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THE UTILITY OF GROUP NARRATIVE THERAPY TO FACILITATE
PSYCHOLOGICAL ADJUSTMENT IN MULTIPLE SCLEROSIS

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Major Research Project

SECTION A: A case for the role of narrative therapy in facilitating
psychological adjustment to Multiple Sclerosis: A review of
the empirical and conceptual literature

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SUMMARY

Section A

This section reviews and critically evaluates the empirical literature on psychosocial interventions for MS, the determinants of adjustment to MS, and the theoretical frameworks to account for these. Further, a conceptual and empirical review of the literature on narrative therapy is provided and an argument advanced for the utility of narrative therapy in facilitating adjustment to MS. Possible areas for further research are outlined.

Section B

This section described a feasibility study to test the effectiveness of group narrative therapy to facilitate adjustment to MS, as indicated by health related quality of life, use of adaptive coping processes, and illness representations. Trends were found for the mental health component of quality of life, confrontive coping, and the consequence component of illness representations. Coupled with overwhelmingly positive qualitative appraisals of the intervention these are promising findings in the context of a feasibility study and support replication using a sufficiently powered study. Issues pertaining to the feasibility of this study were explored and are discussed.

Section C

This section provides a reflection on the skills and abilities developed and learning needs identified whilst undertaking the research. It further offers a critical reflection on the study's methodology and the potential implications for clinical practice. Further potential lines of enquiry are outlined.

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SECTION A

Literature Review

A case for the role of narrative therapy in facilitating psychological adjustment to Multiple Sclerosis: A review of the empirical and conceptual literature

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Abstract

Multiple Sclerosis (MS) is a chronic and progressive neurological disorder that causes myriad disabling functional impairments. MS follows an uncertain and unpredictable trajectory, hence impacts on all facets of life and has a profound effect on psychosocial functioning. This review collates the evidence for psychosocial interventions in MS to date and builds a case for the utility of narrative therapy to facilitate psychosocial adjustment to MS by demonstrating that despite a growing evidence base to support the application of psychosocial interventions, many approaches focus on alleviating emotional distress. Subclinical levels of distress, however, are likely to impede adjustment to the illness experience by adversely affecting patients' quality of life. A review of the psychological determinants of psychosocial adjustment and theoretical frameworks to account for these are presented. It is argued that narrative therapy may be applied to facilitate adjustment by foregrounding multiple layers of lived experience that include, but are not limited to, the experience of psychological distress. Philosophical underpinnings of the approach will be discussed and an explanation of how these translate into therapeutic aims, generally and more specifically in the context of chronic illness and MS, will be provided. Finally, several potential fruitful areas for research are discussed.

A case for the role of narrative therapy in facilitating psychological adjustment to Multiple Sclerosis:

A review of the empirical and conceptual literature

Introduction

This review aims to collate the evidence for psychosocial interventions in Multiple Sclerosis (MS) with the view to building a case for the utility of narrative therapy in facilitating psychological adjustment to MS. To this end, a brief overview of the evidence for psychosocial interventions in MS and the psychosocial correlates associated with positive adjustment will be provided. A number of theoretical paradigms that may account for the observed associations will then be presented. The second half of the review will focus on the key tenets of narrative therapy before advancing an argument why narrative therapy may be a suitable intervention for MS patients. This is followed by a discussion of tentative hypotheses surrounding the pathways through which positive change may be realised, and a comprehensive review of the limited research into the utility of narrative therapy, and group narrative therapy in specific, available to date. Finally, directions for further research are suggested.

Multiple Sclerosis

MS is a chronic and progressive neurological disorder that affects approximately 100,000 people in the UK (The MS Society, n.d.). The onset of the disease typically occurs between the ages of 20 and 40 years and is more common in females than in males by a ratio of approximately 3:2 (The MS society, n.d.). MS is characterised by demyelination of the central nervous system, which refers to the loss of myelin; a protective layer that coats nerve

fibres and has a role in the transmission of nerve signals. Although the aetiology and development of this process is not fully understood, it is believed that it is mediated through an autoimmune reaction in which a combination of genetic and environmental factors may play a part (Compston & Coles, 2008). The disease manifests as plaques or lesions in the central nervous system, hence may affect a variety of functions, causing a wide range of neurological symptoms such as numbness, double vision, fatigue and problems with bladder control, as well as a variety of cognitive impairments (Compston & Coles, 2008).

MS is typically classified as following one of four trajectories: a benign course with little disease activity, a 'relapsing remitting' course marked by intermittent disease exacerbations, a 'secondary progressive' course that is more progressive in nature, and a 'primary progressive' course characterised by a steadily worsening of symptoms with no distinct pattern of relapse and remissions. Progression from a milder course to a more progressive course can occur at any time (Lublin & Reingold, 1996).

Effects of MS on psychosocial functioning

In addition to myriad disabling functional impairments, MS has a profound effect on psychosocial functioning by intruding on daily activities, family, social, and working life, and consequently on one's sense of self. Uncertainty and unpredictability pervades the illness experience from the onset of symptoms and the process of reaching a diagnosis; which, owing to the absence of a diagnostic test often follows a lengthy process of elimination; through to prognosis and the occurrence of relapses. The multifaceted impact of the disease and the uncertain and unpredictable nature of its course can lead to significant levels of emotional distress. Indeed, compared to both the general population and people with other chronic illnesses, MS patients are three times more likely to experience emotional distress

(Fisher & Crawford, 1994). Sadovnick, Eisen, Ebers, and Paty (1991) estimated that lifetime prevalence rates of a major depression among this group of patients are as high as 50 percent.

The National Institute of Clinical Excellence (NICE) acknowledges the need to pay attention to the emotional needs of MS patients alongside their physical needs and stipulates that psychosocial factors are addressed (NICE, 2003). Little guidance, however, is offered as to the form psychosocial interventions should take.

Psychosocial interventions for MS patients

In order to collate the current literature on psychosocial interventions for MS, a systematic literature search was conducted. See Appendix 1 for details of the search strategy.

This search identified two recent reviews on the effectiveness of psychosocial interventions in MS patients. These were considered to provide a comprehensive overview of the available literature. Therefore, any papers published prior to these reviews will not be reviewed separately.

Malcomson, Dunwoody and Lowe-Strong (2007) systemically reviewed thirty-three studies that investigated the effectiveness of psychosocial interventions for MS patients in enhancing quality of life and or emotional well-being. The review concluded that interventions varied greatly in content with many studies lacking adequate scientific quality to enable firm conclusions to be drawn. Limited support was found for the effectiveness of cognitive behavioural therapy (CBT) in reducing symptoms of depression, and for 'wellness and support groups', many of which included components of CBT such as goal setting and behavioural and cognitive techniques to monitor and challenge negative thoughts. Other effective components offered in wellness and support groups included exercise, discussion forums, multi disciplinary team support, and peer support. Notwithstanding encouraging

findings, the methodological quality of reviewed studies was rated as poor. In addition to small sample sizes, areas of particular concern included issues around external validity and measurement bias.

A recent Cochrane review identified sixteen randomised controlled studies (RCTs) on the effectiveness of psychological interventions for MS (Thomas, Thomas, Hillier, Galvin & Baker, 2009). Studies were included that examined interventions that were partly or wholly based on psychological theory in terms of disease specific outcomes, quality of life, psychological functioning or psychiatric symptoms. The authors concluded that there is reasonable evidence in support of cognitive behavioural approaches, the most frequently researched intervention, and limited evidence in support of group psychotherapy in the treatment of depression and in facilitating adjustment. However, due to the diversity of interventions used in the studies reviewed and the relative small sample sizes, no definitive conclusions could be drawn from aggregated findings. Authors conclude that there are large gaps in the evidence base for the use of psychosocial interventions for people with MS.

Finally, a recent pilot RCT (Forman & Lincoln, 2010) found some support for the effectiveness of an adjustment group focused on problem solving, coping skills, and relationships, compared to a waiting list control group in reducing depressive symptomatology. The group, however, failed to improve quality of life. Owing to the small sample size of 40, it is possible that the study lacked sufficient power to detect smaller sized effects. Despite low attrition, the uptake of was poor, representing only a quarter of people who had been screened for low mood and were deemed eligible to take part. This raises questions around the acceptability of this intervention, prompting authors to conclude that other types of interventions need to be evaluated.

In summary, an overview of the literature on psychosocial interventions for MS suggests that the evidence base, in particular for CBT, is growing. The considerable diversity of interventions and methodological shortcomings, however, precludes the ability to draw firm conclusions from the amalgamation of present research. Primary gaps highlighted include the absence of higher quality studies that are sufficiently powered and empirical inquiry into the effectiveness and acceptability of a wider range of therapeutic modalities.

Psychosocial adjustment to MS

The study of different psychosocial interventions to facilitate psychosocial adjustment in MS may benefit from greater insight into the potential mediating pathways. To this end, the next section provides an overview of available evidence surrounding psychosocial correlates of psychosocial adjustment and the theoretical frameworks through which their effects could be understood.

Empirical literature regarding correlates of psychosocial adjustment

A recent systematic review (Dennison, Moss-Morris & Chalder, 2009) of 72 studies identified several predictors of successful and poor psychological adjustment in MS patients. The strongest predictors of successful adjustment included positive re-appraisal, problem-focused coping strategies, seeking social support, and adaptive cognitive representations of MS such as perceived control and self-efficacy. Conversely, coping through avoidance, helplessness and perceived uncertainty about the illness were identified as strong predictors of adjustment difficulties.

Theoretical frameworks

A number of coping theories may account for the protective effect of the psychological factors identified. The literature draws a distinction between ‘coping’ theories and ‘social-cognitive’ theories of coping (e.g. Brennan, 2001). Broadly speaking, they differ in the extent to which coping is considered a static attitudinal trait as opposed to a situation-specific dynamic process reflecting the social and cognitive developments that confrontation with a life-threatening illness gives rise to.

The most widely known ‘coping model’ is Lazarus and Folkman’s (1984) stress-coping model; according to which the experience of psychological distress can be understood as the appraisal of internal and external demands that exceed one’s resources. A subsequent illness-specific extension of this model postulates that adjustment is determined by the relative use of problem-focused and emotion-focused coping strategies, the selection of which is not only a function of the appraisal of the stressor but also of a person’s social context and representation of the disease (Maes, Leventhal & De Ridder, 1996).

Most research into the validity of coping models has focused on the relationship between coping styles and psychological outcomes using cross-sectional designs that preclude inferences of causality (e.g. Parle, Jones & Maguire, 1996). The only coping response supported by evidence from, methodological stronger, prospective studies is active coping (e.g. Manuel, Roth, Keefe & Brantley, 1987; Pakenham, 1999), which is consistently associated with personal control and self-efficacy (e.g. Dodds et al., 1994). Lazarus (1993) posits that the limited utility of coping models in accounting for behavioural responses to physical illness stems from the multidimensional nature of the threat posed by physical illness and the difficulty in pinpointing the immediate threat of concern.

Despite their heuristic value, coping models have also been criticised for having

limited clinical utility (Somerfield, 1997) and for ‘failing to take into account the existential reality of individuals faced with a life threatening illness’ (Spiegel, 1997, p. 170).

Social-cognitive models postulate that coping constitutes a dynamic process (e.g. Janoff-Bulman, 1992). They reject the assumption that coping is a stable attitudinal trait and place more emphasis on the broader social-cognitive adaptations to a person’s ‘assumptive world’ that confrontation with a severe illness necessitates (Parkes, 1988). The assumptive world denotes the cognitive structures that reflect the accumulation of a person’s life experiences, influenced by attachment, social and cultural factors that serve as a template for making sense of the world. Janoff-Bulman (1992) argued that confrontation with a severe illness is likely to challenge fundamental aspects of one’s assumptive world.

A distinct feature of social-cognitive models is the assumption that people normally move through different sets of responses across different stages of illness. This notion is empirically supported by the trauma and bereavement literature (Parkes, 1988; Ehlers & Steil, 1995), which suggests that different sets of coping mechanisms may be adaptive at different times following trauma. In the initial stages, denial and avoidance may serve to protect one’s self-concept from the enormous impact of a crisis. A competing need to integrate new information into existing schemas, however, may gradually prompt individuals to turn towards the crisis (e.g. Horowitz, 1986) by adopting active coping strategies, thereby preparing the assumptive world for future crises.

According to Brennan (2001), neither coping models nor social-cognitive models adequately account for the vast individual differences in the extent to which confrontation with a severe illness renders some, but not all, people vulnerable to the development of psychological distress. He notes that some people appear to be more adept at negotiating the dramatic changes forced upon them when struck by illness, and undergo a positive

transformation characterised by a sense of personal growth. The positive effect of the use of cognitive coping processes such as positive re-appraisal on adjustment to MS lends support to this notion. Further, evidence suggests that the identification of benefits such as improved relationships with family, increased compassion, and enhanced appreciation of life, is associated with positive re-appraisal (Mohr et al., 1999).

Drawing on the assets of both models, Brennon (2001) developed the social-cognitive transition model (SCT) in an attempt to bridge the theory-practice link in the context of physical illness. SCT holds that individual differences in response to illness are a function of the relative influence of a complex matrix of factors including a) the construction of a person's assumptive world, b) the composition of the social contexts through which a crisis is experienced, and c) the characteristic styles of responding inherent in the person faced with it. The model proposes clear directions for psychosocial interventions purported to foster change at intra-psychic and interpersonal levels. For example, in light of the consistent evidence that self-efficacy and personal control are associated with active coping and reduced distress, the model suggests that psychosocial interventions should focus on helping people resume a sense of control and re-appraise the meaning of control to accommodate the actual losses and the associated sense of uncertainty experienced in respect of the future. Reflecting the psychosocial ethos of the model, the model further suggests that interventions should place a greater emphasis on the positive and negative transitions that take place in people's social contexts. This is consistent with evidence that re-appraisal of close attachments foster more valued and intimate relationships (Moorey & Greer, 1989), and that social support is an effective buffer against the effects of stress (Cohen & Wills, 1985).

As explained more fully in subsequent sections, narrative therapy may facilitate the process by which people with a severe illness such as MS make the necessary adjustments to

their assumptive worlds whilst opening up space for personal growth and reconnecting with wider family and community systems.

Narrative therapy

History and epistemological underpinnings

Narrative therapy evolved from a synthesis of several streams within the social sciences and humanities that are grounded in poststructuralist and postmodernist epistemologies (e.g. McLeod, 1996). These epistemologies have in common their rejection of an 'objective reality' that can be unveiled with the application of pragmatic and empiricist approaches. Instead, they argue that realities are socially constructed and constituted and legitimised through language. Essential truths do not exist within this framework of thought. Instead, knowledge is seen as one of many possible interpretations of experience. Hence, central to this worldview is the notion that multiple 'realities' can co-exist (Hoffman, 1990), enabling a celebration of diversity.

Development of narrative therapy and key influences

Michael White and David Epston (1990), who pioneered narrative therapy, embraced this somewhat radical shift in thinking and conceptualising human experiences by adopting the 'narrative' or 'story' metaphor in their therapeutic work. Their work owes much to Foucauldian principles, most notably Foucault's 'analytics of power'. This encapsulates the notion that power shapes people's lives by determining what constitutes 'truth' or 'knowledge', which in turn functions as a vehicle for power. Further borrowing from Foucault, White and Epston asserted that power is best conceived of as a 'subjugating' force that exerts its influence by positioning people in roles that serve to legitimise 'global truths'.

Although guided by Foucauldian principles, White and Epston's construction of the narrative metaphor was strongly influenced by two of Bateson's (1972) key principles, reflecting the approach's links with systems theory. The first is Bateson's use of the metaphor 'map' in representing his notion of the 'interpretative method', which White and Epston conceived of as meaning that "since we cannot know objective reality, all knowing requires an act of interpretation that is determined by how things fit into the known pattern of events" (White & Epston, 1990, p 2). The word map in this sense represents one's internal representations of external 'reality', which privileges certain details and obscures others. The second principle relates to the perception of difference in the interpretation of reality, and in particular, the temporal dimension that Bateson placed upon it. Bateson saw the perception of difference as the catalyst to triggering new responses and proposed that: "the mapping of events through time is essential for the perception of difference and for the detection of change" (White & Epston, 1990, p. 2).

Uniting these two related principles, the narrative metaphor engenders appreciation of the 'multi-storied' nature of lives and stimulates curiosity in the active search for untold stories, thereby creating space for alternative and richer narratives. It perceives of distress in terms of the subjugation of stories that are seemingly incongruent with dominant cultural and societal discourses. The more salient such discourses are to a presenting problem, the greater the sense of oppression and level of subjugation. Narrative therapy encourages individuals to identify and deconstruct the negative influence of attitudes, values, and practices that reside in the wider systems that surround them (Freedman & Combs, 1996).

Clinical application

Informed by the ideas described above, the central aim of narrative therapy is to

separate individual lives from ‘unitary knowledges’, to ‘challenge the techniques of power’ and to ‘resurrect subjugated knowledges’ (White & Epston, 1990). Despite a comprehensive list of techniques developed in pursuit of this, Freedman and Combs (1996) remind therapists that their application can only come to fruition in the context of a therapy that embraces the overarching philosophical stance advocated by White and Epston in which “any techniques that subjugate persons to a dominant ideology” are challenged (White & Epston, 1990. p.2). With this therapeutic stance in place, the therapeutic process broadly includes: externalising conversations in which problem saturated stories are disconnected from individual lives and deconstructed to promote separation from ‘unitary knowledges’; relative influence questions to map the influence of the problem relative to the influence of the person over the problem; drawing out unique outcomes to open space for the construction of alternative narratives; thickening the alternative narrative by linking it to the past and the future; widening the audience to encourage circulation of the preferred story that carries the resurrection of subjugated stories within that community.

The next section offers an overview of the research into the therapeutic value of this approach.

Empirical research

A scoping literature search identified a review of the available research into narrative therapy (Etchison & Kleist, 2000). A systematic literature search to identify additional research papers was conducted, details of which are listed in Appendix 1¹. In addition to the

¹ Since the term ‘narrative’ has multiple meanings within the psychotherapy literature, only papers that described research into narrative therapy underpinned by a postmodern epistemology as explicated above were deemed relevant to the scope of this paper.

review, four papers were identified that met these criteria, suggesting that despite the growing popularity of narrative therapy, research attesting to its utility remains sparse. Outcome studies, in particular, appear in short supply.

The scarcity of empirical research probably reflects the assumption that quantitative research paradigms are inconsistent with the postmodern underpinnings of narrative therapy. In keeping with its core premise, however, it could be argued that failure to engage with dominant scientific discourses renders the approach at risk of being subject to the very subjugating processes that it aims to challenge. Indeed, some scholars have advocated for more systematic research in this area (e.g. McLeod & Balamoutsou, 1996). Some tentative attempts at measuring outcomes of narrative therapy using quantitative approaches have been made and will be discussed alongside a brief overview of the, predominantly qualitative, research available to date.

The review by Etchison and Kleist (2000) revealed a limited number of studies, the majority of which employed a qualitative approach and focused on interpersonal problems as the target of intervention. Using an ethnographic research design, St. James-O'Connor, Meakes, Pickering & Schuman (1997) examined the meanings families engaged in narrative therapy attributed to their experience. The authors concluded that the empowerment of personal agency implicit in the aims of narrative therapy appeared to comprise a key factor in enabling the co-construction of alternative narratives and hypothesised that this may have contributed to the perceived reduction in the presenting problem reported by all participants. They further concluded that this process was facilitated by the presence of an appreciative audience to acknowledge these shifts. The importance of enhancing personal agency was corroborated by findings from a later ethnographic study by the same author group, which examined therapists' experiences of utilising narrative therapy (St. James O'Connor, Davis,

Meakes, Pickering & Schuman, 2004). Using a qualitative method of constant comparison, Coulehan, Friedlander, and Heatherington, (1998) further reported that articulation of alternative descriptions, meanings, and attributions through the construction of alternative narratives helped transform problem descriptions from an individual to an interpersonal level. Similarly, using a single case research design Besa (1994) supported the value of narrative therapy in reducing interpersonal problems within families, specifically parent-child conflicts. Finally, Weston, Boxer, and Heatherington (1998) reported that the construction of narratives around family conflict promotes the development of multiple perspectives on the causes of the conflict.

A case study not included in Etchison and Kleist's (2000) review further suggests that the process of re-authoring family narratives surrounding the experience of affective illness in parents can help foster coherence in otherwise fragmented narratives that endorse cultural 'canons' about mental illness (Focht & Beardslee, 1996).

Group narrative therapy

Since narrative therapy is predicated on the notion that problem-saturated stories are socially and culturally constructed, involvement of the wider context is an integral part of the therapeutic process. Not only does the approach invite perspectives of members from relevant cultures to assist individuals in re-authoring their identities, active attempt are also made to feed alternative narratives back into people's wider contexts. Given the intrapersonal emphasis on the therapeutic process, it has been argued that narrative therapy is particularly conducive to being delivered in a group format (Behan, 1999). Indeed four of the identified studies have adopted a group approach.

Vassalo (1998) documents one of the first efforts to apply the principles of narrative

therapy to a therapeutic group comprising people with a history of psychosis. Reports of the subjective experience of participants suggest that the intervention had a transformative effect by enhancing confidence, improving relationships, and fostering self-acceptance. However, no formal qualitative or quantitative evaluations of this group were undertaken. Hence, this study's scientific validity is compromised by its failure to attempt to demonstrate its effectiveness or link the meaning participants assign to their experiences of the group to the theoretical tenets that underpin narrative therapy.

Using a mixed methodology, Weber, Davis & McPhie (2006) reported that group narrative therapy for women with an eating disorder reduced post-intervention depression scores and eating disorder risk relative to pre-intervention scores in a sample of seven women. Although the sample was too small to apply statistical analyses, the improvements were supported by a qualitative account of participants' experiences, which revealed that externalisation of, and disengagement from, the eating disorder empowered the women to make positive changes in their lives.

Using an ethnographic research design, Poole, Gardner, Flower, and Cooper (2009) examined what older adults with mental health and substance misuse issues found helpful about a narrative group therapy intervention. In addition to the emergence of general themes such as the empowering effect and general sense of acceptance conveyed by the approach, results suggested that many participants particularly valued the supportive effect of the group.

Finally, in an evaluation of the effectiveness of a narrative therapy group for managing anger in people with learning disabilities, Hoole and Morgan (2008) reported marked reductions in behavioural measures of aggression. Quantitative measures of anger, however, failed to support these reports and only showed slight, yet clinically non-significant, improvements.

Critique of the research into narrative therapy

A key strength of the preference for qualitative methodology in the empirical enquiry into narrative therapy is the possibility for some of the processes of change to be elucidated. Not all of the abovementioned studies, however, have clearly specified their research methodology (Vassalo, 1998; Weber, Davis & McPhie, 2006; Hoole & Morgan, 2008), hence the integrity of some of this research is difficult to evaluate.

Of the studies that have specified their methodology, context-sensitive research methods such as ethnography appear to feature strongly in the research to date. This probably reflects the epistemological foundations of narrative therapy. A central facet of an ethnographic research design is the positioning of participants as co-researchers. Given the power differential inherent in the therapeutic setting to which the researchers in the studies discussed above are allied, however, it is unclear to what extent the true positioning of participants as co-researchers could be realised. Further, ethnography commands that researchers own their own perspective by acknowledging their 'constitutive' influence to the subject under study. Although this comprises one of the prime criteria for good qualitative research (Elliot, Fisher & Rennie, 1999), emphasis on the unique product of the participant-researcher encounter goes at the expense of generalisability. Hence, although ethnographic studies may lead to enriched understandings, considered in isolation they translate poorly into guidelines for clinical practice.

Studies that have employed quantitative methodologies are small in number and limited to case studies and mixed method designs. Although, taken together, these studies have delivered promising findings, they lack the scientific rigour needed to draw firm

conclusions around the effectiveness of narrative therapy. Indeed, narrative therapy has not yet been tested using a randomised controlled design, or in other comparison research.

Drawing on these findings, the following sections will discuss how the principles of narrative therapy may be utilised to facilitate psychosocial adjustment to a chronic illness such as MS.

Narrative therapy to facilitate adjustment to MS

Psychological Interventions typically offered to patients suffering with chronic, debilitating, illnesses such as MS tend to target manifestations of distress. In other words, they are symptom-orientated and focus on single, surface level, dimensions of personal narratives. Whilst the treatment of clinical levels of anxiety and depression, commonly found in patients with MS, is imperative, suboptimal levels of coping responses may go unnoticed and subsequently untreated. This might impede opportunities to bolster or develop adaptive coping responses necessary for psychosocial adjustment. Cohler (1982) for example, argued that diagnosis of a serious illness such as MS challenges an individual's cohesive sense of past, present and future, i.e. their personal narrative in its entirety. This means that a person's ability to identify and deploy coping strategies that may have worked very well in the past, is likely impaired, and calls for the need to revise personal narratives in order to integrate traumatic illness experiences.

MS narratives are likely to interface with and foreground several internalised dominant discourses surrounding notions of illness, health, success, morality, death, and so on, all of which become more salient as the lived-experience of MS becomes stronger. Personal narratives that link present experiences of self to the past and the future become severely unhinged, losing their temporal dimension to the extent that "the present no longer

represents what the past implied and the future becomes unthinkable” (Frank, 1995).

Deconstruction of the subjugating discourses that influence the experiences of MS may alleviate their restrictive effect on the formulation of a coherent illness narrative (Frank, 1995).

The literature suggests several ways in which narrative therapy may facilitate coping, thereby promoting adjustment. (Details of the literature search conducted to inform this section are provided in Appendix 1). The process of externalisation and objectification allows distancing from the problem to occur (Carlick & Biley, 2004), and makes the experience more circumscribed (Pennebaker, 1985). This enables novel, and liberating perspectives to be brought to light (Carlick & Biley, 2004), and enriched meanings to be given to the experience (Taylor, 1983). Careful observation of people with severe illnesses such as cancer who demonstrated remarkable levels of resilience has led Petersen, Bull, Propst, Dettinger, & Detwiler (2005) to propose that engagement with the following three activities is conducive to positive adjustment: re-appraisal, meaning making, and integration of experience. The collective application of some of the key tenets of narrative therapy may foster engagement with this set of activities, specifically the process of deconstruction, resurfacing of overlooked stories, and meaning making through the construction of alternative stories that are more congruent with one’s self image and past experiences.

Uncertainty has been consistently associated with increased levels of helplessness and depression (Dennison et al., 2009). Eeltink and Duffy (2004) suggest that uncertainty may comprise a dominant ‘subplot’ for MS patients and propose that narrative therapy may be a helpful vehicle through which the experience of uncertainty can be re-authored and integrated within personal narratives as comprising a normal component of life. Additionally, they assert that dominant subplots such as uncertainty can have oppressive effects by silencing

both patients and their family members for fear of evoking the difficult and painful feelings surrounding themes like deterioration of health and death. Indeed, Frank (1995) claims that the more uncertain the course of an illness, the less likely a so-called 'restitution' narrative, one that resonates with the wider environment and serves as a template for conversations, can be formed. By affording people the opportunity to resist such silencing discourses, and by allowing people's experiences to be represented in language, narrative therapy may help create new opportunities for reconnecting with the wider environment (Hyden, 1997). This process may enhance people's ability to elicit support that resides within their immediate environments, hence may facilitate coping through seeking social support, in particular empathic social support.

Theoretical and empirical challenges

Although the literature surrounding adjustment to physical illness, including MS, is steadily growing, the conceptual landscape to account for known adaptive and maladaptive correlates to psychosocial adjustment remains broad and relatively non-specific. The research informed by coping models suggests that coping comprises a complex, dynamic, and multifaceted process. Hence, although theoretical models such as the SCT have clinical value by aiding our understanding of the individual differences in adjustment to severe physical illness and offering directions for therapeutic interventions, the hypotheses derived from it are endless and do not neatly map onto a single therapeutic intervention. Indeed, Brennan (2001) admits that there are many gaps in the SCT and that the way in which illness affects core assumptions remains poorly understood. Although unidimensional concepts such as self-efficacy and personal control may reflect aspects of the assumptive world, the broader dimensions implicated in it may be better captured by quality of life indices (Brennan, 2001).

Unfortunately, despite valid theoretical reasons to select such global outcome measures, they are poorly suited to the testing of specific hypotheses.

In summary, although the literature has begun to make some claims surrounding the likely 'active ingredients' of narrative therapy, it is clear that these are tentative and far from exhaustive.

General critique and unanswered questions

Given the evidence that several psychological factors appear to play a role in adjustment to MS it is clear that the scope for psychosocial interventions is broad. However, despite a growing number of outcome studies to evaluate the effectiveness of psychosocial interventions for this population, significant weaknesses inherent in the designs of the available research means that no single intervention has gained robust support. Many of the studies that demonstrated positive findings have shown reductions in clinical levels of emotional distress. However, in accordance with a person-centred approach, NICE guidelines for the management of MS advocate for the routine implementation of psychosocial management, irrespective of the presence of clinical levels of distress.

This stance is supported by the coping literature, which highlights the complex and dynamic nature of psychosocial adjustment and considers the experience of clinical levels of distress as representing just one of multiple dimensions. Narrative therapy recognises the presence of multiple layers of lived experience, including, but not limited to, the experience of illness and psychological distress. It aims to diminish the problem-saturated stories that are at the root of the development of psychological distress by privileging stories that are more coherent with one's personal narrative.

Although the emerging literature provides a reasonably sound theoretical argument

for the application of narrative therapy, the model's utility in the context of MS, or indeed chronic illness generally, has not yet been tested empirically. In fact, a review of the available literature suggests that current research into the utility of narrative therapy is limited, in terms of both scope and empirical paradigm. It appears that expansion of the research is hampered by the dominant view that narrative therapy should be evaluated by methods that are epistemologically congruent with the postmodern foundations of the approach. As argued earlier however, by rigidly subscribing to this view and failing to engage with positivist research paradigms narrative therapy risks subjecting itself to the same subjugating processes it aims to circumvent. Hence, in the absence of any empirical evidence, the evaluation of the effectiveness of narrative therapy in a sample of MS patients is a timely topic of research.

Future Research

Future research may wish to expand on existing literature by addressing the following questions:

- Can the limited but emerging evidence for the utility of narrative therapy be demonstrated in a sample of MS patients?
- Can the effectiveness of narrative therapy be demonstrated using a quantitative research paradigm?
- Does narrative therapy enhance MS patients' ability to draw on adaptive coping strategies?
- Are increases in perceived quality of life reflected in ways of coping and in patients' cognitive representations of illness?

- Is delivery of narrative therapy in a group format suitable?
- What are the active ingredients of narrative therapy? To what extent do these map onto the core therapeutic tenets?

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Major Research Project

SECTION B

Journal article

The utility of group narrative therapy to facilitate psychosocial adjustment in multiple sclerosis: A feasibility study

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Abstract

The aim of this study was to begin to test a theoretical argument for the application of group narrative therapy to facilitate psychosocial adjustment to MS, and to ascertain the feasibility of a larger scale randomised controlled trial. Fourteen MS patients received 8-weekly sessions of group narrative therapy delivered at two sites in England. Quality of life, coping processes, and illness representations were assessed at two time points prior to the intervention and immediately after the intervention, and analysed using Wilcoxon Matched-Pairs tests. Additional qualitative measures were taken and analysed using content analysis. The feasibility of a larger scale study was, in part, assessed by means of semi-structured interviews with health professionals involved in the study, and analysed using thematic analysis. Although none of the findings reached statistical significance upon correcting for multiple comparisons, positive trends were revealed for the mental health component of quality of life, confrontive coping, and the consequences component of illness representations. With respect to the feasibility of this study, several issues pertaining to recruitment and data collection emerged from the data that can inform future research. Taken together, the results of this pilot study are promising and warrant further investigation using a sufficiently large sample.

KEY WORDS: narrative therapy; group narrative therapy; multiple sclerosis; psychosocial adjustment; coping with chronic illness; illness representations

Multiple Sclerosis

Multiple Sclerosis (MS) is a chronic and progressive neurological disorder characterised by the loss of myelin, a protective layer that coats nerve fibres and has a role in the transmission of nerve signals (Compston & Coles, 2008). Although the aetiology of this process is not fully understood, it is believed that it is mediated through an autoimmune reaction in which a combination of genetic and environmental factors plays a part (Compston & Coles, 2008). The onset of the disease typically occurs between the ages of 20 and 40 years and is more common in females by a ratio of approximately 3:2 (MS society, 2011). The disease is typically classified as following one of four trajectories: a benign course with little disease activity, a 'relapsing remitting' course marked by intermittent disease exacerbations, a 'secondary progressive' course that is more progressive in nature, and a 'primary progressive' course characterised by a steadily worsening of symptoms. Progression from a milder course to a more progressive course can occur at any time (Lublin & Reingold, 1996).

Effects of MS

The disease manifests as plaques or lesions in the central nervous system, causing a wide range of neurological symptoms such as numbness, double vision, fatigue, as well as a variety of cognitive impairments (Compston & Coles, 2008). MS also has a profound effect on psychosocial functioning as it intrudes on all facets of life and consequently on one's sense of self (Eeltink & Duffy, 2004). This can lead to significant levels of emotional distress. Indeed, MS patients are three times more likely to experience emotional distress compared to the general population and patients suffering from other chronic illnesses (Fisher & Crawford, 1994).

The UK National Institute of Clinical Excellence (NICE) acknowledges the need to

pay attention to the emotional needs of MS patients alongside their physical needs and stipulates that psychosocial factors are addressed (NICE, 2003). Little guidance, however, is offered as to the form psychosocial interventions should take.

Psychosocial interventions for MS

Two recent literature reviews have synthesised current research into the effectiveness of psychosocial interventions for MS. A systematic review of thirty-three studies found limited evidence for the effectiveness of cognitive behavioural therapy (CBT) in reducing symptoms of depression and some evidence for ‘wellness and support groups’ that incorporated CBT techniques, in enhancing quality of life (Malcomson, Dunwoody & Lowe-Strong, 2007). The authors, however, concluded that many of the reviewed studies lacked adequate scientific quality. They further recommended that future research endeavours include rigorous evaluation of interventions other than CBT.

A Cochrane review of sixteen randomised controlled trials (RCTs) found reasonable evidence in support of CBT and limited evidence in support of group psychotherapy in the treatment of depression secondary to MS and in facilitating adjustment, as indicated by quality of life indices (Thomas, Thomas, Hillier, Galvin & Baker, 2009). The diverse range of interventions and the relatively small sample sizes, however, reduced the strength of inferences that could be drawn from aggregated findings.

Narrative therapy to facilitate adjustment to MS

It appears that symptom-oriented interventions such as CBT are overrepresented in the research into psychosocial interventions for MS. Not all MS patients, however, suffer clinical levels of emotional distress. Yet, subclinical levels of distress are likely to impinge on

patients' quality of life, leaving them poorly equipped to adjust to a life of uncertainty.

Quality of life comprises a multidimensional concept containing interacting objective and subjective elements (Costanza, 2008), hence may be difficult to target by focusing on the source of emotional distress alone.

Narrative therapy may sidestep a debate around defining clinical and subclinical levels of distress by capitalising on the many ways in which lives can be 'storied'. Pioneered by White and Epsom (1990), narrative therapy purposefully aims to turn the gaze away from unidimensional or 'problem-saturated' stories about the self towards narratives of strength and resilience. Rooted in a poststructuralist worldview, which rejects the notion of an essential truth, narrative therapy stimulates curiosity in the active search for 'alternative narratives'. Influenced by theorists such as Foucault, the approach perceives distress as the internalisation of dominant cultural and societal discourses that serve to subjugate untold stories about the self. Indeed, narratives around MS are likely to interface with and foreground several of such internalised discourses such as those surrounding notions of illness, disability, health, and so on. The aim of narrative therapy is to enable liberation from their potentially oppressive influence. This is facilitated through the following therapeutic processes: externalising the 'problem'; mapping the influence of the 'problem'; deconstructing 'unitary knowledges'; drawing out unique outcomes to enable enriched narratives to emerge; and widening the audience to encourage circulation of preferred narratives.

Empirical research and narrative therapy

A review of the utility of narrative therapy concluded that although the approach has some useful application, the breadth of research is limited in both scope and empirical

paradigm (Etchison & Kleist, 2000). Probably reflecting its epistemological underpinnings, the majority of the research included in this review employed a qualitative paradigm with an overrepresentation of interpersonal problems as the target problem. This body of research, for example, suggests that people engaged in the construction of (alternative) narratives appear to develop multiple perspectives on the causes of conflict (Weston, Friedlander & Boxer, 1998) and experience a transformation of problem descriptions from an individual to an interpersonal level (Coulehan, Friedlander & Heatherington, 1998).

Group interventions

Given that narrative therapy is predicated on the notion that problem-saturated stories are socially and culturally constructed, active involvement of the wider context is considered an integral part of the therapeutic process. It has been argued, therefore, that the approach is particularly conducive to delivery in a group (Behan, 1999). This notion is supported by studies demonstrating the viability of a group format whilst delivering positive, albeit preliminary, qualitative outcomes in populations with a history of psychosis (Vassallo, 1998) and substance misuse (Poole, Gardner, Flower & Cooper, 2009).

Psychological mechanisms underpinning adjustment to MS

Notwithstanding the emphasis on the social construction of MS, theoretically, narrative therapy would presuppose that adjustment is fostered by a change in people's relationship to MS. In addition to symptom reduction, psychosocial interventions for MS are typically evaluated according to quality of life, as an indicator of adjustment (e.g. Dennison, Yardley, Devereux & Moss-Morris, 2011). Given the multidimensional nature of quality of life, an exploration of the components involved in adjustment may enhance our

understanding of the process underlying it. To this end, the next sections provide an overview of psychosocial correlates of adjustment and the theoretical frameworks, drawing on the coping literature, to account for these.

Psychosocial correlates of adjustment

A recent systematic review identified positive re-appraisal, problem-focused coping strategies, seeking social support, and adaptive cognitive representations of MS such as perceived control and self-efficacy as the strongest predictors of psychosocial adjustment to MS (Dennison, Moss-Morris & Chalder, 2009). Conversely, coping through avoidance, helplessness and perceived uncertainty about the illness were identified as strong predictors of adjustment difficulties. The literature on coping may illuminate our understanding of some of the protective and/or restorative effects of these psychological processes.

Coping

The most widely known coping model is Lazarus and Folkman's (1984) stress-coping model, which conceptualises the experience of psychological distress and the consequent selection of coping strategies as an appraisal of internal and external demands that exceed one's resources. Whilst active and passive coping have been consistently associated with better and poorer adjustment to chronic illness, respectively (see Maes, Leventhal & de Ridder, 1996, for a review), the model's dominant focus on coping behaviour to account for levels of distress, has been subject to criticism (e.g. Pakenham, 1999). A subsequent illness-specific adaptation of the model postulates that the selection of coping strategies is not only a function of the appraisal of the stressor relative to the available coping resources but also of a person's social context and representation of the disease (Maes et al., 1996). Five dimensions of illness representations isolated by Leventhal, Nerenz & Steele (1984) have been

consistently associated with degrees of psychosocial adjustment: identity, consequences, cause, timeline and cure or control (e.g. Scharloo et al., 1998). Strong relationships between several permutations of illness representations and measures of physical disability and emotional distress have also been demonstrated in a sample of MS patients, with the component consequences accounting for the largest proportion of variance (Vaughan, Morris, & Miller, 2003).

Despite their parsimony, some contend that coping models have failed to bridge the gap between research and clinical practice (e.g. Somerfield, 1997). Brennan (2001) attributes this failure to the unwieldy complexity of taxonomies of appraisals and coping responses, and the inability of coping models to accommodate the changes, including positive and negative transitions, that people confronted with serious illness have to make to their 'assumptive worlds' (Janoff-Bulman, 1992). He therefore argues that the dynamic and multifaceted nature of coping processes is best captured by quality of life indices that are broader in focus.

Mechanisms through which narrative therapy may promote adjustment to MS

Eeltink and Duffy (2004) posited that the process of 'restorying' the illness experience by attending to both positive and negative meanings can assist the re-appraisal process needed to make the necessary adjustments to one's assumptive world. Following careful observation of people with severe illnesses such as cancer who demonstrated remarkable levels of resilience Peterson, Bull, Propst, Dettinger, and Detwiler (2005) proposed that engagement with the following three activities is conducive to positive adjustment: re-appraisal, meaning making, and integration of experience. The collective application of some of the key tenets of narrative therapy may foster engagement with this set of activities, specifically the process of deconstruction, resurfacing of overlooked stories, and

meaning making through the construction of alternative stories that are more congruent with one's self image and past experiences.

Rationale

In light of NICE guidance, which advocates the routine implementation of psychosocial interventions in the management of MS, it is clear that the evidence base for psychosocial interventions for MS is in need of expansion beyond interventions focused solely on symptom reduction. The emerging theoretical literature provides a reasonably sound argument for the application of narrative therapy in the domain of chronic illness including MS. It appears that the research in this area is hampered by the dominant view that narrative therapy must be evaluated by methods that are epistemologically congruent with the postmodern foundations of the approach. However, by rigidly subscribing to this view and by failing to engage with positivist research paradigms, narrative therapy risks subjecting itself to the same subjugating processes it aims to circumvent. Hence, in the absence of empirical evidence, the aim of the present study was to begin the process of evaluating the effectiveness and the feasibility of group narrative therapy in a sample of MS patients using a mixed method.

The overarching research questions informing the present study were:

- 1) Can the utility of group narrative therapy be demonstrated in a sample of MS patients?

To this end, drawing on the aforementioned research and theory, the following specific hypotheses were tested:

- a. Group narrative therapy will facilitate adjustment to MS as indicated by an improvement in health related quality of life.
 - b. Group narrative therapy will enhance MS patients' ability to engage with adaptive coping processes, as reflected in an increase of active coping processes relative to emotion-focused coping processes.
 - c. Group narrative therapy will engender more favourable illness representations.
- 2) Is this a feasible research design to test the effectiveness of group narrative therapy in a larger scale study?

Method

Sample

Participants comprised MS patients, recruited by two MS specialist nurses and a clinical psychologist within two NHS Trusts in England. Additionally, participants were recruited through two local branches of the MS society via advertisement in a monthly newspaper (Appendix 2) and a presentation delivered at a meeting. Participants were eligible to take part if they were 18 years or over, were formally diagnosed with MS by a neurologist, and not undergoing any form of psychological treatment.

Nineteen eligible participants with a mean age of 50.6 (sd = 11.6), ranging from 24 to 71, agreed to participate (2 male; 17 female), including fourteen participants at site A and five participants at site B. The time since diagnosis ranged from 2 to 27.5 years (mean = 10.5 years, sd = 7.16). One participant (5.26%) had primary progressive MS, eleven participants (57.9%) had relapse remitting MS, five participants (26.3%) had secondary progressive MS

and two participants (10.5%) had an unknown type.

Design and power

An experimental pre-test post-test design, using a mixed method approach, was used to address the research questions outlined above. The study was initially designed as a pilot randomised controlled trial. However, as it became evident that the required number of participants needed to detect a large (within-between interaction) effect with a power of 0.80 ($n = 34$) could not be obtained, the control group was dropped and an additional baseline time-point was added. The latter served to establish the level of change across two baseline time-points relative to the change over the course of the intervention. A power calculation using G*Power established that 27 and 34 participants, for a one-tailed and two-tailed test respectively, would be required for a matched pairs t-test to detect a large effect size with a power of 0.80.

In light of the challenges encountered in the recruitment process, the initial design was augmented by semi-structured interviews conducted with the professionals involved in recruitment and the delivery of the therapy.

Demographic measures

Relevant demographic and MS-specific details including age, gender, marital and employment status, MS type, and duration of illness were collected using a questionnaire (Appendix 3).

Primary outcome measure

The Short Form 36 Health Survey (standard) version 2.0 (SF-36v2) (*Ware, Kosinski & Dewey, 2000*)

Quality of life was assessed using the Short Form 36 Health Survey (SF-36v2), the most widely used measure of health related quality of life across a variety of populations, including MS patients. The SF-36v2 is a 36-item instrument measuring the impact of health on physical and emotional functioning using 3- to 6-point Likert scale items (Appendix 4). The measure generates two summary scores, a physical health component (PCS), and a mental health component (MCS), derived from eight subscales: physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role-limitations due to emotional problems, and mental health. Satisfactory to high internal reliability (.67 - .94) and test-retest reliability (.60-.81), as well as consistent evidence for the validity of the measure has been found in a population of MS patients (Burks & Johnson, 2000).

Secondary outcome measures

The Ways of Coping Questionnaire (WCQ) (Folkman & Lazarus, 1988)

The Ways of Coping Questionnaire (WCQ) was administered to identify coping processes used in response to a specific stressful encounter. This is the most widely used measure of coping processes containing 66 items that form eight subscales. Items are assessed on a 4-point Likert scale ranging from 'does not apply or not used' to 'used a great deal' (Appendix 5). Satisfactory internal reliability (.61-.79) and sound evidence of construct validity have been reported (Folkman & Lazarus, 1988).

The Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main & Weinman, 2006)

Illness representations were measured using the Brief Illness Perception

Questionnaire (BIPQ). This measure assesses eight single-item components on a 10-point Likert scale: Consequences, Timeline, Personal control, Treatment control, Identity, Concern, Understanding, and Emotional response (Appendix 6). Satisfactory reliability and validity indicators have been established (see Broadbent et al., 2006 for a review of reliability and validity indicators across different conditions).

Qualitative measures

Drawing on previous qualitative research into narrative therapy (St. James-O'Connor, Meakes, Pickering & Schuman, 1997), the following three open-ended questions were included in the post-treatment questionnaires to elicit participants' subjective experience of the group:

- (a) What has been helpful in therapy?
- (b) What has not been helpful in therapy?
- (c) What is your overall experience of narrative therapy?

Additionally, semi-structured interview schedules (Appendix 7) were used to guide interviews with health professionals involved in recruitment and the delivery of the intervention. The interview schedules were organised around broad themes related to the recruitment process and the delivery of the protocol.

Ethics and service user involvement

The study was designed and conducted in accordance with BPS codes of ethics and conduct (2006). A service-user consultation group was set up through the MS society to provide feedback on the planned study procedure (see appendix 8 for a summary). The study

was approved by an NHS Research Ethics Committee (Appendix 9).

The intervention

The intervention followed a protocol designed by the author under supervision, based on an existing workbook for MS patients that draws on narrative therapy principles (Johnson, n.d.). The protocol was further informed by recommendations (e.g. White, 1995; Morgan, 2000) to offer its core elements in an order that ‘scaffolds the zone of proximal development’, and incorporated a model to facilitate the integration of key narrative concepts with the following five group processes: joining, power and control, intimacy, differentiation, and termination (Johnson Laube, 1998). An independent clinical psychologist with experience in narrative therapy vetted the protocol. Small amendments were made during this process. The final version and accompanying workbook (Appendix 10 and 11) included the following components in order of appearance: Externalising and personifying MS related ‘problems’, mapping their effects, retracing the ‘problem’s’ history and deconstructing the context surrounding the problem, identifying unique outcomes, and celebrating achievements.

Procedure

MS nurses in two different sites, and a clinical psychologist involved in patients’ care, albeit not in a therapeutic capacity, invited MS patients to take part through an information pack, encompassing an invitation letter (Appendix 12), information sheet (Appendix 13), consent form (Appendix 14), and two prepaid envelopes. Information packs were either posted to patients’ homes or offered during a consultation. Information packs could also be requested in response to the advertisement in the MS newsletter and were available after a presentation by the author about the research at the MS meeting. Those interested in taking

part were invited to contact the researcher by returning a reply slip, leaving a telephone message, or via e-mail. Participants were contacted by the researcher within a week of having registered their interest to answer questions and ensure that they had read and understood the information leaflet and met eligibility criteria. Participants who were willing and eligible to take part were advised of the dates and times of the group and asked to sign and return the consent form included in the information pack. Care coordinators and GP's were informed of patients' participation (see Appendix 15).

Participants were recruited to one of two groups at two different sites. On receipt of the signed consent forms, participants were sent baseline questionnaires four to six weeks prior to commencing the group, and were asked to complete and return these using a prepaid return envelope provided. Participants who required assistance with completion of the questionnaire were given the option of a telephone interview. One participant with limited mobility opted for this option.

A clinical psychologist with a systemic orientation and a trainee clinical psychologist delivered the intervention at both sites over eight weekly sessions lasting 90 minutes. All sessions were tape-recorded, a random selection of which was subject to an examination of treatment fidelity by an independent systemic psychotherapist. In the absence of established measures of treatment fidelity for narrative therapy and given the pilot status of this study, this was essentially a qualitative exercise.

Participants completed the second baseline questionnaires immediately prior to the first group session and the post-intervention questionnaires immediately after the final session. Whilst including a follow-up time point would have been desirable, this was beyond the scope of the project.

The researcher interviewed the MS nurses and the clinical psychologist who delivered

the group approximately a month after completion of the final group (see Appendix 16 and 17 for the information sheet and consent form).

Data analysis

Quantitative analyses

1. Descriptive statistics were used to describe the demographic characteristics of the sample at baseline and post-treatment.
2. Difference scores were calculated by subtracting scores at baseline 2 from scores post-treatment and scores at baseline 1 from scores at baseline 2. The magnitude of the baseline change score was then compared with the magnitude of the intervention change score.
3. Kolmogorov-Smirnov tests revealed that several of the difference scores were not normally distributed. Therefore, a conservative decision was made to use a series of Wilcoxon Matched-Pairs tests to compare the magnitude of the baseline change score and the intervention change score.

Qualitative analyses

1. Data derived from open-ended questions were analysed using content analysis (Krippendorff, 2004) in to make systematic inferences and establish a measure of frequency (Marks & Yardley, 2004). Participants' responses were organised according to meaning based units (MBUs) across two broad categories pertaining to helpful and unhelpful aspects of therapy. MBUs were used to identify emerging

themes and to develop a coding frame (Appendix 18). Responses were quantified by counting the number of responses in each category. In order to assess the inter-rater reliability, a colleague independently coded a section of the data, using the coding frame. Using Cohen's Kappa, good inter-rater reliability (.85), was established (Appendix 19).

2. Interviews with health professionals involved in the study were transcribed verbatim and analysed using thematic analysis following the method proposed by Braun and Clarke (2006). This method was selected to enable the systematic analysis of 'meaning in context', which is more appropriate for interview data (Marks & Yardley, 2004). It comprises five distinct stages: Familiarisation, generating initial codes, searching for themes, reviewing themes, and defining and naming themes. In order to remain intimately connected to the data, an inductive method of analysis was used. Only patterns of responses pertaining to the overall research question were coded, resulting in 14 categories grouped into five broad themes, accounting for 71.22 percent of the data. In the interest of quality assurance, a supervisor examined the coded data and themes to check that a satisfactory level of coherence and integration had been established.

Results

Attendance and dropout

Three participants from site A and two participants from site B dropped out, totalling 26 percent. Sample characteristics at baseline and post-treatment are listed in Table 1. The sample is too small to conduct statistical comparisons of completers and non-completers

along demographic variables. Of the participants who completed, seven attended all sessions, four missed one session, and three missed two sessions.

Treatment fidelity

The systemic psychotherapist who examined a random selection of session recordings concluded that the intervention demonstrated key aspects of narrative therapy that were scaffolded at the appropriate pace. This included the use of externalising language, and the transformation and co-creation of (group) identities through the outsider witness model that the group format provided.

Quantitative results

The mean age of the sample was 53.07 (sd = 8.4). The majority of the sample was female (92.9 %), married or cohabiting (85.9 %) and not working (64.3 %). The mean length of time since diagnosis was 122.9 months (sd = 75.8). Finally, the majority of participants had been diagnosed with the relapse-remitting course of MS (64.4%). A breakdown of demographic variables for the recruited sample and the sample that remained in the study is provided in Table 1.

Table 1. Demographic characteristics of the recruited sample and the final sample.

	Sample at baseline 1	Sample post-treatment
Mean age (sd)	50.63 (11.65)	53.07 (8.40)
Sex N (%)		
Male	2 (10.5)	1 (7.1)
Female	17 (89.5)	13 (92.9)

Marital Status N (%)		
Married or cohabiting	16 (84.2)	12 (85.7)
Single	1 (5.3)	0 (0)
Divorced	1 (5.3)	1 (7.1)
Widowed	1 (5.3)	1 (7.1)
Employment status N (%)		
Full time	1 (5.3)	1 (7.1)
Part time	3 (15.8)	2 (14.3)
Unpaid	2 (10.5)	2 (14.3)
Not working	13 (68.4)	9 (64.3)
MS type N (%)		
Benign	0 (0%)	0 (0%)
Relapse remitting	11 (57.9)	9 (64.4 %)
Secondary progressive	5 (26.3)	3 (21.4%)
Primary progressive	1 (5.3)	0 (0%)
Not specified	2 (10.5)	2 (14.3)
Mean number of months since diagnosis (sd)	126.0 (85.9)	122.9 (75.8)
Mean number of months since first symptoms (sd)	155.8 (103.1)	152.6 (101.3)
Mean number of months since last relapse (sd)	47.9 (45.3)	46.4 (41.9)

Table 2 lists the means and standard deviations at the three time-points for the two summary scales of the SF-36, and the subdomain scores of the WCQ and the B-IPQ.

Difference scores and associated effect sizes, calculated using the method described by Field (2005), are shown in Table 3 (See appendix 20 for median scores and ranges). Significant differences with and without Bonferroni corrections to account for multiple comparisons are indicated.

Uncorrected significant differences were found for the confrontive coping subscale of the WCQ, $z = -2.36$, $p = .018$, $r = -.45$, and the consequences subscale of the B-IPQ, $z = -2.24$, $p = .025$, $r = -.42$. Although these were no longer significant after adjustment for multiple comparisons, medium to large effect sizes were found for both variables. Finally, a trend and associated medium sized effect was found for one of the summary scores (MSC) of the SF-36, $z = -1.73$, $p = .084$, $r = -.33$. None of the other outcome measures significantly improved in the expected directions.

Table 2. Means and standard deviations of the SF-36, WCQ, and B-IPQ per subscale and time of measurement

	Mean (sd) Baseline 1	Mean (sd) Baseline 2	Mean (sd) Post-treatment
SF-36 (norm-based scores)			
PCS	33.16 (6.44)	33.74 (4.91)	34.49 (8.89)
MCS	38.89 (8.57)	37.28 (9.38)	41.89 (10.23)
WCQ (Mean, sd)			
Confrontive coping	5.54 (3.31)	4.15 (2.85)	5.46 (3.20)
Distancing	5.31 (2.72)	6.24 (3.27)	5.85 (2.88)
Self-controlling	8.92 (2.56)	8.38 (3.97)	8.15 (4.02)
Social support	8.15 (3.46)	8.23 (4.46)	8.62 (3.99)

Accepting responsibility	3.77 (2.86)	3.46 (2.90)	3.23 (2.20)
Escape-Avoidance	8.23 (3.79)	7.23 (4.78)	7.00 (3.98)
Problem solving	7.23 (3.81)	7.92 (4.84)	8.84 (4.24)
Positive re-appraisal	4.23 (3.49)	4.46 (3.71)	6.31 (5.17)
B-IPQ (Mean, sd)			
Consequences	6.43 (2.38)	6.93 (2.02)	5.43 (2.44)
Timeline	9.93 (0.27)	9.93 (0.27)	9.64 (1.34)
Personal control	4.93 (2.56)	4.36 (3.05)	4.93 (3.00)
Treatment Control	5.57 (2.50)	5.71 (2.84)	4.64 (2.73)
Identity	5.93 (1.90)	6.50 (1.99)	5.57 (1.99)
Concern	6.57 (2.82)	6.64 (2.98)	5.54 (2.47)
Understanding	7.14 (2.82)	7.57 (1.91)	7.62 (1.76)
Emotional response	7.14 (2.11)	7.14 (1.79)	6.38 (2.79)

Table 3. Means of difference scores, standard deviations, and effect sizes for the SF-36, WCQ, and B-IPQ.

	Mean baseline change score (sd)	Mean intervention change score (sd)	Effect size
SF-36 ¹			
PCS	.006 (3.88)	.75 (5.58)	r = -.02
MCS	.75 (9.41)	4.61 (8.83)	r = -.33
WCQ ²			
Confrontive coping*	-1.5 (2.48)	1.31 (2.39)	r = -.45
Distancing	.25 (3.52)	-.38 (2.63)	r = -.18

Self-controlling	-.38 (2.96)	-.24 (3.83)	r = .01
Social support	.88 (3.86)	.38 (6.04)	r = .07
Accepting responsibility	-.31 (2.21)	.38 (6.04)	r = .01
Escape-Avoidance	-.63 (3.12)	-.24 (4.46)	r = .08
Problem solving	.75 (2.84)	.92 (5.28)	r = .08
Positive re-appraisal	.50 (2.68)	1.85 (4.60)	r = -.24
B-IPQ³			
Consequences*	.53 (1.74)	-1.50 (2.53)	r = -.42
Timeline	.00 (.00)	-.29 (1.38)	r = .08
Personal control	-.53 (2.87)	.57 (4.09)	r = .09
Treatment Control	.18 (2.21)	.57 (4.09)	r = .24
Identity	.42 (1.70)	-.93 (2.56)	r = .31
Concern	.29 (1.65)	-.85 (1.63)	r = .21
Understanding	.35 (2.40)	.23 (1.79)	r = -.01
Emotional response	-.29 (1.96)	-.85 (2.34)	r = -.24

*p < .05 **p < .05 with Bonferroni correction

¹ Greater differences indicate an improvement

² Greater differences indicate greater use of strategy

³ Smaller differences indicate a reduction in strength of illness perception

Qualitative results

Frequencies per emerging theme from MS patients' responses to open-ended questions, subdivided by helpful and unhelpful aspects, are represented in Table 4 (See Appendix 21 for full statements).

Table 4 Themes and number of statements per theme derived from analysis of open-ended questions (N = 14)

Themes	Number of statements
Helpful aspects of the intervention	
The value of forming supportive networks	6
Benefits of sharing experiences with others affected by MS	10
Helped reconnect with the whole of one's self, not just the self dominated by the MS.	3
Positive, but non-specific statements about the group	11
Unhelpful aspects of the intervention	
Absence of unhelpful aspects	5
Filling out questionnaires	2
Powerful experiences and influences	2
Miscellaneous	1

Helpful aspects

Statements reflecting the perceived benefits of sharing experiences with others affected by MS such as the ability to give expression to one's inner experience, emerged most frequently. E.g.: "Brilliant to talk together about MS and share thoughts" and "It has allowed me to vocalise things I hadn't before".

The next most frequently occurring theme constituted general positive, non-specific, statements about the group, e.g.: "Incredibly interesting and therapeutic" and "fantastic".

The value of forming supportive networks around a joined experience, as reflected in statements such as "Meeting others and feeling 'sameness'", was the third most frequently occurring theme.

The final theme in this category - ‘helped reconnect with the whole of one’s self, not just the self dominated by MS’ - was reflected in statements such as ‘*I have found myself again*’.

Unhelpful aspects

The majority (71.4%) of participants stated that they could not identify any unhelpful aspects. A small minority (28.6%), however, commented on the burdensome nature of ‘filling out questionnaires’, and two participants expressed somewhat unfavourable attitudes towards the powerful experiences and influences that the group elicited, e.g.: ‘*Too many strong experiences*’.

The feasibility of a larger scale study

The 5 themes and 14 subcategories that emerged from analysis of the interviews with professionals are listed in Table 5 (See Appendix 22 for example statements and excerpts from coded interviews).

Table 5 Summary of themes and subcategories emerging from interviews with professionals

Themes	Subcategories
Differences and communalities between groups	Affiliation with facilitator or recruiter and its impact Size of the group Idiosyncratic external influences and their differential impact on a) the group dynamics and b) unfolding group narratives Commonalities between groups
Recruitment processes	Practical constraints Attitudes towards engaging in a psychological therapy group

	<p>Gender differences</p> <p>The impact of differential levels of disability</p> <p>Power of different recruitment pathways and sources</p> <p>Appreciation of interest in MS</p>
Data collection issues	<p>Completion questionnaires perceived as burdensome and/or interfering</p> <p>Sensitivity of questionnaires in capturing the impact of the group</p>
Tension between the structure imposed by the protocol and the underlying theoretical position of narrative therapy	
Impact of group	<p>Supportive</p> <p>Broadening perspective of MS</p> <p>Bringing people out of isolation</p>

Differences and communalities between groups

Delivery of the intervention across two sites enabled tentative inferences to be made with respect to properties unique to each group, with each group serving as an anchor for the delineation of key elements that had a bearing on how the group was established and sustained and enabled narratives to unfold. This was evident in the four subcategories embedded in this theme, each with different implications for the feasibility of a larger scale study.

Affiliation with the facilitator or recruiter was perceived as a strong influence on the engagement process. There was a perception of a clear distinction in this respect between group A and B, e.g.: “...lots more people [in group A] were able to come because they had an *affiliation with me. I think that influenced their decision to join...*”. (facilitator)

A perceived disadvantage of the overwhelming level of interest achieved in group A relative to group B was the resultant size of the group, as evident in: “...*much easier to control 5 or 4 people than it is to control 14 people...*” (facilitator)

Reflecting the widespread influence of the MS society, prior relationships between participants appeared to comprise a common element in both groups, i.e.: “*that [prior relationships] was quite a common feature between the two.*” (facilitator)

Although group size and the presence of prior relationships are likely to have impinged on the operating group dynamics, this did not explicitly emerge from the analysis. It is possible, however, that the subtleties of such processes were overshadowed by the death of a participant in group A, who died during a relapse following the complications of a respiratory tract infection. The facilitator noted that this idiosyncratic event significantly shaped the unfolding group narrative, allowing subplots to come to the fore that were absent or remained dormant in the narrative of group B, e.g. “...*and of course it opened up lots of narratives about death and about mortality and about MS,....we never spoke about it in [group B] because it didn't come up so it wasn't a narrative...*” (facilitator)

Recruitment processes

Several factors were perceived to have impinged on the recruitment process. Firstly, a number of practical constraints, in particular in relation to timing and transport were mentioned, e.g.: “...*another one was his work and shift patterns*” (MS nurse)

Level of disability was also perceived as a factor that could have differentially impacted on recruitment, e.g.: “...*people with more severe types of MS may have more difficulty committing to weekly groups or may actually have difficulty coming here so that may present a barrier.*” (MS nurse)

Further, psychological barriers such as attitudes towards engaging in a ‘therapy group’ were commonly alluded to as presenting barriers to participating, e.g.: “*Yes, I think that [‘the therapy label’] was off-putting...*”. (MS nurse)

A particular preponderance of such psychological barriers was noted amongst men, e.g.: “*...or maybe because he is a man...he doesn’t join groups.*” (MS nurse)

Further, the group facilitator and MS nurses commented on the power of involvement of non-statutory, organisations and the importance of broadening recruitment pathways, e.g.: [in reference to recruitment for a potential future study]... “*probably using different service user groups and other health professionals*” (MS nurse).

A final factor identified as a source of support in recruitment was the general level of appreciation for MS-related research, as evident in statements such as: “*People are just so appreciative of people wanting to do research to help people with MS that they are taking an interest.*” (MS nurse)

Data collection issues

Two broad issues pertaining to the data collection method emerged. Firstly, completion of questionnaires, particularly as part of group sessions was perceived as burdensome, e.g.: “*...and they had to fill out lots of questionnaires which was incredibly boring and laborious and all they wanted to do is talk...*”

To a lesser extent, the sensitivity of questionnaires in capturing the impact of the group was queried, e.g.: “*...and maybe in ways that may not be easily collected in various...eh...[interviewer prompt]... yes, quantified.*”

Adherence to the protocol

The group facilitator commented on the inherent tension between the structure

imposed by the intervention protocol and the post-structuralist epistemology that underpins narrative therapy by highlighting how the use of a relatively rigid protocol may curtail the free flowing nature of conversations that narrative therapists strive towards enabling. This tension is reflected in statements such as: “...*the nature of narrative therapy is that it is dictated by your client. It is very difficult to stick to a structured plan.*” (facilitator)

The death of one of the group members was also mentioned in this context, not only to exemplify the perceived difficulty in adhering to a structured protocol but also to highlight the potential for richer narratives to remain hidden in the absence of an atmosphere where they can be brought to bear, e.g.: “*well it [the death] basically threw us completely,....,it was almost like...it was a narrative group because they talked about it but we had to run it in conjunction with the group...*” (facilitator)

Impact of the group

Although not directly related to issues pertaining to the feasibility of a larger scale study, a final theme emerging from the analysis speaks to participants’ overall experience of the group and was therefore retained. This theme captured the perceived importance of the supportive nature of the group as an active mechanism of change, e.g.: “*...I have seen several of the participants in clinic since the narrative therapy group ended and they have all been very positive about the effects of the group...mainly from a support point of view...*” (MS nurse)

It further captured the perceived power of the group in broadening perspectives of MS, e.g.: “*...mainly from interest in seeing people with different symptoms from themselves ...no two people are exactly the same.*” (MS nurse)

Finally, it captured the perceived value of the group in helping to bring people out of isolation, e.g.: “*... for many years I have been trying to get her to meet other people with MS*

because I think it would help her not to feel quite so isolated...and she said oh well I have *done the 'MS anonymous' [laugh].*" (MS nurse)

Discussion

The aim of the present study was twofold: To begin the process of assessing the utility of group narrative therapy in facilitating adjustment to MS, and to ascertain the feasibility of a larger scale study with the same aim. With regard to the first aim, guided by recommendations derived from the coping literature (i.e. Brennan, 2001) as well as the research around psychosocial interventions for MS (Malcomson et al., 2007; Thomas et al., 2009), adjustment was measured in terms of health related quality of life. The mental health component of this measure showed a clear trend suggestive of an improvement over the course of the intervention relative to the baseline change. It is possible that failure to find a statistical significant effect is due to the study being insufficiently powered. If we take the medium effect found for this variable as an estimate of the actual effect size, a power calculation using G*Power suggests that an RCT design would require a minimum sample size of 40 in order to detect this, although a larger sample is desirable from a representativeness point of view. It is important to bear in mind, however, that participants were not selected based on clinical levels of emotional distress. Hence, the possibility that the scope for detecting change on a measure that assesses perceived mental health is limited must be considered.

Of the eight ways of coping domains and eight illness representation dimensions, only confrontive coping and the component consequences improved significantly over the course of the intervention relative to the baseline change score. Although this effect, disappeared when adjusted for multiple comparisons, the Bonferroni method used is arguably too

conservative (Clarke-Carter, 1997). Further, given the associated medium to large effect sizes, it is again possible that the study was not powered enough to detect a significant effect. Confrontive coping comprises one aspect of active coping. Hence, the identified trend suggests that, as theorised, the intervention stimulated the use of some active coping processes. The curvy-linear pattern of the findings, which suggests that this form of coping worsened between baseline 1 and 2, however, was unexpected. Although it is possible that the group reversed this trend, an RCT design with greater power would be needed to draw firmer conclusions surrounding the tenability of this measure. Finally, given the large body of research to suggest that active coping positively influences adjustment to chronic illness (see Maes et al., 1996 for a review), a larger scale study may also wish to examine the extent to which adjustment in terms of quality of life was mediated by an increase in confrontive coping.

The effect found for the consequences component of the B-IPQ fits with previous research, which showed that of all the illness representations, this variable accounted for most of the variance in measures of physical disability and emotional distress (Vaughan et al., 2003). Again, further research into the hypothesised mediational pathways is needed to investigate the nature of the relationships among variables, the inquiry into which may have important theoretical implications in terms of elucidating change processes.

Analysis of the qualitative data obtained from MS patients suggests that the intervention was perceived as overwhelmingly positive. In fact, emerging themes fit with several of the core tenets of narrative therapy. Specifically, participants indicated that narrative therapy had 'helped them reconnect with the whole of themselves, not just the self dominated by the MS', suggesting that the intervention has the potential to enable people to get back in touch with the essence of themselves by integrating the MS experience into

personal, more richly described, narratives. Other important themes that emerged from these data included the value of forming supportive networks as a forum for sharing experiences with others affected by MS. The importance of this aspect of the group was corroborated by data obtained through interviews with health professionals. Whilst the provision of support offered by a group is arguably not unique to the modality of narrative therapy, or indeed to any therapeutic intervention, these themes are certainly grounded in the theoretical premises of narrative therapy as well as previous research. St. James-O'Connor et al. (1997), for example, identified the presence of an appreciative audience as central to the positive shifts observed in their study. The power of 'spreading the news' by creating what Madigan and Epston (1995) labelled 'communities of concern' is probably best captured by the following quote by Michael White: "*As "self" is a performed self, the survival of alternative knowledges is enhanced if the new ideas and new meanings that they bring forth are put into circulation*" (1988, p. 10). The power of seeking out an audience to re-constitute enriched stories was also poignantly evident in one participant's initiative to publish her story entitled 'Just so you know' in the MS society's newsletter. This story movingly narrates the participants' triumph over her "Menacing Stalker" that had left her isolated and defeated (Appendix 23).

The data derived from interviews with health professionals highlighted several important issues pertaining to the feasibility of a larger scale study. Several differences and communalities between the groups were perceived as having differentially influenced the recruitment process and the delivery of the intervention, including the level of affiliation with the facilitator, the size of the group, and the impact of idiosyncratic events. With regard to the former, whilst care must be taken to ensure that ethical protocols are fully adhered to, as was the case in this study, it is possible that familiarity with the facilitator, the MS nurses, and

other MS patients had a ‘destigmatising’ effect. Indeed, Dennison, Yardley, Devereux and Rona Moss-Morris (2010) noted a disinclination amongst MS patients towards involvement in the ‘stigmatised world of MS’ and stressed the need for services to be offered more sensitively.

The latter also ties in with, and possible accounts for some of the perceived psychological barriers to recruitment. Such barriers seemed particularly evident amongst men and resulted in a markedly disproportionate number of men participating relative to the gender distribution in MS prevalence rates. Although men are known to show greater levels of ambivalence towards engaging in psychological therapy (e.g. Good & Robertson, 2003), the lack of men in this sample has implications for the generalisability of the findings and raises ethical questions around the equality of access to a group of this nature. The same possibly holds true for people with more severe levels of disability. Although steps were taken to be as inclusive as possible, these are concerns that need to be taken into consideration in future research of this nature.

The large size of group A relative to group B was identified as both a help and a hindrance. That is, whilst it provided more fertile grounds for the generation of multiple perspectives, the larger sized group was perceived as more difficult to control, leading to more deviations from the protocol, thus affecting the replicability of the study. Although the literature around optimal group size is sparse, Yalom (1995) has recommended a size of between 8 and 12 people. This may be a good yardstick for future studies to compromise on.

Idiosyncratic events such as the death of a participant significantly affected the delivery of the protocol and the unfolding group narrative. It also underscored the tension between the structured nature of the protocol and the post-structuralist principles of narrative therapy. The way in which group A was able to engage in a meaningful dialogue around the

death of a member and fluidly incorporate its meaning into the unfolding narrative, may be testament to the strength of this approach, suggesting that scope for flexibility must be build into any protocols used in future studies.

Health professionals expressed a strong sense that participants perceived the completion of questionnaires as burdensome and interfering. Whilst data collection coincided with the first and last session to ensure that questionnaires were completed at the designated time points, future research may benefit from separating data collection procedures from the delivery of the intervention more explicitly.

The main strength of this study is that it is the first of its kind to examine the effectiveness of a narrative therapy group for patients with a chronic illness. A further strength is the mixed method design, reflecting a pragmatic paradigm (Tashakkori & Teddlie, 1998) that straddles both objective and subjective epistemologies; hence, may help to bridge the prevailing qualitative methods used in the research in this area with the quantitative methods that constitute the dominant discourse in evidence-based practice. Additionally, inclusion of both quantitative and qualitative methods strengthens the tenuous conclusions drawn from the separate strands of the research.

Limitations of the study

In addition to the small size and limited representativeness of the sample, already discussed, the study has several limitations. Firstly, the lack of a control group significantly reduces the strength of the inferences that can be drawn from the findings. Qualitative data suggests that the supportive aspect of the group contributed to participants' positive evaluation of the intervention. Future research is needed to examine the extent to which this effect is also reflected in outcome measures by including a meaningful control group that has

a comparable supportive function. Secondly, the study did not include a follow up measure; hence, it is not possible to ascertain the extent to which improvements have sustained over time. Finally, there are limitations attached to the use of a measure of coping states as opposed to coping traits. Although the authors of the WCQ (Folkman & Lazarus, 1988) argue that the assessment of coping style is a meaningless endeavour given that the quality of coping strategies can only be judged relative to adaptational outcomes in specific contexts, Pakenham (1999) argues that the WCQ may not encapsulate the full extent of coping strategies used to deal with MS-related problems.

Clinical implications and directions for future research

Taken together, the results of the present study offer tentative support for the utility of narrative therapy. Clearly, replication of the findings, using more robust research designs, is needed in order to make firm recommendations for clinical practice. Qualitative findings, however, offer a clear indication that participants had favourable attitudes towards the approach, suggesting that narrative therapy is an acceptable method. This is further evidenced by an initiative taken by group A to continue meeting as a group on an informal basis. The extent to which the therapeutic modality has engendered these favourable attitudes over and above the supportive aspect of the group alone, however, warrants further investigation. Although social support has been associated with better adjustment to MS (e.g. Wineman, 1990), it is possible that narrative therapy has empowered participants to utilise this important coping resource.

Conclusion

As the first study to test the effectiveness of narrative therapy in the domain of chronic illness, specifically MS, this study provides a unique contribution to the literature on narrative therapy. Although unequivocal support for hypotheses 1a, 1b, and 1c could not be found, the emerging trends for the mental health component of quality of life, confrontive coping, and the consequence component of illness representations, are promising in the context of a feasibility study. Coupled with the overwhelmingly positive qualitative appraisals of the intervention, these support replication of the study using a sufficiently large sample. Future research should strive to overcome the perceived barriers to recruitment and separate data collection procedures from the delivery of the intervention more explicitly. Finally, it is recommended that future studies draw on the wide spectrum of research paradigms in order to permit comparisons with established psychosocial interventions for MS and enhance the existing evidence base to inform clinical practice.

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SECTION C

Critical appraisal

The utility of group narrative therapy to facilitate psychosocial adjustment in multiple sclerosis:

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(Excluding title page, and references)

Overview

This section provides a reflection on the process of undertaking the research described in Section B. It begins with an overview of the skills and abilities that I feel I have developed and the learning needs identified. It then offers a critical reflection on what I would have done differently if I were able to do this project again and how the research has informed my thinking in terms of clinical practice. Finally, further potential lines of enquiry that may advance the research in this area will be outlined.

Research skills learned, research abilities developed, and learning needs identified through undertaking this project:

The process of designing and conducting this study has strengthened my research skills in a number of ways and at a number of levels. Principally, it has deepened my understanding of the epistemological roots of research paradigms and the extent to which their associated methods indirectly influence clinical practice recommendations by determining the type and direction of research in particular areas. In the case of narrative therapy, it appears that its strong allegiance to a postmodern worldview has long been considered incompatible with the positivist underpinning of the quantitative research traditions that largely constitute the 'evidence-base'. This assumption has seemingly stifled quantitative research into this research modality.

Conducting this research has encouraged me to examine critically the (implicit) assumption that the epistemological grounding of a brand of therapy renders it unsuitable to evaluation using a research method that is underpinned by a different epistemology. Theoretically, I noted that the polarised view on philosophies that is at the heart of this apparent tension is increasingly challenged by proponents of methodological pluralism (e.g.

Pathirage, Amaratunga & Haigh, 2008). From a pragmatic perspective, I reflected on the consequences of the apparent rejection of the type of 'knowledge' that quantitative methods privileges, and argued that this has led to the subordination of a therapeutic modality that was developed well over two decades ago relative to methods that are seemingly more congruent with positivist research traditions. As argued in Sections A and B, by fervently rejecting the 'knowledges' derived from quantitative research methods, narrative therapy has failed to achieve the attention it may deserve, hence has effectively subjugated itself to the dominant discourse surrounding evidence based practice by resisting to engage with it. Guided by theoretical arguments underlying methodological pluralism, an attempt to reconcile these tensions in the design of this study has been a key skill that undertaking this research has encouraged me to develop.

Secondly, the pragmatic paradigm that I eventually selected to address the research questions outlined in Section B has further stimulated the development of my research abilities by allowing me to take both 'data' and 'theory' as my starting position, before tentatively synthesising the two. My knowledge and experience of quantitative methods, however, continues to exceed my knowledge and experience of qualitative methods and I recognise that there is scope for developing my qualitative research abilities in order to apply these with greater confidence.

Thirdly, undertaking this study has developed my appreciation of the need to adopt a systematic approach to the planning and coordination of research, specifically the need to build considerable margins into the timescale within which to complete a study's component parts. For example, I feel that I underestimated the timescale for obtaining NHS R&D approval. This took nearly six months from submission of my application on receipt of a satisfactory local feasibility assessment, and five months from obtaining ethics approval. This

delay may have contributed, at least in part, to the relatively small size of my sample by reducing the window for recruitment from an estimated six to eight months to two and four months for group A and group B, respectively.

Although recruitment posed the biggest challenge to this study, this aspect also illustrated the need to have contingency plans in place, in terms of both study design and the analyses of data. Having a relatively broad research question further helped in this respect by enabling the flexibility to absorb, at least to an extent, the consequences of the disappointing sample size by shifting the focus somewhat towards the feasibility aspect of this study, an equally important aim given the lack of research in this area.

Finally yet importantly, undertaking this research served as a reminder of the importance of building and maintaining collaborative relationships with service users and other professionals involved in the research.

If I were able to do this project again, I would have made the following changes:

As discussed in Section B, there are several limitations attached to the design, method, and procedure of the study. Although several of these would have been beyond the scope and timescale of the project to address fully, on reflection, a number of alterations could have reduced their impact, and potentially strengthened the inferences that could be drawn from the findings.

Design and method

By far the strongest limitations are the small sample size and the lack of a control group. Although the scope of the initial pilot RCT design may have been ambitious from the outset, the delays incurred in obtaining R&D approval are also likely to have hindered this.

Therefore, if I were to conduct this study again I would seek to collaborate with other members of patients' clinical care teams, such as neurologists, alongside the MS nurses to reach a potentially larger pool of participants. Additionally, although I had frequent communications with the R&D department whilst awaiting their approval, I would aim to seek clearer advice from the relevant R&D consortium as regards timescales prior to planning the project in order to do so from a more informed position.

Finally, if I were to conduct this study again I would make two key changes to the method. Firstly, I would separate the data collection procedures from the intervention more explicitly in response to indications that participants perceived the completion of questionnaires as somewhat burdensome, and that this had the potential to affect the engagement process. Secondly, I would aim to allow a larger time window post-intervention to enable inclusion of a follow up time-point. The latter would have given an indication of the extent to which the identified trend sustained over time, thereby adding credibility to the approach.

Measures

The measures were selected with the pilot RCT design in mind, with the view to provide data that is comparable with other studies into psychosocial interventions for MS (as reviewed by Malcomson, Dunwoody & Lowe-Strong, 2007; Thomas, Thomas, Hillier, Galvin & Baker, 2006). The choice of the SF-36 (Ware, Kosinski & Dewey, 2000) as the primary outcome measure is also in keeping with the underlying theoretical contention that improved quality of life is an indication of adaptive coping (e.g. Brennan, 2001). Although well-validated, this measure may have been less sensitive to picking up MS-related changes than an MS-specific quality of life measure may be, especially in a small sample. Therefore,

given the small scale of the project, an MS-specific measure may have been a helpful addition.

Further, it would have been preferable to include a measure of social support. Theoretically, the active involvement of the wider context, and the person's ability to draw on it as a resource, is considered an integral component of narrative therapy. Although any positive shifts on a measure of social support cannot be taken as providing support for the effectiveness of narrative therapy, it would begin to illuminate some of the potential processes of change, if associated with positive shifts on other outcome measures. Indeed, the enquiry into processes of change alongside measures of symptom reduction is increasingly advocated in psychotherapy research (e.g. Fonagy, 2010).

As a consequence of doing this study, I would make the following clinical recommendations or changes to my clinical practice:

This study has contributed to the growing, albeit, limited evidence base for the utility of narrative therapy. Further research using larger sample sizes and more robust study designs; however, is needed in order to make firm practice recommendation regarding the implementation of this model in the context of facilitating psychosocial adjustment to MS.

Unfortunately, the uptake of eligible potential participants could not be quantified due to the nature of the recruitment procedure. The attrition rate, excluding the death of one participant (22.2%), however, was commensurate to, or lower than, commonly reported for group interventions (e.g. Lambert & Ogles, 2004), including a CBT group for MS patients, which had an attrition rate of 35% in the treatment arm of the study (Forman & Lincoln, 2010). This is consistent with the possibility that the intervention was perceived as no less acceptable to MS patients who were willing to participate than any other intervention, which

is in line with participants' qualitative accounts post-treatment. There was a sense amongst health professionals involved in the recruitment process, however, that several MS patients were reluctant to engage in a 'therapy group'. This would suggest that for a significant subset of MS patients, a group intervention might not be suitable or, as suggested by Dennison, Yardley, Devereux and Moss-Morris (2010), the prospect of entering a therapeutic group may even be perceived as threatening or stigmatising. The latter really underscores the need to offer groups of this nature with due sensitivity to patients' needs and their current level of psychological adjustment, and raises questions around the timing of offering interventions to patients with chronic illnesses such as MS. Perhaps the idea that adaptation to chronic illness is best conceived of as a process (e.g. Brennan, 2001) should also be applied when inviting patients to join therapeutic groups that centre on a chronic illness. Further research is clearly needed to begin to disentangle some of the variables that are implicated in patients' willingness to engage with a therapeutic group of this nature.

Directions for future research and questions future projects would seek to answer

As argued in Section B, the findings from this feasibility study have highlighted several potential lines of inquiry that future research may wish to address. It appears that a sufficiently powered study to test whether the trends found in this study can be replicated comprises the most fruitful direction for further research at present. Ideally, a study with this aim would use a randomised controlled design with a meaningful comparison group in order to control for common therapeutic factors, most importantly the network of support that a group provides. In the context of a sufficiently large sample, it would also be helpful to make comparisons across different disease parameters, including type of MS and length of time since diagnosis to enable more tailored recommendations to be derived from such a study.

The present study has highlighted several other unanswered questions pertinent to research into narrative therapy as well as psychosocial interventions for MS more widely. Firstly, as explained in the previous section, an exploration of the factors that mediate or moderate MS patients' willingness to engage with psychosocial interventions appears to have merit. Whilst this could begin to be explored using a qualitative exploration, any future outcome study should strive to quantify the uptake of interventions and aim to record reasons for patients' decision to decline the intervention that was offered. Given the conflicting notions of support groups as being seen as helpful on the one hand, but possibly leading to a sense of stigmatisation, on the other hand (Dennison, Yardley, Devereux & Moss-Morris, 2010), it would be helpful to further explore the acceptability of individual and group interventions. A comparison of attrition rates of individual and group interventions, respectively, could be helpful in this respect.

Finally, an exploration into the processes deemed to be therapeutic, for example through an in depth analysis of recorded sessions, may help to advance our understanding of how narrative therapy may lead to change. This may also lead to the identification of strategies that are most efficient in triggering change processes (Fonagy, 2010).

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SECTION D

Appendices

APPENDIX 1: Literature search strategies

Search strategies for the literature review

Search strategy for the literature review on psychosocial interventions for MS patients

An initial scoping literature search was conducted to identify relevant papers, which were scanned for key words. The term ‘multiple sclerosis’ and its abbreviated form ‘MS’ were entered into the electronic databases below coupled with the terms (truncated where relevant) ‘psychological intervention’, ‘psychological therapy’, and ‘psychotherapy’.

Databases searched (until February 2011):

PsychInfo (1806 – present)

Ovid MEDLINE (R)

Embase

Cochrane Library

Google scholar

Papers were selected for potential inclusion in the review if they presented empirical outcome data on the effectiveness of a psychosocial intervention to facilitate adjustment. Due to the relatively large body of literature, meta-analyses and systematic reviews were prioritised over papers reporting on single studies. Two such reviews were identified which served as a basis for the review. These were considered to provide a comprehensive overview of the available literature. Any papers published prior to these reviews will were excluded.

Search strategy for the literature review on empirical research and narrative therapy

An initial scoping literature search using the term ‘narrative therapy’ was conducted to identify relevant papers and terms pertinent to this section of the review. Next, a systematic search was conducted by entering the term ‘narrative therapy’ coupled with one of the following terms (truncated where relevant) in the electronic databases listed below: ‘research’, ‘study’, ‘outcome’, ‘evaluation’, ‘effectiveness’, and ‘utility’.

Databases searched (until February 2011):

PsychInfo (1806 – present)

Ovid MEDLINE (R)

Cochrane Library

Google scholar

Since the term ‘narrative’ has multiple meanings within the psychotherapy literature, only papers that described research into narrative therapy underpinned by a postmodern epistemology were deemed relevant to the scope of this paper. Further, in order to collate the empirical literature on narrative therapy, only papers that reported quantitative or qualitative data to evaluate outcomes of an intervention based on narrative therapy principles were selected for potential inclusion in the review. This search identified one review. Papers published prior to this review were excluded. Selected papers were cross-referenced and subjected to cited reference searches.

Search strategy for the literature review on narrative therapy to facilitate adjustment to MS

Papers identified through the initial scoping literature search that formed the basis for the

review of the empirical literature on narrative therapy were scanned for key terms. An additional scoping literature search was conducted to identify papers pertinent to the application of narrative therapy to facilitate adjustment to MS and to chronic illness more generally. The term ‘narrative therapy’ was entered into the electronic databases listed below in combination with the following terms: ‘multiple sclerosis’, ‘MS’, ‘illness’, ‘disease’, and ‘disability’.

Databases searched (until February 2011):

PsychInfo (1806 – present)

Ovid MEDLINE (R)

Cochrane Library

Google scholar

Sources were selected and key ideas extracted for inclusion in this section of the review if they presented a conceptual or empirical account of the underlying processes through which narrative therapy may facilitate adjustment to MS or chronic illness more generally. Sources that focussed on MS were prioritised over other types of chronic illness. Selected sources were cross-referenced and subjected to cited reference searches.

APPENDIX 2: Advert in MS society's newsletter

People with MS who live in [location] are invited to take part in a research study into the effectiveness of a psychological therapy.

Researchers at [name NHS Trust] and Canterbury Christ Church University are conducting research to evaluate the effectiveness of 'group narrative therapy' for improving psychosocial adjustment in MS patients.

If you have been formally diagnosed with MS and are not currently undergoing any psychological treatment you may be eligible to take part. The study will be conducted in [name sites] at [name of centre].

Participants have a 50/50 chance of being allocated to receive the treatment as part of the study. The treatment will involve eight weekly sessions of narrative therapy with each session lasting an hour and a half. Participants who are not allocated to receive the treatment will form a 'control group' and will be offered the treatment at the end of the study. All participants will be asked to complete a series of questionnaires at the beginning and at the end of the study.

If you would like to receive more information about this study and/or about taking part, please contact Ananda van den Heuvel, Trainee Clinical Psychologist, on a.vandenheuvel42@canterbury.ac.uk or by phoning the 24-hour research message service at the Salomons campus of Canterbury Christ Church University on 01892507679. When leaving a message please clearly state your name and telephone number and indicate that the message is for Ananda van den Heuvel.

APPENDIX 3: Demographic Measures



Narrative therapy for multiple sclerosis

Participant number:

Please answer all questions on the enclosed questionnaires

You do not need to write your name on any of the questionnaires

Part 1. General questions. Please answer all questions.

1. How old are you?

 years

2. Are you

 Male Female

3. What is your marital status?

Single
Married
Divorced
Widowed

Living with partner

4. Do you live by yourself?
 with your partner?
 with other adults?

5. What is your employment status?

Full time employment
 Part time employment
 Voluntary work
 Not working

6. How would you describe your ethnic group?

White

- British
- Irish
- Any Other White background

Mixed

- White and Black Carribean
- White and Black African
- White and Asian
- Any Other Mixed background

Chinese or other ethnic group

- Chinese
- Any Other Ethnic background

Mixed

- White and Black Carribean
- White and Black African
- White and Asian
- Any Other Mixed background

Chinese or other ethnic group

- Chinese
- Any Other Ethnic background

Black or Black British

- Caribbean
- African
- Any Other Black background

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Any Other Asian background

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Any Other Asian background

APPENDIX 4: SF-36v2 – This has been removed from the electronic copy

APPENDIX 5: Ways of Coping Questionnaire (WCQ) - This has been removed from the electronic copy

APPENDIX 6: Brief Illness Perception Questionnaire - This has been removed from the electronic copy

APPENDIX 7: Semi-structured interview schedules

Group Narrative Therapy for MS patients – semi-structured interview schedules

Interview schedule – group facilitator

1. What was your experience of running this group?
2. How easy or difficult was it to adhere to the protocol for this client group?
 - Which aspects of the protocol seemed helpful/unhelpful?
 - How could the protocol be changed or improved to better suit the needs of this client group?
3. What were the challenges to running this group?
4. Has the group affected participants in ways you had not anticipated?

Interview schedule – MS nurses

1. What has been your experience of recruiting participants for the narrative therapy group?
 - What parts of the recruitment procedure did you think worked well/were well received by participants?
 - What parts could be improved upon if a similar study was done in the future?
2. What do you see as the obstacles to taking part in a study such as this?
 - Did you encounter any obstacles that you had not anticipated?

3. In what way could the recruitment procedure be improved if a similar study was run in the future?

APPENDIX 8: Summary feedback and responses to service user consultation group

Summary of comments from the consultation group and responses from the researcher

- 1) Confidentiality may be an issue of concern

RESPONSE: It is very important that participants feel the sessions provide a safe space to share experiences and feelings. Confidentiality is of utmost importance, therefore. The information sheet explains confidentiality issues and any confines to it. The Psychological Services team that will host the groups will keep records of clients in line with their usual practice. Please let me know if any of you have any further concerns around this.

- 2) A recommendation was made to ensure that participants have realistic expectations around the effectiveness of the therapy.

RESPONSE: I hope that the information sheet is clear on this but please let me know if you feel there is a potential for false expectations to be raised.

- 3) A recommendation was made to ensure that participants are made aware of the time scale of the project and of any delays that may occur in the proceedings (including getting back to participants).

RESPONSE: I hope that the letter of invitation offers clarity regarding this.

- 4) Most people felt that recruitment is best managed by MS nurses and that invitation by letter only may be a bit impersonal. However, not all MS patients have been assigned an MS nurse and so this strategy may exclude a small subset of people that would be eligible to take part.

RESPONSE: Contact with the MS nurse in [locality A] and [locality B] has been established. Both have agreed to support the study. It has further been decided to widen the recruitment strategy to attract more people by involving the MS society more closely. Both local MS societies are aware of the project and willing to give their full support. Adverts will be placed in newsletters and a presentation delivered at monthly meetings.

- 5) Questions around financial benefits could be sensitive.

RESPONSE: Participants will not be asked any questions around their income or any benefits that they are in receipt of.

- 6) Generally, people did not foresee any problems with the postal survey comprising questions about participants' physical and mental health, their ways of coping and their beliefs about MS. Some felt that a postal survey is preferable over a face-to-face or telephone interview as it gives people the freedom to complete it in their own time, hence is least intrusive.

RESPONSE: Provided the ethics board agrees with this strategy, questionnaires will be sent out by post. Participants will be provided with a telephone number to contact the researcher should they experience any distress as a direct result of completing the survey.

APPENDIX 9: Ethics and R&D approval letters – This has been removed from the electronic copy

APPENDIX 10: Protocol intervention

OUTLINE NARRATIVE THERAPY GROUP

General considerations related to group processes

Therapeutic stance

The therapist actively models questioning throughout and encourages group members to internalise this style of questioning. However, in adopting an 'editorial role' the therapist will attempt to guide the group through a series of stages. Each stage will inform the content of the questions, and facilitate the construction of a 'group narrative', which will run alongside, or in parallel with, group members' personal narratives.

Each stage is associated with a unique set of 'process prescriptions', interventions that help group members reflect on group process issues, using emergent themes, and linking these with their personal narratives.

The Joining Stage

The joining stage is affected by the idiosyncratic ways in which each participant has prepared for group membership and the possibilities for finding commonalities.

The Power and Control Stage

This stage is influenced by members' prior experiences with unresolved or negative outcomes of conflict. Abandonment and ostracism are potential crises that must be negotiated to preserve the integrity of the group and to allow it to mature. The members are encouraged to realise that the group body contains multiple motives, realities, and levels of awareness, that there are competing and conflicting sensory, cognitive, and emotional experiences present within the group and that the solution to containing these many facets is in flexibility rather than rigidity. The group body contains conflict, and at times, certain components are more vocal or dominant than others.

The Intimacy Stage

This stage is affected by members' experiences of closeness and dependence and notions of what permits differences to be expressed within a context of similarity. The group develops values and a sense of identity. The members are asked to comment upon and articulate what the "real self" of the group body is like and what it values.

The Differentiation Stage

This stage of group development is the unique exploration of individual difficulties, and here-and-now experiences of events and relationships within the group life. The group becomes a place where exceptions to the problem occur. As the group body develops and matures, the members are asked to evaluate these developments, to determine what they think made the group ready for these changes and how the group

became aware of its need and readiness for change.

The Termination Stage

This is the point when the value of the group experience is questioned, validated, and

integrated into the ongoing individual life story. As the group plays out the dynamics of the 'illness or disorder', the individual is potentially free to leave the 'illness or disorder' in the group body. Therefore, separating from the group becomes a desirable outcome, as the group body will continue to "carry" the 'illness or disorder' for the previous members.

SESSION 1 – introduction and externalising + personification*

General introductions

Housekeeping

Establishing ground rules

Exercise 1

Brainstorm around expectations for the group - feedback to be documented on flip chart, which will be kept to aid reflection at the end of each session.

Exercise 2

Invite people to pair up and discuss what their hopes and fears are for the group. Feed back to group - to be recorded on flip chart.

Exercise 3:

An introduction to narrative therapy - Brainstorm in pairs. Feedback to be recorded on flipchart.

Introduction to narrative therapy:

Stories people tell of themselves and their experience of MS, the impact of MS on people's personal narratives and their view of themselves, and a discussion around the aims of narrative therapy: To rediscover alternative stories that are equally true but have become obscured by more dominant MS related stories. Part of the process is to share these stories with others with similar experiences with the hope that this will empower group members to share these stories with 'wider audiences' (e.g. friends and family).

Hand out workbook

Externalising:

Because 'MS' unites all members of the group, this will be the first 'problem' to be externalised.

Group members will be invited to name their 'MS problem', which can take the form of a metaphor or a visual representation. Group members will be directed to examples from the workbook to help generate ideas (i.e. an angry man, a dreadful mother-in-law, a spoilt child etc), and invited to write and/or draw what MS is like to them, and think of a name that embodies their representation/description.

Therapist to facilitate brief discussion to help generate more ideas and bring more 'knowledge' into the room. In order to develop the 'group narrative' and to promote

movement through the 'joining stage of the group', attention should also be paid to drawing out common themes.

Objectifying and personifying MS:

Group members are directed to page 3 of the workbook where they are asked to personify their MS character. Therapist to facilitate a brief discussion to identify how people's life stories have been influenced by MS and how people evaluate the effects. Again, promote commonalities in experiences to emerge.

NB Although the first session should coincide with the joining stage, group members may differ in how they position their MS. Although the objective of the 'joining phase' is to search for and work with commonalities of experience, their effects, and the meaning given to them, this may begin to highlight difference and may instigate transition to the 'power and control' stage, providing fruitful opportunities to work with and embrace difference.

General reflections about expectations

Group dynamics considerations

To facilitate 'successful resolution' of the 'joining phase, process prescriptions should focus on those that support the 'joining phase',

e.g.: How is your MS character likely to behave in this group?

What makes MS offensive to you, to other people in your life; how will MS become offensive to the group?

What are some of the effects that MS has had on your life story?

What would you like to know about other people's experiences that would help you feel safe within the group grapevine?

SESSION 2

Documenting the effects

Exercise 1

Building on the first session, session 2 will start with a graphical representation of the effects of MS on people's lives by placing the various labels for MS in the centre of a flipchart and connecting links to their effects (e.g. MS makes me tired/planning impossible//life uncertain) to form a spider web.

Tracing the history and deconstructing

This involves an enquiry into the problem's history and the history of the person's relationship to the problem, taking into account people's wider contexts and cultures that

assist in sustaining it with the aim to deconstruct these.

Exercise 2

Direct group members to page 5 in the workbook to 'track their relationship with MS over time.

E.g. yesterday I was unable to get out of bed all day because of MS: Ten years ago: MS did not affect my life at all.

Ask members to split in pairs and discuss what they have noticed when doing this exercise.

Then switch discussion to deconstruction questions

When did you first notice the problem? How long ago?

What do you remember before the problem entered your life?

What are some of your beliefs about MS?

How did these ideas develop? Where do they come from?

Are you comfortable with these ideas?

Who supports these ideas?

What ideas/habits feed the problem?

What problems/ideas team up with your MS character

At the end of session 2 participants will be asked to complete a short questionnaire to identify their MS 'sub-plots', e.g. uncertainty, lack of control, fatigue, etc. The important thing is that these subplots are generated by group members and are not imposed.

General reflections about expectations

SESSION 3 - widening the context, identifying unique outcomes and re-appraising meaning

Identifying unique outcomes

Therapeutic conversations will be guided towards exploring times when the problem had less, little or no influence over the person.

Exercise 1

Invite group members to split into pairs to reflect on the times when MS [or their preferred label] did not get in the way of their lives, or had less influence over it. Invite people to ask their partner specific questions about this event, then invite people to share their 'unique outcome' with the group. Therapist to direct discussions towards reconstructing meaning and enriched understandings.

Exercise 2

Invite group members to turn to page 6 of the workbook to construct two timelines, a positive event timeline, and a negative event timeline, covering the same period of time. Ask group members to reflect on what they noticed when doing this, and invite people to share examples that they feel safe sharing with the group. The therapist can then ask questions to elicit meanings and enable an enriched narrative to emerge, e.g. through 'landscape of action' and 'landscape of identity questions'. Landscape of action questions explore the concrete contexts of a unique outcome (e.g. when, what where etc). Landscape of identity questions then aim to explore the meaning of the unique outcomes (e.g. when you did X, what does that mean about you, your values, your qualities, your strengths etc). The aim is to contribute to a 'richer' description of a person's life, their values, commitments, beliefs, and strengths etc, and to assist people in reconnecting with these. Split into pairs after modelling between therapists.

The identification of unique outcomes is likely to highlight individual differences, hence to facilitate the power and control stage of the group. Process prescriptions aimed at facilitating the conflict phase may include:

1. How might [MS] try to keep the group from addressing difference?
2. Now that differences in experiences begin to emerge, if someone were to stand up against the MS in one way (i.e. to not allow the MS to influence you in this way-whatever that may be), and you were to stand up to it in the same way, would there be a different outcome to your story?

General reflections about expectations

SESSION 4 and 5 – Externalise and personify MS related problems identified in session 2*

An attempt will be made to identify common themes or problems that emerged from the survey conducted after session 2. These will be made explicit (e.g. by writing them down on a flip chart).

The same techniques will be used as outlined under sessions 1-4 to enable unique outcomes to emerge and for stories to be re-authored.

Process prescriptions during this phase may be those in support of 'differentiation' where the group and the group story provides a framework from which personal stories, unique to individual group members, can be given a voice e.g.:

1. If you are feeling that [name of problem] is not as dominant in your life, how might others in the group begin to notice its shrivelling?
2. What have you learned from hearing the differences and similarities in MS stories that has helped you change your story of the MS?

3. How does the decision to reveal yourself outside of the MS, or not, affect your story of shyness and your expectations of yourself in group?

As a Reflecting Team exercise

General reflections about expectations

SESSION 6 – Widen the audience - Reflecting Team exercise: MS

Building on the previous session that focused on unique outcomes – this session will use a reflective team exercise to further thicken alternative stories and develop the emerging 'group narrative'.

The purpose of this is to facilitate discussion around the wider cultural beliefs that assist in the maintenance of the problem, and to contribute to 'richer descriptions' of people's lives by enabling multiple perspectives from peers to be vocalised. The larger group will be split into two or three smaller groups. In each group, one member will 'tell' their story around an identified problem. Another member will have a conversation with him or her, ensuring that the life of the person telling his or her story remains at the centre. The remaining group members will act as a reflective team. After approximately 10-15 minutes, the conversation will be stopped and the reflective team will be invited to share their thoughts. Guidelines for reflective teams run by peers instead of therapists have been developed (Behan, 1999):

Interviewer may ask (write on flip chart questions):

- Listen very carefully to the story, especially for how it relates to your own experience.
- Notice any images which come up for you from this person's life and from yours.
- Be ready to acknowledge your appreciation for what s/he is going through.
- Be curious about the developments in this person's life.
- Be tentative in your comments. Use the 'curious mood' and phrases that leave openings for uncertainty: 'I was wondering ...' or 'I'm not sure about this but ...'
- Be prepared to answer questions about what struck you and why.

Reflections of observers and then of whole group.

Process prescriptions during this phase may be those designed to promote development through the intimacy phase and are aimed at facilitating the co-construction of alternative group narratives

Get the group to think about the following questions and record their responses on a flip chart:

1. How can the group use its closeness to keep [names chosen to represent 'problems'] from making a comeback, to prevent it from being so strong and powerful?

2. If all the troubling characters we have named were to go to another room and we were left here without them, what would it be like here and what would it be like over there?

General reflections about expectations

SESSION 7 – Repeat of reflecting team exercise around subplots

In session exercise or homework:

Members will be invited to write letters in which they make their commitments to their alternative stories about themselves known.

General reflections about expectations

SESSION 8 – Widening the audience*

The purpose of the final session is to celebrate people's achievements and document commitments based on alternative stories.

Participants will be invited to pair up with a fellow group member to share the content of their letter. Partner to feed back achievements to wider group.

Process prescriptions at the end of therapy may include:

1. How have you let go of other people or experiences in your old story?
2. How will you continue to work on your story, to expand and discover new chapters?
3. How will the group continue to be an audience for your unfolding story?
4. How are you changing the old story of X?

*Within each of the sessions, time will be made available for people to share their thoughts and experiences of the process and how they feel it relates to them.

General reflections about expectations

APPENDIX 11: Workbook



Narrative Therapy Workbook



My MS character looks like....

A large, empty rectangular box with a black border, intended for the user to draw or describe their MS character.



Or can be described as....

Therefore, the name that best describes my MS character is



How does your MS character affect you?

What does it do?

What are its tricks, methods, or rules?

What does it make you think?

How does it make you feel?

How has it affected your hopes for the future?

How is your MS character likely to behave in this group?



Tracking the history of my relationship with MS

The part of my life taken up with the MS
MS

The part of my life not taken up with the MS

Yesterday:

Three weeks ago:

Two months ago:

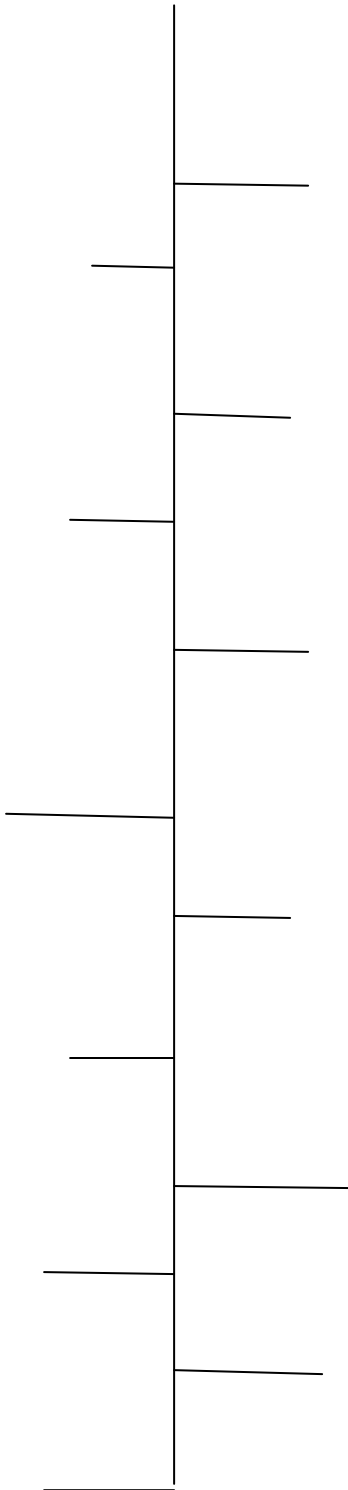
One year ago:

Five years ago:

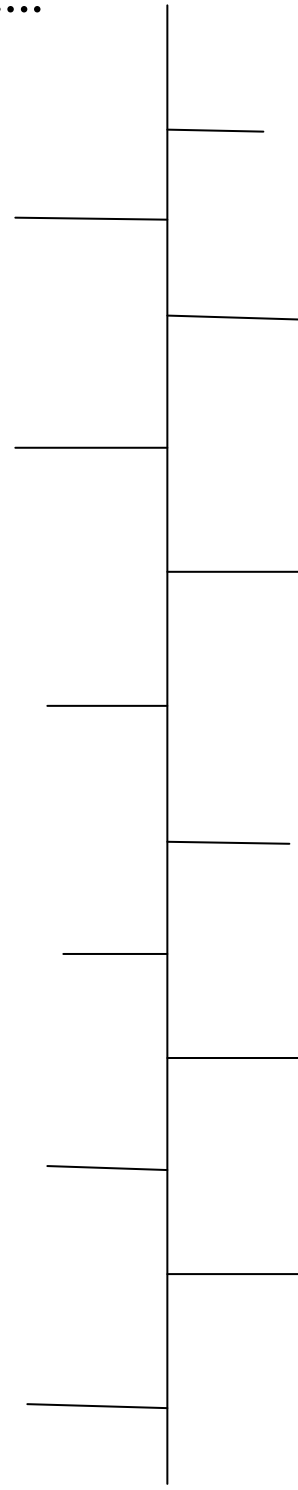
Ten years ago:



This last year....



Negative event timeline



Positive event timeline



How is it that my MS creature could not spoil the positive events identified?

What does this say about my values, desires and preferences and my ability to follow these?

_____ Who would be least surprised by you saying this?

_____ What does this mean for the future?



How can the group use its closeness to keep the identified problem from making a comeback, to prevent it from being so strong and powerful?

If all the troubling characters we have named were to go to another room and we were left here without them, what would it be like here and what would it be like over there?

APPENDIX 12: Invitation letter participants

Date

Dear Mr/Mrs,

Re: Invitation to participate in a study on Narrative Therapy

I am writing to invite you to take part in a study that researchers are currently conducting at [name of site and department] to test the effectiveness of Narrative Therapy in promoting psychological adjustment to Multiple Sclerosis (MS).

You are invited to take part because you were diagnosed with MS at some point in the past and therefore may be eligible to take part in this study.

The enclosed information sheet provides details of the study. If, after reading this, you are interested in taking part, please return the reply slip at the bottom of this letter to the research coordinator using one of the two freepost envelopes enclosed. You can also contact the research coordinator via e-mail or telephone, details of which are provided on page 3 of the information sheet. Within 7 days of receiving your reply slip/e-mail/telephone message, the research coordinator will contact you by telephone to further discuss the study. This will also give you an opportunity to ask any questions you may have.

It is important not to return the enclosed consent form before speaking to the research coordinator.

Yours sincerely,

MS nurse

I would like to take part in the narrative therapy study and would like to be contacted to discuss my involvement in more detail.

My telephone number is.....

Please indicate if there are particular days/times at which you cannot be contacted.....
.....
.....
.....

APPENDIX 13: Information sheet for MS patients

PARTICIPANT INFORMATION SHEET

Group narrative therapy for patients with multiple sclerosis: A small scale randomised controlled trial

You are being invited to take part in a research study for people with Multiple Sclerosis (MS). Before taking part it is important that you understand why the research is being done and what taking part involves. Please read the following information carefully. Feel free to discuss it with relatives, friends, your GP, or MS nurse. You can also contact the researcher direct if there is anything that you would like to discuss further. Please see page 4 for contact details.

What is the purpose of the study?

Research has shown that coping with MS can be physically and emotionally challenging. MS patients commonly experience periods of low mood and anxiety. The provision of more emotional support alongside the management of the physical symptoms of MS may improve patients' ability to cope with the disease.

The purpose of this study is to test the effectiveness of a psychological intervention known as 'narrative therapy'. Narrative therapy focuses on the stories we create of ourselves to make sense of who we are. A chronic illness such as MS can dominate patients' personal story in such a way that it pushes other, equally important, parts to the background. Narrative therapy aims to help patients re-tell the overlooked parts of their personal story to regain a sense of self that is separate from MS.

Why have I been chosen?

We need to recruit about 42 participants in total. You have been approached because you have been diagnosed with MS. We do not select patients based on how their doctor or MS nurse feels they are coping. Patients are invited regardless of how they feel.

Do I have to take part?

No, it is up to you whether you take part or not. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from the study at any time after having agreed to take part, without giving any reason. This will not affect your care or any psychological support offered within your service.

What will happen to me if I decide to take part? What will I be asked to do?

Providing you fit the criteria for the study, you will be allocated to one of two groups: 1) group narrative therapy delivered by a clinical psychologist trained in this method, or 2) Treatment As Usual (TAU), which involves the usual care you receive. You will have a 50/50 chance of being allocated to either of the groups, which will be determined by a computer program.

If you have been allocated to the narrative therapy groups you will receive eight weekly sessions of narrative therapy delivered by a clinical psychologist who has received training in this form of therapy. Each session will last an hour and a half and will take place at [insert name of centre]. If you are allocated to the 'Treatment As Usual' group, you will be offered the therapy at the end of the study, no longer than 6-8 months after you agree to take part.

All sessions will be audio taped to ensure that the therapy is delivered in the way it was planned.

You will be asked to complete a number of questionnaires at the beginning and at the end of the study. The questionnaires include questions about your physical and emotional symptoms, your thoughts, and feelings about MS and about the way in which you generally cope with stressful situations. Completion of the questionnaires will take a maximum of 30-45 minutes depending on how much MS affects you. They will be sent to you in the post along with a freepost envelope so that completed questionnaires can be returned free of charge. If you need assistance with completion of the questionnaires, we can complete them over the phone with you.

If you take part in this study, you will not have to change your medication and your usual treatment will not be affected in any way.

What are the possible disadvantages and risks of taking part?

The main disadvantage to taking part is the time involved in travelling to and attending the therapy sessions and completing the questionnaire booklets. As it is a 'talking therapy', delivered in a group format, it is possible that talking about your physical and emotional experiences in the group is difficult for you. However, as all members in the group are MS patients, you may find it helpful to share your experience with people who may be familiar with your difficulties. Travel expenses for attending the therapy sessions will not be covered, but this would be true of any person receiving psychological treatment in the service.

What are the possible benefits of taking part?

We hope that the treatment will help you feel less distressed and better able to adjust to living with MS. However, this cannot be guaranteed. The information we get from the study will contribute to our knowledge around which psychological interventions is of most benefit for patients with MS. This information may help us to offer better psychological support to MS patients.

What if new information becomes available?

Sometimes during the course of a study, new information becomes available about the treatment that is being studied. If this happens the researchers will tell you about it and discuss with you whether you want to or should continue to take part in the study. If you decide to withdraw, this will not influence the care you receive within the MS service. If you decide to continue you will be asked to sign an updated consent form.

What happens when the study stops?

If you received narrative therapy you will return to your normal care after the eight sessions. If you have been allocated to the 'treatment as usual' group, you will be offered narrative therapy at the end of the study.

Will my taking part in this study be kept confidential?

Yes. All the questionnaires and information given by you will be confidential and coded to make it anonymous. This means that your name will not appear on any of your questionnaires. Questionnaires will be numbered and numbers will be linked to your name on a password-protected file. All information collected about you during the study that leaves the clinic will be kept strictly confidential in accordance with the Data Protection Act 1998. Data from this study will be retained for 10 years in an anonymous form and subsequently disposed of securely. However, because the therapy will be delivered in a group, complete confidentiality of what you choose to bring to the group cannot be guaranteed.

What happens to the results of the study?

The study will be written up for publication in scientific journals and/or may be presented at scientific conferences. You will not be identified in any publication or presentation. If you would like to know the results of the study, we can provide you with a summary sheet.

Who is organising the research?

The study is being conducted by Ananda van den Heuvel, a Trainee Clinical Psychologist at Canterbury Christ Church University. The research is supervised by Dr Fergal Jones from Salomons and Dr Janet Rich from Sussex Partnership Trust.

Contact for further information

If you would like to discuss your potential involvement further please contact:

Study co-ordinator: Miss Ananda van den Heuvel

Job title: Trainee Clinical Psychologist

Telephone number: 01892507679 (please leave a message with your name and number) Email address: av42@canterbury.ac.uk

Address: David Salomons Estate, Broomhill Road Southborough
Tunbridge Wells Kent, TN3 0TG

Thank you for taking the time to read this information sheet.

APPENDIX 14: Consent form for MS patients

Centre number:

Participant Identification Number:

CONSENT FORM

Title of Project: Group narrative therapy for patients with multiple sclerosis: A pilot randomised controlled trial

- | | Please initial
box |
|--|-------------------------------|
| 1 I confirm that I have read and understand the Participant Information Sheet for the above study and have had the opportunity to ask questions. | <input type="checkbox"/> |
| 2 I understand that my participation is voluntary and that I am free to withhold personal information or to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 3 I understand that sections of any of my medical notes may be looked at by members of the research team, where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. | <input type="checkbox"/> |
| 4 I understand that the groups will be audio taped to ensure that the therapy is delivered in the way it was planned and give permission for this. | <input type="checkbox"/> |
| 5 I give permission for my GP, Care Co-ordinator, MS Consultant and/or nurse to receive details of my participation in this study. | <input type="checkbox"/> |
| 6 If, for any reason, I withdraw from the study I give consent to data from questionnaires I have already complete to be included in the results. | <input type="checkbox"/> |
| 7 I agree to take part in the above study | <input type="checkbox"/> |

Name of participant

Date

Signature

Researcher

Date

Signature

APPENDIX 15: Cover letter and information sheet for care coordinators

Date

Dear ,

Re: [Name of patient] involvement in a study to assess the effectiveness of Narrative Therapy

I am writing to inform you that the above named patient has consented to take part in a study organised by researchers from [name NHS Trust] and Canterbury Christ Church University. The purpose of this study is to assess the effectiveness of group narrative therapy in promoting the psychological adjustment to Multiple Sclerosis.

I enclose an information sheet with details of the study and inclusion criteria. I would be grateful if you could get let me know if you have any concerns about their participation or reason to believe that participation in this study is not in their best interest.

If I do not hear from you, I will assume that you have no such concerns.

Yours sincerely,

Ananda van den Heuvel

Trainee Clinical Psychologist and Study Coordinator

Care Team Information Sheet

Study title

Group narrative therapy for Multiple Sclerosis (MS): A pilot RCT

What is the purpose of the study?

Research has shown that coping with MS can be physically and emotionally challenging. MS patients commonly experience periods of low mood and anxiety. The provision of more emotional support alongside the management of the physical aspects of MS may improve adjustment to the disease.

The purpose of this study is to test the effectiveness of a psychological intervention known as 'narrative therapy'. Narrative therapy focuses on the stories we create of ourselves to make sense of who we are. A chronic illness such as MS can dominate patients' personal story in such a way that it pushes other, equally important, parts to the background. Narrative therapy aims to help patients re-tell the overlooked parts of their personal story to regain a sense of self that is separate from MS.

Inclusion Criteria

To take part participants:

- Must be aged 18 years or older
- Must have received a formal diagnosis of Multiple Sclerosis
- Must be considered to be sufficiently psychologically robust to take part in a narrative therapy group
- Must be able to give informed consent to take part in the study

Exclusion Criteria

- Patient who are currently undergoing some form of psychological treatment will be excluded from taking part

What does taking part entail for participants?

- (a) Participants who are eligible to take part will be allocated to one of two conditions: 1) group narrative therapy delivered by a clinical psychologist trained in this method or 2) TAU, involving the usual care patients receive.
- (b) Participants who have been allocated to the group narrative therapy condition will receive eight weekly sessions of narrative therapy delivered by a clinical psychologist who has received training in this form of therapy. Each session will last an hour and a half and will take place at [name of centre]. Participants allocated to the TAU condition, will be offered the therapy at the end of the study no longer than 6-8 months after agreeing to take part.

- (c) Participants will be asked to complete a questionnaire booklet containing questions about their physical and emotional symptoms, their thoughts and feelings about MS and about the way they tend to cope with stressful situations. This booklet will take a maximum of 30-45 minutes to complete. Questionnaire booklets will be sent to participants in the post along with a freepost envelope so that completed questionnaires can be returned free of charge. Participants who need assistance with completion of the questionnaires, can complete them over the phone with the research coordinator.

Contact details

If you have any questions about this study or concerns about your patient's involvement, please contact the study coordinator.

Study coordinator: Miss Ananda van den Heuvel

Job title: Trainee Clinical Psychologist

Telephone number: 01892507679

Email address: av42@canterbury.ac.uk

Address: David Salomons Estate
Broomhill Road Southborough
Tunbridge Wells Kent
TN3 0TG

APPENDIX 16: Information sheet for collaborators

PARTICIPANT INFORMATION SHEET

Group narrative therapy for patients with multiple sclerosis: A small scale randomised controlled trial

You are being invited to take part in an interview to evaluate the narrative therapy study that you helped facilitate. Before taking part, it is important that you understand what taking part involves. Please read the following information carefully.

What is the purpose of the interview?

The group was designed to help MS patients cope with the emotional aspects of their MS. As you know, we encountered some challenges in the recruitment phase of the study. We hope that the interview process can help outline some of these challenges in order to inform the design of future studies of a similar nature. Further, we hope that the interviews will help to illuminate aspects of the group that participants found helpful and unhelpful.

Do I have to take agree to be interviewed?

No, it is up to you whether you agree to this or not. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw from this decision at any time, without giving any reason.

What will happen to me if I decide to take part? What will I be asked to do?

If you agree to be interviewed, the study co-ordinator will make an appointment to interview you about your experiences of facilitating the narrative therapy group. The interview will last no longer than half an hour.

Interviews will be audio taped to ensure that what you say can be accurately documented.

What are the possible disadvantages and risks of taking part?

The only disadvantage to agreeing to be interviewed is your time commitment. The interview will last approximately half an hour.

What are the possible benefits of taking part?

Sharing your subjective experience of facilitating this study may help us begin to make sense of the active ingredients of narrative therapy and the challenges clinicians are likely to encounter when attempting to set up a group of this nature.

Will my taking part in this study be kept confidential?

Yes. All information given by you will be confidential. Steps will be taken to minimise the chance that any information you share in the interview can be linked to you. It is important to bear in mind, however, that the small size of the research team has the potential to undermine efforts to protect your identities. Prior to the write up and/or dissemination of this study, you will be offered the option to view your statements, and for any to be removed. Recordings of the interview will be kept strictly confidential in accordance with the Data Protection Act 1998. Data from this study will be retained for 10 years in anonymous form and subsequently disposed of securely.

What happens to the results of the study?

The study will be written up for publication in scientific journals and/or may be presented at scientific conferences. You will not be identified in any publication or presentation. If you would like to know the results of the study, we can provide you with a summary sheet.

Who is organising the research?

The study is being conducted by Ananda van den Heuvel, a Trainee Clinical Psychologist at Canterbury Christ Church University. The research is supervised by Dr Fergal Jones from Salomons and Dr Janet Rich from Sussex Partnership Trust.

Contact for further information

If you would like to discuss your potential involvement further please contact:

Study co-ordinator: Miss Ananda van den Heuvel

Job title: Trainee Clinical Psychologist

Telephone number: 01892507679 (please leave a message with your name and number)

Email address: av42@canterbury.ac.uk

Address: David Salomons Estate

Broomhill Road Southborough

Tunbridge Wells Kent

TN3 0TG

Thank you for taking the time to read this information sheet

APPENDIX 17: Consent form for collaborators

Centre number:

Participant Identification Number:

CONSENT FORM

Title of Project: Group narrative therapy for patients with multiple sclerosis: A pilot randomised controlled trial

Please initial box

- 1 I confirm that I have read and understand the Participant Information Sheet for the above study and have had the opportunity to ask questions.
- 2 I understand that my participation is voluntary and that I am free to withhold personal information or to withdraw at any time, without giving any reason.
- 3 I understand that the interviews will be audio taped to ensure my responses are accurately documented and that I will be given the opportunity to review my statements prior to dissemination of the results in any format. .
- 4 I agree to take part in the above study

Name of participant Date Signature

Researcher Date Signature

APPENDIX 18: Coding frame for content analysis

Coding frame for content analysis on data derived from open-ended questions

Answers were organised according to ‘meaning based units’ with the following themes emerging subdivided by helpful and unhelpful aspects:

Helpful aspects

1. The benefits of forming supportive networks: Any references to the value of the group in providing an opportunity to connect with others.
2. Benefits of sharing experiences: Any references to the value of the act of sharing, expressing, and reflecting on inner experiences.
3. Helped reconnect with the whole of one’s self, not just the notion of self that is dominated by the MS: Any reference to the successful exploration of the person beyond the MS.
4. Positive, but non-specific statements about the group: Any non-specific but positive labels given to describe the group.

Unhelpful aspects

5. Absence of unhelpful aspects, e.g. statements such as “nothing” or “none”.
6. Filling out questionnaires: Any negative evaluation of the process of completing questionnaires.
7. Powerful experiences and influences: Any reference to facets of the group that were experienced as too powerful/overwhelming.
8. Miscellaneous

APPENDIX 19: Inter-rater reliability

Inter rater reliability analyses for the content analysis

		Rater 2								Total
		1.00	2.00	3.00	4.00	5.00	6.00	7.00	8.00	
Rater 1	1.00	3	0	0	0	0	0	0	0	3
	2.00	2	8	0	0	0	0	0	0	10
	3.00	0	0	2	0	0	0	0	0	2
	4.00	0	0	1	8	0	0	0	0	9
	5.00	0	0	0	0	2	0	0	0	2
	6.00	0	0	0	0	0	2	0	0	2
	7.00	0	0	0	0	0	0	2	0	2
	8.00	0	0	0	0	0	1	0	1	2
Total		5	8	3	8	2	3	2	1	32

Cohen's Kappa = .85, $p < .00$

APPENDIX 20: Median and ranges of difference scores

Medians and ranges of difference scores for the SF-36, WCQ, and B-IPQ

	Median baseline change score (range)	Median intervention change score (range)
SF-36 ¹		
PCS	0 (12)	1.1 (21.4)
MCS	-.75 (28.3)	2.8 (34.9)
WCQ ²		
Confrontive coping	-1 (9)	2 (7)
Distancing	0 (10)	0 (9)
Self-controlling	-1 (10)	1 (14)
Social support	0 (12)	2 (22)
Accepting responsibility	-1 (8)	0 (12)
Escape-Avoidance	0 (11)	0 (14)
Problem solving	0 (10)	1 (24)
Positive re-appraisal	0 (9)	2 (19)
B-IPQ ³		
Consequences	0 (7)	-1.5 (9)
Timeline	0 (0)	0 (6)
Personal control	0 (13)	0 (17)
Treatment Control	0 (10)	-1 (10)
Identity	0 (8)	0 (11)
Concern	0 (7)	-1 (5)
Understanding	0 (10)	0 (6)
Emotional response	0 (7)	0 (7)

¹ Greater differences indicate an improvement² Greater differences indicate greater use of strategy³ Smaller differences indicate a reduction in strength of illness perception

APPENDIX 21: Themes derived from the content analysis and statements per theme

Themes derived from the content analysis of open-ended questions and statements per theme

Helpful aspects of the group	Statements
The benefits of forming supportive networks	Meeting new people Definitely meeting others with MS Making friends Supporting each other Meeting others and feeling 'sameness' I wish it could be a regular group meeting
Benefits of sharing experiences	Sharing experiences Being inspired by others Sharing experiences about symptoms etc Brilliant to all talk together about MS and share thoughts Better understanding of others' experiences Able to reflect on others and share ideas Talking about it, discussing it with one another. Realising there are lots of people worse than me who are 'just people' To openly talk about my MS experience, feelings, thoughts, strengths etc that I have It has allowed me to vocalise things I hadn't before
Helped reconnect with the whole of one's self, not just the self dominated by the MS.	Made me realise all the positive things, not just bad I have found myself again Drawn me out of my corner
Positive, but non-specific statements about the group	Very much so Very positive Incredibly interesting and therapeutic Fantastic Really enjoyed this group Very good, very absorbing Good Great, useful A good enjoyable positive one Very good Very helpful
Unhelpful aspects of the group	
Absence of unhelpful aspects	Nothing other than "it's ended" Nothing Nothing Nothing None of it
Filling out questionnaires	Possibly these forms Filling in forms
Powerful experiences and influences	Some of the more dominant people in the group

	Too many strong experiences
Miscellaneous	Time of the day not good

APPENDIX 22: Example extracts per theme and excerpts from interviews with initial codes. Excerpts from interviews with initial codes have been removed from the electronic copy.

Example of extracts from interviews with professionals involved in the study by themes and categories

1. Differences and communalities between groups	2. Recruitment processes Barriers	3. Data collection issues	4. Tension between the structure imposed by the protocol and the underlying theoretical position of narrative therapy	5. Impact of group
<p><u>1.1 Affiliation with facilitator or recruiter and its impact</u></p> <p>Firstly, the group that was running in [locality A], lots of the members had already had already seen me in the past so they had an affiliation with me, compared to the group in [locality B] who had no affiliation with me whatsoever and didn't know anything about me because there is no psychological input at all in [locality B]. I think that influenced the groups tremendously.</p>	<p><u>2.1. Practical constraints</u></p> <p>and I think you'll find with a lot of people with MS that it is timing. You know if it is a bad time of the day for them and it happens to be then that detracted somebody from doing it but different people have different bad times during the day so you can't really...ehm.</p> <p><u>2.2. Attitudes towards engaging in a psychological therapy group (with other people with MS).</u></p> <p>Yes, I think that ['therapy label'] was off putting and I was quite surprised by some of the responses of some people it was very</p>	<p><u>3.1. Completion questionnaires perceived as burdensome and/or interfering</u></p> <p>...and had to fill out lots of questionnaires which was incredibly boring and laborious and all they wanted to do is talk...</p> <p><u>3.2. Sensitivity of questionnaires in capturing the impact of the group</u></p> <p>...and maybe in ways that may not be easily eh collected in various...[interviewer prompt]... quantified.</p>	<p>the nature of narrative therapy is that it is dictated by your client. It is very difficult to stick to a structured plan</p>	<p><u>5.1. Supportive element</u></p> <p>I have seen several of the participants in clinic since the narrative therapy group ended and they have all been very positive about the effects of the group... eh...mainly from a support point of view...</p> <p><u>5.2. Broadening perspective of MS</u></p> <p>...mainly from interest in seeing people with different symptoms from themselves as MS can have a variety of symptoms and I think the interest was that no two people are exactly the same. Symptoms are variable and differ in severity</p>

<p><u>1.2 Size of the group</u></p> <p>much easier to control 5 or 4 people than it is to control 14 people...</p> <p><u>1.3 Idiosyncratic external influences and their differential impact on a) the group dynamics and b) unfolding group narrative</u></p> <p>so we had to take a whole session out from whatever we were supposed to do... to discuss this...just to talk about death and of course it opened up lots of narratives about death and about actually about mortality and about MS and it actually it is not something you can just ignore...so actually it did open up lots of different narratives. We never spoke about it in [group B] because it didn't come up...so it wasn't a</p>	<p>much...well I don't need anything...[group B]</p> <p><u>2.3. Gender differences in the level of attraction to the group</u></p> <p>Or maybe because he is a man...he doesn't join groups.</p> <p><u>2.4. The impact of differential levels of disability</u></p> <p>..people with more severe types of MS may have more difficulty committing to weekly groups or may actually have difficulty coming here so that may present a barrier.</p> <p><u>2.5. Power of different recruitment pathways and sources</u></p> <p>Somehow the local 'still active with MS' group got hold of copies of the invitations to participate and I think that most of the people were drawn from that group so that in itself was very positive as well. You know there are other ways of accessing possible participants.</p> <p><u>2.6. Appreciation of</u></p>			<p>across patients as well as disabilities</p> <p><u>5.3. Bringing people out of isolation</u></p> <p>Because for many years I have been trying to get her to meet other people with MS and things because I think it would help her not to feel quite so isolated and things and she is a young Mum and she said oh well I sat there and I have done the 'MS anonymous' ...[laugh]</p>
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<p>narrative...</p> <p><u>1.4.</u> <u>Commonalities</u> <u>between groups</u></p> <p>that [prior relationships amongst group members] was quite a common feature between the two of them.</p>	<p><u>interest in MS</u></p> <p>People... eh... are just so appreciative of people wanting to do research to help people with MS that people are taking an interest. I think because so often they're told well you've got MS and there is nothing we can do for you and that is a message they often get, especially from the medical side of things. So if somebody offers them something else and is showing an interest then they really appreciate it...</p>			
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APPENDIX 23: Copy letter from participant published in MS newsletter – This has been removed from the electronic copy.

APPENDIX 24: Abridged research diary

Abridged research Diary

25.10.10

I am informed of the unexpected death of one of the participants of group A by another participant. The group had been running for four sessions and had reportedly gelled well during this time. I feel sad and reflect on the consequences for the group. This will undoubtedly add another dimension to the unfolding group narrative. A theme that otherwise may have remained dormant has catapulted the group into a different arena without even a gentle warning. Ethical questions cross my mind. I had not factored in the possibility of a death due to the complications of MS and reflect on the multitude of possibilities this could give rise to, perhaps unwelcome ones for some.

01.11.11

Recruitment in [locality B] is not picking up. This seems incongruent with the enthusiasm expressed by the local MS society and the pace of recruitment in [locality A]. I wonder how the project is presented to MS patients in [locality B] and wish I had more influence and control over the process. The success of the project, a piece of work that is contributing to my professional identity, now feels fragile. I arrange a meeting with my supervisor to discuss the difficulties with recruitment.

02.11.11

I remind myself of previous research projects and realise that the weight I attach to this project has stifled my ability to generate workable solutions. I attempt to reflect

on the strategies I relied on in the past to overcome such difficulties and conclude that the need to build and maintain collaborative relationships is key. Recruitment of research participants does not feature in the MS nurses' job description. I realise that for this project to become a success I have to convey my conviction that this is a worthwhile project to those involved. Perhaps face-to-face / telephone contact is better than relying on e-mail.

06.11.11

During supervision I reflect on the difficulties we have had with recruitment and am reminded of the feasibility aspect of this study, which is data in itself that can be harnessed. In consultation with my supervisor, I decide to shift the focus more towards the feasibility aspect of the study.

28.01.11

Interviews with collaborators have been arranged. Group B has come to an end. I feel in control and inspired by a renewed sense of positivity about the project and its potential. Having spoken to collaborators I feel as though this sentiment is shared. I look forward to upcoming interviews.

10.02.11

Interview with the MS nurse responsible for recruitment in group A.

I arrive with a sense of excitement. The MS nurse is clearly keen to talk and share her thoughts. I admire her passion for her work with MS patients. I note that in answering my questions she is keen to give a positive portrayal of the group by

giving anecdotal accounts of patients who have completed it and have spoken highly of the group. Eager to hear about the apparent success of the group (I have not yet entered and analysed my quantitative data) I must have subtly encouraged her to elaborate and, regrettably, find myself having to pull us back from the many digressions to the interview script. Is there a fear that the structured nature of the research format cannot do justice to the richness of the experiences being narrated? I notice a wave of doubt about my research method. Does my method and the data impoverish people's experiences? I notice a sense of guilt. The MS nurse suggests involving the neurologist in recruitment. I wonder whether I have done enough to make this project a success? Does the MS nurse feel she has done enough? Her final comment alludes to people's willingness to participate being driven by an appreciation for people doing research into MS and I feel somewhat burdened by the idealisation of the researcher that this comment hints at.

17.02.11

Interview with the facilitator of the group, also my research supervisor.

My sense of initial awkwardness makes me acutely aware of the abrupt role and power shifts. I wonder how this dynamic, and my discomfort around it, will influence the data and my willingness to use prompts. As the interview progresses the awkwardness begins to fade. I note that I have a tendency to, at least implicitly, assume responsibility for perceived failings at the different stages of the project, perhaps driven by a need to stay in charge of the project.

10.03.11

Interview with the MS nurse responsible for recruitment in group B.

Aware that recruitment for group B has been particularly challenging I arrive with a slight sense of trepidation as I prepare to ask questions about the obstacles encountered during the recruitment phase without giving the impression that anyone is to blame. I wonder whether the MS nurse shared this sense of uneasiness. Before I turn on the voice recorder, she shows me the publication in the latest MS society's newsletter of a movingly written piece about the group by one of the participants she recruited. Although the brief conversation that followed successfully dissolved some of the uneasiness, the MS nurse clearly indicated that she feels she could have done a better job at recruitment. She followed the same method as the nurse in [locality A] and so I wonder whether I have inadvertently fuelled a sense of competition between the nurses, both of whom appear wholly devoted to their jobs and the care for MS patients.

31.03.11

Whilst transcribing my data I note that the slight hint of my uneasiness with parts of the interviews is evident in my voice and manner of speech. Nevertheless, I feel satisfied with the richness of the transcripts and although feeling slightly daunted and disoriented by the process that lies ahead, I look forward to making sense of it with some excitement.

28.04.11

As I coded the data and extracted themes I became struck by how easily my own constructions were triggered by words following an associative process. I became

aware of the propensity of such words to influence the inferences that I am making. I returned to the literature on thematic analysis to re-assure myself that “I am doing it right” and wondered to what extent I have ‘adjusted’ my lens to the correct ‘focal length’ to sense codes and establish themes. I played around with this metaphorical focal length of the lens and experiment with ‘widening the angle’. The interpretation tells an interesting, comprehensible, story. I feel more confident about the reliability of the analysis.

APPENDIX 25: Feedback to ethics

13 July 2011

Dear Ethics Panel,

Re: [reference number]

I have now completed my research project. I attach a summary of the study and the findings for your interest. Please contact me if you require any further feedback.

Yours sincerely,

Ananda van den Heuvel

Trainee Clinical Psychologist

Feedback Summary

The utility of group narrative therapy to facilitate psychosocial adjustment in multiple sclerosis: A feasibility study

Multiple Sclerosis (MS) is a chronic and progressive neurological disorder characterised by the loss of myelin, a protective layer that coats nerve fibres and has a role in the transmission of nerve signals. In addition to myriad disabling functional impairments, MS has a profound effect on psychosocial functioning by intruding on daily activities, family, social, and working life, and consequently on one's sense of self. Psychosocial adjustment to MS is not merely a function of disease parameters. Many psychological determinants have been found to predict successful and unsuccessful adjustment, respectively. The National Institute of Clinical Excellence stipulates that psychosocial factors in MS are addressed alongside patients' physical needs. Little guidance, however, is offered as to the form psychosocial interventions should take.

Much of the research into psychosocial interventions sought to investigate the effectiveness of therapeutic models that focus on alleviating emotional distress. Such interventions tend to focus on the 'problem' as the source of distress. Subclinical levels of distress, however, can significantly impinge on patients' quality of life, leaving them poorly equipped to manage the uncertainty that pervades a life with MS. Narrative therapy purposefully moves away from a 'symptom-oriented' approach to focusing on the many ways in which lives can be 'storied', hence aims to uncover hidden narratives of strength and resilience that can be capitalised on.

This research sought to ascertain the feasibility of a larger scale study to test the utility of group narrative therapy to facilitate psychosocial adjustment in MS.

Fourteen MS patients, split across two groups, received 8-weekly sessions of group narrative therapy. Quality of life, coping processes, and illness representations were assessed at two baseline time points prior to the intervention and immediately after the intervention. The magnitude of the difference between the two baseline scores was compared with the magnitude of the difference between the second baseline and the post-treatment score to ascertain the extent to which the latter exceeded the former. Additional qualitative measures were taken and analysed using content analysis. In order to investigate the feasibility aspect of the study further, interviews were undertaken with MS specialist nurses involved in the recruitment of participants and with the clinical psychologist who delivered the intervention. Interviews were transcribed and analysed using thematic analysis.

Although the study was not powered to detect a significant effect if one exists, emerging trends for the mental health component of quality of life, 'confrontive coping', and perceptions of the consequences of MS on patients' lives warrant replication of the study using a sufficiently large sample effort of a larger scale study. This conclusion is supported by overwhelmingly positive qualitative appraisals of the intervention.

With respect to the feasibility of this study, several issues pertaining to recruitment and data collection emerged from the data that can inform future research.

Taken together, the results of this pilot study are promising and warrant further investigation using a sufficiently large sample. A paper to report on these findings is currently in preparation for submission to an appropriate journal.

APPENDIX 26: Journal instructions for authors

Submission information

Thank you for your expression of interest in publishing your writing with Dulwich Centre Publications.

The International Journal of Narrative Therapy and Community Work

If you are interesting in publishing your writing with us, it is most likely that you will be wishing to publish in this journal. Four issues are produced each year. Most issues are orientated around a particular theme and we place information about these themes in advance up on our web site.

Throughout the course of a year, we receive many more manuscripts that we can hope to publish and while this is lovely (we like receiving manuscripts from people!), it also means that unfortunately we have to turn away many people's writings. We always try to assist prospective authors to find other publishing avenues or other ways in which to distribute the ideas about which they are writing to the people who would most benefit from them.

Publishing is in many ways about distributing ideas, making links, and building a sense of community through the written word. Even if we cannot publish someone's writing in our journal or books, we try to find ways in which ideas can be distributed and further links made. We seek to ensure that authors who submit their work for publication have a positive experience of the process, even if we are unable to publish their writing.

General publishing principles

The following principles guide our publishing:

1. Opening space for conversations

We aim to publish writings which open space for conversation. The emphasis is on the sharing of story rather than polemics or statements of fact. We hope with each publication to engage readers' own thoughtfulness and to contribute to discussions within the field.

2. The person / community is not the problem

We aim to publish writings which are consistent with the principle that the 'person is not the problem, the problem is the problem'. In other words, we publish papers which are written from a non-pathologising stance and that are broadly congruent with the ideas of narrative practice.

3. Care with the politics of representation

We want people to have a chance to represent their own experience in the writings rather than authors representing the experiences of others. At the very least this means that, wherever appropriate, anyone referred to in the writings has a chance to read and reflect on the ways in which they have been represented. We also aim to take care with the politics of representation in relation to issues of gender, class, race, sexual preference, culture, ability, and age.

4. Direct relevance to practitioners

We aim for our publications to offer writings of direct relevance to practitioners. We prioritise descriptions of hopeful and helpful work which will provide practical ideas to those working in the field.

5. Seeking new authors

As much as is possible, we are always seeking to publish a significant amount of work from new authors, those who have not published their work before. Many good practitioners don't have a sense that they could write up their work for publication, and we see it as part of our role to offer support, encouragement, and collaboration. We are particularly interested in generating opportunities for young authors and authors from perspectives/communities/cultures whose work and ideas are generally under-represented in the written word.

6. Collective processes of review to forecast possible effects of each paper

Publishing is a collective process. Prior to publication, each piece is read by a significant number of people: to try to forecast the possible effects of the paper on a range of different readers, to check accuracy, to receive feedback on how it could be improved, to address issues relating to the politics of representation, and so on. This is always invigorating. There is a sense of anticipation that is associated with receiving this initial feedback prior to the publication because people's responses are impossible to predict. What is often most interesting are the differences in response depending upon the cultural background, gender, class, or sexuality of the reader. We wish to encourage practitioners to write about their work and so try to make their experience of submitting their work a good one. Developing a constructive formal review process for *The International Journal of Narrative Therapy and Community Work* has been a key part of this. Importantly, these collective processes of review also generate connections between practitioners, further enriching relationships within a community of ideas.

7. Expanding the thinking and parameters of narrative practice

Another principle involves publishing new work which expands our thinking and the parameters of narrative practice. We do not want to be simply confirming what is already familiar. Sometimes manuscripts are sent to us that introduce new therapeutic practices and ways of thinking about therapy and/or community work. At other times, one person's dedication to a particular topic breaks new ground. This was particularly true in relation to the special issue of the *Dulwich Centre Newsletter* on sexual abuse by priests, therapists, and other professionals. Ann Epston (1993) was committed to raising this issue in professional networks before many others were discussing it. We also put significant effort into researching and seeking out challenging perspectives from outside the field which will contribute to invigorating narrative practice. In recent years, the work of Esben Esther Pirelli Benestad on bi-gender, transgender perspectives (2001), and the work of America Bracho on community work approaches (2000) have significantly influenced discussions in the field through the publication of their work and their presentations at conferences. Publishing interviews with Paul Freire (1999), with leaders of the Truth and Reconciliation Commission (Boraine 1998), with Joan Nestle about her work with the Lesbian Herstory Archives (2003), with Noam Chomsky (1995), and others, has had the effect of stretching our thinking and inviting new conversations. Similar challenges have also come from publishing the work of various community groups. A considerable percentage of the papers we publish are not written from the standpoint of 'professional knowledge' but instead contain the stories, perspectives, and ideas of those who have sought counselling, or are involved in community organising. These perspectives from 'outside' the professional realm make a significant contribution to refreshing and reconceptualising therapeutic practice.

8. The effects of the process of publishing

Many narrative therapists are interested in the significant effects that documentation can have within a therapeutic process. While the publications we create are by no means primarily 'therapeutic', we try to make the process of publication a rewarding one for authors. This is most relevant when we are documenting the stories and insider knowledges of individuals and groups who have experienced significant trauma and/or abuse. It is our experience that when care is taken around these processes, documents can be created which richly describe the skills and knowledges of the particular individual or group and that offer a great deal to therapists and community workers, while simultaneously contributing to a further reduction in the effects of trauma or abuse in the lives of the author(s) (see WOWSAFE 2002, Silent Too Long 2000, Cecily 1998).

9. Archiving history

While our primary focus remains on looking ahead and the development of new ideas, practices, and conversations, we are aware that the written word also serves as a key forum for the documentation of history. The field of narrative therapy and community work is relatively young and yet it is developing very quickly. In differing ways, our publications seek to document the history of this field.

Perhaps the most obvious example of archiving history was the creation of the book *Family therapy: Exploring the field's past, present and possible futures* (Denborough, 2001). We recognised that some younger practitioners who are vitally interested in narrative practice were not necessarily aware of how these ideas were linked to various family therapy traditions. We are interested in documenting the history of therapeutic and community work ideas and practices in ways that assist practitioners.

10. Responding to social issues

Finally, we also use the written word as a way to respond to current social issues. For more information click [here](#).

Collaborative processes

Many of the papers that end up being published in *The International Journal of Narrative Therapy and Community Work* are the result of collaborative processes between the author(s) and Dulwich Centre Publications. Many papers originate as interviews, and considerable collaboration often takes place in relation to drafts and re-writes. We greatly value the process of these collaborations and believe that these processes are as important as the final outcome.

Review process

We have a formal review process for all papers for *The International Journal of Narrative Therapy and Community Work*. Once we are seriously considering a paper for publication we send it off for peer review by at least two members of the International Advisory Group.

This Advisory group consists of members from Mexico, Hong Kong, Australia, New Zealand, South Africa, Norway, Ireland, Denmark, Austria, Israel, UK, and USA. We have listed here the current members of the International Advisory Group:

Norma Akamatsu, Makungu Akinyela, Elsa Almaas, Chris Beels, Esben Esther Pirelli Benestad, America Bracho, Susanna Chamberlain, Gene Combs, Saviona Cramer, Vicki Dickerson, David Epston, Jill Freedman, Yael Gershoni, Kenneth V. Hardy, Rachel Hare-Mustin, Ann Hartman, Mark Hayward, Alan Jenkins, Maxine Joy, Zoy Kazan, Dirk Kotzé, Rudi Kronbichler, Joan Laird, Tracey Laszloffy, Bill Lax, Dean Lobovits, Geir Lundby, Stephen Madigan, Elspeth McAdam, Vanessa McAdams-Mahmoud, Imelda McCarthy, Jonathan Morgan, Margaret Newmark, Marilyn O'Neill, Amaryll Perlesz, Loretta Perry, Colin Riess, Shona Russell, Yvonne Sliep, Jane Speedy, Gaye Stockell, Taimalie Kiwi Tamasese, Angela Tsun, Charles Waldegrave, Kaethe Weingarten, Barbara Wingard, John Winslade, Jeff Zimmerman

A transparent review process

We have taken care to develop an alternative review process to the 'blind review process' that characterises the publication of many journals. We do not believe that anonymity is necessary in order to offer clear, honest feedback. At the same time we wish to provide reviewers with a context to be direct with us as publishers, about our publishing responsibilities.

The process we have developed is as follows:

- A couple of members of the Advisory Group are approached to formally review each major paper.
- Authors are informed as to who we have approached to formally review their paper.
- We ask reviewers a series of questions (see below) that are related to our responsibilities as publishers. The answers to these will only be read by those at Dulwich Centre Publications.
- We also ask reviewers to write a paragraph directly to the author summarising their response to the paper
- If the paper is accepted for publication, a small number of other members of the Advisory Group and/or others are asked to offer reflections on the paper. These reflections are passed directly to the author.

It is our hope that this alternative review process addresses both our responsibilities as publishers as well as trying to ensure a good experience for authors.

Word limits

We don't have strict word limits although most of the papers we publish are less than 5000 words. We believe that these matters can be negotiated in collaboration with authors down the track.

Instructions to authors and style sheet

Before submitting your manuscript, please refer to our **detailed instructions to authors and style sheet**. This contains everything you need to know to prepare your work to meet our publishing standards.

With all this in mind, we look forward to receiving your manuscript. This can either be posted to us:
Hutt St PO Box 7192 Adelaide, SA, Australia 5000

Or emailed to us: dulwich@dulwichcentre.com.au

We look forward to reading your writing and getting back to you as soon as we can.

Warm regards,

Cheryl White
David Denborough
Dulwich Centre Publications

Formal review questions:

These are the questions we send to reviewers to inform the peer review process.

We would appreciate your responses to the following questions. If you cannot respond to each of these questions, then please use them as a guide to your review.

- Do you think this article makes an original contribution to the field of narrative therapy and community work and/or contributes to the application of narrative ideas in unique ways?
- If so, what sort of contribution do you think it makes?
- Were there aspects of the paper that were particularly meaningful to you as a reader? If so, which sections and why?
- Were there any aspects of the paper that you either didn't understand and/or did not agree with? If so, which sections and why?
- Are there any particular themes that the paper currently does not address that you think deserve attention?
- Do you have any concerns about the publication of this article? If so, please explain your concerns and what steps (if any) could be taken to address them.
- Do you have any reflections in relation to the writing style, clarity, organisation of the piece?
- Do you have any concerns about the accuracy of any part of the paper?

- Is there any relevant literature that is not cited that you believe would be important to cite?
- After reading this paper, are you thinking differently about any aspect of your own practice as a therapist? If so, how? What difference, if any, will the reading of this paper make to your work?

Your response to this final question will be forwarded to the author:

- If you were to convey to the author your response to this paper in a short paragraph, what would you say?

