMSSNA) and The Royal College of Nursing, (RCN). Data from previous studies have stressed the importance of the perspective of HCPs in the design, development, implementation and evaluation of appropriate MS care. However, thus far, research has focussed on patient perceptions and experiences.

Research found CBT to be a common therapeutic approach used to deliver MS interventions, with positive results in alleviating psychological symptoms such as depression and physical symptoms such as pain. In some instances, mindfulness was used alongside CBT and again showed effective outcomes around improving QoL. However, both approaches also had their limitations, particularly around individual client/patient needs. Interventions were commonly delivered in a group or one-to-one format, both of which had mixed responses from participants.

Despite the evidence that the perceptions and experiences of HCPs is important for the delivery of quality care, literature surrounding the perceptions of HCPs in MS care has been found to be under researched. Only two studies were found to directly address HCPs perceptions of a psychosocial intervention in MS care. Findings from these studies highlighted the importance of drawing upon the existing experience of HCPs in the delivery of psychosocial interventions for MS care. However, one of these studies focused on the delivery of a specific CBT psychosocial intervention, whilst the other explored training to deliver a fatigue intervention, leaving questions around how further existing interventions may be perceived by HCPs. The remaining literature focused on exploring HCP’s perceptions of MS services and the unmet needs they face alongside people with MS.

Given the limited previous research into understanding the perceptions of HCPs working with people with MS and their insights into the acceptability and effectiveness of existing interventions, further work is warranted. The need for research to aid rehabilitation in MS is imperative and remains ongoing (Sutliff, 2016). Listening to the views of HCPs working to support people with MS will shed light on the acceptability and effectiveness of the delivery of appropriate interventions as well as guiding training and education for HCPs.

2.0 RESEARCH METHODOLOGY

2.1 Research design

A qualitative approach was utilised due to the exploratory nature of the study. Qualitative research has an interest in understanding people’s beliefs, experiences, attitudes, behaviour and interactions (Pathak et al, 2013). It involves listening to people’s views and voices to obtain insights into the world as another experiences it (Austin & Sutton, 2014). This type of research produces in-depth data (Braun & Clarke, 2013) and allows for a more holistic view of the reality of which HCPs experience (Black, 1994).

2.2 Theoretical position

As a researcher it is fundamental to know the ontological and epistemological position that is held for the research to be truly meaningful. Researchers need to understand the role that they have in the research process by knowing who they are and what they hold true (Darlaston-Jones, 2007). It is by understanding this that research can then be meaningfully interpreted as there is clarity about the decisions behind which affect the research outcomes (Moon & Blackman, 2014).

Ontology refers to what exists in the world and how it is constructed (Tebes, 2005). There are many variations of ontology, where on the one end of the continuum that which exists in reality is separate from human practices and understandings, known as realism (Braun & Clarke, 2013). On the other end of the continuum, there are multiple interpretations of reality, which cannot be separated from human practices and depends on human interpretation, known as relativism (Guba, 1990). The researcher in this study adopted a critical realist approach, which sits between the realism and relativism positions. This approach is commonly used in qualitative research (Braun & Clarke, 2013) and adopts the perspective that there is a reality which exists independent of our thoughts, which can only be partially accessed (Haigh et al, 2019) due to knowledge being socially influenced. Truth is achieved through glimpses of the whole which is being described (Bergen et al, 2010). We do not need to observe an entity to know that it exists, as only the results of causal forces can be observed, rather than the causal force itself (Clark et al, 2007). For the current research this meant that the survey responses gathered from participants could help to provide insight into the perceptions of psychosocial HCPs around the acceptability and effectiveness of psychosocial interventions for MS care, which a relativist approach would not have been able to achieve.

Epistemology is concerned with how meaningful knowledge can be created, it is how we look at the world and make sense of it (Willig, 2013). Similar to ontology, epistemology also has varying approaches, from positivism to constructionism. Positivism assumes that meaning already resides in objects and so when we recognise them, we discover meaning which has been lying in objects all along (Al-Saadi, 2014). In research valid knowledge is obtained through the unbiased collection of data, therefore requiring scientific methods which control for variables and remove contamination (Braun & Clarke, 2013).

Constructionist epistemologies hold the view that our knowing of the world is based upon how we come to understanding through our own perceptions and interpretations, which depend upon our social and cultural contexts (Burr, 2003; Gergen, 1999). There are therefore numerous ways to produce truths and no singular reality providing the foundation for true knowledge. The current research took a contextualist approach, which sits between positivism and constructionism. This approach does not assume a single reality amongst different contexts. It allows for the researcher's personal influences to be considered whilst interpreting the participants' interpretations (Madill et al, 2000). Throughout the current study the researcher took time to reflect on these personal influences and their role as a researcher, completing a reflective account (Appendix C). By taking the time to critically reflect, the researcher was able to identify shared aspects of participant identity. This included being a British female HCP within the same age range as participants. The researcher also reflected upon the shared experience in the delivery of psychosocial interventions and their beliefs around the benefits and challenges of the delivery of these. However, the level of in-depth knowledge of MS was not something which the researcher shared with the participants. Having this indifference, was felt to increases the validity of the analysis as the researcher was unable to make any presumptions around responses directly linked to MS, such as outcomes for people with MS and the effects of MS symptoms.

2.3 Data collection – Online surveys

An open-ended online qualitative survey was used to collate the views of the psychosocial HCPs who participated. The online survey was created and hosted using the online programme Qualtrics. An online survey was chosen for this study as it allows for the views of psychosocial HCPs to be collected whilst also considering the time pressures this group of professionals are under (Golla et al, 2011). Qualitative surveys are said to be more appropriate when a population is hard to engage or access (Braun et al, 2020) and for those who might not otherwise be able to participate in qualitative research, it gives them the flexibility needed to be able contribute and share their voice (Davey et al, 2019). An online survey provides the convenience of completion from home or work and via a variety of devices such as a computer or mobile phone. There is no pressure to complete the survey at a particular time or time limit, other than the end date of the study. Therefore, making the research more accessible and reduces the burden on research participants (Reips, 2002). Online methods allow for numerous approaches to sampling and recruitment (McInroy, 2016) meaning that psychosocial HCPs from different areas of the UK were able to participate in the research, allowing for wide geographical reach (Evans & Mathur, 2005).

Due to being able to provide anonymity, online methods may be less daunting and encourage more open responses than face-to-face interviews (McEvoy, Clarke & Thomas, 2021), therefore helping towards gaining the best level of understanding of participants. Online research may help participants to feel more comfortable and decrease inhibitions to participate knowing that their responses will remain confidential (McDermott & Roen, 2012). Research has shown that participants may be more likely to respond to sensitive questions more honestly online (Bartell & Spyridakis, 2012). The interactive nature of being online, may also lead to participants being more engaged than with a standard self-completion questionnaire (Gunter, Nicholas, Huntington & Williams 2002). It also allows for the opportunity to gain a diverse range of perceptions and experiences (Toerien & Wilkinson, 2004), which is needed for quality and validity of knowledge (Suzuki et al 2007).

By not using face-to-face methods the risk of interviewer bias, equipment failure, environmental distractions and geographical limitations were eliminated. Online surveys are also less time consuming as data is not having to be transcribed, which in itself can bring about the risk of errors being made (Easton, McComish & Greenberg, 2000, Braun & Clarke, 2013, pg 80). The benefit of eliminating geographical limitations was particularly important with the current sample who are a geographically dispersed population (D'Amico, Haase & Ziemssen, 2019). Data generated from surveys has been found to be more focused than that generated from interview data (Braun & Clarke, 2013). Participants may also be more protective of their professional identity and competence if being interviewed face-to-face (Braunet al 2020). Previous research has found participants having concerns around the perceptions of others on their fitness to practice when discussing their work (Rance, Moller &

Douglas, 2010). Therefore, the use of an online survey for the current study may allow for HCPs to feel less anxious in sharing their perceptions and experiences in their job role.

Qualitative surveys have been described as an “excellent tool”, for understanding an individual’s experiences or their practices and for gathering information on views and perspectives (Terry & Braun, 2017). Qualitative surveys have been used to good effect in previous research seeking to explore individual’s lived experiences, including the perceptions of HCPs (Braun et al, 2020). A number of studies have carried out these surveys using online methods. In a study by McEvoy et al (2021), an online qualitative survey was used to explore the therapists’ accounts of social class in therapy. The researcher highlighted several benefits to using this qualitative method, demonstrating its value in psychology research. The online survey provided rich diverse data which gave an insight into a large geographically dispersed group. The researcher also spoke of the anonymity of the survey being a high advantage, with some participants stating that it made them feel more comfortable to discuss their class. The openness of the online survey also allowed for participants to not be restricted in the amount they wanted to write, therefore no preconceived ideas were imposed. The researcher of the study stated that the main limitation of the study was the inability to be able to probe or follow up responses, however it was felt that the advantages of the study greatly outweighed this.

The use of an online qualitative survey has limitations and these were considered for the current study. Firstly, online surveys come with the risk of participants misinterpreting or not understanding a question and without an interviewer being present they are not able to see clarification. This can then result in questions not being answered fully. To address this potential risk a stakeholder specialising in MS psychosocial interventions was contacted to review the qualitative survey. From this consultation it was advised to change some of the wording of certain survey questions to make them clearer as to what was being asked.

Another limitation which was considered was the risk of non-response rates. This could be in the form of participants not completing the survey questions or not starting them. To reduce the risk of this occurring it was important to consider how the survey would be distributed so that only those online platforms with relevance to the current study were selected (Seymour, 2001). Other useful ways to help avoid low response rates include ensuring that the participant information sheet includes the importance of their responses for the study and ensuring that materials and the terminology used in the survey are clear (McInroy, 2016). The current study also provides participants with the opportunity to enter a prize draw as an incentive to take part in completing the survey.

2.4 Method of data analysis

For the current research study two methods of data analysis were deemed as being appropriate, those being thematic analysis (TA) and interpretative phenomenological analysis (IPA). Both research methods are said to be suitable for research questions which aim to explore participant experiences and perceptions. The use of qualitative surveys are also suitable for both methods of data analysis, however interviews, focus groups and participant diaries are found to be more ideal for IPA (Hefferson & Rodriguez, 2011).

Thematic analysis (TA) was the chosen method to analyse the survey data which was collected. Braun and Clarke (2017) highlight that TA, “is a method for identifying, analysing and reporting patterns (themes) within qualitative data” (pg 297). This analysis was chosen as it allows for an in-depth exploration of open-ended responses from questionnaires whilst also allowing for flexibility when analysing data (Castleberry & Nolen, 2018). Its flexibility can also be applied in terms of the sample size, research question and method of data collection (Braun & Clarke, 2016).

TA has been applied frequently in the field of health and wellbeing (Braun and Clarke, 2014), including being used to help understand factors that influence public health decisions (Taylor-Robinson et al, 2008). It has also been used to explore the experiences and perspectives of intervention delivery providers (Brown et al, 2007), including views around the acceptability of these (Whelan et al, 2014).

There are various ways which TA can be used when analysing data which need to be considered (Braun & Clarke, 2006). Firstly, the themes within the data can be identified by using either an inductive (bottom up) or theoretical approach (top down). When using an inductive approach, the data is coded without trying to fit it into a predetermined structure, framework or theory (Byrne, 2021). An inductive approach is therefore data-driven. In contrast to this, a researcher using a theoretical approach to the analysis would seek to identify themes which are driven by the researcher’s theoretical or analytic interest (Braun & Clarke, 2006; Byrne, 2021). A theoretical approach is therefore theory-driven. Due to the lack of pre-existing theory and little being known about the perceptions of psychosocial HCPs on psychosocial interventions for people with MS, an inductive approach was deemed appropriate. This allows for new insights to be identified and an understanding of a range of participant experiences in an area which is under researched. A theoretical approach would not allow for such richness of data overall.

Another consideration when using TA is the level for which the themes are identified; semantic (explicit) level or a latent (interpretative) level. When using a semantic approach, the themes are identified within the surface of the data, they mirror participant's language and concepts (Braun & Clarke, 2013). There is no interpretative frame around the participant's words. At a latent level the identification of themes goes beyond that at a semantic level. It involves interpretation and identifying underlying assumptions, ideas or ideologies (Byrne, 2021). For the current piece of research, a semantic approach was chosen to identify the themes. This would ensure that the analysis did not move away from the voice of the participants. Braun and Clarke (2013), also highlight the benefit of a semantic approach requiring less theoretical and conceptual knowledge in order to make sense of the data.

2.5 Survey design

When creating a qualitative survey there are several factors which need to be taken into consideration with the content and structure. Thought needs to be given to how and what questions are asked, the number of questions to use, the order questions will go in and the potential responses these questions may generate (Terry & Braun, 2017).

Due to the lack of previous research surrounding HCPs perceptions of psychosocial interventions, the survey questions for the current study were developed by the researcher and their experience of developing and creating psychosocial interventions in healthcare. Guidance from Braun and Clarke (2013) was adhered to in the development stages and the researcher consulted with their supervisory team, all of whom are HCPC registered. A small informal advisory group of HCPs including two trainee health psychologists specialising in psychosocial interventions for neurological care and a HCPC registered clinical psychologist, were asked to review the survey questions as they were developed.

Gaining clarity around the wording of survey questions is particularly important when using surveys (Smyth, 2016). Following the completion of the survey a consultation was held with a stakeholder specialising in MS psychosocial interventions to review the survey and give advice around recruitment. From this consultation it was advised to change some of the wording of the survey questions as it was felt that it may not be clear to some participants what is being asked. Following the stakeholder’s advice some adaptions were made to the survey to help increase the readability and reliability of the survey. Adaptions included reducing the number of questions asked from 14 to 12 ensuring to focus on the aims of the study, rewording of some of the questions and including a question on models and theoretical approaches (See Table 1 for adaptions)

Table 1: Initial survey questions and adaptions

Initial survey questions	Final questions after adaptions
1) What type of MS intervention do you deliver? (Please could you include information on the content, duration and category of MS it addresses)	1) Which psychosocial interventions do you currently deliver or have you delivered for people with MS? (Please could you include information on the content, duration and category of MS it addresses)
2) In what way does this intervention aim to help MS patients?	2) In what way does the intervention(s) mentioned in question 1 aim to help people with MS?
3) What in your opinion works well with this intervention?	3) What model(s) or theoretical approach(es) is the intervention(s) mentioned in question 1 based upon?
4) What in your opinion does not work well or needs changing with this intervention?	4) In your opinion, what works well with existing interventions that you deliver/have delivered?
5) What do you think helps patients to adhere to and complete and intervention?	5) In your opinion, what works less well with existing interventions that you deliver/have delivered?
6) Why do you think some patients do not adhere to or complete an intervention?	6) What do you think motivates people with MS to take part in psychosocial interventions?
7) From your experience of delivering interventions what do you think motivates and MS patient to engage?	7) What do you think helps people with MS to adhere to and complete an intervention/programme of psychosocial support?
8) From your experience of delivering interventions why do you think some MS patients may not engage in an intervention?	8) What are the barriers to taking part in a psychosocial intervention for people with MS?
9) At what stage of being diagnosed do you think patients are more likely to engage with an intervention?	9) What are the barriers to adherence to, or completing an intervention for people with MS?
10) What aspects of delivering an MS intervention do you find most rewarding?	10) What challenges do you face as a professional delivering psychosocial interventions for people with MS?
11) What challenges do you face as a professional delivering MS interventions?	11) What do you think is currently missing in the design and delivery of psychosocial interventions for people with MS?
12) What do you think makes a successful MS intervention?	12) Are there any others aspects of your experience or thoughts regarding MS psychosocial interventions that you would like to tell us about?
13) What do you think is missing in the delivery of MS interventions?	
14) Is there anything else which you would like to add?	

The online qualitative survey was hosted in Qualtrics, an online survey platform. The survey firstly consisted of participant information (Appendix E) including an online consent form (Appendix F) and privacy notice (Appendix D). The main body of the survey consisted of 12 qualitative questions with prior clear instructions of how to complete this (Appendix G). To allow for an easier flow of the survey, questions which were addressing a similar aspect of the topic were clustered together. Questions 1-3 focused on gaining information around the type, structure, aims and theoretical background of the psychosocial intervention being delivered. Questions 4 and 5 asked for participants to share their views around what they felt worked well and less well with the psychosocial intervention. Questions 6-9 focused on gaining an understanding of what motivates people with MS to attend a psychosocial intervention, including exploration of adherence to this and barriers. Questions 10 and 11 asked for participants to share examples of the challenges that they face as a professional delivering psychosocial interventions and what they feel is missing in the delivery of these. Question 12 invited participants to share any further comments which they felt would be useful for the researcher to know. Using this at the end of a survey can provide useful and unanticipated data (Braun et al 2020)

The final section of the survey recorded demographic information (Appendix H), as recommended by Braun and Clarke (2017). This information included detail on gender, age, job role, frequency of work, length of time worked in the MS field, length of time delivering psychosocial interventions in the MS field, professional qualifications and professional body. This data is important for being able to reflect upon the relationship between the results and the sample used. It therefore, helps in showing on what basis any claims can be made from the data and the transferability of these (Braun & Clarke, 2013). Following on from the demographic questions the survey contained a debrief page (Appendix I) thanking participants for taking part in the study. The researcher’s contact details were highlighted on this page should participants have any questions/comments regarding the study. Although it was not anticipated that participants taking part in the research would experience any distress physically, psychologically or emotionally from the study. Contact details were provided of support that participants can access should they experience any distress arising from the survey.

2.6 Participants

2.6.1 Demographics

The sample was made up of 32 HCPs over the age of 18 years who currently deliver a psychosocial intervention for patients with MS. For the purpose of this research psychosocial HCPs were defined as those who have clinical professional qualifications, are a member of a clinical or health professional body and deliver a psychosocial intervention. Psychosocial interventions for people with MS can include CBT, relaxation, self-management, mindfulness, motivational interviewing and coping skills training (Sesel et al, 2018).

Of the 32 participants who completed the survey all were female. The participants were aged between 24 years and 62 years, with a mean age of 44.7. On average participants had been working in the MS field for 8.84 years and delivering psychosocial interventions in the MS field for 7.72 years. Participants job roles varied and included four occupational therapists, ten MS nurses, three MS clinical nurses, three neuropsychologists, two clinical psychologists, five counsellors, three assistant psychologists and two trainee psychologists. All participants held professional qualifications such as, the Diploma of Occupational Therapy, registered general nursing (RGN), Diploma in Community Health, Professional Doctorate in Health Psychology, MSc in Health Psychology, Professional Doctorate in Clinical Psychology, Diploma in Clinical Neuropsychology and Bachelor of Counselling. Participants were also all members of a professional body which enabled them to deliver psychosocial interventions in MS care. These included the Health and Care Professions Council (HCPC), The Nursing and Midwifery Council (NMC), The United Kingdom Multiple Sclerosis Specialist Nurse Association (UKMSSNA), The Royal College of Nursing, (RCN), The British Psychological Society (BPS) and The Royal College of Occupational Therapists (RCOT).

Detail of participant demographics can be found in Table 2, which has been aggregated to maintain participant anonymity and confidentiality. The practice of changing the names of participants within qualitative research alone, has been said to be inadequate for protecting the privacy of study participants. To further minimise the risk of breaching confidentiality, demographic tables presenting individual participant information line-by-line should not be used (Morse & Coulehan, 2015). Using this line-by-line approach can aid to identification of participants and threaten anonymity. Descriptions should therefore be aggregated and presented as group data, in ranges. (Morse, 2008).

Table 2: Participant demographics

			Frequency of work		Length of time worked in MS field		Experience delivering psychosocial interventions in MS		Age		Gender	
Profession	Total Number	Setting (number of participants)	Part time	Full time	From to (years)	Average (years)	From to (years)	Average (years)	From to (years)	Average (years)	Male	Female
Occupational therapist	4	Neurorehabilitation centre (2) Community (2)	3	1	3 - 19	12.8	2 - 14	6	33 - 60	43.3	0	4
MS nurse	10	MS centre (2) Hospital (1) Residential (1) Community (3) Hospital & community (3)	3	7	2 - 18	10	1 -16	9.6	42 - 58	51.4	0	10
MS clinical nurse	3	MS centre (1) Community (1) Hospital & community (1)	1	2	10 - 15	13.3	10 - 15	13.3	51 - 62	54.7	0	3
Neuropsychologist	3	Hospital (3)	1	2	5 - 20	10.3	5 - 20	10.3	42 - 47	44	0	3
Clinical psychologist	2	Hospital (2)	0	2	3 – 4	3.5	3 - 4	3.5	35 - 41	38	0	2
Assistant psychologist	3	Residential (3)	1	2	2 - 3	2.3	1 - 2	1.7	24 - 33	28.7	0	3
Trainee psychologist	2	Residential (2)	0	2	2 - 4	3	2 - 4	3	32 - 34	33	0	2
Counsellor	5	Community (1) Private clinic (2) MS centre (2)	4	1	3 - 20	8	3 – 20	7.4	38 – 54	43.6	0	5

2.6.2 Participant recruitment

Prior to recruiting for participants for the current study a consultation was held with a stakeholder specialising in MS psychosocial interventions, where advice was sought around recruitment and the HCPs who would likely make up the study sample.

To help capture data from professionals working within evidence-based interventions and provide a more credible sample to make conclusions from, participants were recruited via a number of methods. MS charities around the UK were invited to take part in the research via phone-calls, after which follow-up emails were sent out with an invitation for the research (Appendix J). Where a phone call was not possible an email was sent in the first instance with the invitation attached. Recruitment for the current study took place from January 2020 to October 2020. At the time of participant recruitment, the COVID-19 pandemic resulted in many HCPs being transferred into other roles within the NHS and charity staff being placed on furlough. This led to a number of charities being unable to support the research at this time. From those who were able to support the research a post was placed on the National MS Society's online research page and National Counselling Directory online noticeboard. The MS Trust distributed information of the research through their mailing list, social media pages and training events. Through the MS Trust the MS Nurse's Association were also informed of the research and again information was sent out via a mailing list. The social media platforms Twitter and Facebook were used to promote the research as well as opportunity sampling through the researcher's contacts. Social media has been shown to be an effective recruitment technique, including for those studies using historically hard-to-reach populations (Goodman, 2011; Gelinas et al, 2017). Therefore, making it an increasingly important recruitment resource (Gelinas et al, 2017). It was through social media that an email was also circulated by the Health Psychology Exchange to its volunteers.

2.6.3 Sample size

The question of how to determine an appropriate sample size in qualitative research is one which garners debate. Unlike quantitative research, there is no shared set of standards or acceptable formulae to determine sample size. One important consideration that is often referenced when determining sample size in qualitative research is the concept of data saturation. This has been defined as 'information redundancy' and describes the point at which no further themes, codes or information can be identified from the data (Braun &

Clarke, 2019). Braun and Clarke (2019) state that, "…when it comes to reflexive TA, data saturation is *not* a particularly useful, or indeed theoretically coherent, concept" (pg 215). It has been argued that for as long as data is collected and analysed there will always be new insights that can be made (Low, 2019). The use of data saturation has been said to be used by researchers using a more structured deductive approach, where researchers will have developed an idea of themes ahead of the analysis. This concept was therefore not be deemed appropriate for the current research, for which it would not be possible to predict a saturation point when using an inductive approach, as the approach is data-driven. Braun and Clarke (2019) also state that the concept of data saturation is not consistent with the values and assumptions of reflexive TA.

Sample size is also determined by a number of factors including the research question, scope of the study, depth of individual responses, characteristics and diversity amongst the population and the motivation of participants (Braun et al, 2020). Although not all these factors can be anticipated for prior to carrying out a study, it was known that the population in the current study was a hard-reaching group due to them being time poor (Golla et al, 2011) and made up of a small number of people from whom to draw upon (NICE, 2014). Therefore, rather than aiming for an exact sample size the main consideration for the researcher was to recruit individuals who might provide rich and diverse perspectives in to gain rich deep data findings (Creswell, 2002). The recommended minimum sample size given by Braun and Clarke (2013) of between 15-50 participants was used as a guide for the current study.

Thirty-two participants were recruited in the final sample for the study. Previous qualitative studies in healthcare using surveys, of which some were online, have shown a similar sample size comprising of highly motivated participants providing a good degree of detailed information. Grogan et al (2018) recruited 34 participants for their study on coping with endometriosis, Clarke and Spence (2013) recruited 30 participants for their study exploring experiences of lesbian and bisexual women and a study by Benham-Hutchins et al (2017) recruited 34 participants for their study exploring the experiences of patients with chronic disease.

It should also be noted that during the time of recruitment, the COVID-19 pandemic led to many MS HCPs being transferred into frontline roles within the NHS. This resulted in lower engagement in the online survey and fewer opportunities to recruit participants, which may have impacted the sample.

2.7 Procedure

For those who showed an interest in the study through social media and advertisements they were able to access the survey via a link made publicly available. Once the link was accessed participants were provided with an information sheet (Appendix E), consent form (Appendix F) and privacy notice (Appendix D). Once the literature had been read and consent given participants were guided to the online survey. Instructions on how to complete this were provided at the start of the survey and throughout where appropriate. Prior to starting the survey participants were asked to create a four-digit ID number which they would need should they choose to withdraw from the study at any point. Once participants had completed the survey and the following demographic information, the debrief page was shown (Appendix I). At this stage participants were then given the opportunity to enter a prize draw to win a £100 online shopping voucher.

Should a participant, charity or organisation have preferred to complete the survey via a hard copy this was made available with a prepaid envelope and contained the same information as the online version. This was requested by the MS Trust who were then able to distribute these amongst those attending a training event.

2.8 Data analysis

Braun and Clarke's (2006) guide of the six phases of analysis was applied to the data (Figure 2). Whilst working through the six phases, data were analysed participant by participant and rather than summarizing the response to each question individually, the data was treated as one cohesive dataset to not miss the understanding of an issue which is often seen in responses to other questions (Terry & Braun, 2017).

Figure 2: Six phases of Thematic Analysis

1. Familiarising yourself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Whilst analysing the data the six phases were not used in a linear fashion but in rather more of an iterative way, which involved going back and forth through the phases. Ensuring this flexibility when using guidelines for qualitative analysis allows for the researcher to use the appropriate approach which fits the research question and data (Patton, 1990)

Phase one of conducting TA involves becoming familiar with all aspects of the data which has been collected. Braun and Clarke (2006) speak of the importance of, 'immersing', yourself into the data by repeatedly reading it and making notes of points that can be used at a later phase. Transcription of verbal data has therefore been said to be a good way to gain this familiarisation. Although the current research did not need to transcribe verbal data, time was spent transferring online survey responses into a data table which allowed the opportunity to start becoming familiar with participant responses. These were then re-read and initial coding notes were taken. The next phase of the analysis involved producing codes from the data which appear interesting and relevant to the research question. For this phase these codes where highlighted within the text and key words/phrases were written alongside (Appendix K). Once the entire dataset has been coded phase three of analysis begins. This phase involves arranging the codes into potential themes and bringing together the relevant extracts. It is here where the different level of themes are considered as well as the relationship between the codes previously identified. To aid this phase thematic maps were used to help start organising the codes (Appendix L). Phase four of the analysis is to refine the themes which have been devised, which is carried out in two stages. Firstly, the extracts taken from the data are checked to unsure they fit under the themes. The following stage involves the researcher checking if the themes accurately reflect the entire data set and then going on to ensure that any missed data is coded. Once the researcher had a good awareness of their themes and how they fit together they moved onto phase five of the analysis during which the themes are refined and defined. This phase enables the researcher to gain a deeper insight of what each theme is about and determine what elements of the data are captured within these themes (Braun & Clarke, 2006). Within this phase the researcher named the themes, organised the extracts within these and began to add narrative. The sixth phase of the analysis was where the final analysis was completed, and the report written.

Throughout the data analysis Braun and Clarke’s (2006) 15-point checklist of criteria for good thematic analysis was referred to. The purpose of using the checklist as a guide was to avoid falling into any of the pitfalls that can result in a poor analysis; failing to analyse the data, using data collection questions as themes, claims not being supported by the data, no consistency between interpretations and the theoretical framework being used (Braun & Clarke, 2006). One criticism which often arises when considering the use of qualitative research is its subjectivity and how this can bias the researcher, preventing any objective understanding (Ratner, 2002). However, recognising this subjectivity and reflecting on any potential distorting values can enhance objectivity (Ratner, 2002). Clarke and Braun (2013) state that subjectivity is essential to good qualitative research and that this concept does not produce bias that undermines the research. Rather than viewing subjectivity as a criticism and a threat to knowledge production, it is viewed as a resource (Braun & Clarke, 2019). Braun and Clarke further put forward that data analysis is about interpreting and creating, themes do not emerge passively from the data. To further the importance of deep reflection and engagement with data, Braun and Clarke (2019) have since developed upon their initial TA approach to facilitate better TA practise and in doing so have developed a method known as reflexive TA. The approach requires continual questioning of the assumptions being made in interpreting and coding data. With themes being actively created by the researcher, the acknowledgement of themes not passively emerging is reinforced by replacing the stage of ‘searching for themes’ with ‘generating themes’. Reflexive TA is implemented with the researcher striving to be fully aware of how they see the world and the theoretical assumptions which inform their use of TA. To aid this process of reflection, the researcher sought feedback from their supervisory team to assess validity of the themes from the data analysis.

2.9 Quality and rigour in qualitative research

As the use of qualitative research in the healthcare education has increased significantly over the past 20 years, guidelines have been published for researchers to achieve methodological rigour and research quality (Johnson et al, 2020). To ensure rigour, credibility and quality qualitative research in the current study, Tracy’s (2010) eight ‘big-tent’ criteria were followed. The framework aims to provide a tool to promote excellence for qualitative research which brings together various paradigms. Tracy’s key markers of quality include 1) worthy topic, 2) rich rigour, 3) sincerity, 4) credibility, 5) resonance, 6) significant contribution, 7) ethics and 8) meaningful coherence (see Table 3 for application of these markers). Alongside this, Meyrick’s (2006) framework which provides focus for assessing the rigour of qualitative research was used. The framework highlights two core principles of quality: transparency and systematicity. Both Tracy (2010) and Meyrick’s (2006) frameworks were chosen as they are flexible, comprehensive and can be used amongst different paradigms, therefore fitting with the current researcher’s epistemological and ontological standpoints.

Table 3: Application of Tracy's 'big tent' criteria

Criteria for quality	Application of criteria to the current study
Worthy topic	According to the National Multiple Sclerosis Society (2020) MS affects more than 2.3 million people worldwide, with over 100,000 people in the UK being diagnosed (NHS, 2021). Although research into reducing the number and severity of relapses through pharmacological interventions has made advancements, there still remains no cure for MS (Clarke & Coote, 2015). A literature review on psychosocial interventions for people with MS showed limited information regarding the perceptions of HCPs, in particular the acceptability of interventions, therefore warranting further work. Data from previous studies have stressed how important the need is to take into account not only the perspective of the patient but also that of HCPs, as it is these that help to provide further insight into the patient's life and give a complete picture leading to appropriate MS interventions.
Rich rigour	To ensure rigour in the study, the researcher was transparent in providing detail on the aims of the research, rationale behind the sample, detail on the data collection, steps taken during the data analysis and how the data shaped the conclusions
Sincerity	Throughout the current study the researcher took time to reflect on personal influences and their role as a researcher, completing a reflective account (Appendix C). The epistemological and theoretical stance of the researcher is stated in the study.
Credibility	During the development of the online survey a stakeholder specialising in MS psychosocial interventions was contacted to review the qualitative survey. From this consultation it was advised to change some of the wording of certain survey questions to make them clearer so as to avoid participants misinterpreting or not understanding questions. The use of the online survey eliminated the risk of interviewer bias, environmental distractions and geographical limitations. The findings of the study included a detailed description of the themes which included quotes from the participants to illustrate these. The researcher sought feedback from their supervisory team to assess validity of the themes from the data analysis.
Resonance	The findings from the study resonate with the delivery of psychosocial interventions for other chronic health conditions.
Significant contribution	The research findings provide recommendations for improving the effectiveness and acceptability of psychosocial interventions for people with MS. Suggestions have also been made for future research.
Ethical	Ethical approval for the study was obtained from the University of the West of England's Ethics committee. The health research authority confirmed that NHS ethical approval was not required for the current study as the researcher will not be on an NHS site nor using patient or staff data. The necessary ethics for the research project were considered, including consent (Appendix M)
Meaningful coherence	Research procedures and designs were carefully considered in order to select those which would achieve the aims and purpose of the study.

2.10 Ethical considerations and approval

The following ethical factors were taken into consideration for the study.

2.10.1 Ethical approval

Permission for this study to go ahead was sought from the Faculty of Health and Applied Sciences Research Degrees Committee of the University of the West of England and approval was obtained on 12th June 2019. Ethical approval for the study was obtained on 20th December 2019 from the University of the West of England's Ethics committee (Appendix M & Appendix N).

The health research authority confirmed that NHS ethical approval was not required for the current study as the researcher will not be on an NHS site nor using patient or staff data

2.10.2 Participant informed consent

Prior to starting the online survey participants were provided with online literature to allow them to make an informed decision as to whether they would like to take part in the study. This included a privacy notice, participant information and consent form (Appendices D, E, & F). The consent form outlined the rights the individual has should they decide to participate. Participants were fully informed of the nature of the study including the reasons for the study and what will be involved.

Participants were informed in the consent form and information sheet that taking part in the study is voluntary. Should a participant of decided that they wanted to withdraw from the study after completing and submitting their online survey they were be able to contact the researcher to withdraw their data by providing their unique ID number. Participants were also informed that they will have up to 2 weeks after submitting the survey to do this.

2.10.3 Participant safety

It was not anticipated that participants or researchers taking part in the study would experience any distress physically, psychologically or emotionally from the study. Participants were able to complete the online survey whenever they chose and at their own pace within the given timeframe for submission. This allowed for participants to complete the survey in the comfort of an environment of their choice and not have any feelings of pressure from an interviewer. However, there is always the potential for research participation to unexpectedly raise uncomfortable or distressing issues. To address these participants were provided with contact details of the researcher should the issue be related to the project itself. Contact details were also provided of support that participants can access should they experience any distress arising from the survey (Appendix I).

Due to the nature of the survey questions, there is the risk that participants may disclose identifying information of patients. To address this, information on how to complete the survey was be provided at the start, part of which will instruct participants to avoid mentioning any identifying information of patients in their survey responses. Should identifying information still be included after survey submission, the researcher will ensure that this is not included in the write-up.

2.10.4 Confidentiality and Storage of data

The identity of those taking part in the study remained undisclosed and completed surveys were only accessible by myself. At the start of the study participants were asked to create a unique ID number which they would provide if they wished to withdraw at a later date. No names were taken for data collection. Completed surveys were submitted via a link from which participants were not identifiable. Some data may be linked to demographic responses such as intervention delivered, area of the UK, job role.

Participants were asked to provide their email address should they chose to be included in a prize draw, however this was not used for any further correspondence other than to contact the winner of the prize.

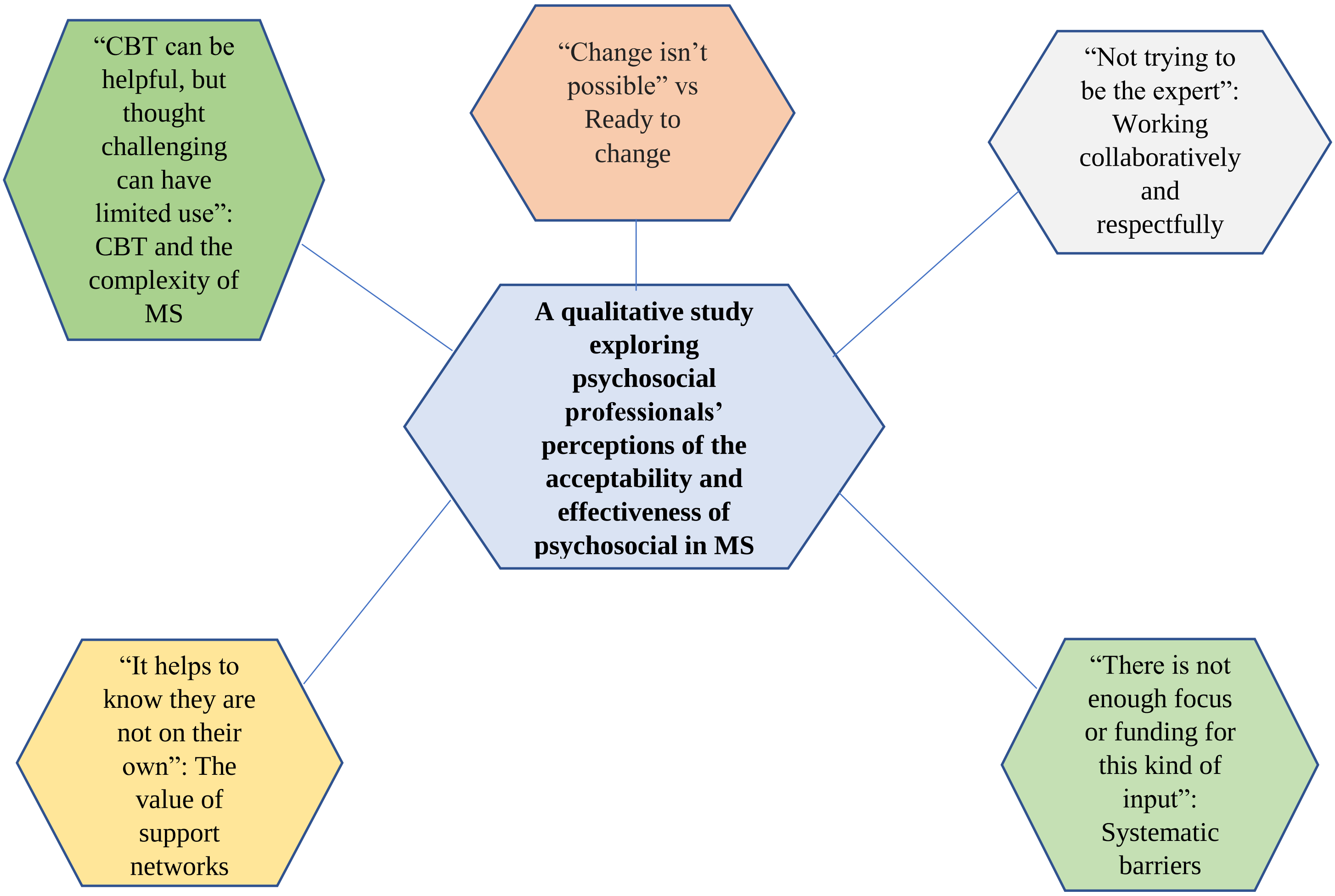
Prior to starting the study participants were informed that the research will comply in accordance with the (EU) 2016/679 General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Data from the study was stored on a password protected laptop and drive which only the researcher has access to. Hard copies were stored in a secure lockable cabinet. Upon completion of the study participants are able to request access to their data should they choose to do by providing their unique ID number. The data will be retained for a minimum of 6 years, and for as long as all interest in the project continues. Once these stages have passed, the computer files will be deleted, and hard copies shredded.

3.0 DATA ANALYSIS – RESULTS

From the data analysis five themes were identified; 1) “CBT can be helpful, but thought challenging can have limited use”: CBT and the complexity of MS, 2) “Change isn’t possible” vs Ready to change, 3) “Not trying to be the expert”: Working collaboratively and respectfully, 4) “It helps to know they are not on their own”: The value of support networks and 5) “There is not enough focus or funding for this kind of input”: Systematic barriers. These are set out in the thematic map (Figure 3), where each theme is outlined with its associated subthemes. Each theme will now be defined followed by a description of its subthemes and a detailed analysis.

Quotes from participant’s survey responses have been used to help illustrate the themes, for which pseudonyms have been used for anonymity. While each theme has been presented separately, at times they overlapped in the narratives of the participants.

Figure 3: A thematic map of themes



3.1 Summary of psychosocial interventions delivered by Healthcare Professionals

From the survey responses almost all participants mentioned that they used a psychosocial intervention in the form of a group and half of participants delivered psychosocial interventions for MS care one-to-one, a breakdown of these can be seen in Table 4.

Table 4: Psychosocial interventions for MS care and their aims

Type of intervention delivery	Number of HCPs delivering this intervention	Number of interventions supporting any stage of MS	Number of interventions supporting early stages of MS	Number of interventions supporting later stages of MS	Overall aim of intervention
Group	25	4	1	2	Emotional management, symptom management, fatigue management, improve QoL, education of MS, gain acceptance of MS, increase motivation to make changes
One-to-one	16	3	2	2	Emotional management, symptom management, improve QoL, goal setting, education of MS, gain acceptance of MS, building support networks, understanding personal identity

Fourteen of the thirty-two participants mentioned in their survey responses that they made use of CBT techniques and theories as the foundation of the intervention which they delivered. This was used for both group and one-to-one sessions. The use of ACT techniques was also described as being used alongside CBT at times. Further models or specific aspects of CBT and/or ACT which were highlighted by participants to aid intervention delivery can be seen in figure 4 below

Figure 4: Therapeutic models/theories used by HCPs in psychosocial intervention delivery

1. Transtheoretical model of change (TTM) (Prochaska & DiClemente, 1983)
2. Shifting illness perspectives model (Paterson, 2001)
3. Health belief model (Rosenstock, 1974)
4. Leventhal common-sense model (Leventhal, Phillips & Burns, 2016)
5. SMART goal setting (Doran, 1981)
6. ABC model (Ellis, 1991)
7. COM-B model (West & Michie, 2020)
8. Seligman's PERMA model (Seligman, 2011)
9. Self-determination theory (SDT) (Ryan & Deci, 2000)
10. Motivational interviewing (Miller & Rollnick, 2012)
11. Compassion focused therapy (CFT) three motivation systems model (Gilbert, 2010).

3.2 Theme 1: "CBT can be helpful, but thought challenging can have limited use": CBT and the complexity of MS

This theme focuses on the opportunities and limitations of CBT in psychosocial intervention delivery, particularly when addressing the complex and diverse nature of MS.

HCP's spoke of delivering psychosocial interventions to target specific MS outcomes such as pain management and emotional management. CBT interventions were commonly discussed by participants as helpful in the management of fatigue in people with MS, including use of the FACETS model. Psychosocial CBT fatigue interventions were said to have benefits for clients/patients, including improving self-management of MS through the development of strategies and helping to promote the feeling of being listened to and understood. HCPs spoke of clients/patients who experience fatigue often felt isolated with their symptoms. The use of psychosocial interventions for fatigue was said to help normalise MS symptoms and provide reassurance that there are ways to manage these.

"Fatigue management looks at current strategies and offers planning both at work and home. ..There is also the aspect of being believed, often MS fatigue is met with comments from family and friends with "I'm tired too" This only serves to underline the fact that MS fatigue is little understood, leaving the person living with MS feeling more isolated than ever. Most

clients feel for the first time someone understands, and even more importantly that there is something that can help" (Jackie)

"Use the FACET programme for MS fatigue and 5 area CBT approach for self-management and trying to improve quality of life…Help to normalise their experiences, gain understanding of the effects of MS to them and enabling them to feel able to access coping strategies…" (Hannah)

To further aid in helping those with MS to better understand, cope with and accept their health condition, CBT interventions made common use of psychoeducation. This was achieved by validating concerns, helping identify how best to manage symptoms and what to expect from MS, as well as discussing the challenging thoughts and feelings that can be experienced. HCPs highlighted the usefulness of this being carried out when individuals are newly diagnosed with MS.

"Good psychoeducation at the beginning and validation of experiences…helps towards improving self-management of symptoms, and psychological adjustment to emotional, cognitive and physical consequences of MS" (Jane)

One participant spoke of the usefulness of an HCP from outside of their team coming into a group session to provide information of specific MS symptoms and to help clients/patients to manage bladder symptoms more effectively.

"The addition of professional input from colleagues/ practitioners out with the centre is also extremely useful. For example, at a living well program delivered last year, many clients had the opportunity to speak directly to a urologist who was a guest speaker. Some were surprised to know their bladder issues were connected to their MS, and heartened that there was something that could be done. Until then they had assumed it was just something they had to live with" (Jackie)

Mindfulness and/or relaxation techniques were used alongside CBT interventions by some participants. Using these techniques was described as having several benefits for people with MS, including helping to gain acceptance of their condition, developing healthier thought patterns, fatigue and pain management and improving confidence in an individual's ability to use self-management strategies.

"The mindfulness and relaxation techniques can be a useful way to encourage healthier thoughts, decrease pain and improve fatigue" (Chloe)

"Mindfulness and relaxation sessions, 30 minute weekly scheduled session to manage fatigue levels… Individual's report feeling relaxed and enjoy spending time engaging in their interests which distracts from issues of health that might be negatively impacting mood. Also, improving the confidence an individual has in their abilities to manage their own health." (Anita)

Goal setting with clients/patients was a common CBT technique used within psychosocial interventions. The use of the SMART technique (MacLeod, 2012) was frequently mentioned when participants spoke of goal setting. Participants said that by using goal setting it helped maintain motivation, encouraged responsibility to make changes, helped to make changes less overwhelming, gave opportunity to address any barriers, helped with symptom management and encouraged intervention engagement. Encouraging clients/patients to keep a written diary and complete homework tasks was also discussed as a helpful way to monitor the client's/patient's progress whilst also maintaining engagement and motivation. Diaries also provided individuals with the opportunity to reflect on their lifestyle and re-evaluate their priorities.

"The sessions make use of CBT techniques and also incorporate relaxation and mindfulness. I use tools such as SMART goal setting… Techniques such as SMART help to break things down and make the change seem less daunting… Diaries can be a useful tool to also monitor progress." (Chloe)

"I use goal directed motivational techniques to help patient engagement in therapy on a one to one and group setting… Setting SMART goals to address patient needs… Improves engagement in taking responsibility for their physical well-being through working towards the patient's own goals" (Maxine)

Despite its benefits in increasing motivation and engagement, techniques such as SMART goal setting and mindfulness were said to be challenging for people with lower cognition levels. Due to its focus on cognitive principles, HCPs raised that some aspects of CBT may not be as effective or acceptable for those clients who faced difficulties with their cognitive ability. Clients/patients were at times unable to participate with session material, maintain concentration, or express their thoughts or feelings. Some clients/patients therefore needed further support in understanding the techniques and knowing how to apply them

"*Although I find CBT to be a great approach, it's important to be mindful that a client's cognitive ability can impact their level of understanding and so at times CBT aspects need to be adjusted or further support offered where possible." (Nina)*

"Mindfulness requires a certain level of attention, or cognitive ability meaning that it is not accessible for all individuals with MS, who may be impaired in these areas. Therefore, alternatives that relieve fatigue and mood difficulties in the same way, would be useful… Cognitive ability, sometimes attention impairments can make it difficult for patients to take part". (Anita)

The use of one-to-one CBT interventions were thought to be useful in this instance as they allowed for a more collaborative approach, where the HCP and client/patient were able to create action plans and SMART goals which were tailored to meet the specific needs of the clients/patients. By supporting individuals in the process of creating their own SMART goals, this helped to increase confidence in clients/patients managing their condition. HCPs also highlighted the benefit of being able to focus more on formulation when using a one-to-one intervention whilst also being able to adjust the length of the intervention accordingly.

"CBT can be helpful, but thought challenging can have limited use in this population…it can be challenging to meet the needs for all unless in a 1:1 intervention which is formulation led." (Amanda)

"I deliver one-to-one counselling sessions…Encourages the client to feel more confident and motivated when identifying goals to work towards… I use tools such as SMART goal setting…SMART helps to break things down and make the change seem less daunting." (Chloe)

The challenges that come with the diverse and complex needs of MS were also highlighted in responses by HCPs discussing the use of CBT group psychosocial interventions. The use of group interventions created difficulties in meeting individual needs. These needs were said to vary greatly, particularly amongst the different stages of MS and at times of relapse in symptoms. Being able to provide a group intervention that can be easily adapted to address this was said to be challenging.

“*It can also be difficult to make sure that the sessions are meeting the needs of everyone in the group, who may be at different stages or experiencing a relapse in symptoms.” (Lynne)*

“Creating an intervention that is accessible for people at different stages of their MS – from newly diagnosed to advanced. And for a group whose symptoms can be so diverse. The psychological needs are completely different for each individual, so it can be challenging…” (Amanda)

It was this lack of an individualised approach which at times impacted negatively upon client/patient confidence and motivation. The diverse nature of MS amongst group members not only created challenges for HCPs but also at times generated psychological discomfort for those participating. Sharing personal experiences around MS within the group, particularly when group members were at different stages of their condition created fear and anxiety. For some participants, this drew attention to the negative aspects of MS and highlighted to them how their own condition may progress in the future. The difficulties in being able to create an individualised approach within a group whilst also trying to provide a comfortable environment for group members was said by HCPs to result in some group members disengaging from an intervention.

“*We have had group members leave because of not wanting to listen to others speak of how their condition can progress.” (Janet)*

“I have had times where group members have become not as engaged in sessions and when I have approached them outside of sessions they have shared how they find it difficult being around others who are at a more advanced stage of MS and seeing how the symptoms are impacting their lives” (Gemma)

Summary

This theme highlighted that CBT can at times be an effective and acceptable psychosocial intervention for people with MS. CBT was a commonly used intervention used to support clients/patients in developing healthier thought patterns and coping strategies to aid in the self-management of the physical and psychological aspects of their condition. This therapeutic method was most beneficial for fatigue management. Techniques such as psychoeducation could be used to help normalise MS symptoms and create feelings of acceptance. When used alongside mindfulness, CBT helped to build upon confidence to use self-management strategies for fatigue. However, despite its common use in psychosocial interventions for people with MS, CBT was limited. The cognitive decline amongst people with MS made it challenging to understand the cognitive principles that underpin CBT. Individuals required additional support with CBT techniques and with the majority of interventions being delivered in a group, this led to the inability to be fully flexible in meeting individual needs and being able to support understanding of CBT principles. Therefore, bringing into question the effectiveness and acceptability of CBT psychosocial interventions when used outside of support in fatigue management for people with MS.

3.3 Theme 2: "Change isn't possible" vs Ready to change

This theme focuses on intervention readiness and in particular the barriers surrounding engagement and adherence to a psychosocial intervention for people with MS.

Participants mentioned that to be able to encourage client/patient engagement with an intervention, there needs to firstly be an understanding of the intervention. However, participants revealed in their survey responses that from their experience there is a lack of understanding amongst clients/patients as to how interventions can support them with their MS. Some clients/patients failed to see the value of psychosocial interventions and how it could help them, therefore resulting in a lack of motivation to engage.

"I think that part of it is because there is a lack of understanding of what we do, clients can feel that because we can't 'cure' or lessen their physical illness then there isn't anything we can support them with" (Val)

Further to this client/patient beliefs around MS brought into question eligibility to attend. These clients/patients held the belief that MS is purely a physical illness and so therefore, they would not be considered for a psychosocial intervention. If they were to attend it was felt that they would be taking someone else's space who needed it more than them.

"Not having enough knowledge of what is available or feeling that their condition is purely physical and therefore not aware of being able to attend a group". (Lucy)

"In general I do not think patients really know what psychosocial interventions have to offer until they turn up. Many will decline therapy due to this" (Melissa)

Alongside the lack of understanding of psychosocial interventions from clients/patients there was also a common belief that there was a lack of understanding and a low value held of psychosocial interventions in MS care amongst other HCPs. Participants shared experiences of the challenges they faced due to the misconceptions around MS held by others. The lack of understanding around the possibilities of people with MS being able to change their QoL for the better, was said to create a resistance in psychosocial support then being offered to these clients/patients. Two participants spoke of other HCPs informing clients/patients that they would not be able to do anything to improve their condition. There was also the misconception that MS is purely a physical condition and therefore dismissing the psychological aspects that play a role. This lack of awareness was said to impact client/patient treatment plans and initial engagement with clients/patients being *"left feeling hopeless and demotivated." (Chloe).*

"Resistance and lack of support from other healthcare professionals and sometimes patient's family members as they don't see MS as being a condition where a psychosocial intervention can be of any use… More awareness of the interventions amongst healthcare professionals. I've had experiences where GP's have said to clients that there is nothing that can be done for their MS." (Janet)

"The Mental Health Team in my area tend to think of health as physical or mental so will often not accept MS patients or discharge them quickly stating their problem is physical and not requiring their intervention, as the problems are due to their MS. They seem unable to understand the certainly with MS physical and mental health are intertwined and need a holistic approach to manage and often cannot be split nicely into 2 separate areas. So this is very frustrating for MSSNs and patients." (Helen)

Participants said that clients/patients benefit and engage most with an intervention when there is an already existing motivation from the client/patient to want to actively adjust areas of their lifestyle. This motivation may come in different forms such as wanting a better QoL, having a support network and wanting to gain more control of symptoms. Some participants highlighted that this level of motivation to engage with an intervention is dependent upon different factors including, where the client/patient currently is with regards to their stage of diagnosis and the symptoms that they are experiencing.

"I think that the patient has to be in the mindset to want to make changes to get the most out of the intervention…Wanting to better their quality of life, wanting to gain back control of their symptoms…" (Lucy)

Some individuals with MS came forward to access a psychosocial intervention after facing challenges within their home, work and/or relationships and wanted support to manage this. HCPs spoke of people with MS being motivated to engage with interventions when first diagnosed with the condition. How individuals go onto then accept and respond to their diagnosis will then determine their next steps regarding whether they access support for their condition. Therefore, making the time of initial diagnosis a crucial time for psychosocial interventions to be readily available and for clients/patients to be aware of how to access these.

"Motivation can also come from an acknowledgement from the person themselves that they are struggling with work/ symptoms/ acceptance of their MS/ relationships etc and feel they need to reach out for support" (Jackie)

"I think people with MS are motivated to help themselves, especially when first diagnosed. Maybe if psychosocial interventions were more readily available it would be a good time then." (Susan)

Where referrals for clients/patients to attend an intervention have been received by a family member of the client/patient, patient motivation was described as often compromised. HCPs described resistance towards what is being discussed in the intervention due to not feeling as if they have chosen to attend. Therefore, impacting on intervention effectiveness with the aims of the intervention challenging to achieve.

"I have had occasions where clients have come to the sessions more because they have been asked to by a family member and therefore motivation and engagement level is extremely low." (Chloe)

"It can be difficult when clients come more because a family member has said they need to rather than out of their own motivation to do so. I find that in this situation clients can become quite resistant towards session material and so aren't able to get what they really need from it" (Lynne)

The beliefs that clients/patients held around change and their MS condition were said by participants to be another factor influencing engagement. Some clients/patients felt that *"change isn't possible" (Lucy).* These individuals felt that nothing could be done to help ease their experience of MS and that making changes or lifestyle adjustments would not make a difference for them. Therefore, there was no felt purpose of attending a psychosocial intervention for their condition. It was also hard for some individuals to accept their condition, they wanted to continue living day to day as they had been prior to their diagnosis.

"The fact that MS is a degenerative condition so it can be hard to encourage someone to engage in a treatment that 'isn't going to make them better'. They find it hard to see how making any changes will benefit them" (Carolyn)

"During assessment some patients just feel that an intervention is not something which will help them in anyway. They say that they have MS and that's that, there's nothing that can take it away so they don't see the point in looking at adjusting parts of their lifestyle" (Nina)

Clients/patients were said to often experience a range of psychological outcomes, influencing their level of willingness to make changes and ability to manage their MS. HCPs were at times faced with changeable and resistant responses from clients/patients, due to struggles with acceptance of their condition, feelings of personal failure and a range of challenging emotions. One of the most described symptoms of MS was fatigue, with 12 participants referring to this as influencing intervention engagements. Participants spoke of the impact that this symptom can have on an individual's motivation towards completing an intervention and engaging with the session activities. it was quite common for clients/patients to stop attending an intervention due to fatigue.

"Patients are depressed and angry that they have the disease and sometimes no therapy works for them" (Emma)

"Patients often have an overwhelm of psychosocial factors impacting on the management of their condition" (Melissa)

"Inability to accept the struggles they have with the diagnosis/not feeling they are eligible for psychosocial support as it's a 'physical illness', not wanting to be labelled and therefore avoiding MS specific support" (Jo)

"One of the common reasons for not completing an intervention is due to relapse and fatigue, it can change the motivation of the client and they start to develop the 'what's the point' way of thinking" (Val)

Summary

This theme has highlighted the concept of those clients/patients who are highly motivated to engage in a psychosocial intervention vs those who are not ready to engage. The want for a better QoL, to have control over symptoms and to gain a support network were a few of the motivators for people with MS to engage in a psychosocial intervention. However, a lack of understanding is said to exist around psychosocial interventions for people with MS, including what these interventions are and how they can support individuals. With this lack of understanding coming from both clients/patients and other HCPs, the delivery of an effective and acceptable psychosocial intervention becomes challenging with regards to engagement levels and adherence. There is the risk of misinforming clients/patients who may benefit from attending a psychosocial intervention for their condition and the needs of clients/patients therefore becoming missed. An individual's diagnosis and symptoms were said to have an impact upon motivation to engage, for which it was highlighted ensuring the availability of psychosocial interventions at this point should be considered.

3.4 Theme 3: "Not trying to be the expert": Working collaboratively and respectfully

This theme focuses on the approaches and practises used by HCPs to ensure for effective and acceptable delivery of psychosocial interventions. It highlights the use of a person-centred approach which is collaborative, respectful and responds to the needs and preferences of the client/patient.

When answering survey questions around what works well with psychosocial interventions for MS care and what helps with adherence, participants spoke of different facilitator skills and therapeutic approaches. Participants spoke of using a collaborative approach with individuals, rather than using a didactic approach. The use of collaboration helped to tailor and adjust interventions according to what the client/patient was experiencing with their condition. HCPs also spoke of avoiding a delivery style which portrays continuously appearing to be the 'expert'. This approach was said to result in clients/patients being more motivated and actively involved in the intervention.

"From my experience patients respond well when the individual delivering the session works collaboratively with the group rather than trying to be the expert. Using this approach helps to encourage more responses from the group to aid the session." (Elizabeth)

The need for clients/patients to feel listened to was frequently mentioned during survey responses. By using a collaborative approach and actively engaging clients/patients, HCPs were able to acknowledge and demonstrate empathy towards a client's/patient's experiences. This resulted in helping clients/patients to feel less isolated, to reflect upon their feelings and explore other perspectives.

"If they are involved in all aspects of the intervention i.e., the assessment, the formulation, and the intervention then they tend to be more engaged, interactive and motivated to continue with the programme." (Carolyn)

"Having staff that run the group do so in a friendly, empathic manner and ensure that time and space is given for group members to share their thoughts as it helps them to feel less isolated" (Janet)

Participants spoke in their survey responses of the importance of respecting clients/patients, being polite and taking an interest in the person with MS rather than labelling individuals by their condition. This also included taking the time to acknowledge what is going on in the client's/patient's environment rather than seeing the individual as separate from this. The use of a motivational approach to acknowledge achievements and steps which clients/patients have made towards making changes was described as important in helping to reinforce positive behaviour. The use of affirmations was also spoken of in helping clients/patients focus on their individual strengths and feel motivated to achieve their goals. Demonstrating this level of respect towards clients/patients resulted in more positive responses of engagement and was also said to improve the overall client/patient experience. When reviewing achievements, HCPs said that this was also useful for helping to ensure the client/patient is on track with their goals and to readjust strategies to aid these if needed.

"A professional's skill to see beyond the long-term condition and to show respect by not defining the person by it is key when supporting those with long term conditions otherwise they will disengage" (Lynne)

"An important part of being a therapist when working in this field is to be able to support the client in helping them to see their strengths and how to make the most of these. I've had times where using this has led a client who is having a bad day to feel enlightened and hopeful in achieving their goals…I use these techniques often as an opportunity to help the client

identify what they have done well and affirm what positive individual skills they have. The client's mindset quite often appears more positive after this conversation" (Chloe)

Individuals with MS can experience a variety of symptoms which can vary amongst those attending an intervention. As a HCP delivering an intervention, having an awareness of MS, including what a client/patient may experience emotionally was said to be an important aspect of building a positive and engaging therapeutic relationship. This awareness helped to create a more supportive environment in which the HCP can help to normalise aspects of what the client/patient is experiencing.

"Having a therapist that uses an empathic approach and has an awareness of the impact of MS can make such a positive difference when working with clients". (Chloe)

"Help to normalise their experiences, gain understanding of the effects of MS to them and enabling them to feel able to access coping strategies is what we aim to do". (Hannah)

The differences in MS symptoms between clients/patients was discussed by participants. A need to be responsive and flexible in the approach used to meet the individual needs of each client/patient was cited as important in effective practice.

"Not all clients experience the same symptoms of MS or respond to diagnosis in the same way so the intervention needs to be appropriately adapted to meet this need" (Val)

"I think that MS is a very unique condition and the symptoms are unique to each individual therefore the approach needs to be very individualised…" (Carolyn)

Some participants said that they were flexible with the interventions which they delivered by adjusting the length of the intervention or using an open-ended approach depending on what was required by the clients/patients. Others delivered interventions which ranged between 6-8 weeks in duration of which some of these used a rolling programme, allowing clients/patients to attend the intervention again if needed. By allowing for delivery of psychosocial interventions to be more flexible, HCPs highlighted that this may provide opportunity for clients/patients to build upon support networks and develop upon strategies to help towards management of their condition.

"…I often keep the length of the programmes open. Putting a set '6' sessions onto one-to-one support can often cause panic leading up to the end session and some people just require

ongoing support in the 24-hr neurorehabilitation setting. Particularly if their condition has progressed to the point where they are totally reliant on others for all aspects of care and support." (Julie)

"I think that the best approach is a flexible approach. During my time delivering MS interventions I have found that the delivery is always different…This means that the duration of the programme can vary between 6-8 weeks depending on what the group is needing." (Nina)

However, this need to adapt facilitation style was said to come with its challenges. Participants expressed difficulties in knowing which approach to take at times with the intervention delivery and some said that they were not confident in being able to adapt their approach due to having a limited amount of knowledge around some of the stages of MS, which is required for intervention delivery. This made it challenging during times of relapse in MS symptoms, where HCPs found that they experienced a level of resistance from their client/patient towards the intervention being delivered. One participant spoke of the negative impact that this can also have upon the rest of the group.

"*Relapse can also be another challenging time with some patients becoming negative towards session material, stating it's not working for them. This is more challenging to address when in a group as there is the risk of another group member also becoming negative once they hear someone else talking negatively" (Nicola)*

A lack of guidance in particular areas such as diagnosis and treatment approaches, was also spoken of. With the raised concerns around limited knowledge and guidance, it was felt that this placed risks upon the continuity of psychosocial interventions with psychosocial practitioners describing feeling less confident in their skills.

"It would be good to have some guidance/key recommendations with certain things to ensure that everyone is providing the same support…" (Helen)

"As I see patients in the early stages of MS, when I do see patients in the later stages I don't feel as confident in being able to offer the right support as I don't have as much knowledge or experience to do so" (Janet)

"MS is so different in different individuals which can make it hard at times to know the best approach to take for the intervention…" (Maria)

Summary

This theme focused on the person-centred approach used to deliver psychosocial interventions in MS care and what needs to be considered to promote the effectiveness and acceptability of these. The accounts made clear that with the breadth of MS symptoms, intervention delivery needs to be flexible rather than using a one size fits all approach for it to be effective in meeting client/patient needs. However, the acceptability in using this approach proved challenging and questionable at times with some HCPs not having an in-depth knowledge of MS to be able to be flexible in their delivery. A clear need for further guidance and support in delivering interventions to this group, particularly in more advanced stages, was reported.

3.5 Theme 4: "It helps to know they are not on their own": The value of support networks

This theme focuses on group psychosocial interventions and the value of peer support. This theme also highlights the role of professionals and family/friends in helping to deliver an effective psychosocial intervention that is acceptable in MS care.

One of the common benefits which participants spoke of when delivering group psychosocial interventions for people with MS was that it helps to reduce the feelings of isolation for clients/patients with their condition. Those in the group were said by HCPs to be able to relate to and hear from others with similar experiences. This in turn encouraged individuals to engage in the session and was particularly beneficial during challenging times, such as when a client/patient was experiencing a relapse in symptoms.

"I think that peer support works really well, people can feel less alone…" (Janet)

"The support group reduces their feelings of isolation and encourages them to share their experiences. The feedback is often that it helps to know that they are not on their own…This helps the most at times when symptoms of MS are worsening and residents report that it reduces the feelings of isolation." (Julie)

Participants highlighted that delivering in the form of a group offers a different type of support to that which can be offered by an HCP delivering an intervention. This level of support was described as helping to increase motivation for clients/patients to engage in the intervention. Having MS can bring about varied emotional responses. Participating in a group was said to allow for individuals to share their thoughts and feelings with someone who understands. By sharing these, clients/patients were able to gain more understanding of their condition, normalise their experiences and therefore help individuals to gain more acceptance of their MS. Listening to their peers speak of their experiences around MS and how they have made successful use of particular strategies, was shown in responses to also provide encouragement for others in the group to follow in this path and start to implement their own strategies to help manage their condition.

"The group has the benefit of peer support and encouragement when listening to others who have used strategies successfully". (Val)

"Group sessions can provide the motivation to make lifestyle changes and put strategies in place." (Angela)

"It allows the individual to share their thoughts and feelings around their condition with others who can have a level of understanding of what they are going through. Just being able to talk to others in the group helps to gain more acceptance of their MS and also dispels any myths they have heard about the condition." (Elizabeth)

The need for professional support outside the intervention sessions was highlighted by participants as being important in helping clients/patients adhere to and complete an intervention. Participants described a variety of ways in which this support was carried out, including telephone support, check-ins, reminders to attend sessions and progress reviews.

"…support doesn't stop after sessions, frequent reminders from staff, schedules such as calendars…Remembering schedules/plans to complete the intervention… reliance on staff for support to attend scheduled sessions…" (Anita)

"checking-in with clients; sending clients motivational e-mails which serves as a reminder to reinforce positive behaviour" (Grace)

"Telephone reviews where patient progress can be reviewed and praised and ongoing support are important in maintaining patient motivation to attend" (Karen)

Alongside those delivering the interventions, support from other HCPs and working as a multidisciplinary team was said to be needed for the psychosocial intervention to be fully effective in meeting the variety of needs of the clients/patients. Being able to communicate with HCPs from other disciplines was described as allowing the opportunity for those delivering psychosocial interventions to not only discuss different approaches, but to also support one another in what can be a challenging job role.

"I regularly need to link in with other professionals as MS can be complex and the symptoms present in a number of different ways that often mean Speech and Language support are required to help with communication. Physio to help with increasing activity, OT to help with increasing daily activities and dietetics to support with healthy living and diet." (Julie)

"MS is so different in different individuals which can make it hard at times to know the best approach to take for the intervention, support from colleagues is important for this" (Maxine)

One participant spoke of collaboratively working with a urologist to deliver session material to help educate group members of their condition which received positive results.

"The addition of professional input from colleagues/practitioners out with the centre is also extremely useful. For example, at a living well program delivered last year, many clients had the opportunity to speak directly to a urologist who was a guest speaker. Some were surprised to know their bladder issues were connected to their MS, and heartened that there was something that could be done. Until then they had assumed it was just something they had to live with" (Jackie)

Alongside professional support, the support from family and friends outside of sessions was said by participants to aid client/patient motivation to engage with the intervention and enabled them to get the most out of doing so.

"It also helps if the client has a form of support outside of the sessions to help motivate them to continue with the work" (Chloe)

"Support and encouragement from family and friends is so important" (Janet)

"Self-motivation and encouragement from the clinician and family support network are vital in helping the patient gain the most that they can from the intervention" (Sally)

Two participants spoke of how beneficial it can be to have the client's/patient's family involved in the intervention. It was said that by doing so the client's/patient's family gain more of an understanding of MS and the benefits of psychosocial interventions. The client's/patient's treatment plan can be more successful and individuals feel more encouraged and positive to continue attending sessions.

"..getting the patients family involved has always been helpful. We include a session where the family are asked to come along and the feedback is always positive with family members stating that it has given them a greater insight into what can come with MS and why the group is so important. I have also had feedback from group members after this saying that their family members are actually more supportive and encouraging with them attending sessions which makes the process easier for them and helps them feel more positive in what they are doing." (Nicola)

"Treatment plans are often more successful if families are appropriately involved in the therapy too." (Carolyn)

One common area which was spoken of was the need for some clients/patients to have support with being able to attend the intervention. For some, poor mobility and/or pain meant a reliance on others around them to provide transport to be able to attend sessions and made it difficult to commit to the intervention. With HCPs in the current study all delivering psychosocial interventions in person, the acceptability of these interventions is therefore questionable for individuals wanting to engage who have been physically affected by MS. Further barriers to intervention engagement and adherence included difficulties for clients/patients to attend intervention sessions due to not being able to get time off from work and their employer not supporting this. With a lack of support from employers and MS psychosocial interventions being delivered during client/patient working hours, this at times resulted in some individuals unable to access support despite having the motivation and readiness to do so. However, for others the difficulties in support networks not having an understanding of their condition lead to a lack of motivation and commitment to attend intervention sessions.

"People that rely on family/friends to attend the sessions can find it difficult to be able to commit….they rely on others to drive them due to not being able to drive themselves because of poor mobility/pain". *(Janet)*

"Clients can find it hard to get the time to attend, work is not always supportive of them taking time off to attend" (Val)

"It can be difficult for a patient to remain fully motivated in an intervention if they have family members who do not support them with the process. This is quite often because there is a lack of understanding of what can be achieved by attending the sessions." (Nicola)

Summary

This theme highlighted the need for support from both professionals and family/friends to increase effectiveness and acceptability of interventions. However, the challenges that come alongside the reliance that some clients/patients have upon friends/family may impact upon the acceptability of interventions, particularly those individuals that need to support to travel to therapy centres or work. There is also a need for an MDT approach to help ensure all client/patient needs are met, although this came into question at times due to a lack of awareness of interventions for people with MS. The delivery of psychosocial interventions in the form of a group was said to be particularly effective in creating less feelings of isolation and increasing motivation to implement new coping strategies.

3.6 Theme 5: "There is not enough focus or funding for this kind of input": Systematic barriers

This theme focuses on the systematic barriers to effective delivery, which are faced by HCPs providing psychosocial interventions for MS care.

Participants spoke of common factors in the delivery of psychosocial interventions which they deemed as missing or lacking, therefore creating a challenge in providing effective and acceptable MS care. HCPs felt that interventions for people with MS were undervalued systematically and raised concerns around having a lack of time to be able to carry out their role and deliver interventions. This limited time meant that clients/patients had to be prioritised according to their physical need at times. It also meant that intervention delivery schedule times interfered with client/patient day to day responsibilities, such as work.

"We have limited times that we can deliver the intervention which means that people have to take time out of work to attend" (Janet)

"Insufficient time to follow up… large a caseload which results in the need to prioritise physical health issues." (Louise)

"*Not having enough allocated time to deliver the interventions…They are important and should be made much more available. Neuro psychology and medical and health psychology are not valued highly enough by commissioners."* (Katie)

There was a general feeling of having a lack of resources which could be seen amongst the participant survey responses. The lack of resources has made it difficult for HCPs to be creative in the delivery of psychosocial interventions, therefore potentially having a detrimental effect on client/patient engagement. A lack of resources also created challenges for HCPs in being able to adapt interventions in order to meet the different needs of clients/patients and therefore they have not been able to deliver an intervention as effectively as it could possibly be.

"Due to a lack of funds I'm not able to be as creative as I would like when delivering interventions which I think is important to help maintain engagement from group members…I think it would also be helpful to have some literature on the interventions which we deliver to handout to clients and other healthcare professionals" (Val)

"More resources needed to help adapt interventions for the different needs that patients have for the different types of MS…" (Janet)

End of life care and support for those very severely disabled was also discussed as 'overlooked' and leaving patients with MS limited support when they were most in need.

"…The existing service does not offer intervention for patients who are severely physically disabled by the condition, or for end-of-life pathways. There is a severe deficit in services for end of life that concerns me greatly". (Melissa)

Another challenge highlighted by participants in being able to deliver effective and acceptable interventions were the staffing levels in this area of MS care. It was felt that the delivery of MS psychosocial interventions is an area which is poorly staffed. This has led to certain staff providing support to clients/patients which they are not trained to deliver. This brings into question the level of effectiveness of the support provided, with HCPs feeling that a lack of knowledge in some areas of MS is an area of concern. By improving the staffing level in the delivery of MS psychosocial interventions, HCPs felt that this may have the positive effect of identifying client's/patient's needs sooner and therefore help towards preventing individuals reaching crisis.

"*Lack of staff available to undertake the interventions, lack of suitable premises, lack of time, lack of expert knowledge. It would be good to have some guidance/key recommendations with certain things to ensure that everyone is providing the same support. Ideally all MS services should have access to an MS psychologist…Due to very minimal local psychological support and 1 year + waiting lists this support also falls onto the MSSNs to provide despite us not being qualified psychologists/counsellors" (Helen)*

"There is not enough focus or funding for this kind of input…it seems to me that if this area was properly staffed and funded, many issues could be identified and managed long before crisis time." (Jackie)

Many participants raised their concerns around delays and the availability for clients/patients in being able to access psychosocial interventions for MS care, resulting in a lessened responsiveness of care. HCPs highlighted motivation to engage as being a key component for intervention readiness. However, delays and the lack of availability run the risk of having an adverse impact upon client/patient readiness, particularly as HCPs felt that people with MS are more motivated when first diagnosed. There is also the concern that due to the progressive nature of MS, individuals will have progressed further in the condition. This may create challenges in the delivery of psychosocial interventions as physical and psychological symptoms progress.

"They want and need them and cannot access them in my area on the NHS… NHS wait times for any meaningful talking therapy, sometimes over a year" (Anne)

"I think people with MS are motivated to help themselves, especially when first diagnosed. Maybe if psychosocial interventions were more readily available it would be a good time then" (Susan)

"…by the time I see some clients their condition has progressed both physically and psychologically. There is also the issue of some HCPs not feeling a referral is necessary and so a patients needs gets missed." (Nina)

Summary

This theme highlighted the many workplace and systematic challenges faced by HCPs in ensuring psychosocial interventions in MS care are effective and acceptable. Psychosocial interventions for people with MS were described as being undervalued and as a result has led to these becoming inadequately resourced. End of life care for the more severely impacted was described as lacking. HCPs described being unable to carry out their job role as effectively as they would like due to a lack of resources including time, physical resource such as space, and appropriate training and guidance in working with this population. Waiting lists were described as long, with patients often reaching support when they had already progressed physically and psychologically. Risks were identified as adverse effects on clients/patients motivation to engage once they had reached services, individual needs unable to be met and clients/patients reaching crisis before being supported.

4.0 DISCUSSION

This qualitative study aimed to understand psychosocial HCP's perceptions of the effectiveness and acceptability of psychosocial interventions in MS care. This study is one of few qualitative studies to explore the perceptions of HCPs in MS care and to the best of the researcher's knowledge, it is the first to explore perceptions of the effectiveness and acceptability of the psychosocial interventions delivered to MS clients/patients. Data analysis identified five themes; 1) "CBT can be helpful, but thought challenging can have limited use": CBT and the complexity of MS, 2) "Change isn't possible" vs Ready to change, 3) "Not trying to be the expert": Working collaboratively and respectfully, 4) "It helps to know they are not on their own": The value of support networks, 5) "There is not enough focus or funding for this kind of input": Systematic barriers. These findings will now be discussed in relation to the research aim and previous literature. The strengths and limitations of the study will be reviewed and this will be followed by suggestions for future research and recommendations for good practice in the field of psychosocial interventions for MS care.

4.1 "CBT can be helpful, but thought challenging can have limited use": CBT in and the complexity of MS

Drawing upon their existing experience, HCPs identified that at times CBT can be an effective and acceptable method for the delivery of psychosocial interventions for people with MS. CBT was said to be particularly beneficial in the management of fatigue, a common symptom experienced by individuals with MS (Biernaacki et al, 2019). HCPs using CBT in the delivery of psychosocial fatigue interventions, spoke of its usefulness in developing strategies to improve self-management and ultimately enhance QoL for people with MS. Evidence for the use of fatigue management psychosocial interventions for individuals with chronic conditions has been shown by Van Heest et al (2017). The psychological aspects for people with MS and further chronic conditions has been improved when using CBT interventions (Ehde and Jensen, 2004; Gotterberg et al, 2016; Ytterberg et al, 2017).

The use of psychoeducation was deemed as playing an important role in CBT interventions. HCPs spoke of using psychoeducation to help clients/patients to better understand their condition and therefore be in a position to be able to challenge any negative thoughts and feelings they experience around their MS. For those individuals seeking support for fatigue, the use of psychoeducation was said to help improve the impact fatigue has. Disease related education has been highlighted as playing an important role in helping individuals to adapt to their condition (Kalb & Reitman, 2012). Ytterberg et al (2017), evidenced that psychotherapists working with people with MS, found that some individuals struggled with acceptance of their condition and were unable to make connections between their fatigue and cognitive difficulties. NICE (2019) guidelines also recommend the need to provide information on MS and symptom management to people with MS and their family.

HCPs spoke of integrating mindfulness and CBT in their intervention delivery, as also seen in the study by Kermani et al (2020). This was said to have many benefits including developing healthier thought patterns, fatigue and pain management, gaining acceptance of having MS and improving confidence in the ability to use coping strategies to help manage their condition. These benefits are consistent with the findings from Merkes et al (2010), Senders et al, (2018), Crowe et al, (2016), Barwick et al (2020) and Kermani et al (2020). The use of goal setting was commonly spoken of by HCPs and in particular the use of SMART goals (MacLeod, 2012) was used to aid this process. By implementing goal setting into the intervention, HCPs said that this helped to make change appear less overwhelming and also helped to address any potential barriers. The use of a one-to-one approach in the delivery of CBT allowed for HCPs to be more collaborative and flexible in goal setting with clients/patients. The use of action plans and SMART goals could be created to help aid confidence in the management of an individual’s management of MS and meet client/patient needs. The ability to focus on specific topics in one-to-one interventions so that people achieve more out of the intervention is consistent with the findings from das Nair et al (2016) and Van Heest et al (2017). Another fundamental aspect of CBT is the setting of homework (Tang & Kreindler, 2017) and HCPs stated that they found this a beneficial way to monitor progress. This was particularly noted when delivering fatigue interventions, where it was said to encourage clients/patients to reflect and re-evaluate their priorities. Both goal setting and homework was said to help maintain client/patient motivation and engagement.

However, despite its common use in psychosocial interventions for people with MS, CBT was limited. The use of CBT became less effective and less acceptable when delivering an intervention for people with MS who experienced cognitive impairment. Being able to engage with CBT was said to require a certain level of cognitive ability. HCPs said that for those who were lacking in cognitive ability due to their MS, it led to difficulties in them being able to maintain concentration, an inability to express thoughts or feelings and ultimately unable to participate in session material. Therefore, this led to some clients/patients needing further support to understand the CBT techniques and how to apply them. Some participants also spoke of the same difficulties when delivering mindfulness. Previous studies support this by evidencing the difficulties that people with MS have faced in understanding the fundamental aspects of CBT due to their cognitive impairment and fatigue levels (Gotterberg et al, 2016; Hind et al, 2010; Ytterberg et al, 2017). Bogosian et al (2016) also highlighted the challenges faced with mindfulness including engaging with concepts such as acceptance and self-compassion.

The majority of CBT interventions were delivered in the form of a group which was shown in participant responses to be challenging at times, due to its inability to be fully flexible in meeting the varying level of individual needs. This was said by HCPs to be particularly prominent when group members were at different stages of MS or at times of relapse. This is consistent with the findings from Plow et al (2009), Peters et al (2019) and Lahelle et al (2019). Group interventions were said by HCPs to also promote negative experiences at times for those in the group. HCPs spoke of group members disengaging from the intervention at times due to feelings of fear and anxiety that were generated. It was said that individuals found it difficult to listen to others in the group sharing their personal experiences of MS as it highlighted to them how their own condition may progress. Palant & Himmel's (2019), study exploring social support for patients with inflammatory bowel disease (IBD), put forward that talking extensively about symptoms means there is more focus on the negative aspects of the disease and that hearing others feeling better can lead to anxiety and frustration at times as they can question why they are not feeling the same. Similar findings were also shown by Embuldenyia et al (2013), where it was highlighted that sharing experiences amongst a group, diagnosed with a chronic condition, can generate a competitive culture of "whose condition was worse".

The use of a one-to-one approach in the delivery of CBT was seen as being an effective and acceptable method in addressing the challenges faced by delivering group interventions. Not only were HCPs able to focus on tailoring the session content, they were also able to adjust the length of the intervention as needed. One-to-one interventions were said to provide a safe environment allowing clients/patients to talk openly and share how they are feeling. Van Heest et al (2017), state that the client-centred approach of providing a comfortable environment to share private information and set goals contributes to the effectiveness of a one-to-one approach.

4.2 "Change isn't possible" vs Ready to change

Encouraging people with MS to engage with a psychosocial intervention was said to come with its challenges. An understanding of psychosocial interventions for MS care was said by HCPs to be lacking. This lack of understanding came in the forms of clients/patients not being aware of what support they could receive, feeling nothing could be done to ease their experience of MS and feeling that their condition is purely physical so they would therefore not be eligible for a psychosocial intervention. This lack of understanding interventions in MS care has resulted in poor motivation towards intervention engagement and clients/patients declining intervention support. However, this lack of understanding was not only said to be amongst clients/patients but also other fellow HCPs. Responses from HCPs in the study highlighted misconceptions held by other HCPs, including beliefs that MS is purely a physical condition and that there is nothing that can be done to improve the condition in order to have a better QoL. These misconceptions from other HCPs impacted upon not only client/patient motivation and engagement with an intervention, but also client/patient treatment plans. Similar findings by Jaglal et al (2014) found that negative views surrounding neurological conditions, including those from healthcare providers, has resulted in those with a neurological condition being unaware of the support services which they can access or not seeking them out. The challenges of differing views amongst multidisciplinary working are further evidenced by Firth-Cozens (2001). Methley et al (2017), found that it was a lack of knowledge and confidence in managing the needs of people with MS, particularly mental health needs which was spoken of amongst GPs and specialist nurses. Evidence of this lack of knowledge impacting goal setting for clients/patients was also seen in a study by Ytterberg et al (2017).

A client/patient readiness to engage in a psychosocial intervention for MS care was also said to be dependent upon an individual's stage of MS diagnosis, symptoms that individuals are experiencing and their cognitive ability. This may include the range of psychological outcomes that can come alongside MS such as struggling with acceptance, challenging emotions and a belief of personal failure. Evidence of these challenges are seen in the study by Carter et al (1998), where HCPs have raised concerns around the mental health difficulties that can arise for people with MS, particularly around times of relapse. It is because of this risk of people with MS developing cognitive difficulties and/or emotional dysfunctions, that it has been suggested that interventions be delivered earlier in diagnosis (Hung & Yarmark, 2016). However, in the study by Ytterberg et al (2017), psychotherapists stated that they felt it may not be beneficial for individuals with MS to commence CBT too soon after diagnosis, due to the uncertainty that is faced for these individuals which can make it difficult to deliver change-orientated therapy.

4.3 "Not trying to be the expert": Working collaboratively and respectfully

With the breadth of MS symptoms that can be experienced (MS Society, 2021; Glanz et al, 2007; Amato et al, 2012), HCPs frequently spoke of the need to have an approach which was flexible and responsive to the needs of the client/patient for interventions to be effective. The importance of considering individual factors has also been suggested as a means of avoiding potential psychological harm being caused to an individual participating in an intervention (Spitzer & Pakenham, 2016). The flexibility in delivery sometimes came in the form of adjusting the duration of the intervention or using a rolling programme format. The need for tailoring approaches to meet individual needs is recommended by the NICE (2019) guidelines, where it is highlighted that relapses, deteriorating symptoms and progression need to be considered. Treatment plans need to be adjusted accordingly during the duration of the disease (Giovannoi & Rhoades, 2012). Of these symptoms fatigue was commonly spoken of by HCPs (Biernaacki et al, 2019), with it impacting engagement in intervention sessions and at times resulting in clients/patients stopping their attendance. In previous research people with MS have spoken of fatigue as being one of the most disabling symptoms of their condition, with it having a significant impact on physical and cognitive function (Roberts, 2017). Interventions delivered specifically to address fatigue were mentioned by HCPs. Previous research has shown that interventions developed around specific symptoms are important in helping people with MS adjust to their condition, particularly fatigue (Thomas et al, Khan et al, 2014).

However, the acceptability of being able to apply this flexible approach proved challenging at times, with some HCPs stating they were unsure of how to adapt their delivery and others stating that their lack of knowledge around some of the MS stages meant they were not confident in adapting their approach. Having a knowledge of MS was said to be important for building a positive therapeutic relationship, in which a HCP is able to help with normalising aspects of what a client/patient is experiencing. This lack of knowledge and confidence amongst HCPs is consistent with the previous literature of Ytterberg et al (2017), Methley et al (2017) and Jaglal et al (2014). Researchers highlighted the importance of having specific knowledge in MS in order to be able to adapt intervention activities accordingly (Ytterberg et al, 2017), to assess correctly for MS services (Methley et al, 2017) and help facilitate participation in CBT (Gotterberg et al, 2016).

Further facilitator qualities which were deemed to be important for the effectiveness and acceptability of psychosocial interventions in MS care included using a collaborative approach, avoiding taking on the role of ‘expert’, displaying empathy, acknowledging client achievements and respecting the client/patient by avoiding labelling them by their MS condition. These qualities were said to increase positive engagement, focused clients/patients on their individual strengths, created less feelings of isolation and allowed time for reflection. These findings are consistent with the views of HCPs in a study by Peters et al (2019), in which it was viewed that delivering interventions as an active participant rather than an ‘expert’, created a more inclusive environment where participants in the group were able to share their expertise on MS. Further evidence can be seen in the study by Methley et al (2017) who highlighted a person-centred approach can help to improve the experiences of people with MS, helping them to feel more understood whilst also developing trust. Williams et al (2020) also spoke of the impact of positive personal interactions in reducing anxiety and providing reassurance.

4.4 “It helps to know they are not on their own”: The value of support networks

HCPs spoke of a need for support from both family/friends and other HCPs alongside the intervention to help client/patient adherence and motivation to complete the intervention. Continued support outside of intervention sessions from HCPs included telephone support, check-ins, progress reviews and reminders to attend the sessions. These findings are consistent with a review by Roberts (2017), who stated that due to cognitive dysfunction clients/patients may need support remembering appointments, medication and information from discussions. Working as a multidisciplinary team in the delivery of interventions was said to help meet the individualised needs of people with MS and help to provide further education around MS. Previous research into MS care has also spoken of the importance of an integrated MDT approach to care for all facets of the disease (Gallien et al, 2014; Roberts, 2017), increase knowledge of MS for HCPs (Methley et al, 2017) and to increase the efficacy of therapy, provide patient satisfaction and improve the QoL for people with MS (Sorensen et al, 2019). It has also been described as the best way of working for both patients and HCPs involved (Firth-Cozens, 2001).

Further to the support from MDTs, the support from family/friends was said by HCPs to help aid client/patient engagement and led to more positive outcomes from attending the intervention. Two HCPs found that having family involved in the intervention sessions led to a more successful treatment plan. Previous literature also reinforces the need for social support alongside interventions (Gotterberg et al, 2016; Gil-Gonzalez, 2020). This may be due to the benefits of social support as identified by Kever et al (2021), who found that higher social support was associated with better mental health, QoL, subjective cognitive function and less fatigue. Similar associations with social support have also been seen in the study by Ratajska et al (2020), where results showed high levels of social support being associated with better mood and QoL. With poor mobility being one of the most widespread and impactful consequences of MS (Baird et al, 2018), this meant that individuals often relied on family/friends for transport to be able to attend sessions, making it difficult to commit to attending at times. It is due to the challenges that are faced by people with MS around their symptoms that Leclaire et al (2018), stated that weekly intervention sessions may not be feasible.

Psychosocial interventions were commonly delivered in the form of a group. Research suggests that peer support is a key element in management for people with chronic diseases (Embuldeniya et al, 2013). HCPs in the current study felt that the group environment was effective as it offered a different type of support to that solely provided by HCPs. It was said that those in a group were able to relate to one another and listen to others with similar experiences, which in turn had a positive impact upon reducing feelings of isolation and increased feelings of motivation. Clarke & Coote (2015), found that participants in a group may feel part of a team and more motivated to complete an intervention. Other studies have also highlighted the feelings of companionship and acceptance arising from group interventions (Learmouth et al, 2013; Aubrey & Demain, 2012). HCPs said that by people with MS listening to their peers in the group, it allowed individuals to share their emotions with someone who understands them. This was said to help individuals to gain more understanding of their condition, normalise their experiences and gain more acceptance. Thorn and Kuhajda (2006), state that group members can support one another in challenging dysfunctional automatic thoughts and beliefs, moving individuals onto a different thought process regarding their condition. Rafiee et al (2020) highlight how being part of a group and supported can improve QoL in MS. HCPs said that by listening and sharing with their peers it also encouraged those in the group to develop and implement their own coping strategies. Part of this may be the result of those in the group not wanting to let down their peers (Clarke & Coote, 2015).

4.5 "There is not enough focus or funding for this kind of input": Systematic barriers

The need for adequate resources in the form of time, staffing and supporting materials was commonly spoken of amongst HCPs. Nearly half of participants spoke of having a lack of time to be able to carry out their role. This led to HCPs having to prioritise clients and at times intervention delivery interfering with client daily responsibilities, such as work. This is consistent with the study by Golla et al (2011), where HCPs spoke of feeling overstrained and not having enough time to arrange adequate support for clients/patients with MS. HCPs in the Wilkinson et al (2018) study stated that some services were unable to provide adequate or at times any support to people with MS. A further challenge contributing to a lack of time were staffing levels, which HCPs described as poor in MS intervention care. This resulted in some HCPs providing support to their clients/patients in an area which they were not trained in. Previous research has shown practice and specialist nurses in MS left to work outside of their remit due to lengthy delays and decreased access to other services such as mental health (Methley et al, 2017). Wilkinson et al (2018) highlighted in their study that the rising number of people with MS is leading to a demand upon services leaving MS nurses with caseloads above a sustainable level. Researchers have recommended that more resources need to be invested into building a functioning team and increasing human resource capacity (Giovannetti et al, 2018; Jaglal et al, 2014).

There was a general feeling amongst HCPs of a lack of supporting materials and guidance to aid the delivery of interventions. This was said to create challenges in meeting individualised needs and HCPs feeling they were not able to deliver as effectively as they could. Concerns were also raised around delays in clients/patients being able to access interventions in MS care and the lack of availability of them. This was reported as being particularly 'overlooked' in end of life care for the more severely impacted. Waiting lists were described as long, with patients often reaching support when they had already progressed physically and psychologically. A report by Mynors et al (2016), showed similar findings with the provision of MS specialist nursing being relatively well provided for in some areas and in others it was inadequate. Jaglal et al (2014) also spoke of the difference in neurological community-based services with those in rural areas lacking. HCPs in the study by Peters et al (2019), spoke of the need for interventions to be more available outside of main centres to allow people with MS in more rural areas to attend without having to travel long distances.

4.6 The Chronic Care Model for Neurological Conditions (CCM-NC) (Jaglal et al, 2014)

The CCM-NC (Jaglal et al, 2014) seems to provide a useful framework to understand the findings in this study, with all components seen amongst participant's responses. Table 5 below, details the three components of the CCM-NC, illustrated with quotes from HCPs in the current study. With the CCM-NC being devised from the perceptions of professionals who work with individuals with neurological conditions it can help to provide some understanding as to why these components were also raised by HCPs in the current study. However, with the current study survey focusing on psychosocial interventions in MS care, by following the components of the CCM-NC it does generate questions around the effectiveness and acceptability of interventions. The CCM-NC suggests that all features of the model are needed to develop the outcome of activated patients and families, proactive service delivery teams, a person-centred health system and healthy public policy for people with neurological conditions. With responses from HCPs suggesting that components of the CCM-NC are lacking in MS care, it would be said that consideration should be taken into improving these areas in order to ensure that psychosocial interventions are fully meeting the needs for people with MS. However, care should be taken when making these assumptions as the developers of the CCM-NC highlight in their study that a limitation of their study was that people with neurological conditions were not interviewed and this would be the next step taken for the researchers in validating the model. Although, contributions were received from health and community-based service providers, advocacy groups and neurological health charities.

Table 5: The CCM-NC (Jaglal et al, 2014) illustrated with HCP's quotes

Components of CCM-NC		HCP's comments from the current study
Socio-economic & political context	Acceptance & openness to neurological conditions	*"It can be difficult for a patient to remain fully motivated in an intervention if they have family members who do not support them with the process. This is quite often because there is a lack of understanding of what can be achieved by attending the* sessions." (Nicola)
	Evidence informed policy	HCPs spoke of the frequent use of CBT to inform psychosocial intervention delivery, *"Use the FACET programme for MS fatigue and 5 area CBT approach for self-management and trying to improve quality of life…" (Hannah*)
	Investments & funding	*"There is not enough focus or funding for this kind of input…it seems to me that if this area was properly staffed and funded, many issues could be identified and managed long before crisis time." (Jackie)*
Community integration	Supported transitions	*"The individuals I support are inpatient residents, therefore frequent reminders from staff, schedules such as calendars…Remembering schedules/plans to complete the intervention… reliance on staff for support to attend scheduled sessions…" (Anita)*
	Caregiver support	*"As I see patients in the early stages of MS, when I do see patients in the later stages I don't feel as confident in being able to offer the right support as I don't have as much knowledge or experience to do so" (Janet)*
	Life enhancing resources	*"Lack of transport, difficulty in securing time off work…Having to use annual leave if the workplace does not allow time if to attend" (Jackie*)
Health system	Knowledge & awareness of neurological conditions	*"Some clients have also spoken of responses from other healthcare professionals who have said that there is nothing that can be done for their condition which has left them feelings hopeless and demotivated" (Chloe)*
	Availability & access to services	*"They want and need them and cannot access them in my area on the NHS… NHS wait times for any meaningful talking therapy, sometimes over a year" (Anne)*

4.7 Recommendations for psychosocial interventions in MS care

Several recommendations and considerations have arisen from the study's findings for HCPs and stakeholders involved in the design and delivery of psychosocial interventions in MS care. The NICE guidelines for MS quality standards (2016) and management of MS in adults (2019) has been reviewed alongside these (Table 6).

Table 6: Recommendations from the current study and NICE guidelines (2016, 2019)

NICE Guidelines (2016, 2019)	Recommendations from the current study
Providing information and support (2019): People with MS and their family members/carers to be offered oral and written information at the time of diagnosis. Including information on MS, symptom management, treatments and support available.	*Education:* Educating other HCPs, people with MS and their friends/family as to what psychosocial interventions in MS care are may help address any incorrect or negative beliefs that are held towards interventions and improve timely access to services. Consideration should be taken as to when this information is provided to people with MS, with the point of diagnosis being highlighted by HCPs in the current study, to be when individuals are most motivated.
Ongoing information and support (2019): Information, support and care needs are to be reviewed regularly, with continued support to be offered to people with MS and their family/carer. *Coordination of care (2019):* Care for people with MS should use a coordinated multidisciplinary approach, involving those who have the expertise to best meet the individuals needs	*Support networks* To meet the individual needs of people with MS, a supportive network made up of multidisciplinary HCPs and family/friends is encouraged alongside psychosocial interventions.
Training and competencies (2016) All practitioners including health, public health and social care, who are involved in assessing, caring for and treating adults with MS should have the relevant and sufficient training and competencies in order to be able to deliver the actions and interventions as set out in the quality standard	*Training and resources* Staffing levels, time allocated to interventions, training around MS and supporting materials for session delivery need to be adequately resourced. Those services which are lacking need to address how service capacity is used to be more effective with the limitation in resources (Wilkinson et al, 2018).

NICE Guidelines (2016, 2019)	Recommendations from the current study
Equality and diversity considerations (2019) People with MS commonly experience cognitive problems, which can include problems with attention, memory, decision-making and planning. All information should therefore be made accessible to people with cognitive problems.	*Meeting individual needs* CBT is a commonly used therapeutic method, however consideration should be taken for those individuals with MS who have lower levels of cognition and who therefore, may find elements of CBT challenging.
Coordinated care (2016) Adults with MS have different needs which will change during times of relapse, deteriorating symptoms and progression of their condition. Information, advice and support should be tailored to the individual person and relevant to their specific needs. A single point of contact will help to ensure people with MS can access care and support from HCPs which is appropriate to their needs.	*Meeting individual needs* The delivery and design of interventions should follow a flexible approach to meet the differing needs amongst people with MS. However, HCPs should be mindful of what this support may consist of at time of diagnosis. One-to-one intervention sessions are useful in helping address individual needs and may provide further positive outcomes if used as a mixed approach with group sessions

4.8 Strengths, limitations and directions for future research

Several strengths have been demonstrated in this research. Firstly, most of the existing literature surrounding psychosocial interventions in MS care has focused on the experiences of clients/patients. There is limited focus on the experiences of HCPs and so, this study contributes to an area of literature which has been under researched. To the researcher's best knowledge, it is also the first study to explore HCPs perceptions of the acceptability and effectiveness of psychosocial interventions in MS care. The use of inductive TA strengthened this by allowing for new insights and understanding of a range of participant perceptions.

The use of the online survey provided a practical way to gather responses taking into consideration the time pressures of the population in the current study. HCPs in the current study came across open in sharing their views around not only what they felt worked well but also the many challenges they faced. The use of the online survey allowed HCPs to share these with the reassurance that their responses were anonymous and confidential. Due to being able to provide anonymity, online methods may be less daunting and encourage more open and honest responses (McEvoy, Clarke & Thomas, 202; Bartell & Spyridakis, 2012), therefore helping towards gaining the best level of understanding of participants. The standardization of survey questions also allowed for comparisons to be easily made across the data (Braun, Tricklebank & Clarke, 2013), and therefore aided the process of identifying patterns and developing themes in the data analysis. During the development stage of the online survey a consultation was held with a stakeholder whom specialized in psychosocial interventions in MS care. The survey was reviewed and advice was given around the wording of the survey questions. Following the stakeholder's advice, some adaptions were made to the survey to help increase the readability and reliability of the survey.

The demographic survey showed the sample of 32 participants varied with regards to the number of years participants had worked within the field of MS delivering psychosocial interventions. This ranged from one year to twenty years' experience. The use of an online survey provided the ability to recruit participants from a variety of settings including the community, home visits, MS hospital clinics, MS support centres, neurorehabilitation centres, residential care, and private clinics. This helps towards gaining a more holistic view of the effectiveness and acceptability of psychosocial interventions in MS care.

Throughout the study, the researcher made time to reflect on their place within the research. The developments and refinements that take place whilst working through the stages of TA reflect the researcher's engagement with the data and their interpretation of them (Braun & Clarke, 2019). The current study used a contextualist approach which allowed for the researcher's personal influences to be considered whilst interpreting the participant's data.

There are some limitations with this study. With regards to the sample the majority of those that participated in the survey were MS nurses and all were female. However, an analysis of NHS workforce statistics has shown 89% of nurses to be female (NHS Digital, 2018). Although there was variation amongst participant ages with an average age range of 28.7 – 54.7 years, 25 of the participants were aged 43.6 years and above. It is also unclear as to where participants were geographically located, as this was not asked for in the demographic questionnaire. Previous studies have shown social inequalities in health care (Hacking et al, 2011) and the availability of MS services lacking in rural areas (Jaglal et al, 2014). Therefore, future research may benefit from including this geographical information, to see if HCPs perceptions around psychosocial interventions in MS care vary across the UK. The ethnicity of participants was not asked for in the current study. Research suggests that BME HCPs working in the NHS have poorer work life experiences and fewer opportunities for development and progression (West & Nayar, 2016). Ethnic identity has also been found to influence health outcomes and practices (Public Health England, 2018). Future research should therefore consider the role that ethnicity may play in the experiences and perceptions of HCPs in the delivery of psychosocial interventions for MS care.

The participant sample size would have ideally been moderate with between 50-100 surveys being completed (Braun & Clarke, 2013). With the COVID-19 pandemic present at time of recruitment this resulted in a number of MS HCPs being transferred into frontline roles within the NHS. This reduced engagement in the online survey more than anticipated and provided fewer opportunities to be able to recruit participants. Nevertheless, as evidenced in this thesis, the data was rich and varied.

Despite the method of using an online survey having its benefits in accommodating for the needs of the participant population, there were some limitations to this in the current study. As is widely stated in qualitative literature, the use of an online survey meant that it was not possible to further probe into responses or ask follow-up questions. For example, participants were asked in the survey to state the type of MS that they supported through their intervention which they delivered. However, some participants did not provide this information, therefore the effectiveness and acceptability of psychosocial interventions could not be determined with regards to type of MS. Future research may benefit from exploring how effective and acceptable psychosocial interventions are at time of diagnosis and as the condition progresses. Defining which components and approaches work best for clients/patients at different stages of MS and at times of relapse seems noteworthy.

To further address the issue of survey responses not providing all the required information, it may have been beneficial to make further use of consultations with patient and public involvement (PPI) stakeholders. With consultations held with specialists in MS at the initial phase of the research proving valuable in survey development, once feedback from the initial stakeholder consultations had been received and addressed, consideration could have been made around further piloting the online survey. By involving PPI stakeholders in the early stages of research it can help to strengthen the relevance and quality of the research alongside also aiding the recruitment process (National Institute for Health Research, 2021).

The data from Qualtrics records not only the number of surveys that have been completed but also those which have been opened and not finished. Data from Qualtrics showed there to be a number of these surveys which had been opened and not completed. However, due to the anonymity of the online format it cannot be certain as to the reasoning for this.

4.9 Conclusion

In summary, this study has brought into question the effectiveness and acceptability of existing psychosocial interventions in MS care. It gives a unique insight into HCP's perceptions of psychosocial interventions whilst also providing key recommendations to achieve the standards set out by NICE (2016, 2019). The use of an online qualitative survey gave HCPs in the current study a platform to safely voice their thoughts and feelings, and the anonymity of this provided rich and varied data.

With MS being a condition with an unpredictable prognosis and individuals experiencing a variation of symptoms, the current study stresses the need for psychosocial interventions which are anchored in person-centred care. HCPs are encouraged to be flexible and responsive in the delivery of psychosocial interventions to meet the needs of an individual's disease progression. The use of groups was brought into question, as the ability to meet individual's needs may be hampered. It is for this reason that a mixed approach which includes one-to-one and group interventions was recommended. Support networks including family/friends and MDTs should also be encouraged, with the current study showing its effectiveness when used alongside a psychosocial intervention.

No conclusions can be drawn with regards to the effectiveness and acceptability of psychosocial interventions for the different stages of MS. Further studies are therefore needed to ascertain this.

The study indicated that the successful delivery of effective and acceptable psychosocial interventions is also a question of resources, time, and the availability of MS services. Organisational support is necessary, and the current study suggests that those services which are lacking need to address how service capacity is used in order to be more effective with the limitation in resources (Wilkinson et al, 2018) and to meet recommended guidelines set out by NICE (2019, 2016). This may be in the form of staffing levels, time allocated to interventions, training around MS and supporting materials for session delivery need to be adequately resourced. This insight into HCP's perceptions of the delivery of psychosocial interventions in MS care, stresses the need for not only clients/patients to be involved in psychosocial intervention research but also for HCPs to be considered more in future research.

This study has provided valuable insight and knowledge of the perceptions of HCPs of psychosocial interventions in MS care. Findings provide health psychologists and HCPs with useful considerations and recommendations for the design and delivery of future psychosocial interventions in MS care. With the fundamental need for organisations to address how service capacity is used, collaboration of HCPs across specialist services may help to provide not only shared knowledge (Methley et al, 2017) but also the opportunity for health psychologists to play more of a role in those services in need of further delivery support. Health psychologists are also well placed to provide training and education to support fellow HCPs in feeling more confident to be able to deliver effective and acceptable interventions. This may include providing education around MS, which therapeutic needs should be addressed at each stage of MS and how to adapt interventions to meet these needs. Health psychologists can also support in disseminating information regarding psychosocial interventions in MS care to further HCPs outside of the field of MS to help improve timely access to MS services for people with MS.

5.0 REFERENCES

Akkus, Y., & Akdemir, N. (2011). Improving the quality of life for multiple sclerosis patients using the nurse-based home visiting model. *Scandinavian Journal of Caring Sciences,* 26 (2), 295-3503. DOI: 10.1111/j.1471-6712.2011.00933.x

Al-Saddi, H. (2014). Demystifying Ontology and Epistemology in Research Methods https://www.researchgate.net/publication/260244813_Demystifying_Ontology_and_Epistemology_in_Research_Methods/link/0f31753049646167320000000/download

Amato, M. P., Battaglia, M. A., Caputo, D., Fattore, G., Gerzeli, S., Pitaro, M., et al. (2002). The costs of multiple sclerosis: A cross-sectional, multicenter cost-of-illness study in Italy. *Journal of Neurology,* 249, 152–163. DOI: 10.1007/PL00007858

Amato, M.P., Hakiki, B., Goretti, B., Rossi, F., Stromillo, M.L., Giorgio, A., Roscio, M., Ghezzi, A., Guidi, L., Bartolozzi, M.L., Portaccio, E., & De Stefano, N. (2012). Association of MRI metrics and cognitive impairment in radiologically isolated syndromes, *Neurology,* 78(5), 309-314. DOI: 10.1212/WNL.0b013e31824528c9

Artemiadis, A.K., Anagnostouli, M.C., & Alexopoulos, E.C. (2011). Stress as a risk factor for multiple sclerosis onset or relapse: a systematic review. *Neuroepidemiology,* 36(2), 109-120. DOI: 10.1159/000323953

Asano, M., Berg, E., Johnson, K., Turpin, Merill., & Finlayson, M.L. (2013). A scoping review of rehabilitation interventions that reduce fatigue among adults with multiple sclerosis. *Frontiers in neurology,* 5 (177), 729-738. DOI: 10.3389/fneur.2014.00177

Aubrey, G., & Demain, S. (2012). Perceptions of group exercise in the management of multiple sclerosis. *International Journal of Therapy and Rehabilitation,* 19(10), 557–565. DOI: 10.12968/ijtr.2012.19.10.557

Austin, Z., & Sutton, J. (2014. Qualitative research: getting started. *The Canadian journal of hospital pharmacy,* 67(6), 436-440. DOI: 10.4212/cjhp.v67i6.1406

Ayala, G.X., & Elder, J. (2011). Qualitative methods to ensure acceptability of behavioral and social interventions to the target population. *Journal of public health dentistry,* 71, 69-79. DOI: 10.1111/j.1752-7325.2011.00241.x

Baer, R., Crane, C., Miller, E., & Kuyken, W. (2019) Doing no harm in mindfulness-based programs: Conceptual issues and empirical findings. *Clinical psychology review,* 71, 101-114. DOI: 10.1016/j.cpr.2019.01.001

Baird, J.F., Sandroff, B.M., & Motl, R.W. (2018). Therapies for mobility disability in persons with multiple sclerosis. *Expert review of neurotherapeutics*, *18*(6), 493–502. DOI: 10.1080/14737175.2018.1478289

Barr, V.J., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., & Salivaras, S. (2003). The expanded Chronic Care Model: an integration of concepts and strategies from population health promotion and the Chronic Care Model. *Hospital Quarterly,* 7(1), 73-82. DOI: 10.12927/hcq.2003.16763.

Bartell, A.L., & Spyridakis, J.H. (2012, October 8th-12th). *Managing risk in internet-based survey research.* Presented at IEEE in professional communication conference (IPCC) (pp. 1-6). Piscataway: IEEE. DOI: 10.1109/IPCC.2012.6408600

Barwick, F., Poupore-King, H., & You, D. (2020). Integrated cognitive behavioural therapy (CBT) and mindfulness group treatment for insomnia and chronic pain. *Sleep,* 43(1), A198. DOI: 10.1093/sleep/zsaa056.514

Benham-Hutchins, M., Staggers, N., Mackert, M., Johnson, A.H & deBronkart, D. (2017). “I want to know everything”: A qualitative study of perspectives from patients with chronic diseases on sharing health information during hospitalization. *BMC Health Services Research,* 17(1), 1-10. DOI: 10.1186/s12913-017-2487-6

Bergen, M., Wells, J.S.G., & Owen, S. (2010). Relating realist metatheory to issues of gender and mental health. Journal of psychiatric and mental health nursing, 17(5), 442-451. DOI: 10.1111/j.1365-2850.2010.01559.x

Biernacki, T., Sandi, D., Kincses, Z.T., Fuvesi, J., Rozsa, C., Matyas, K., Vecsei, L., & Bencski, K. (2019). Contributing factors to health-related quality of life in multiple sclerosis. *Brain and behaviour,* 9(12). DOI: 10.1002/brb3.1466

Black N. (1994). Why we need qualitative research. *Journal of epidemiology and community health*, *48*(5), 425-6.

Bogosian, A., Hughes, A., Norton, S., Silber, E., & Moss-Morris, R. (2016). Potential treatment mechanisms in a mindfulness-based intervention for people with progressive multiple sclerosis. *British journal of health psychology,* 21(4), 859-880. DOI: 10.1111/bjhp.12201

Bonavita, S., Tedeschi, G., Atreja, A., & Lavorgna, L. (2020). Digital triage for people with multiple sclerosis in the age of COVID-19 pandemic. *Neurological sciences,* 41, 1007-1009. DOI: 10.1007/s10072-020-04391-9

Borghi, M., Bonino, S., Graziano, F., & Calandri, E. (2018). Exploring change in a group-based psychological intervention for multiple sclerosis patients. *Disability and Rehabilitation,* 40 (14), 1671-1678. DOI: 10.1080/09638288.2017.1306588

Borrill, C., West, M., Shapiro, D., & Rees, A. (2000). Team working and effectiveness in health care. *British journal of health care management,* 6(8), 364-371. DOI: 10.12968/bjhc.2000.6.8.19300

Braun, V., & Clarke, V. (2006.) Using thematic analysis in psychology. *Qualitative research in psychology,* 3(2), 77-101. DOI: 10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. SAGE publications

Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers?. *International journal of qualitative studies on health and well-being,* 9(1). DOI: 10.3402/qhw.v9.26152

Braun, V., Tricklebank, G., & Clarke, V. (2013). ‘‘It shouldn’t stick out from your bikini at the beach’’: Meaning, gender, and the hairy/hairless body. *Psychology of Women Quarterly, 37*(4), 478-493. DOI: 10.1177/0361684313492950

Braun, V., & Clarke, V. (2019). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative research in sport, exercise and health,* 13(2), 201-216. DOI: 10.1080/2159676X.2019.1704846

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative research in sport, exercise and health,* 11(4), 589-597. DOI: 10.1080/2159676X.2019.1628806

Braun, V., Clarke, V., Boulton, E., Davey, L., & McEvoy, C. (2020). The online survey as a qualitative research tool. *International journal of social research methodology,* 1-14. DOI: 10.1080/13645579.2020.1805550

Brown, C., Hennings, J., Caress, A.L., & Partridge, M.R. (2007). Lay educators in asthma self-management: Reflections on their training and experiences. *Patient Education and Counseling, 68*(2), 131-138. DOI: 10.1016/j.pec.2007.05.009

Burgess, D.J., Beach, M.C., &Saha, S. (2017). Mindfulness practice: A promising approach to reducing the effects of clinician implicit bias on patients. *Patient education and counselling,* 100(2), 372-376. DOI: 10.1016/j.pec2016.09

Burr, O., Berry., A., Joule, N., & Rayman, G. (2020). Inpatient diabetes care during the COVID-19 pandemic: A diabetes UK rapid review of healthcare professionals' experiences using semi-structured interviews. *Diabetic medicine,* 38(1). DOI: 10.1111/dme.1444

Burr, V. (2003). *Social Constructionism.* (2nd edition). London: Psychology Press.

Byrne, D. (2021). A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Quality & quantity.* DOI: 10.1007/s11135-021-01182-y

Carletto, S., Tesio, V., Borghi, M., Francone, D., Scavelli, F., Bertino, G., Malucchi, S., Bertolotto, A., Oliva, F., Torta, R., & Ostacoli, L. (2017). The effectiveness of a body-affective mindfulness intervention for multiple sclerosis patients with depressive symptoms: A randomized controlled clinical trial. *Frontiers in psychology,* 8, 2083. DOI: 10.3389/fpsyg.2017.02083

Carletto, S., Cavalera, C., Sadowski, I., Rovaris, M., Borghi, M., Khoury, B., Ostacoli, L., & Pagnini, F. (2020). Mindfulness-based interventions for the improvement of well-being in people with multiple sclerosis: A systematic review and meta-analysis. *Psychosomatic medicine, 82***,** 600-613. DOI: 10.1097/PSY.0000000000000819

Carter, H., McKenna, C., MacLeod, R., & Green, R. (1998). Health professionals' responses to multiple sclerosis and motor neurone disease. *Palliative medicine,* 12(5), 383-394. DOI: 10.1191/026921698668830097

Cashman, S.B., Reidy, P., Cody, K., & Lemay, C.A. (2004). Developing and measuring progress toward collaborative, integrated, interdisciplinary health care teams. *Journal of interprofessional care,* 18(2), 184-196. DOI: 10.1080/13561820410001686936

Castleberry, A. & Nolen, A. (2018). Thematic analysis of qualitative research data: Is it as easy as it sounds?. *Currents in pharmacy teaching and learning*, 10 (6), 807-815. DOI: 10.1016/j.cptl.2018.03.019

Chiaravalloti, N.D., & Deluca, J. (2008). Cognitive impairment in multiple sclerosis. *The Lancet Neurology,* 7 (12), 1139-1151. DOI: 10.1016/S1474-4422(08)70259-X

Chwastiak, L.A., & Ehde, D.M. (2007). Psychiatric Issues in Multiple Sclerosis. *Psychiatric Clinics of North America,* 30 (4), 803-817. DOI: 10.1016/j.psc.2007.07.003

Clark, A.M., MacIntyre, P.D., & Cruickshank, J. (2007). A critical realist approach to understanding and evaluating heart health programmes. *Health: An interdisciplinary journal for the social study of health, illness, and medicine*, 11(4), 513-539. DOI: 10.1177%2F1363459307080876

Clarke, R., & Coote, S. (2015). Perceptions of participants in a group, community, exercise programme for people with multiple sclerosis. *Rehabilitation research and practice,* 2015. DOI: 10.1155/2015/123494

Clarke, V., & Braun,. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The psychologist,* 26(2), 120-123. DOI:

Clarke, V., & Braun, V. (2017). Thematic analysis. *The journal of positive psychology*, 12(3), 297-298. DOI: 10.1080/17439760.2016.1262613

Clarke, V., & Spence, K. (2013). ‘I am who I am’? Navigating norms and the importance of authenticity in lesbian and bisexual women’s accounts of their appearance practices. *Psychology & Sexuality,* 4(1), 25-33. DOI: https://doi.org/10.1080/19419899.2013.748240

Cosio, D., Jin, L., Siddique, J., & Mohr, D. (2011). The effect of telephone-administered cognitive behavioural therapy on quality of life among patients with multiple sclerosis. *Annals of Behavioural Medicine,* 41 (2), 227-234. DOI: 10.1007/s12160-010-9236-y.

Cornwell, J. (2014). "Engaged, empowered staff are the key to better patient care": NT. *Nursing times,* 110(14), pp. 11.

Creswell, J. W. (2002). Educational research: Planning, conducting, and evaluating quantitative. Upper Saddle River, NJ: Prentice Hall.

Crotty, M. (1998). The foundations of social research: Meaning and perspectives in the research process. SAGE publications.

Crowe, M., Jordan, J., Burrell, B., Jones, V., Gillon, D., & Harris, S. (2016). Mindfulness-based stress reduction for long-term physical conditions: A systematic review. *The Australian and New Zealand journal of psychiatry,* 50(1), 21-32. DOI: 10.1177/0004867415607984

D'Amico, E., Haase, R., & Ziemssen, T. (2019). Review: Patient-reported outcomes in multiple sclerosis care. *Multiple sclerosis and related disorders,* 33, 61-66. DOI: 10.1016/j.msard.2019.05.019

Darleston-Jones, D. (2007). Making connections: The relationship between epistemology and research methods. The Australian community psychologist, 19(1), 19-27. DOI: https://www.researchgate.net/publication/284970190_Making_connections_The_relationship_between_epistemology_and_research_methods/link/56a02de708ae4af52546f7e5/download

das Nair, R., Kontou, E., Smale, K., Barker, A., & Lincoln, N.B. (2016). Comparing individual and group intervention for psychological adjustment in people with multiple sclerosis: A feasibility randomised controlled trial. *Clinical rehabilitation,* 30(12), 1156-1164. DOI: 10.1177/0269215515616446

Davey, L., Clarke, V., & Jenkinson, E. (2019). Living with alopecia areata: An online qualitative survey study. British journal of dermatology, 180(6), 1377–1389. DOI: 10.1111/bjd.17463

Davies, E. (2021). What is cognitive behavioural therapy (CBT)? Types of therapy. https://www.bacp.co.uk/about-therapy/types-of-therapy/cognitive-behavioural-therapy/

Davies, F., Edwards, A., Brain, K., Edwards, M., Jones, R., Wallbank, R., Robertson, N.P., & Wood, F. (2015). 'You are just left to get on with it': Qualitative study of patients and carer experiences of the transition to secondary progressive multiple sclerosis. *BMJ open,* 5(7). DOI: 10.1136/bmjopen-2015-007674.

Dieleman,S.L., Farris, K.B., Feeny, D., Johnson, J.A., Tsuyuki, R.T., & Brilliant, S. (2004). Primary health care teams: Team members' perceptions of the collaborative process. *Journal of interprofessional care,* 18(1), 75-78. DOI: 10.1080/13561820410001639370

Diepeveen, S., Ling, T., Suhrcke, M., Roland, M., & Marteau, T.M. (2013). Public acceptability of government intervention to change health-related behaviours: A systematic review and narrative synthesis. *BMC public health*, 13(756). DOI: 10.1186/1471-2458-13-756

Easton, K.L., McComish, J.F., & Greenberg, R. (2000). Avoiding Common Pitfalls in Qualitative Data Collection and Transcription. *Qualitative Health Research*, *10*(5), 703–707. DOI: 10.1177/104973200129118651

Ehde, D.M., & Jensen, M.P. (2004). Feasibility of a cognitive restructuring intervention for treatment of chronic pain in persons with disabilities. *Rehabilitation psychology, 49*(3), 254–258. DOI:10.1037/0090-5550.49.3.254

Ehde, D.M., Alschuler, K.M., Day, M.A., Ciol, M.A., Kaylor, M.L., Altman, J.K., & Jensen, M.P. (2019). Mindfulness-based cognitive therapy and cognitive behavioural therapy for chronic pain in multiple sclerosis: a randomized controlled trial protocol. *Trials,* 20(1), 1-12. DOI: 10.1186/s13063-019-3761-1

Eklund, V.A., & MacDonald, M.L. (1991). Descriptions of persons with multiple sclerosis, with an emphasis on what is needed from psychologists. *Professional Psychology-Research and Practice,* 22 (4), 277-284. DOI: 10.1037/0735-7028.22.4.277

Embuldeniya, G., Veinot, P., Bell, E., Bell, M., Nyhof-Young, J., Sale, J.E.M., & Britten, N. (2013). The experience and impact of chronic disease peer support interventions: a qualitative synthesis. *Patient education and counselling.* 92(1), 3-12. DOI: 10.1016/j.pec2013.02.002

Ennis, M., Thain, M., Baker, G.A., & Young, C.A. (2006). A randomized controlled trial of a health promotion education programme for people with multiple sclerosis. *Clinical Rehabilitation,* 20 (9), 783-792. DOI: 10.1177/0269215506070805

Evans, J., & Mathur, A. (2005). The value of online surveys. *Internet research,* 15(2), 195-219. DOI: 10.1108/10662240510590360

Everett, T. (2010). Muscle work, strength, power and endurance. In Trew, M., & Everett, T. (Eds). *Human movement – An introductory text* (6th ed., pp. 109-121). London: Elsevier Churchill Livingston.

Firth, N. (2014). Effectiveness of psychologically focused group interventions for multiple sclerosis: A review of the experimental literature. *Journal of health psychology*, 19(6), 789-801. DOI: 10.1177/1359105313479630

Firth-Cozens, J. (2001). Multidisciplinary teamwork: the good, bad, and everything in between. *Quality in health care,* 10, 65-69. DOI: 10.1136/qhc.10.2.65

Forsman, A.K., Nordmyr, J., & Wahlbeck, K. (2011). Psychosocial interventions for the promotion of mental health and the prevention of depression among older adults. *Health promotion international,* 26(1), 85-107. DOI: 10.1093/heapro/dar074

Fraser, R., Ehde, D., Amtmann, D., Verrall, A., Johnson, K. L., Johnson, E., & Kraft, G. H. (2013). Self-management for people with multiple sclerosis: report from the first international consensus conference, november 15, 2010. *International journal of MS care*, 15(2), 99–106. DOI: 10.7224/1537-2073.2012-044

Gallien, P., Gich, J., Sánchez-Dalmau, B.F., & Feneberg, W. (2014). Multidisciplinary management of multiple sclerosis symptoms. *European Neurology,* 72(1), 20-25. DOI: 10.1159/000367620.

Galushko, M., Golla, H., Strupp, J, Karbach, U., Kaiser, C., Ernstmann, N., Pfaff, H., Ostgathe, C., & Voltz, R. (2014). Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: a qualitative study. *Journal of Palliative Medicine*, 17(3):274-281. DOI: 10.1089/jpm.2013.0497.

Gedik, Z., Sorias, O., & Idiman, E. (2015). Do coping styles mediate relationship between disability status and psychosocial loss in people with relapsing remitting multiple sclerosis? *Journal of Health Psychology,* 22 (6), 707-721, DOI: 10.1177/1359105315611958

Gelinas, L., Pierce, R., Winkler, S., Cohen, I.G., Lynch, H.F., & Bierer, B.E. (2017). Using social media as a research recruitment tool: Ethical issues and recommendations. *The American journal of bioethics,* 17(3), 3-14. DOI: 10.1080/15265161.2016.1276644

Gergen, K. J. (1999). *An invitation to social construction.* London: Sage.

Gil-Gonzalez, I., Martin-Rodriguez, A., Conrad, R., Angeles, M., & Perez-San-Gregorios, M.A. (2020). Quality of life in adults with multiple sclerosis: a systematic review. *BMJ,* 10(11). DOI: 10.1136/bmjopen-2020-041249

Giovannetti, A., Borreani, C., & Bianchi, E., Giordano, A., Cilia, S., Cipollari, S., Rossi, I., Cavallaro, C., Clerici, V.T., Rossetti, E., Stefanelli, M.C., Totis, A., Pappalardo, A., Hanafin, S., & Cowley, S. (2003). Multidisciplinary communication in the Irish public health nursing service: A study. *British journal of community nursing,* 8(12), 544-549. DOI: 10.12968/bjcn.2003.8.12.11850

Giovannoni, G., & Rhoades, R.W. (2012). Individualizing treatment goals and interventions for people with MS. *Current opinion in neurology,* 25, 20-27. DOI: 10.1097/01.wco.0000413321.32834.aa

Glanz, K., Rimer, B., & Lewis, F. (2002). Health behaviour and health education. San Francisco, CA: John Wiley & Sons, Inc.

Goertz, G., & Mahoney. (2012). *A tale of two cultures: Qualitative and quantitative research in the social sciences*. Princeton university press.

Golla, H., Galushko, M., Pfaff, H., & Voltz, R. (2012). Unmet needs of severely affected multiple sclerosis patients: The health professionals' view. *Palliative Medicine, 26*(2), 139-51. DOI: 10.1177/0269216311401465

Graziano, F., Calandri, E., Borghi, M., & Bonino, S. (2014). The effects of a group-based cognitive behavioural therapy on people with multiple sclerosis: A randomized controlled trial. *Clinical Rehabilitation,* 28 (3), 264-274. DOI: 10.1177/0269215513501525

Grogan, S., Turley, E., & Cole, J. (2018). ‘So many women suffer in silence’: A thematic analysis of women’s written accounts of coping with endometriosis. *Psychology & Health,* 33(11), 1364-1378. DOI: https://doi.org/10.1080/08870446.2018.1496252

Grossman, P., Kappos, L., Gensicke, H., D’Souza, M.D., Mohr, D.C., & Penner, I.K., et al. (2010). MS quality of life, depression, and fatigue improve after mindfulness training: A randomized trial. *Neurology,* 75 (13), 1141-1149. DOI: 10.1212/WNL.0b013e3181f4d80d

Gunter B., Nicholas D., Huntington P., & Williams, P. (2002). Online versus offline research: Implications for evaluating digital media. *Aslib proceedings,* 54(4), 229–239. DOI: http://dx.doi.org/10.1108/00012530210443339

Haigh, F., Kemp, L., Bazeley, P., & Haigh, N. (2019). Developing a critical realist informed framework to explain how the human rights and social determinants of health relationship works. *BMC public health,* **19(**1571). DOI: 10.1186/s12889-019-7760-7

Ham, C. (2014). Improving NHS care by engaging staff and devolving decision-making report of the review of staff engagement and empowerment in the NHS. https://www.kingsfund.org.uk/publications/articles/improving-nhs-care-engaging-staff-and-devolving-decision-making

Hefferson, K., & Gil-Rodriguez, E. (2011) Methods: Interpretative phenomenological analysis. *The Psychologist*, 24, 756-759. https://thepsychologist.bps.org.uk/volume-24/edition-10/methods-interpretative-phenomenological-analysis

Hind,D., O'Cathain,A., Cooper, C.L., Parry, G.D., Isaac., C.L., Rose, A., Martin, L., & Sharrack. (2010). The acceptability of computerised cognitive behavioural therapy for the treatment of depression in people with chronic physical disease: A qualitative study of people with multiple sclerosis. *Psychological health,* 25(6), 699-712. DOI: 10.1080/08870440902842739

Hofmann, S.G., Sawyer, A.T., Witt, A.A., & Oh, D. (2010). The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *Journal of Consulting and Clinical Psychology,* 78 (2), 169-183. DOI: 10.1037/a0018555

Hommel, K.A., Hente, E., Herzer, M., Ingerski, L.M., & Denson, L.A. (2013). Telehealth behavioural treatment for medication nonadherence: A pilot and feasibility study. *European journal of gastroenterology & hepatology,* 25(4), 469-473. DOI: 10.1097/meg.0b013e32835c2a1b

Hung, Y., & Yarmak, P. (2016). Neurorehabilitation for multiple sclerosis patients with emotional dysfunctions. *Frontiers in neurology,* 6(272). DOI: 10.3389/fneur.2015.00272

Occhipinti, G., Confalonieri, P., Veronese, S., Grasso, M.G., Patti, F., Zaratin, P., Battaglia, M.A., & Solari, A. (2018). Participant perspectives of a home-based palliative approach for people with severe multiple sclerosis. *PLoS one,* 13 (7). DOI: 10.1371/journal.pone.0200532

Glanz, B.I., Holland, C.M., Gauthier, S.A., Amunwa, E.L., Liptak, Z., Houtchens, M.K., Sperling, R.A., Khoury, S.J., Guttmann, C.R., & Weiner, H.L. (2007). Cognitive dysfunction in patients with clinically isolated syndromes or newly diagnosed multiple sclerosis. *Multiple sclerosis journal,* 13(8), 1004-10. DOI: 10.1177/1352458507077943

Golla, H., Galushko, M., Pfaff, H., & Voltz, R. (2012). Unmet needs of severely affected multiple sclerosis patients: The health professionals' view. *Palliative medicine,* 26(2), 139-151. DOI: 10.1177/0269216311401465

Goodman, L. (2011). Comment: On respondent-driven sampling and snowball sampling in hard-to-reach populations and snowball sampling not in hard-to-reach populations. Sociological Methodology, 41(1), 347-353. doi:10.1111/j.1467-9531.2011.01242.x

Gotterberg, K., Chruzander, C., Backenroth, G., Ahlström, G., & Ytterberg, C. (2016). Individual face-to-face cognitive behavioural therapy in multiple sclerosis: A qualitative study. *Journal of clinical psychology,* 72(7), 651-662. DOI: 10.1002/jclp.22288

Grossman, P., Kappos, L., Gensicke, H., D'Souza, M., Mohr, D.C., Penner, I.K., & Steiner, C. (2010). MS quality of life, depression, and fatigue improve after mindfulness training: A randomized trial, *Neurology,* 75(13), 1141-1149. DOI: 10.1212/WNL.0b013e3181f4d80d

Guba, E. (1990). The Paradigm Dialog. London: Sage.

Hacking, J.M., Muller, S., & Buchan, I.E. (2011). 'Trends in mortality from 1965 to 2008 across the English north-south divide: comparative observational study', *British medical journal*, 342(7794), 423. DOI: 10.1136/bmj.d508

Harris, M., Lawn, S.J., Morello, A., Battersby, M.W., Ratcliffe, J., McEvoy, R.D., & Tieman, J.J. (2017). Practice change in chronic conditions care: An appraisal of theories. *BMC Health services research,* 17(170). DOI: 10.1186/s12913-017-2102-x

Hersche, R., Weise, A., Michel, G., Kesselring, J., Barbero, M., & Kool, J. (2019). Development and Preliminary Evaluation of a 3-Week Inpatient Energy Management Education Program for People with Multiple Sclerosis-Related Fatigue. *International journal of MS care*, *21*(6), 265–274. DOI: /10.7224/1537-2073.2018-058

Hind, D., Cotter, J., Thake, A., Bradburn, M., Cooper, C., Isacc, C., & House, A. (2014). Cognitive behavioural therapy for the treatment of depression in people with multiple sclerosis: a systematic review and meta-analysis. *BMC Psychiatry,* 14(5), DOI: 10.1186/1471-244X-14-5

Holmes, J.M., Ford, E., & Yuill, F. (2012). Attendance at a Psychological Support Group for People with Multiple Sclerosis. *Disability and rehabilitation,* 34(15), 1323-1327. DOI: 10.3109/09638288.2011.642927

Jaglal, S.B., Guilcher, S.J.T., Bereket, T., Kwan, M., Munce, S., Conklin, J., Versnel, J., Packer, T., Verrier, M., Marras, C., Pitzul, K.B., & Riopelle, R. (2014). Development of a Chronic Care Model for Neurological Conditions (CCM-NC). *BMC Health services research,* 14 (409). DOI: 10.1186/1472-6963-14-409.

Jick, S. S., Li, L., Falcone, G. J., Vassilev, Z. P., & Wallander, M. A. (2014). Mortality of patients with multiple sclerosis: A cohort study in UK primary care. *Journal of Neurology*, 261(8), 1508–1517. DOI: 10.1007/s00415-014-7370-3

Johnson, J.L., Adkins, D., & Chauvin, S. (2020). A review of the quality indicators or rigor in qualitative research. *American journal of pharmaceutical education,* 84(1). DOI: 10.5688/ajpe7120

Jones, F., & Kulnik, S.T. (2018). Self-management. In Lennon, S., Ramdharry, G., & Verheyden, G. (Eds). *Physical management for neurological conditions (*3rd ed., pp. 379-396). Edinburgh:Elsevier Churchill Livingston.

Kalb, R., & Reitman, N. (2012). Multiple sclerosis: A model of psychosocial support: 5th edition. https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Psychosocial-Cavallo-5th-Edition_Final-Links.pdf

Kazantzis, N., Beck, J.S, Dattilio, F.M, Dobson, K.S., & Rapee, R.M. (2013). Collaborative empiricism as the central therapeutic relationship element in CBT: An expert panel discussion at the 7th international congress of cognitive psychotherapy. *International journal of cognitive therapy,* 6(4), 386-400. DOI: 10.1521/ijct.2013.6.4.386

Kermani, L.S., Fazilat-Pour, M., Mousavi-Nasab, S.M.H., & Mimand, H.E. (2020). Effectiveness of mindfulness – integrated Cognitive Behavioural Therapy on the emotional states and quality of life pf patients with multiple sclerosis: A clinical trial study. *Journal of Semnan University of medical sciences,* 22(3), 446-451. DOI: 10.29252/koomesh.22.3.446

Kever, A., Buyukturkoglu, K., Riley, C.S., De Jager, P.L., & Leavitt, V.M. (2021). Social support is linked to mental health, quality of life, and motor function in multiple sclerosis. *Journal of neurology*, 268(5), 1827-1836. DOI: 10.10007/s00415-020-10330-7

Khan, F., Amatya, B., & Galea. (2014). Management of fatigue in persons with multiple sclerosis. *Frontiers in neurology,* 5(177). DOI: 10.3389/fneur.2014.00177

Kidd, T., Carey, N., Mold, F., Westwood, S., Miklaucich, M., Konstantara, E., Sterr, A., & Cooke, D. (2017). A systematic review of the effectiveness of self-management interventions in people with multiple sclerosis at improving depression, anxiety and quality of life. *PLoS one,* 12(10). DOI: 10.1371/journal.pone.0185931

Lahelle, A.F., Øberg, G.K., & Normann, B. (2019). Group dynamics in a group-based, individualized physiotherapy intervention for people with multiple sclerosis: A qualitative study. *Physiotherapy research international,* 25(3). DOI: 10.1002/pri.1829

Learmonth, Y. C., Marshall-McKenna, R., Paul, L., Mattison, P., & Miller, L. (2013). A qualitative exploration of the impact of a 12-week group exercise class for those moderately affected with multiple sclerosis. *Disability and rehabilitation*, 35, 81–88. DOI: 10.3109/09638288.2012.688922

Leclaire, K., Cecil, A., LaRussa, A., Stuart, F., Hemond, C.C., Healy, B.C., Chitnis, T., Weiner, H., Huffman, J., & Glanz, B.I. (2018). *Short Report:* A Pilot Study of a Group Positive Psychology Intervention for Patients with Multiple Sclerosis. *International journal of MS care,* 20(3), 136-141. DOI: 10.7224/1537-2073.2017-002.

Lincoln, N.B., Dent, A., Harding, J., Weyman, N., Nicholl, C., Blumhardt, L.D. (2002). Evaluation of cognitive assessment and cognitive intervention for people with multiple sclerosis. *Journal of Neurology, Neurosurgery & Psychiatry,* 72 (1), 93-98. DOI: 10.1136/jnnp.72.1.93

Lincoln, N.B., Yuill, F., Holmes, J., Drummond, A.E., Constantinescu, C.S., Armstrong, S., & Phillips, C. (2011). Evaluation of an adjustment group for people with multiple sclerosis and low mood: A randomized controlled trial, *Multiple sclerosis,* 17(10), 1250-1257. DOI: 10.1177/1352458511408753

Low, J. (2019). “A pragmatic definition of the concept of theoretical saturation.” *Sociological focus,* 52(2), 131–139. DOI:10.1080/00380237.2018.1544514

Luong, H.K., Drummond, S.P.A., & Norton, P.J. (2020). Elements of the therapeutic relationship in CBT for anxiety disorders: A systematic review. *Journal of anxiety disorders,* 76. DOI: 10.1016/j.janxdis.2020.102322

MacLeod, L. (2012). Making SMART goals smarter. *Physician Executive*, 38 (2), 68-72.

MacNeill, V., Sanders, C., Fitzpatrick, R., Hendy, J., Barlow, J., Knapp, M., Rogers, A., Bardsley, M., & Newman, S. P. (2014). Experiences of front-line health professionals in the delivery of telehealth: a qualitative study. *The British journal of general practice: the journal of the Royal College of General Practitioners*, *64*(624), 401–407. DOI: 10.3399/bjgp14X680485

Madill, A., Jordan, A. and Shirley, C. (2000) Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*. 91 (1), 1-20. DOI: 10.1348/000712600161646

Maghzi, A. H., Houtchens, M. K., Preziosa, P., Ionete, C., Beretich, B. D., Stankiewicz, J. M., Tauhid, S., Cabot, A., Berriosmorales, I., Schwartz, T., Sloane, J. A., Freedman, M. S., Filippi, M., Weiner, H. L., & Bakshi, R. (2020). COVID-19 in teriflunomide-treated patients with multiple sclerosis. *Journal of neurology*, *267*(10), 2790–2796. DOI: 10.1007/s00415-020-09944-8

Malterud, K. (2016). Theory and interpretation in qualitative studies from general practice: Why and how? *Scandinavian journal of public health*, 44(2), 20-129. DOI: 10.1177/1403494815621181

McDermott, E., Roen, K. (2012). Youth on the virtual edge: Researching marginalized sexualities and genders online. *Qualitative health research*, 22(4), 560–570. DOI: 10.1177/1049732311425052

McEvoy, C., Clarke, V., & Thomas, Z. (2021). 'Rarely discussed but always present': Exploring therapists' accounts of the relationship between social class, mental health and therapy. *Counselling & psychotherapy research*, 21(2), 324-334. DOI: 10.1002/capr.12382

McInroy, L.B. (2016). Pitfalls, potentials, and ethics of online survey research: LGBTQ and other marginalized and hard-to-access youths. *Social work research*, *40*(2), 83–94. DOI: 10.1093/swr/svw005

Merkes, M. (2010). Mindfulness-based stress reduction for people with chronic diseases. *Australian journal of primary health*, 16(3), 200-10. DOI: 10.1071/PY09063.

Messmer Uccelli, M., Specchia, C., Battaglia, M.A., & Miller, D.M. (2009). Factors that influence the employment status of people with multiple sclerosis: A multi-national study. *Journal of neurology*, 256, 1989-1996. DOI: 10.1007/s00415-009-5225-0

Methley, A.M., Chew-Graham, C.A., Cheraghi-Sohi, S., & Campbell, S.M. (2017). A qualitative study of patient and professional perspectives of healthcare services for multiple sclerosis: implications for service development and policy. *Health and social care in the community,* 25(3), 848-857. DOI: 10.1111/hsc.12369

Methley, A., Campbell, S., Cheraghi-Sohi, S., & Chew-Graham, C. (2017). Meeting the mental health needs of people with multiple sclerosis: A qualitative study of patients and professionals. *Disability and Rehabilitation*, 39(11), 1097-1105. DOI: 10.1080/09638288.2016.1180547

Meyrick, J. (2006). What is good qualitative research?: A first step towards a comprehensive approach to judging rigour/quality. *Journal of health psychology,* 11(5), 799-808. DOI: 10.1177%2F1359105306066643

Midtbust, M.H., Alnes, R.E., Gjengedal, E., & Lykkeslet, E. (2018). Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences. *BMC health services research,* 18(709). DOI: 10.1186/s12913-018-3515-x

Moon, K., & Blackman, D. (2014). A guide to understanding social science research for natural scientists. *Conservation Biology*, 28(5), 1167-1177. DOI: 10.1111/cobi.12326/full

Morse, J.M. (2008). "What's your favourite colour?". Reporting irrelevant demographics in qualitative research. *Qualitative Health Research,* 18(3), 299-300. DOI: 10.1177/1049732307310995

Morse, J.M., & Coulehan, J. (2015). Maintaining confidentiality in qualitative publications. *Qualitative Health Research*, 25(2), 151-152. DOI: 10.1177/1049732314563489

Moss, B.P., Mahajan, K.R., Bermel RA, Hellisz, K., Hua, L.H., Hudec, T., Husak, S., McGinley, M.P., Ontaneda., D., Wang, Z., Weber, M., Tagliani, P., Cardenas-Robledo, S., Zabalza, A., Arrambide, G., Carbonell-Mirabent, P., Rodriguez-Barranco, M., Sastre-Garriga, J., Tintore, M., … Fitzgerald, K.C. (2020). Multiple sclerosis during the COVID-19 pandemic. *Multiple sclerosis journal,* 26(10), 1163-1171. DOI: 10.1177/1352458520948231

MS Society. (2021). Early signs of MS. https://www.mssociety.org.uk/about-ms/signs-and-symptoms/early-signs-of-ms

MS Society. (2021). Types of MS. https://www.mssociety.org.uk/about-ms/types-of-ms

MS Trust. (2018). Signs and symptoms. https://mstrust.org.uk/about-ms/ms-symptoms/signs-and-symptoms#early-signs-of-ms

MS Trust. (2020). Types of MS. https://mstrust.org.uk/about-ms/what-ms/types-ms

Mynors, G., Bowen, A., & Doncaster, D. (2016). MS Specialist Nursing in the UK 2016: Report on progress towards equitable provision: September 2016. https://mstrust.org.uk/sites/default/files/MS%20Specialist%20Nursing%20in%20the%20UK%202016%20-%20updated.pdf

National Institute for Health and Clinical Excellence (NICE). (2009). Depression in adults with a chronic physical health problem: Treatment and management. http://publications.nice.org.uk/depression-in-adults-witha-chronic-physical-health-problem-cg91

National Institute for Health and Clinical Excellence (NICE). (2014). Costing statement: Multiple sclerosis: management of multiple sclerosis in primary and secondary care. https://www.nice.org.uk/guidance/cg186/resources/costing-statement-193250413

National Institute for Health and Clinical Excellence (NICE). (2016). Multiple sclerosis: Quality standard. https://www.nice.org.uk/guidance/qs108

National Institute for Health and Clinical Excellence (NICE). (2019). Multiple sclerosis in adults: management. https://www.nice.org.uk/guidance/cg186

National Institute for Health and Clinical Excellence (NICE). (2021). NICE recommends range of effective treatments for people with chronic primary pain and calls on healthcare professionals to recognise and treat a person’s pain as valid and unique to them. https://www.nice.org.uk/news/article/nice-recommends-range-of-effective-treatments-for-people-with-chronic-primary-pain-and-calls-on-healthcare-professionals-to-recognise-and-treat-a-person-s-pain-as-valid-and-unique-to-them

National Institute for Health Research. (2021). Briefing notes for researchers – public involvement in NHS, health and social care research 2021. https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371

National Multiple Sclerosis Society. (2020). What is MS?. https://www.nationalmssociety.org/What-is-MS/MS-FAQ-s

NHS (2018). Multiple Sclerosis. https://www.nhs.uk/conditions/multiple-sclerosis/

NHS Digital. (2018). Narrowing of the NHS gender divide but men still the majority in senior roles NHS. https://digital.nhs.uk/news-and-events/latest-news/narrowing-of-nhs-gender-divide-but-men-still-the-majority-in-senior-roles

NHS. (2021). Facts and figures of multiple sclerosis. https://www.nbt.nhs.uk/our-services/a-z-services/bristol-avon-multiple-sclerosis-centre-brams/facts-figures-ms

O'Hara, L., Cadbury, H., De Souza, L., & Ide, L. (2002). Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: A randomized controlled trial. *Clinical Rehabilitation,* 16 (2), 119-128. DOI: 10.1191/0269215502cr478oa

Palant, A., & Himmel, W. (2019). Are there also negative effects of social support? A qualitative study of patients with inflammatory bowel disease. *BMJ,* 9(1). DOI: 10.1136/bmjopen-2018-022642

Parkin, D., Jacoby, A., McNamee, P., Miller, P., Thomas, S., & Bates, D. (2000). Treatment of multiple sclerosis with interferon beta: an appraisal of cost-effectiveness and quality of life. *Journal of Neurology Neurosurgery & Psychiatry,* 68 (2), 144-149. DOI: 10.1136/jnnp.68.2.144

Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative research. *Perspectives in clinical research, 4*(3), 192. DOI: 10.4103/2229-3485.115389

Patton, M.Q. (1990). Qualitative evaluation and research methods, second edition. Beverly Hills CA: Sage.

Peters, S., Wilkinson, A., & Mulligan, H. (2019). Views of healthcare professionals on training for and delivery of a fatigue self-management program for persons with multiple sclerosis. *Disability and rehabilitation,* 41(23), 2792-2798. DOI:10.1080/09638288.2018.1478993

Plow, M.A., Mathiowetz, V., & Lowe, D.A. (2009). Comparing individualized rehabilitation to a group wellness intervention for persons with multiple sclerosis. *American journal of health promotion,* 24(1), 23-26. DOI: 10.4278/ajhp.0712111

Pozzilli, C., Brunetti, M., Amicosante, A.M.V., Gasperini, C., Ristori, G., Palmisano, L., et al. (2002). Home based management in multiple sclerosis: Results of a randomised controlled trial. *Journal of Neurology, Neurosurgery & Psychiatry,* 73 (3), 250-255. DOI: 10.1136/jnnp.73.3.250

Public Health England. (2018). Local action on health inequalities: Understanding and reducing ethnic inequalities in health. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/730917/local_action_on_health_inequalities.pdf

Rafiee, S.H., Taklavi, S., Abolghasemi, A., & Langroodi, H.G. (2020). Positive group-psychotherapy in multiple sclerosis: The effect on psychological symptoms and quality of life. *Caspian journal of neurological sciences*, 6(2), 100-107. DOI: 10.32598/CJS.6.21.231.1

Rance, N. M., Moller, N. P. & Douglas, B. A. (2010). Counsellors with eating disorder histories: A story of being “normal”. *Eating Disorders: The Journal of Treatment & Prevention*, *18(5),* 377-392. DOI:

Ratajska, A., Glanz, B.I., Chitnis, T., Weiner, H.L., & Healy, C. (2020). Social support in multiple sclerosis: Associations with quality of life, depression and anxiety. *Journal of psychosomatic research,* 138.

Ratner, C (2002). Subjectivity and objectivity in qualitative methodology. *Forum Qualitative Sozialforschung, 3*(3). DOI: http://nbn-resolving.de/urn:nbn:de:0114-fqs0203160.

Reips, U.D. (2002). Standards for Internet-based experimenting. *Experimental Psychology*, 49(4), 243–256. DOI: 10.1026/1618-3169.49.4.243

Rejdak, K., Jackson, S., & Giovannoni, G. (2010). Multiple sclerosis: a practical overview for clinicians. *British Medical Bulletin*, 95 (1), 79-104. DOI: 10.1093/bmb/ldq017

Roberts, M. (2017). An overview of multiple sclerosis and its holistic management. *Nursing times*, 113(1), 19-23. DOI: https://www.nursingtimes.net/clinical-archive/neurology/an-overview-of-multiple-sclerosis-and-its-holistic-management-19-12-2016/

Rosenstock, I. M. (1974). Historical Origins of the Health Belief Model. *Health Education Monographs*. 2(4):328-335. DOI: 10.1177/109019817400200403

Rudick, R.A., Miller, D., Clough, J.D., Gragg, L.A., & Farmer, R.G. (1992). Quality of Life in multiple sclerosis: Comparison with inflammatory bowel disease and rheumatoid arthritis. *Archives of Neurology,* 49(12), 1237–1242. DOI:10.1001/archneur.1992.0053036003501

Rutherford, J., & McArthur, M. (2004). A qualitative account of the factors affecting team-learning in primary care. *Education for primary care,* 15(3), 352-360. DOI: https://web-b-ebscohost-com.ezproxy.uwe.ac.uk/ehost/detail/detail?vid=0&sid=3aef86f7-1b23-468d-a699-d269ab8bb9db%40pdc-v-sessmgr01&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=ehh&AN=13778359

Ryan, R.M., & Deci, E.L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist,* 55(1), 68–78. DOI: 10.1037/0003-066X.55.1.68

Sekhon, M., Cartwright, M., & Francis, J.J. (2017). Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. *BMC health services research,* 17(1). DOI: 10.1186/s12913-017-2031-8

Sekhon, M., Cartwright, M., & Francis, J.J. (2018). Acceptability of health care interventions: A theoretical framework and proposed research agenda. *British journal of health psychology*, 23(3), 519-531. DOI: 10.1111/bjhp.12295

Senders, A., Borgatti, A., Hanes, D., & Shinto, L. (2018). Association Between Pain and Mindfulness in Multiple Sclerosis: A Cross-sectional Survey. *International journal of MS care*, *20*(1), 28–34. DOI: 10.7224/1537-2073.2016-076

Sesel, A.L., Sharpe, L., & Naismith, S.L. (2018). Efficacy of psychosocial interventions for people with multiple sclerosis: A meta-analysis of specific treatment effects. *Psychotherapy and psychosomatics*, 87(2), 105-111. DOI: https://doi.org/10.1159/000486806

Seymour, W.S. (2001). In the flesh or online? Exploring qualitative research methodologies. *Qualitative Research,* 1(2), 147–168. DOI: 10.1177%2F146879410100100203

Simmons, R.D., Tribe, K.L., & McDonald, E.A. (2010). Living with multiple sclerosis: Longitudinal changes in employment and the importance of symptom management. *Journal of neurology*, 257, 926–936. DOI: 10.1007/s00415-009-5441-7

Simpson, V. (2015). Models and theories to support health behaviour intervention and program planning. *Purdue extension*. https://mdc.itap.purdue.edu/item.asp?itemID=21894

Simpson, R., Mair, F.S., & Mercer, S.W. (2017). Mindfulness-based stress reduction for people with multiple sclerosis – a feasibility randomised controlled trial. *BMC Neurology*, 17 (1*)*, 1-12. DOI: 10.1186/s12883-017-0880-8

Sleeman, K. E., Koffman, J., Bristowe, K., Rumble, C., Burman, R., Leonard, S., Noble, J., Dampier, O., Bernal, W., Morgan, M., Hopkins, P., Prentice, W., & Higginson, I.J. (2015). 'It doesn't do the care for you': a qualitative study of health care professionals' perceptions of the benefits and harms of integrated care pathways for end-of-life care. *BMJ open*, *5*(9). DOI: 10.1136/bmjopen-2015-008242

Smyth, J.D. (2016). Designing questions and questionnaires. In Wolf, C., Joye, D., , Smith, T.W., & Fu, Y-C. (Eds.), *The Sage handbook of survey methodology* (pp. 218–235). Sage.

Sorensen, P.S., Giovannoni, G., Montalban, X., Thalheim, C., Zaratin, P., & Comi, G. (2019). The multiple sclerosis care unit. *Multiple sclerosis journal*, 5, 627-636. DOI: 10.1177/1352458518807082

Stojanov, A., Malobabic, M., Milosevic, V., Stojanov, J., Vojinovic, S., Stanojevic, G., & Stevic, M. (2020). Psychological status of patients with relapsing-remitting multiple sclerosis during coronavirus disease-2019 outbreak. *Multiple sclerosis and related disorders*, 45. DOI: 10.1016/j.msard.2020.102407

Sue Ryder. (2019). Time to get it right: A report on the provision of health and social care services for people with neurological conditions in England https://www.sueryder.org/sites/default/files/2019-02/Sue-Ryder-Time-To-Get-It-Right-report-2019.pdf

Sutliff, M.H., Bennett, S.E., Bobryk, P., Halper, J., Saslow, L.A., Skutnik, L.T., Smith, C., Zackowski, K., & Jones, D.E. (2016). Rehabilitation in multiple sclerosis: Commentary on the recent AAN systematic review. *Neurology clinical practice*, 6(6), 1323-1327, DOI: 10.1212/CPJ.0000000000000318

Suzuki, L.A., Ahluwalia, M.K., Arora, A.K., & Mattis, J S. (2007). The pond you fish in determines the fish you catch: Exploring strategies for qualitative data collection. The Counseling Psychologist, 35(2), 295–327. DOI: 10.1177/0011000006290983

Tang, W., & Kreindler, D. (2017). Supporting Homework Compliance in Cognitive Behavioural Therapy: Essential Features of Mobile Apps. *JMIR mental health*, *4*(2). DOI: 10.2196/mental.5283

Tavee, J., Rensel, M., Planchon, S.M., Butker, R.S., & Stone, L. (2011). Effects of meditation on pain and quality of life in multiple sclerosis and peripheral neuropathy: A pilot study. *International journal of MS care,* 13(4), 163-168. DOI: 10.7224/1537-2073-13.4.163

Taylor-Robinson, D.C., Milton, B., Lloyd-Williams, F., O'Flaherty, M., & Capewel, S. (2008). Planning ahead in public health? A qualitative study of the time horizons used in public health decision-making. *BMC Public Health,* 8(1). DOI:10.1186/1471-2458-8-415

Tebes, J. (2005). Community science, philosophy of science, and the practice of research. *American journal of community psychology,* 35(3/4), 213-230. DOI: 10.1007/s10464-005-3399-x

Terry, G., & Braun, V. (2017). Short but often sweet: The surprising potential of qualitative survey methods. In V. Braun, V. Clarke, & D. Gray (Eds.), *Collecting qualitative data: A practical guide to textual, media and virtual techniques,* (pp. 15–44). Cambridge University Press.

Thomas, P.W., Thomas, S., Kersten, P., Jones, R., Slingsby, V., Nock, A., et al (2014). One year follow-up of a pragmatic multi-centre randomised controlled trial of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. *BMC Neurology,* 14 (1), 109. DOI: 10.1186/1471-2377-14-109

Thomas, S., Kersten, Thomas, P.W., Slingsby, V., Nock, A., Jones, R., Davies Smith, A., Galvin, K.T., Baker, R., & Hillier, C. (2015). Exploring strategies used following a group-based fatigue management programme for people with multiple sclerosis (FACETS) via the Fatigue Management Stratgeies Questionnaire (FMSQ). *BMJ open,* 5(10). DOI: 10.1136/bmjopen-2015-008274

Thorn, B.E., & Kuhajda, M.C. (2006). Group cognitive therapy for chronic pain. *Journal of clinical psychology,* 62(11), 1355-1366. DOI: 10.1002/jclp.20315

Toerien, M., & Wilkinson, S. (2004). Exploring the depilation norm: A qualitative questionnaire study of women's body hair removal. Qualitative research in psychology, 1(1), 69–92. DOI: 10.1191/1478088704qp006oa

Toomey, E., Flannery, C., Matvienko-Sikar, K., Olander, E., Hayes, C., Heffernan, T., Hennessay, M., McHugh, S., Queally, M., Kearney, P., Byrne, M., & Heary, C. (2020). Exploring healthcare professionals' views of the acceptability of delivering interventions to promote healthy infant feeding practices within primary care: A qualitative interview study. *Public health nutrition,* 1-11. DOI: 10.1017/S1368980020004954

Topcu, G., Griffiths, H., Bale, C., Trigg, E., Clarke, S., Potter, K.J., Mhizha-Murira, J.R., Drummond, A., Evangelou, N., Fitzsimmons, D., & Nair, R. (2020). Psychological adjustment to multiple sclerosis diagnosis: A meta-review of systematic reviews. *Clinical psychology review,* 82. DOI: 10.1016/j.cpr.2020.101923

Tracy, S.J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative inquiry*, 16(10), 837-851. DOI: 10.1177/1077800410383121

Turner, A.P., & Knowles, L.M. (2020). Behavioral interventions in multiple sclerosis. *Federal practitioner: for the health care professionals of the VA, DoD, and PHS, 37*(1), 31–S35.

Turton, W. (2014). An introduction to psychosocial interventions. In Walker, S. (Eds), *Psychosocial intervention in mental health nursing,* (pp 4-22). Learning matters.

Van Heest, K.N.L., Mogush, A.R., & Mathiowetz, V.G. (2017). Effects of a one-to-one Fatigue management course for people with chronic conditions and fatigue. *The American Journal of Occupational Therapy,* 71(4), 1-9. DOI: 10.5014/ajot.2017.023440

Wagner, E.H., Austin, B.T., Von Korff, M., & Milbank, Q. (1996). Organizing care for patients with chronic illness. *The Milbank Quarterly, 74*(4), 511-544. DOI:10.2307/335039

West, M.A., & Markiewicz, L. (2004). *Building team-based working: A practical guide to organizational transformation*. Oxford: Blackwell publishing. DOI: 10.1002/9780470774700.fmatter

West, E., & Nayar, S. (2016). A review of the literature on the experiences of black, minority and internationally recruited nurses and midwives in the UK healthcare system. https://www.nmc.org.uk/globalassets/sitedocuments/other-publications/literature-review.pdf

Whelan, B., Thomas, K.J., Van Cleemput, P., Whitford, H., Strong, M., Renfrew, M.J., Scott, E., & Relton, C. (2014). Healthcare providers' views on the acceptability of financial incentives for breastfeeding: A qualitative study. *BMC pregnancy and childbirth*, *14*, 355. DOI: 10.1186/1471-2393-14-355

Whetten-Goldstein, F.S., Goldstein, L.B., & Kulas, E.D. (1998). A comprehensive assessment of the costs of multiple sclerosis in the United States. *Multiple Sclerosis*, 4 (5), 419-425. DOI: 10.1177/135245859800400504

Willig, C. (2013). *Introducing Qualitative Research in Psychology*. 3rd ed. Berkshire, England: Open University Press.

Wilkinson, C., White, S., & Fronzo, C. (2018). Are multiple sclerosis services meeting the NICE quality standard?. *British journal of neuroscience nursing*, 14(2). DOI: 10.12968/bjnn.2018.14.2.73

Williams, M., Jordan, A., Scott, J., & Jones, M.D. (2020). Service users' experiences of contacting NHS patient medicines helpline services: A qualitative study. *BMJ open*, 10(6). DOI: 10.1136/bmjopen-2019-036326

Xyrichis, A., & Lowton, K. (2008). What fosters or prevents interprofessional teamworking in primary and community care? A literature review. *International journal of nursing studies*, 45(1), 140-153. DOI: 10.1016/j.ijnurstu.2007.01.015

Ytterberg, C., Chruzander, C., Backenroth, G., Kierkegaard, M., Ahlström, G., & Gottberg, K. (2017). A qualitative study of cognitive behavioural therapy in multiple sclerosis: Experiences of psychotherapists. *International journal of qualitative studies on health and well-being*, 12(1), 383-394. DOI: 10.1080/17482631.2017.1325673

APPENDIX A

What is the evidence of effectiveness of psychosocial interventions to increase quality of life in adults with Multiple Sclerosis: A systematic review

Abstract

Background: Individuals with Multiple Sclerosis (MS) are faced with emotional and social challenges. MS patients have been shown to have lower quality of life (QoL) compared to the general population and other groups of chronic diseases. Previous reviews exploring psychosocial interventions for individuals with MS found mixed results in improving QoL, concluding more robust evaluation and further evidence is needed to determine effectiveness. The current systematic review will be conducted to help fill the gap in evidence that is needed.

Objectives: To identify all randomised controlled trials (RCT's) which have investigated effectiveness of psychosocial interventions on QoL in adult MS patients, to explore effectiveness of interventions identified, to assess methodological quality of studies identified, to build upon and update existing literature in order to make more reliable conclusions as to how effective psychosocial interventions are for improving QoL in MS.

Methodology: Seven electronic databases were searched alongside grey literature for RCT's published up to January 2018. Included studies were assessed for methodological quality using the Effective Public Health Practice Project (EPHPP) tool. Due to heterogeneous nature of studies a narrative synthesis of types of psychosocial interventions was used.

Selection Criteria: Studies eligible for inclusion were published in English and included adults diagnosed with MS regardless of stage. Only RCTs with a QoL measure were included with this being the primary outcome. Studies with an intervention primarily focused on physical activity were excluded.

Results: The search yielded 8,696 studies after removing duplicates, 15 RCTs met inclusion criteria. Four were of strong methodological quality, nine moderate and two weak. All studies showed psychosocial interventions to improve QoL, although the level and duration of improvement differed. Types of psychosocial interventions included mindfulness, psychotherapy, homecare, coping skills/self-care strategies, educational and cognitive rehabilitation.

Conclusion: The review highlighted encouraging results for using psychosocial interventions in improving QoL for individuals with MS. The benefits of psychotherapy interventions such as CBT were reported with aspects of other interventions being highlighted for consideration such as, multi-disciplinary team working, education of MS coping strategies, booster sessions and mindfulness. However, due to methodological limitations further strong studies are needed to ascertain effectiveness, particularly amongst different ethnic groups, individuals with severe MS and gender differences. More information is also needed around the cost-effectiveness. Future research should explore non RCTs to expand the current review.

1. Introduction

Multiple Sclerosis (MS) is a chronic autoimmune disease of the central nervous system and the most common disabling neurological disease to affect young adults with almost 70% manifesting symptoms between ages of 20 and 40 years (1). The prevalence of MS in the UK in 2010 was 289 per 100 000 in women and 115 per 100 000 in men which was an increase of roughly 2.4% between 1990 and 2010 (2). It has also been shown that there is a significant 1.7-fold increased risk of all-cause mortality in patients with MS compared to the general population (3).

The symptoms of MS appear in different forms and is usually progressive. Symptoms include sensory and motor loss, fatigue and pain (4) and if left untreated can lead to life threatening complications. The different forms of MS fall under categories; relapsing-remitting (RR) MS which is the way most individuals begin MS, people with RR MS experience distinct relapses of symptoms with full or partial recovery. Primary-progressive (PP) MS describes symptoms progressive from onset and gradually worsening rather than distinct relapses. Secondary-progressive (SP) MS for many people comes after RR MS and describes symptoms which progressively worsen and relapses are unlikely. Progressive-relapsing (PR) MS refers to symptoms which are progressive from onset and relapses will be experienced with full or partial recovery (5).

Due to its progressive nature, coping with MS is ongoing and with it being much more than a medical disease, individuals are confronted with emotional and social challenges (6). MS patients often have complex needs requiring support from a variety of community services, resulting in huge financial costs for patients, families of the patient and the community. Costs can include home care, loss of earnings for the patient and caregiver and expensive medical treatment (7, 8). Previous research has shown mental health comorbidity in MS is associated with disability, social harms, increased somatic symptoms, diminished treatment adherence and reduction in QoL in MS patients (9, 10). Due to lack of effective prevention, treatment and cure for MS this has led to increasing interest from researchers into the QoL for MS patients (11). Compared to the general population MS patients have been shown to have lower QoL (12), this is also significantly lower than individuals with other chronic diseases such as inflammatory bowel disease and rheumatoid arthritis (13).

A number of studies have explored effectiveness of psychosocial interventions in improving QoL for MS patients. A review by Malcomson et al (2007) (14) on psychosocial interventions in people with MS found evidence to support the value of education, goal-setting, homework assignments, exercise, discussion forums and multidisciplinary team support to improve well-being and QoL. However, due to a number of studies demonstrating weak methodological quality this led to difficulty drawing conclusions around which interventions work best and authors suggesting further trials are needed to determine effectiveness of psychosocial interventions. A systematic review on mindfulness based interventions in MS (15) demonstrated there may be benefits in mindfulness in terms of QoL, mental health and some physical health aspects. Due to limited evidence found from the review authors suggested further high-quality studies are needed. A further systematic review carried out on self-management interventions for people with MS (16) found these interventions helped improve health-related QoL in 6 out of 7 studies reviewed. However, the authors put forward that more robust evaluation is required to determine effectiveness as a number of methodological issues were identified. A review by Thomas et al (2006) (17) on psychological interventions for MS indicated the ways these could be potentially helpful, particularly cognitive behavioural therapy, in helping individuals adjusting to and coping with MS. However, as with previous reviews further evidence was said to be needed. Therefore, the current systematic review will be conducted to fill the gap of effective evidence that is needed. To help increase the effectiveness of judging the benefits of the interventions only RCTs will be included in the search (18).

1.1 Aims of the review

The purpose of this systematic review is to:

* Identify all RCT's which have investigated effectiveness of psychosocial interventions on QoL in adult MS patients
* To use a narrative analysis to synthesis effectiveness of interventions identified
* To assess methodological quality of studies identified
* To build upon and update existing literature in the field in order to make more reliable conclusions as to how effective psychosocial interventions are for improving QoL in MS

2. Methodology

This systematic review was carried out in compliance with the steps outlined by the PRISMA checklist for reporting systematic reviews and meta-analyses (19).

2.1 Search strategy

A systematic search was initially conducted in December 2017 and completed in January 2018 using seven electronic databases. Each database was searched without date limits, that is from inception, to the search date and included: PsycINFO, the Cochrane Library, CINAHL, Psych articles, AMED, MEDLINE and the Web of Science. To identify grey literature Google Schoolar and EThOS were searched alongside the manual screening of references for included articles. A combination of search terms relating to MS, psychosocial interventions and QoL were used to create a search strategy. Boolean operators and search symbols were adjusted according to the database used (see appendix 1 for full search terms). After removing duplicates, titles were screened followed by abstracts being read and reviewed in relation to eligibility criteria. Full-texts were then screened for papers with potential relevance to the review. The process and outcome of the search can be seen in Figure 1.

2.2 Eligibility criteria

Studies selected for inclusion had to be published in English, there was no restriction on date in order to provide a full review of studies that have been carried out. Those which included male and female adults (>18 years) with a diagnosis of MS, regardless of MS stage were acceptable for inclusion.

Only RCTs were included as this design is considered most effective for judging benefits of interventions (18). All other designs, literature reviews, meta-analyses and pilot studies were excluded. Studies using quantitative and mixed methods were included, with only quantitative results being used. Studies using qualitative only methods were excluded.

Studies had to include a control group in the form of a waitlist or alternative intervention and a QoL measure, with this being a primary outcome, given that the review was focusing on QoL as an outcome.

Studies included interventions which were psychosocial, this could be individual or group based. Interventions including other populations, such as carer's and family members were included, however due to the focus of the review only results for MS patients were used. Interventions with a primary focus on physical activity were excluded as the review was to identify interventions aiming to improve QoL, without necessarily focusing on physical health.

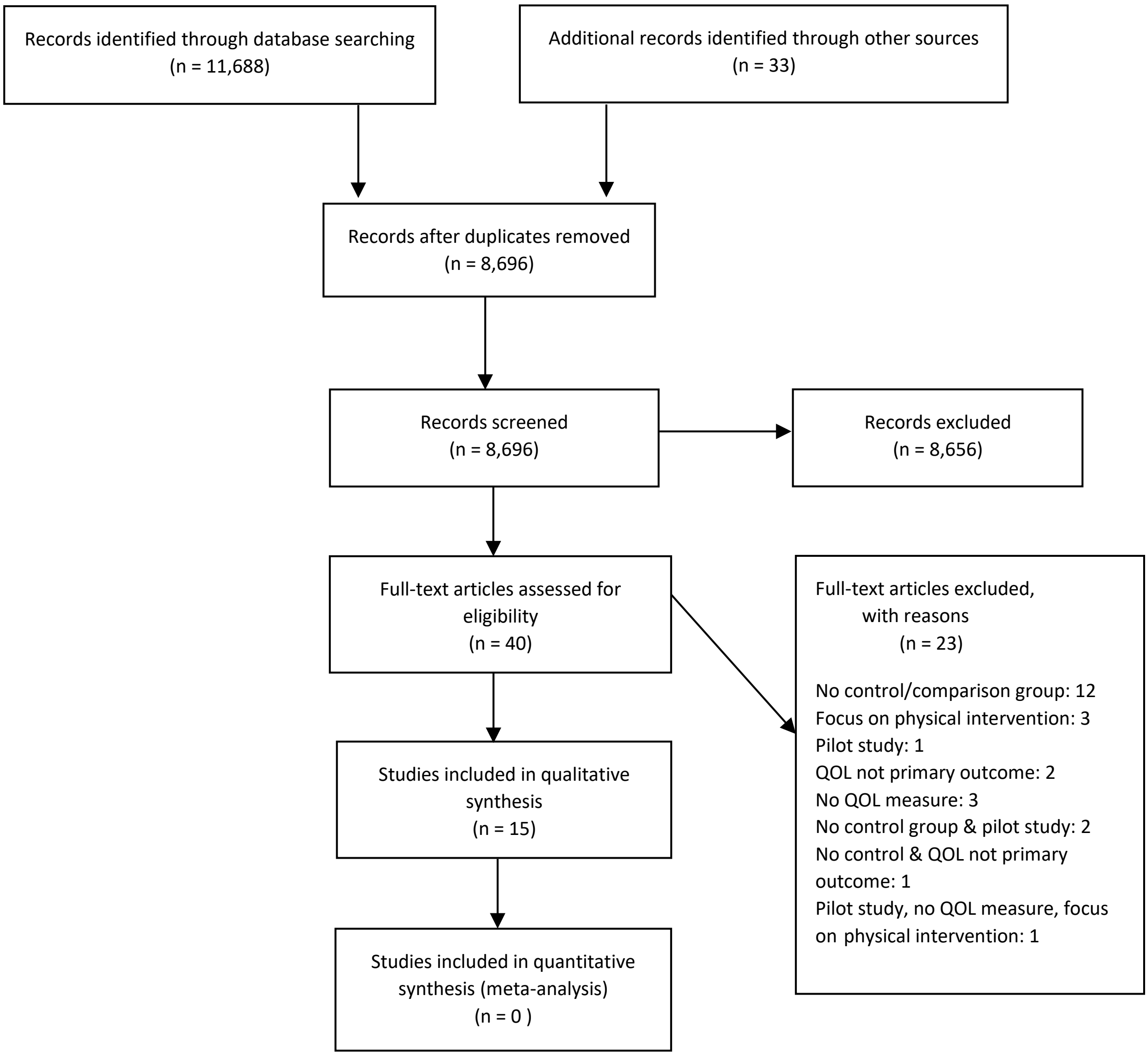


Figure 1: PRISMA diagram of search and selection process

2.3 Data extraction

The first author extracted relevant data from final studies using the Cochrane data extraction and assessment template (20). Extracted information included: population and setting (recruitment, location, criteria, population), methods (design, allocation, duration), participants (number initiating study, baseline imbalances, withdrawals/exclusions, age, gender, illness severity, ethnicity), intervention groups (number in groups, theoretical basis, duration, intervention description), outcomes (timing, person measuring, measures, reliability, validity) and results (comparison, outcome, subgroup, time point, results, number of missing and moved participants, statistical method).

2.4 Quality appraisal

Risk of bias amongst final studies was assessed by the first author using the Effective Public Health Practice Project (EPHPP) quality assessment tool for quantitative studies (21). The EPHPP was developed for evaluation of interventions in public health. The tool assesses eight domains; selection bias, study design, confounders, blinding, data collection methods and withdrawals and drop-outs. Each domain was graded as strong, moderate or weak, giving an overall global rating of strong if a study received no weak ratings, moderate for one weak rating and weak for two or more weak ratings. The quality of each study was reviewed by a second assessor and any differences resolved through discussion. Findings were used in the synthesis in order to make more considered conclusions regarding effectiveness of interventions discussed.

2.5 Data synthesis

Due to heterogeneous nature of the studies, it was not possible to conduct a meta-analysis on results obtained. Therefore, results from across the studies are presented in a narrative form categorised by type of psychosocial intervention used. Categorisation by psychosocial intervention was deemed as being most appropriate to intervention effectiveness.

3. Results

The search initially yielded 11,688 titles following the database search; an additional 33 titles were obtained through hand searching reference lists, EThOs and Google Scholar. After removing duplicates 8,696 articles remained and 8,656 were excluded based on title and abstract review. Of the 40 full-text studies reviewed 25 failed to meet inclusion criteria, leaving 15 studies in the final review. Reasons for exclusion can be seen in Figure 1.

Table 1 describes the 15 studies in this review. To facilitate narrative synthesis, data tabulation includes information on participants, location, psychosocial intervention used, control groups, QoL measures, EPHPP global outcomes, QoL findings and further primary outcomes.

3.1 Overview of included studies

Most studies were conducted in the UK (26, 31, 33, 35, 36) and America (25, 27, 32), with others in Turkey (22), Italy (24, 28, 34), Switzerland (29), Iran (23) and Norway (30). Sample sizes ranged from 32 (23) to 240 (31) with 59% including over 100 participants. The mean age of participants ranged from 31 years (23) to 56 years (27), with females representing between 48% (23) and 90% (35) of the overall sample. Four studies provided data regarding ethnicity of participants with majority being White British or White English (27, 32, 35, 36), a small number of African-American and Hispanic participants were also reported (27, 32). Socioeconomic status of participants was reported by 11 studies (24, 26-28, 30-36) with employment ranging between 10.83% (30) and 68.29% (28), this included part-time or full-time employment.

13 studies stated number of years since MS diagnosis which ranged between less than 1 year (36) and 18.6 years (34). No information on years since diagnosis was provided by two studies (23, 31). 76% of studies reported the majority of participants were diagnosed with Relapsing-Remitting MS. One study reported no information on MS type (23).

Study characteristics therefore need consideration when making conclusions regarding effectiveness of psychosocial interventions. Points to be mindful of include applicability of findings to UK settings due to 10 studies being conducted outside the UK. The population selected should also be considered for generalisability due to a high number of female participants, a wide range of years reported since MS diagnosis and lack of information regarding ethnicity of participants.

The types of psychosocial interventions included were mindfulness, psychotherapy, homecare, coping skills/self-care strategies, educational and cognitive rehabilitation.

Table 1: Characteristics of included studies

Author/Year/ Location	**Participants**	**Psychosocial Intervention Content / Duration / Follow-up**	**Control**	**QOL Measure**	**EPHPP Global Outcome**	**Main findings for QOL**	**Further primary outcomes**
Akkus et al. (2011) (22) Turkey	Intervention: 28 Control: 28	Nurse-based home intervention • Ran according to NANDA • 8 x 60-90 min visits over 4 months • Visits included training, consulting and care services • No follow-up, pretest-posttest	Standard care with 2 visits	MSQOL-54 (Turkish version)	Moderate	•Significant difference between groups for physical composite with intervention group increasing (*p* = 0.02) • Nonsignificant increase for mental health composite (*p* = 0.06) Significant change in 'role limitation because of emotional problems' (*p* = 0.04)	None
Abolghasemi et al. (2016) (23) Tehran	Intervention: 16 Control: 16	Supportive-expressive therapy • Led by 2 clinical psychologists • 12 x 75 minute group sessions • Topics: expression of thoughts and feelings, symptom control, strategies to manage existing concerns, goals • No follow-up, pretest-posttest	Medical treatment and wait-list	WHOQOL-B	Weak	• Significant difference between groups in enhancing QOL (ES = 0.418, P < 0.01)	• Significant difference between groups in enhancing hope (ES = 0.178, P < 0.01)
Carletto et al. (2017)(24) Italy	Intervention: 45 Control: 45	BAM • Led by clinical psychologists • Weekly 3 hr group sessions over 8 weeks and a full day 7 hr session. • Topics: awareness practices, relationship practices, sensorimotor psychotherapy. • Daily 45 min mindfulness homework • Follow-up at 6 months	PEI • Led by a psychotherapist • Same duration as BAM without full day session • Discussion of MS topics, relaxation exercises • Homework	FAMS	Moderate	• BAM but not the PEI improved QOL post intervention (SE = 2.47, P < 0.01) and at follow-up (SE = 2.44, *p* = 1).	• BAM showed greater reduction in depression than PEI post-intervention (SE = 2.4, *p* = 0.004) and follow up (SE = 2.27, *p* = 0.009) • No effect on fatigue symptoms • Medium effect on reducing anxiety and perceived stress in both groups • Illness rated as less threatening after BAM (SE = 0.99, *p* = 1)

Table 1 continued

Author/Year/ Location	**Participants**	**Psychosocial Intervention Content / Duration / Follow-up**	**Control**	**QOL Measure**	**EPHPP Global Outcome**	**Main findings for QOL**	**Further primary outcomes**
Cosio et al. (2011) (25) America	Intervention: 62 Control: 65	T-CBT • Led by trained psychologists • 16 week telephone sessions, 50 mins a session • Patient workbook • Topics: Behavioural activation, cognitive restructuring, problem solving, social support, fatigue management, positivity • Follow-up at 16 weeks	T-SEFT for same duration as T-CBT	Single item from MS QOL instrument	Strong	• T-CBT showed significant improvements in QOL over time compared to T-SEFT (SE = 0.17, *p* = 0.004)	• T-CBT showed improvements in depression and positive effect compared to T-SEFT
Ennis et al. (2006) (26) UK	Intervention: 32 Control: 30	Health promotion education • Led by healthcare professionals • 8 weekly 3 hr group sessions • Followed OPTIMISE programme • Topics: exercise, fatigue management, stress management, nutrition, health practices • Health check prior to intervention • Follow-up at 3 months	Usual care	SF-36	Strong	• QOL improved in intervention group in certain domains more than control; physical (*p* = 0.03), mental health and general health (P < 0.01). • Further improvement at 3 months for mental health and general health	• Significantly higher health promotion activity in intervention group (P < 0.01) and self-efficacy for health promotion activity (P < 0.01) at 3 months • 83% of participants rated programme as very useful
Finlayson et al. (2011) (27) America	Intervention: 94 Control: 96	Teleconference fatigue management • Led by occupational therapist • 6 weekly 70 min group sessions • Program manual, cordless phone provided • Topics: fatigue, communication, body mechanics, goal setting, activities, balanced living • Worksheets and homework • Catch-up sessions given for any missed • Follow-up at 6 months	Wait-list	SF-36	Moderate	• Intervention showed significant improvement in role physical subscale compared to control (P < 0.05) • 6 of 8 dimensions showed significant improvement in intervention during effectiveness and efficacy analysis, this maintained at follow-up with small to moderate effect	• Intervention was more effective than control for reducing fatigue impact but not severity

Table 1 continued

Author/Year/ Location	**Participants**	**Psychosocial Intervention Content / Duration / Follow-up**	**Control**	**QOL Measure**	**EPHPP Global Outcome**	**Main findings for QOL**	**Further primary outcomes**
Graziano et al. (2014) (28) Italy	Intervention: 41 Control: 41	Group-based CBT • Led by an experienced psychologist. • 4x 2 hr sessions over 2 months and follow-up at 6 months • 6 sub-groups based on age • Topics: identity change, life goals, strategies to reach goals, managing emotions, communication • Homework, daily relaxation exercises • Follow-up at 6 months	3 informative sessions over same 6 month period and same setting as CBT group	9 item scale adapted from MSQOL-54	Weak	• QOL increased in the intervention and decreased in control at follow-up ($P < 0.05$)	• Well-being increased for males and slightly decreased for females at follow-up ($P < 0.05$) • Increase in self-efficacy in CBT group post intervention compared to control ($P < 0.05$) • Non-significant decrease in depression and increase in identify and coherence in CBT group
Grossman et al. (2010) (29) Switzerland	Intervention: 76 Control: 74	MBI • Led by 2 certified experienced teachers • 8 x 2.5 hr weekly group sessions, 7 hr session at week 6 • Intake interview to define realistic goals. Post interview to evaluate goals, experiences. • Topics: mindfulness training including stressful situations and interactions • Daily 40 minute homework • Follow-up at 6 months	Regular hospital care provided by neurology department	PQOLC and HAQUAMS	Moderate	• MBI showed improvements on all subscales of PQOLC post intervention compared to control ($ES = 0.86$, $P < 0.001$) • Improvements maintained at follow-up other than negative affect and sense of belonging non-significant ($ES = 0.51$, $p = 0.003$) • MBI showed improvements on fatigue/thinking and mood subscales of HAQUAMS post intervention ($ES = 0.43$, $P < 0.05$) and follow-up ($ES = 0.28$, $p = 0.04$)	• MBI showed improvements on CES-D scale, these reduced from post intervention to follow-up

Table 1 Continued

Author/Year/ Location	**Participants**	**Psychosocial Intervention Content / Duration / Follow-up**	**Control**	**QOL Measure**	**EPHPP Global Outcome**	**Main findings for QOL**	**Further primary outcomes**
Hanssen et al. (2016) (30) Norway	Intervention: 60 Control: 60	MDT cognitive rehabilitation • Led by neuropsychologist and occupational therapist • Group and individual sessions • 4hrs neuropsychological assessment, 6hrs cognitive group sessions, 6 x 10 min phone calls • Used GAS goal attainment • Topics: cognitive functions, goal setting, executive functions, communication and challenges • Follow-up at 7 months	4 week ordinary inpatient MS rehabilitation programme	MSIS-29 Norwegian version	Moderate	• Psychological aspects of HRQoL shown to improve in intervention group more than the control after 4 months (*p* = 0.06) and 7 months (*p* = 0.03).	• Executive functioning improved at 4 and 7 months in both groups • Improvements shown in intervention group only for well-being • Scores for HSCL-25 scale improved significantly for intervention group at 4 months (*p* = 0.05).
Lincoln et al. (2002) (31) UK	Intervention: 79 Control: 82 Assessment group: 79	Cognitive intervention • Detailed cognitive assessment, report sent to staff involved in patients care • Received cognitive rehabilitation programme for any deficits • Monitored progress with weekly diaries • Visited for maximum of 6 months after assessments completed • Follow-up at 8 months	Control: No further psychological assessment Assessment group: Detailed cognitive assessment, reports sent to staff involved in patients care	SF-36	Strong	• No significant differences between groups on physical and mental health composite scores • Significant differences on questions assessing overall QOL at 8 months but not at 4 months. Higher in treatment group	• No significant difference on mood, activities of daily living, memory problems, neurological status

Table 1 Continued

Author/Year/ Location	**Participants**	**Psychosocial Intervention Content / Duration / Follow-up**	**Control**	**QOL Measure**	**EPHPP Global Outcome**	**Main findings for QOL**	**Further primary outcomes**
Mathiowetz et al. (2005) (32) America	Intervention: 70 Control: 70	Energy conservation course • Led by occupational therapists • 6 X 2 hr group sessions • Based on Packer at al's energy conservation course • Lectures, discussions, activities • Topics: importance of rest, communication, body mechanics, priorities, balanced living, modification of the environment, ergonomic principles • Homework • Follow-up 13 weeks	Delayed treatment	SF-36	Moderate	• Intervention showed significant increase on vitality (ES = 0.99 – 1.14) and mental health (ES = 0.53 – 0.60) subscales compared to control	• Intervention showed significant reduction for physical (ES = 0.74 – 0.90) and social (ES = 0.69 – 0.77) subscales of FIS
O'Hara et al. (2002) (33) UK	Intervention: 73 Control: 96	Professionally guided self-care • Assigned to group or one-to-one sessions depending on needs • 2 sessions over a month for 1-2hrs • Information booklet given to support sessions • Topics: covered physical, social and psychological domains • 6 month follow-up	Unknown	SF-36	Moderate	• SF-36 scores improved over time in mental health (*p* = 0.04) and vitality (*p* = 0.05). • Control group's responses on SF-36 deteriorated over time (excluding general health)	• Help with daily activities seen as less essential in intervention group (*p* = 0.04) • Maintained level of independence (*p* = 0.062) • Control group significant decrease in independence (*p* = 0.001) • Both groups deteriorated in mobility over time,

Table 1 Continued

Author/Year/ Location	**Participants**	**Psychosocial Intervention Content / Duration / Follow-up**	**Control**	**QOL Measure**	**EPHPP Global Outcome**	**Main findings for QOL**	**Further primary outcomes**
Pozzilli et al. (2002) (34) Italy	Intervention: 133 Control: 68	MDT home-based management • Led by neurologist, urologist, psychologist, physician, nurse, social worker • Home visits and telephone follow-ups • Phone line available 5 days a week 9am-5pm • Care included: observation, medication, education, psychological support, • 12 month follow-up	Routine hospital care	SF-36	Moderate	• Significant difference between two groups favouring the intervention in 4 QOL dimensions; general health, bodily pain, role-emotional, social functioning (P < 0.001)	• No functional differences between groups • Decrease in depression on CDQ score for intervention (-7.8%) and an increase was seen for control group (+0.7%)
Simpson et al. (2017) (35) Glasgow, Scotland, UK	Intervention: 25 Control: 25	MBSR • Led by 2 experienced physicians • 7 group sessions • Based on standard MBSR without full day retreat • Materials to practise at home • Follow up at 3 months	Wait-list	EQ-5D-5 L	Strong	• MBSR showed small beneficial effects on QOL post-intervention (ES = 0.17, *P* = 0.48) • Improvement in QOL at follow-up was negligible (ES = 0.08, *p* = 0.71)	• Perceived stress improved with a large effect post-intervention for MBSR (ES = 0.93, *p* < 0.01) • Improvements in perceived stress reduced at follow-up (ES = 0.26, *p* = 0.39)
Thomas et al. (2014) (36) UK	Intervention: 84 Control: 80	Fatigue management programme • Led by 2 health professionals • 6 weekly 90 min group sessions • Manualised FACETS programme • Topics: ways to normalise fatigue, helpful ways of thinking around fatigue, use energy more effectively • Handbook and booklets • Homework • Follow up at 1 year	Current local practice	MSIS-29, V.1	Moderate	• Significant improvements in intervention group compared with control at follow-up which was not seen at 4 months (SE = -0.24, *p* = 0.046)	• Significant improvement in fatigue self-efficacy for intervention at 4 months (SE = 0.36, *p* = 0.048) which reduced slightly at follow-up (SE = 0.34, *p* = 0.09).

Key: NANDA = North American Nurse Diagnosis Association; MSQOL-54 = Multiple Sclerosis Quality of Life; WHOQOL-B = World Health Organisation's Quality of Life Brief; BAM = Body-affective mindfulness; PEI = Psycho-educational intervention; FAMS = Functional Assessment of Multiple Sclerosis; T-CBT = Telephone-administered cognitive behavioural therapy; T-SEFT = Telephone-administered supportive emotion-focused therapy; SF-36 = Short Form Health Survey; MBI = Mindfulness-based intervention; PQOLC = Profile of Health-Related Quality of Life in Chronic Disorders; HAQUAMS = Hamburg Quality of Life Questionnaire in Multiple Sclerosis; MDT = Multidisciplinary team; GAS = Goal attainment scaling; MSIS-29 = Multiple Sclerosis Impact Scale; HRQoL = Health-related quality of life; HSCL-25 = Hopkins Symptom Checklist; FIS = Fatigue Impact Scale; CDQ = Clinical Depression Questionnaire; MBSR = Mindfulness-based stress reduction

3.2 Quality appraisal

Using the EPHPP quality assessment tool, two studies were appraised to be weak quality, nine moderate and the remainder strong (see Table 1 for EPHPP global ratings). Amongst weak studies there was lack of blinding outcome assessors or study participants, which was also amongst four moderate studies, therefore increasing chances of reporting bias. Six studies were weak in selection bias for reasons including participants self-referring, recruitment from voluntary charities and less than 60% agreement to participate. Overall, controlling for confounders was generally strong apart from one study which was unclear (23). Withdrawals and drop-outs mostly rated as strong and study design and data collection methods were strong amongst all studies. Therefore, when using these findings to aid synthesis considerations should be made as to the reliability of particular aspects of included studies and their outcomes (see appendix 2 for full EPHPP results).

3.3 Intervention effectiveness

It was considered for an intervention to be classed as effective if there was significant improvement in QoL amongst the intervention group, in comparison to the control group, on any given patient reported outcome (see Table 1). Where reported by author's effect sizes were included to identify the magnitude of results given.

3.4 Intervention characteristics

3.4.1 Mindfulness:

Three studies delivered mindfulness interventions, all were delivered in person to a group of participants. Types of mindfulness included Body-Affective Mindfulness (BAM) (24), Mindfulness-Based Stress Reduction (MBSR) (35) and a Mindfulness-Based Intervention (MBI) which closely followed MBSR (29). Two studies were moderate quality (24, 29) and one was strong (35). All studies varied in control group type; wait-list (MBSR), usual care (MBI) and a psycho-education intervention (BAM). QoL measures also varied and included the EQ-5D-5 L (35), the Functional Assessment of Multiple Sclerosis (FAMS) (24) and the German-language Profile of Health-Related Quality of Life in Chronic Disorders (PQOLC) which was used alongside the German version of the Hamburg Quality of Life Questionnaire in Multiple Sclerosis (HAQUAMS) (29). BAM and MBI were similar in duration and included a full day retreat. BAM was the only intervention to invite caregivers to participate.

QoL was shown to improve post-intervention for both the MBI (ES 0.86) and BAM. This was maintained at 6 month follow-up by BAM, whereas improvements in negative effect and sense of belonging on the PQOLC measure were no longer significant at 6 month follow-up for the MBI (ES 0.51).The MBI also showed greater improvements at both endpoints of fatigue/thinking and mood. The subscales of lower and upper limb mobility did not differ. There was only a small beneficial effect on QoL post-intervention for the MBSR group (ES 0.17) and at 3 month follow-up these results were negligible (ES 0.08).

In summary, evidence for effectiveness of mindfulness was mixed, however all interventions showed benefits reducing over time, suggesting a short-term effect for this type of intervention. Although, with only the MBSR study rating as strong, the evidence of effectiveness is limited. Interventions were delivered by individuals with a number of years' experience and were similar regarding topic content and duration which was 7/8 sessions. However, the two interventions showing most significant effect included a full day retreat. Both the MBI and BAM stated due to location of intervention delivery it made it difficult for participants to travel, resulting in high-refusal and drop-out rates for BAM.

3.4.2 Psychotherapy:

Four studies used psychotherapy of which 3 used cognitive behavioural techniques (CBT). One CBT intervention was delivered in person to a group of participant's (28) whilst the other was delivered over the telephone (T-CBT) (25). The third study, known as FACETS, was a group based intervention with CBT being used with a combination of techniques (36). The final study used supportive-expressive (SE) therapy (23). One study was strong in quality (25), one was moderate (36) and two were weak (23, 28). Studies varied in type of control group used; usual care and wait-list (23), informative sessions (28), current local practice (36) and telephone-administered supportive emotion-focused therapy (T-SEFT) (25). Tools to measure QoL also varied and included the Italian version of the Multiple Sclerosis Quality of Life (MSQOL-54) (28), the World Health Organization's Quality of Life-Brief (WHOQOL-B) (23) and the Multiple Sclerosis Impact Scale V.1 (MSIS-29, V.1) (36). One study measured QoL using a single item from the Multiple Sclerosis Quality of Life instrument (25), the item was measured on a scale of 0-10 and asked individuals to rate their QoL. The use of a single-item measure however, may not be able to be generalized to QoL tools that are based on measuring a number of QoL domains (10). Duration of interventions differed, the shortest being the group-based CBT which delivered four 2 hour sessions over 2 months and the longest being the T-CBT which was delivered over 16 weeks with sessions lasting 50 minutes. The SE intervention was the only study lacking follow-up.

All psychotherapy interventions showed improvement in QoL compared to control groups. For the group CBT improvement increased over time with there being a significant difference between post-treatment and at 6 month follow-up, whilst the control group showed a decrease overtime in QoL. Similarly the T-CBT reported significant QoL score improvement over the course of the intervention which was greater than those who received T-SEFT. The FACETS programme showed improvements at 1 year follow-up which was not seen at 4 months. There was significant difference between QoL in the intervention and control groups. As there was no follow-up for the SE results were only taken post-intervention which showed a significant difference in enhancing QoL (ES 0.418).

In summary, all psychotherapy interventions showed significant results. This was particularly evident in those using CBT which continued to show improvement over time. All interventions were similar in topics delivered and were administered in person to groups, apart from one which was delivered over the telephone. They were all delivered by psychologists apart from one which was delivered by health professionals (FACETS). It should be noted that two studies (23, 28) had a weak global rating due to lack of blinding or lack of information on blinding, small sample size and lack of information on confounders, therefore, limiting the evidence of effectiveness.

3.4.3 Home-Based Interventions

Two studies used a home based intervention which included nurse-based (22) and multidisciplinary (MDT) (34), both studies rated moderate in quality. Both studies had control groups whom received usual care. Tools used to measure QoL included the SF-36 health survey (34) and the Multiple Sclerosis Quality of Life Scale (MSQOL-54) (22). The nurse-based intervention was conducted over 4 months with weekly visits for the first 4 sessions, bi-weekly for the 5th and 6th sessions and monthly thereafter. No details were given regarding length or number of visits for the MDT intervention, the only information provided was regarding follow-up at 12 months. The nurse-based intervention ran in accordance with the North American Nursing Diagnosis Association (NANDA) guidelines.

Results for the nurse-based intervention showed significant difference for the physical health composite of the QoL scale used, with scores increasing for the intervention group. Although scores for the mental health composite increased in the intervention group this was insignificant ($p = 0.06$). The MDT intervention reported significant difference in QoL at one year follow-up, with scores for the intervention group increasing in 4 of the SF-36 health dimensions, which included general health, bodily pain, role-emotional and social functioning.

In summary, both home-based interventions showed significant results for certain components of QoL. The MDT approach was particularly effective with benefits still present at one year, showing that including a variety of professionals in an individual’s care should perhaps be considered when developing interventions. However, it should be noted that participants and interviewers weren’t fully blinded in this study, therefore individuals with a preference for hospital care may have declined to participate. Both studies being rated as moderate also means results can be questioned. Due to the short duration of the nurse based-intervention it cannot be clear as to whether this approach would have lasting longer term benefits.

3.4.4 Coping Skills/Self-Care Strategies

Two studies focused on coping skills and self-care strategies. These included a teleconference-delivered programme (27) and a professionally guided self-care programme (33). Both studies rated moderate in quality. Studies varied in type of control group used; wait-list (27) and usual care (33). The SF-36 health survey was used in both studies to measure QoL. Delivery of interventions differed, the professionally guided self-care programme consisted of 2 sessions over a one month period between 1 and 2 hours. This intervention differed in that it was delivered both to a group and a one-to-one depending on participants’ needs. The teleconference intervention was delivered weekly.

Both studies reported significant improvements for QoL in certain domains. The professionally guided self-care intervention showed significant increase in vitality and mental health QoL compared to the control group at 6 months. The control group’s responses on the SF-36 deteriorated over time. The teleconference intervention demonstrated significant improvement in role physical subscale compared to the control. During effectiveness and efficacy analysis the teleconference intervention showed significant improvements, which remained at follow-up with a small to moderate effect size. Authors of this study did mention that assessors were not blinded only the participants.

In summary, coping skills/self-care interventions showed significant results in certain domains of QoL, suggesting that teaching individual's strategies to use may be of use to incorporate into MS interventions. Both interventions were similar in topics covered and provided participants with information to take away. However, differences in duration and setting of the interventions means it is unclear as to how these factors should be considered when assessing effectiveness of coping skills/self-care interventions. The moderate methodological rating also means results can be questioned.

3.4.5 Educational Interventions

Two studies used educational interventions. These included a health promotion education programme (26) and an energy conservation (EC) course (32), of which one was strong in quality (26) and one moderate (32). Studies used different control types, one received usual care (26) and the other was a delayed control (32). Both studies used the SF-36 health survey to measure QoL. Interventions were similar in their approach with the health promotion programme following the OPTIMISE programme which aims to provide knowledge, skills and confidence to undertake health-promoting activities for those with MS and the EC intervention being based on the theory of psychoeducational group development.

The health promotion education programme showed improvement in the intervention group more than the control in certain domains of the SF-36 QoL, which included physical, mental health and general health. However, only mental health and general health improved further at three months. Similarly, the energy conservation intervention showed improvement on the SF-36 with those in the intervention increasing on the vitality (ES 0.99) and mental health (ES 0.53) subscales compared to the control.

In summary, educational interventions showed significant results for certain domains of QoL, particularly mental health. It is important to note that participants in the health promotion intervention were not blinded and those in the EC intervention were already motivated to want to improve their fatigue. Both interventions were similar in topics covered focusing on aspects such as fatigue, balanced living and health practices, highlighting the importance of intervention content aiming to increase knowledge and skills. Interventions were delivered to groups made up of around the same number of participants, although did differ slightly with regards to duration and setting, with the EC intervention being run across community settings and the health promotion programme being delivered in a hospital.

3.4.6 Cognitive Rehabilitation:

Two studies used cognitive rehabilitation (30, 31) of which one was of strong quality (31) and one moderate (30). Studies differed regarding control groups, one offered neuropsychological assessment and feedback, an opportunity to attend lectures on MS and care from the ordinary 4-week rehabilitation programme (30). The second intervention had two groups, this included a control group where individuals received no further assessment and an assessment group where participants received detailed cognitive assessments with reports written for staff involved in patient care (31). Studies used different tools to measure QoL, one study used the Norwegian version of the Multiple Sclerosis Impact Scale (MSIS-29 NV) (30) and the second study used the SF-36 health survey alongside two questions from the SF-54 which asked participants to rate their QoL and how satisfied they are with their QoL. The moderate quality intervention used a combination of both individual and group sessions (30). Prior to the completion of the intervention participants were supported through the process of formulating Goal Attainment Scaling (GAS) goals, which is a method for quantifying attainment of individual goals set in rehabilitation. Participants in the alternative intervention were visited for a maximum of 6 months after assessments were completed.

The two interventions differed in outcomes towards QoL. The strong quality study showed few significant differences between groups. Significant differences were found at 8 months for questions assessing overall QoL but not at 4 months. Those in the control group rated their QoL significantly higher in comparison to those in the assessment group but not in the intervention group. The moderate quality study showed significant improvements in the psychological aspects of HRQoL at 4 and 7 months compared to control group.

In summary, findings from cognitive rehabilitation interventions was mixed. However, participants were not blinded and were aware of the study aims in the study showing most significance. Both showed benefits at 7/8 months, suggesting that perhaps more time to be able to implement intervention techniques and plans was helpful. Similarly, both interventions included neuropsychological assessments to aid individual care. The intervention shown to have most significant results included both group and individual sessions with numerous topics covered. The alternative intervention used only individual sessions and focused on developing individual cognitive rehabilitation programmes. Therefore, a combination of individual and group delivery methods may be more beneficial.

4. Discussion

This systematic review aimed to synthesise the evidence of effectiveness of psychosocial interventions on QoL in adult MS patients from RCTs carried out in the area. The review also aimed to critically appraise methodological quality of studies identified and build upon and update existing literature in order to make more reliable conclusions as to how effective psychosocial interventions are for improving QoL in MS. 15 studies from the search were eligible for inclusion in the review.

Overall, all studies apart from one cognitive rehabilitation intervention (31) showed improved QoL post-intervention, although level and duration of improvement differed. The majority of interventions used a group face-to-face approach and some combined this with individual sessions. Psychotherapy interventions were found most beneficial for improving QoL and this improvement was greater over time in those using CBT (25, 28, 36). This is promising considering follow-up was 12 months for two studies and 6 months for the remaining study. This also supports Thomas et al’s (2006) (17) review which indicated CBT being particularly helpful. However, methodological limitations are noted with two studies being rated weak, raising the question of how effective this intervention is. There was also long-term improvement found from the home-based intervention using an MDT approach (34). The positive result shown from this after one year puts forward potential benefit of an MDT approach. An MDT approach has been previously highlighted by research as being valuable in supporting QoL in MS (14). Both educational and the coping skills/self-care strategy interventions suggest benefits of teaching strategies to help manage aspects of MS. This has also been found in a previous systematic review on self-management interventions (16). There were mixed results for using mindfulness with benefits seen post-intervention reducing over time in two of the three studies (24, 35), suggesting only a short-term effect for this intervention. However, authors did propose supplementation of regular booster sessions to maintain gains (29) and the use of eHealth programs to render interventions more accessible (24). It may also be helpful to consider merging mindfulness alongside a further intervention type that has longer term benefits. The one study to not show effect on QoL post-intervention was a cognitive rehabilitation intervention, rated strong in methodological quality (31). However, authors did report the study sample as being small in relation to its “very heterogeneous” group. The remaining cognitive rehabilitation intervention which used a combination of both individual and group sessions (30) did show a significant improvement in psychological aspects of HRQOL at both four and seven month follow-ups.

Five studies referred to costings; the MDT home-based intervention highlights great economic potential by reducing hospital admissions without increasing cost of care (34). However, the nurse-based home intervention was described as possibly too costly for Turkey where the study took place. (22). One education programme stated the intervention would not require additional skills outside of those already used by staff in a neurological setting or additional resources (26). The FACETS CBT study reported the intervention could be relatively inexpensive to local practices and can be readily incorporated into these (36). Finally the professionally guided self-care programme described the intervention as being “low-cost” (33). Although there was no report on cost-effectiveness for mindfulness interventions, previous studies have described them as brief and cost-effective (37). Studies from many countries have stated MS results in heavy economic burden (38). The use of psychosocial interventions for MS may therefore not only be beneficial for improving QoL, but also economic costs surrounding healthcare support as the condition progresses. It should be noted, information surrounding cost-effectiveness was limited in the current studies highlighting the need for further investigation.

4.1 Limitations of the studies

There are some methodological issues worth noting amongst studies in this review and to consider for future research. Firstly, the majority of the samples were made up of women which ranged between 48% and 90%, this may be due to MS being found to be more prevalent in females (39) or possibly men being less willing to take part in research (40). However, a female majority sample makes it difficult to generalise findings to the male population, particularly as previous research has shown males and females responding differently to interventions. A study by Pieh et al (2012) showed women with chronic pain and depressive symptoms improved considerably more than males with the same symptoms (41). 76% of studies reported the majority of participants were diagnosed with Relapsing-Remitting MS, which again questions how representative participants were to the general population. This may be a further reasoning behind the higher female sample as men have been found to have more progression in disability of the disease (42).

Four studies provided data regarding ethnicity of participants (27, 32, 35, 36) with the majority White British or White English and most studies conducted in the UK or America. An individual's preferences for and decisions about MS treatment, alongside their ability to engage with interventions may be impacted by cultural and personal values. Many individuals with MS state they would like a more active role in the management of their health, although this varies with regards to extent and type of participation they prefer (43-45), for example a study on Italian MS patients found they like to play a passive role in their clinical care (46).

Another point to be mindful of is where participants were selected from. A number of studies recruited from voluntary groups such as the MS Society (27, 32, 33, 22) and some recruited from voluntary groups alongside other methods (29, 35, 36,). The use of voluntary groups does raise the issue that participants may have higher levels of motivation to engage in interventions than those from the general population. They are also likely to be well informed around MS, making it difficult to know what part the intervention played in the results.

Four studies included another intervention type to act as a control group rather than a wait-list or usual care (24, 25, 28, 31). This poses risk of the control intervention having effect on the outcomes and the tested intervention not being strong enough to exceed this (47). The majority of studies provided information regarding characteristics of the intervention, such as duration, format and facilitators, however only 46% provided data regarding attendance rate of sessions (25, 26, 29, 30, 32, 35, 36) which ranged from 60% and 94% attendance. Adherence to programme content was also missed in the reporting of data, this raises issues when identifying particular aspects of interventions may be of most use (48).

In summary future research should therefore aim to:
* consider gender when studying psychosocial interventions for MS
* examine psychosocial interventions for patients with severe MS
* conduct studies using samples from a range of ethnicities
* consider using samples from the more general population rather than charities
* provide information regarding programme attendance and adherence

4.2 Limitations and strengths of the current review

A high number of irrelevant studies were generated amongst the initial search, highlighting that although there may have been low specificity in the search strategy, it meant there may have been less chance of missing important studies, which has been found to occur when specificity is high (49). The EPHPP quality tool used is considered valid and reliable and appropriate for the study design included in the review. A seconder assessor was involved in analysing the quality tool results.

The current review was limited to include studies published in English due to resource restraints. Therefore, possibility of language bias cannot be excluded. Due to the heterogeneous nature of included studies this meant a meta-analysis could not be performed, therefore no statistical inferences regarding effectiveness can be made. It is also important to note this review only included RCT's and although this is a good way to measure effectiveness of interventions, it may have been beneficial to have included high quality non RCT's as these may have contributed more than the weak designed RCTs.

Conclusion

In summary, there are encouraging results reported for using psychosocial interventions in improving QoL in adults with MS. Looking at the study results a CBT group approach appears to be an intervention to be considered. Alongside CBT further factors found helpful or suggested from different interventions included an MDT approach, providing education on strategies to manage MS and booster sessions to maintain gains. With mindfulness having a short-term beneficial effect it may be that this could be combined with another approach. However, despite encouraging result's there are methodological limitations to be mindful of with only 4 studies being of strong quality. It is also unclear if these studies can be generalised to male and female MS patients as well as those from different ethnic groups. It is also uncertain as to how beneficial psychosocial interventions are for individuals with severe MS. Further studies are therefore needed to ascertain effectiveness of psychosocial interventions in improving QoL for these population groups. It may be beneficial for future research to expand upon the current review by including non RCT studies, as well as future studies including further information on intervention adherence. The cost-effectiveness of using psychosocial interventions for MS remains unclear, highlighting need for further investigation of this. Despite this, the evidence does provide health-care providers with considerations as to what may be beneficial when looking to develop the care for individuals with MS.

References

1) Redjdak, K., Jackson, S., & Giovannoni, G. (2010). Multiple sclerosis: a practical overview for clinicians. *British Medical Bulletin*, 95 (1), 79-104. DOI: 10.1093/bmb/ldq017

2) Mackenzie, I. S., Morant, S. V., Bloomfield, G. A., MacDonald, T. M., & O'Riordan, J. (2013). Incidence and prevalence of multiple sclerosis in the UK 1990-2010: A descriptive study in the General Practice Research Database. *Journal of Neurology, Neurosurgery and Psychiatry*, 85(1), 76–84. DOI: 10.1136/jnnp-2013-305450

3) Jick, S. S., Li, L., Falcone, G. J., Vassilev, Z. P., & Wallander, M. A. (2014). Mortality of patients with multiple sclerosis: A cohort study in UK primary care. *Journal of Neurology*, 261(8), 1508–1517. DOI: 10.1007/s00415-014-7370-3

4) Chiaravalloti, N.D., Wylie, G., Leavitt, V., & DeLuca, J. (2012). Increased cerebral activation after behavioural treatment for memory deficits in MS. *Journal of neurology*, 259 (7), 1337–1346. DOI: 10.1007/s00415-011-6353-x

5) Lublin, F., & Reingold, S. (1996). Defining the clinical course of multiple sclerosis: Results of an international survey. *Journal of Neurology,* 46 (4), 907-911. DOI: 10.1212/WNL.0000000000000560

6) Eklund, V.A., & MacDonald, M.L. (1991). Descriptions of persons with multiple sclerosis, with an emphasis on what is needed from psychologists. *Professional Psychology-Research and Practice*, 22 (4), 277-284. DOI: 10.1037/0735-7028.22.4.277

7) Whetten-goldstein, F.S., Goldstein, L.B., & Kulas, E.D. (1998). A comprehensive assessment of the costs of multiple sclerosis in the United States. *Multiple Sclerosis,* 4 (5), 419-425. DOI: 10.1177/135245859800400504

8) Parkin, D., Jacoby, A., McNamee, P., Miller, P., Thomas, S., & Bates, D. (2000). Treatment of multiple sclerosis with interferon beta: an appraisal of cost-effectiveness and quality of life. *Journal of Neurology Neurosurgery & Psychiatry,* 68 (2), 144-149. DOI: 10.1136/jnnp.68.2.144

9) Chwastiak, L.A., & Ehde, D.M. (2007). Psychiatric Issues in Multiple Sclerosis. *Psychiatric Clinics of North America,* 30 (4), 803-817. DOI: 10.1016/j.psc.2007.07.003

10) Chiaravalloti, N.D., & Deluca, J. (2008). Cognitive impairment in multiple sclerosis. *The Lancet Neurology,* 7 (12), 1139-1151. DOI: 10.1016/S1474-4422(08)70259-X

11) Benito-Leon, J., Morales, J.M., Rivera-Navarro, J., & Mitchell, A. (2003). A review about the impact of multiple sclerosis on health-related quality of life. *Disability and Rehabilitation,* 25 (23), 1291–303. DOI: 10.1080/09638280310001608591

12) Gedik, Z., Sorias, O., & Idiman, E. (2015). Do coping styles mediate relationship between disability status and psychosocial loss in people with relapsing remitting multiple sclerosis? *Journal of Health Psychology,* 22 (6), 707-721, DOI: 10.1177/1359105315611958

13) Rudick, R.A., Miller, D., Clough, J.D., Gragg, L.A., Farmer, R.G. (1992). Quality of life in multiple sclerosis. Comparision with inflammatory bowel disease and rheumatoid arthritis. *Archives of Neurology,* 49 (12), 1237-1242. DOI: 10.1001/archneur.1992.00530360035014

14) Malcomson, K.S., Dunwoody, L., & Lowe-Strong, A.S. (2007). Psychosocial interventions in people with multiple sclerosis. *Journal of Neurology,* 25 (4), 1-13. DOI: 10.1007/s00415-006-0349-y

15) Simpson, R., Booth, J., Lawrence, M., Byrne, S., Mair, F., & Mercer, S. (2014). Mindfulness based interventions in multiple sclerosis-a systematic review. *BMC Neurology,* 14 (15). DOI: 10.1186/1471-2377-14-15

16) Kidd, T., Carey, N., Mold, F., Westwood, S., Miklaucich, M., Konstantara, E., Sterr, A., & Cooke, D. (2017). A systematic review of the effectiveness of self-management interventions in people with multiple sclerosis at improving depression, anxiety and quality of life. *PLoS ONE,* 12(10), DOI: 10.1371/journal.pone.0185931

17) Thomas, P.W., Thomas, S., Hillier, C., Galvin, K., & Baker, R. (2006). Psychological interventions for multiple sclerosis. Cochrane Database of Systematic Reviews, 25 (1). DOI: 10.1002/14651858.CD004431.pub2

18) Barton, S. (2000). Which clinical studies provide the best evidence? : The best RCT still trumps the best observational study. *British Medical Journal*, *321* (7256), 255–256. DOI:10.1136/bmj.321.7256.255

19) Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G., The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine,* 6 (7), e1000097. DOI: 10.1371/journal.pmed1000097.

20) The Cochrane Public Health Group. Cochrane data extraction template – Cochrane public health. (Updated 24th November 2011, accessed January 2018). Available from https://ph.cochrane.org/...cochrane.../CPHG%20Data%20extraction%20template_0.do...

21) Thomas, B.H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing evidence for public health nursing interventions. *World views on evidence-based nursing,* 1 (3), 151-201. DOI: 10.1111/j.1524-475X.2004.04006.x

22) Akkus, Y., & Akdemir, N. (2011). Improving the quality of life for multiple sclerosis patients using the nurse-based home visiting model. *Scandinavian Journal of Caring Sciences,* 26 (2), 295-3503. DOI: 10.1111/j.1471-6712.2011.00933.x

23) Abolghasemi, A., Farhang, S., Taherifard, M., Kiamarsi, A., Saharkhiz Arabani, A. (2016). The effect of supportive-expressive therapy on hope and quality of life in patients with multiple sclerosis (MS). *Archives of Psychiatry and Psychotherapy,* 18 (4), 20-27. DOI: 10.12740/APP/64975

24) Carletto, S., Tesio, V., Borghi, M., Francone, D., Scavelli, F., Bertino, G., et al. (2017). The effectiveness of a body-affective mindfulness intervention for multiple sclerosis patients with depressive symptoms: A randomized controlled clinical trial. *Frontiers in Psychology,* 8, 2083. DOI: 10.3389/fpsyg.2017.02083

25) Cosio, D., Jin, L., Siddique, J., & Mohr, D. (2011). The effect of telephone-administered cognitive behavioural therapy on quality of life among patients with multiple sclerosis. *Annals of Behavioural Medicine,* 41 (2), 227-234. DOI: 10.1007/s12160-010-9236-y.

26) Ennis, M., Thain, M., Baker, G.A., & Young, C.A. (2006). A randomized controlled trial of a health promotion education programme for people with multiple sclerosis. *Clinical Rehabilitation,* 20 (9), 783-792. DOI: 10.1177/0269215506070805

27) Finlayson, M., Preissner, K., Cho, C., & Plow, M. (2011). Randomized trial of a teleconference-delivered fatigue management program for people with multiple sclerosis. *Multiple Sclerosis Journal,* 17 (9), 1130-1140. DOI: 10.1177/1352458511404272

28) Graziano, F., Calandri, E., Borghi, M., & Bonino, S. (2014). The effects of a group-based cognitive behavioural therapy on people with multiple sclerosis: A randomized controlled trial. *Clinical Rehabilitation,* 28 (3), 264-274. DOI: 10.1177/0269215513501525

29) Grossman, P., Kappos, L., Gensicke, H., D'Souza, M.D., Mohr, D.C., & Penner, I.K., et al. (2010). MS quality of life, depression, and fatigue improve after mindfulness training: A randomized trial. *Neurology,* 75 (13), 1141-1149. DOI: 10.1212/WNL.0b013e3181f4d80d

30) Hanssen, K.T., Beiske, A.G., Landro, N.I., Hofoss, D., & Hessen, E. (2016). Cognitive rehabilitation in multiple sclerosis: A randomized controlled trial. *Acta Neurologica Scandinavica,* 133 (1), 30-40. DOI: 10.1111/ane.12420

31) Lincoln, N.B., Dent, A., Harding, J., Weyman, N., Nicholl, C., Blumhardt, L.D. (2002). Evaluation of cognitive assessment and cognitive intervention for people with multiple sclerosis. *Journal of Neurology, Neurosurgery & Psychiatry,* 72 (1), 93-98. DOI: 10.1136/jnnp.72.1.93

32) Mathiowetz, V.G., Finlayson, M.L., Matuska, K.M., Chen, H.Y., & Luo, P. (2005). Randomized controlled trial of an energy conservation course for persons with multiple sclerosis. *Multiple Sclerosis,* 11 (5), 592-601. DOI: 10.1191/1352458505ms1198oa

33) O'Hara, L., Cadbury, H., De Souza, L., & Ide, L. (2002). Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: A randomized controlled trial. *Clinical Rehabilitation,* 16 (2), 119-128. DOI: 10.1191/0269215502cr478oa

34) Pozzilli, C., Brunetti, M., Amicosante, A.M.V., Gasperini, C., Ristori, G., Palmisano, L., et al. (2002). Home based management in multiple sclerosis: Results of a randomised controlled trial. *Journal of Neurology, Neurosurgery & Psychiatry,* 73 (3), 250-255. DOI: 10.1136/jnnp.73.3.250

35) Simpson, R., Mair, F.S., & Mercer, S.W. (2017). Mindfulness-based stress reduction for people with multiple sclerosis – a feasibility randomised controlled trial. *BMC Neurology,* 17 (1*),* 1-12. DOI: 10.1186/s12883-017-0880-8

36) Thomas, P.W., Thomas, S., Kersten, P., Jones, R., Slingsby, V., Nock, A., et al (2014). One year follow-up of a pragmatic multi-centre randomised controlled trial of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. *BMC Neurology,* 14 (1), 109. DOI: 10.1186/1471-2377-14-109.

37) Hofmann, S.G., Sawyer, A.T., Witt, A.A., & Oh, D. (2010). The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *Journal of Consulting and Clinical Psychology,* 78 (2), 169-183. DOI: 10.1037/a0018555

38) Amato, M. P., Battaglia, M. A., Caputo, D., Fattore, G., Gerzeli, S., Pitaro, M., et al. (2002). The costs of multiple sclerosis: A cross-sectional, multicenter cost-of-illness study in Italy. *Journal of Neurology*, 249, 152–163. DOI: 10.1007/PL00007858.

39) Harbo, H. F., Gold, R., & Tintoré, M. (2013). Sex and gender issues in multiple sclerosis. *Therapeutic Advances in Neurological Disorders*, 6 (4), 237–248. DOI: 10.1177/1756285613488434

40) Markanday, S., Brennan, S. L., Gould, H., & Pasco, J. A. (2013). Sex-differences in reasons for non-participation at recruitment: Geelong Osteoporosis Study. *BMC Research Notes*, *6*, 104. DOI: 10.1186/1756-0500-6-104.

41) Pieh, C., Altmeppen, J., Neumeier, S., Loew, T., Angerer, M., & Lahmann, C. (2012). Gender differences in response to CBT-orientated multimodal treatment in depressed patients with chronic pain. *Psychiatrische Praxis,* 39 (6), 280-285. DOI: 10.1055/s-0032-1305097

42) Bergamaschi, R. (2007). Prognostic factors in multiple sclerosis. *International Review of Neurobiology,* 79, 423-447. DOI: 10.1016/S0074-7742(07)79019-0

43) Arora, N.K., & Mc Horney, C.A. (2000). Patient preferences for medical decision making: Who really wants to participate?. *Medical Care*, 38, 335-341. DOI: 10.1097/00005650-200003000-00010

44) Mansell, D., Poses, R.M., Kazis, L., & Duefield, C.A. (2000). Clinical factors that influence patient's desire for participation in decisions about illness. *Archives of International Medicine,* 160 (19), 2991–2996.

45) Heesen, C., Kasper, J., Köpke, S., Richter, T., Segal, J., & Mühlhauser, I. (2007). Informed shared decision making in multiple sclerosis - inevitable or impossible? *Journal of Neurological Science,* 259 (1-2), 109–17. DOI: 10.1016/j.jns.2006.05.074.

46) Giordano, A., Mattarozzi, K., Pucci, E., Leone, M., Casini, F., Collimedaglia., L., & Solari, A. (2008). Participation in medical decision-making: Attitudes of Italians with multiple sclerosis. *Journal of the Neurological Sciences,* 275 (1-2), 86-89. DOI: 10.1016/j.jns.2008.07.026.

47) DiCenso, A., Guyatt, G., Willan, A., & Griffith, L. (2002). Interventions to reduce unintended pregnancies among adolescents: systematic review of randomised controlled trials. *British Medical Journal,* 324 (7351), 1426-1430. DOI:10.1136/bmj.324.7351.1426

48) Paraskeva, N., Guest, E., Lewis-Smith, H., & Harcourt, D. (2018). Assessing the effectiveness of interventions to support patient decision making about breast reconstruction: A systematic review. *The Breast,* 40, 97-105. DOI: 10.1016/j.breast.2018.04.020

49) Harden, A., Peersman, G., Oliver, S., & Oakley, A. (1999). Identifying primary research on electronic databases to inform decision-making in health promotion: The case of sexual health promotion. *Health Education Journal*, 58 (3), 290-301. DOI: 10.1177/001789699905800310

Appendix 1

Full search strategy

1) "multiple sclerosis" OR
   "relapsing-remitting MS" OR
   "primary-progressive MS" OR
   "secondary-progressive MS" OR
   "progressive-relapsing MS" OR
   MS

2) AND psychosocial OR
   intervention* OR
   psychological OR
   CBT OR
   mindfulness OR
   "acceptance and commitment therapy" OR
   psychotherapy OR
   "peer support" OR
   "cognitive behavio#r*" OR
   counselling OR
   counseling OR
   "cognitive therap*" OR
   "behavio#r* therap*" OR
   "psychological therap*" OR
   "support group" OR
   psychoeducation OR
   "interpersonal psychotherapy*" OR
   psychodynamic

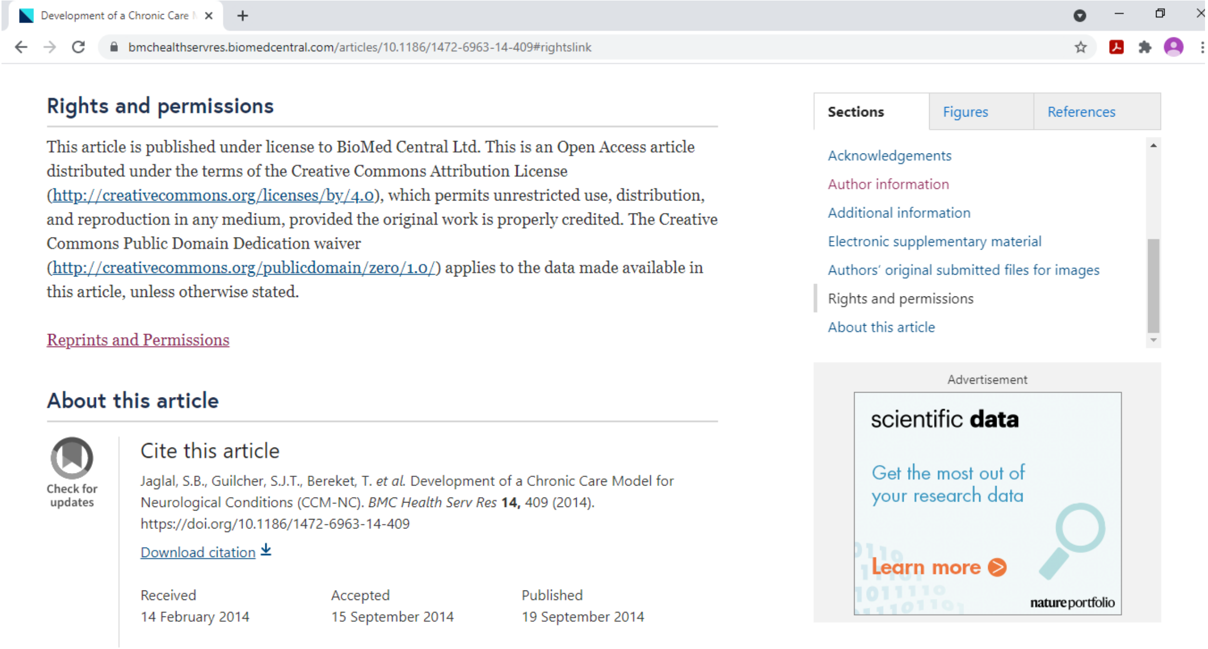
3) AND "quality of life" OR
   wellbeing OR
   "well being" OR
   "well-being" OR
   fatigue OR
   depression OR
   anxiety OR
   pain OR
   "mental health" OR
   stress OR
   "health distress" OR
   "emotional dysfunction" OR
   "life satisfaction" OR
   "social interaction*" OR
   "health perception*" OR
   "social function"

Appendix 2

Summary of risk of bias assessment according to the EPHPP

	Selection Bias	Study Design	Confounders	Blinding	Data Collection Methods	Withdrawals and drop-outs	Global Rating
Akkus et al (2011) (22)	Moderate	Strong	Strong	Weak	Strong	Moderate	Moderate
Abolghasemi et al (2016) (23)	Moderate	Strong	Weak	Weak	Strong	Strong	Weak
Carletto et al (2017) (24)	Weak	Strong	Strong	Moderate	Strong	Moderate	Moderate
Cosio et al (2011) (25)	Moderate	Strong	Strong	Moderate	Strong	Strong	Strong
Ennis et al (2006) (26)	Moderate	Strong	Strong	Moderate	Strong	Strong	Strong
Finlayson et al (2011) (27)	Weak	Strong	Strong	Moderate	Strong	Moderate	Moderate
Graziano et al (2014) (28)	Weak	Strong	Strong	Weak	Strong	Moderate	Weak
Grossman et al (2010) (29)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Hanssen et al (2016) (30)	Moderate	Strong	Strong	Weak	Strong	Strong	Moderate
Lincoln et al (2002) (31)	Moderate	Strong	Strong	Moderate	Strong	Moderate	Strong
Mathiowetz et al (2005) (32)	Moderate	Strong	Strong	Weak	Strong	Moderate	Moderate
O’Hara et al (2002) (33)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate
Pozzilli et al (2002) (34)	Moderate	Strong	Strong	Weak	Strong	Strong	Moderate
Simpson et al (2017) (35)	Moderate	Strong	Strong	Moderate	Strong	Moderate	Strong
Thomas et al (2014) (36)	Weak	Strong	Strong	Moderate	Strong	Strong	Moderate

APPENDIX B – PERMISSION FOR USE OF FIGURE 1



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Jaglal, S.B., Guilcher, S.J.T., Bereket, T. *et al.* Development of a Chronic Care Model for Neurological Conditions (CCM-NC). *BMC Health Serv Res* **14,** 409 (2014). https://doi.org/10.1186/1472-6963-14-409

Download citation

Received	Accepted	Published
14 February 2014	15 September 2014	19 September 2014

APPENDIX C

Reflective chapter

Reflection and reflective practice are essential attributes that aid competence as a healthcare professional (HCP). Hargreaves and Page (2013), highlight that reflection asks you to stop and think regularly about what you are doing and why. It gets you to focus on your own actions and feelings as well as the effect you have on individuals around you. The BPS (2012) identifies reflective practice as central for continuing professional development (CPD). Furthermore, the HCPC (2019) sets out its expectation for HCPs to engage meaningfully in reflection. As a qualitative researcher it is essential to develop a qualitative sensibility, which refers to the position one holds within the research question and data analysis (Braun & Clarke, 2013). In order to develop this Braun and Clarke (2013) put forward numerous skills and orientations which include the ability to reflect on and step outside your cultural position. This includes being able to put assumptions aside so that the research being carried out is not shaped by these. This is also known as 'bracketing' which aims to address bias and pre-exiting assumptions, so as to help minimize the perspective of the researcher in the interpretation of data (Payne, 2007). Braun and Clarke (2013) also speak of the importance of critically reflecting on the research process, including one's role as a researcher. This includes reflecting upon how we may share aspects of participant identity, known as an insider, or how we may not share some aspects of participant identity, known as an outsider. By being self-aware of these we can be more aware of our own beliefs, values and identity construction and the influence these may play upon our research (Le Gallais, 2008).

Within this reflective piece of writing, I aim to enhance the quality of the current research study by understanding how my positioning and interests as a researcher affect each stage of the research process.

Researcher's knowledge and experience

My experience in carrying out qualitative research prior to the current research was limited to a piece of research which I conducted a number of years ago during my MSc in Health Psychology. For this piece of research I used interpretative phenomenological analysis (IPA) to analyse the data, meaning that prior to the current study I have had no prior experience of using thematic analysis (TA). My lack of knowledge and experience of qualitative research did make me doubt as to if I should pursue the current research project, in fear that I may not be able to provide the sufficient qualitative analysis skills needed in order to produce a meaningful study. However, the findings of my previous systematic review exploring psychosocial interventions and quality of life for people with multiple sclerosis (MS), alongside reading the literature available in this field deemed it important to carry out the current piece of research to fill a gap in the literature. I also saw this as an opportunity to build upon my skills and knowledge as a researcher, knowing that I would like to pursue further research opportunities in my career as a health psychologist. Alongside the literature my shared identity as a healthcare professional delivering psychosocial interventions also situated the current research study. My beliefs around the benefits of psychosocial interventions and the importance of healthcare professionals having a voice can be said to have played a role in developing the research aims.

Prior to commencing my research, I have spent a vast amount of time surrounding myself with qualitative literature and online research videos to help deepen my understanding of the analytical approaches which may be appropriate for my study. It was through this exploration of the literature and discussions with my supervisor and fellow peers on the health psychology doctorate that I deemed TA to be the most appropriate approach for analysing the data from my study. The more I have read about qualitative analysis the more I have felt drawn to this approach and felt that it suits my way of working. Being a psychotherapist, I have the privilege of being able to listen to the experiences of others supporting them to gain insight into their thoughts, feelings and behaviours. Qualitative analysis also allows for this insight into the worlds of individuals which quantitative research cannot provide, it allows me to hear about individual experiences which I myself have not experienced. In my work as a psychotherapist, I make frequent use of cognitive behaviour therapy (CBT) to support clients, this approach focuses on what is happening in the present rather than the past. This also sits within qualitive research and a critical realist approach, as like with the work I do with my clients only the results of causal forces can be observed, rather than the causal force itself (Clarke et al, 2007).

Prior to the systematic review which I carried out, my knowledge and experience within the field of MS has been limited. Alongside reading literature on MS I have built up contacts within MS charities. Building these contacts has helped me to gain an insight into how healthcare professionals (HCPs) support people with MS and also some of the challenges faced in this area of work. I am mindful however, that is only a small part of the population.

Although I have deepened my knowledge of MS through my own research and liaising with HCPs in the field, I do not have direct experience of working in MS. I feel that this therefore, along with the limited research surrounding the current study, suited an inductive approach to the analysis.

Having completed an MSc in Health Psychology I have gained knowledge of the theories and models which may underpin the development of psychosocial interventions in healthcare. I have also gained an awareness of what may influence an individual to attend and adhere to a treatment intervention. Alongside the knowledge gained from the MSc I have a number of years' experience in delivering psychosocial interventions both in a one-to-one and group setting. This has included working both in a private clinic and a prison my roles as a psychotherapist and deputy treatment manager for a substance misuse programme. My experience in the delivery of psychosocial interventions is an area which I made sure to acknowledge during the stages of data analysis and one which I will address in more detail later within this reflective writing.

Ethics process

I found the ethics process a beneficial one to go through which helped to aid the development of my research study. I had completed ethics applications previously, although my most recent was as part of my MSc project which was a number of years ago. With the current project being at a doctorate level I soon became aware when starting my application, of a feeling of anxiety. I felt a sense of pressure to ensure that the application was of a good enough standard so that it was approved, as the go ahead for my whole study was dependent on this. However, this sense of pressure was also useful as it forced me to go through each element of the ethics form and think through any potential issues and ways that these may be managed. After submitting my ethics application, I received a letter from the ethics board with conditions to be addressed regarding the population and storage of data. Upon receiving this from the board I did feel a bit disappointed that I hadn't addressed these conditions in my initial application. However, this proved to be very useful, particularly around the population I had planned to target, as it encouraged me to consider ways that I could ensure parity across different professions and as a result I adjusted my population type to address this. The ethics process has taught me that it's important to be thorough when considering each aspect of the research plan. It has also highlighted that it is OK for an application to be returned with conditions as this can be a great opportunity to get another perspective and address the original plans to make for a stronger study.

Recruitment process

The recruitment process for the current study has been one of the most challenging areas of the research. My initial plan for recruitment was to go back to the Multiple Sclerosis Therapy centre from where I had maintained contact with the chief executive after knowledge building for my systematic review. After previously receiving a positive response around my planned research in a meeting, I made the assumption that I would be able to recruit from this avenue with the centre being linked to 50 others across the country it seemed like this was a good way to gain a number of participants. Unfortunately, this did not go to plan and without this support I was left wondering if the study was still going to be achievable and realistic for me to be able to carry out, given my lack of professional contacts in the field of MS. I made the decision to write to a number of further charities and neurological departments to ask for support with recruitment. This brought about further disappointment when I received no responses or responses informing me that it would not be something which the charity is unable to support with or have time to do so due to the impact of COVID-19 at that moment in time. It was upon receiving a positive response from the MS Trust that I felt the research could get moving again. Throughout the process of the recruitment, I have made sure to maintain regular contact with the MS Trust with updates and made arrangements to go in to speak face-to-face about my study. Alongside the support from the MS Trust and social media platforms I slowly started to receive completed online surveys. As well as challenging, the recruitment process has also taken more time than was originally planned for in my timeline. For this I have had to remind myself to be realistic in that the participant group which I was recruiting was a hard-to-reach group. Having now recruited 32 participants, feels an achievement. Despite its challenges I have taken away some points for consideration for any future research recruitment. One of my big learning points was to not put so much reliance onto one source for recruitment, unless this has been officially agreed. Which I acknowledge was a decision which was likely influenced by my lack of professional contacts in the MS field and my initial perception of myself as a researcher stopping me making further contacts. Secondly, I feel that where possible it is important to be able to meet with professionals face-to-face and maintain contact. Although I initially did not feel completely comfortable making the continued contact, I believe this played a big part in receiving the support I had from the MS Trust and ultimately helped towards my recruitment. Finally, I will consider my timeframe more so that it is more fitting with the population group that is being recruited. I feel that my limited experience in qualitative research has also played a role here as I perhaps did not account for the extra time needed for this type of research compared to a quantitative study.

Participant demographics – Insider and outsider positions as a researcher

Prior to the data analysis process I took some time to review the participant (Table 1) demographics and identified which of those I shared (insider position) or did not share (outsider position) so as to increase my level of self-awareness around my potential for influence upon the research findings.

Table 1: Insider and outsider positions as a researcher

Demographics for exploration	**Researcher identity**	**Participant group identity**
Gender	Female	Female
Age	Range 35-45 years	Average range 35-45 years
Job role	Counsellor / psychotherapist / trainee health psychologist	Occupational therapists, MS nurses, psychologists, counsellors
Job setting	Prison / community hub for substance misuse / private clinic	Hospital, residential setting, MS therapy centre, community
Experience in MS field	No direct experience	Average of 8.84 years' experience
Delivery of psychosocial interventions	15 years' experience	Average of 7.72 years' experience
Qualifications	Hold professional qualifications and a member of a professional body	Hold professional qualifications and a member of a professional body

Data analysis

The data analysis process was not as I initially expected, which is again likely to be the result of my limited prior experience in carrying out TA. Although I had read numerous literature around how to carry out TA I underestimated how much time the process takes to arrive at the final themes for the analysis. I was therefore grateful that I already had the participant responses written down in the surveys and did not have to spend extra time transcribing. This allowed me to spend more time reading over the data and becoming familiar with it. Having completed multiple combinations of codes and themes using maps and post-it notes around my room, I did question if I was following the right path and if it should take this amount of repetition in going back over the different stages of TA. Guidance from my supervisor was useful here in confirming that this was a normal and expected part of the process. Having used an online survey to gather participant responses I was surprised as to how much good quality data was generated. This did make it difficult when selecting the most appropriate quotes for themes, as it felt like there were numerous quotes which could be included and I did not want to miss any important information for the reader. However, I also did not want to overwhelm the reader with too many quotes. I addressed this by spending time going through each one and keeping those which really highlighted the key point from the theme. I found that having time away from my data and returning sometime later helped me to not get overwhelmed by the process and brought some clarity. When it came to writing up my data analysis, I feel I was able to transfer my skills from my previous job role as deputy treatment manager. My experience in this role of writing progress reports for clients and evaluating responses from feedback forms I feel helped me in focusing on the key points made by participants and staying on these. Upon reflection, after reading the survey responses I also feel that the use of the online survey helped to avoid the potential risk of me slipping into my psychotherapist role if a face-to-face interview was to have been used. My personal identification as a female healthcare professional (HCP) in the age range of 35-45 years was shared with the group of participants, all of whom were female HCPs themselves. A number of participants worked as either a MS nurse, of which I myself have no experience, or in a psychologist role like myself. However, the shared knowledge of MS held amongst the group was not a demographic which I shared. Having this indifference, I feel has helped to increase the validity of my analysis, as I did not have an in-depth knowledge around MS to make any presumptions around responses directly linked to the condition, such as outcomes for people with MS and the effects of MS symptoms. I was also aware that having delivered both group and one-to-one psychosocial interventions for 15 years, I also shared identity with participants. Although my experience has not been with people with MS I am aware of the challenges that can come with delivering interventions. Reading through the participant responses I found myself being able to identify with some of the challenges spoken of such as time constraints and the negative perceptions held by others around interventions. Despite this, I still found myself feeling surprised and shocked at times at the further difficulties that HCPs faced in the MS field. My experience of delivering interventions has also enabled me to see first-hand the benefits that these can have for individuals. It is through this experience that I have developed the belief that psychosocial interventions are needed and play an important role in individual well-being and quality of life. Although sharing some of these experiences with participants can perhaps offer me an understanding and awareness into the participant's responses, this also runs the risk of potentially impacting the perceived validity of my findings (Le Gallais, 2008). Recognising these values and experiences which I shared with participants, was important when writing the data analysis, so as to ensure that I was objective in still accurately representing the voice of the participants rather than my own coming through. These values, experiences, theories that we carry around with us can inform our research in a number of ways, even unconsciously (Sandelowski, 1993). To help maintain control of intrusion of bias I ensured to take the time to step back and read over what I had written for each theme, ensuring that what I was reading fitted the reality of the data. I also found it helpful to make sure I was adhering to the six stages of conducting TA to keep me focused on the data.

Conclusion

In conclusion, the process of self-reflection has been an important aspect of my thesis which has helped me to become self-aware of the part that I as a researcher play in the outcomes. It has encouraged me to stop and really consider how my beliefs, values and lived experiences can shape my research. Alongside my role as a researcher, taking the time to reflect has been beneficial in giving me the opportunity to acknowledge the progress I was making in my study, which was particularly beneficial during the more challenging times. Writing and undertaking this thesis has been one of the most challenging whilst at the same time rewarding experiences. The process has led me to have to change my day-to-day life in order to accommodate for the needs of my thesis, which has been quite often at the expense of my own wellbeing. This is something which I have struggled with, due to the feelings of hypocrisy arising around the fact that I am studying to be a health psychologist. Despite the many physical and emotional challenges faced, the process of carrying out my thesis has been an experience from which I have learnt so much and my confidence as a researcher and professional in health psychology has grown. It has also taught me so much about myself personally and shown me what I can achieve by pushing myself out of what I feel most comfortable with. I am now looking forward to having more time back again for me to focus on my own wellbeing and finding out what the next step in my career as a health psychologist entails.

References

BPS. (2012). *Continuing professional development policy.* https://www.bps.org.uk/sites/www.bps.org.uk/files/Professional%20Development/CPD%20Policy.pdf

Braun, V., & Clarke, V. (2013). Successful qualitative research: A practical guide for beginners. SAGE publications

Hargreaves, J., & Page, L. (2013). *Reflective Practice*. Polity Press

HCPC. (2019). *Benefits of becoming a reflective practitioner.*http://www.hcpc-uk.co.uk/globalassets/news-and-events/benefits-of-becoming-a-reflective-practitioner----joint-statement-2019.pdf

Le Gallais, T. (2008). Wherever I go there I am: Reflections on reflexivity and the research stance. *Reflective practice: International and multidisciplinary perspectives.* 9(2), 145-155. DOI: 10.1080/14623940802005475

Payne, S. (2007). Designing and conducting qualitative studies. In Michie, S., & Abraham, C (Eds), *Health psychology in practice* (pp. 126-159). The British Psychological Society and Blackwell Publishing.

Sandelowski, M. (1993). Theory unmasked: The uses and guises of theory in qualitative research. *Research in nursing and health,* 16(3), 213-218. DOI: 10.1002/nur.4770160308.

APPENDIX D – PRIVACY NOTICE

University of the West of England (UWE)
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Study Title: A qualitative study exploring health care professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care

Privacy Notice for Research Participants

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in 'A qualitative study exploring health care professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care '. 'Personal data' means any information relating to an identified or identifiable natural person (the data subject). An 'identifiable natural person' is one who can be identified, directly or indirectly, including by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together "the Data

Protection Legislation"). General information on Data Protection law is available from the Information Commissioner's Office (https://ico.org.uk/).

How do we use your personal data?
We use your personal data for research with appropriate safeguards in place on the lawful bases of fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes. We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by Faculty Research Ethics Committee, Ethics application reference HAS.19.09.031, and the email contact of the research committee is researchethics@uwe.ac.uk for queries, comments or complaints. This research project adheres to the Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at: www1.uwe.ac.uk/research/researchethics. We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent.

What Data do we collect?
The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

Who do we share your data with?
We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent.

How do we keep your data secured?
We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet. Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your rights and how to exercise them

Under the Data Protection legislation, you have the following **qualified** rights:

(1) The right to access your personal data held by or on behalf of the University;
(2) The right to rectification if the information is inaccurate or incomplete;
(3) The right to restrict processing and/or erasure of your personal data;
(4) The right to data portability;
(5) The right to object to processing;
(6) The right to object to automated decision making and profiling;
(7) The right to complain to the Information Commissioner's Office (ICO).

Please note, however, that some of these rights do not apply when the data is being used for research purposes if appropriate safeguards have been put in place.

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet, UWE Bristol's Research Ethics Committees (research.ethics@uwe.ac.uk) or UWE Bristol's research governance manager (Ros.Rouse@uwe.ac.uk)

APPENDIX E – PARTICIPANT INFORMATION SHEET

University of the West of England (UWE)
Department of Psychology
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QY

Tel: +44 (0)7834993423

Email: natalie2.garnett@live.uwe.ac.uk

Study Title: A qualitative study exploring health care professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care

Participant Information Sheet

You are invited to take part in this study which contributes to my Professional Doctorate in Health Psychology from the University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Natalie Garnett of the University of the West of England, Bristol natalie2.garnett@live.uwe.ac.uk

What is the aim of the research?

The research is looking at understanding the perceptions of healthcare professionals working with people with MS and their insights into the acceptability and effectiveness of existing interventions. To help explore this, healthcare professionals are invited to participate in a survey. The aim of the survey will be to collect information that will be made anonymous. The results of the study will be analysed and written in a report which will be made available on the University of the West of England's open-access repository. The anonymised results may also be used in conference papers and peer-reviewed academic papers.

Why have I been asked to take part?

We are interested in your perceptions of MS care as a health professional working with people with MS.

Who is eligible to participate?

Any healthcare professional who delivers or is involved in a psychosocial intervention for Multiple Sclerosis patients.

Do I have to take part?

You do not have to take part in this research, participation is voluntary. If you do decide to take part, you are able to withdraw from the research without giving a reason up until 2 weeks after submitting the questionnaire. If you want to withdraw from the study within this period please contact the researcher, Natalie Garnett with your unique ID number. Deciding not to participate or withdrawing from the study does not have a penalty.

What will participating in the study involve?

The survey consists of a series of questions related to your perceptions of psychosocial interventions for people with MS. We want to understand *what you think* and how you feel about these interventions and why you think and feel this why.

There are *no right answers* – we are interested in the range of opinions and thoughts that people have. You can write as little or as much as you desire (additional space is provided if you run out of space). We want you to write your views, in your own words.

At the end of the survey are some quantitative demographic questions for you to answer. We are asking these questions so we can gain a sense of who is taking part in the research. The survey should take no more than 15/20 minutes to complete.

Completing and returning the survey will be an indication that you have read the consent statement and consent to take part in this study

What are the benefits of taking part?

If you take part, you will be helping us to potentially gain a better understanding of health care professional's perceptions of psychosocial interventions for people with MS which could help guide future training and education, and the development of psychosocial interventions for people with MS.

By completing the survey you will have the choice of being be entered into a prize draw for a £100 online voucher from your choice of Amazon, Debenhams, John Lewis, M&S or Next.

Are there any risks involved?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can stop the survey or withdraw should you wish to do so. If you need any support with completing the survey please contact the researcher, Natalie Garnett.

How will my data be used?

All the information we receive from you will be treated in the strictest confidence and your name will not be required at any stage. The data gathered will be analysed and extracts may be anonymously quoted in the write up of the study. The data may be linked to some demographic response categories (e.g. where in the country you work, type of intervention), but not in a way that could reveal your identity as a participant.

Data will be kept secure on a password protected laptop and password protected drive in accordance with the Data Protection Act 2018 and General Data Protection Regulation requirements. All collated data will be entered into computer files, and the hard copies will also be retained. The data will be retained for a minimum of 6 years, and for as long as all interest in the project continues. Once these stages have passed, the computer files will then be deleted, and hard copies shredded.

Agreeing to take part in this research (returning the completed survey) means that you agree to this use of the information you provide.

When do I need to complete the survey by?
For your data to be used towards the study, your completed survey must be submitted by 1st May 2020.

Where will the results of the research study be published?
A report will be written containing the study's findings. This report will be available on the University of the West of England's open-access Research Repository. The study may also be submitted for journal publication. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?
The project has been reviewed and approved by the Faculty/University of the West of England Research Ethics Committee. Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at: Researchethics@uwe.ac.uk

Who do I contact if I have any questions?
If there are any further queries about this study, please do not hesitate to contact me via email natalie2.garnett@live.uwe.ac.uk
If you have any concerns or issues with the study, please contact my UWE supervisor, Dr. Liz Jenkinson: elizabeth2.jenkinson@uwe.ac.uk

Thank you for agreeing to take part in this study.

APPENDIX F -PARTICIPANT CONSENT FORM

University of the West of England (UWE)
Department of Psychology
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QY

Tel: +44 (0)7834993423

Email: natalie2.garnett@live.uwe.ac.uk

Study Title: A qualitative study exploring health care professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care

Informed Consent Form

Please ensure that you have read through the participant information sheet and asked any questions which you may have regarding the study prior to starting the questionnaire. If you have any questions about this research please contact Natalie Garnett at natalie2.garnett@live.uwe.ac.uk

Please note that by participating in this study it is assumed that you consent to the following:

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form
- I have had an opportunity to ask questions about the study, and have them answered
- I know that my participation in this study is entirely voluntary
- I agree to anonymised quotes from my survey responses possibly being used in the final report
- I understand that I can withdraw from the study at any point, and that I am under no obligation to give reason for this
- I understand that I may withdraw any or all of the information I provide at any time up to 2 weeks after submitting my completed survey.
- I agree to take part in the study

APPENDIX G – ONLINE SURVEY

UWE Bristol
University of the West of England

A qualitative study exploring healthcare professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care

Participant Survey

The below survey consists of a series of 12 questions related to your perceptions of psychosocial interventions for people with Multiple Sclerosis. There are no right answers, we are interested in a range of opinions and thoughts that people have. Please answers all the questions in your own words and feel free to write as little or as much as you desire.

Please create your unique ID number using the last 2 number from your phone number and the first two numbers from your date of birth

e.g Phone number: 079215679**13** Date of birth: **25**th March 1981
The ID number here would be 1325

ID Number:

1) Which psychosocial interventions do you currently deliver or have you delivered for people with MS? (Please could you include information on the content, duration and category of MS it addresses)

2) In what way does the intervention(s) mentioned in question 1 aim to help people with MS?

3) What model(s) or theoretical approach(es) is the intervention(s) mentioned in question 1 based upon?

4) In your opinion, what works well with existing interventions that you deliver/have delivered?

5) In your opinion, what works less well with existing interventions that you deliver/have delivered?

6) What do you think motivates people with MS to take part in psychosocial interventions?

7) What do you think helps people with MS to adhere to and complete an intervention/programme of psychosocial support?

8) What are the barriers to taking part in a psychosocial intervention for people with MS?

9) What are the barriers to adherence to, or completing an intervention for people with MS?

10) What challenges do you face as a professional delivering psychosocial interventions for people with MS?

11) What do you think is currently missing in the design and delivery of psychosocial interventions for people with MS?

12) Are there any others aspects of your experience or thoughts regarding MS psychosocial interventions that you would like to tell us about?

APPENDIX H – DEMOGRAPHIC SURVEY

UWE Bristol University of the West of England

A qualitative study exploring healthcare professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care

Demographic Survey

Thank you for taking the time to complete the previous survey. Below are some demographic questions, we are asking these questions so we can gain a sense of who is taking part in the research.

1) How old are you?

☐

2) I am (Please tick):

Male __
Female__
Other__

3) What is your job role?

☐

4) Within which setting is your job role based?

☐

5) How often do you work (please tick)?

Full-time __
Part-time __

6) How long have you been working in the MS field?

☐

7) How long have you been delivering psychosocial interventions in the MS field?

8) Are you a member of a professional body? (If yes, please state which professional body)

9) Do you have any professional qualifications? (If yes, please state what these are)

APPENDIX I - PARTICIPANT DEBRIEF

University of the West of England (UWE)
Department of Psychology
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QY

Tel: +44 (0)7834993423

Debriefing Form

Thank you for your participation in this study.

Your participation will remain completely confidential. However, if you subsequently decide that you would not like your survey to be included in the study, you have a withdrawal period of two weeks after the submission of your survey to contact me via email natalie2.garnett@live.uwe.ac.uk with your unique ID number.

If you would like any emotional support regarding your work with MS patients the following support is available:

- The National Multiple Sclerosis Society hosts the MS Navigators program where professionals can help you with resources, emotional support services and wellness strategies https://www.nationalmssociety.org/Resources-Support

If you have any further questions about this study, you may contact my UWE Supervisor Dr. Elizabeth Jenkinson via email elizabeth2.jenkinson@uwe.ac.uk

As a thank you for participating in this study you have the opportunity to be entered into a prize draw to win a £100 online voucher for your choice of either Amazon, Debenhams, John Lewis, M&S or Next. If you would like the opportunity to be entered into the draw please leave an email address in the space below which you can be contacted on

APPENDIX J – INVITATION LETTER

UWE Bristol | University of the West of England

Study Title: A qualitative study exploring psychosocial professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care

Dear Invitee,

My name is Natalie Garnett. I am a Trainee Health Psychologist studying at the University of the West of England. I am kindly requesting your participation in a doctoral research study which contributes to my Professional Doctorate in Health Psychology. The study is titled: *A qualitative study exploring psychosocial professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in Multiple Sclerosis care.* The aim is to gain an understanding of how healthcare professionals think and feel about the psychosocial interventions they deliver for people with multiple sclerosis.

The study involves completing an online survey consisting of 12 questions followed by some demographic questions. Participation is completely voluntary and you may withdraw from the study at any time. The study is completely anonymous, therefore, it does not require you to provide your name or any other identifying information.

As a thank you for completing the survey you will have the opportunity to enter a prize draw for a £100 online voucher for your choice of either Amazon, M&S, John Lewis, Debenhams or Next.

If you would like to participate in the study please click the survey link at the end of this email invitation. Your participation in the research will be of great importance in helping towards us gaining a better understanding of psychosocial professionals' perceptions of psychosocial interventions for people with MS, which could help guide future training, education and the development of psychosocial interventions for people with MS.

Thank you for your time and participation

Sincerely

Natalie Garnett (BA, MSc, Ad.Dip.CP)
Trainee Health Psychologist

Please click link to begin survey

https://uwe.eu.qualtrics.com/jfe/form/SV_1ReQXSdElBkbAs5

APPENDIX K – EXAMPLES OF INITIAL TA CODING

ID Number	Participant survey responses	Initial coding
(Omitted for confidentiality)	1) One-to-one counselling sessions in person and online. Sessions are tailored to the individual's needs and therefore vary in duration. Sessions are weekly and 50 minutes in duration. Topics covered include goal setting, emotional management, developing support networks, pain management. I have worked with clients with relapsing remitting MS.	- 1-2-1 support - online support - Individuals needs - goals, emotional / pain management, support - type of SM RR
	2) Helps to develop an acceptance of how the individual may need to make changes to their everyday lifestyle. Encourages the client to feel more confident and motivated when identifying goals to work towards. Building support networks helps to decrease feelings of isolation. The sessions also aim to help the client feel more in control of their emotions and develop ways to help manage their physical pain symptoms.	- acceptance - motivation - support - emotional / pain management
	3) The sessions make use of CBT techniques and also incorporate relaxation and mindfulness. I use tools such as SMART goal setting, the ABC model and the stages of change	- CBT - mindfulness - relaxation
	4) What works well with the intervention is when the client already has a level of motivation to make changes and address how they are feeling. It also helps if the client has a form of support outside of the sessions to help motivate them to continue with the work. Techniques such as SMART help to break things down and make the change seem less daunting. The stages of change can work well alongside this to monitor progress. Diaries can be a useful tool to also monitor progress. I use these techniques often as an opportunity to help the client identify what they have done well and affirm what positive individual skills they have. The client's mindset quite often appears more positive after this conversation. The	- pre-existing motivation - external support - SMART goals, perception of change - stages of change - progress - diaries – progress - mindfulness/relaxation

	mindfulness and relaxation techniques can be a useful way to encourage healthier thoughts, decrease pain and improve fatigue	
	5) I have had occasions where clients have come to the sessions more because they have been asked to by a family member and therefore motivation and engagement level is extremely low. Client fatigue also plays a part in the client's motivation level. Some clients do need extra support with techniques such as SMART goal setting due to levels of cognition.	- motivation level, support? - fatigue
	6) Having a positive support network around them and having an understanding beforehand of what the intervention will aim to address. Feeling that someone is listening to them, particularly if they have had a previous negative experience with therapy.	- Support - awareness of interventions - facilitator approach
	7) Having SMART goals to work towards, having strategies in place to help manage any relapses. Having a therapist that uses an empathic approach and has an awareness of the impact of MS can make such a positive difference with clients. An important part of being a therapist when working in this field is to be able to support the client in helping them to see their strengths and how to make the most of these. I've had times where using this has led a client who is having a bad day to feel enlightened and hopeful in achieving their goals.	- SMART goals - symptom management - empathy, awareness - support / therapist approach
	8) Relapses in symptoms, fatigue, lack of motivation, money (for private therapy), waiting list time, time to attend if have other commitments and responsibilities. Some clients have also spoken of responses from other healthcare professionals who have said that there is nothing that can be done for their condition which has left them feeling hopeless and demotivated.	- MS symptoms - motivation - Finances, - external factors - understanding of condition
	9) Relapses in symptoms, fatigue, no support outside of sessions from family/friends	- MS symptoms

		- Lack of external support
	10) Client resistance during times of relapse, lack of longer-term support to refer the client to after the intervention. As I worked in a private clinic it does mean that clients have to pay for the intervention which can be a barrier to getting clients to engage	- Relapse in symptoms - Lack of follow-up support - Finances
	11) Support to refer the client to following on from the intervention. More understanding amongst other healthcare professionals of the interventions that are available and the aims of these	- Support following intervention - HCPs awareness of interventions, communication
	12) Not answered	N/A
(Omitted for confidentiality)	1) Interventions that may be considered psychosocial include fatigue management, and living well with MS courses. Both courses last for 6-8weeks. Fatigue management looks at current strategies and offers planning both at work and home. Pacing, delegation, change in work pattern, introduction of regular rest periods, mindfulness, yoga , Pilates and complimentary therapies are all offered as aids to symptom management including fatigue	- Fatigue management - Living well with MS programme
	2) Firstly these interventions allow people with MS to breathe. Permission to stop and reflect on current practice and the opportunity to change things, try a new approach, especially if what they are doing is not working. There is also the aspect of being believed, often MS fatigue is met with comments from family and friends with "Im tired too" This only serves to underline the fact that MS fatigue is little understood, leaving the person living with MS feeling more isolated than ever. Most clients feel for the first time someone understands, and even more importantly that there is something that can help	- Time out - Self reflection - Empathy, lack of understanding, support - Awareness of intervention, awareness of condition
	3) CBT, mindfulness	- CBT - mindfulness

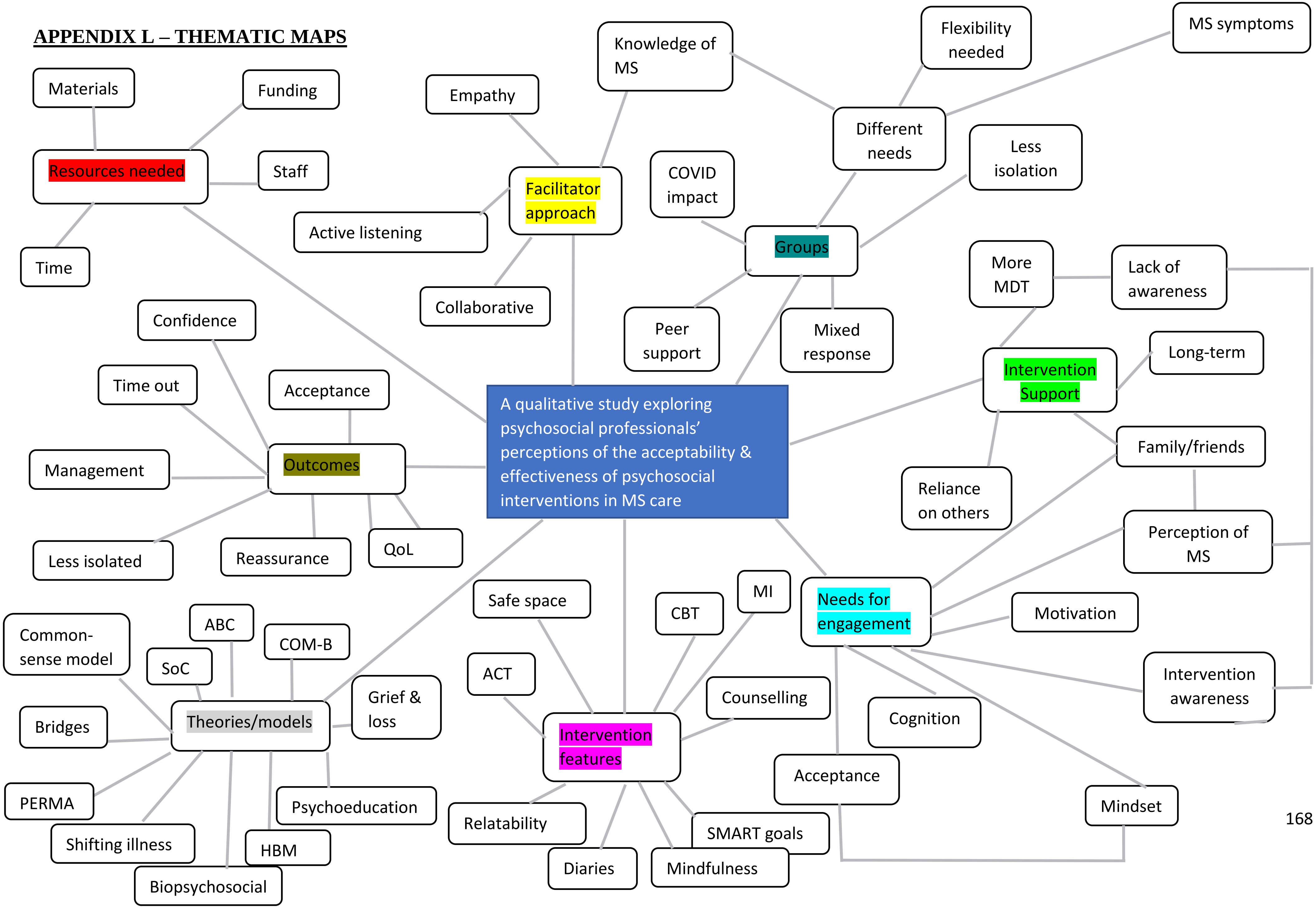
	4) Group work offers invaluable peer support. The addition of professional input from colleagues/ practitioners out with the centre is also extremely useful. For example, at a living well program delivered last year, many clients had the opportunity to speak directly to a urologist who was a guest speaker. Some were surprised to know their bladder issues were connected to their MS, and heartened that there was something that could be done. Until then they had assumed it was just something they had to live with	- Peer support - MDT working, support - education
	5) Concentrating "living well" on newly diagnosed clients was, in my opinion short sighted. It now incorporates topics that all PWMS can benefit from irrespective of how long they have been living with it.	- Needs for types of MS
	6) Generally encouragement from their hospital based MS Nurse, GP, sometimes their neurologist, and often family to seek further support. In my experience, and perhaps due to their comfort with using internet etc, younger clients are more likely to search for supports that older clients. Motivation can also come from an acknowledgement from the person themselves that they are struggling with work/ symptoms/ acceptance of their MS/ relationships etc and feel they need to reach out for support	- Support - communication, awareness of intervention - Quality of life
	7) Good communication is essential. I also think that accepting self referral only is a mistake, after all who is going to make that call for help when handed an info leaflet at what I'd possibly their lowest ebb? I have found that if the client agrees to referral to my service, and their details being shared, a call from myself or a member of the team results in attendance at their first assessment and engagement throughout agreed inputs. An introduction of a phone or text reminder has made a noticeable positive difference on attendance. Simple but very effective	- Communication - Awareness of intervention
	8) Lack of transport, difficulty in securing time off work, relapse, multiple hospital appointments, poor memory, low mood, denial, financial worry, worry about	- Impact of personal circumstances

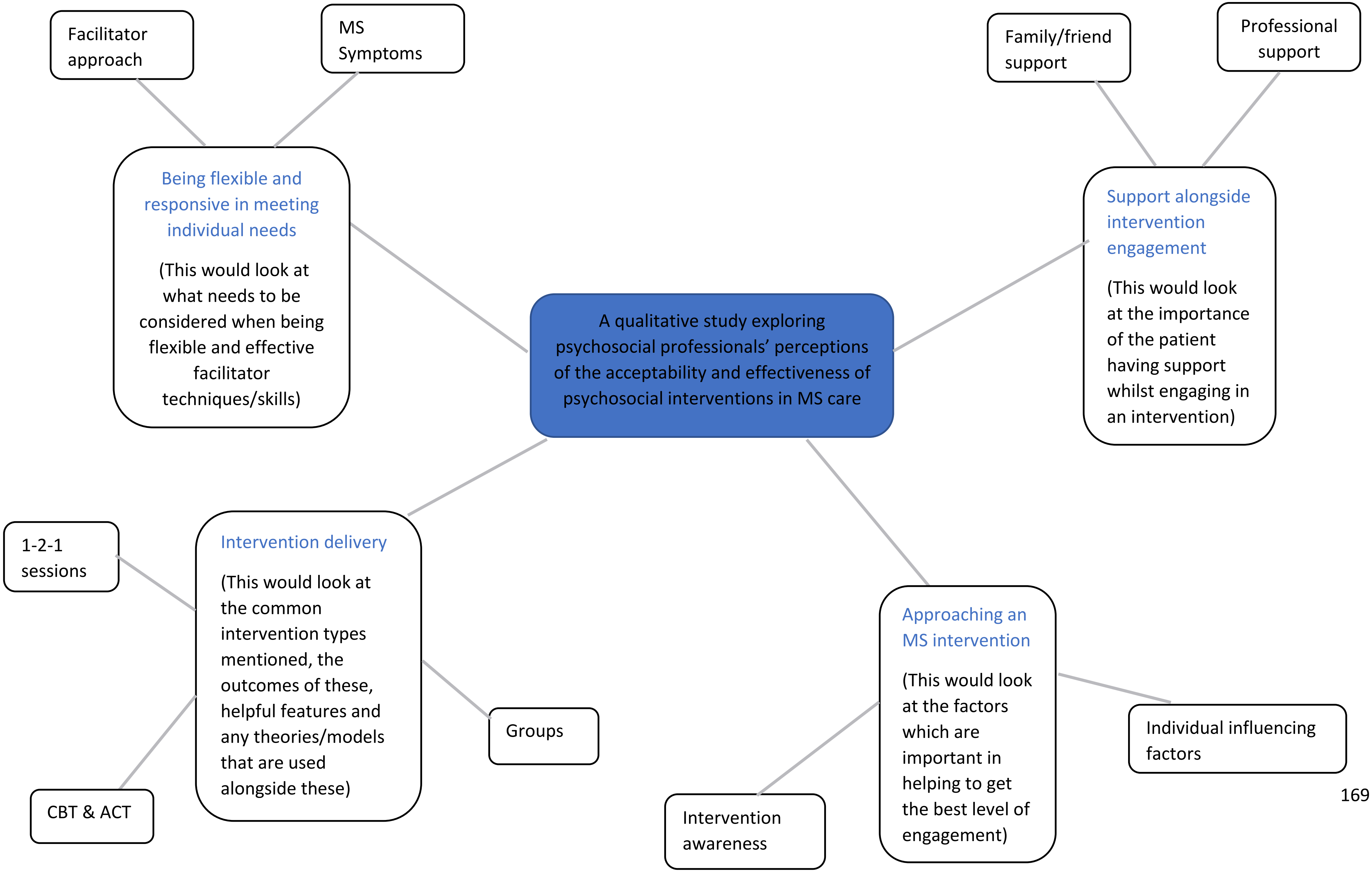
	taking a place someone else may need more, and significantly ' 'not wanting to see someone worse than me	- Lack of support from others, personal responsibilities - Impact of MS/symptoms - Fear of future - Awareness of what will gain, individual needs.
	9) Much the same, financial difficulty, affording transport costs, travel may be physically challenging especially if public transport is the mode of travel. Depression or low mood has huge impact on engagement. Having to use annual leave if the workplace does not allow time if to attend, long waiting times	- Impact of personal circumstances - impact of MS symptoms - Impact of low mood - Support from others, personal responsibilities - Lack of services
	10) Financial constraint means part time hours for staff, attendance numbers have to be good to evidence need. Endorsement from fellow healthcare professionals	- Lack of funding - perception of the value of MS interventions
	11) There is not enough focus or funding for this kind of input. I currently deliver this kind of intervention in a 3rd sector organisation, funded mainly through fundraising. Some funds do come from the NHS, but when you think about it all of our clients are NHS patients. If you look at the facts, ie patients seeing their consultants once or twice a year and their hospital based MS nurses perhaps a little more than that, it becomes very clear that all MS patients are already self managing, effectively or not is quite another question, but it seems to me that if this area was properly staffed and funded, many issues could be identified and managed long before crisis time	- lack of funding, - lack of staff
	12) I think there is a real need for GP education in the value of psychosocial interventions for their MS patients.	- Awareness, training, education, support from others

(Omitted for confidentiality)	1) I run support groups for MS residents, allowing them to openly discuss how their feelings and experiences of MS. This helps the most at times when symptoms of MS are worsening and residents report that it reduces the feelings of isolation. This is an ongoing open weekly group and residents can attend as they wish however the majority of them tend to complete 6-week blocks. The diagnosis of MS is mainly secondary progressive by the time the individuals have become residents as their condition has progressed from primary progressive or relapse/remit and their needs require 24hour care. I also complete one to one emotional support sessions for residents who require this and these are structured via biopsychosocial formulations. Again, these sessions are ongoing but average around 1.5 hour weekly sessions for 8 weeks.	- support groups - 1-2-1 support - emotional management - symptom management - biopsychosocial
	2) The support group reduces their feelings of isolation and encourages them to share their experiences. The feedback is often that it helps to know that they are not on their own. The one to one sessions support the individuals with their specific difficulties and provides them with coping strategies, and action plan and goals.	- peer support - goals
	3) Transtheoretical model of change and one to one sessions. Biopsychosocial formulation. I apply the shifting illness perspectives model and also the Leventhal common-sense model	- Transtheoretical model of change - biopsychosocial - shifting illness perspectives model - Leventhal common-sense model
	4) Giving the individual the time to talk to someone separate to their friends and family about how they feel regarding their condition. Often they will say that they don't like to burden others that are close to them.	- share feelings
	5) Putting an end time to the intervention, which is why I often keep the length of the programmes open. Putting a set '6' sessions onto one to one support can often cause panic leading up to the end session and some people just require ongoing support in the 24-hr neurorehabilitation setting. Particularly if their	- flexible approach - individual needs

	condition has progressed to the point where they are totally reliant on others for all aspects of care and support.	
	6) Having others around them that are in similar situations	- peer support
	7) Having a belief that the intervention/programme can help them in some way	- awareness of the intervention
	8) Some physical limitations of the condition i.e. some individuals have significant cognitive impairments and others are unable to communicate effectively anymore	- MS symptoms
	9) Illness and infections can be the biggest barrier as sessions are often missed	- MS symptoms
	10) I regularly need to link in with other professionals as MS can be complex and the symptoms present in a number of different ways that often mean Speech and Language support are required to help with communication. Physio to help with increasing activity, OT to help with increasing daily activities and dietetics to support with healthy living and diet. Therefore liaising with all different professions can be time consuming and effective communication is so important.	- MDT support - complexity of MS
	11) I struggle to find specific interventions for MS that can support a broad range of symptoms and individuals therefore I often make programmes with different sessions throughout that are tailored to the individuals in my group at that time rather than sticking with one programme that I continually roll out.	- Lack of variety in interventions - flexible approach
	12) I think because MS is so unique to the individual, all support is person centred and tailored to those needs and often as the condition progresses the support given changes. I feel that having a individual allocated to a person diagnosed with MS from the start to support them through the symptom management and degeneration would really help the individual (like a key worker role).	- adapt to needs - support

APPENDIX L – THEMATIC MAPS





A qualitative study exploring psychosocial professionals' perceptions of the acceptability and effectiveness of psychosocial interventions in MS care

Being flexible and responsive in meeting individual needs

(This would look at what needs to be considered when being flexible and effective facilitator techniques/skills)

Facilitator approach

MS Symptoms

Support alongside intervention engagement

(This would look at the importance of the patient having support whilst engaging in an intervention)

Family/friend support

Professional support

Intervention delivery

(This would look at the common intervention types mentioned, the outcomes of these, helpful features and any theories/models that are used alongside these)

1-2-1 sessions

CBT & ACT

Groups

Approaching an MS intervention

(This would look at the factors which are important in helping to get the best level of engagement)

Intervention awareness

Individual influencing factors

APPENDIX M – ETHICS APPLICATION

Ethical Review Application Form

Please complete **Relevant** sections of the form.
If you think a question is not applicable to your project, provide an explanation as to why you think so please

Section 1: Applicant Details	
First Name	Natalie
Last Name	Garnett
Faculty	HAS
Department	Psychology
Co-researcher Names (internal and external) Please include names, institutions and roles. If there are no co-researchers, please state N/A.	N/A
Is this application for a staff or a student?	Student
Student Course details	Postgraduate Research
Name of Director of Studies / Supervisor	Dr Elizabeth Jenkinson
Comments from Director of Studies / Supervisor *For student applications, supervisors should ensure that all of the following are satisfied before the study begins:* • *The topic merits further research;* • *The student has the skills to carry out the research;* • *The participant information sheet is appropriate; and procedures for recruitment of research participants and obtained informed consent are appropriate.* *The supervisor must add comments here. Failure to do so will result in the application being returned*	
I am happy to support this application as part of her Professional Doctorate research.	

Section 2: Project	
Section 2:1 Project details	
Full Project Title	
A qualitative study exploring psychosocial professionals' perceptions of the acceptability and effectiveness of existing psychosocial interventions in Multiple Sclerosis care	
Project Dates These are the dates for the overall project, which may be different to the dates of the field work and/or empirical work involving human participants.	
Project Start Date	January 2020
Project End Date	31/12/2021
Dates for work requiring ethical approval You must allow **at least 6 weeks** for an initial decision, plus additional time for any changes to be made.	
Start date for work requiring ethical approval	09/02/2020
End date for work requiring ethical approval	01/03/2020
How is the project funded? (e.g. externally, internally, self-funded, not funded – including scholarly activity) Please provide details.	
Not funded	

Is external ethics approval needed for this research?	No

If Yes please provide the following:

For NHS Research please provide a copy of the letter from the HRA granting full approval for your project together with a copy of your IRAS form and supporting documentation, including reference numbers.

Where review has taken place elsewhere (e.g. via another university or institution), please provide a copy of your ethics application, supporting documentation and evidence of approval by the appropriate ethics committee.

NHS ethics is not required for the proposed study (see attached for email response)

Section 2:2 Project summary

Please provide a concise summary of the project, including its aims, objectives and background. (maximum 400 words)
Please describe in non-technical language what your research is about. Your summary should provide the committee with sufficient detail to understand the nature of the project, its rationale and ethical context.

Multiple Sclerosis (MS) is a chronic autoimmune disease of the central nervous system and the most common disabling neurological disease to affect young adults (1). It is estimated that there are around 127,000 people who are diagnosed with MS in the UK (2). It has also been shown that there is a significant 1.7-fold increased risk of all-cause mortality in patients with MS compared to the general population (3). Due to its progressive nature, coping with MS is ongoing and individuals are confronted with emotional and social challenges (6).

Studies have been carried out using both qualitative and quantitative data to explore the views of MS patients about the acceptability and effectiveness of psychosocial interventions. Some of the findings from the studies included the importance of consulting patients and limitations to the use of smartphone technology in healthcare such as reduced contact with professionals (21). A study based on group CBT suggested that those delivering group interventions are aware of resistance and openness to change coexisting in the change process. It was also suggested that a group intervention should be a minimum of 3 sessions focusing on promoting identity redefinition, a sense of coherence and self-efficacy whilst also including follow-up sessions once the group was completed (22).

When considering the acceptability and effectiveness of psychosocial interventions it is important for us to take into account the perceptions of healthcare professionals (HCPs) as the success of future MS interventions relies on their engagement and expertise. Despite this, the view of HCPs on psychosocial interventions for MS sufferers has been found to be under researched thus far. Peters et al (2018) (24) explored HCP's views on training for a MS fatigue management programme. However, key components of what worked regarding the intervention itself were not discussed. Methley et al (2016) (25) explored patients and professionals perspectives and made suggestions including repositioning aspects of MS care, such as primary care into the community and having more timely access to services. Although the study identified the importance of person centred care it did not make recommendations regarding the content of psychosocial interventions. A study carried out in Rome and Milan (26) examined patient and healthcare staff's experiences of a home-based palliative approach for adults with severe MS. The results highlighted a possible need for altering intervention duration and investing more time and resources into a functioning team. However, the study highlighted in its limitations that at one venue the referring physician focus group was not held and not all team members attended the healthcare professional's focus group, therefore some important aspects of the teams experience may not have been identified.

Alongside prior education, the perspectives of professionals guide professional behaviour (27). Given the limited previous research in understanding the perceptions of HCPs working with people with MS and their insights into the acceptability and effectiveness of existing interventions, further work is warranted.

What are the research questions the project aims to answer? (maximum 200 words)

The proposed research aims to explore psychosocial professionals’ perceptions of the acceptability and effectiveness of psychosocial interventions in MS care. The research will therefore inform the design of future interventions delivered by MS health services, and training for healthcare professionals.

Please describe the research methodology for the project. (maximum 250 words)

The proposed research will consist of an online qualitative survey made up of a series of open ended questions. The questions will be based upon exploring the views of psychosocial professionals on psychosocial interventions for MS.

Section 3: Human Participants

Does the project involve human participants or their data? *If not, please proceed to Section 5: Data Collection, Storage and Disposal, you do not need to complete sections 3-4.*	Yes

Section 3.1: Participant Selection

Who are your participants?

Psychosocial professionals over the age of 18 years old who are involved in the delivery of psychosocial interventions for Multiple Sclerosis patients. For the purpose of the proposed research psychosocial professionals are seen as individuals who have professional qualifications in delivering psychosocial interventions (e.g. practitioner psychologists, counsellors, psychotherapists, Psychological Well-being practitioners, CBT therapists, psychotherapists and specialist nurses) and are a member of a professional body. Participants will self-select into the study based on the information provided.

Will you be recruiting students as research participants who are from outside your faculty and/or from multiple faculties? If you plan to recruit student participants from across UWE (rather than solely from your home faculty) your ethics application will be reviewed by UREC instead of the FREC.	No

Please explain the steps you will take to select your participant sample.

Psychosocial professionals will be recruited via a number of methods in an opportunity sample. This will include through advertisements on webpages of MS charities, social media, professional bodies, opportunity sampling through researchers contacts and advertisements. The MS Trust charity and the leading UK MS Therapy centre will email the advert through their mailing lists. Participants will self-select into the study based on the information provided.

However, NHS ethics is not required for the proposed study as the researcher will not be on site, nor using patient or staff data (see attached for email response).

Please explain how you will determine the sample size.

Braun and Clarke (2013) recommend a minimum sample size between 15-50 participants for a qualitative survey. The proposed research will therefore aim for 30 participants

Following feedback from the RD1 and previous ethics submission the study will now be recruiting psychosocial professionals who deliver MS psychosocial interventions. Previous studies including psychosocial professionals in their recruitment, have shown that this may include professionals such as practitioner psychologists, counsellors, psychotherapists, Psychological Well-being practitioners, CBT therapists, psychotherapists and specialist nurses (Harcourt et al, 2018, Psychological Professions network UK 2019).

Please tell us if any of the participants in your sample are vulnerable, or are potentially vulnerable and explain why they need to be included in your sample.

NB: Please do not feel that including vulnerable, or potentially vulnerable participants will be a bar to gaining ethical approval. Although there may be some circumstances where it is inappropriate to include certain participants, there are many projects which need to include vulnerable or potentially vulnerable participants in order to gain valuable research information. This particularly applies to projects where the aim of the research is to improve quality of life for people in these groups.

Vulnerable or potentially vulnerable participants that you **must** tell us about:

- Children under 18
- Adults who are unable to give informed consent
- Anyone who is seriously ill or has a terminal illness
- Anyone in an emergency or critical situation
- Anyone with a serious mental health issue that might impair their ability to consent, or cause the research to distress them
- Young offenders and prisoners
- Anyone with a relationship with the researcher(s)
- The elderly

The sample will not involve recruiting participants who are vulnerable or potentially vulnerable

Section 3.2: Participant Recruitment and Inclusion

How will you contact potential participants? Please select all that apply.

☒ Advertisement
☒ Emails
☐ Face-to-face approach
☐ Post
☒ Social media
☐ Telephone calls
☐ Other
If Other, please specify:

What recruitment information will you give potential participants?

Please ensure that you include a copy of the initial information for participants with your application.

Research Template Participant Information Sheet
Research Template Privacy Notice

Prior to starting the study participants will be provided with an information sheet, privacy notice and consent form. The information sheet will include the aims of the research, who is eligible to take part, how to withdraw from the study, what will be involved, the benefits and risks of participating, how the data will be used including where it will be published, who has ethically approved the study and researcher contact details. The privacy notice will provide further detail as to what happens with the participant's data.

(Please see attached participant information sheet, privacy notice and consent form)

How will you gain informed written consent from the participants?

Please ensure that you include a copy of the participant information sheet and consent form with your application.

Research Template Consent form
Research Template Privacy Notice

Prior to starting the study participants will be provided with online literature to allow them to make an informed decision as to whether they would like to take part in the research. This will include an online information sheet, privacy notice and consent form. The consent form will outline the rights the individual has should they decide to participate. Prior to giving consent to participate in the research participants will be fully informed of the nature of the study including the reasons for the study and what will be involved. If participants consent, they can click through to the survey by indicating agreement on the online consent form.

(Please see attached participant information sheet, privacy notice and consent form)

What arrangements are in place for participants to withdraw from the study?

Participants will be informed in the consent form and information sheet that taking part in the study is voluntary. Should a participant decide that they want to withdraw from the research after completing and submitting their online survey they will be able to contact the researcher to withdraw their data by providing their unique ID number. Participants will also be informed that they will have up to 2 weeks after submitting the survey to do this. Deciding not to participate or withdrawing from the study does not have a penalty and participants will not be questioned for reasons should they decide to withdraw.

(Please see attached participant consent form and information sheet)

Section 4: Human Tissue

Does the project involve human tissue?	No

If you answer 'No' to the above question, please go to Section 5

Please describe the research methodology that you will use.

This should include an explanation of why human tissue is required for the project and a description of the information that you and the research team will have access to about the participants/donors.

Click or tap here to enter text.

Please describe how you propose to obtain/collect, process, securely store and dispose of the human tissue.

Click or tap here to enter text.

Please explain if and how samples will be anonymised.

Where samples are not anonymised, please explain how confidentiality will be maintained, including how this information will be securely and appropriately stored and disposed of.

Click or tap here to enter text.

Section 5: Data Collection, Storage and Disposal

Research undertaken at UWE by staff and students must be GDPR compliant. For further guidance see Research and GDPR compliance

☒Please confirm that you have included the UWE Privacy Notice with the Participant Information Sheet and Consent Form

☒ By ticking this box, I confirm that I have read the Data Protection Research Standard, understand my responsibilities as a researcher and that my project has been designed in accordance with the Standard.

Section 5.1 Data Collection and Analysis

Which of these data collection methods will you be using? Please select all that apply.

☐ Interviews
☒ Questionnaires/surveys
☐ Focus groups
☐ Observation
☐ Secondary sources
☐ Clinical measurement
☐ Digital media
☐ Sample collection
☐ Other
If Other, please specify: Click or tap here to enter text.

Please note that online surveys must only be administered via Qualtrics
Please ensure that you include a copy of the questionnaire/survey with your application.

The online survey will be conducted via Qualtrics

What type of data will you be collecting?

☐ Quantitative data
☒ Qualitative data

Please describe the data analysis and data anonymisation methods.

Analysis:
Thematic analysis (TA) will be used to analyse the data that is collected. Braun and Clarke (2017) (30) highlight that TA, "is a method for identifying, analysing and reporting patterns (themes) within qualitative data" (pg 297). This particular type of analysis has been chosen as it allows in depth exploration of open ended responses from questionnaires whilst also allowing for flexibility when analysing data (31). Braun and Clarke's (2006) (32) guide of the six phases of analysis will be applied. A realist and inductive approach to the analysis will be adopted and data will be analysed at semantic level in line with Braun and Clarke guidance (2006, 2013) (28, 32)

Data anonymisation:
The identity of those taking part in the study will remain undisclosed and completed surveys will only be accessible by myself. At the start of the study participants will be asked to create a unique ID number which they will need to provide if they wish to withdraw at a later date. No names will be taken for data collection. Completed surveys will be submitted via a link from which participants will not be identified.

The demographic information sheet follows that which is suggested by Braun and Clarke (2017) (30). Demographic information will not be used alongside any of the participant's accounts that are used in the write-up to avoid any chance of participants being identified. The demographic information will help to ensure that the group being used is varied and diverse and come from a broad range of settings.

Participants will be asked to provide their email address should they chose to be included in the prize draw, however these will not be used for any further correspondence other than to contact the winner of the prize. Contact emails will not be linked to participants' data and will be stored separately.

Participants will be asked to avoid including any identifying information of patients in their survey responses. Should any identifying information still be mentioned in the survey, these will not be included in the write-up.

Section 5.2 Data Storage, Access and Security

Where will you store the data? Please select all that apply.

☐ H:\ drive on UWE network
☐ Restricted folder on S:\ drive
☒ Restricted folder on UWE OneDrive
☒ Other (including secure physical storage)
If Other, please specify: Password protected laptop and drive and a lockable cabinet

Please explain who will have access to the data.

The researcher, Natalie Garnett and supervisors, Dr Liz Jenkinson and Dr James Byron-Daniel will only have access to the data.

Please describe how you will maintain the security of the data and, where applicable, how you will transfer data between co-researchers.

Prior to starting the study participants will be informed that the research will comply in accordance with the (EU) 2016/679 General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Data from the study will be stored on a password protected laptop and password restricted folder on UWE OneDrive drive which only the researcher will have access to. Hard copies will be stored in a secure lockable cabinet in the office (3a19) of my supervisor Dr Liz Jenkinson at UWE.

Section 5.3 Data Disposal

Please explain when and how you will destroy personal data.

The data will be retained for a minimum of 6 years, and for as long as all interest in the project continues. Once these stages have passed, the computer files will then be deleted, and hard copies shredded. Participants may request access to their data should they choose to do so.

Section 6: Other Ethical Issues

What risks, if any, do the participants (or donors, if your project involves human tissue) face in taking part in the project and how will you address these risks?

It is not anticipated that participants who take part will experience any distress physically, psychologically or emotionally from the study. Participants will be asked to complete an online survey which they can complete whenever they choose and at their own pace within the given timeframe for submission. This allows for participants to also complete the survey in the comfort of an environment of their choice and not have any feelings of pressure from an interviewer. However, there is always the potential for research participation to unexpectedly raise uncomfortable or distressing issues. To address this participants will be provided with contact details of the researcher should the issue be related to the project itself. Contact details will also be provided of support that participants can access should they experience any distress arising from the survey.

Due to the nature of the survey questions there is the risk that participants may disclose identifying information of patients. To address this, information on how to complete the survey will be provided at the start, part of which will instruct participants to avoid mentioning any identifying information of patients in their survey responses. Should identifying information still be included after survey submission, the researcher will ensure that this is not included in the write-up.

NHS ethics is not required for the proposed study (see attached email response)

Are there any potential risks to researchers and any other people as a consequence of undertaking this project that are greater than those encountered in normal day-to-day life? For further information, see guidance on safety of social researchers.	
There are no risks to researchers or any other people which have been identified in the undertaking of the proposed research	
How will the results of the project be reported and disseminated? Please select all that apply.	
☒ Peer reviewed journal ☒ Conference presentation ☐ Internal report ☒ Dissertation/thesis ☒ Written feedback to participants ☒ Presentation to participants ☐ Report to funders ☐ Digital media ☐ Other If Other, please specify: Click or tap here to enter text.	
Does the project involve research that may be considered to be security sensitive? For further information, see UREC guidance for security sensitive research.	No
Please provide details of the research that may be considered to be security sensitive.	
N/A	
Does the project involve conducting research overseas?	No
Have you received approval from your Head of Department/Associate Dean (RKE) and is there sufficient insurance in place for your research overseas?	Not applicable
Please provide details of any ethical issues which may arise from conducting research overseas and how you will address these.	
N/A	

Section 7: Supporting Documentation

Please ensure that you provide copies of all relevant documentation, otherwise the review of your application will be delayed. Relevant documentation should include a copy of:

- The research proposal or project design.
- The participant information sheet and consent form, including a UWE privacy notice.
- The questionnaire/survey.
- External ethics approval and any supporting documentation.

Please clearly label each document - ensure you include the applicant's name, document type and version/date (e.g. Joe Bloggs - Questionnaire v1.5 191018).

Section 8: Declaration

☒ By ticking this box, I confirm that the information contained in this application, including any accompanying information is, to the best of my knowledge, complete and correct. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the right of the participants.

Name: Natalie Garnett
Date: 20/09/2019

This form should be submitted electronically to the Research Ethics Admin Team: researchethics@uwe.ac.uk and email copied to the Supervisor/Director of Studies where applicable, together with all supporting documentation (research proposal, participant information sheet, consent form etc).

Please provide all the information requested and justify where appropriate.

For further guidance, please see http://www1.uwe.ac.uk/research/researchethics (applicants' information)

APPENDIX N – ETHICAL APPROVAL LETTER

Ethics letter has been redacted for confidentiality reasons