

A Model of Anger Expression in Multiple Sclerosis Patients

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Abstract

Anger in Multiple Sclerosis (MS) is an acknowledged clinical problem; however research is limited and mainly focuses on depression and does not study anger as an individual entity. The current studies, using both quantitative and qualitative approaches, investigated possible vulnerability factors and triggers which could be possibly associated with anger expression in MS participants. Additionally, a descriptive model of anger in MS was developed.

Study 1 investigated emotional, social and cognitive vulnerability factors in MS participants and a control group. Multiple regressions revealed that five factors accounted for 41% of anger variance in MS participants (anger ruminations, anxiety state, anxiety trait, depression and social support). Three factors accounted for 43% of anger variance in control participants (anger ruminations, trait anxiety and fatigue).

Studies 2 and 3 investigated the possible effect of health care professionals' (HCPs) response and communication styles in healthcare contexts on anger. A methodology for developing and validating vignettes was reported. ANOVAs revealed that HCPs and MS patients identified styles that were low in empathy and low in attending to patients' needs, as likely to provoke anger. HCPs significantly underestimated provoked levels of anger, compared to MS participants.

Studies 4 and 5 used a qualitative approach (content analysis) to elucidate MS patients' and HCPs' perceptions of anger. HCPs identified communication styles as a category which could increase anger in MS patients. Patients' behaviour also emerged

as a category which could contribute to HCPs' levels of anger. Training was also identified as a category which could help to manage patient anger.

MS participants identified four main categories. MS participants identified the categories of HCPs' behaviour and unpredictability of MS as possibly contributing to anger levels. The category of 'effects on health' emerged as a possible consequence of anger. The category of 'anger frequency' highlighted the variations in how often MS participants experienced anger.

A model of anger expression in MS was proposed which incorporated vulnerability factors associated with anger, communication styles and response styles from HCPs. The model was discussed in the context of past literature. Interestingly, it was concluded that factors associated with anger levels in MS participants are not disease factors unique to MS. Strengths and limitations of the studies, implications for clinical practice and future research were outlined.

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Declaration

I Anisha Paddam declare that the work presented in the following thesis is completely my own work.

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Signed

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Section 1

Chapter One: Introduction

1.1 Background Summary

Anger has become an increasingly high profile emotion with heightened media attention being paid to ‘problem anger.’ The Mental Health Foundation commissioned a questionnaire on anger and released the Boiling Point Report to highlight the increase in ‘problem anger’ and the lack of services within the National Health Service (NHS) to treat angry patients (Mental Health Foundation, 2008). The report outlined that 32% of healthcare professionals (HCPs) and laypeople had a close friend or relative that had problems with anger and over half would not know where to seek help. HCPs additionally reported they were unsure how to manage a patient whose predominant problem was anger.

HCPs acknowledged that they were poorly equipped to manage anger, and this is partly due to lack of empirical research on anger as a unique entity. In the context of current psychological disorders, anger is predominantly seen clinically as an emotion which is associated with mood disorders such as depression and anxiety. There is evidence to support the high co-morbidity of anger with 36% of patients with depression also displaying high levels of anger, 61% with bipolar disorder displaying high levels of anger (Benazzi, 2003) and 48% of patients with post traumatic stress disorder reporting significant problems with anger (Murphy, Cameron, Ramirez, Rosen, & Drescher, 2004). Individuals have fewer successful coping strategies for controlling anger than any other emotional state (Wegner & Pennebaker, 1993). Lack of empirical studies of anger can cause problems for healthcare systems which have little scientific research to guide their training for staff or management strategies for angry patients.

In addition to the association between anger and psychological disorders, high levels of anger have also been reported in patients with Multiple Sclerosis (MS) (Langdon & Thompson, 1999) as measured on the Spielberger State Trait Anger Expression Inventory (STAXI; Spielberger, 1988). Minden and Schiffer (1990) reported that 64% of MS patients reported anger and more recently 57% of MS patients reported displaying mild levels of anger (Feinstein & Feinstein, 2001). A pilot workshop conducted with 12 specialist MS nurses found that 92% of nurses had experienced anger from MS patients ‘quite often.’ Thirty three percent of nurses reported that up to half of their time was spent managing patient anger. Interestingly, only 17% of nurses felt that they were adequately supported ‘almost all of the time’ in managing MS patient anger (D. Langdon, personal communication, February 25, 2006). Consequences of anger expression in MS patients include reducing effective communication with HCPs (Kalb, 2005). Potentially, anger could reduce optimal access to healthcare and affect health of MS patients.

While anger has been noted in MS populations, as Feinstein and Feinstein (2001) reported, studies fail to ‘address the important clinical issues of what to make of multiple sclerosis patients whose predominant complaint isirritability and anger’ (p.196).

1.1.1 Aim of Studies

This thesis aims to explore, empirically, vulnerability factors and triggers which could be associated with anger expression in MS patients. Vulnerability factors are defined as markers which are common characteristics or symptoms present in MS patients. Triggers are defined as factors which could immediately arouse anger and may be

present in specific healthcare contexts. A descriptive model of possible contributors to anger expression in MS is formulated.

Background to Studies

1.2 Multiple Sclerosis

Multiple sclerosis is a chronic autoimmune disease of the central nervous system, affecting 85,000 adults in the United Kingdom. Current estimates suggest approximately 2.5 million people worldwide have been diagnosed with MS (Compston & Coles, 2008). The onset of MS typically starts in young adulthood (Coles, 2009) with approximately 70% of cases diagnosed between 20 and 40 years of age. It is estimated that approximately 50% of patients with MS will eventually die of medical complications arising from the disease (Ebers & Paty, 1997).

1.2.1 The Process of MS

In MS, white blood cells (leukocytes) migrate to areas of white matter in the brain and spinal cord and cause an inflammation response leading to swelling. Insulating myelin is stripped from around axons and plaques/lesions are formed. It is assumed that inflammation leads to demyelination and axonal loss. Myelin sheaths are completely lost in the lesions; axons may be spared but are surrounded by scar tissue. Damaged myelin leads to disruption of nerve communication and neurological transmission of messages can be slowed or completely blocked. Consequently, there is diminished or complete loss of bodily functions which are controlled by the central nervous system (Waugh & Grant, 2001).

1.2.2 Types of Multiple Sclerosis

Multiple sclerosis is divided into different subtypes. The most common variants are: primary progressive MS, relapsing remitting MS and secondary progressive MS.

Primary Progressive MS (PPMS) is characterised by a gradual progression of the disease from its onset with no remissions; rate of deterioration is variable (Ingle, Sastre-Garriga, & Miller, 2005). Approximately 10-15% of patients are diagnosed with this type and it has an equal gender ratio.

Relapsing Remitting MS (RRMS) is characterised by relapses during which time new symptoms can appear and old ones resurface or worsen. Eighty to 85% of MS patients have this diagnosis (Compston & Coles, 2008). The relapses are followed by periods of remission, during which time the person can fully or partially recover from the deficits acquired.

Secondary Progressive MS (SPMS) develops after a number of years in people who have RRMS. The risk of developing SPMS increases with disease duration and usually begins around 40 years of age (Coles, 2009). SPMS is characterised by a gradual worsening of the disease between relapses, although relapses are much less frequent than in RRMS (Coles, 2009).

1.2.3 Diagnosis and Symptoms of MS

MS is often seen as an organ or antigen specific disease caused by an immune mediated injury to the myelin, to the oligodendrocytes and axons (Compston & Coles, 2008). Studies have also linked virii and bacteria to MS (Freedman, Dosemeci, &

Alavanja, 2000). Research also confirms a genetic component to MS (Compston & Coles, 2008).

MS is diagnosed on the basis of clinical and paraclinical evidence for at least two demyelinating lesions, affecting different sites within the brain or spinal cord, separated in time (Compston & Coles, 2008). The McDonald criteria, revised in 2005, defined two separate MRI episodes for a confirmed diagnosis (Polman, Reingold, & Edan, 2005).

Common symptoms associated with MS are visual disturbances, optic neuritis, loss of muscle strength, tremors, spasticity, impairment of sense of touch, pain, bladder/bowel dysfunction, cognitive dysfunction, fatigue, depression and other mood or psychotic disorders (Boissy & Cohen, 2007).

1.2.4 Treatment and Symptom Management of MS

Steroids can be administered to reduce inflammation of the central nervous system. Disease modifying drugs (DMT), which may slow the progression of the disease, and complementary and alternative medications (CAM) are often taken by patients (Apel-Neu & Zettl, 2008).

1.2.5 Disease modifying therapies

Beta interferon, glatiramer acetate and natalizumab are common DMTs used in the United Kingdom (Coles, 2009). Interferons are effective in reducing relapses in RRMS by 25% and reducing lesion load as measured by MRI scans by 70% (O'Connor, 2002). Glatiramer acetate reduces relapses by approximately 29%-37% (Barten, Allington, Procacci, & Rivery, 2010). Natalizumab is only used with MS patients who have severe RRMS, defined as having two or more disabling relapses in

the previous year and increased lesion load in MRI scans and having not responded well to other disease modifying therapies. It has been shown to decrease relapse rates by 68% (Barten et al., 2010). Currently it can only be used in hospital settings due to possible severe side effects such as progressive multifocal leukoencephalitis (Tourbah, 2008).

1.2.6 Section Summary

- MS is a chronic disease of the CNS.
- MS is characterised by an array of symptoms including cognitive, emotional and physical symptoms.
- Treatments focus on symptom management and disease modification.

MS is associated with high levels of anger (Langdon & Thompson, 1999). The next section will therefore consider the definition of anger and models of anger before reviewing anger expression in clinical populations and MS populations.

Section2

1.3. Anger

1.3.1 Definitions of Anger

Anger is a complex emotion often portrayed as a primarily negative emotion. Anger is frequently triggered on a daily basis in various degrees due to violations of individuals' beliefs, or when there are actual or perceived barriers to goals (Izzard, 1977).

Spielberger (1988) defines anger as an emotional state which varies in intensity from mild irritation to intense rage. Spielberger conceptualises anger as an experience of the emotion and the expression of the emotion. Therefore, Spielberger divided anger

experience into state and trait. State anger is the temporal variation in intensity of angry feelings, which fluctuate according to situations and events. Trait is defined as the stable personality trait and refers to how often angry feelings are experienced. Spielberger divided the expression of anger into two components: out and in. 'Anger out' refers to the verbal or physical expression of anger, while 'anger in' is the internalisation and suppression of anger.

Spielberger's definition does not address the constellation of events and processes that occur during an anger experience. Kassinove and Sukholodsky (1995) considered a multidimensional approach to anger, defining the anger experience as consisting of physiological (general sympathetic arousal), cognitive (irrational beliefs, automatic thoughts), phenomenological (subjective awareness, labelling of angry feelings) and behavioural (facial expressions, behaviours) variables: *'a label given to a constellation of specific uncomfortable subjective experiences and associated cognitions that have various associated verbal, facial, bodily and autonomic reactions. It is a transient state, in that it eventually passes, and it is a social role, in that our culture or subculture allows for the display of certain kinds of behaviours associated with the internal experience, but punishes others. Thus anger is felt in people's conscious awareness and is communicated through the verbalisations and bodily reactions'* (Kassinove & Sukhodolsky, 1995, p.25).

1.4. Theories and Models of Anger

Most theorists agree that anger arises when a person perceives that they have been or are likely to be prevented psychologically or physically from attaining a goal (Izzard, 1977). If restraints are subtle anger may not occur; if barriers are obvious anger is

more likely to occur. Main models of anger are explained in more detail below. It must be noted that these models describe dysfunctional anger, which is not primarily seen in MS patients. MS patients are usually characterised by subtler forms of anger such as irritation (see section 1.6). However, these models can shed light on possible causal pathways, which could contribute to anger expression in MS, and thus aid in developing a descriptive model of possible factors which could contribute to anger in MS populations.

1.4.1 Anger Determinants and Consequences Model

Novaco (1994) proposed a theoretical model of dysfunctional anger: “Anger determinants and consequences” model (figure 1.1). He suggested that anger is a subjective emotional state involving the presence of both psychological and cognitive factors. Anger is triggered by environmental events, which in turn impinge on cognitions, behaviour and physiological arousal. The behavioural component can influence the environment as well as cognitions and physical arousal. Novaco’s model suggests there is a two way interaction between cognitions and physiological arousal.

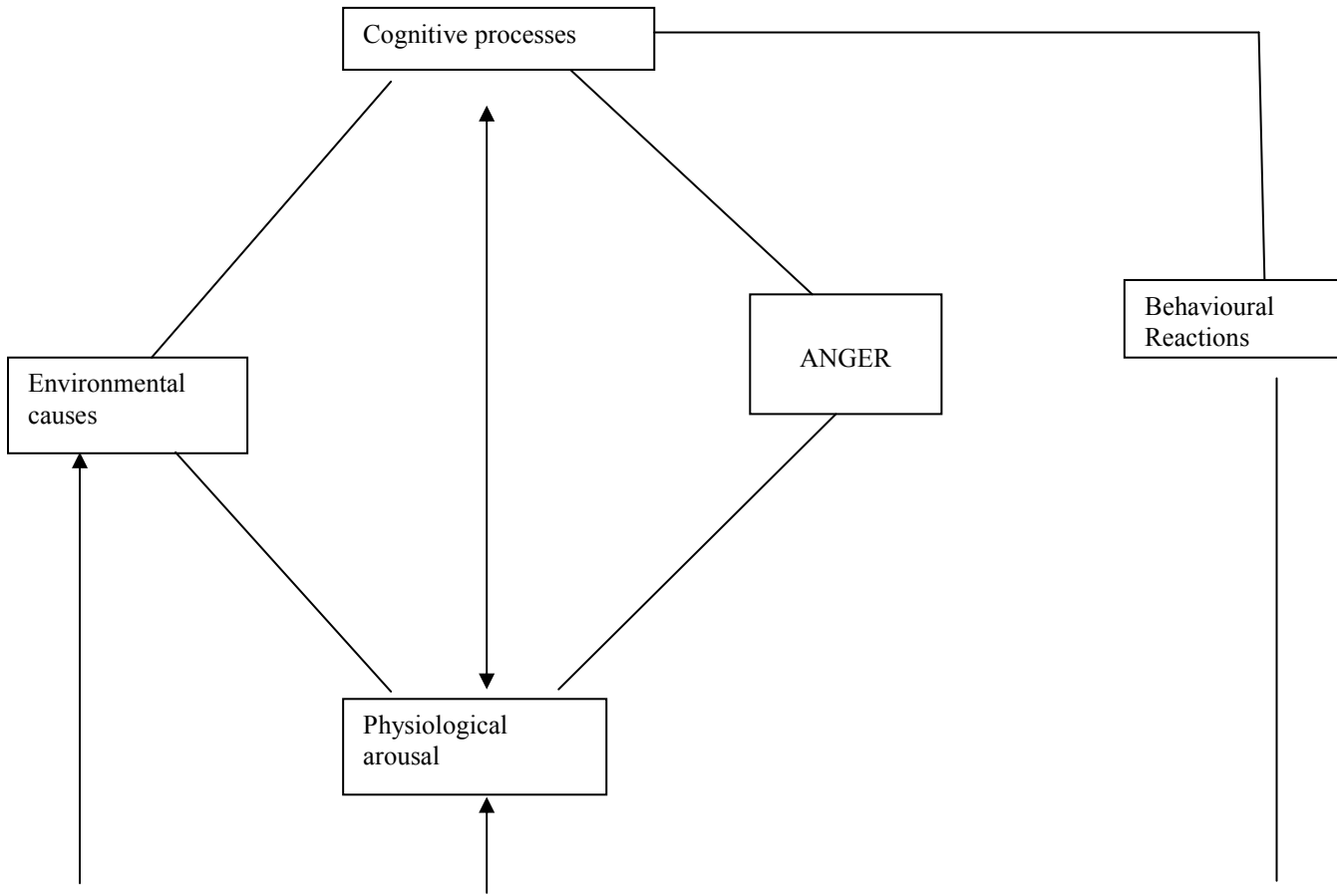


Figure 2.1

Novaco's 'Anger Determinants and Consequences Model' (Novaco, 1994).

1.4.2 The Anger Avoidance Model

Gardner and Moore (2008) developed a model of anger which encompasses clinical anger, the 'Anger Avoidance Model.' They defined clinical anger, as having heightened intensity, frequency and duration consequently leading to interpersonal, health and occupational difficulties. They theorised that clinical anger is triggered in conjunction with an interaction of an aversive history (for example maltreatment or neglect), biological vulnerability, cognitive misinterpretations and past life events.

This model suggests that through aversive early life experiences and social-family environments, people learn to scan the environment for potential triggers of anger. Evidence comes from studies on people with violent pasts, who show attentional biases towards anger-related cues following insult (Cohen, Eckhardt, & Schagat, 1998). These individuals are more likely to misinterpret cues as provoking anger. These cognitive misinterpretations lead to ineffectively processed anger causing emotional dysregulation. The model suggests that anger can be either manifest in internalised avoidance (hostile rumination) or externalised avoidance (aggressive behaviour), defined by early history. This model can be criticised for putting too much weight onto early life experiences and has not been tested experimentally (Gardner & Moore, 2008).

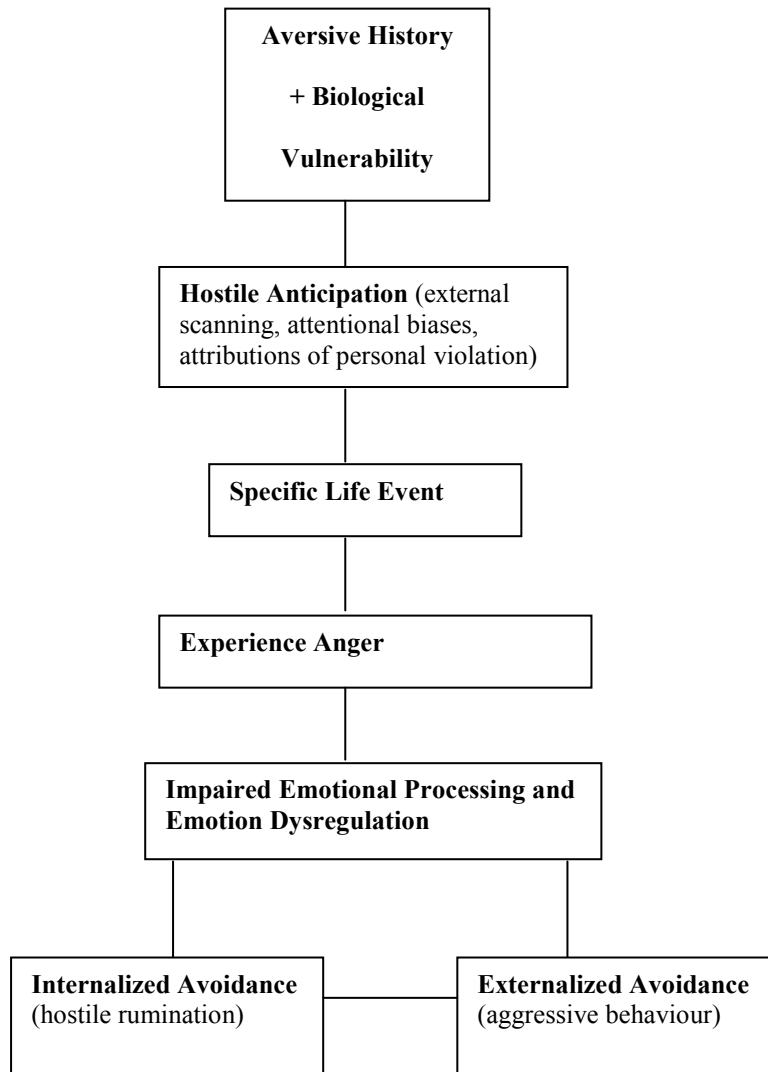


Figure 1.2

The Anger Avoidance Model (Gardner & Moore, 2008)

1.4.3 The General Aggression Model

Researchers have tried to acknowledge the complexity of anger by increasing the scope of models, in part by integrating experience in the form of social learning (Bandura, 1983), social appraisal in the form of social-information processing theory (Crick & Dodge, 1994), physiology in the form of excitation transfer theory (Zillmann, 1983), and social interaction theory (Tedeschi & Felson, 1994).

The general aggression model (GAM; Anderson & Bushman, 2002; Anderson & Carnagey, 2004) is a theoretical model composed of input variables, routes, and outcomes. At the most fundamental level, the GAM posits that an aggressive response is influenced initially by the interaction of two input variables: individual differences and situational factors. Depending on the nature of the input variables, aggressive behaviour may be more or less likely. These factors increase aggressive behaviour through three routes: affect, cognition and arousal. Activation of these routes facilitates anger-related feelings, aggressive thoughts, and real or perceived physiological arousal. Activation of one pathway increases activation of the other pathways.

Upon activation of these pathways, the individual immediately appraises the situation and other relevant factors. This immediate appraisal is quick and if time and/or cognitive resources are not available for further processing, immediate appraisal results in an impulsive action, which may be aggressive or angry. If time and cognitive resources are available, the individual evaluates further the results of the primary appraisal, as well as other relevant factors, in a more thoughtful and deliberate manner. This process, reappraisal, is conscious, slow, and leads to a thoughtful action that may be aggressive or non-aggressive. Social interaction can then influence aggressive displays. For example, an aggressive response may elicit higher levels of provocation from the target, which in turn will facilitate the display of another aggressive or angry response by the individual. Similarly, an aggressive response may be reinforced by the target “backing down”. Although this model has been used to describe and understand anger it lacks empirical data.

1.4.4 Limitations of Models

The limitations of these models in relation to this thesis are that they mainly attempt to explain explosive, violent anger episodes in aggressive individuals. The clinical pattern of anger in MS is not typically violent (Minden & Schiffer, 1990) and therefore these models may not be wholly appropriate. However, these models speculate that anger is triggered by environmental triggers, situational factors or early life experiences to varying degrees (Anderson & Carnagey, 2004; Gardener & Moore, 2008; Novaco, 1994), but they do not detail the types of environmental or individual characteristics which could be associated with the arousal of anger. These models also make it clear that individuals experience anger if triggers are present; thus we need to consider which individual, social and environmental factors associated with MS are likely to provoke anger. Specific literature on anger in clinical populations and MS populations will be explored to decide which factors to investigate. These models also highlight that cognitive distortions or deficits play a role in anger expression; this will also be considered.

1.5 Anger in Clinical Populations

Anger has been mostly studied in patient populations with mood, personality or learning disorders, where anger is dysfunctional and expressed in episodes of physical violence (Lancee, Gallop, McCay, & Toner, 1995; Taylor, Novaco, Gillmer, & Thorne, 2005). Anger has also been found to be high in individuals with intellectual disabilities. Black, Cullen and Novaco (1997) found that psychological deficits in anger regulation are among the core elements of challenging behaviour in people with learning disabilities. Anger has additionally been found in neurological populations. Patients with acquired head injuries demonstrate high levels of anger expression (Demark & Gemenhardt, 2002). Patients with advanced neurological diseases have

been observed to have high levels of anger expression. It is thought that this is due to a reaction to the illness and loss associated with the neurological conditions (Philip, Gold, Schwarz, & Komesaroff, 2007). MS is a neurological condition which is associated with great losses in physical and cognitive functioning; therefore, it is unsurprising that this clinical population also has high levels of anger expression (Nocentini et al., 2009). It could also be possible that anger in MS is aroused due to emotional dysregulation and due to difficulties they can experience with impulse control (Krause et al., 2009).

1.6 Anger in Multiple Sclerosis

Anger in MS takes a subtler form and is often displayed as frustration and irritability (Minden & Schiffer, 1990). Previous discussions of anger in MS usually comes from studies on depression, where it has been noted that MS patients are often ‘angry, irritable, worried rather than discouraged...withdrawn’ (Minden & Schiffer, 1990, p.100). As this area has been sparsely researched it is unclear if anger expression in MS is greater than anger displayed in other neurological populations or if indeed the anger exhibited in MS is greater than expected for the level of disability caused from MS. However, it is apparent that anger in MS does affect relationships with health care professionals (Kalb, 2005) which is important considering that MS is a lifelong incurable disease.

Only one specific study has investigated potential associates of anger in MS (Nocentini et al., 2009). This study attempted to investigate possible contributors to anger (measured on the STAXI; Spielberger, 1988) in an Italian sample of MS patients, in relation to clinical factors measured by the Expanded Disability Status Scale (Kurtze, 1983), depression measured by the Chicago Multiscale Depression

Inventory (CMDI; Nyenhuis et al., 1998) and anxiety measured by the State Trait Anxiety Inventory (STAI; Spielberger, Gorsuch & Lushene, 1989). Nocentini et al. (2009) found that disease severity was not associated with anger, suggesting that anger in MS patients is not simply a reaction to the physical disabilities caused by the disease. However, depression and anxiety were significantly correlated with anger. Such work suggests that anger may be related to the psychological symptoms of anxiety and depression seen in this group, although it is difficult to infer causality from a correlation alone. Such a hypothesis could be investigated by examining the effects of manipulating or treating depression and anxiety in this group on levels of anger. A control group was not included in the study by Nocentini et al. (2009) making it unclear if similar factors accounted for anger in healthy populations or whether this association was unique to MS. Another limitation of this study was that Nocentini et al. (2009) only investigated three possible factors; as the authors state themselves *'we did not investigate other emotions, personality or coping styles'* (Nocentini et al, 2009 p.1315) which may have contributed to anger experiences in MS participants.

The few remaining studies which specifically address anger in MS focus on anger at the point of diagnosis of MS and are of a qualitative nature (Edwards, Barlow, & Turner, 2008). In qualitative studies, MS patients complain about the way in which the diagnosis is communicated and type of information they are given at point of diagnosis (Solari et al., 2007). Therefore, these studies highlight that environmental factors present in healthcare contexts could arouse MS patient anger.

1.6.1 Section Summary

- Multiple Sclerosis patients have high levels of anger.
- Most models of anger suggest that barriers to goals in conjunction with appraisal, cognitions, feelings and external environmental triggers result in anger.
- Currently there is sparse literature on the possible contributors of anger in MS patients.

Models of anger inform our thinking that both individual and cognitive factors play a role in the arousal of anger. The next section outlines possible vulnerability factors that could be associated with anger in MS patients. Factors which will be considered are: factors which have already been found to be associated with anger in MS populations; symptoms of MS which in other clinical populations have been associated with anger; and other symptoms of MS which could be potentially be associated with anger. These factors are: depression, anxiety, fatigue, social support, anger ruminations and cognitive deficits.

Section 3 Possible Vulnerability Factors Associated with Anger in MS Patients

1.7. Depression

Mood and behavioural changes are found in MS patients (Minden, 2000) and affect patients' quality of life (Janardhan & Bakshi, 2002). Depression is clinically characterised by the presence of five of the following for at least a two week period: sad mood on most days, loss of pleasure, sleeping problems, fatigue, psychomotor retardation or agitation, negative self image, feelings of guilt and self blame, reduced

concentration and suicidal thinking (Diagnostic and Statistical Manual of Mental Disorders, 2005).

1.7.1 Depression and Multiple Sclerosis

MS patients have higher rates of depression than the general population and other medical or neurological illnesses (Schubert & Foliart, 1993). Lifetime prevalence rates are estimated to be 45-50% (Sadovnick, Remick, & Allen, 1996).

Studies on depression in MS must be interpreted within their methodological limitations; for example Schubert and Foliart's study can be criticised for accepting a diagnosis of depression made by a clinician who was not blind to the patient's MS. The majority of samples investigating depression are taken from MS clinics and therefore the results may not generalise to MS patients in the community. However, a study by Patten and Metz (2002) investigated prevalence rates of depression in a community sample of Canadian MS patients. Within their population sample of 115,071 participants, they found 12 month prevalence rates of depression of 25.7% compared to 8.9% for people without MS. MS can lead to emotional lability; thus many MS patients with depression are not formally diagnosed with depression (Feinstein, 2004). Therefore, recorded depression rates in MS may not truly mirror the exact rates in MS populations.

Arnett, Barwick and Beeney (2008) suggested that depression in MS could be caused by MS disease factors (e.g. for example changes in neurological functioning) and common MS sequelae (symptoms which are likely to be associated with the onset of MS). The relationships between these variables are moderated by factors external to patients which could increase the likelihood of depression (e.g. social support and

illness representations). Their model of depression proposes that depression can be consequential due to the onset of MS; however this may not be the only cause. They suggest that other common symptoms associated with MS such as fatigue, pain, cognitive dysfunction and physical ability can further increase levels of depression. However, the lack of robustness of some relationships suggests they may be moderated by other variables which could either increase or decrease the likelihood of developing depression: stress, coping, social support and conceptions of the self and illness. Furthermore, each factor may be associated with each other; therefore Arnett et al. (2008) graphically present their model in a circular template to show possible relationships between factors (see figure 1.3). They suggest that not all interactions between the common MS sequelae and moderators need be active to arouse depression.

Arnett et al. (2008) reported that the model is not uni-dimensional and speculated that depression possibly relates to the moderators and other variables and vice versa. Limitations include that this model is unable to determine cause and effect and has not been tested empirically. It must also be noted that this model may not include all the possible common sequelae or possible moderators which could influence depression.

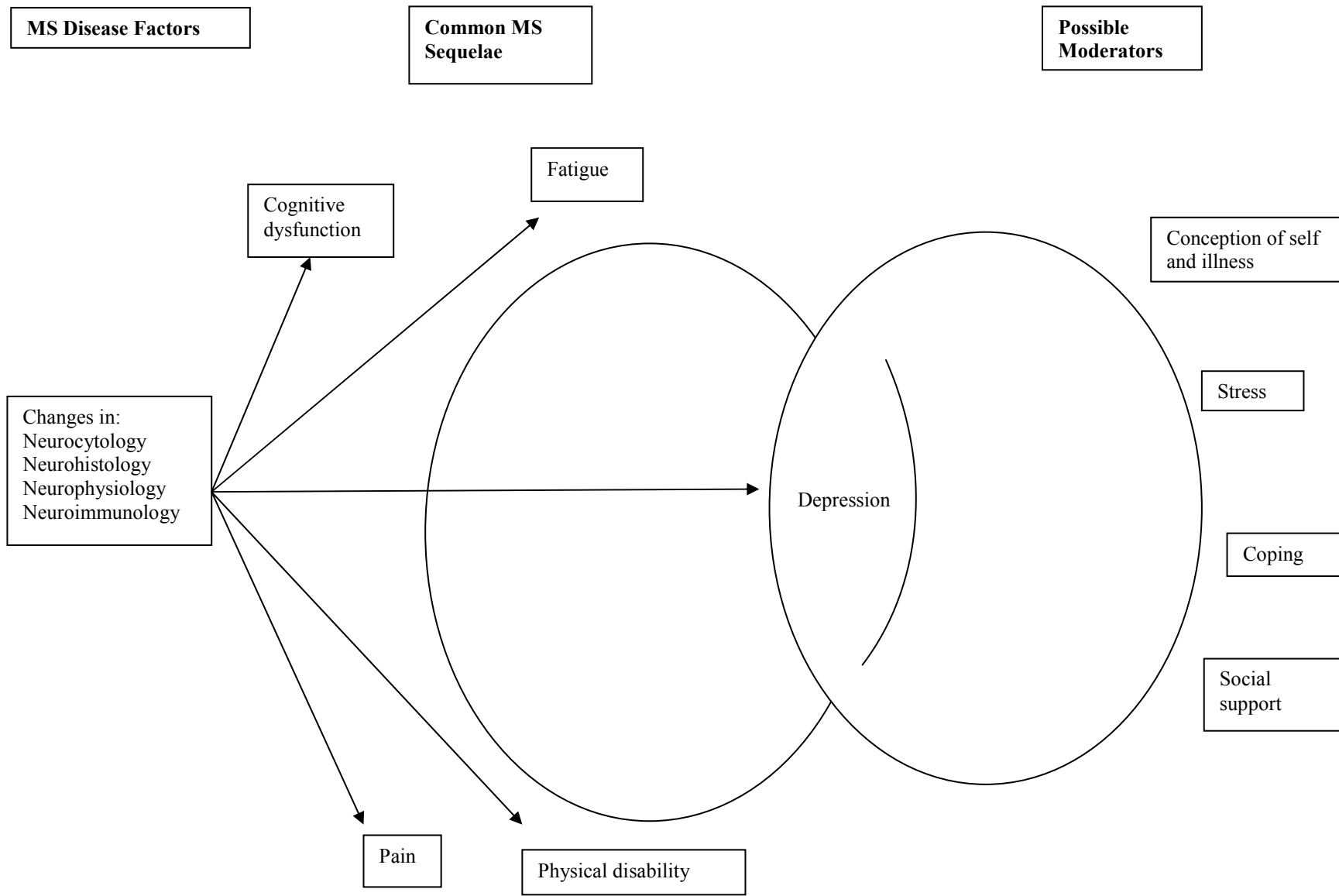


Figure 1.3
Arnett et al.'s (2008) Model of Depression in MS Patients

1.7.2 Depression, Anger and Multiple Sclerosis

Empirical studies with non-MS populations have investigated the link between depression and anger. Studies of arthritis sufferers have reported that anger is associated with depression (Achterberg-Lewis, 1982). Quantitative depression scores on the Beck Depression Inventory (BDI; Beck, 1978) have been related to levels of anger on visual analogue scales by patients with chronic pain (Wade, Price, Hamer, & Schwartz, 1990). Path analysis statistics have found anger levels on the STAXI (Speilberger, 1988), to be related to levels of depression measured on the BDI in chronic headache pain patients (Tschannen, Duckro, & Margolis, 1992). Twin studies suggest that aspects of anger expression and proneness to irritability display heritability comparable to that of major depressive disorder (Wang, Trivedi, Treiber, & Snieder, 2005).

Studies investigating depression in MS populations have found that rather than displaying typical clinical symptoms of depression such as withdrawal and low mood, MS patients display irritability and anger (Minden & Schiffer, 1990). Depression has been significantly correlated with anger expression in MS populations (Nocentini et al., 2009), although it must be noted that causality has not been determined. Therefore, it must also be considered that the apparent relationship between depression and anger in MS could be mediated by a third factor. This thesis will attempt to replicate and extend findings by Nocentini et al. (2009) by investigating the association between depression and anger further.

1.8 Anxiety

MS patients have increased levels of emotional distress including anxiety. Anxiety is an unpleasant emotion accompanied by physical sensations such as heart palpitations, nausea, shortness of breath, sweating, increased blood pressure and feelings of nervousness. Behaviour in response to anxiety is both voluntary and involuntary directed at ensuring one escapes or avoids sources of anxiety.

Anxiety can be divided into anxiety state and anxiety trait (Cattell, 1966). Anxiety state is defined as a transitory condition, which can fluctuate due to circumstances. Anxiety trait is defined as a subjective feeling of apprehension, tension and worry and is a stable personality characteristic (Spielberger, Jacobs, Russel, & Crane, 1983).

1.8.1 Anxiety and Multiple Sclerosis

MS patients have shown higher levels of anxiety than the normal population and other patient groups, including those with chronic illnesses, such as diabetes (Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002). Janssens et al. (2003) found that in a study of 101 newly diagnosed MS patients, 34% had high levels of anxiety measured on the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). In another study of 140 MS outpatients who attended a neurological clinic, 35.7% had a diagnosis of anxiety over the course of their lifetime when assessed using the structured clinical interview for DSM-IV disorders and the HADS scale (Korpstil & Feinstein, 2007). A study of MS patients in Norway using neuropsychiatric clinical examinations and the Hopkins Symptom Checklist-25 (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974), found that 19.3% reported anxiety which was above the level of the general population (Beisk et al., 2008). Such levels of anxiety are

unsurprising given the unpredictable nature of MS. However, as these studies are from clinic samples of MS patients, levels in community samples could be lower.

Anxiety levels tend to fluctuate during the course of MS. One longitudinal study reported that anxiety levels decreased over a two-year period, suggesting that anxiety is more prominent at diagnosis. A cross sectional study reported that MS patients who had recently experienced an exacerbation of symptoms reported higher levels of anxiety, measured by the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1971), than those who were in remission and compared to the general population (MCabe, 2005). Additionally, it has been found that MS patients who were in the relapsing stage had higher levels of anxiety as measured on the STAI (Spielberger et al., 1970) and a more negative attitude towards themselves and lack of self confidence compared to those patients who were in the remission stage (Papuce & Pawlowska, 2005). This could suggest either that the pathology of MS is triggered due to anxiety or that anxiety arises because of the disability caused by the inflammation.

1.8.2 Anxiety, Anger and Multiple Sclerosis

Anxiety and anger have been theoretically linked. It has been theorised that anxiety and fear can elicit an anger response as a defence to the demands of the stresses of the environment (Hollinworth, Clark, Harland, & Johnson 2005). This has been observed in hospital settings where in-patients may be trying to manage new inflexible routines. The patient may lose a sense of personal control which then gives rise to anxiety. As a consequence anger is evoked to restore control (Novaco, 1976). However, this is only speculative and assumes that anger is the direct result of anxiety. As models of anger highlight (see section 1.4), environmental factors also play a role in anger expression. Perhaps anger is only elicited in anxiety provoking situations if other specific

environmental factors are present (for example factors which prevent goals from being attained). Conversely, it has been empirically found that highly anxious people inhibit their expression of anger and try to suppress or avoid their angry feelings (Deffenbacher, Oetting, Lynch, & Morris, 1996) which would suggest that anxiety does not contribute to anger expression but suppression. Nocentini et al. (2009) did find a significant correlation between anger expression and anxiety in MS populations, although causality cannot be determined from this study. Anxiety therefore is another factor which will be investigated in this thesis.

1.9 Fatigue

Symptoms that were most prominent and disabling in MS were considered. As fatigue is one of the most disabling symptoms reported by MS patients (Krupp, 2003) it was considered worthy of investigation.

Fatigue is characterised by an increase in weakness and a persistent sense of tiredness even without any physical exercise (Keselbrener et al., 2000) and 65% of MS patients report experiencing fatigue on a daily basis (Minden et al., 2006). A study of MS patients in North America assessed fatigue on the Modified Fatigue Impact Scale (MFIS; MS Council, 1998) and the Fatigue Severity Scale (FSS; Krupp, LaRocca, Muir-Nash, & Scheinberg, 1989) and concluded that 74% of MS patients reported severe levels of fatigue (Hadjimichael, Vollmer, & Oleen-Burley, 2008). Prevalence rates reportedly range from 53% to 87% (Strober & Arnett, 2005). Seventy-six percent of MS patients acknowledged that fatigue they suffered once having been diagnosed with MS was different to what they had experienced previous to their diagnosis (Murray, 1985).

1.9.1 Fatigue and Anger

Currently there are no specific studies investigating the association of anger and fatigue. However, it can be speculated that fatigue and anger could be associated. Fatigue impinges on MS patients' daily lives affecting home lives, social lives and employment (Lobentaz et al., 2004). Fatigue leads to a decrease in activity, which prevents MS patients from completing domestic chores and often leads to termination of employment (MacAllister & Krupp, 2005; White, Wilson, Davis, & Petajan, 2000). Therefore, fatigue could lead to isolation which could cause MS patients to become frustrated and angry. However, while it is possible that fatigue is associated with anger, it could be the case that the causal relationship could be bi-directional. Anecdotal accounts of anger often refer to anger as a 'draining' emotion. It must also be considered that other factors which are associated with fatigue and anger, such as a decrease in social networks could influence their relationship. Fatigue will be investigated in this thesis for it's possible association with anger.

1.10 Social Support

Social support was considered as it has been linked to anger in other populations and it was considered to be pertinent in MS, where patients describe a decrease of social support (Rokach, 2004).

Social support includes the supportive input that individuals receive from their environments and through social interactions (Helgeson, 2003). The importance of social support has been noted in research on patient populations where low levels of social support, assessed on the Social Support Questionnaire (Sarason, Levine, Bashman & Sarason, 1983) can affect health; low levels of social support have been linked to illness (Diong et al., 2005). Social support is linked with high levels of

stress, and stress is often implicated in poor health (Diong & Bishop, 1999). Lower levels of perceived social support, measured by the Multidimensional Perceived Social Support Scale (PSSS; Zimet, Dahlen, Zimet, & Farley, 1988), have been associated with adverse effects on both physical and mental well being (Holland & Holahan, 2003).

1.10.1 Social Support and Multiple Sclerosis

MS patients experience reduced employment and personal social interactions as the disease course progresses (Verbrugge & Jette, 1994). Rokach (2004) found that MS patients described themselves as being lonely and isolated and these feelings were different to that described by healthy controls. In a review of longitudinal and cross sectional studies of MS, Amato, Zipoli and Portaccio (2006) concluded that the cognitive deficits found in MS patients often cause limitations in work and social life, leading to isolation.

Social support in MS patients has been linked to health state. Lack of social support and failure to utilise social support was predictive of relapse (Brown et al., 2006). MS patients who reported high levels of perceived social support from family members on the PSSS (Zimet et al., 1988) reported better social and emotional functioning. Higher levels of perceived social support from friends were associated with higher patient vitality and better mental health. Perceived social support from significant others were also related to better general health (Krokavcova et al., 2008). However the sample in this study only recruited MS patients from MS clinics. MS patients who do not regularly attend MS clinics may have very different levels of social support.

1.10.2 Social Support and Anger

Anger and social support have been associated in empirical studies of ‘anger prone’ individuals. Higher levels of anger are related to lower levels of social support as measured on the PSSS (Johnson & Greene, 1991). Anger prone individuals also report fewer and less satisfying sources of social support than their less angry peers (Deffenbacher et al., 1996).

1.10.3 Transactional Model of Anger and Social Support.

The theoretical transactional model of anger describes anger in regard to social relationships, stress and physiological aspects (Smith, 1992). This model proposes that individuals who have high levels of anger experience, have higher stress in their environments and use more maladaptive coping strategies to deal with stress, compared to individuals who have lower levels of anger. When angry individuals are confronted with stressful situations they themselves increase stress in their environment as they evoke similar angry reactions from others. Such individuals tend to have poor social networks due to their angry temperaments. Evidence for this theory is provided by the observation that individuals with high levels of anger do have lower levels of social support (Houston & Vavak, 1991). It has been suggested that individuals with high levels of anger gain a reputation for being difficult to engage with, making it hard to maintain social relationships and consequently affecting their levels of social support (Deffenbacher, 1992). Angry individuals also have fewer perceived social support resources available to them (McCann, Russo, & Benjamin, 1997). However, it could be possible that isolated individuals express anger as they do not have positive reinforcement from social networks to ‘buffer’ their experiences of anger. Therefore, low levels of social support could be a contributor to anger expression as well as anger expression contributing to levels of social support.

As already highlighted other factors such as cognitive processing could affect social skills in ‘anger prone’ individuals and thus contribute to the association of anger and social support.

1.10.4 Anger, Social Support and MS

Although previous research has investigated social support in MS patients and found it to be associated with emotional and physical well being (Rokach, 2004), it has not been investigated for it’s possible specific link to anger arousal. Previous literature does report a strong link between anger and social support levels in non-MS groups. As MS patients do report low levels of social support and display high anger levels it would be interesting to investigate whether there is a link between MS patients’ levels of social support and levels of anger expression. This thesis will investigate this possible link.

1.11 Anger Ruminations

Anger ruminations are characterised as ‘unintentional and recurrent cognitive processes that emerge during and continue after an episode of anger experiences’ (Sukhodolsky, Golub, & Cromwell, 2001, p.690). While this is a normal process in most people, it is exaggerated rumination that causes problems, as individuals dwell on an anger episode and concentrate on the negative aspects of the event (Nolen-Hoeksema & Marrow, 1991). Individuals who ruminate tend to perseverate on causes of anger but do not actively seek to change their situation and are less likely to engage in structured problem solving (Larsen & Diener, 1992; Lyubomirsky & Nolen-Hoeksema, 1995).

Anger ruminations are triggered in response to internal or external factors (Defenbacher, 1999). Internal triggers include memories of prior anger-provoking events and external triggers include an actual identifiable event. Anger rumination theory suggests that memories of prior anger experience can trigger new episodes of state anger. Attention to anger experiences can lead to amplification of the intensity and duration of anger and counterfactual thoughts may be recalled to retaliation (Sukhodolsky, Golub, & Cromwell, 2001).

1.11.1 Anger Ruminations and Health

Individuals who disproportionately ruminate are less likely to engage in active problem solving (Larsen & Diener, 1992), suggesting that anger ruminations prevent individuals from allocating cognitive resources to specific domains. In a laboratory study of rumination, Glynn, Christenfield and Gerin (2002) increased stress levels in undergraduate participants during a mental arithmetic task. After the session, participants returned to the laboratory after either 20 minutes or one week. On return, participants were asked to recall the stressful task and ruminate over it. Both groups showed an increase in blood pressure, showing that anger ruminations after 20 minutes and after longer periods of time after the initial anger provoking event can affect physical wellbeing. Participants who are distracted from ruminating showed a decrease in angry mood and had faster heart rate recovery (Neumann, Waldstein, Sollers, Thayer, & Sorkin, 2004). In a clinical sample of adolescents, anger ruminations were linked to aggressive behaviour outcomes (Peled & Moretti, 2007). These results suggest that recall of an emotional stressor and anger ruminations of stressors can have potential detrimental effects on health in healthy control participants and those from clinical populations. However, it must be noted that while these studies have asked participants to ruminate on specific anger provoking events,

it would be impossible to know if participants were just ruminating on these events or if other variables were also adding to the arousal of anger. Additional factors such as personality traits were not accounted for.

1.11.2 Multiple Sclerosis and Anger Ruminations and Anger

There is currently no literature on the effect of anger ruminations on anger in MS populations. However as MS patients do have high levels of anger, it could be the case that they either ruminate more on anger provoking experiences compared to healthy control participants or that they encounter more anger provoking experiences and thus ruminate more frequently. Patients with MS often have neurological cognitive deficits such as deficits in executive function, which causes them to find it difficult to 'shift set' (McIntosh-Michaelis et al., 1991), therefore once MS patients begin to ruminate it may be even harder for them to adapt, heightening angry feelings and intensities, contributing to high anger levels. Models of anger (see section 1.4) additionally theorise that anger affects cognitive processing; thus dysfunctions in cognitive processing could in turn cause higher levels of anger ruminations. It must also be considered that high levels of anger expression may cause higher levels of anger ruminations, rather than vice versa.

1.12 Neurological Cognitive Deficits

Most models of anger suggest a cognitive component to anger. Angry individuals have ineffective cognitive processing which affects emotional processing of emotions and anger (Anderson & Carnagey, 2004). MS patients additionally have neurological cognitive deficits which are demonstrated on validated neurological scales, which could further impact on cognitive processing and anger.

1.12.1 Cognition and MS

Estimates report that up to 70% of MS patients have cognitive deficits during the course of their disease (Chiaravalloti & DeLuca, 2008). A Swiss study with MS patients in the early stages of MS found that 29% of MS patients were cognitively impaired (Simioni, Ruffieux, Bruggllmann, Annoni, & Schluep, 2007). Importantly cognitive deficits can affect a patient's quality of life, negatively influencing their work commitments and social plans (Chiaravalloti & DeLuca, 2008).

Common cognitive impairments found in MS patients affect speed of processing, working memory, executive memory and long term memory (Chiaravalloti & DeLuca, 2008).

Working memory can be defined as a cognitive network that provides mechanisms for temporary storage and manipulation of information which is needed for complex tasks like language comprehension, learning and reasoning (Baddeley, 1992). Pelosi, Geesken, Holly, Hayward and Blumhardt (1997) found MS patients performed worse on working memory tasks compared to a group of healthy controls.

Patients diagnosed with MS will during the course of the disease have to learn to adjust, problem solve and adapt, due to the physical disabilities, social and psychological impacts of the disease. Executive functions are engaged in such situations (Shallice & Burgess, 1991). Fifteen to 20% of individuals with MS have impaired executive functions (Fischer, 2001).

Long term memory is the ability to learn or recall new verbal or visual material. This form of memory is often disrupted in MS patients (Amato & Ponziani, 1995) and studies report that long term memory problems are found in 40-65% of MS patients

(Rao, Reingold, Ron, Lyon-Caen, & Comi, 1993). Some studies suggest retrieval deficits contribute to memory impairments (Rao et al., 1993) while other studies propose impairments in encoding (DeLuca, Barbieri-Berger, & Johnson 1994).

1.12.2 Cognitive Deficits, Anger and MS

There are no specific studies on anger expression and cognitive deficits in MS. However, studies have shown cognitive deficits to have negative associations with MS patients' everyday tasks and activities. Rao, Leo, Bernardin and Unverzagt (1991) reported that MS patients who had cognitive deficits participated in less social activities, were more likely to be unemployed and were less likely to complete household chores. MS patients with high levels of cognitive impairment are more likely to be unable to work outside of their homes, need assistance in their daily lives and have fewer support networks (Mohr & Cox, 2001). Additional studies have reported that MS patients have deficits in decision making which could affect functioning during everyday tasks, due to deficits in new learning (Nagy, Bencsik, & Rajda, 2006). It could be speculated that inability to complete such tasks or to live or socialise independently could contribute to anger and frustration as personal goals are unmet. As already mentioned, it could also be speculated that neurological cognitive deficits could impact on anger expression, as deficits could affect cognitive processing which is a component of anger expression (see section 1.4). It must also be noted that anger expression could also affect cognitive deficits.

Cognitive functioning has also been found to be associated with emotional symptoms such as depression (Arnett, 2005). In a review article Arnett, Barwick and Beeney (2008) noted a consistent link between depression and cognitive functioning. As previously noted depression in MS is strongly characterised by anger. Therefore,

when considering vulnerability factors that may possibly be associated with anger expression in MS patients, cognitive deficits must be prioritised.

1.12.3 Section summary

Possible vulnerability factors which could be associated with anger in MS patients:

- Depression and anxiety are empirically associated with anger in MS populations.
- It could be possible that fatigue could be associated with anger in MS, although this is yet to be tested empirically.
- Higher levels of anger expression are linked to lower levels of social support in other populations; thus they could be linked to anger expression in MS populations.
- Anger ruminations intensify anger and lead to high levels of anger expression in other populations and thus could also contribute to anger in MS populations.
- Neurological cognitive deficits could be associated with anger expression, although this has not been tested empirically in clinical populations.

Section 5 1.13 Triggers Associated with Anger

As well as considering vulnerability factors possibly associated with anger, we must consider possible triggers which could contribute to immediate anger expression to aid the creation of a descriptive model of anger in MS populations. Environmental triggers could include interactions with and communication styles of HCPs who play important and enduring roles in the lives of MS patients.

1.13.1 Importance of MS Health Care Professionals

There are approximately 200-300 specialist MS nurses in the UK to deal with 85,000 cases of MS (MS Research Trust, 2001). Literature from other in-patient groups suggests that nurse-patient relationships are the most important aspect of care giving linked to positive patient outcomes (Ozcan, 2006).

The importance of doctor - patient relationships has also been highlighted by research, which reports that patients with life threatening illnesses repeat word for word what doctors have said to them during consultations to family members (Roter & Hall, 1992). As with nursing staff, doctor-patient relationships have also been found to negatively influence patients' emotional well being (Suchman, Markakis, Beckman, & Frankel, 1997).

Health care professionals play essential roles in the lives of MS patients, in particular MS nurses who liaise with community services, GPs and specialist clinicians to coordinate care (Swainger, 2001). Given the importance of the continued role of HCPs in MS patients' lives, the way in which HCPs interact with MS patients could affect patients' levels of emotional well being and anger.

1.14 Interaction Styles and Anger

Interaction styles of nurses and other medical staff has been cited as a possible trigger of in-patients' anger (Barondess, 2003). Interaction styles that may minimise anger from patients are: empathetic engagement, capacity to communicate effectively and responsiveness to individual needs (Barondess, 2003).

Lack of rapport between health care professionals and in-patients in UK hospitals has been reported as a possible trigger for patient anger (Winstanley & Whittington, 2004). Patient anger, once triggered in health care settings, has been found to remain with patients in later encounters with community practitioners (Winstanley & Whittington, 2004). Consequently angry feelings can be transferred from original trigger clinical settings and continue to affect patient relationships with other HCPs. This can be constructed in terms of theoretical models of anger, which have been discussed in section 1.4. For instance, Novaco's (1994) 'Anger and Determinants Model' proposes that anger is elicited by external environmental triggers; in this case poor rapport with a HCP may be a trigger of anger which in turn affects cognitions and behavioural responses. Winstanley and Whittington's (2004) research found that once anger has been triggered in patients these feelings are generalised to other practitioners. The Anger Avoidance model (Gardener and Moore, 2008) proposes anger is likely to be triggered due to past experiences which affect emotional responses in future situations. Therefore, patients who have had past anger provoking experiences with HCPs may be more likely to display levels of anger in similar contexts.

Patients who are unhappy with their interactions with clinicians are more likely to be emotionally distressed, which could cause high levels of anger expression (McCauley & Tarpley, 2004). It must be noted that other (both environmental and vulnerability) factors could also impact on negative interactions between staff and patients, although direction of causality is yet to be determined.

1.14.1 Limit-Setting Styles and Association with Anger

Empirical research exploring possible characteristics of HCPs' interactions with patients that could affect anger expression is mainly with research on psychiatric in-patients, who often display violent and aggressive behaviour. As psychiatric patients' characteristics tend to stimulate strong reactions in HCPs, it can often lead to problems in creating a good working relationship between therapists and patients (Ward, 2004). Consequently, HCPs control relationships by using specific interaction styles, such as limit-setting styles (Ward, 2004).

Limit-setting styles are defined as styles where HCPs place limits on the interactions they have with patients (Lancee, Gallop, McCay, & Toner, 1995). High limit-setting styles are characterised by rigid intolerance, authoritarian attitudes, a lack of involvement of patient choice in their own care and a lack of empathy (Nolan, Soares, Dallender, Thomsen, & Arnetz, 2001). Authoritarian and controlling interaction styles have a negative impact on therapeutic relationships with patients and have led to aggressive outcomes on psychiatric wards (Abderhalden, Needham, Friedli, Polemans, & Dassen, 2002).

Limit-setting styles are associated with a decrease in empathy (Nolan et al., 2001). Empathy is the ability to genuinely understand the patient's perspective. Secker et al. (2004), found that in-patients reported that HCP's lack of empathetic skills were a contributor to angry and aggressive incidents. Rigid and authoritarian interaction styles could possibly convey a lack of understanding towards the patient from the patient perspective and possibly contribute to a negative therapeutic relationship.

However, interestingly one study on psychiatric in-patients reported that while patients attributed their levels of anger and violence to rigid and non-empathetic interaction styles, HCPs attributed aggression to the illness (Duxbury, 2002). Such results highlight the possible difference in importance that patients and HCPs place on interaction styles.

Lancee et al. (1995) identified six limit-setting styles which were used by HCPs with psychiatric in-patients: belittlement, platitudes, solutions without options, solutions with options, affective involvement without options and affective involvement with options. Styles which attended to the individual patient experience, had high levels of empathy and offered patients a choice in their care, were associated with the lowest levels of anger expression as reported by patients. Whilst this study indicates an association between limit setting styles and patient anger, it must also be noted that other environmental factors, such as the clinical settings or personal rapport previously built up with HCPs could also impact on anger expression. It must also be considered that temperaments and personalities of patients would also contribute to levels of anger expression.

1.14.2 Limit-Setting Styles and Anger in MS Patients

MS patients acknowledged, in a qualitative study, that interactions and communicative styles between themselves and health care professionals can generate negative feelings and affect their emotional wellbeing (Edwards, Barlow, & Turner, 2008).

Research is yet to investigate whether limit-setting style of interactions could influence MS patients' anger expression. As MS patients do have prolonged and

intense relationships with health care professionals and spend considerable amounts of time in clinical settings, it could be the case that types of limit-setting styles displayed from health professionals to manage MS patients care, and expressed care could contribute to anger expression in MS patients.

1.15 Communication Styles and Anger

Much of the literature on communication styles comes from studies with patients who have terminal illnesses. Sheppard (1993) suggested communication between patients and health care professionals is more than just transmitting information; it involves recognising and acknowledging feelings. Therefore, it is unsurprising that style of communication is a key aspect of care quality (Oermann, Lambert, & Templin, 2000). Communication additionally involves acknowledging and processing non-verbal cues. DiMatteo, Hays and Prince (1986) report that exchange through non-verbal cues becomes particularly important when communicating emotional information.

In a qualitative study Elder, Jeffery, Zink and Hasse (2005), reported that the biggest complaint that patients with preventable problems had was 'bad' communication between the patient and the doctor, which was defined as communication styles which were primarily task orientated. Such levels of communication led patients to use non-adaptive strategies such as avoidance, where they failed to seek medical care. Three main types of communication styles between patients and HCPs have been related to patient outcomes (Ong, De Haes, Hoos, & Lammes, 1995): task orientated behaviour, defined as technical skills that HCPs use to solve problems; affective behaviour, defined as showing concern, warmth and attentive listening; and partnership building, which is defined as involving patients in their care. Task orientated approaches have

been found to be valued in patients who suffer from terminal illnesses and want information on their diagnosis and prognosis (Chaitchik, Kreitler, Shaked, & Schwartz, 1992). Affective behaviours have been linked to patient satisfaction and well being in patients who turn to HCPs for emotional support (Thom & Campbell, 1997). Cancer patients who want to take an active role in their care (Roter & Hall, 1992) have valued partnership building. Therefore, patients at different points of their illness or who want to be less or more active in their care, may value different communication styles.

McCabe (2004) identified four types of communication style that in-patients reported HCPs employed to communicate and the resulting effect on patients' emotional well being. The four styles employed were: patient centred communication, attending behaviour, empathy and humour. McCabe found that communication styles which attended to individuals' experiences and demonstrated cheerfulness, were most likely to ensure patients felt secure and to decrease negative emotions such as anxiety. Additionally styles of communication which fail to acknowledge the uniqueness of the individual have been associated with the arousal of anger (Plaas, 2001). However, as with limit- setting styles, it must also be noted that other factors such as personality could be influencing anger expression. Additionally, patients' levels of anger could impact on communication styles which could in turn cause a greater level of anger expression.

1.15.1 Communication Styles and Anger in MS Patients

MS patients have specifically expressed anger in relation to the way they were initially given information about their diagnosis (Edwards, Barlow, & Turner, 2008) and reported that such information was communicated ambiguously (Solari et al.,

2007). MS patients have identified that information needs to be tailored to the individual in terms of language, amount of information and sensitivity (Fallowfield & Jenkins, 2004). MS patients reported that they would like nurses to give them sufficient time to build rapport before sensitive information is communicated (White, White, & Russell, 2007).

Previous research on communication styles in MS patients is primarily qualitative and exploratory (Edwards et al., 2008) or is focused on communication of specific information or diagnosis (Freeman & Thompson, 2000; Solari et al., 2007). Empirical research is yet to identify specific styles of communication that could be associated with anger expression in MS patients. In building a coherent descriptive model of anger, it is important to investigate the possible role of communication styles as a possible trigger associated with anger expression in MS patients, which will be considered by expanding McCabe's (2004) study.

1.15.2 Section Summary

Evidence that possible external triggers in the form of HCPs' limit-setting styles and communication styles can affect anger expression in patient groups:

- HCPs play important roles in the wellbeing of MS patients.
- Interactions with health care professionals can affect anger in other patient groups.
- Limit-setting styles in particular appear to affect anger in psychiatric in-patients.
- Communication styles are associated with levels of anger in in-patients and MS patients.

- HCPs' interaction styles and communication styles are yet to be investigated empirically in relation to their effects on MS patients.

Section 6

1.16 Outline of Thesis

This thesis aims to begin to explore which vulnerability factors and environmental triggers are associated with anger expression in MS patients. Hypotheses are partly inspired by Arnett et al's. (2008) model of depression (see section 1.7.1). Arnett et al. proposed that any symptom or characteristic associated with MS can be placed at the intersection between the common sequelae factors and possible moderators, as each factor possibly influences each other. Thus, anger can be placed at the intersection between the common sequelae and possible moderators/external factors (see figure 1.4). However, for the purpose of this thesis the common sequelae in this model are renamed as vulnerability factors. Common sequelae were renamed in this study because Arnett et al. defined common sequelae as any symptom which could be associated with the onset of MS and thus influence depression. However, in the current studies the proposed model only takes into account factors which could be associated with anger in MS, rather than all common symptoms of MS. It was felt that renaming common sequelae as vulnerability factors would make this distinction clear. Vulnerability factors are proposed as possibly being associated with anger expression in MS due to previous empirical data on anger in this or other populations, or factors which could be reasonably thought to contribute to anger and are related to likely symptoms of MS. Possible moderators are renamed triggers because Arnett et al. proposed that moderators would have a role in influencing the relationship between depression and the common sequelae. However, our model proposes that while triggers could moderate the relationship between anger and vulnerability factors, the

triggers are also likely to elicit the arousal of immediate anger independently. It was felt that renaming made this association clearer. Similar to the original moderators, these are factors which are external to individuals and have been empirically found to be associated with immediate levels of anger in clinical populations.

The proposed descriptive model of anger speculates there is an increased risk of anger after the onset of MS. Possible vulnerability factors which could increase the expression of anger are: depression, anxiety, fatigue, cognitive dysfunction, social support and anger ruminations. Possible triggers which could contribute to anger expression are communication and response styles (based on limit-setting styles defined by Lancee et al., 1995). Such triggers could also mediate the relationship between anger and vulnerability factors and make anger more or less likely to occur. The model of anger retains the original circular template as each factor possibly influences each other. It is also feasible that while anger is influenced by vulnerability factors and triggers, anger could also feed into these factors and triggers. Although the empirical studies in this thesis are unable to determine causality this model theoretically assumes putative causal links. This model is modified throughout the thesis as each study investigates possible associates of anger.

1.16.2 Relation to Models of Anger

The models of anger presented in section 1.4 speculate that environmental triggers, situational factors or early life experiences (Anderson & Carnagey, 2004; Gardener & Moore, 2008; Novaco, 1994.) trigger anger expression. The ‘triggers’ specified in our model can be conceptualised as environmental and situational factors. However, early life experiences are not identified in our model of anger, as the purpose was to

investigate which factors associated with MS could contribute to anger expression. The models of anger presented in section 1.4 also all highlight a cognitive component to the expression of anger. MS patients experience neurological cognitive deficits (see section 1.12) which could impact on cognitive processes which have been speculated to trigger anger (Anderson & Carnagey, 2004; Novaco, 1994). Thus, the model of anger presented in this thesis considers the role of cognition. Therefore, this model relates to previous models of anger in that they aided our thinking in which possible factors to explore in MS patients which could contribute to anger.

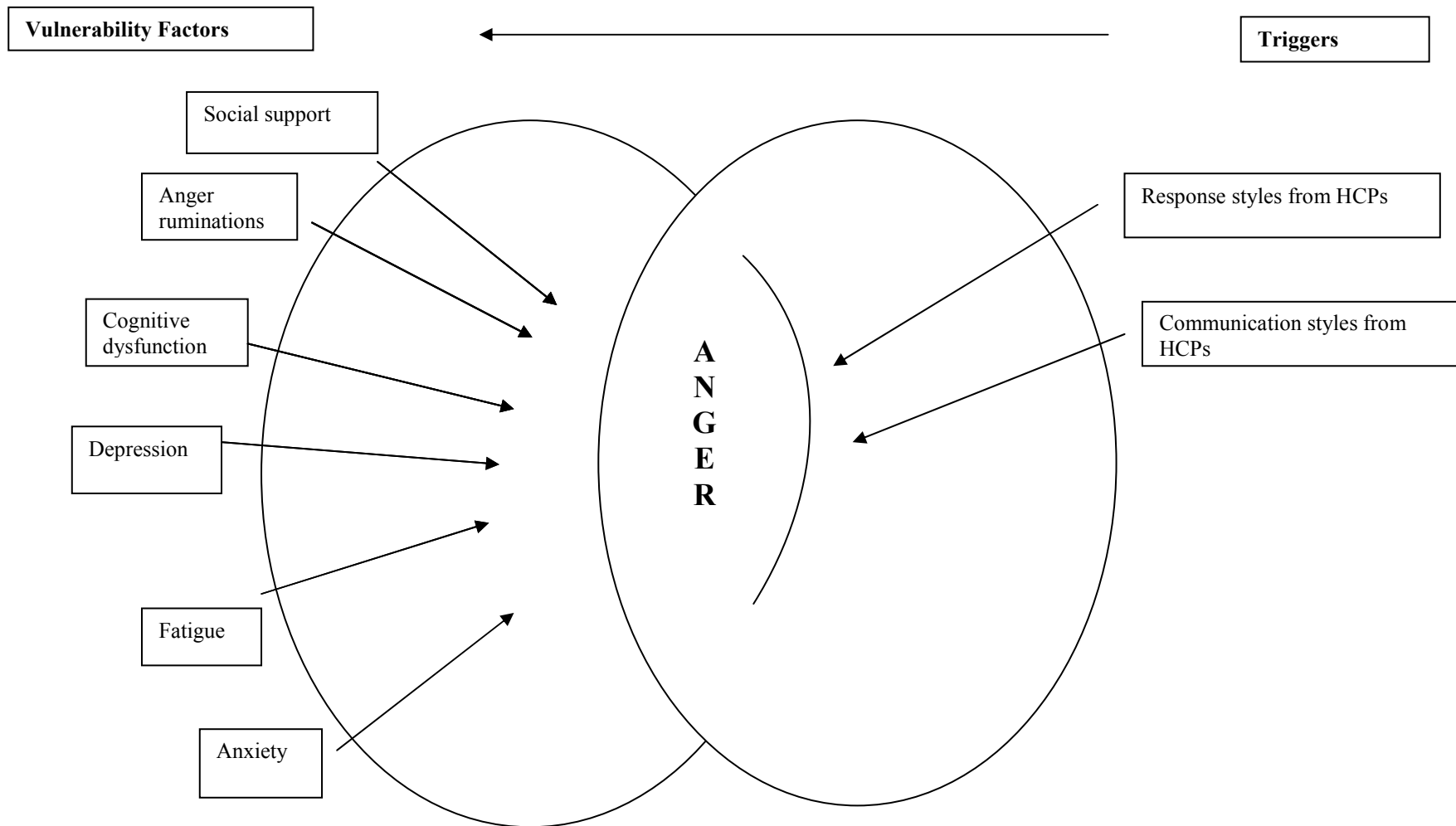


Figure 1.4
Proposed Model of Anger in MS Patients (1) based on Arnett et al.'s Model of Depression

Key → Possible contributors to anger in MS patients.

1.16.3 Rationale for Approach

The studies in this thesis primarily use a quantitative approach. Although qualitative data was gathered in studies four and five, these were converted into quantitative form using content analysis. Therefore, a variety of approaches was used in this thesis. Five studies were conducted addressing the following issues:

- 1) Possible vulnerability factors associated with anger expression in MS patients (quantitative).
- 2) External triggers in the form of limit-setting styles from HCPs (quantitative).
- 3) External triggers in the form of communication styles from HCPs (quantitative).
- 4) HCPs' perceptions of MS patient anger and their own anger experienced professionally (qualitative).
- 5) MS patients' perceptions of their anger expression (qualitative).
- 6) A descriptive model of anger expression in MS patients will consequently be presented.

As anger in MS is an under-researched area and in line with the National Service Frameworks for Long Term Conditions (Department of Health, 2005), the inclusion of a methodology which allows data to be thoroughly explored and not be bound by only hypothesis testing (Braun & Clarke, 2006) is useful. The use of gathering qualitative methods in studies four and five helped to gather additional information which may not be obtained from the empirical studies which adds to the richness of data collected. Qualitative analysis allows the researcher to fully grasp and understand individual perspectives of the world (Elliot, Fische, & Rennie, 1999). This understanding is essential in this thesis where new data is being gathered and a descriptive model is being formulated.

It must be noted that while qualitative data were gathered in this thesis, content analysis is not a purely qualitative approach (Hayes, 2000). In line with Hayes' (2000) description, in this thesis content analysis allows the researcher to convert the qualitative data collected into quantitative forms using frequency counts of occurring themes.

Chapter Two: Study 1- Vulnerability Factors Associated with Anger Expression in MS Patients

2.1. Introduction: Summary of Study 1

The aim of study one was to investigate possible vulnerability factors that could be associated with anger expression in MS patients. Factors were identified from symptoms commonly associated with MS and which had previously been associated with anger in either MS populations (depression and anxiety), with anger in other populations (social support and anger ruminations) or factors which could be theoretically linked with anger expression (fatigue and cognitive deficits). As sections 1.7-1.13 explain in detail the reasoning for investigating the chosen vulnerability factors, only a brief description is given below, after a description of the dependent variable is given. To investigate if anger expression is triggered by factors unique to MS populations, a control group of healthy individuals also took part in the study.

Anger expression was the dependent variable, measured with the Spielberger state trait anger expression inventory (STAXI; Spielberger, 1988). This definition and measure was chosen as it is expressed anger in MS patients which impacts on family members, support networks and staff in the NHS. Additionally it is this overt expressed anger which has been the target of previous research in MS (Nocentini et al., 2009). As anger in MS patients is usually expressed in subtler forms such as irritation and frustration it was important to ensure that the dependent variable was not a measure of aggression, which is a behavioural consequence of anger, or hostility which is characterised as mistrust and

cynicism. Some scales focus solely on these types of anger, for example the Cook-Medley Hostility Inventory (Cook & Medley, 1954).

The STAXI is a comprehensive assessment of anger which incorporates measures of internalised anger ('anger in') externalised anger ('anger out') and control of anger which together comprise the final score of anger expression. This measure therefore completely captures the anger experience. Additionally, as the STAXI has been used to measure 'normal' variation in anger, it may be particularly sensitive to anger experiences in MS, which are not usually violent or severe levels of anger (Langdon & Thompson, 1999). The STAXI has also been validated and used in MS populations to assess expressed anger (Langdon & Thompson, 1999; Nocentini et al., 2009).

Nocentini et al. (2009) found depression, state anxiety and trait anxiety to be significantly correlated with anger expression in MS patients. Study one will attempt to replicate and extend these findings by investigating a larger number of vulnerability factors (see below) which Nocentini et al. (2009) did not consider. In line with Nocentini et al.'s work, this study will also explore the role of physical disability. It has been hypothesised that anger expression in MS patients could be a reactive response to the physical disabilities caused by MS. However, no association has yet been found between physical disability and anger expression (Nocentini et al., 2009).

Models of dysfunctional anger (see section 1.4) highlight the importance of cognitive processing in the expression of anger (Anderson & Bushman, 2002; Anderson &

Carnagey, 2004; Kassinove & Tafrate, 2002; Novaco, 1994). MS patients have neurological cognitive deficits (Mohr & Cox, 2001). Such deficits could affect cognitive processing and resources. The general aggression model (Anderson & Bushman, 2002; Anderson & Carnagey, 2004) states that a lack of cognitive resources leads to immediate appraisals of potentially anger provoking events, resulting in angry reactions. Additionally, MS patients who have neurological cognitive deficits are less able to complete daily tasks without assistance and have fewer social support networks (Mohr & Cox, 2001), which could influence levels of anger expression.

Social support has been empirically linked with anger in non clinical 'anger prone' populations (Deffenbacher et al., 1996). Anger expression and social support has not been empirically investigated in MS patients. However, MS patients do report lower levels of social support than healthy control participants (Rokach, 2004). Thus, social support was identified as a possible vulnerability factor.

Anger ruminations amplify and increase the intensity of anger expression in non-clinical populations (Sukhodolsky et al., 2010). Additionally individuals who ruminate are prevented from allocating cognitive resources to problem solving. This could create a lack of cognitive resources which the General Aggression Model suggests could lead to the expression of anger (Anderson & Bushman, 2002; Anderson & Carnagey, 2004). As MS patients have higher levels of anger than the general population it could be hypothesised that they ruminate for a longer duration or more frequently on anger

episodes. This factor was identified as another vulnerability factor possibly associated with anger expression in MS patients.

Fatigue has not been empirically linked with anger expression in any population. However, it is reported to be one of the most disabling symptoms of MS (Krupp, 2003). Fatigue impinges on completing domestic chores, social life and work life (Lobentaz et al., 2004) resulting in individuals with MS becoming physically dependent on others which could lead to anger and frustration. Fatigue is associated with depression in MS populations (Schreurs, De Ridder, & Bensing, 2002) further strengthening the possible association between fatigue and anger in MS patients.

Consequently, vulnerability factors investigated were: depression, anxiety state, anxiety trait, social support, cognitive deficits, anger ruminations and fatigue. Additionally physical disability was documented.

The main hypotheses were:

- MS patients will have higher levels of: anger expression, depression, anxiety state, anxiety trait, cognitive deficits, anger ruminations and fatigue than control participants and have lower levels of social support compared to the control group.
- Social factors, emotional factors, cognitive deficits and physical disability will be uniquely associated with anger expression in MS patients and not healthy control participants.

2.1.1 Design of Study One

Fifty two healthy control participants and MS patients completed this study. Participants were matched on age, gender and pre-morbid IQ (see sections 2.6.3 & 2.6.4). Participants were asked to fill in self report questionnaires which measured emotional, social and cognitive factors to investigate which vulnerability factors were associated with anger expression. The questionnaires were presented in the following order (see section 2.3): Hauser Ambulation Index (HAI; Hauser, Dawson & Lehrich, 1983), Brief Repeatable Battery of Neuropsychological Tests (BRBN; Rao, 1990), Chicago Multiscale Depression Inventory (CMDI; Nyenhuis et al., 1998), State Trait Anxiety Inventory (STAI; Spielberger et al., 1970), Anger Rumination Scale (ARS; Sukhodolsky, 2001), Spielberger State Trait Anger Expression Inventory (STAXI; Spielberger, 1988), Wechsler Test of Adult Reading (WTAR; Wechsler, 2001), Multidimensional Perceived Social Support Scale (PSSS; Zimet et al., 1988) and the Fatigue Severity Scale (FSS; Krupp et al., 1989). Healthy participants were not required to fill in the HAI. Standard administration guidelines were followed.

The dependent variable was anger expression measured on the STAXI and the independent variables investigated were: depression, anxiety state, anxiety trait, social support, cognitive deficits, anger ruminations, fatigue and physical disability. Data were analysed using Pearson's correlations to detect significant correlations with anger expression. Factors which were significantly correlated with anger expression were placed into a forced entry multiple regression model (see section 2.6).

2.2. Method

2.2.1 Ethical Permission

Ethical permission to undertake this study was granted by Royal Holloway University of London Ethical Committee and NHS East Kent Research Ethics Committee. All participants gave written informed consent (approval letters can be found in appendix 1).

2.2.2 Inclusion and Exclusion Criteria for Patient Group

All patients were aged between 20 years and 70 years old and had a clinical diagnosis of MS (McDonald, Compston, & Edan, 2001). Patients were excluded if they had any other type of medical condition, disability, severe mental health problems or if English was not their first language.

2.2.3 Inclusion and Exclusion Criteria for Healthy Control Group

Healthy volunteers were aged between 20 and 70 years old. All healthy participants confirmed that they had no medical illness or significant mental health problems. All participants confirmed English was their first language.

2.2.4 Sample Size Requirements

Eight predictor variables were investigated. As no previous effect sizes could be estimated from previous research a medium effect size was presumed (Field, 2000). The suggested sample size for a multiple regression for eight predictors with a medium effect size is 120 participants (Miles & Shevlin, 2001). It was considered that not all eight predictors would be placed in the final regression models; thus up to 50 participants

would be recruited and a power calculation would be calculated to check the power of the test at the end of the study.

2.2.5 MS Patient Participants

One hundred and twenty MS patients were approached via a monthly MS clinic. Patients were introduced to the researcher, Anisha Paddam (AP), after their appointment with the specialist MS team where the neurologist provided patients with a letter explaining AP's work. The researcher took patients to a separate room and provided them with additional information. Patients were able to ask questions and were given an information sheet to take away. Participants were given two weeks to decide if they would like to take part in the study. The researcher telephoned potential participants and organised a convenient time and venue for the study to commence. If patients did not wish to take part they notified AP and all further contact was ceased (information sheets and consent forms can be found in appendix 2).

2.2.6 Healthy Control Participants

Healthy volunteers were recruited via contacting local big businesses within the Surrey and London areas. Companies were sent letters explaining the study. Employees contacted AP if they wished to participate. Once contact was made AP organised an appropriate venue and time for the study to commence (information sheets and consent forms can be found in appendix 2).

2.3 Measurement Scales

MS patients and healthy control participants filled in a battery of questionnaires which were presented in display booklets (see appendix 3) and ordered in this way: Hauser Ambulation Index (HAI; Hauser, Dawson & Lehrich, 1983), Brief Repeatable Battery of Neuropsychological Tests (BRBN; Rao, 1990), Chicago Multiscale Depression Inventory (CMDI; Nyenhuis et al., 1998), State Trait Anxiety Inventory (STAI; Spielberger et al., 1970), Anger Rumination Scale (ARS; Sukhodolsky, 2001), Spielberger State Trait Anger Expression Inventory (STAXI; Spielberger, 1988), Wechsler Test of Adult Reading (WTAR; Wechsler, 2001), Multidimensional Perceived Social Support Scale (PSSS; Zimet et al., 1988) and the Fatigue Severity Scale (FSS; Krupp et al., 1989).

Healthy participants were not required to fill in the HAI. Standard administration guidelines were followed. Each scale is discussed individually below.

2.3.1 Socio-demographic Variables

Demographic variables were collected: gender, age, ethnicity, nationality, employment, use of medications and type of MS (if appropriate).

2.3.2 Hauser Ambulation Index

Physical disability was measured by a single observation from the researcher using The Hauser Ambulation Index (Hauser, Dawson, & Lehrich, 1983). A decision about disability is made based on a person's speed in walking 25 feet and the level of assistance needed. Ability was scored on an ordinal scale from 0 to 9, where 0 represents asymptomatic and 9 represents restriction to a wheelchair.

2.3.3 Brief Repeatable Battery of Neuropsychological Tests-Cognitive Index

The BRBN (Rao, 1990) comprises: selective reminding test, 10/36 spatial recall test, symbol digit modalities test, paced auditory serial addition test, delayed recall of the selective reminding test, delayed recall of 10/36 spatial recall test and word list generation.

Verbal immediate and delayed recall memory was assessed using the Selective Reminding Test (SRT; Buschke & Fuld, 1974). Participants were read aloud a list of 12 words and were asked to repeat back, in any order, as many of the words they could remember on 6 trials. On each trial they were reminded of the words they had forgotten and again asked to recall as many words as they could. Words that were spontaneously recalled on two consecutive trials were scored as long term recalled words. Words that had been recalled on two consecutive trials were considered to be in long term recall on all following subsequent trials regardless of subsequent recall. If a word was consistently recalled on all subsequent trials then it was also scored as a consistent long term retrieval word. Overall, over the six trials 12 scores were obtained for each participant; long term recall and consistent long term retrieval. Possible scores could range from 0-12 on each trial. After a delay participants were asked to recall again as many of the 12 words they could remember; therefore correct delayed recall responses were also recorded.

Spatial immediate and delayed recall memory was assessed with the 10/36 Spatial Recall Test (Rao, 1990). Participants viewed a grid which had a pattern made up of ten counters. Participants were asked to view this board for 10 seconds and then reproduce from

memory the pattern on the board. This was repeated on three trials. Immediate correct recall responses were recorded. In addition, after a delay participants were asked to reproduce from memory the pattern, so correct delayed recall responses were also recorded. This therefore produced two individual scores which ranged from 0-10.

Complex attention, concentration and speed accuracy in visual search scanning were measured with the Symbol Digit Modalities Test (SDMT; Smith, 1982). Participants were given a sheet with a list of symbols, each of which corresponded to a particular number. Participants were asked to use this key to match the correct number to as many of the symbols given on another sheet of paper in 90 seconds. The number of correct matches were recorded and summed. The possible range of scores was 0-110. This test produced one single score for each participant.

Sustained attention and speed of processing was assessed with the Paced Auditory Serial Addition Task (PASAT; Gronwall, 1977). Participants were asked to listen to a consecutive string of numbers which were presented at the rate of three and two seconds (on two separate trials). Participants were asked to add two numbers in a row and give their answer before they heard the next number. Participants then had to add the next number they heard to the one they had just heard previously. The correct number of answers was summed for the two different rates of the test. Possible scores ranged from 0- 60. This test therefore produced two individual scores for each participant.

The Word List Generation (WLG; Rao, 1990) was used to measure verbal associative fluency. Participants were asked to spontaneously produce words which were consistent with the category name 'animals' in 90 seconds. Only words associated with this category were scored as correct. The sum of correct words was used as the overall score.

To obtain a single score of cognitive impairment to be used in further analysis, a cognitive impairment index was constructed (Calabrese et al., 2009; Camp et al., 1999; Patti et al., 2009). This index used each of the overall scores from the 6 tests. The mean and standard deviation was calculated for the control participants' data on each of the cognitive tests. MS Participants scores and control participant scores were compared to the control participant means and standard deviations. A grading system was applied to each score on each test, dependent on the number of standard deviations they were below the control mean. For example if the participant scored above the control mean they were given 0 (as only cognitive impairment was relevant). One was assigned if the participant scored below the control mean, but at or above 1 SD below that mean. Two was assigned if the participant achieved a score of $> 1SD$ below the control mean, but ≥ 2 SDs below that mean. All scores continued to be graded in this way, in line with previous research (Calabrese et al., 2009; Camp et al., 1999; Patti et al., 2009). The grades were summed across all the tests to obtain an overall single measure of cognitive dysfunction for each participant in each group. This total was used for statistical analysis.

Participants who scored two standard deviations below the control mean on three or more tests were considered to be cognitively impaired. The index was created in this way as

there is a lack of consensus of a clear definition of cognitive impairment (Patti et al., 2009). Other ways of creating a cognitive index were considered, for example summing Z scores of individual tests of the BRBN (Lazeron et al., 2005) and defining cognitive impairment on the basis of one standard deviation below the control mean. However, the method used here was chosen as it allows comparisons with other studies which have used the same procedure and it is the technique which has been used most widely in MS populations (Amato et al., 2001; Camp et al., 1999; Patti et al., 2009).

2.3.4 Chicago Multiscale Depression Inventory

The Chicago Multiscale Depression Inventory was administered to assess levels of depression (Nyenhuis et al., 1998). The CMDI consisted of 50 items. Forty two of the items are one word or a brief phrase describing a symptom of depression, for example, 'sad,' 'easily awakened,' 'glum,' 'criticised.' Eighteen items were not symptoms of depression and used to prevent a uniform response to negative items, examples of these items are 'loved,' 'peaceful,' 'capable.' Participants responded according to how much they had experienced each item in the past week on a five point likert scale. Scores were summed from the 42 items to obtain an overall score of depression which could range from 42-210. This summed overall score was used in analysis. This CMDI provides a reliable and valid test of depression amongst healthy populations, clinical populations and neurological patients (Nyenhuis et al., 1998) and specifically MS patients (Chang et al., 2003).

2.3.5 State Trait Anxiety Inventory

The State Trait Anxiety Inventory (Spielberger et al., 1970) was administered to obtain measures of immediate anxiety (state) and general levels of anxiety (trait). The STAI consists of two self reporting scales: the state anxiety scale and the trait anxiety scale. The state anxiety scale consists of 20 statements where the participant was asked to describe how much these statements represented how they felt 'right now' on a likert scale of 1-4. Examples of such statements include: 'I feel calm,' 'I feel upset,' 'I am worried.' The trait scale consisted of 20 statements where the participant was asked to describe how much these statements represented how they 'generally feel' on a scale of 1-4. Examples of such statements include: 'I feel pleasant,' 'I feel nervous and restless,' 'some unimportant thought runs through my mind and bothers me.' Scores were summed to obtain single scores of state and trait anxiety. Range of possible scores on both scales was 20-80. Summed scores of the state and trait inventories were used in analysis. The STAI is a reliable self report method of measuring anxiety, which has been widely used in clinical research (Oei, Evans, & Crook, 1990), with MS patients (Nocentini et al., 2009) and with healthy populations (Oei et al., 1990).

2.3.6 Anger Rumination Scale

Anger ruminations were assessed using the Anger Rumination Scale (Sukhodolsky et al., 2001). The ARS measures the tendency to think about current anger-provoking situations and to recall anger episodes from the past and counterfactual thinking about one's anger experience. The scale consists of 18 statements and asks participants to rate how true each statement is of them, on a four point likert scale, ranging from almost never to almost always. The scale consists of four subscales measuring: angry after thoughts with

five items, angry memories with five items, fantasies of revenge with four items and understanding causes with four items. Examples of statements on the angry after thoughts subscale include: 'I re-enact the anger episode in my mind after it has happened,' 'When something makes me angry I turn this matter over and over again in my mind.' Examples of angry memories include: 'I keep thinking about events that angered me for a long time,' 'I ruminate about my past anger experiences.' Examples of fantasies of revenge include: 'I have long living fantasies of revenge,' 'I have day dreams and fantasies of a violent nature.' Examples of understanding causes include: 'I think about the reasons people treat me badly,' 'I analyse events that make me angry.' The possible range of scores for the afterthought and memories subscales were 5- 20, and for the revenge and understanding causes subscales the possible ranges of scores were 4-16. These individual scales were summed to produce a single score of anger ruminations and the possible range of scores for this was 18-72. The overall single score was used in analysis. The ARS has been shown to have good reliability and validity (Sukhodolsky et al., 2001).

2.3.7 Spielberger State Trait Anger Expression Inventory

The dependent variable, anger expression, was measured using the State Trait Anger Expression Scale (Spielberger, 1988). This questionnaire consists of 44 items measuring the experience and expression of anger. It is comprised of the state anger scale, trait anger scale and the anger expression scale which is divided into subscales of anger out, anger in and anger control. The state anger scale (SAS) and trait anger scale (TAS), consists of 10 questions with a four point likert scale. The SAS scale asked participants to read each statement and identify on a four point scale, which ranged from not at all to very much so, how much the statements mirrored how they feel 'right now.' Examples of items on

this scale include: 'I am furious.' 'I am mad,' 'I feel like swearing.' The TAS scale asked participants to read 10 statements and identify on a four point scale, which ranged from almost never to almost always, how much each statement generally reflected how they feel. Examples of items include: 'I am quick tempered,' 'I am a hot headed person,' 'I fly off the handle.' Scores on each scale were summed to obtain an overall score of anger trait and anger state. Possible ranges of scores on these two scales were 10-40.

Anger out was measured with eight statements which asked participants to identify how much the statements were likely of them 'generally' on a four point scale, which ranged from almost never to almost always. Items included: 'I express my anger,' 'I do things like slam doors,' 'I argue with others.' These scores were summed to obtain a single score which could range from eight to 32.

Anger in was measured with eight statements which asked participants to identify how much the statements were likely of them 'generally' on a four point scale, which ranged from almost never to almost always. Items included: 'I keep things in,' 'I withdraw from people,' 'I tend to harbor grudges that I don't tell anyone about.' These scores were summed to obtain a single score which could range from eight to 32.

Anger control was measured with 8 statements which asked participants to identify how much the statements were likely of them generally on a four point scale, which ranged from almost never to almost always. Items included: 'I control my temper,' 'I am patient

with others,' 'I keep my cool.' These scores were summed to obtain a single score which could range from eight to 32.

An overall measure of anger expression, which was used in statistical analysis, was obtained from the following formula:

Anger expression = anger out + anger in – anger control + 16.

The possible range of scores on the anger expression scale was 16-48. This scale has been validated and used in clinical populations (Cullari, 1994) as well as MS populations (Nocentini et al., 2009).

2.3.8 Wechsler Test of Adult Reading

The Wechsler Test of Adult Reading (WTAR; Wechsler, 2001) was used to measure pre-morbid IQ for both groups of participants. The reading test consisted of 50 words. Participants were asked to pronounce each word as accurately as possible. Correct responses were summed to obtain a raw number, which then, according to participants' age, was converted into a standardised score.

2.3.9 The Multidimensional Perceived Social Support Scale

The Multidimensional Perceived Social Support Scale (Zimet et al., 1988) was used to quantify the amount of support participants felt they had. The revised scale of 12 items was used in this study. The 12 items consisted of three subscales which each had four items measuring social support from significant others, family and friends. Participants were asked how much they agreed with each statement on a seven point likert scale

which ranged from strongly disagree to very strongly agree. Examples of items on the significant others subscale include: 'There is a special person, with whom I can share joys and sorrows,' 'I have a special friend who is a real source of comfort for me.' Examples of items on the family subscale include: 'I can talk about my problems with my family,' 'My family is willing to help me make decisions.' Examples of items on the friends subscale include: 'I can count on my friends when things go wrong,' 'I can talk about problems with my friends.' Possible ranges of scores on each subscale were 7-28. These subscales were summed to obtain an overall single score which could range from 7-84. This overall single score was used in analysis. This scale has been standardised and is considered to be a reliable and valid measure of support (Blumenthal et al., 1987).

2.3.10 Fatigue Severity Scale

The concept of fatigue was measured using the Fatigue Severity Scale (Krupp et al., 1989). The FSS consists of nine items which were rated on a seven point scale. The items ask participants how often they experience fatigue and which areas of their life it impacts onto. Participants are asked to read each item and rate whether they strongly disagree or agree with each item. Examples of items include: 'I am easily fatigued,' 'fatigue interferes with my physical functioning,' 'fatigue interferes with me carrying out certain duties and responsibilities.' The possible range of scores which could be obtained were 9-63. In line with guidelines, the overall single score used in analysis was the average rating of all nine items. The FSS is the most used scale in clinical research and has been reported to have acceptable internal consistency, stability over time and sensitivity to clinical changes (Flachenecker et al., 2002).

2.4 Procedure

2.4.1 Procedure for MS Group

Patient participants were given the choice of completing questionnaires in their homes or at Royal Holloway University and were reimbursed for any travel. All patients except one chose to complete the questionnaires at home. Each questionnaire was read aloud and responses were written down by AP. Patients' emotional states were observed and test sessions would have been discontinued if patients became distressed or fatigued in the event. No sessions were discontinued.

2.4.2 Procedure for Control Participants

All participants were given the option of being tested in their work place, at their homes or at Royal Holloway University. Participants were reimbursed for travel. Twenty five participants were tested in their work place, 23 were tested at Royal Holloway University and nine were tested in their homes. The questionnaires were presented and administered in the same way as for patient participants (see section 2.4.1).

Participants were matched between groups on age, gender and WTAR scores.

2.5 Analysis Plan

The data was analysed in the following steps: (1) Kurtosis and skewed Z values for each scale were examined to test for normal distribution. If the data were significantly skewed they were transformed using log, square root or reciprocal methods to obtain a normal distribution. Transformed data was used in further analysis. To ensure that data could be compared across both participant groups transformations were applied to both sets of

participant data. Questionnaires which were transformed were: Fatigue Severity Scale (square root transformation), Multidimensional Perceived Social Support Scale (square root transformation) and the Chicago Multiscale Depression Inventory (log transformation). (2) Pearson correlations performed with each measure against anger expression. (3) Following Bonferroni's correction, factors which were significantly correlated with anger expression were placed into a multiple regression model.

2.6 Results

2.6.1 Excluded Data

Originally 52 healthy controls were recruited. However, mean age, gender ratios and WTAR scores did not match the MS group's means. Therefore data was discarded from participants below the age of 24 years and a further 23 older participants were tested. The researcher matched 52 controls to the 52 MS patients on age, WTAR and gender. The importance of ensuring that both groups were matched was so that direct comparisons could be made and there was no loss of power resulting from co-varying variables.

2.6.2 Missing Data

Two data points were missing; one MS participant was unable to perform both PASAT tasks. The missing data values were entered into SPSS as 99, as this value was outside of the range of values for a possible PASAT score.

Outliers were screened and in accordance with statistical guidelines, defined as any value which was 3 standard deviations above or below the mean. Three values were found, one value in the fatigue measurement scale in the control group, one value in the social

support scale and one value in anxiety state measurement scale for the MS group. These values were removed from the analysis.

2.6.3 MS Patient Demographics

Fifty two MS patients completed the study. Mean age was 46.4 years, six were male. Pre morbid IQ mean was 108. All participants were British born but nationality was varied: 49 were English, one was Polish and one was Spanish. Thirty seven had relapsing remitting MS, six had primary progressive MS and nine had secondary progressive MS. The mean score on the HAI was 3.7 indicating that the sample was not severely physically impaired (see table 2.1).

Table 2.1

Demographic Information on the MS sample

Characteristic	<u>n</u>	%
Age at time of survey (years)		
20-29	2	4
30-39	9	17
40-49	22	42
50-59	13	25
60-69	6	12
Age at time of Diagnosis (years)		
15-24	7	14
25-34	15	29
35-44	20	39
45-54	7	14
55-64	2	4

Duration of MS (years)

1-10	27	52
11-20	22	42
21-30	1	2
31-40	2	4

Type of MS

RRMS	37	71
PPMS	6	12
SPMS	9	17

Disease modifying therapy

Copaxone	16	30
Rebif	5	10
Avonex	5	10
No medication	26	50

Employment status

Unemployed	24	46
Employed	23	44
Retired	4	8
Student	1	2

2.6.4 Healthy Control Group Demographics

Seventy five participants took part but only 52 matched healthy volunteers were included in this study. Mean age was 46.3 years, eight were male. Pre morbid IQ mean was 108. All participants were British born. Nationality varied; nine were Indian, one participant was Chinese, two were Irish and 40 participants were English.

2.6.5 Matching MS and Control Group

A MANOVA reported no significant differences on age, WTAR scores and gender between groups. Frequency of males and females are also given (see tables 2.2 and 2.3).

Table 2.2

Mean Scores and Standard Deviations for Age WTAR and Gender

Group	<u>M</u>	<u>SD</u>	<u>Frequency of males to females</u>
MS			
Age	46.40	9.37	
WTAR	108.23	10.54	
Gender			6:46
Controls			
Age	46.35	10.85	
WTAR	108.65	7.73	
Gender			8:44

Table 2.3

Multivariate Analysis of Variance F ratios for Age, WTAR and Gender

<u>MANOVA</u>		
Variable	Values	p
Age (F (1, 102))	.001	.98
WTAR (F (1, 102))	.054	.06
Gender (F (1,102))	.325	.33

2.6.6 Descriptive Statistics from MS Group and Control Group

Descriptive statistics from the MS group and control group are given in Table 2.4. As data for anger in MS patients has rarely been studied, scores on all of the anger subscales are given.

Table 2.4

Descriptive Statistics for Measures used in Study One for MS and Control Groups

Questionnaires	MS Group (n=52)			Control Group (n=52)		
	<u>M</u>	<u>SD</u>	<u>Range</u>	<u>M</u>	<u>SD</u>	<u>Range</u>
HAI	3.7	2.5	0-9			
CI	16.6	7.2	2-34	5.7	4.2	0-17
CMDI-Total	98.2	27.9	42-161	1.8	21.9	48-145
STAI-State	36.2	10.4	25-64	34.1	10.5	20-63
STAI-Trait	43.3	9.4	25-64	39.4	9.31	25-64
ARS-Total	37.6	10.6	18-65	34.9	11.6	10-67
STAXI -Expression	26.5	10.0	7-57	20.9	8.1	6-38
STAXI- State	10.5	1.7	10-18	10.4	1.8	10-22
STAXI- Trait	20.0	5.4	11-32	17.9	5.2	10-36
STAXI- In	18.0	4.2	17-32	16.5	4.2	9-30
STAXI- Out	14.9	3.7	8-24	13.4	3.2	8-27
STAXI- Control	22.7	5.2	13-36	25.3	4.7	16-36
PSS-Total	4.2	13.7	12-84	69.4	10.8	37-84
FSS	5.5	1.58	9-63	3.5	.84	10-63

Note abbreviations: HAI –Hauser ambulation index; CMDI- Chicago mutliscale depression inventory; CI- cognitive impairment index; STAI-Spielberger’s state trait anxiety inventory; ARS- Anger ruminations scale; STAXI- Spielberger’s State trait anger expression inventory; PSS- Multidimensional perceived social support scale; FSS- Fatigue severity scale.

2.6.7 Inspection of Measurement Scales

To explore if data were normally distributed, initially histograms were plotted and visually checked. Histograms indicated that distributions of depression scores in the healthy control group were positively skewed, and it could be argued that data from

social support measures in the healthy control group are reflective of a bimodal distribution. Fatigue and social support scores were negatively skewed in the MS group.

Once data was visually checked, Kurtosis and skewed Z values for each scale were measured. While a value of 0 for both scales indicates a perfectly normally distributed population, statistical guidance suggests that values under 2.58 and -2.58 are normally distributed (Field, 2005). If data was skewed then the Kolmogorov-Smirnov test was performed to investigate if data was significantly skewed. If so, the significantly skewed data was transformed.

Data sets which had either a Kurtosis or skewed value outside of the range -2.58 and 2.58 and were significantly skewed on the Kolmogorov-Smirnov test in the MS group were fatigue and social support. For fatigue, $K=1.83$, $S=-4.68$, $D(52)=0.18$, $p<0.05$. These were transformed using a square root transformation ($K=1.64$, $S=0.47$). For social support, $K=2.35$, $S=-4.63$, $D(52)=0.14$, $p<0.05$. These were transformed using a square root transformation ($K=0.97$, $S=1.24$).

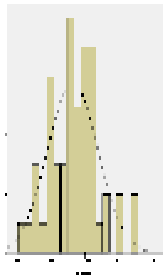
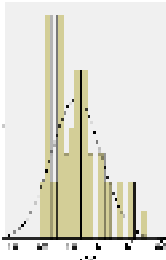
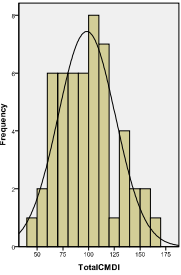
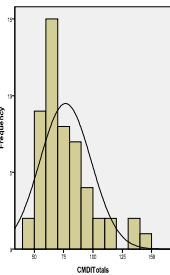
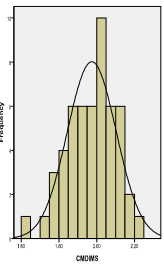
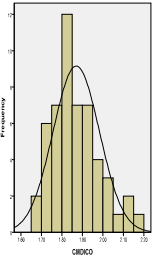
In the control group, data sets which had either a Kurtosis or skewed value outside of the range -2.58 and 2.58 and were significantly skewed on the Kolmogorov-Smirnov were depression; $K=1.47$, $S=3.83$, $D(52)=0.16$, $p<0.01$. This was transformed using a log transformation, $K=0.21$, $S=2.01$.

Kurtosis and skewed Z values were checked again after transformation of data for skewness. No data were significantly skewed after the transformations. To ensure that

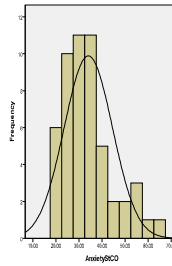
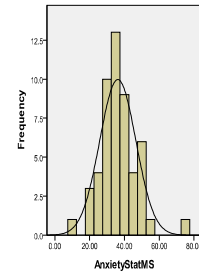
data could be compared across samples both data sets from the MS group and healthy participants were transformed. Table 2.5 displays which measures were transformed.

Table 2.5

Measures which were Normally Distributed and Transformed in Participant Groups.

Measure	Normally distributed?	Before Transformation		After Transformation	
		MS group distribution plot	Control distribution plot	MS group distribution plot	Control distribution plot
CI	Normally distributed in both groups.			n/a	n/a
CMDI	Normally distributed in MS group. Skewed in control group. Normally distributed after log transformation on both groups of data.				

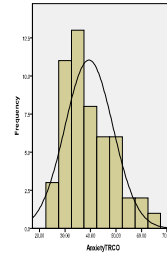
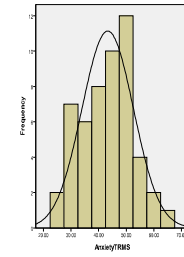
STAI State Normally distributed in both groups.



n/a

n/a

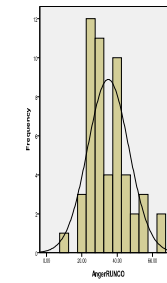
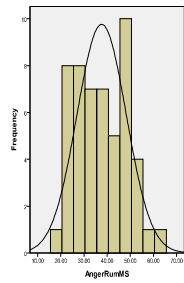
STAI Trait Normally distributed in both groups.



n/a

n/a

ARS Normally distributed in both groups.

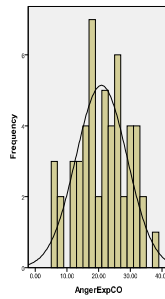
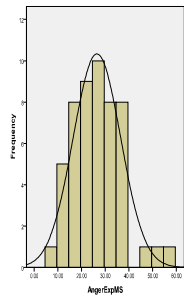


n/a

n/a

**STAXI
Expression**

Normally distributed in both groups

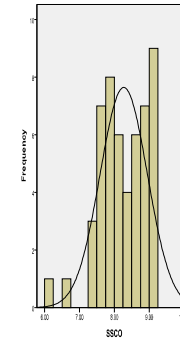
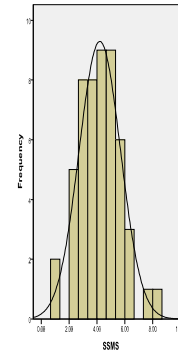
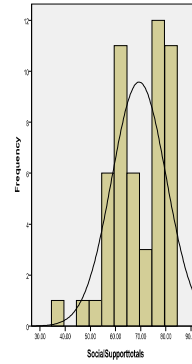
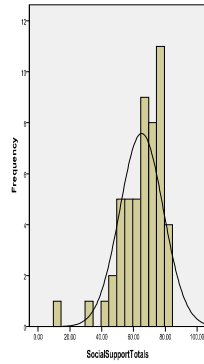


n/a

n/a

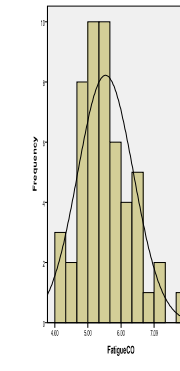
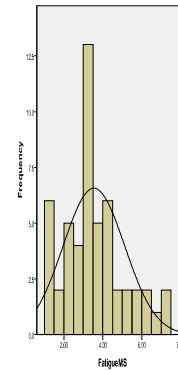
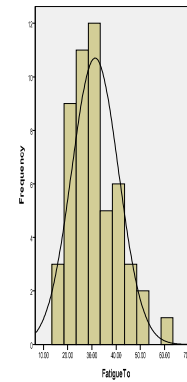
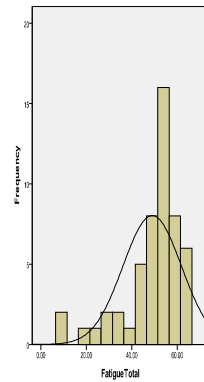
PSS

Normally distributed in control group. Skewed in MS group. Normally distributed after square root transformation on both groups of data



FSS

Normally distributed after square root transformation on both groups of data



Measurement scales for each vulnerability factor were inspected to identify the numbers of participants who scored in the 'abnormal' range using published guidelines (see table 2.6). Essentially, defining whether individuals score in the abnormal ranges of measurement scales is subjective and there is no statistical agreement on which method is best. Differing ways of defining individuals in the abnormal range were considered including taking Z scores lower than -2 of all measurement scales. After taking statistical guidance it was decided that as there are published guidelines to use for cut-off scores for the individual measurement scales, these would be used, as it provided an evidence based approach and allows comparison to be made with other studies (see table 2.6). As there were no published guidelines for the anger ruminations scale, advice was taken from the author of the scale and the 95th percentile was used (D. Sukhodolsky, personal communication, 3rd January 2011). In the case of the multidimensional perceived social support scale no published cut offs could be found and the first author could not be contacted, the 5th percentile was used (as lower numbers indicate lower social support) and this approximated a similar level of abnormality to the anger rumination scale.

Table 2.6**Participants Scoring in Abnormal Ranges on Individual Measurement Scales.**

Measurement Scale	Basis for Cut off Values	Number of MS participants scoring in abnormal range (%)	Number of healthy participants scoring in abnormal range (%)
CI	Camp et al. (1999). 2SD's below control mean on 3 ⁺ tests	26 (50%)	0 (0%)
CMDI	Nyenhuis et al. (1998) 1.5 SD above the control mean	17 (32%)	10 (5%)
STAI State	Spielberger et al. (1970). 75 th percentile	18 (35%)	11 (21%)
STAI Trait	Spielberger et al. (1970). 75 th percentile	20 (38%)	11 (21%)
ARS	95 th percentile (D. Sukhodolsky, personal communication, 3 rd January 2011)	2 (4%)	2 (4%)
STAXI Expression	Spielberger et al. (1988) and Nocentini et al., (2009). 75 th percentile	24 (46%)	12 (23%)
PSS	5 th percentile (following guidance from ARS).	9 (17%)	2 (4%)
FSS	Valko et al. (2008). 2SD above control mean	30 (58%)	2 (4%)

Note abbreviations: HAI –Hauser ambulation index; CMDI- Chicago Multiscale Depression inventory; CI- cognitive impairment index; STAI-Spielberger's state trait anxiety inventory; ARS- Anger ruminations scale; STAXI- Spielberger's State trait anger expression inventory; PSS- Multidimensional perceived social support scale; FSS- Fatigue severity scale.

2.6.8 Chi Squared Results

Individual chi squared tests were carried out to compare the proportions of abnormal scores on each measurement scale between the two groups. To account for multiple testing Bonferroni's correction was calculated by dividing the significance level by the amount of tests: $0.05/8=0.006$. Significant differences between MS patients and healthy participants were found on the cognitive index, $\chi^2(1)=34.67$, $p=0.001$ and fatigue scale, $\chi^2(1)=35.38$, $p=0.000$.

2.6.9 ANOVA to Compare Means

ANOVAs were performed to compare means across groups of participants and in consideration of possible type 1 error Bonferroni's correction was applied (see table 2.7.). Bonferroni's correction was calculated by dividing the significance level of 0.05 by the number of hypothesised statistical tests which were carried out: $0.05/8=0.006$.

Table 2.7

ANOVAs to Compare Means on each Measure for MS and Control Groups

Questionnaires	Values	p
CI (F(1,102))	87.3	<.01**
CMDI (F(1,102))	18.8	<.01**
STAI-State (F(1,102))	1.2	.28
STAI-Trait (F(1,102))	4.2	.04*
ARS (F(1,102))	1.2	.28
STAXI-Expression (F(1,102))	9.3	<.01**
PSSS (F(1,102))	319.2	<.01**
FSS (F(1,102))	62.3	<.01**

Note abbreviations: CI- cognitive impairment index; CMDI- Chicago mutliscale depression inventory; STAI-Spielberger's state trait anxiety inventory; ARS- Anger ruminations scale; STAXI- Spielberger's State trait anger expression inventory; PSS- Multidimensional perceived social support scale; FSS- Fatigue severity scale.

* significant at level 0.05

** significant at level 0.01

After Bonferroni's correction was applied MS patients did not demonstrate significantly higher levels of any vulnerability factors compared to the healthy control group at the Bonferroni corrected probability level of 0.006. However some trends were in evidence. MS participants had higher levels of cognitive deficits, depression, anger expression and fatigue at a probability level of 0.01 and anxiety trait at a probability level of 0.05. MS participants had lower levels of social support than healthy control participants at a probability level of 0.01.

2.6.10 Correlations for MS Group

Pearson's parametric correlations were performed to assess which predictor variables were correlated with anger expression and therefore could be placed into the multiple

regression model. To account for multiple testing Bonferroni's correction was applied to the significance level of Pearson's correlation. Bonferroni's correction was calculated by dividing the significance level of 0.05 by the number of hypothesised statistical tests: $0.05/8=0.006$. See table 2.8.

Table 2.8

Pearson's Correlations Between each Independent Variable and Anger Expression (MS Group).

Variable	Pearson's correlation with Anger expression	p
HAI	-.22	.11
CI	-.15	.30
CMDI	.41	.003**
STAI State	.44	.001**
STAI Trait	.48	.000**
ARS	.47	.001**
PSSS	.39	.004**
FSS	.02	.88

Note abbreviations: HAI –Hauser ambulation index; CMDI- Chicago mutliscale depression inventory CI- cognitive impairment index; STAI-Spielberger's state trait anxiety inventory; ARS- Anger ruminations scale; PSS- Multidimensional perceived social support scale; FSS- Fatigue severity scale.

**significant at level 0.006 (Bonferroni's correction).

Only correlations which had a significance level of $p < 0.006$ with anger expression were considered: anger ruminations ($r=0.46$, $p<0.001$), anxiety state ($r=0.44$, $p<0.001$), anxiety trait ($r=0.48$, $p <0.000$), depression ($r=0.41$, $p<0.003$) and social support ($r=0.39$, $p<0.004$).

2.6.11 Correlations for Control Group

Significant correlations with anger expression were identified as they were for the MS group. Bonferroni's correction was calculated by dividing the significance level 0.05 by the number of statistical tests which were carried out: $0.05/7 = 0.007$. See table 2.9.

Table 2.9

Pearson's Correlations between each Independent Variable and Anger Expression (Healthy group)

Variable	Pearson's correlation with Anger expression	p
CI	-.15	.30
CMDI	.25	.08
STAI State	.27	.04*
STAI Trait	.54	<.001**
ARS	.60	<.001**
PSSS	-.19	.19
FSS	.42	.002**

Note abbreviations: CI- cognitive impairment index; CMDI- Chicago mutliscale depression inventory; STAI-Spielberger's state trait anxiety inventory; ARS- Anger ruminations scale; PSS- Multidimensional perceived social support scale; FSS- Fatigue severity scale.

* Significant at 0.05

** Significant at 0.007 (Bonferroni's correction).

Only correlations which were significant at $p < 0.007$ with anger expression were considered: anger ruminations ($r=0.60$, $p<0.001$), anxiety trait ($r=0.54$, $p<0.001$) and fatigue ($r=0.42$, $p<0.002$).

2.6.12 Multiple Regression

Factors which were identified as significantly correlating with anger expression were placed into a regression model.

2.6.13 Sample Size for Multiple Regression

A medium effect size was presumed as effect size could not be estimated from previous literature (Field, 2000). The suggested sample size for five predictor variables and a medium effect size is 90 participants. For three predictor variables and a medium effect size 80 participants is suggested (Miles & Shevlin, 2001). This study recruited 52 participants which is below the recommended sample size. Power calculations indicated that the study did have adequate power (see sections 2.6.15 & 2.6.17).

2.6.14 Regression for MS Patient Group

The five predictors which correlated with anger expression at a significance level of $p < 0.006$ were entered in the multiple regression model using a forced entry method. Multicollinearity was checked by ensuring that no correlation between predictor variables was more than 0.9 ($r > 0.9$), that the variance inflation factor (VIF) was not above 10 (Myers, 1990) and that the average VIF was not substantially above 1 (Bowerman & O'Connell, 1990). Tolerance statistics were also above 0.2. Assumptions concerning independent errors and homoscedasticity were found to be satisfactory (see tables 2.10 and 2.11).

Table 2.10**Means, Standard Deviations and Intercorrelations for Anger and Predictor Variables for MS Group**

Variable	M	SD	1	2	3	4	5
Anger	26.5	10.0	.46**	.44**	.48**	.41**	.39**
Expression							
Predictor Variables							
1.Anger	37.6	10.1		.46**	.70**	.59**	.39**
Rumination							
2.Anxiety	36.2	10.4			.43**	.58**	.42**
State							
3.Anxiety	43.3	9.3				.59**	.47**
Trait							
4.Depression	98.2	27.9					.51**
5.Social	4.2	1.5					
Support							

** Significant at 0.01

Table 2.11**Regression Analysis Summary for Variables Predicting Anger Expression in MS Group**

Variable	B	SEB	β
Constant	5.04	15.45	
Anger Ruminations	.43	.09	.62
Anxiety State	.07	.09	.09
Anxiety Trait	.12	.13	.14
Depression	-.92	8.98	-.01
Social Support	-1.17	.75	-.22

Note. $R^2 = .41$ ($N=52$, $p < 0.01$)

The total model was significant ($F(5, 46)=6.45$, $p < 0.001$) with the predictor variables accounting for 41% of expressed anger in MS patients. Individually, each predictor did

not significantly contribute to anger expression apart from anger ruminations: $B=.43$, $\beta=.09$, $t(46)=4.9$, $p<0.001$.

2.6.15 Power Calculation for Multiple Regression for MS Group

The statistical power of the multiple regression was calculated. For an alpha level of 0.006, 5 predictors, an observed r^2 of 0.41 and a sample size of 52, the power calculated was 0.97. According to Cohen (1988) this represents that the level of power was sufficient to detect genuine effects.

2.6.16 Regression results for the Control Group

The three predictors which correlated with anger expression, anger ruminations, anxiety trait and fatigue were put into a forced method multiple regression model. Multicollinearity was checked by ensuring that no correlation between predictor variables was more than 0.9 ($r>0.9$), ensuring that variance inflation factor (VIF) was not above 10 (Myers, 1990) and that the average VIF was not substantially above 1 (Bowerman & O'Connell, 1990). Tolerance statistics were also above 0.2. Assumptions concerning independent errors and homoscedasticity were found to be satisfactory (see tables 2.12 and 2.13).

Table 2.12

Means, Standard Deviations and Intercorrelations for Anger Expression and Predictor Variables for Control Group

Variable	<u>M</u>	<u>SD</u>	1	2	3
Anger Expression	20.9	8.1	.60**	.54**	.42**
Predictor Variable					
1.Anger Ruminations	34.9	11.7		.53**	.57**
2.Anxiety Trait	39.4	9.4			.49**
3.Fatigue	31.3	9.7			

** Significant at <0.001

Table 2.13

Regression Analysis Summary for Variables Predicting Anger Expression in Control Group

Variable	B	SEB	β
Constant	-1.7	6.02	
Anger Ruminations	.29	.09	.42**
Anxiety Trait	.25	.12	.29*
Fatigue	.46	.13	.05

Note. $R^2 = .43$ ($N=52$, $p < 0.001$)

* $p < 0.05$

** $p < 0.001$

The total model was significant ($F(3,48) = 12.01$, $p < 0.001$) with the predictor variables accounting for 43% of expressed anger in healthy control participants. Individually anger ruminations ($B = .29$, $\beta = .42$, $t(48) = 3.0$, $p < 0.001$) and anxiety trait ($B = .25$, $\beta = .29$, $t(48) = 2.2$, $p < 0.05$) made significant contributions to the model.

2.6.17 Power Calculation for Multiple Regression for Control Group

The statistical power of the multiple regression was calculated. For an alpha level of 0.007, 3 predictors, an observed r^2 of 0.43 and a sample size of 52, the power calculated was 0.99. According to Cohen this represents that the level of power was sufficient to detect genuine effects.

2.7 A Model of Anger

A putative model of anger expression in MS patients was presented in section 1.16 (see figure 1.4). This model can be modified with the results obtained in this study to graphically represent the five factors that accounted for 41% of expressed anger in this study (see figure 2.1).

A model of anger expression in healthy participants is presented graphically to represent the three factors that accounted for 43% of expressed anger in this study (see figure 2.2). It should be noted that causality cannot be determined in either model by this study.

Vulnerability Factors

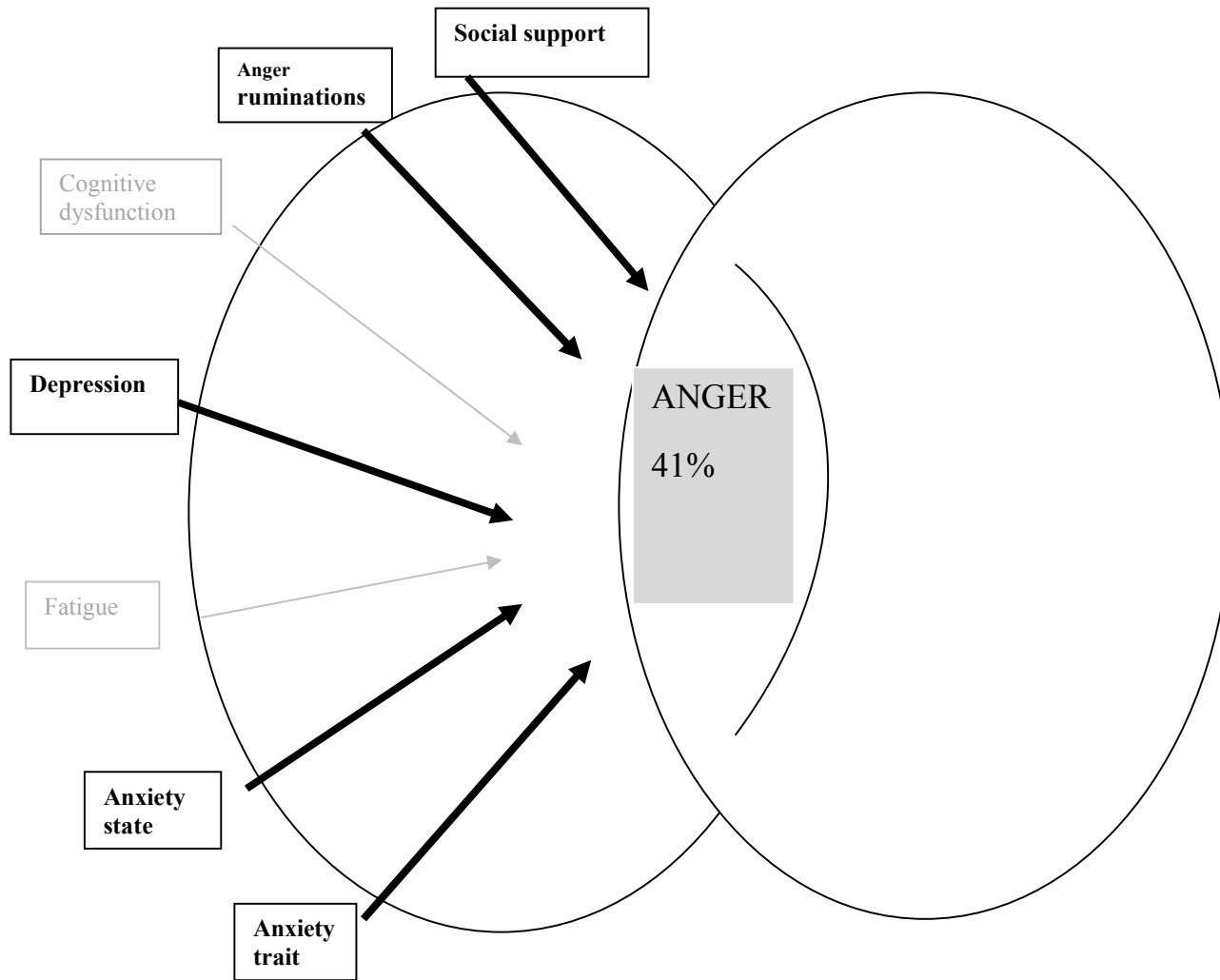


Figure 2.1
Model of Anger in MS (2). Factors Accounting for 41% of Anger Expression
Key —> Significant (empirically tested) relationship to anger in MS.
—> Non significant (empirically tested) possible relationship to anger in MS.

NOTE: No causality implied.

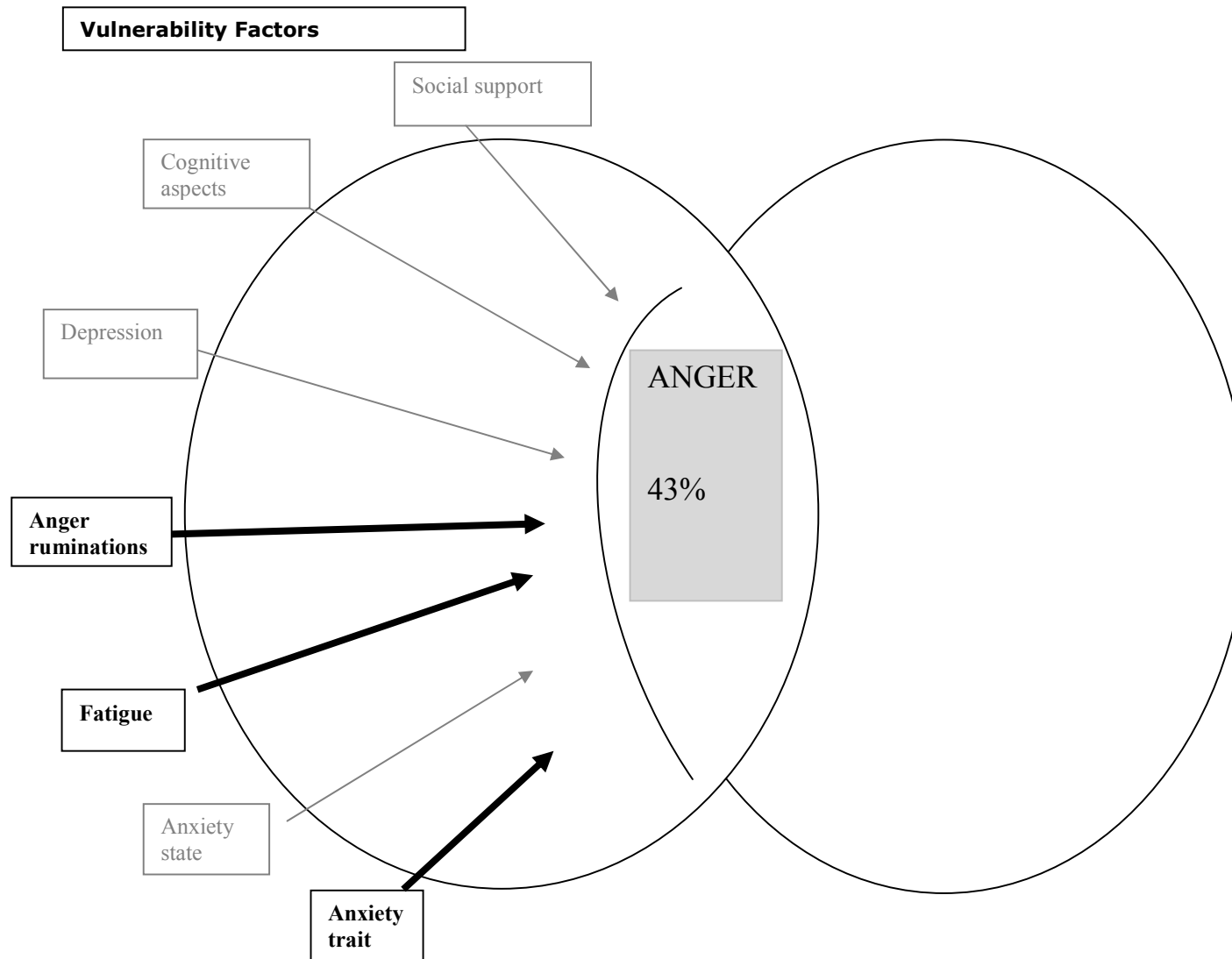


Figure 2.2 Model of Anger in Control Participants. Factors Accounting for 43% Control Participants

Key → Significant (empirically tested) relationship to anger in control participants.

→ Non significant (empirically tested) possible relationship to anger in control participants.

NOTE: No causality implied.

2.8 Discussion

Five vulnerability factors, anger ruminations, social support, depression, anxiety trait and anxiety state were associated with anger expression in the MS group and accounted for 41% of the variance. Three vulnerability factors, anger ruminations, anxiety trait and fatigue, were associated with anger expression in the healthy group and accounted for 43% of the variance.

The first hypothesis cannot be fully accepted as MS participants did not have significantly higher levels of anger expression, neurological cognitive deficits, depression, anxiety, anger ruminations and fatigue compared to control participants or significantly lower levels of social support when a conservative adjustment was applied. However there was a trend towards significance as the MS group did have higher levels of anger expression, neurological cognitive deficits, depression and fatigue compared to the healthy control group at a probability level of 0.01 and anxiety trait at a significance level of 0.05. MS participants had lower levels of social support compared to the healthy group at a significance level of 0.01.

The second hypothesis predicted that social factors, emotional factors, cognitive deficits and physical disability would be associated with anger expression in MS patients and that these factors would be different to those that were correlated with anger expression in healthy control participants. While social and emotional factors were related to anger expression in the MS group, cognitive and physical symptoms were not significantly associated with anger in this group. In part, these non significant results replicate previous work suggesting that anger expression is not a simple linear association with the physical disabilities that MS causes (Nocentini et

al., 2009). The sample in the current study was not severely physically impaired (as measured with the HAI), therefore the possibility cannot be excluded that, had there been a wider range of physical disability, an association with anger expression might have been found.

As most models of anger theorise that cognitive processes are associated with anger expression, it is surprising that neurological cognitive deficits, which could impact on cognitive processing, were not significantly linked to anger expression. However because an overall single index score of cognitive deficits was used in analysis, it may have masked an association between an individual cognitive test score and anger expression. Had individual measures of cognition been used in analysis, e.g. working memory, significant associations may have been found. Additionally if a measure of cognitive processes had been taken, e.g. cognitive appraisals, then an association with anger expression may have been found as models of anger theorise.

Anger ruminations and social support had the largest impact on the variance of anger expression followed by anxiety trait, anxiety state and depression in the MS sample. Thus, it is the new factors which have not been previously explored which were most influential, rather than depression which is most often reported in conjunction with anger in MS. Anger ruminations also had the largest impact on the variance of anger expression in the healthy populations.

Interestingly, there was a small variation in emotional factors and social external networks which contributed to anger expression in MS participants compared to healthy participants indicating that hypothesis two cannot be completely accepted.

Thus, while the vulnerability factors associated with anger in MS participants are not unique to MS, this study does seem to suggest that a subtly different combination of vulnerability factors are associated with the arousal of anger in MS populations. Clinically, it could be suggested that health care professionals should be made aware not to overlook vulnerability factors which may contribute to the arousal of patient anger but are not influential alone. However, the modest sample sizes in this study mean that it lacks statistical power, these observations may be thus unreliable and should be treated tentatively.

Only anger ruminations independently contributed to anger expression in MS patients, indicating that the remaining factors account for overlapping proportions of the variance. In the healthy population sample, only fatigue did not individually contribute to the variance of anger expression suggesting that fatigue accounted for overlapping portions of the variance.

Each factor which significantly contributed to anger expression is discussed in the following section.

2.8.1 Depression

Depression was significantly associated with anger expression in MS participants, but had the least impact on the variance of anger. Depression did not contribute independently to the overall model, suggesting that it accounts for overlapping portions of the variance. These results provide further evidence for clinical observations linking anger and depression in MS (Minden & Schiffer, 1990) and empirical studies (Nocentini et al., 2009). However, these results surprisingly revealed that while depression is the most researched factor associated with anger in MS

patients, it did not have the most impact on anger expression. It is possible that the association of depression and anger in other studies is a result of the depression measure capturing the overlapping effects of other vulnerability factors such as anger ruminations and social support. The sample of MS patients did vary in levels of depression and only 32% in this sample were classified as severely depressed. In a selected sample with higher frequency of severe depression, findings may have been different.

MS patients' depression could be linked to perception of the uncertainty of the disease (Wienham, Schwetz, Goodkin, & Rudick, 1996) and the perceived intrusiveness of the disease on daily activities (Devins et al., 1993). These perceptions could cause MS patients to become fearful of the future, causing MS patients to feel as if they lack control, leading to frustration and anger. Depression also affects self image; MS patients may believe that they are to blame for the MS, causing them to become angry at their selves. In line with the Psychodynamic approach, this anger could be turned inwards resulting in depression (Arieti, 1978). These speculative interpretations await evidential support.

While this study provides evidence that depression and anger expression are linked, causality was not examined. It could be the case that high levels of anger expression evoke low mood, as social networks contract as individuals withdraw their support from angry individuals there is a decrease in positive reinforcement, leading to depression. Additionally, a third factor that has not been studied could be influencing the relationship between depression and anger expression.

2.8.2 Anxiety

Anxiety state and trait were both significantly associated with anger expression and had the fourth and third largest impact respectively on the variance in anger in MS participants. These results validate previous research which has theorised and empirically tested the link between anxiety and anger (Hollinworth et al., 2005; Nocentini et al., 2009).

Only anxiety trait was significantly associated with anger expression in healthy participants and accounted for the second largest variance of anger expression and independently contributed to the model of anger expression. Unlike MS patients, stable personality traits rather than temporary anxiety states had a larger impact on anger expression in healthy control participants. Anxiety state is a transitory condition reflecting how anxious individuals are at the time of being questioned. Anxiety state fluctuates during the course of MS depending on exacerbations and relapses (MCabe, 2005). The majority of patients in this study (71%) were diagnosed with the relapsing remitting subtype of MS, perhaps indicating that anxiety state was high due to a recent relapse or anticipation of a relapse. However, this is only speculative and could only be confirmed by future studies assessing the current clinical state of participants at the time of testing.

Anxiety trait is a stable personality characteristic (Spielberger et al., 1983). Over one third of MS patients and 11 control participants scored in the abnormal ranges of anxiety trait. As mentioned previously anger is theorised to be linked with anxiety; anger is demonstrated when anxious individuals attempt to restore control over anxiety provoking situations. Perhaps individuals who have high levels of anxiety trait

would interpret situations more frequently as anxiety provoking leading to more frequent and perhaps higher levels of anger expression. Causality has not been determined, therefore, it is not known if anger triggers anxiety or anxiety triggers anger or if the relationship between the two variables is mediated by a third factor.

2.8.3 Fatigue

Fatigue was significantly associated with anger expression in the healthy control group. It had the least impact on the variance of anger expression in the healthy control group compared to the other variables which were significantly associated with anger expression in the healthy control group (anger ruminations and anxiety trait). It was anticipated that fatigue would be associated with anger expression in MS patients, considering it is often described as one of the most disabling symptom of MS (Fisk et al., 1994) preventing socialising, physical activities, interfering with responsibilities and work (Freal, Kraft, & Coryell, 1984). It could be speculated that as fatigue in MS patients is always likely to be present, patients learn to accept it as a consequence of ill health. Fatigue contributes to the worsening of other MS symptoms (Freal et al., 1984); perhaps MS patients' anger is associated with and triggered by the worsening of these symptoms rather than fatigue.

Control participants may suffer from fatigue intermittently. Thus, fatigue may be an unexpected hindrance to healthy controls that are in good health, have satisfying lifestyles and careers. In addition to this hindrance they may be less well equipped to manage such symptoms. Therefore it is possible, that even slight levels of fatigue, as displayed predominantly by the current sample (only 2 had severe levels of fatigue), could be a potential trigger of anger expression.

2.8.4 Social Support

Social support was significantly correlated with anger expression in MS patients and made the second largest contribution to the variance of anger expression. Unexpectedly the correlation between social support and anger expression was positive, contrary to previous literature (Deffenbacher et al., 1996).

The transactional model of social support theorises that individuals with higher levels of anger have poorer social networks (Deffenbacher, 1992). However, the results from this study suggest that higher levels of social support are correlated with anger expression in MS patients. It could be the case that due to the various symptoms of MS, patients may have many well established networks of relationships, e.g. MS nurses, neurologists, nurses specialising in pain, continence nurses and physiotherapists. Such a team of professionals in conjunction with support from family members and friends would create larger social networks. Due to the unpredictable nature of MS, expressed anger in this context may be less likely to alienate carers, who would remain compassionate and supportive and may even display higher levels of compassion and support. This high level of social support may then create a positive feedback cycle where MS patients are more likely to express anger due to the support it evokes. It could also be the case that anger causes social support as carers and family friends attend to patients who vocalise their anger as they attempt to calm patients down, thus MS patients may elicit anger to maintain social support. Further research is needed to explore this possible link. It must also be considered that another factor could mediate this relationship.

2.8.5 Anger Ruminations

Anger ruminations had the biggest contribution to anger expression variance and independently contributed to the model in both groups. Anger ruminations are unintentional emotional cognitive processes which cause an individual to ruminate over a past experience of anger, intensifying and prolonging the anger experience. Most models of anger suggest that cognition plays a significant role in the expression of anger. Novaco's (1994) 'Anger determinants and consequences' model suggests that anger is due to various determinants which impinges on the cognitive processes and then affect behaviour. When individuals ruminate over anger episodes it not only intensifies their anger but also increases the duration of the anger. This increased intensity could cause individuals to become irrational and cause misinterpretations or maladaptive cognitive processes. However as causality was not determined it could be the case that high levels of anger expression trigger anger ruminations, as individuals have more experiences of anger to ruminate on. Possibly anger expressions accentuate ruminations, or simply anger ruminations and expressions could be symptoms of feeling angry. It should additionally be noted that ruminations could mediate the effects of other vulnerability factors such as depression and anxiety, which are frequently characterised by ruminations, on anger expression.

2.8.6 Strengths and Limitations

The results of this study validated and extended Nocentini et al.'s (2009) findings. The current study was successfully able to tease apart complex emotional, social and cognitive factors and assess which factors contributed to anger expression in MS populations. Additionally, new factors were found to be associated with anger expression in MS populations; social support and anger ruminations. Identification of

such factors and elimination of others (i.e. neurological cognitive deficits) will allow researchers to focus on smaller specific subsets of factors in the future.

This study was successful in identifying vulnerability factors in the healthy population, which have not previously been studied, concluding that such factors associated with anger are not completely the same as those in MS patients, although there may well be shared factors across groups. Additional strengths include the completeness of the data sets and acceptable Cronbach alpha levels.

Weaknesses must be considered, including the use of self report questionnaires which were not validated by clinical interviews. As a cognitive impairment index was used in the analysis, this could also have impacted on the results. Had individual measures been analysed separately for different cognitive domains, an association with anger may have been found. The cognitive index could have been created following different guidelines as outlined in section 2.3.3, which could have led to different results. However, as discussed in section 2.3.3, the method by which the CI was created followed guidelines which have been most widely used in MS populations (Amato et al., 2001; Camp et al., 1999; Patti et al., 2009).

The sample also had limitations. As participants were volunteers, it is possible that a dis-proportionate number of 'angry' individuals took part in this study, thus affecting generalisability. MS participants in this sample presented with various types of MS that could have affected the results. As the MS participants were not split into these diagnostic groups it is not known if different factors would have correlated with anger expression for different types of MS. Future work could investigate this. Additionally

it was not known if participants were in a relapse or if they were experiencing or anticipating worsening of symptoms at the time of the study. This could have affected results, as it is possible that if MS participants were currently relapsing or currently had increased worsening of symptoms they will have been experiencing more frustration, irritability or anger. Additionally, such participants could well have possibly been experiencing higher levels of other vulnerability factors which may have impacted on the resulting levels of anger. Future studies need to consider taking this into account.

The sample of participants included some participants with and without neurological cognitive impairments which could have affected the reliability and validity of other measures. However, research has shown that self report quality of life scales, like depression and fatigue, are not affected by cognitive impairments (Baumstarck-Barrau, et al., 2011).

It must also be kept in mind that some data sets had to be transformed. This decision was taken, rather than performing non parametric tests, as it was felt that skewness in the MS groups reflected the expected distributions. For example it is expected that MS participants would have high levels of fatigue and social support due to the nature of their illness and that the control group would have low levels of depression. Additionally parametric tests are more robust and likely to have more power. However it is also accepted that transforming data sets may actually have masked key differences between the groups.

The majority of MS patients did not score in the highest range of the STAXI; only 46% of MS patients scored above the 75th percentile, in the abnormal range. There was no significant difference in the proportions of MS patients and control participants who scored within the abnormal ranges of anger expression, indicating that MS patients do not show explosive and violent forms of anger which differ from healthy participants. This is in line with previous literature which found similar results of anger expression as measured on the STAXI in MS populations (Langdon & Thompson, 1999) and in line with clinical observations. Subtler levels of anger can nevertheless impact on a patient's wellbeing and healthcare. A selected sub group of MS populations with high incidence of abnormal anger could have produced different results.

It should be noted that statistical guidance was sought on the use of cut-offs for individual measurement scales, and it was decided to use published cut-offs for each individual measurement scale. However, an internally consistent basis for defining scores on the questionnaires could have been used, which may have provided a different set of results. While the researcher was aware of this, it was felt that using cut-off scores in published studies was an evidence based approach and allowed comparisons with other studies.

Participants were not separated into groups representing high and low levels of anger. Whilst it was helpful and appropriate to use chi square to compare levels of abnormal anger scores (section 2.6.8), there were not enough participants who would fall into the 'high' and 'low' anger groups. Thus a categorical approach was not viable in this study. Further research could carry this forward and investigate possible differences

between the association of potential vulnerability factors and levels of anger expression.

While control participants and MS participants were matched for age, IQ scores and gender, they completed questionnaires in different venues, which could have biased the results.

Significant predictor variables in both MS and control participants accounted for less than half of the variance of expressed anger. Additional factors need to be identified and investigated. For example personality, pre-morbid anger scores and medication could be investigated to explore their association with anger expression.

Despite these limitations, this study highlights the need to study anger expression in more depth and clinically suggests that HCPs need to be made aware of interactions of various vulnerability factors which in combination could lead to anger expression in MS patients.

Further research needs to expand on these results and investigate possible external and more immediate factors which could contribute to anger expression in MS patients to provide a more holistic model of anger expression in MS participants. Study two will begin to address the contribution of external factors to the arousal of anger expression.

Chapter Three: Study 2- Response Styles and Anger Expression in MS

Patients

3.1 Introduction- Summary of Study 2

While study one investigated possible vulnerability factors, the aim of study two was to investigate possible external triggers which could be associated with anger in MS patients. Possible triggers were identified from literature on psychiatric in-patients who display high levels of anger in response to limit-setting styles used by HCPs to control their interactions with psychiatric in-patients (Lancee et al., 1995) (see section 1.14.1).

Lancee et al. (1995) identified six limit-setting styles which were characterised by varying degrees of empathy:

- Belittlement- defined as ‘to think, represent, or speak of as small or unimportant.’
- Platitude- defined as ‘generic responses with a lack of attention to the specific circumstances.’
- Solutions without options- defined as ‘explaining rules or telling a patient what to do without offering possible courses of action.’
- Solutions with options- defined as explaining rules to a patient and offering alternatives to the patient, from which they must choose.
- Affective involvement without options- defined as ‘expressing care and concern or attending to the subjective experience of the patient without offering possible courses of action.’

- Affective involvement with options- defined as ‘expressing care and concern or attending to the subjective experience of the patient with additionally offering some solutions to the patient with their involvement.

Limit-setting styles were presented in four different scenarios (Lancee’s terminology): the patient wants something that is not possible, the patient refuses to participate in what is required, the patient demands instant gratification, or the patient demands immediate emotional attention. The limit-setting styles were presented to psychiatric patients in the form of role-plays and patients estimated their self reported levels of anger state on the STAXI (Speilberger, 1988); that is immediate levels of anger, in response to the limit setting styles. Belittlement generated the greatest levels of anger, followed by platitudes. Offering a solution, affective involvement plus offering options generated lower levels of anger. These styles attended to the individual patient experiences and demonstrated an empathetic response to their situations. Additionally such styles offered patients a choice in their care, in line with a patient centered approach.

Research is yet to investigate, empirically, the effect of interaction styles on anger in MS populations. Study two will investigate which response styles are associated with anger in MS patients, based on Lancee et al.’s (1995) limit-setting styles. Limit-setting scenarios in experimental research with psychiatric patients are devised to vary in restraint and empathy to mirror practices in clinical settings. Restraint is needed as such patients often react aggressively to staff (Lancee et al., 1995). However, MS patients do not tend to demonstrate highly aggressive forms of anger; thus it is unlikely that HCPs

would manage MS patients' anger by routinely placing physical constraints on their actions. Therefore, this study will focus on how varying levels of empathy, which Lancee et al. (1995) varied in his limit-setting style scenarios, could impact on anger. Empathy has been linked to patient well being, with low levels of empathy being linked to negative patient well being (Secker et al., 2004). Empathy will follow Lancee et al.'s (1995) definitions of belittlement, solutions without options and affective involvement without options and these will be renamed, for the purposes of this study, as low, medium and high levels of empathy.

These response styles were presented to participants in the form of vignettes describing interactions. These response styles were presented in three patient contexts which followed three of Lancee et al.'s (1995) four scenarios. The three patient contexts used in the current study were: a patient does not participate in what is required, a patient demands instant gratification and a patient demands immediate emotional attention. Advice from experts was sought and it was concluded that these three patient contexts were likely to closely mirror real life MS patient - HCP interactions. Lancee et al. (1995) did not find a significant main effect of patient context. However, theories of anger suggest that anger is more likely to be elicited when barriers prevent goals which are highly desirable (Izzard, 1977) and consequences of not attaining goals are concrete and immediate. Therefore study 2 will extend Lancee et al.'s (1995) study by investigating whether contexts where barriers prevent the attainment of urgent goals (context where a patient requires instant gratification) are more likely to elicit higher levels of anger than contexts where barriers do not prevent the attainment of urgent

immediate goals (contexts were a patient demands emotional attention and refuses to take part in what is necessary). Lancee et al., (1995) did not investigate whether HCP's and patients' anger was aroused in response to limit-setting styles to the same degree. This study will further extend the work of Lancee et al. (1995) and investigate if there are group differences in the arousal of anger of HCPs and MS patients by asking both groups to imagine that they are MS patients in given vignette scenarios and rate their anger in response to the interaction style detailed in the vignettes. Given that anger in MS patients has been found to be higher than anger arousal in the normal population (Langdon & Thompson 1999), it could be the case that HCP's underestimate MS patients' anger arousal.

The dependent variable was self reported measures of anger state, measured on the STAXI (Spielberger, 1988), which were filled in after each vignette. Anger state is an immediate measure of anger arousal which changes due to situations. As discussed earlier (see section 2.3.7) the STAXI has been previously used with MS populations (Nocentini et al., 2009).

The main hypotheses were:

- Response styles which were low in empathy would be associated with higher levels of anger state compared to response styles which were higher in empathy.
- Contexts in which patients experience barriers to urgent goals would be associated with higher levels of anger state compared to contexts in which patients do not experience barriers to urgent goals.

- HCPs will underestimate MS patients' levels of aroused anger.

3.1.1. Design of Study 2

Seventy four HCPs and 49 MS patients completed this study. Vignettes were created by the main researcher to represent three response styles (low empathy, medium empathy and high empathy) presented in three patient contexts (a patient does not participate in what is required, a patient demands instant gratification and a patient demands immediate emotional attention) based on Lancee et al.'s (1995) definitions (see section 3.4.4). Vignettes were rated on how well they represented each target construct by mental health professionals (see section 3.4.4). Vignettes detailed an interaction between an MS nurse and MS patient. Participants were asked to read each vignette and imagine that they were the patient in the scenario and then rate their levels of anger state in response to the vignette on the State subscale of the STAXI (Spielberger, 1988).

This study adopted a mixed 3*3*2 ANOVA. The first within subjects factor was the response style which had three levels and the second within subjects factor was patient context which had three levels. The between subjects factor was group, which had two levels. The dependent variable was anger state (see section 3.6). Main effects of group, response style and patient context were reported. Contrasts compared low empathy against high empathy, medium empathy against low empathy and high empathy against medium empathy. Contrasts for patient contexts compared a context where a patient demands instant gratification against a context where a patient does not participate in

what is required and a context where a patient demands instant gratification against a context where a patient demands immediate emotional attention.

3.2 Method

3.2.1 Ethical Permission

Ethical permission to undertake this study was granted by Royal Holloway, University of London Ethical Committee and East Kent Research Ethics Committee (approval letters in appendix 1).

3.2.2 Inclusion and Exclusion Criteria for HCPs Participants

Health care professionals were included if they were aged between 18 and 65 years old, had worked with MS patients for at least 1 year in their current employment, had English as their first language and gave informed consent. HCPs were to be excluded from the study if they reported significant mental health problems, but none were declared.

3.2.3 Inclusion and Exclusion Criteria for MS Patient Participants

MS patients were included if they were aged between 18 and 65 years old, had a clinical diagnosis of MS (McDonald et al., 2001) had English as their first language and gave informed consent. Patients were excluded if they had any significant mental health issues.

3.2.4 Sample Size Requirements

An ANOVA design investigated the three levels of response styles and three levels of patient context for the two groups of participants (3*3*2). A power calculation to determine the recommended sample size was calculated. Effect size could not be estimated from previous literature in this field, therefore based on the assumption of a medium effect size (Field, 2000) with an alpha level of 0.5, the required sample size was 64 participants in each group (Cohen, 1992). The actual sample size for the HCP group was 74. The actual sample size for the MS group was 49 which was 15 participants below the threshold.

3.2.5 HCP Participants

Three hundred and seventy five MS health care professionals were contacted for their participation in this study via the MS Trust. Health care professionals' names and addresses were not known to the researchers and contact was made by posting information sheets and vignettes to the MS Trust, who posted them on to appropriate HCPs including MS nurses, occupational therapists, physiologists and psychologists (information sheets and consent forms can be found in appendix 2).

3.2.6 MS Patient Participants

Ninety eight MS patients were approached for their participation via an MS clinic. Patients were introduced to the researcher (AP) after their appointment with the specialist MS team where the neurologist gave patients a letter explaining AP's work. The researcher took patients to a separate room and provided them with a further letter and information sheet about the study. Patients were also given the opportunity to ask

questions. Patients were given the information sheet to take away and were given two weeks to decide if they would like to take part in the study. AP telephoned potential participants after two weeks and organised to either send the vignettes by post or arrange a convenient time and venue for the study to commence with/without the researchers presence. Vignette packs were sent to 24 patients in the post. If patients did not wish to take part they contacted the researcher and all further contact was ceased (information sheets and consent forms can be found in appendix 2).

3.3 Procedure

3.3.1 Procedure for HCPs

Vignettes were presented in packs, via the post. Each pack consisted of two sets of vignettes: response style vignettes (this study), communication vignettes (study three, chapter four) and a short questionnaire on anger (study four, chapter five). Both vignettes and qualitative questionnaires were presented at the same time to ensure that costing was kept to a minimum. Within each set, the order of vignettes (studies three and four) was randomised using a random number table. In addition participants were given the sets of vignettes in randomised orders. The packs also contained an information sheet, instruction sheet, consent form, a demographic background questionnaire and a freepost envelope. Packs were sent to the MS Trust who distributed them to 200 MS nurses and 175 therapists. Therefore, all HCP participants completed vignettes in their own time without the presence of the researcher.

Participants were instructed to read each vignette in the order they were presented and imagine that they were the patient in the vignette. Then they were asked to rate how

angry they would feel in regards to the nurse's response style to the patient, on the anger state STAXI subscale, if they were the patient in the vignette.

3.3.2 Procedure for MS Patients

Patient participants were given vignette packs which were ordered and randomised in the same way as for HCPs (section 3.3.1). Patient participants were given the choice of completing the vignettes in their own homes, in outpatient rooms in the MS clinic or at Royal Holloway University. Additionally patients were given the choice of the researcher's presence. All participants decided to take part in the study at home, 25 participants with the researcher present and 24 without the researcher present. Participants were asked to read and respond to each vignette in the same way as HCPs (see section 3.3.1), that is they were asked to rate how angry they would feel in response to the nurse's response style to the patient in the vignette, if they were actually the patient in that vignette.

3.4 Vignettes

3.4.1 Definition of Vignettes

Vignettes are short descriptions of events which are either based on real life or fictitious events. They are designed to obtain specific information from participants about their perceptions, knowledge and attitudes towards a given situation (Hughes & Huby, 2002). There are different types of vignettes. The factorial-survey approach (Ludwick & Zealer, 2001) presents participants with different versions of a single vignette that vary in specific attributes (e.g. race of the character). Researchers examine the impact that these specific attributes have on participants' responses. Other types of vignettes present

a person's reported experience and reactions (Hughes & Huby, 2002) and ask participants to respond to specific topics raised in the vignettes. Other vignettes are longer in length (up to a page) and can include personal information and conversations, and describe an interaction. Participants are asked to comment on the interactions or conversations.

3.4.2 Process of Constructing Vignettes

Target situations to be studied must be identified. These can be gathered from past literature, by observation or by interviewing participant populations to discover themes. Once themes have been identified the vignettes can be drafted with attention being paid to language. Language must be specific to the group of people being tested and must not contain words or concepts that participants are unable to grasp. Characters in the vignettes can be framed in one of three ways (Salomon, Tandon, & Murray, 2001):

- 1) No reference made to age or sex of the character.
- 2) The vignette can refer to somebody similar to the participant.
- 3) Refer to specific age and sex for each vignette.

Additionally, vignettes must aim for *vignette equivalence*, which requires that factors presented in vignettes are understood in the same way by all respondents (Salomon, Tandon, & Murray, 2004). Therefore concrete terms should be used. Using a set of vignettes also improves equivalence, by minimising the impact of idiosyncratic interpretation of any one vignette by participants.

3.4.3 Reliability of Vignettes

Vignettes should be rated to demonstrate reliability by an independent panel that has expertise in the field which is to be researched but is independent of the project. Kappa statistics can be used to assess reliability. The kappa statistic (Cohen, 1960) is an index, which compares the recorded agreement with that expected by chance. It can be seen as the chance-corrected proportional agreement and values range from +1 to -1. While these statistics are easily calculated with software (Valiquette, Lesage, Cyr, & Toupn, 1994) they do not make distinctions among various types and sources of disagreement (Viera & Garrett, 2005). The kappa statistic may be low even if there are high levels of agreement and even if individual ratings are accurate. Whether the kappa statistic implies a good or bad rating system depends on what model one assumes about the decision making of raters (Feinstein & Cicchetti, 1990) and with ordered category data, the researcher must select weights arbitrarily to calculate weighted kappa (Schorer & Weib, 2007). Due to limitations of kappa statistics some researchers use mean ratings and standard deviations to assess whether there is agreement amongst judges. There is no consensus on which method should be used.

3.4.4 Creation of Response Style Vignettes

Response style vignettes were created using Lancee et al.'s (1995) definitions of 3 limit setting styles: belittlement, solutions without options and affective involvement without options. These were renamed low, medium and high empathy for the current study.

These response styles were presented in three different patient contexts, again following the work of Lancee et al. (1995): the patient does not participate in what is required, the patient requires instant gratification, and the patient wants immediate emotional attention. These contexts were constructed so as to vary in levels of how obvious barriers were to achieving the desired goals by the patient in the vignettes and vary in whether the consequences of such goals would be immediate. Contexts where a patient does not participate in what is required (characterised as a patient who did not want to take medication) and where a patient demanded emotional attention (characterised as a patient who had a domestic fight with a partner) were contexts where the barriers to achieving desired goals were not obvious and resulting consequences were not immediate (e.g. MS symptoms are unlikely to worsen after missing one medication dose or the situation with the partner is unlikely to deteriorate if a patient does not receive instant emotional support). The context where a patient requires instant gratification (characterised as a patient who needs help from the HCP to get out of the wheelchair to access the toilet) was the context where barriers to achieving the end goal are obvious and would lead to immediate consequences.

Vignettes detailed an interaction between an MS nurse and MS patient. Clinical expertise of MS populations and the work of MS nurses were employed to create scenarios which were reflective of real life interactions. Nine vignettes were designed based on the factorial survey approach to vignettes. Therefore, the three patient contexts remained the same, but the response style of the MS nurse to the MS patient in the vignettes differed to reflect the three levels of empathy. Creating vignettes as a set also

contributed to vignette equivalence. Vignette text was kept short (up to 12 lines) for participant convenience. Consequently, characters were framed by only mentioning gender and name. To ensure vignettes were close to real life the names of characters were chosen to reflect the diversity of the UK population and to reflect names that participants had possibly encountered in real life interactions. The language of vignettes was chosen to be appropriate for both MS specialist health professionals and patients. Every effort was made to use respectful and neutral language.

Internal and external validity was enhanced by employing clinical expertise of health professionals to ensure situations in the vignettes mirrored similar situations found in clinical settings. Order effects were reduced by ensuring that the vignettes were given in a randomised order. Participants were additionally asked to specifically respond to how the vignette made them feel and not draw on prior experience.

Once created the vignettes were rated by an expert panel of postgraduate mental health professionals to measure reliability. Four judges rated each response vignette on a likert scale from 1 to 10 (1= not representative at all, 10= very representative), on how well each vignette represented each of the three types of response styles.

Expert statistical advice (Dr Pal, personal communication, June 2007) was that vignettes with mean ratings above six and standard deviations below three should be accepted as sufficiently valid to represent the target construct. On closer observation, it was noted that while some vignettes met this criterion for the target variable, they were not reliable

measures of the target construct. In some cases target constructs for a specific vignette were either rated lower, or the same as, different constructs that the vignette was not meant to represent. Thus, vignettes 2, 3, 5, 7, and 8 were redrafted and rated by six independent judges as reliably portraying the target constructs. It was realised that originally the vignettes were too subtle in their portrayal of constructs, and had sought to be too realistic. Instead, given the few lines the participants have to absorb the scenario and nuances of the interaction, some exaggeration was required.

The final means and standard deviations for the vignettes used in the current study are given in table 3.1. The target constructs for each vignette are given in bold. It must be noted that even after redrafting vignette 8 it produced a very low rating on the high empathy dimension which it was meant to reflect. This must be borne in mind when interpreting the results.

Table 3.1

Mean Ratings for Response Style Vignettes

Means and Standard Deviations for Judges Ratings for each Vignette			
Response style Vignette	Low Empathy	Medium Empathy	High Empathy
1	9.8 (0.5)	7.5 (0.5)	1.5 (0.5)
2	7.0 (3.8)	4.5(4.3)	0.8 (0.4)
3	8.3 (2.1)	2.7 (3.7)	1.3 (1.4)
4	6.8 (2.5)	8.3 (2.9)	4.3(2.5)
5	5.8 (2.2)	8.3 (1.7)	6.0 (1.4)
6	8.3 (2.9)	9.0 (2.0)	5.3(2.5)
7	1.3 (0.5)	7.3 (3.7)	8.0 (2.5)
8	0.8 (0.4)	1.5(1.8)	2.3 (2.0)
9	2.5 (0.6)	8.3(1.7)	9.5 (1.0)

3.5. Measures

3.5.1 Socio-demographic Variables

Demographic variables were collected (refer to section 2.3.1 for further details; see appendix 4).

3.5.2 Spielberger State Trait Anger Expression Inventory

The dependent variable was anger state as measured by the anger state subscale of the STAXI (Spielberger, 1988), to assess participants' levels of immediate anger in response to each vignette (see section 2.3.7 for details of measurement scale).

3.5.3 Vignettes

Nine vignettes which detailed an interaction between a nurse and an MS patient were presented to each participant. Vignettes detailed a specific response style, either high, middle or low levels of empathy, in three contexts (see appendix 4 for final vignettes).

3.6 Analysis Plan

The data was analysed in the following steps: (1) Descriptive statistics were explored. (2) A mixed 3*3*2 ANOVA was performed. The first within subjects factor was the response style which had three levels (low empathy, medium empathy and high empathy). The second within subjects factor was patient context which had three levels (a patient does not participate in what is required, a patient demands instant gratification and a patient demands immediate emotional attention). The between subjects factor was group, which had two levels (health care professional group and multiple sclerosis group). The dependent variable was anger state. (3) Contrasts compared low empathy against high empathy, medium empathy against low empathy and high empathy against

medium empathy. (4) Contrasts for patient contexts compared a context where a patient demands instant gratification against a context where a patient does not participate in what is required and a context where a patient demands instant gratification against a context where a patient demands immediate emotional attention.

The analysis details: (1) Mean anger ratings for each response style. (2) Mean anger ratings for each participant group. (3) Mean anger ratings for each patient context. (4) Mean anger ratings for each vignette. (5) Main effect of response style and contrasts. (6) Main effect of patient context and contrasts. (7) Interaction of response styles and group.

3.7 Results

3.7.1 HCP Participants Demographics

Of the 375 contacted, 74 HCPs consented and completed the study. All 74 were female with a mean age of 40.2 years. All were British born but nationality varied; 72 were English, one was Australian and one was from New Zealand. All were employed.

3.7.2 MS Patient Participants Demographics

Forty nine MS patients took part in the study. Forty one were female and the mean age was 22 years. All were British born but nationality varied; 45 were English, three were Indian and one was Spanish. 24 were employed, 21 were unemployed and four were retired. Thirty seven had RRMS, four had PPMS, eight had SPMS. In terms of DMTs, 18 were taking Copaxone, seven were taking Rebif, four were taking Avonex, one

participant was on a Terifuomide trial and one participant was taking low dose naltrexone (LDN) (see table 3.2).

Table 3.2
Demographic Characteristics of MS Participants

Characteristic	<u>N</u>	%
Age at time of survey (years)		
20-29	2	4
30-39	10	20
40-49	25	52
50-59	10	20
60-69	2	4
Age at time of Diagnosis (years)		
15-24	3	6
25-34	18	37
35-44	23	47
45-54	5	10
Duration of MS (years)		
1-10	29	59
11-20	15	31
21-30	2	4
31-40	3	6
Type of MS		
RRMS	37	76
PPMS	4	8
SPMS	8	16
Disease modifying therapy		
Copaxone	18	37
Rebif	7	14
Avonex	4	8
Terifumide trial	1	2

LDN	1	2
No medication	18	37
Employment status		
Unemployed	21	43
Employed	24	49
Retired	4	8

3.7.3 Normal Distribution and T Scores

State anger scores were checked for normal distribution. Skewness and kurtosis statistics were within acceptable limits. Raw scores were converted into T scores for both the HCPs and MS groups to check for any abnormal levels of anger for each vignette. For both groups no scores fell above the 75th percentile of the STAXI (Spielberger, 1988) indicating that immediate levels of anger were unlikely to be at 'abnormal' levels (figures 3.1 & 3.2).

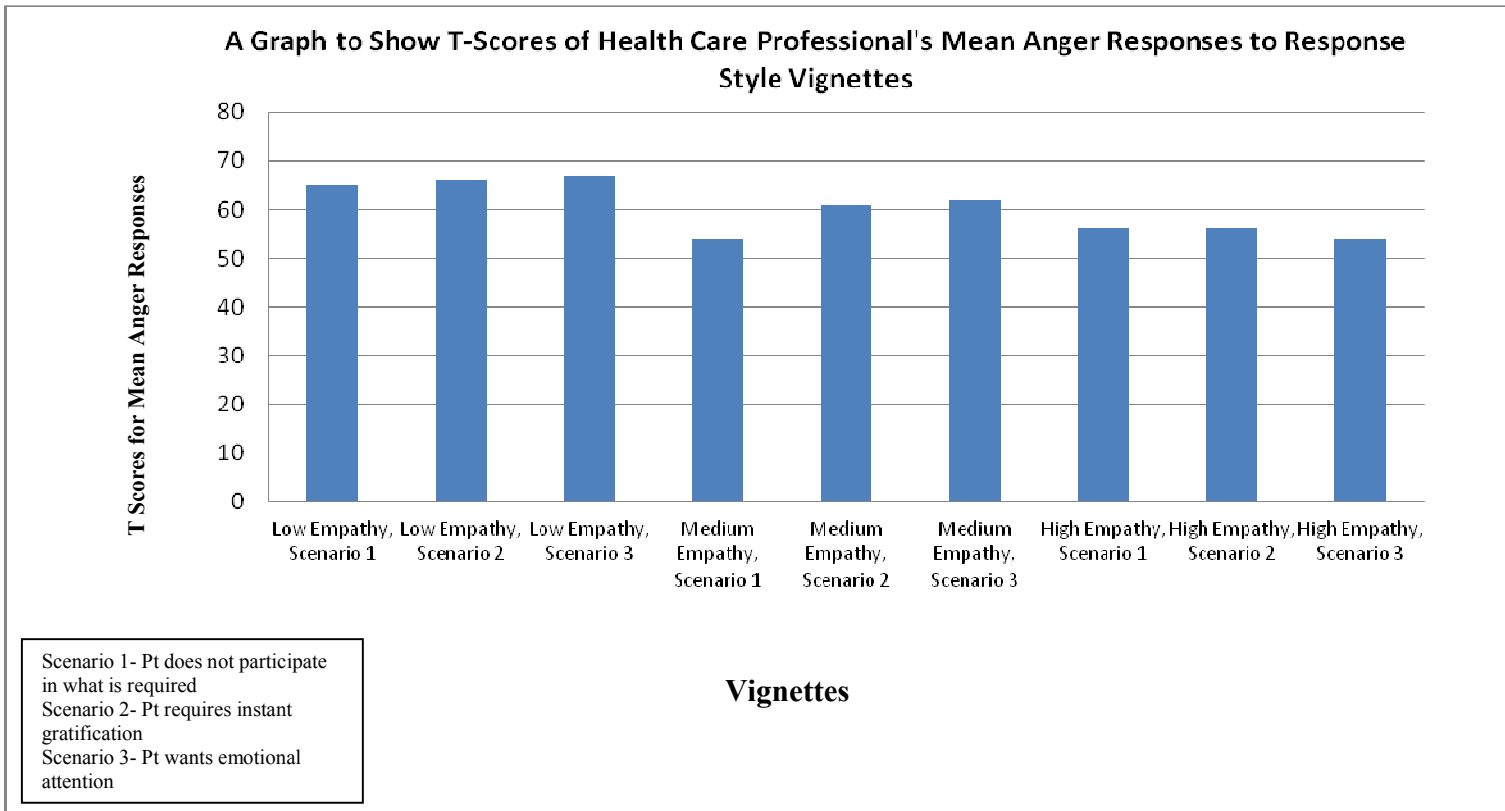


Figure 3.1
T Scores for HCPs' Mean Anger State Scores (standard deviation 10, mean 50)

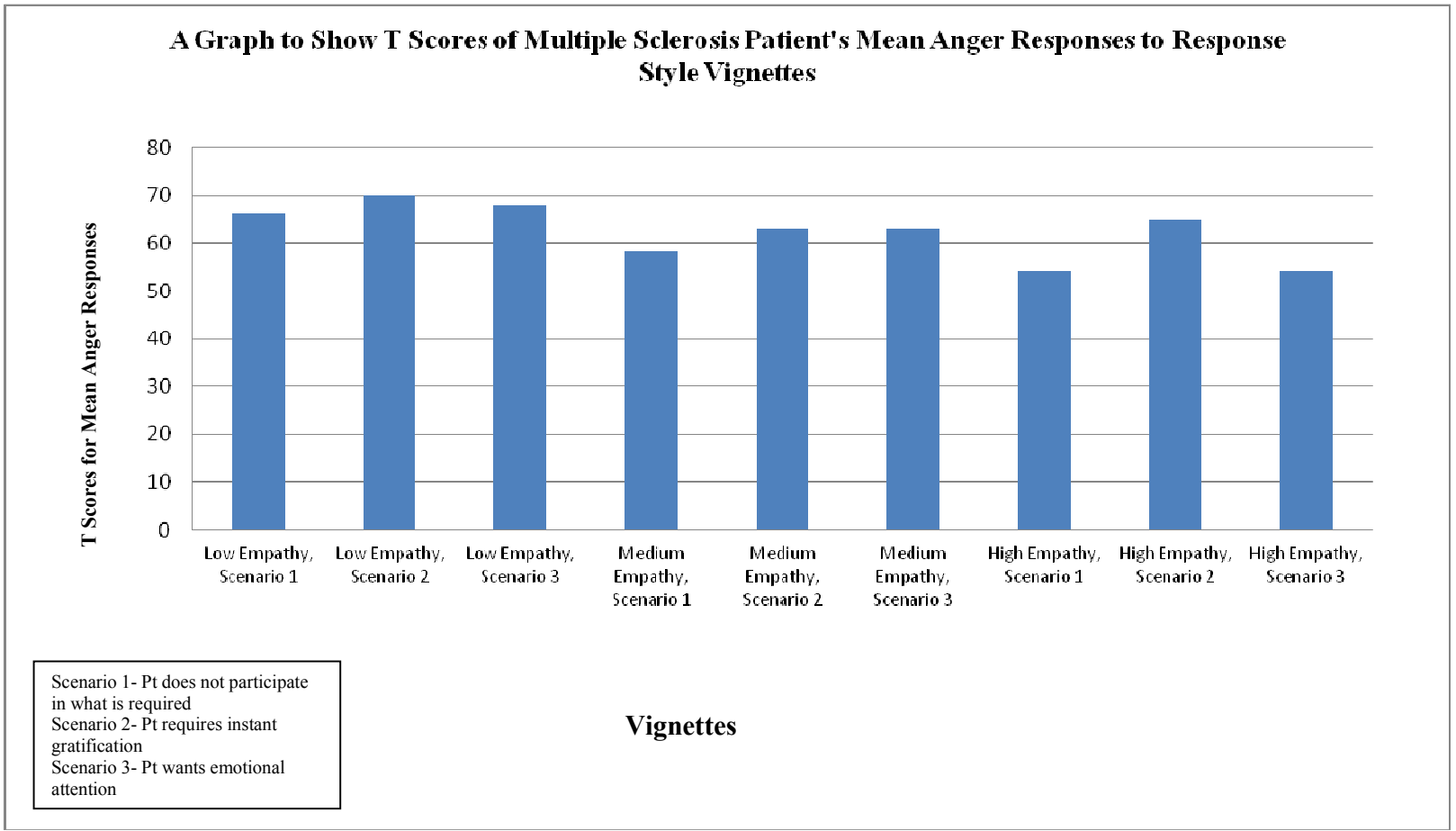


Figure 3.2

T Scores for Multiple Sclerosis Patients' Mean Anger State Scores (standard deviation 10, mean 50)

3.7.4 Mean Anger Ratings for each Response Style

Mean anger responses were calculated for each of the three response styles across both groups of participants and individually for both groups (see table 3.3)

Table 3.3

Mean Anger Ratings, Standard Deviations and Range for Response Styles for HCP and MS Groups

Response Styles	Mean Anger Ratings (standard deviations) Across Both Groups	Range	Mean Anger Ratings (standard deviations) For HCP Group	Range	Mean Anger Ratings (standard deviations) For MS Group	Range
Low Empathy	22.7 (8.4)	10-40	17.6 (8.1)	10-40	18.9 (8.8)	10-40
Medium Empathy	16.1 (8.7)	10-40	15.8 (6.8)	10-40	18.5 (7.8)	10-40
High Empathy	11.4 (6.4)	10-40	14.6 (4.4)	10-25	15.5 (5.0)	10-40

Low empathy vignettes yielded numerically the highest anger ratings. MS patients numerically rated each response style as more likely to provoke anger compared to HCPs.

3.7.5 Mean Anger State Ratings for each Participant Group

Mean anger state ratings were calculated for each of the participant group (see table 3.4).

Table 3.4

Mean Anger State Ratings, Standard Deviations and Range for each Participant Group

Group	Mean Anger Ratings (standard deviations)	Range
Health care professionals	15.9 (7.3)	10-40
Multiple sclerosis	17.8 (9.3)	10-40

Generally, the MS group numerically had higher anger state ratings compared to the health care professionals group.

3.7.6 Mean Anger State Ratings for each Patient Context

Mean anger state ratings for each patient context are given below (see table 3.5)

Table 3.5

Mean Anger State Ratings, Standard Deviations and Range for Patient Contexts

Patient Context	Mean Anger Ratings (standard deviations)	Range
Patient does not participate in what is required	15.3 (7.3)	10-40
Patient requires instant gratification	17.4 (8.3)	10-40
Patient wants emotional attention	18.1 (8.5)	10-40

The means reflect that it was situations where patients need emotional help that were rated numerically as most likely to provoke anger.

3.7.7 Mean Anger State Ratings for each Vignette

Mean anger responses were calculated for each response style presented in the three patient contexts (see table 3.6).

Table 3.6

Mean Anger Ratings, Standard Deviations and Range for each Response Style in each Patient Context across both Groups of Participants

Response Style	Patient does not participate in what is required. Mean and (standard deviation)	Range	Patient requires Instant gratification. Mean and (standard deviation)	Range	Patient wants emotional attention. Mean and (standard deviation)	Range
Low Empathy						
MS group	21.7 (8.7)	10-40	26.1 (9.0)	10-40	24.7 (8.4)	11-40
HCP group	21.2 (7.8)	11-40	19.9 (7.8)	11-40	22.8 (8.6)	10-40
Medium Empathy						
MS group	13.8 (4.9)	10-30	19.1 (8.4)	10-40	18.9 (8.5)	10-40
HCP group	11.9 (2.6)	10-27	16.8 (6.7)	10-40	18.4 (7.2)	10-40
High Empathy						
MS group	11.8 (6.5)	10-24	11.6 (4.6)	10-40	11.9 (3.7)	10-40
HCP group	10.3 (0.9)	10-15	10.9 (2.3)	10-22	11.7 (3.4)	10-25

The vignette which yielded the highest numerical mean anger state responses was the response style of low empathy in a patient context where the patient requires instant gratification, as rated

by the MS participants. HCPs numerically rated the low empathy response style in a patient context where a patient wants emotional attention as provoking the highest levels of anger. MS participants numerically rated the high empathy response style in a patient context where a patient requires instant gratification as provoking the lowest levels of anger. HCPs rated the vignette which was high in empathy in a patient context where a patient did not participate in what was required, as provoking lowest levels of anger.

3.7.8 ANOVA

3*3*2 ANOVA was performed. Sphericity was violated as $p < .05$. Corrected values of the conservative measure Greenhouse Geisser are reported (see table 3.7).

Table 3.7

Analysis of Variance Results for Main Effects and Interaction Effects of Response Style and Patient Context

Variable	<u>Df (2=1dp)</u>	<u>SS</u>	<u>MS</u>	<u>F</u>
Response style	1.4	2.2836.8	15801.3	229.5***
Error (response style)	174.9	12040.9	68.9	
Patient context	1652.7	1.86	903.2	38.8***
Error (patient context)	1.9	5242.4	903.2	
Group	1	92.7	92.7	4.9*
Error (Group)	121	2272.1	18.8	
Response Style x Group	1.5	204.3	141.4	0.2

* $p < 0.05$

*** $p < 0.001$

3.7.9 Main Effect of Response Style and Contrasts

There was a significant main effect of response style, $F(1.4, 174.9)=229.5$. Contrasts compared all response styles with each other. To account for multiple testing Bonferroni's correction was applied which was calculated by dividing the significance level of 0.05 by the number of hypothesised contrasts: $0.05/3=0.02$. There was a significant difference between high empathy response styles and low empathy response styles, $F(1,121)=282.6$, $p<0.001$. The contrast of high empathy and medium empathy was also significant, $F(1,121)=139.4$, $p<0.001$. Lastly there was also a significant difference when low empathy and medium empathy response styles were contrasted, $F(1,121)=92.8$, $p<0.001$. Thus, the most empathetic response styles were rated as significantly provoking lower levels of immediate anger compared to lower empathetic response styles.

3.7.10 Main Effect of Patient Context and Contrasts

There was a main effect of patient context, $F(1.9, 225.4)=38.8$. Contrasts compared the context where a patient demands instant gratification with patient contexts where a patient refuses to participate or wants emotional attention. To account for multiple testing Bonferroni's correction was applied which was calculated by dividing the significance level of 0.05 by the number of hypothesised contrasts: $0.05/3=0.03$. Contrasts revealed a significant difference when a context where a patient requires instant gratification was compared with a context where a patient does not participate in what was required, $F(1,121)=42.3$, $p<0.001$. A significant difference was not found when a context where a patient requires instant gratification was compared with a context where a patient wants emotional attention.

3.7.11 Main Effect of Group

There was a significant main effect of group, $F(1,121)= 9.3$, $p<0.05$, indicating that HCP and MS patients ratings of each vignette differed significantly i.e. that anger in MS patients tended to be higher overall.

3.7.12. Interaction of Response Styles and Group

The ANOVA revealed that there was no significant interaction between response styles and group, $F(1.4, 174.9)= 2.06$, $p>0.05$.

3.8 A Model of Anger

In regards to the model of anger (see figure 3.3), response styles which are low in empathy are possible triggers which could contribute and provoke immediate anger state in MS patients. In contrast to study 1, this study measured immediate state anger and not overall expressed anger. This must be kept in mind when looking at figure 3.3. When looking at the model it must be noted that causality cannot be determined in this study.

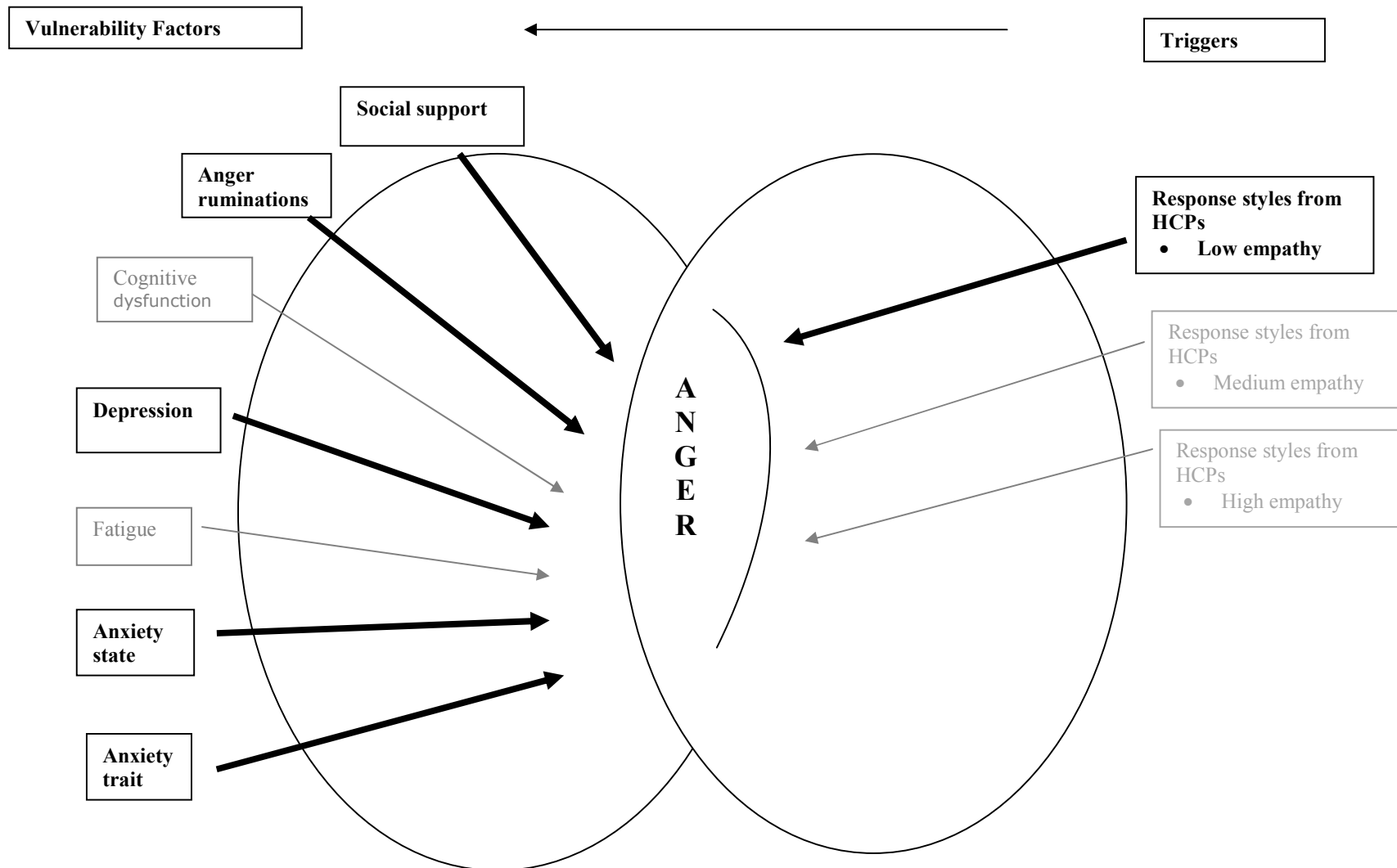


Figure 3.3

Model of Anger in MS Patients (3)

Key → Significant (empirically investigated) relationship to anger in MS.

→ Non significant (empirically investigated) relationship to anger in MS.

NOTE: No causality implied.

3.9 Discussion

It was hypothesised that response styles which were low in empathy would be associated with higher levels of anger state compared to response styles which were higher in empathy. ANOVA confirmed the experimental hypothesis.

It was hypothesised that contexts where patients were prevented from obtaining urgent goals were more likely to be associated with higher levels of anger state compared to contexts where patients were prevented from attaining less immediate urgent goals. The results were not conclusive in respect to this prediction.

It was hypothesised that HCPs would underestimate levels of aroused anger in MS patients. This hypothesis can be accepted as significant main effects of group indicated that MS participants had significantly higher ratings of anger state compared to HCPs.

It is unsurprising to find a significant effect of response styles. The main effect and contrasts reported that there was a significant difference between all response styles. It was always high empathy response styles which elicited lower immediate anger ratings, compared to medium and low empathy response styles. These results suggest that attending to a patient's subjective experience and tailoring responses to the patient's specific dilemmas may minimise anger arousal. Expressing genuine concern ensures patients feel valued and cared for at an individual level. These results, in part, replicate Lancee et al.'s. (1995) findings. Lancee et al. (1995) reported that HCPs rated belittlement and platitude styles as provoking most levels of anger. In the current study, low empathy response styles mirrored belittlement response styles thus

indicating that MS patients and HCPs rated limit setting/response styles in similar ways to previous research.

In accordance with previous literature these results provide support for Davis (1991) who found that styles which were restraining and did not portray genuine empathy caused higher levels of frustration in psychiatric in-patients. Empathy has also been found to be the most important factor in determining patient satisfaction with therapeutic relationships with general practitioners (Lewis, 1994). Additionally it has been found that patients who have terminal illnesses report that nurses who see patients in the community away from clinical settings value the importance of empathy and friendliness, believing that especially on a first meeting it helps to create a rapport (Davies & Oberle, 1990). While the data presented here was in relation to empathy expressed in clinical settings from HCPs, due to the nature of MS, nurses and other health care professionals visit MS patients in community settings. Thus as MS patients have identified the importance of empathy in possibly contributing to anger in clinical settings, it could also have implications for anger expression in community settings.

Empathy in these vignettes were not only portrayed by the HCPs appearing genuine and warm but additionally HCPs in the empathetic vignettes also asked patients how they were feeling and took more time in explaining issues to patients (this can be deduced by the length of empathetic vignettes compared to length of non empathetic vignettes). Thus, MS patients in this study may also have been acknowledging that HCPs who displayed interaction styles which were high in empathy, took time to clarify issues and asking questions about patients' feelings were demonstrating

positive interaction styles. Heaven and Maguire (2003) described similar interaction styles with these components being effective in improving patient well being in palliative care. Importantly this study highlights that while most of the information on interaction styles and empathy comes from psychiatric in-patients and patients with terminal illnesses, it is just as important in neurological populations such as MS.

Intriguingly a main effect of patient context was found unlike in the study by Lancee et al. (1995). Contrasts revealed a significant difference between contexts where a patient demanded instant gratification (vignette portrayed a patient who was unable to get out of a wheel chair independently to use the toilet) and a context where a patient refused to participate in what was required (vignette portrayed a patient who did not want to take medication). This finding is in line with theories of anger which report that anger is more likely to occur if barriers to achieving goals are obvious (Izard, 1977). It could be argued that the context where a patient needs the physical help of a HCP to attain a goal of going to the toilet (instant gratification), involves an obvious barrier, which if not overcome will possibly lead to public embarrassment and thus concrete outcomes of denied gratification.

However, significant differences were not found when the context of instant gratification was compared to a context where a patient demanded emotional attention (vignette portrayed a patient asking for comfort after a domestic fight with a partner). A possible reason as to why a significant difference was found between the context where patients demand instant gratification and the context where patients refuse to take part in what was required, could be because in the first scenario the patient is actually physically prevented from attaining a goal of going to the toilet by the HCP

delaying helping them, therefore provoking higher levels of anger state. However, in the context where the patient refuses to take medication, the patient makes this choice him/herself and is not prevented by HCPs, thus this situation may provoke lower levels of anger state.

It could be argued that no significant differences were found between the instant gratification context and emotional need context as patients in the emotional context are prevented from attaining their goal of comfort, since the HCP is unable to visit them immediately. Theoretical models of anger also propose that expectations placed on other people's behaviours can cause anger (Kassinove & Tafrate, 2002). Therefore, if participants were expecting HCPs to help patients in both contexts and they did not, expectations are not met, possibly contributing to levels of anger. Another interpretation of these results could be that rather than the barriers to goals provoking higher levels of anger state, it could be the consequences of not achieving goals. Being denied emotional support in a crisis and being denied assistance to avoid serious embarrassment are both experiences that diminish patients' sense of self worth and the perceived caring of the nurse and this could provoke higher levels of anger state. However, interpretation is speculative as participants were not asked questions about whether their anger levels were in response to perceived barriers or feared outcomes. Thus, the results in relation to context are inconclusive.

The main effect of group indicated that MS patients' anger ratings were significantly higher than HCPs'. Therefore, while MS patients and HCPs rated the same response styles as most and least likely to provoke anger, MS patients reported significantly higher ratings of anger state. This could indicate that while HCPs were aware of how

various response styles affected MS patient anger, they underestimated the severity of their angry feelings. Past literature suggests that MS patients generally have higher levels of anger than the healthy population (Langdon & Thompson, 1999). The results may indicate that the higher scores of the MS patients reflect higher baseline anger or stress, although this is speculative. It has been found that healthy individuals and patients differ in what aspects they value most in patient-HCPs therapeutic relationships (Friis, Elverdam, & Schmidt, 2003). Perhaps the results here also indicate this. However, as participants were not interviewed about this, it is not known if they do value different aspects of therapeutic relationships. Additionally the literature on the differences in values placed on therapeutic relationships comes from cancer patients and relatives, who would probably have different relationships with HCPs due to the terminal nature of their disease.

3.9.1 Strengths and Limitations

This study produced high Cronbach alpha levels for each vignette indicating that the STAXI state subscale (Spielberger, 1988) was a reliable measure of anger state for each vignette in these populations.

This study is the first attempt to investigate ‘limit-setting styles’ in an MS population and not only found similar results to Lancee et al. (1995), but additionally expanded previous results by finding a group and patient context effect. Further, this study has identified that particular response styles could lead to immediate triggers of anger state, which have never been empirically identified before in an MS population.

As these results replicated Lancee et al.'s work they provide some evidence that despite the possible limitations of vignettes compared to role-plays, vignettes may be a reliable way of presenting response styles.

Regarding the model of anger presented in Chapter 1, response styles can also be theoretically added to the model as possible external factors which could trigger anger in MS patients.

Limitations of this study must also be highlighted. While vignettes were rated by independent judges on how accurately they represented the response styles, they were not rated on how well each vignette was representative of each of the patient contexts. Thus, results relating specifically to patient contexts must be interpreted with caution.

Furthermore, even though every effort was made to produce vignettes that accurately represented high, medium or low empathy, in a few cases (vignettes 6 and 7) there was not a large difference between the ratings of target constructs and other constructs. It must be specifically noted that vignette 8 which was meant to portray high empathy was rated very low on the target dimension. Therefore it is difficult to conclude confidently that this vignette was representative of high empathy. Therefore the current study should be replicated with redrafted vignettes which have a larger difference in ratings for target constructs and other constructs and have higher ratings of the dimensions that they are meant to be portraying. Due to time constraints vignettes could not be re-drafted for a third time. Additionally, although every effort was made to keep vignettes short and of a similar length, vignettes did ultimately vary in length to portray different response styles, which could have biased responses. Length of

vignettes should have been controlled more strictly to have increased confidence in interpreting results.

Additionally vignettes were created to portray various amounts of empathy. However, empathy encompasses more than just genuinely understanding a patient's perspective. It also portrays HCPs who give more time to patients and listen attentively. These characteristics were also displayed in the vignettes which portrayed 'high empathy.' Therefore, it is not really known if participants were acknowledging that empathy decreased anger or if it was specific attributes like listening or giving patients extra time which decreased anger. The problem in trying to tease these elements apart is that in real life empathy does overlap with these concepts. As participants were not interviewed and did not write any extra comments after the vignettes this cannot be investigated.

In total there were nine vignettes which were each followed by the STAXI one after another; this could have meant that there were some carry over effects. Participants may still have felt angry after the last vignette they rated which would have affected their ratings for the next vignette. Future studies could consider an experimental design where level of arousal is monitored and returned to a baseline score, before continuing with rating the next vignette. As the vignettes attempted to reflect specific situations that MS patients might realistically encounter, their anger ratings might have been higher than HCPs because they were better able to empathise with patients in the vignettes. It could be argued that asking HCPs to rate vignettes on situations that they had never been in as a patient was less valid. As HCPs work in the MS environment

and interact with MS patients on a daily basis, it was assumed that they would have experience of similar situations presented in the vignettes, albeit as HCPs.

The majority of participants in this study were female (all HCPs were female). While this is a reflection of gender distribution in real life, as most HCPs in MS are female and MS has a higher incidence in females (Compston & Coles 2008), it could also be considered a limitation. Past literature reports that there is a gender difference in the experience and expression of anger (Thomas, 2003). Thus, it is not known if male HCPs would have responded differently in this study. It must also be noted that while results have been compared across groups, the groups were not matched on age or gender due to the way in which HCPs were recruited. As some participants took part in this in their own time without the researcher present it is not known under which circumstances the vignettes were filled in, i.e. if it was a noisy environment, additionally this could have affected their ratings of the vignettes.

Additionally it must also be noted that the sample size for the MS group was 15 participants below the recommended threshold for power (Cohen, 1992). Due to the time limitations of the study it was not feasible to recruit the additional participants. Therefore results should be interpreted with caution as potentially significant effects may have been missed.

The lack of a healthy group of participants who neither work with MS or have MS could also be viewed as a weakness. It would have been interesting to investigate their anger ratings compared to those of MS patients or HCPs.

Despite these limitations, it can be reasonably concluded that both HCPs and MS patients rated response styles which have high levels of empathy as keeping anger to a minimum. A significant group difference was found which indicated that HCPs significantly underestimated anger levels elicited from MS patients.

Further research could extend this study by varying particular response styles and investigating if they are appropriate for the reduction of anger in specific patient contexts, as literature has also suggested that different types of interaction styles are appropriate at different points in patient-HCP's relationships. When patients are sharing emotional information, patients seem to value interaction styles which promote empathy, warmth and emotional support (Thom & Campbell, 1997). However it has also been observed that patients who are experiencing emotional situations 'close off' communication with HCPs and may not 'take in' what HCP's are advising (Dunkel-Schetter, 1984). It would interesting to investigate how anger state levels vary as these contexts and interaction styles vary.

Different subtypes of MS patients, other patient populations and health care professionals who varied in types of training could be explored to investigate how their anger ratings might differ. Additionally, further research could also investigate if the same response styles provoke the same amounts of anger if vignettes detailed interactions in community settings rather than health care settings. Past literature has found that younger patients value being asked their opinion on their care, which could be classified as a component of empathy (Degner & Solan, 1992). Thus future research could investigate if there is an age difference in how empathetic interaction styles are rated.

This study began to investigate environmental triggers and supports the conclusion that the way in which HCPs respond to MS patients can trigger immediate anger. With this in mind it would now be interesting to investigate further how HCPs' approaches and communication styles could affect MS patients' levels of anger. The next study continued to explore possible environmental triggers in the form of communication styles from HCPs.

Chapter Four: Study 3- Communication Styles and Anger

Expression in MS patients

4.1. Summary of Study 3

Study two investigated possible environmental triggers in the form of response styles of HCPs and their potential effect on MS patients' levels of anger. Not only did this study indicate that empathy plays an important role in keeping anger to a minimum, it also highlighted the important role that HCPs' behaviour could potentially have in affecting anger levels in MS patients. This study will further explore this role. Study 3 will investigate communication styles from HCPs towards MS patients and the association with anger levels, based on McCabe's work (2004) (see section 1.15).

Psychiatric in-patients identified HCPs' communication styles in a qualitative study and how these potentially affect patients' well being (McCabe, 2004). Four types of communication style were identified :

- Patient centred communication
- Attending behaviour
- Empathy
- Humour

When nurses had a lack of patient centred communication styles, patients reported that nurses were more preoccupied with completing tasks. This type of communication consequently led to a negative effect on patients who felt that they could not 'bother the busy nurses'. Instead, patients reported that they would rather wait for a senior member of staff to relay their concerns to, who may not be on hand

that day. Some patients additionally viewed these nurses as ‘workers’ instead of professionals.

Attending behaviour is described as the physical demonstration of nurses’ accessibility and readiness to listen to patients through the use of non-verbal communication (Stein-Parbury, 1993). Such non-verbal communication includes genuineness, warmth and appropriate body language (Burnard, 1990; Stein-Parbury, 1993). McCabe (2004) found that when patients experienced this type of communication style they felt secure, safe and reassured leading to a positive effect on their emotional well being.

McCabe (2004) reported that patients identified that nurses who used humour and were friendly helped them to relax and feel positive. Humour also helps to establish a rapport and trust while decreasing anxiety and tension (Astedt-Kurki, 2001), thus having a positive effect on emotional well being.

MS patients have specifically identified that patient centred communication styles were related to more positive emotional well being and a lack of communication were related to negative well being. (Freeman & Thompson, 2000; Lode et al., 2007).

This study investigated communication styles that HCPs could use during their care based on McCabe’s (2004) identification of communication styles from psychiatric in-patients, to see if they were related to anger in MS populations. Of the four communication styles identified by McCabe, study three investigated three of them: patient centred communication, attending behaviour and humour. Empathy was not

investigated as a communication style as study two had already investigated empathy in the form of response styles. A vignette methodology was used (see section 3.4 for information on vignettes) to investigate the three communication styles in high and low forms (e.g. low and high levels of patient centred communication, attending behaviours and humour). This study predicted that lower forms of the communication styles would be associated with higher levels of anger state compared to higher levels of communication styles (e.g. low levels of attending behaviour would be associated with higher levels of anger state compared with high levels of attending behaviour). Given that previous literature reports that MS patients have specifically reported that low levels of communication styles with patients is associated with negative well being, it was predicted that low levels of patient centred communication would be significantly associated with higher levels of anger state compared with low levels of attending behaviour and humour. This study will extend McCabe et al.'s work (2004) by investigating if HCPs underestimate levels of aroused anger in MS patients, given that MS patients have been reported to have higher levels of anger compared to the normal population (Langdon & Thompson, 1999).

The dependent variable was self reported measures of anger state as measured on the STAXI (Speilberger, 1988), completed after each vignette. Anger state was used as it is an immediate measure of anger arousal which changes due to situations. As discussed earlier (see section 2.3.7) the STAXI has been previously used with MS populations (Nocentini et al., 2009).

The main hypotheses were:

- Communication styles which demonstrate low levels of patient centred communication, low levels of attending behaviour and low levels of humour will be associated with higher levels of anger state compared to communication styles which demonstrate HCPs as having high levels of patient centred communication, attending behaviours and humour.
- Low levels of patient centred communication style will be associated with higher levels of anger compared to low humour and low attending behaviour communication styles.
- HCPs will underestimate MS patients' levels of state anger.

4.1.1. Design of Study 3

Seventy three HCPs and 49 MS patients completed this study. Vignettes were created by the main researcher to represent high and low levels of patient centred communication, attending behaviour and humour communication styles based on McCabe's (2004) definitions (see section 4.4.1). Vignettes were rated on how well they represented each target construct by mental health professionals (see section 4.4.1). Vignettes detailed an interaction between an MS nurse and MS patient. Participants were asked to read each vignette and imagine that they were the patient in the scenario and then rate their levels of anger state in response to the vignette on the State subscale of the STAXI (Spielberger, 1988) presented after each vignette.

This study adopted a mixed 6*2 ANOVA. The first within subjects factor was the communication style which had six levels (high communication with patient, low communication with patient, high attending behaviour, low attending behaviour, high humour and low humour.) The between subjects factor was group, which had two

levels. The dependent variable was anger state (see section 4.6). Main effects and interactions were reported.

4.2 Method

4.2.1 Ethical Permission

Ethical permission to undertake this study was granted by Royal Holloway, University of London Ethical Committee and NHS East Kent Research Ethics Committee (approval letters can be found in appendix 1).

4.2.2 Inclusion and Exclusion Criteria for HCPs

For inclusion criteria for health care professionals refer to section 3.2.2

4.2.3 Inclusion and Exclusion Criteria for MS Patients

For inclusion criteria for MS patients refer to section 3.2.3

4.2.4 Sample Size Requirements

A power calculation was performed to determine the recommended sample size for a mixed ANOVA design investigating the six types of communication styles (three styles in high and low forms), in two groups of participants (6×2). The actual sample size for the HCP group was 73, which was above the recommended threshold. The actual sample size for the MS group was 49 which was 15 participants below the threshold. The overall sample size was 122, seven participants below the recommended amount.

4.2.5 HCP Participants

The HCPs who participated in this study were the same as those in study two (see section 3.2.5). However, one fewer HCP completed the study (all information sheets and consent forms can be found in appendix 2).

4.2.6 MS Patient Participants

The same MS participants participated in this study as in study 2 (refer to section 3.2.6) all information sheets and consent forms can be found in appendix 2.

4.3 Procedure

4.3.1 Procedure for HCPs

As the vignettes for communication were sent in the same packs as the limit-setting style vignettes (study 2) the same procedure was followed for both studies 2 and 3 (refer to section 3.3.1). Participants were asked to read the vignettes and rate how angry they would feel if they were the patients in the scenarios.

4.3.2 Procedure for MS Patient Participants

The procedure was followed as for study 2 (refer to section 3.3.2). Participants were asked to read the vignettes and rate how angry they would feel if they were the patients in the scenarios.

4.4 Vignettes

Please refer to sections 3.4 for information on the definition, choice and reliability of vignette methodology.

4.4.1 Construction of Communication Vignettes

Communication vignettes were constructed based on McCabe's (2004) definitions of communication styles. Six vignettes were constructed to represent high and low levels of attending behaviour, patient centred communication and humour.

Vignettes detailed an interaction between an MS nurse and MS patient. As in the construction of the response style vignettes, clinical expertise of MS populations and

the work of MS nurses were employed to ensure scenarios in the vignettes were reflective of real life scenarios in healthcare settings. The characters were framed in the same way as the response style vignettes and language was given the same attention as the response style vignettes (see section 3.4.4).

These vignettes were longer than the response style vignettes as this was necessary to capture the specific communication styles. It was felt that communication styles would not be portrayed realistically in only 12 lines. These vignettes were up to half a page long. Given that only six vignettes were presented, length of vignettes were unlikely to fatigue participants.

These vignettes were not created as set of vignettes with similar scenarios as with the response styles, as it was felt that different scenarios were needed to correctly portray the varying communication styles. As with the response style vignettes each was followed by the state subscale of the STAXI (Spielberger, 1988) to assess participants' anger responses to each vignette. Internal and external validity was addressed in the same way as for the response style vignettes (see section 3.4.4).

Eight graduate health professionals rated each communication vignette on a likert scale from 1 to 10 (1= not representative at all, 10= very representative), on how well the vignette represented each of the three types of communication (good patient centred communication, attending behaviour and humour). Means and standard deviations were obtained for each vignette to ensure they were reliable. The same criterion for reliability was used as for the vignettes in study 3, to accept vignettes which represented high levels of communication, attending behaviour and humour

(see section 3.4.4). However to accept vignettes that represented low levels of communication, attending behaviour and humour, expert statistical advice (Dr Pal, personal communication, June 2007) was to accept mean ratings that were below 3 and had a standard deviation below 3 (see table 1). Final vignettes are given in appendix 5.

It must be noted that despite efforts to create vignettes which were distinguished by a markedly higher or lower score on their defining dimension than the other vignettes, this was not always well achieved. For example vignettes which were meant to portray high attending behaviour and high patient centred communication were rated similarly on constructs of ‘good communication’ and ‘attending behaviour.’ Similarly ratings for ‘humour’ did not differ greatly across any of the three types of vignettes. Therefore caution must be used when assuming that the vignettes are truly representative of ‘low’ and ‘high’ levels of the specified communication styles.

Table 4.1
Mean Ratings for Communication Style Vignettes

Vignettes	Ratings of each Vignette on each Communication Style (SD)		
	Good Communication	Attending Behaviour	Humour
High Patient centred Communication	7.5 (2.2)	7.2 (1.9)	2.0 (1.8)
Low Patient Centred Communication	2.3 (2.1)	3.8 (2.3)	3.8 (1.5)
High Attending Behaviour	8.8 (1.4)	9.4 (1.6)	1.6 (1.3)
Low Attending Behaviour	2.8 (1.6)	1.4 (1.8)	1.5 (0.0)
High Humour	8.4 (1.3)	8.5 (1.3)	9.0 (1.1)
Low Humour	4.0 (1.9)	3.1 (1.2)	3.0 (1.8)

* Target constructs for each vignette are given in bold.

4.5. Measures

4.5.1 Socio-demographic Variables

The same demographic information was collected as previous studies (see section 2.3.1).

4.5.2 Communication Vignettes

Six communication vignettes were created to investigate the three communication styles based on McCabe's (2004) work (see appendix 5).

4.5.3 Spielberger State Trait Anger Expression Inventory

Each vignette was followed by the state subscale of the State Trait Anger Expression Scale (Spielberger, 1988), to assess participants' levels of immediate anger in response to how they would feel if they were the patient in the vignette (See section 2.3.7 for details of measurement scale).

4.6 Analysis Plan

The data were analysed in the following steps: (1) Descriptive statistics were explored (2) A 6*2 mixed ANOVA was performed. The within subjects factor was the communication styles which had six levels (high patient centred communication, low patient centred communication, high attending behaviour, low attending behaviour, high humour and low humour). A single six level within-subjects factor design was used rather than a two factor within-subjects factor with three levels, because due to discrimination of vignettes not being well achieved (see table 4.1), it cannot be safely concluded that each vignette is truly representative of 'high' and 'low' levels of each of the communication styles specified. Therefore the communication styles were treated as single six level within-subjects factors. The between subjects factor was group; this had two levels (health care professional group and multiple sclerosis

group). The dependent variable was anger state as measured on the state subscale of the STAXI. Contrasts compared each pair of vignettes with each other to assess if lower levels of the communication styles were significantly associated with higher levels of anger compared to higher levels of the communication styles. Contrasts then compared the 'low' exemplar of each communication style with each other to assess which of these styles was associated with highest levels of anger state.

The analysis details: (1) Descriptive statistics of HCPs' and MS patients' responses (2) Mean anger ratings for each communication style (3) Mean anger ratings for each participant group (4) Main effect of communication styles and contrasts (5) Main effect of group (6) Interaction of communication styles and group. No contrasts were performed on the two way interaction as these were not hypothesised.

4.7 Results

4.7.1 HCP Participant Demographics

Seventy three HCPs consented and completed this study. All were female. The mean age was 40.6 years. All participants were English born but nationality varied, 71 were British, one was Australian and one was from New Zealand.

4.7.2 MS Participant Demographics

Refer to section 3.7.2 for details on patient demographics

4.7.3 Normal Distribution and T Scores

The anger state scores were checked for normality of distribution. Skewness and kurtosis statistics were within acceptable limits. Raw scores were converted into T scores (with a mean of 50 and a standard deviation of 10). For both groups no scores

fell above the 75th percentile of the STAXI (Spielberger, 1988) indicating that levels of anger state were unlikely to be at 'abnormal' levels (figures 4.1 & 4.2).

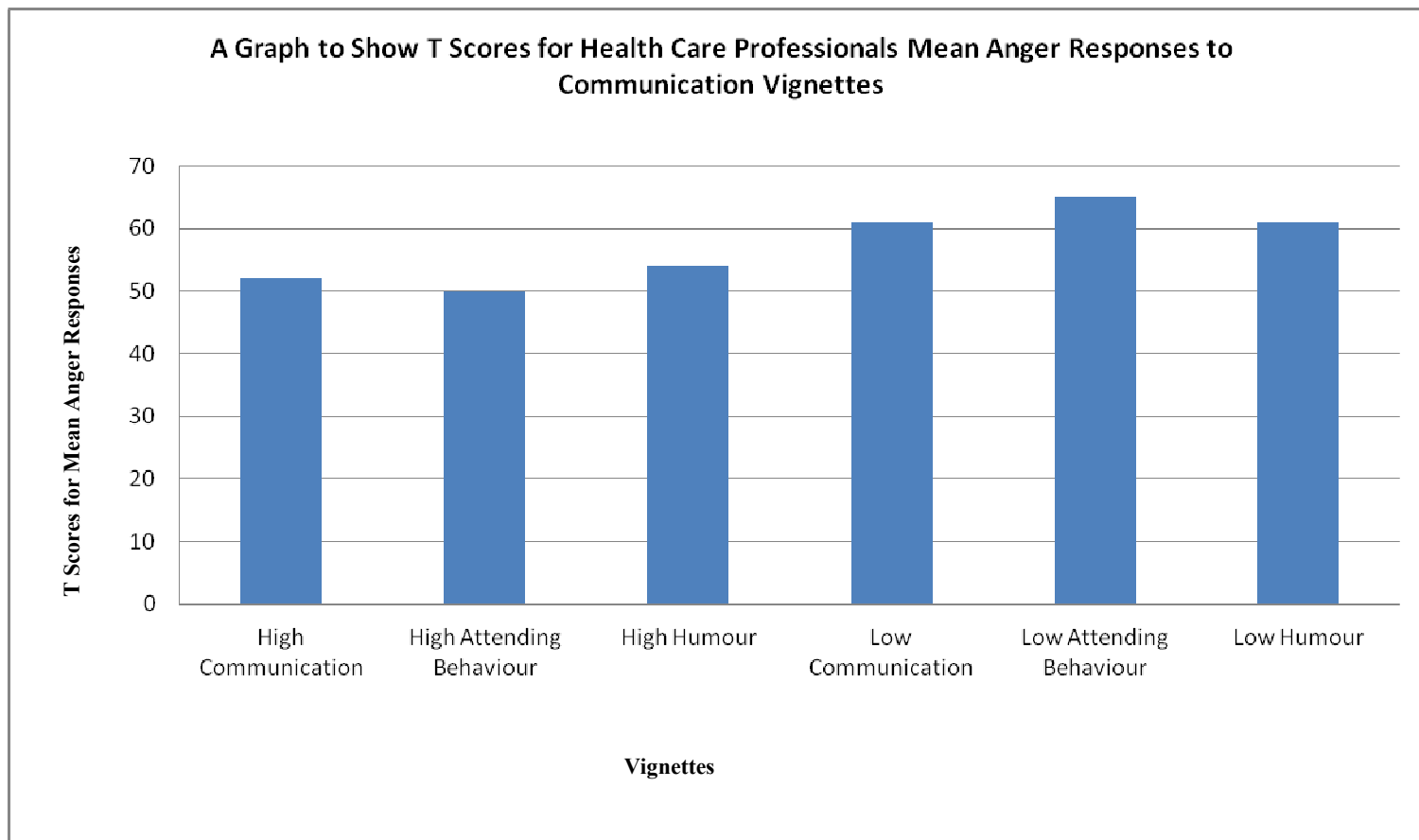


Figure 4.1
T Scores for Health Care Professionals' Mean Anger State Scores (standard deviation 10, mean 50)

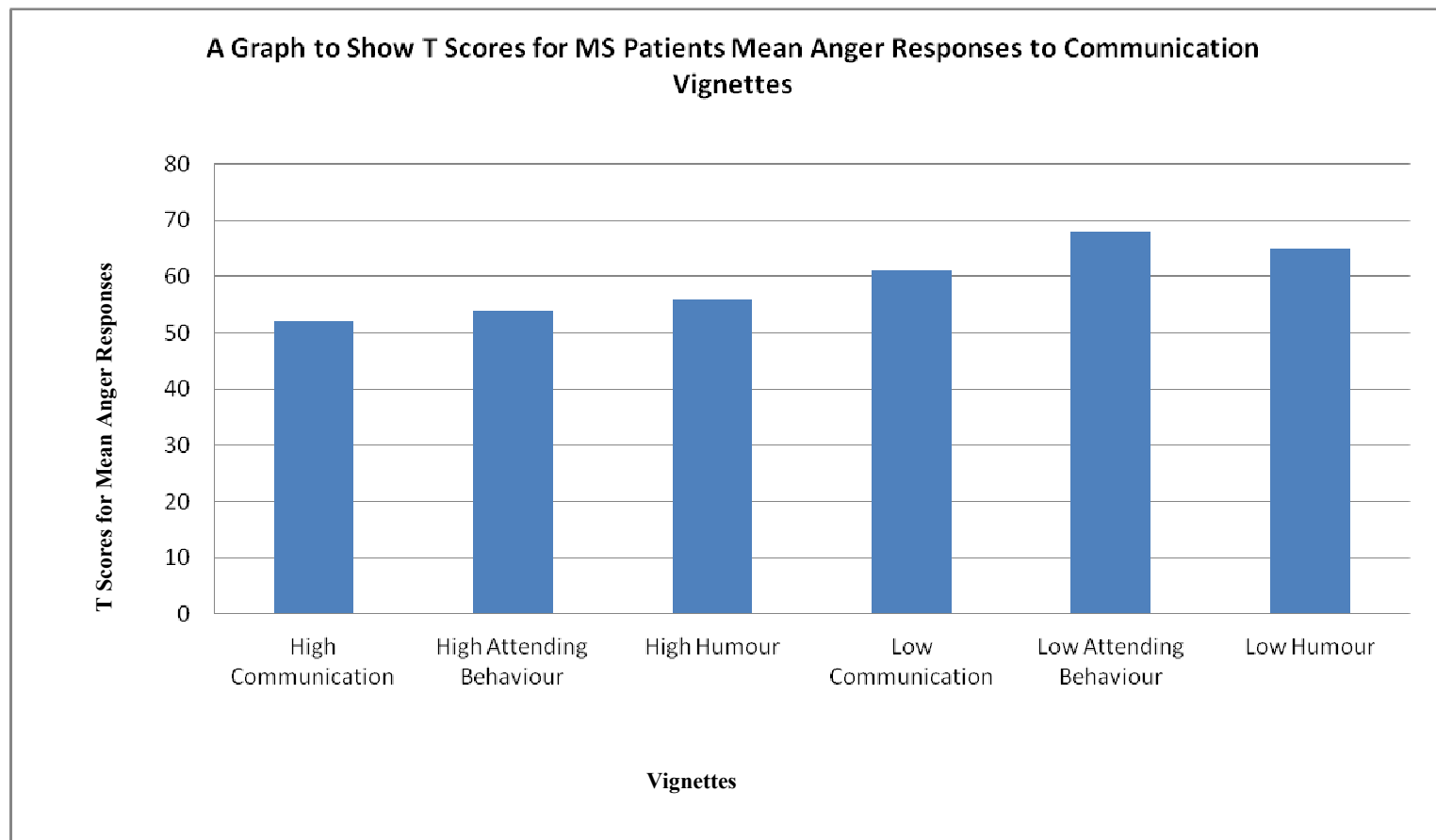


Figure 4.2
T Scores for Multiple Sclerosis Patients' Mean Anger State Scores (standard deviation 10, mean 50)

4.7.4 Mean Anger State Ratings for each Communication Style

Mean anger state responses were calculated for each of the six communication styles across both groups and individually for each group (see table 4.2).

Table 4.2

Anger State Response Means, Standard Deviations and Range for Communication Style Across both Groups and Individually for MS and HCP Groups

Communication Style	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
	Anger State Ratings Across both groups		Anger State Ratings for HCP Group		Anger State Ratings for MS Group	
High patient centred communication	11.0 (2.8)	10-30	10.8 (2.7)	10-30	11.3 (3.0)	10-25
High attending behaviour	11.1 (3.0)	10-30	10.3 (.085)	10-16	11.9 (4.5)	10-30
High humour	12.4 (4.4)	10-40	11.8 (3.0)	10-25	13.0 (6.0)	10-40
Low patient centred communication	15.7 (5.9)	10-40	15.7 (5.1)	10-40	15.7 (7.1)	10-40
Low attending behaviour	23.4 (8.5)	11-40	21.4 (7.2)	11-37	25.4 (9.8)	12-40
Low humour	17.5 (7.4)	10-40	15.5 (5.6)	10-40	19.5 (9.1)	10-40

High patient centred communication styles and high attending behaviour were rated numerically as the communication styles which were least likely to provoke immediate anger from MS patients and HCPs. Low attending behaviour and low humour were rated numerically lowest, as the communication styles which were most likely to provoke immediate anger from MS patients. HCPs rated low attending behaviour and low patient centred communication styles as most likely to provoke immediate anger.

4.7.5 Mean Anger State Ratings for each Participant Group

Mean anger responses for each participant group were calculated.

Table 4.3

Mean Anger State Ratings, Standard Deviations and Range for each Participant Group

Group	Mean Anger Ratings (Standard Deviations)	Range
Health care professionals	14.3 (5.9)	10-40
Multiple sclerosis	16.1 (8.5)	10-40

The MS group numerically rated the communication vignettes higher compared to HCPs (see table 4.3).

4.7.8 ANOVA

A 6*2 ANOVA was performed on the data. Sphericity was violated as $p < 0.05$.

Therefore the corrected values of the conservative measure Greenhouse Geisser are reported (see table 4.4).

Table 4.4

Analysis of Variance Results for Main and Interaction Effects

Variable	DF (1dp)	SS	MS	F
Communication style	3.4	13548.9	4038.8	129.2**
Error (communication)	405.9	12693.3	31.3	
Group	1	106.1	106.1	7.3*
Error (group)	121	764.9	14.6	
Communication style x Group	3.4	421.7	125.7	4.02*

* $p < 0.05$

** $p < 0.001$

4.7.9 Main Effect of Communication Styles

There was a significant main effect of communication styles, $F(3.4,405.9)=129.2$, $p<0.001$.

4.7.10 Contrasts

Contrasts were based on hypotheses and thus compared pairs of communication styles together: high patient centred communication vs low patient centred communication, high attending behaviour vs low attending behaviour and high humour vs low humour. Additional exploratory contrasts compared the three low exemplars of the communication styles to investigate which out of these styles was associated with highest levels of immediate anger. To account for multiple testing Bonferroni's correction was applied by dividing the significance level 0.05 by the quantity of contrasts ($0.05/6=0.008$), giving a significance level of 0.008.

Patient Centred Communication Contrasts

High levels of patient centred communication were contrasted with low levels of patient centred communication. A significant effect was found, $F(1,121)=81.4$, $p<0.001$, indicating that low levels of patient centred communication were rated as provoking significantly higher levels of anger state compared to high levels of patient centred communication.

Attending Behaviour Contrasts

High levels of attending behaviour were contrasted with low levels of attending behaviour. A significant effect was found, $F(1,121)=281.0$, $p<0.001$, indicating that

low levels of attending behaviour were rated as provoking significantly higher levels of anger compared to high levels of attending behaviour.

High Humour Contrasts

High levels of humour were contrasted with low levels of humour. A significant effect was found, $F(1,121)=74.7$, $p<0.001$, indicating that low levels of humour were rated as provoking significantly higher levels of anger compared to high levels of humour.

Contrasts of Low Levels of Communication Styles

Contrasts compared low exemplars of each communication style with each other: low patient centred communication vs low attending behaviour, low patient centred communication vs low humour and low attending behaviour vs low humour. Low patient centred communication compared to low attending behaviour produced a significant effect, $F(1,121)=140.2$, $p<0.001$. The means indicated that low attending behaviour was rated as provoking significantly higher levels of anger state compared to low patient centred communication. A significant effect was also found when low attending behaviour was compared to low humour, $F(1,121)=81.21$, $p<0.001$. The means indicate that low attending behaviour was rated as provoking significantly higher levels of anger state than low humour. It must be noted that as the low attending vignette was rated lower on all dimensions in comparison to the low humour vignette (see table 4.1) it may be that it was not the low attending dimension on the vignette that accounted for the differences found. A significant effect was not found when low patient centred communication was compared to low humour, $F(1,121)=9.9$, $p>0.008$.

Therefore, low levels of attending behaviour was always rated as provoking significantly higher levels of anger state than low patient centred communication and low humour.

4.7.11 Main Effect of Group

There was a main effect of group, $F(1,121)=7.3$, $p<0.05$, indicating that HCPs' and MS patients' anger state ratings significantly differed from each other. The means indicated that the MS group had significantly higher anger ratings than the HCPs.

4.7.12 Interaction of Communication Styles and Group

The ANOVA revealed a significant interaction between communication styles and group, $F(3.4, 405.9)=4.0$, $p<0.05$. Indicating that MS and HCPs groups rated the communication styles significantly differently from each other. As there were no priori hypotheses in relation to this interaction, no contrasts were performed and this was not explored any further.

4.8 A Model of Anger

In relation to the model of anger in multiple sclerosis (see figure 4.3) it could be suggested that communication styles displayed from HCPs towards MS patients could contribute to levels of anger, and specifically low levels of attending behaviours.

Causality cannot be determined by this study.

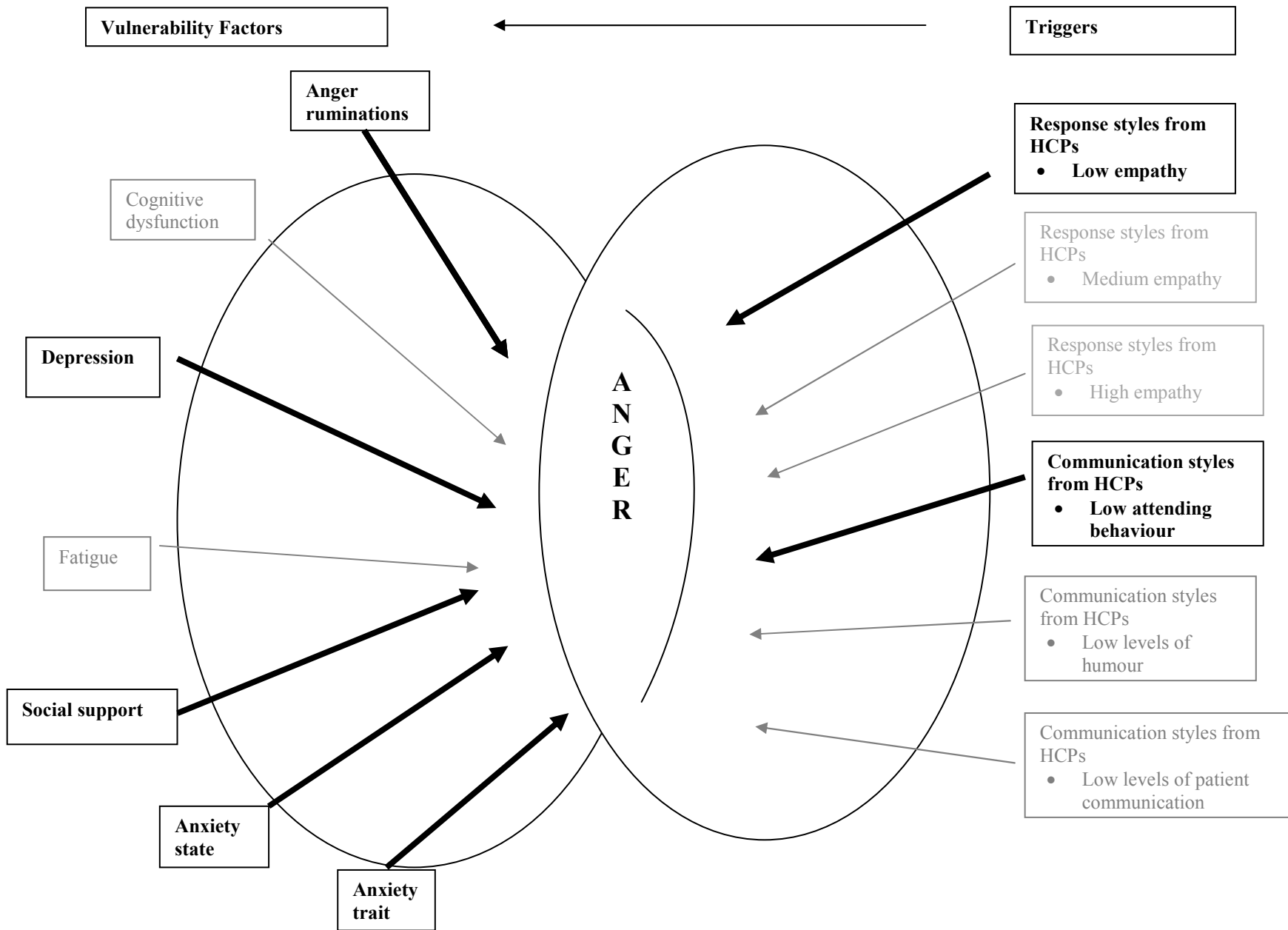


Figure 4.3
Model of Anger in MS Patients (4)

Key —▶ Significant (empirically investigated) relationship to anger in MS.
 —▶ Non significant (empirically investigated) relationship to anger in MS.
 NOTE: No causality implied.

4.9 Discussion

It was hypothesised that communication styles which were characterised as having low levels of patient centred communication, attending behaviour and humour would be associated with higher levels of anger state compared to high levels of patient centred communication, attending behaviour and humour. The first experimental hypothesis can be accepted. The second hypothesis predicted that low levels of patient centred communication style would be associated with triggering higher levels of anger compared to low levels of attending behaviour and low levels of communication. The second experimental hypothesis cannot be accepted. The third hypothesis predicted that HCPs would underestimate levels of anger arousal in MS patients. The third hypothesis can be accepted.

Significant main effects were found for communication styles. Communication styles which were characterised by high levels of patient centred communication, attending behaviour and humour were associated with significantly lower levels of anger ratings when compared to low levels of patient centred communication, attending behaviour and humour. Therefore, communication styles which had lower levels of patient centred style communication, physical displays of empathy and low levels of humour were rated by both professionals and patients as being associated with arousal of anger state.

Contrasts revealed that low levels of attending behaviour yielded significantly higher ratings of anger state compared to low humour and low patient centred communication styles, therefore the second experimental hypothesis cannot be accepted. High levels of attending behaviours characterise HCPs who display

empathetic body language and a readiness to interact with patients. The results suggest that HCPs who do not present as physically approachable could arouse high levels of anger state, more so than HCPs who display low patient centred communication or low levels of cheer. This can be linked to previous literature which notes that it is body language, tone of voice and facial expressions that are the most effective factors in communicating to patients when discussing emotional information (DiMatteo, Hays, & Prince, 1986). Thus, the absence of such physical behaviour (low attending behaviour) could arouse anger as patients deem communication to be ineffective. Affective behaviours such as the physical stance of empathy is related to patients' satisfaction (Lewis, 1994).

Interestingly, low levels of communication with patients were not identified as the factor which was associated with highest levels of anger state in MS patients compared to low levels of attending behaviour. Low levels of communication convey HCPs who explain what is needed or carry out tasks but do not necessarily attend to individual patients' subjective needs. In the context of previous literature it has been found that 'task orientated behaviour,' is valued by patients who have terminal illnesses as they rely on information and knowledge from HCPs and the ability of HCPs to take charge of their issues (Chaitchik, Kreitler, Shaked, & Schwartx, 1992). Thus, different communication styles are valued in different contexts by patients depending on what type of support they are seeking. The results from this study could reflect the awareness that both MS patients and HCPs realise that often health care professionals only have time to simply communicate what is needed in health care settings, especially if HCPs also need to carry on with a task which will help progress patients' situations. The communication style which is reflective of task centred

approaches needs to be investigated further to explore the acceptable levels or situations where such low levels of communication with patients do not provoke high levels of anger.

It can be concluded that it is communication styles where HCPs physically display low levels of the stance of empathy (attending behaviours) that are significantly associated with the highest levels of immediate anger. Clinically this may be important as while there may not always be time to deliver patient centred communication styles to each patient, HCPs who are able to show a 'readiness' to communicate with patients and physically display the stance of being able to support MS patients could keep immediate levels of anger low in MS patients.

In the context of background literature, this study revealed that health professionals and MS patients were aware that communication styles affect MS patients' levels of anger. Davis (1991) found that health care professionals' attitudes were associated with levels of violence and anger in psychiatric patients. This study expands this research into the MS population. Past research suggested that level of communication is essential to general nursing care quality (Oermann et al., 2000). The results of this study found that both MS patients and HCPs identified that nursing styles could trigger anger.

A significant main effect was found for group indicating that MS patients rated vignettes as provoking significantly higher levels of anger state than HCPs. This suggests that HCPs significantly underestimated the levels of anger provoked in MS patients in relation to communication styles. MS patients' ratings may reflect their

ability to empathise more strongly with the patients in the vignettes as they themselves may have been in similar situations. HCPs may have been less able to empathise as they may not have personally experienced such situations as patients. HCPs may have experienced and viewed this situation as an observer, consequently such vignettes may have inspired lesser levels of anger in HCPs. As mentioned in section 3.9 it has been noted that healthy individuals tend to value different aspects of communication styles (Friis et al., 2003), which could reflect the differences in anger ratings in this study. Past literature has reported that physicians describe the need to spend little time on communication (Manojlovich & Antonakos, 2008). This could also extend to health care professionals in MS, thus partly explaining different ratings of communication styles compared to MS patients. Additionally HCPs may have more knowledge and sympathy about constraints HCPs face in the vignette situations which may have affected their anger ratings.

In terms of theoretical models of anger these data add to the literature which suggests that situational factors contribute to the arousal of anger (Anderson & Carnagey, 2004). Specifically this study highlights that communication styles in the context of clinical settings can provoke the arousal of anger. Additionally in terms of the Anger Avoidance Model of Anger (Gardner & Moore, 2008) it could be theorised that communication styles with HCPs which provoke anger could lead to hostile anticipation, that is, patients then scan the environment for other potential anger provoking events, leading to anger expression.

4.9.1 Strengths and Limitations

A strength of this study is that it is the first attempt to empirically explore both HCPs' and MS patients' perceptions of communication styles in MS populations. In regards to the anger model proposed (see figure 4.3) it also allows for the identification of other factors which could contribute to anger levels in MS patients.

As these results were able to replicate and provide evidence for previous research on communications styles, a strength of this study is that it provides evidence that vignettes are an effective way of portraying real life communication styles between HCPs and patients. The vignettes in this study were also validated by an independent panel of graduate health professional raters.

Limitations of the study must be noted. While every effort was made to ensure that vignettes were created to be distinguished by a markedly higher or lower score on its defining dimension in comparison to the other vignettes, this was not well achieved. Even though judges rated each vignette to portray the target constructs, on closer inspection it was found that often the target constructs that a vignette was meant to portray were rated similarly to other constructs. For example the mean for the low humour vignette in representing low humour was 3.0 but the mean for this vignette in representing attending behaviour is 3.1. Therefore, it could be argued that there was not a clear distinction between low humour and low attending behaviour. Similarly the low attending vignette was rated lower on all dimensions in comparison to the low humour vignette, therefore even though significant differences were found between the low attending behaviour vignette and the low humour vignette, it may be that it was not the low attending dimension on the low attending vignette that accounted for

the significant differences. The problem may be that low levels of humour would probably coincide with low levels of attending behaviour in real life and it would be hard to tease these constructs apart in vignettes.

Other limitations of this study include that vignettes may not have been able to authentically portray the communication styles. Attending behaviours for example are not only communicated verbally but also physically. While independent judges did rate these vignettes as portraying these styles, it may still have been difficult to describe fully and precisely the communication styles. Thus consequently participants may not have fully grasped the communication styles. If this study was replicated it would be interesting to see if the same results were obtained by using role-plays.

The scenarios were scripted with the help of clinical experts to reflect genuine scenarios that MS patients may face. Therefore MS patients may have been able to identify more closely with the vignettes compared to HCPs, consequently affecting their anger ratings. HCPs may have observed these situations previously but only as a bystander, which could affect their ratings of the vignettes and their ability to rate the vignettes as if they were the actual MS patient in the scenarios.

Additionally the length of vignettes were not controlled in this study. Thus, it could be that the length of vignettes could have affected results. Future studies should consider keeping the vignettes to a similar length. It was also observed that from the six vignettes administered at least two of the vignettes contained evaluative responses about the patient. For example vignette 1 had the sentence 'x (patient) was pleased' in response to the communication style elicited by the HCP and vignette 3 had the

sentence 'x (patient) was grateful' in response to the communication style elicited by the HCP. These responses could have biased participants' responses. Future studies need to ensure that such statements are removed.

As with study two; some participants took part in this in their own time without the researcher present. Therefore it is not known under which circumstances the vignettes were filled in, i.e. if it was a noisy environment. This could have biased responses and the reliability of the data gathered.

As with study two, limitations in the sample due to gender and exclusion of a healthy control group must also be considered. The participants in this study had also taken part in study two, thus it is not known how much the exposure to the other vignettes would have primed their responses to this study.

Additionally participants could have been eliciting demand characteristics and only provided answers that they thought they should. Additionally, it must be highlighted that the quantity of MS participants in this sample was 15 participants below the recommended threshold estimated by the power calculation (see section 4.2.4). It is recommended that future research replicates this study with a larger sample size.

MS patient anger was only investigated in the context of health care settings. Therefore it is unknown if anger in community and in particular home settings would be triggered by similar communication styles delivered by non-health care professionals. It could be the case that MS patients might be more or less tolerant of spouse's behaviour and communication styles.

Despite these limitations, it can be concluded that both HCPs and MS patients identified communication styles which attended to individual patient experiences, conveyed physical stances of empathy and receptive body language and communication styles which were high in empathy, as keeping anger state in MS patients to a minimum. Group differences indicated that MS patients' anger ratings were always higher than HCPs' anger ratings of each communication style.

Further research could investigate communication styles in more depth, by creating graded levels of each communication style (not just high and low). Additionally the effect of culture could be investigated. The sample of participants in this study were all British born. Studies indicate that communication styles can be culturally influenced. In Western cultures, it is accepted that emotions and feelings are verbalised and shared between HCPs and patients. However, in some Asian cultures it is not culturally accepted to disclose personal and emotional feelings with HCPs (Takayama, Yamazakia, & Katsumatab, 2001). Future studies could look at the association between which communication styles participants of different ethnic backgrounds view as appropriate and the resulting effect on levels of anger. Studies could investigate if similar results are found if the vignettes detailed interactions in the community rather than in healthcare settings. Research could also investigate if anger in different subtypes of MS is aroused by the same communication styles.

Chapter Five: Study 4- HCPs' Perceptions of MS Patient Anger and Professionals' anger

5.1 Summary of Study 4

The quantitative studies, one, two and three investigated vulnerability factors and environmental triggers which could contribute to MS patients' levels of anger. The nature of study four was exploratory, aimed at gathering richer data on HCPs' perspectives on MS patients' levels of anger. Such data would help to assess whether HCPs and MS patients identify similar triggers which could be possibly associated with MS patients' levels of anger. This is important to study given that HCPs have long therapeutic relationships with MS patients, therefore a joint understanding of what could possibly trigger anger in MS patients could help to manage MS patient anger clinically.

Another aim of study four was to gather data on HCPs' perceptions of their anger experienced in context of clinical settings. Past literature has not focused on professionals' anger, rather it has focused on HCPs' reaction to patients' anger, e.g. it has been found that HCPs manage psychiatric inpatients levels of aggression and anger by using restraint (Lancee et al., 1995). Less research has focused on the anger experienced by professionals' and the impact that this may have on their professional abilities and personal sense of self worth. A study with oncology patients reported that higher levels of emotional exhaustion experienced by HCPs were associated with high levels of HCPs' anger in clinical settings (Muscatello et al., 2006). Such exhaustion has been linked to absenteeism in HCPs (Vicenta & Santiago, 2007) and it is a key factor in quality of care (Manzano & Ayala, 2012). Additionally another study has found that HCPs' perceptions of levels of anger in their fellow colleagues and

patients in psychiatric settings is associated with the type of nursing style that they use (De Benedictis et al., 2011). Specifically in MS, 92% of HCPs in a pilot study reported that they had experienced anger from MS patients 'quite often' which could lead to the arousal of their own anger (D. Langdon, personal communication, February 25th, 2006). This study will continue to explore this under researched area.

A qualitative approach, using structured questionnaires, was used to gather data. Structured questionnaires were used in studies four and five mainly due to the way in which data was gathered. As questionnaires were sent to participants in the post (see section 5.2) it was felt that this was the best way to ensure that a large quantity of participants would return questionnaires. The researcher did not have the opportunity to actually interview HCPs. Additionally, as data were primarily gathered with the intention of complementing studies one, two and three, it was felt that specific questions should be asked. HCPs were asked to provide any extra comments on the topic at the end of the questionnaire, which would give them the opportunity to respond more openly.

Qualitative methods are widely used in the domain of psychology (Roulston, 2001) as they provide 'real life' information on factors which otherwise would be hard to obtain (Agampodi, Agampodi, & Piyaseeli, 2008). Qualitative methods are a suitable way to investigate anger as it allows researchers to explore the many dimensions of the complex emotion, rather than solely relying on quantitative methods, which may limit the researchers' view (Mason, 2006). In conjunction with the quantitative methods presented, qualitative methods will allow other concepts that have not been studied to emerge, adding richness to a sparsely investigated field.

Content Analysis

There are many types of qualitative analysis including discourse, narrative, interpretive phenomenological, thematic and content analysis. Figure 5.1 depicts which main qualitative approaches are used to analyse different types of data (Leech & Onwuegbuzie, 2008).

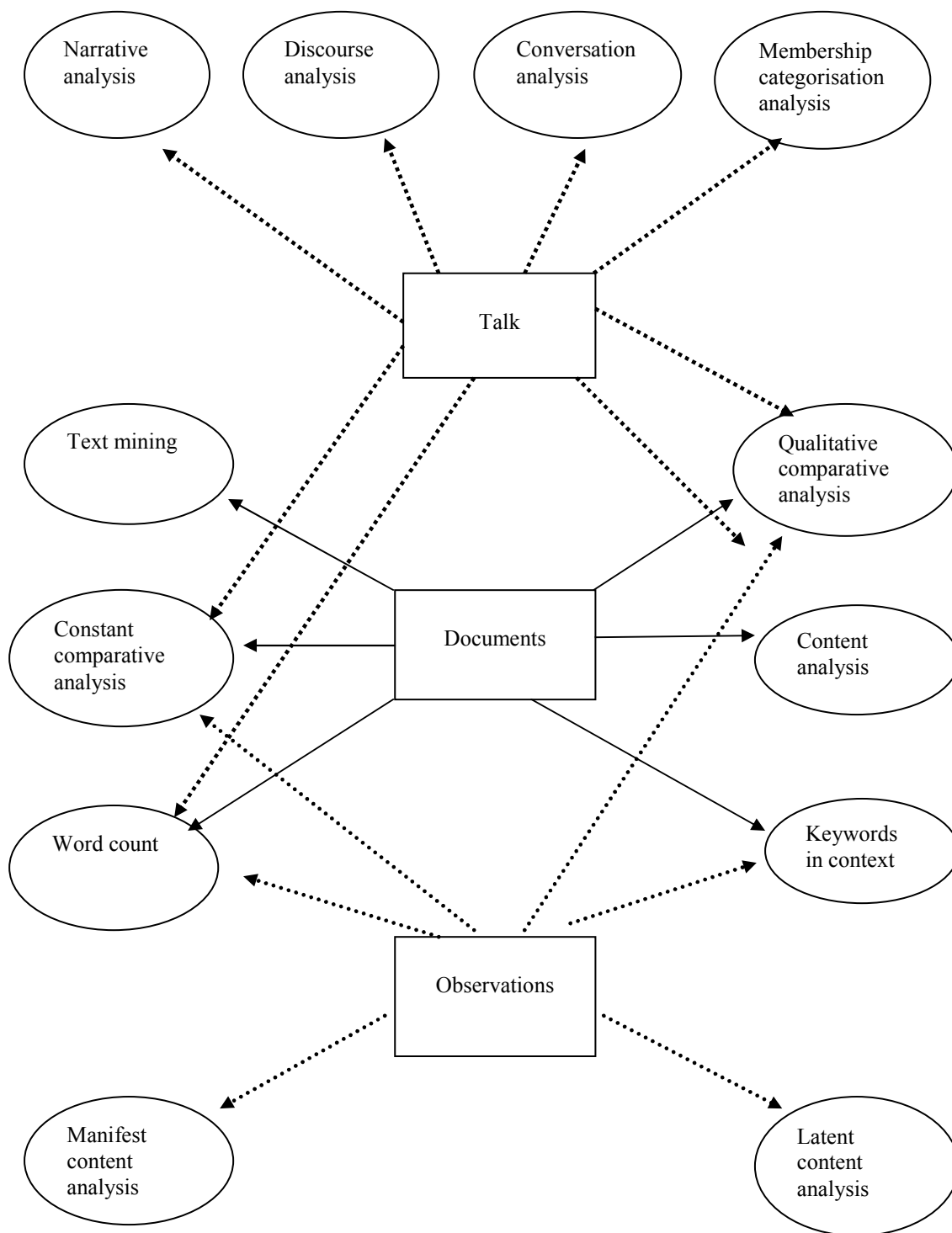


Figure 5.1

Organisation of types of analysis by type of data (Leech & Onwuegbuzie, 2008).

Following this diagram it was decided that content analysis was the most suitable method to analyse the qualitative data in this study. Content analysis has been defined as ‘objective, systematic and quantitative description of the manifest content of communication’ (Berelson, 1952). Content analysis allows data to be described in a set of categories and permits researchers to count the frequency of data in each category. These frequencies allow researchers to determine which concepts are cited most and least throughout the data (Leech & Onwuegbuzie, 2008). Thus, content analysis comprises both a mechanical (frequencies) and an interpretative component (Krippendorff, 1980) and is a way in which qualitative data can be quantified.

To investigate HCPs’ views of MS patients’ anger and anger experienced by HCPs’, the Reflective Experience Survey was used. The survey asked participants to answer multiple choice questions and answer structured questions about their perceptions of possible factors associated with MS patient anger and their own anger experienced professionally.

The main research questions for this study were:

- What triggers and consequences will HCPs identify as being associated with MS patient anger and their own anger? Will these triggers and consequences be similar to those identified by MS patients and HCPs from past literature?
- What skills and training will HCPs identify which could decrease MS patients’ anger and their own anger?

5.1.1 Design for Study Four

This study adopted a qualitative approach design. Seventy four HCPs consented and completed this study (see section 5.2). HCPs were sent a Reflective Experience Survey in the post which consisted of two parts. The first part consisted of 10 multiple choice answer

questions which asked participants about their own anger that they experienced at work and MS patient anger. The second part consisted of five questions which asked HCPs about their personal experiences of anger from MS patients (see section 5.2). HCPs were asked to provide as much information as possible when answering the questions. The Reflective Experience Survey was constructed by the main researcher and Professor D. Langdon and part one of the survey had been used in a previous workshop on anger with specialist MS HCPs (D. Langdon, personal communication, February 25, 2006).

Data were analysed using a content analysis to categorise data and provide a frequency count of the data in each category (see section 5.2). The number of HCPs contributing to each category was given alongside quotations illustrating that category. At each stage of the analysis process an independent researcher with expertise in qualitative methods carried out an audit trail and assessed whether AP's judgements were sound. Quality measures were considered to judge whether credibility, dependability and transferability had been achieved (see section 5.5.1.).

5.2 Participants, Procedures and Method

Three hundred and seventy five HCPs were contacted and 74 HCPs consented and completed the study, which were the same MS health care professionals who took part in study two (see sections 3.2.5 and 3.7.1; all information sheets and consent forms can be found in appendix 2). The information sheets explained that direct quotes may be used in this study. Inclusion and exclusion criteria for health care professionals were identical to studies two and three (see section 3.2.2). Full ethical approval was given by the East Kent Research Ethics Committee and Royal Holloway Ethics Committee. The Reflective Experience Survey was

mailed to HCPs along with the vignette packs for studies two and three (see section 3.3), thus questionnaires were filled in without the presence of the researcher.

The Reflective Experience Survey

The Reflective Experience Survey was constructed by Professor D. Langdon and Anisha Paddam and consisted of two parts. Part one consisted of ten multiple choice questions. The multiple choice questions had been used in a previous workshop on anger with specialist MS HCPs (D. Langdon, personal communication, February 25, 2006). The first five questions asked HCPs about their own experiences of anger experienced at work. HCPs were asked to respond to these questions by choosing from a list of predetermined answers (see appendix 6). The questions were:

- 1) *How often do you find yourself angry at work?*
- 2) *What makes you angry (rank in order of importance)?*
- 3) *Do you feel that you can manage your anger and are adequately supported?*
- 4) *Have you experienced displays of anger from other professionals?*
- 5) *Do you feel that you can manage their (professionals') anger and are adequately supported?*

The remaining five questions asked HCPs about MS patient anger. They were asked to respond by choosing an answer from a list of predetermined answers (see appendix 6):

- 6) *Have you experienced displays of anger from patients?*
- 7) *What makes them angry (rank in order of importance)?*
- 8) *How much of your patient contact time is spent managing patient anger?*
- 9) *Does patient anger interfere with (rank in order of importance)?*
- 10) *Do you feel that you can manage their anger and are adequately supported?*

The answers were scored by summing up responses to each predetermined answer and converting them to percentages. For questions two, seven and nine, where participants were asked to rank multiple choice answers in order of importance, responses which were ranked as number one by each participant were summed, converted to percentages and given in the results section (see table 5.2).

The second part of the questionnaire consisted of five structured questions asking HCPs about their personal experiences of anger from MS patients. The questions were:

- 1) *From your own experiences, please highlight the types of 'nursing styles' you have used when dealing with patients, which have evoked an angry response from a patient.*
- 2) *In the situation above, do you feel that there was anything you could have done to stop the anger arising from the patient?*
- 3) *Which situation / interactions cause you to have anger towards a patient?*
- 4) *Do you feel you have sufficient training and awareness of why anger arises in MS patients and health care professionals like yourself?*
- 5) *If not, what sorts of training would be helpful?*

HCPs were asked to provide as much information as possible in response to these questions. Responses were analysed using content analysis following the steps below. The same steps were used to analyse data in chapter six (see section 6.2).

Stage One- Transcribing the Data

The first stage of analysis involves familiarising oneself with the data and understanding the depth and breadth of its content (Braun & Clarke, 2006). This was achieved in this study by

preparing and transcribing the data by re-reading and entering data onto an excel spreadsheet. If participants left questions blank these were not incorporated into the analysis.

Stage Two- Unit of Analysis

The next stage is the selection of the ‘unit of analysis’ which are the parts of information which will be assigned to categories in later analysis. As the data collected here was in the form of small quotations or slightly longer sentences, each sentence were the units of analysis.

Stage Three- Coding the Data

The unit of analysis provides the basis for developing a coding system. A coding unit refers to the constellation of words or statements that relate to the same central meaning (Baxter, 1991) and allows researchers to simplify complex data so as to describe underlying meanings. It is the first stage where data are given a structure (Howitt & Cramer, 2005). Codes can be pre-determined where participants only respond using a list of pre-set alternative replies (e.g. multiple choice questionnaires). Such pre-coding limits the data collected and can be biased by researchers’ personal objectives. Although codes in this study were not pre-determined the nature of the questions asked, meant that participants answers were inevitably primed e.g. ‘do you feel you have sufficient training and awareness of why anger arises in MS patients and health care professionals like yourself ?’ Therefore the resulting codes that emerged from data were essentially deductive.

The units of analysis were coded so that units of analysis which were related to similar concepts had the same codes. Some parts of units had more than one central meaning and thus were assigned two codes. This was decided by the main researcher in collaboration with

Dr Eatough, who was an independent researcher who assessed whether AP's judgements were sound. All data were coded.

Stage four-Creating Categories

Once units of analysis have been coded, categories are formed to describe codes of a similar nature. A category is a group of content that shares commonality (Krippendorff, 1980). For example codes in a set of data may have codes for sexist and racist comments. These codes can be grouped together into a category called 'discrimination.' Krippendorff explains that categories must be exhaustive and mutually exclusive; therefore no data related to the purpose should be excluded due to lack of a suitable category. Additionally data should not fall between two categories or fit into more than one. Responses in this study were only coded into one category where possible, however if a participant gave more than one answer for example, "*Listening to what the client wants. Client centred practice.*" (62, q2) then this would be coded as fitting into the category of listening to patients and using client centred approaches. This was only the case on two occasions and have been highlighted in the results section by an asterisks (see table 5.3). All codes were placed into categories and no data was excluded. Like codes, categories can be pre-determined. Categories in this study were essentially pre-determined and deductive due to the structured questions which were asked, e.g. 'please highlight the types of nursing styles you have used when dealing with patients, which have evoked an angry response.' Such questions inevitably primed the answers given by participants. Once the main categories were formulated they were divided into sub components to help to clarify and summarise the complex data that was engulfed by the main category (see table 5.1 for an example). The sub components were decided by the main researcher and Dr Eatough.

Stage Five- Frequency Counts and Interpretation.

Once categories and components were defined, the number of HCPs who endorsed each category were counted, providing a summary of the data. The number of HCPs contributing to each category is given alongside quotations illustrating that category.

Table 5.1

An example of Coding and Categorisation

Unit of analysis	Codes	Main Category	Components of Main Category
“Dealing with difficult situations training.”	Generic training linked to anger	Formal training	1) Anger training in non MS patient groups
“Yes we have good training on anger management.”	Generic training linked to anger	Formal training	
Yes course provided by hospital regarding anger in MS patients.”	Specific training in MS	Formal training	2) Anger training specific to MS groups

At each stage an independent researcher with expertise in qualitative methods carried out an audit trail and assessed whether AP’s judgements were sound. The independent researcher was not blind to AP’s judgements. If there were discrepancies between the researchers on how data should be coded or categorised this was resolved by in-depth discussion. If discrepancies were not resolved after this a third independent researcher would be asked for their opinion (Professor D. Langdon) and their opinion would be taken as final. However the former or latter situations did not occur and Dr Eatough and AP agreed on all judgements made.

The results section reports data from part one of the reflective experience survey in a tabular form. Part two of the survey is reported in forms of summary tables for each category and alongside a narrative.

5.3 Results

5.3.1 Part One of Reflective Experience Survey

Responses were quantified for each answer of the reflective experience survey (see table 5.2).

Table 5.2
HCP's Responses to Part 1 of Reflective Experience Survey

Question	Possible Responses	% of Responses
How often do you find yourself feeling angry at work?	a) Hardly ever	66%
	b) Quite often	27%
	c) Frequently	7%
	d) Almost all the time	0%
What makes you angry? (rank in order of importance)	Ranked first	
	a) Repetitive questions by patients	15%
	b) Other patient demands	1%
	c) Carer demands	1%
	d) Other professionals	11%
	e) Limited resources	38%
Do you feel that you can manage your anger and are adequately supported?	f) NHS polices/admin	34%
	a) Almost all the time	83%
	b) Frequently	12%
	c) Quite often	4%
Have you experienced displays of anger from other health professionals?	d) Hardly ever	1%
	a) Hardly ever	71%
	b) Quite often	26%
	c) Frequently	3%
Do you feel that you can manage their anger and are adequately supported?	d) Almost all the time	0%
	a) Almost all the time	71%
	b) Frequently	15%
	c) Quite often	7%
Have you experienced displays of anger from patients?	d) Hardly ever	7%
	a) Hardly ever	42%
	b) Quite often	47%
	c) Frequently	11%
What makes them angry? (rank in order of importance)	d) Almost all the time	0%
	Ranked first	
	a) Your actions	14%
	b) Actions from other professionals	10%
	c) Limited healthcare resources	22%
	d) Physical restrictions of MS	44%
	e) Low mood increasing their irritability	4%
f) Cognitive impairment leading to disinhibition	5%	
How much of your patient contact time is spent	g) Financial pressures	1%
	a) Less than a quarter	88%

managing patient anger?	b) Less than a half	8%
	c) Three quarters	0%
	d) Almost all	0%
	e) 1-2 hours a week	4%
Does patient anger interfere with.... (rank in order of importance)	Ranked first	
	a) Communication with you	18%
	b) Access to other professionals	8%
	c) Appropriate use of medication	0%
	d) Self management of MS symptoms	26%
	e) Patient's family relationships	48%
Do you feel that you can manage their anger and are adequately supported?	a) Almost all the time	68%
	b) Frequently	18%
	c) Quite often	8%
	d) Hardly ever	6%

When HCPs were asked about their anger experienced at work, the majority of HCPs (66%) responded that they were 'hardly ever' angry at work. It is interesting to note that by far, the major emotional stress on professionals reportedly comes from institutional factors, whilst clinical and patient factors contribute only a relatively small stress (see table 5.2). Forty seven percent of HCPs reported that they had experienced anger from MS patients 'quite often' and attributed this anger from patients to: physical restrictions of MS, limited healthcare resources, actions of professionals and low mood. The majority of HCPs (88%) estimated that they spent 'less than a quarter of their working time' managing patient anger and that if they did encounter anger from patients, they mostly felt adequately supported in dealing with anger 'almost all the time'.

5.3.2 Results for Reflective Experience Survey Part Two

Content analysis revealed three main categories that HCPs identified could cause MS patients and themselves to have high levels of anger as well as identifying possible training that could decrease anger from both patients and themselves.

The main categories were:

- Communication
- Patient behaviours
- Training

5.3.3 Communication

Communication was acknowledged as having the power to give rise to or prevent patient anger. This final category was divided into four components:

- Effective communication.
- Non effective communication.
- Telling patients facts and ‘truths.’
- Failure to decrease anger.

Each of these components had sub components. Table 5.3 gives the number of HCPs who endorsed each component, followed by a narrative explanation.

Table 5.3

Number of HCPs endorsing components and sub components of communication category

Components and sub components of Communication Category	Number of HCPs contributing to each category (% of total sample)	Example Quotations
Effective communication decreases anger	44* (59%)	
Listening to verbal and non verbal cues.	15* (20%)	<i>“Not listened to all cues/non-verbal cues and therefore misinterpreted the situation.” (45,q3).</i>
Giving time to patients	10 (14%)	<i>“Taking more time to talk things through.” (66,q2).</i>
Client centred nursing styles	20* (27%)	<i>“Being more empathetic to their situation.” (66,q2).</i>
Non effective communication increases anger	40** (54%)	
Dismissive attitudes	16**(22%)	<i>“Being patronising.” (26,q1). “Being dismissive and being distracted.” (49,q1).</i>
Humour	2 (3%)	<i>“Over cheerfulness, (can lead to anger).” (33,q1).</i>
Clarity of information	10 (14%)	<i>“When I haven’t been clear with my reasoning.” (32,q1). “Use of professional/medical knowledge to exclude the patient.” (2, q2)</i>
Not listening	13**(18%)	<i>“Not listening properly.” (8,q1).</i>
Telling patients facts and ‘truth’s increases	34 (46%)	

anger

Initial diagnosis	5 (7%)	<i>"When being told diagnosis." (36,q1).</i>
Symptoms/functional disabilities	13(18%)	<i>"Patients coming to terms with loss of function." (20,q1). "Discovering their disabilities." (5,q1).</i>
Being honest/blunt	10 (14%)	<i>"Sometimes when being very honest." (59,q1) "Being too blunt." (22,q1).</i>
Handling expectations	6 (8%)	<i>"Better handling expectations." (26,q2).</i>
Failure to decrease anger	18 (24%)	
HCP's cannot decrease anger	18 (24%)	<i>"No, response is normal and one of loss." (20,q2)</i>

* A HCP gave two responses which fell under two of the subcomponents, 'listening to verbal and non verbal cues' and 'client centred nursing styles'. ** A HCP gave two responses which fell under the two subcomponents 'dismissive attitudes' and 'not listening.'

5.3.3.1 Effective communication

A large number of HCPs (45) recognised effective communication, such as being attentive to patients, as being preventive of patient anger and believed it was an essential aspect of the patient/HCP interaction.

"Effective communication skills and attention to detail often prevents situations arising where anger is a patient's response."(49,q2).

Fifteen HCPs specifically identified listening to both verbal and non verbal cues as a vital aspect of effective communication. Listening allows professionals to gain an insight into experiences from the patient's point of view. Additionally, non verbal cues could serve as an important communication tool in MS populations, where verbal communication may be affected.

A minority of HCPs (10) indicated that giving patients sufficient time contributed to effective communication and kept anger low. Specifically, they suggested that time allowed patients to process information thoroughly and express their personal concerns. Twenty HCPs also identified nursing styles which are tailored to individuals and give patients a choice in their

care as aiding reduction in anger; possibly such styles are empathetic to the individual's situation.

5.3.3.2 Non Effective Communication

Unsurprisingly, non-effective communication was identified by 41 HCPs as having the power to give rise to patient anger. Some HCPs (16) reported that patronising and dismissive attitudes were factors in non-effective communication. Such attitudes could convey to patients that they are unimportant which could hinder patients from approaching HCPs and accessing health care. A very small minority of HCPs (2) commented that the use of humour could provoke anger in patients, possibly as these HCPs may be perceived as mocking:

“I tend to joke around a lot with patients to lighten their mood. This is mostly received very well but just occasionally I have annoyed patients by doing this.” (63,q1).

Ten HCPs identified that clarity of information and use of complex language contributes to non-effective communication and provokes anger. Lack of clarity and medical jargon compounded with the cognitive deficits MS patients could have, could cause confusion for patients. Additionally, 13 HCPs identified that not listening to patients' verbal or non-verbal cues contributes to ineffective communication. This could trigger anger as HCPs fail to respond to patients' concerns.

5.3.3.3 Communicating Facts Truthfully

Quite a few HCPs (34) reported that having to communicate painful information and 'truths' to patients could contribute to anger. Five HCPs specifically commented that having to communicate the initial diagnosis could contribute to anger, as patients may not be ready to accept the diagnosis:

“Explaining a situation truthfully when a client could not ‘hear’ the truth.” (72,q1).

Additionally, 13 HCPs identified that communicating deterioration in physical abilities could arouse anger in patients.

HCPs acknowledged that it is not just communicating facts which could cause anger but the style in which it is done. While some patients may value a professional who tells them the diagnosis and symptoms truthfully, other patients may find this honesty too hard to cope with. Some HCPs (10) acknowledged that being honest and blunt with patients about the unpredictable nature of the disease could contribute to high levels of patient anger. A minority of HCPs (6) however, reported that anger levels could be decreased if patient expectations are handled adequately.

5.3.3.4 Failure to Decrease Anger

Interestingly, approximately a quarter of HCPs (18) felt that there was nothing that they could do to decrease anger in MS patients. Such HCPs reported that they felt that anger was a natural emotion that patients were using to vent their frustration:

“I think it’s part of a grieving process at diagnosis and I feel we have to expect and empathise at this difficult time.”(4, q2).

While only a small number of HCPs commented on this, it is pertinent for a study on anger in MS to acknowledge this and consider that regardless of recommendations made in an attempt to reduced anger in MS patients, anger may still be prevalent as it is a natural emotion. Additionally, these comments suggest that although HCPs encounter patient anger, they do not necessarily view this anger as a ‘problem’ which needs to be reduced. This could be due to the subtle forms of anger that MS patients are typically observed to display. If expressed anger was of a more violent form this may not be the case.

5.3.4 Patients' Behaviour

Patient behaviours were identified as possibly contributing to the arousal of HCPs' anger.

This category had three components:

- Verbal abuse
- Demanding
- Non-compliance

Each of these had sub components. Table 5.4 gives the number of HCPs who contributed to each component, followed by a narrative explanation.

Table 5.4

Number of HCPs endorsing components and sub components of patients behaviours

Components and Sub Components of Patient Behaviour Category	Number of HCPs contributing to each category (% of total sample)	Example Quotations
Verbal abuse	20 (27%)	
Aggression	6 (8%)	<i>“Are persistently verbally abusive.” (9,q3).</i>
Discrimination	2 (3%)	<i>“Sexist comments annoys me.” (2,q3). “Racism.” (26,q3).</i>
Rudeness	12 (16%)	<i>“Inappropriate rudeness to another member of staff.” (15,q3).</i>
Demanding patients	17 (23%)	
Unavailable services	10 (14%)	<i>“Making demands and demanding a service for which they do not have an assessed need.” (23,q3)</i>
Unrealistic expectations	6 (8%)	<i>“Unrealistic expectations. Inflexibility, being unwilling to try solutions to a problem.” (23,q3)</i>
Cognitive difficulties	1(1%)	<i>“As cognitive impairment is one of the symptoms of MS it can make the patient unrealistic about their situation.” (42,q3).</i>
Non compliance	32 (43%)	
DNA	10 (14%)	<i>“When they do not keep appointments.” (20,q3).</i>
Treatment/advice	19 (26%)	<i>“Patients do not comply with agreed treatment.” (29,q3).</i>
Repetitive demands	3 (4%)	<i>“Continually fail to comply with advice but continually request appointments for the same issues.” (18,q3).</i>

5.3.4.1 Verbal abuse from Patients

Approximately a quarter of HCPs (20) reported that verbal abuse from patients gave rise to their anger. Six HCPs described that verbal abuse could be displayed in terms of aggressive behaviour such as shouting and a minority of HCPs (2) indicated that verbal abuse could take the form of discrimination. Discriminatory comments could be perceived as derogatory and

as judging individuals on personal attributes rather than their professional competences. Such comments may be deeply hurtful possibly causing HCPs to become angry.

Patients who display rude behaviour were identified by 12 HCPs as potentially arousing their anger. Rudeness may result in patients not listening to HCPs advice or explanations:

“Clients who are rude do not listen to explanations, advice and do not appreciate knowledge and experience we have.” (1,q3).

Persistent rudeness could possibly, in the long term, cause HCP’s to have low self esteem as they may feel the remarks are personal, affecting their working morale and consequently have a negative effect on patients’ healthcare and their own health.

5.3.4.2. Demanding Patients

Some HCPs (17) reported that demanding patients aroused their anger when they demanded services or treatments which were out of their control. As HCPs are in frequent contact with patients, patients may ‘vent’ their frustrations about lack of resources towards HCPs. A minority of HCPs (6) reported that demanding patients who have unrealistic expectations can provoke their anger. They reported that high expectations may have a negative impact on patients self care as it may prevent patients from learning to adapt to their new situation.

One HCP suggested that possible cognitive difficulties could cause patients to be unrealistic:

“As cognitive impairment is one of the symptoms of MS it can make the patient unrealistic about their situation” (42,q3).

If this is the case, then HCPs should be mindful of such factors and help patients to acknowledge the unrealistic nature of their demands.

5.3.4.3 Non-Compliance

A number of HCPs (32) reported that attitudes of non-compliance potentially aroused anger. Ten HCPs reported that patients who do not comply with appointment times could contribute

to their levels of anger. Importantly, HCPs reported that it was patients who did not inform them of cancellations which provoked anger as it wasted resources.

Nineteen HCPs identified patients who do not comply with advice and treatment provoked their anger:

“Non compliance with medically/clinically important, process, then complaining when consequences ensue.” (14, qu3).

It is possible that not adhering to treatment or advice may cause patients to relapse more frequently. It may be difficult for HCPs to assess whether relapses are a response to this non-compliance, potentially causing frustration for HCPs and patients. Furthermore, resources are potentially wasted if patients are accepting deliveries of medication but not actually using them. A small number of HCPs (3) commented that patients who were repetitive in demands which could not be met further contributed to arousal of anger.

5.3.5 Training

In order to explore the skills that HCPs could draw on to manage anger in MS patients, HCPs were asked specific questions on training/skills.

Three main categories of training emerged:

- Formal training
- Personal experiences
- Useful training

Each of these had sub components. Table 5.5 gives the number of HCPs who contributed to each component followed by a narrative explanation.

Table 5.5

Number of HCPs endorsing components and subcomponents of training category

Components and Sub Components of Training Category	Number of HCPs contributing to each category (% of total sample)	Example Quotations
Formal training	54(73%)	
Anger/aggression training in non MS populations	30 (41%)	<i>"Dealing with difficult situations training." (30,q4).</i>
Anger training in MS patients	1(1%)	<i>"Yes course provided by hospital regarding anger in MS patients." (46,q4).</i>
No formal specific training	23(31%)	<i>"I have never been trained." (56,q4). "Can't think I have ever had any specific training" (70,q4).</i>
Personal experiences	17 (23%)	
Personal experiences in own life	11 (15%)	<i>"Experience has raised my awareness of areas likely to cause dissatisfaction." (23q4). "No- I have just based my understanding on my experience." (41,q4).</i>
Unnecessary to have formal training	6 (8%)	<i>I'm not sure this can be learnt." (64,q4).</i>
Useful training	42 (57%)	
Counselling skills	6 (8%)	<i>"Counselling and listening skills." (68,q5) "Listening to patients." (73,q5)</i>
Anger awareness/recognition/management	23 (31%)	<i>"To understand and have knowledge of anger management techniques." (44,q5).</i>
Patients perspective	5 (7%)	<i>"Information on a patient perspective." (27,q5).</i>
Ongoing training	5 (7%)	<i>"Updates are always beneficial." (39,q5).</i>
Expert in the team	3 (4%)	<i>"Having a psychologist available within team." (26,q5).</i>

5.3.5.1 Formal Training

A number of HCPs (30) identified they had some type of formal training in the area of anger. However, such training was in the form of generic anger management or violence courses not tailored specifically towards understanding anger in MS populations:

“I have had one training day on violence and aggression. This was very helpful at the time but was many years ago.”(72, q4).

Some HCPs (23) identified that they had no specific skills or formal training in how to manage anger expression in MS patients. Surprisingly only one HCP reported having attended a specific formal training day on anger in MS. It must be mentioned that while only one HCP attended a specific course, it could be that other HCPs were offered such courses but were unable to attend. Thus, while anger is clinically observed as a prevalent emotion in MS patients, almost all HCPs questioned could not recall any specific formal training on the issue.

5.3.5.2 Personal Experiences

Several HCPs (17) reported that their ‘training’ in how to manage anger in MS populations came from past personal experiences and additionally years of professionally interacting with MS patients, patients from other populations or other personal experiences:

“Experience has raised my awareness of areas likely to cause dissatisfaction.” (23q4).

Self learning techniques and strategies that may aid in decreasing patient anger are highly important and useful. However, a problem may arise as patient anger and personal anger in the general population may be displayed and caused by differing factors (see study one). Therefore, HCPs may face situations at work where their personal training is inadequate. Interestingly a small minority of HCPs (6) commented that training in this area was unnecessary, as they believed that such skills could not be learnt. These HCPs essentially believed that MS patient anger is reduced using interpersonal skills like empathy:

“I am not sure that it is about training but has a large emphasis on treating people with dignity and respect. I’m not sure this can be learnt.” (64, q4).

5.3.5.3 Useful training

Over half of the HCPs (42) identified the need for training. Approximately a third (23) identified that generic anger management training would be useful. Seven HCPs felt that being taught counselling and listening skills would be useful as it would teach them how to cope with emotive situations and benefit their communication skills, consequently influencing anger in patients.

A smaller minority (5) highlighted the importance of training which emphasised the patient’s perspective:

*“Workshops with patient input in their views/opinions rather than purely professional skills.”
(57, qu5).*

Such training provides clinicians with holistic information, which could benefit patient/HCP interactions. Five HCPs reported ongoing training as beneficial to keep skills in line with current developments in the field. Additionally, three HCPs believed that having an expert in the team, like a psychologist, would help to manage patient anger and provide them with a point of contact when they needed immediate advice or supervision.

5.4 A Model of Anger

These qualitative findings can be placed into the Model of Anger in MS patients (see figure 5.3). HCPs indicated that it was HCP behaviours, specifically non-effective communication and communicating facts to patients, which could contribute to arousal of MS patient anger. These findings can be hypothetically placed into the model as they have not been tested empirically.

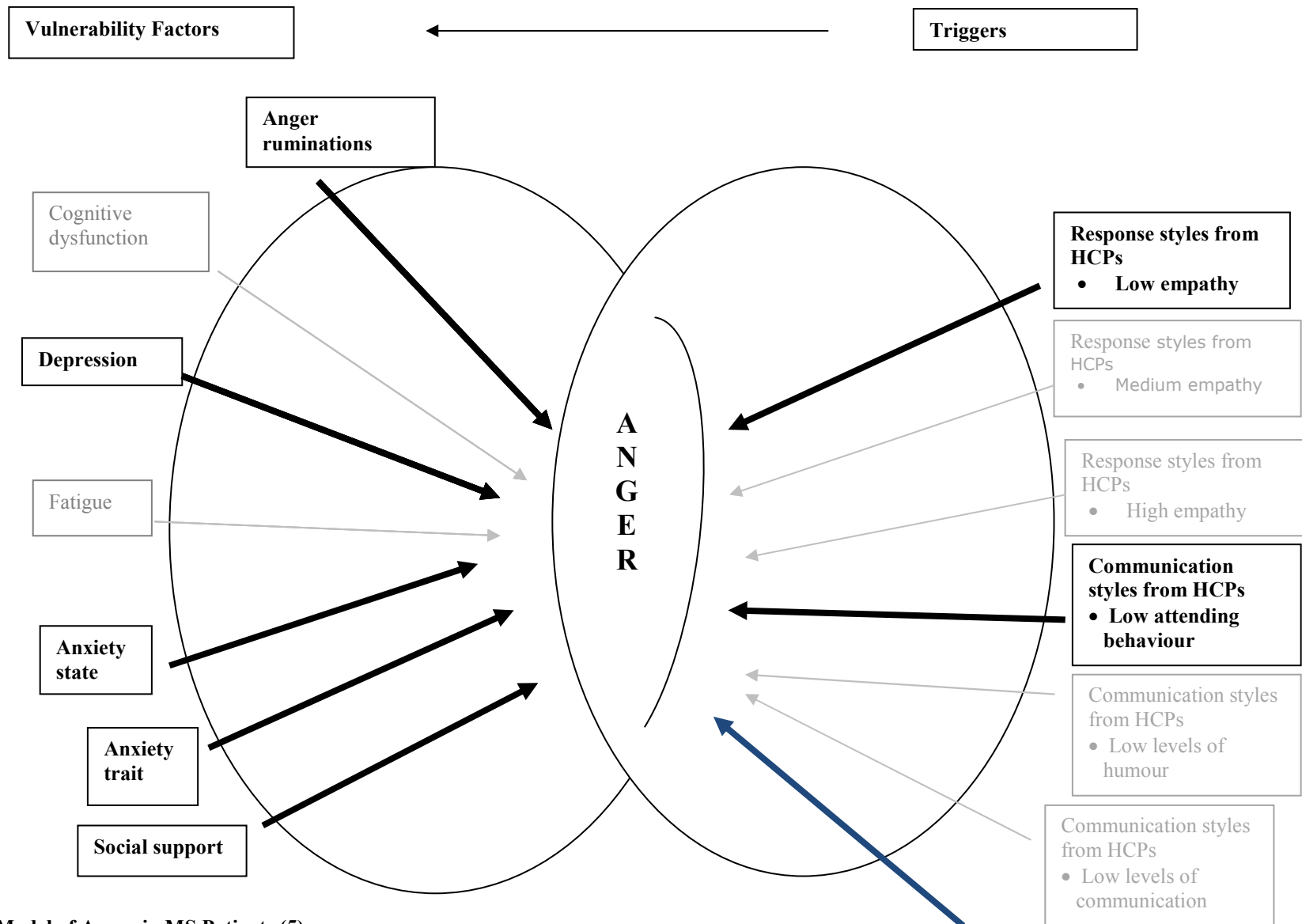


Figure 5.2 Model of Anger in MS Patients (5)

Key → Significant (empirically investigated) relationships to anger in MS.
 → Non significant (empirically investigated) possible relationships to anger in MS.

→ Qualitative associated factors with anger in MS (not empirically investigated).

NOTE: Causality not implied.

5.5 Discussion

The Reflective Experience Survey was created to explore HCPs' perceptions of anger expression in MS patients and to complement the quantitative responses that have been obtained from studies one, two and three. Primarily the data in this study found MS patients' anger to be relatively infrequent and not very disturbing or demanding on HCP's time from HCP's perspectives. In relation to past literature the data does not support studies which have found that HCPs experience frequent levels of anger from MS patients (D. Langdon, personal communication, February 25th, 2006). The data additionally highlighted that possible conclusions about possible triggers and modulators of HCP's anger need to take into account that HCPs do not often experience anger at work and that MS patients do not often behave in angry or aggressive ways towards HCPs.

The majority of responses in part one of the survey highlighted that HCPs believed that it was the physical constraints of MS and limited healthcare resources that were most likely to trigger anger from MS patients. Only a minority of participants commented that it was their actions and actions from other HCPs that influenced anger. This is in accordance with past literature which suggests that HCPs report that it is illness factors which are related to patient aggression (Duxbury, 2002). However, as we did not ask HCPs to specifically comment on this, it is speculative.

In part two of the survey, HCPs identified non-effective communication styles (defined as dismissive attitudes, use of medical jargon and inadequate listening) as being a possible factor in contributing to MS patient anger. These results provide further evidence for the importance of expert nurse/patient relationships, where trained specialist MS nurses can empower improvements in the patient's mood, coping and confidence (Kirker, Young, &

Warlow, 1995). Level of communication has previously been found to be the biggest complaint in patients with preventable problems (Elder et al., 2005). These results complement the results found in studies two and three where HCPs and patients identified that it was response and communication styles which attended to individual needs which were less likely to provoke anger. It must however be noted that due to the nature of the questions in this study such responses could have been primed (see section 5.5.2).

Humour was interestingly identified as a negative communication style in part 2 of the reflective survey by 2 HCPs. McCabe (2004) reported the use of humour as a positive communication style as it helps to build a rapport and consequently decrease anger and negative emotions. It could be that humour is an emotion which polarises individuals. Either individuals appreciate humour or find it irritating. Additionally, humour is individual and up to personal taste. Thus, humour and cheerfulness demonstrated by HCPs could be viewed by some patients, as indicating that the HCPs do not take their situation seriously. Furthermore, false cheer could also be seen as pitying which could give rise to anger. Emotional recognition in MS patients has not been studied fully. However, MS patients do show affective disturbances (Kesselring & Klement, 2001). An empirical study has found that MS patients have significant impairments with emotional recognition which might be due to deficits in emotional processing (Krause et al., 2009). Thus, it could be that anger and other emotions such as humour should be viewed in the context of difficulties with emotional processing. It is beyond the scope of this study to investigate this notion further.

Less research has investigated possible reasons why HCPs become angry in clinical situations. The reflective experience survey has helped to shed light on this. Part one of the reflective experience survey identified that HCPs' anger was most likely to be aroused due to

limited NHS resources (34%), policies (38%) and repetitive questions from patients (15%). Thus, it is interesting to note that actually it is non-clinical aspects which cause most anger in HCPs. In part two of the survey, HCPs responded that it was abusive and demanding patients which aroused their anger. These responses provide further evidence for studies reporting that interacting with such patients can lead to anger. Taylor et al. (2005) found doctors who worked with mental health patients had emotional exhaustion, which arose from dealing with distressed, angry, demanding and blaming patients. Aggression and abuse could specifically arouse anger as it could lead to feelings of disempowerment, anxiety, depression and fearfulness, which has been found in social workers who work in clinical settings (Littlechild, 2002). Although it must be noted that only 1% of HCPs reported in part 1 of the Reflective Experience Survey that their anger experienced at work was due to patients; thus HCPs are unlikely to suffer from high levels of emotional exhaustion due to patients' levels of aroused anger.

The majority of HCPs reported that non-compliant patients played a part in the arousal of their anger. HCPs reported that they could become frustrated with such patients who demand resources or continuous medical input for the same symptom/condition for which they had not previously complied with treatment. Such demands could contribute to a heavy work load and past literature has found high caseloads to be reason for anger in a sample of HCPs who worked in NHS hospitals (Thomas, 2003).

Additionally, HCPs reported that demanding patients often had unrealistic expectations. However, one HCP did identify that this could be due to the neurological cognitive deficits that MS patients may have. Estimates have reported that up to 70% of MS patients have cognitive deficits during the course of their disease (Rao, 1997). Importantly 15–20% of individuals with MS have impaired executive functions (Fischer, 2001). Executive function

plays a role in planning, adapting and adjusting (Shallice & Burgess, 1991). As these processes are disrupted in MS patients, it could be difficult for patients to adapt to their levels of functioning and this may cause them to have unrealistic expectations. This highlights that while HCPs should be aware of potential anger in MS patients, they should also be made aware of the possible cognitive impairments in MS patients and how these could leave them vulnerable to expressing anger.

Strikingly, the majority of HCPs had no or little formal training specific to anger in MS. Only one HCP had specific training in anger in MS populations. However, 18 HCPs believed that they could not do anything to decrease anger in MS patients, believing that anger was a natural process that MS patients go through. It must be noted that anger is a primary emotion which can be adaptive (Izard, 1977). Therefore, while clinically we can attempt to ensure that anger does not become violent and explosive, it may be unrealistic to assume that anger in MS patients or indeed other populations can be eliminated or needs to be eliminated.

Additionally, six HCPs reported that they did not need any formal training in anger and MS because skills like empathy cannot be taught. Thus, HCPs seemingly reported that they felt equipped by the virtue of their personal characteristics and experience to manage patient anger. However, due to the small sample size, it is difficult to generalise these findings and the area of training should be explored thoroughly in future studies.

It must be noted that while the Reflective Experience Survey has obtained information on possible factors which cause anger in MS patients and HCPs, it also highlighted that the vast majority of HCPs spend less than a quarter of their time managing MS patient anger, indicating that while MS patients do express anger it does not appear to be a very frequent

problem found in clinical settings. It could be that HCPs may not view anger as a problem in clinical settings even when it does occur, as it may be conceptualised as an adaptive and reasonable response to MS. As specific questions were not asked on this, it is only speculative.

5.5.1 Quality Measures

For any qualitative analysis it is imperative to ensure that appropriate quality measures are in place to ensure that the resulting analysis is credible. In qualitative analysis researchers explain that analysis should be ‘trustworthy’ (Berg & Welander-Hansson, 2000). Trustworthiness can be achieved by ensuring that the data has credibility, dependability and transferability (Berg & Welander-Hansson, 2000).

Credibility refers to the actual focus of the research and how well the data and the analysis address the intended focus of the research (Polit & Hungler, 1999). To ensure that data is credible attention must be paid to selection of participants. Patton (1987) explains that it is essential to choose participants with various experiences as it increases the richness of data. In the current study, we recruited HCPs who have specialist expertise in MS, from a variety of professions, including occupational therapists, nurses and speech and language therapists. Additionally HCPs varied in age, which added to credibility. Choosing which data to analyse is also a crucial aspect of credibility. If data are too small, for example single words, this may result in fragmentation. If the data are too long, it may be difficult to manage as it could contain various meanings (Graneheim & Lundman, 2004). The data in this study were in the form of sentences which are a reasonable length. Another aspect of credibility is to ensure that the categories are a true representation of the data and no data is excluded. Categories and components were checked by an independent researcher adding to the credibility.

Dependability is the degree to which data changes over time and the changes made in the researcher's decisions during the analysis process (Graneheim & Lundman, 2004). To ensure data was dependable in this study, participants were asked the same questions, rather than changing questions as insights into the research area were gained.

The last aspect of trustworthiness to be considered is transferability. This is defined as 'the extent to which findings can be transferred to other settings or groups' (Polit & Hungler, 1999). While it is ultimately the reader's decision as to whether or not the results of studies can be transferred to other contexts, this decision can be helped by concisely describing the demographics of participants, the context in which the research was carried out, data collection methods and process of data analysis used. These concepts have been described for the current study as well as presenting meaningful quotations in the analysis to aid transferability. It should be noted however that the sample only included participants who work in the NHS; thus transferability to other settings will be limited.

Another area to consider when analysing data in a qualitative fashion is the researcher's reflections and opinions. The researcher will hold his/her own opinions and views of phenomena to be studied. The danger is that these opinions will impinge on the analysis of data and categories that emerge. To ensure that this was kept to minimum the researcher in this study was partly able to bracket her views while collecting and analysing data as specific questions were asked, which were not amended as data were collected. It was felt that this reduced the chance of the researchers' views impinging on the final analysis. However in hindsight it has been acknowledged that the structure of the questionnaires used in this study reflected the researchers' opinions, as anger was constructed as a 'problem' from the outset and it was presumed that HCPs experienced anger at work in response to patient

characteristics. Therefore categories in the analysis were essentially deductive. Thus the researcher allowed her views on anger to influence the data collected and therefore was unable to completely bracket her own opinions. In hindsight the researcher should have asked open ended questions on the types of emotions that MS patients may experience and investigated whether anger would have emerged inductively, and if so how it is perceived and managed.

5.5.2 Strengths and Limitations

General strengths of this study include that the qualitative responses were able to complement and provide additional insight into the results obtained from studies one, two and three. The content analysis was also checked by an independent researcher, which aided in maintaining the quality of the analysis. Additionally HCPs' responses regarding which factors could contribute to anger in MS patients can be compared to MS patients' responses in chapter six. In relation to the proposed model of anger in MS (figure 5.2), this study allowed for the identification of HCPs' behaviours to be added to the model.

Limitations of the study include the richness of the data gathered from part two of the reflective experience survey. While the analysis allowed for the inductive emergence of categories, it must be acknowledged that as specific structured questions were asked and as participants had taken part in previous studies (two and three) it would have constrained responses and increased the likelihood of some categories to emerge. Thus, data gathered is not as rich as it could have been if an unstructured questionnaire or interview method was used.

Part one of the reflective experience survey used a multiple choice style of questioning which forces participants to make a choice from a list; therefore answers may not necessarily reflect

participant's true feelings. In hindsight, it was felt that the predetermined answers on the multiple choice were not evenly spaced. For example, options for question 1 are 'hardly ever,' 'quite often,' 'frequently,' and 'almost all the time.' There could have been an option in between 'hardly ever' and 'quite often,' to aid in even spacing of answers. Furthermore both parts of questionnaire were returned via the post; thus circumstances in which they were filled out would have varied across participants, possibly biasing responses. Additionally responses were not clarified or explored further by the researcher, limiting the richness of the data gathered. However, using this method ensured that the most amounts of participants could be reached.

This study did not ask HCPs about the types of anger that they experienced from MS patients. Thus, it is not known if HCPs experienced low levels of frustration from patients or more aggressive forms. In hindsight this should have been captured.

The uneven gender ratio of the sample should also be commented on. This could have biased the results as past literature has found that females and males experience and perceive anger differently (Thomas, 2003). However, it could be said that this uneven gender ratio is a true reflection of the uneven gender ratios of specialist HCPs in MS. The participants in this study were also previously exposed to vignettes on communication and response styles from previous studies therefore this exposure may have primed their responses or they have been eliciting demand characteristics as HCPs may have reported what they thought they should.

Regardless of these limitations, HCPs identified that their interactions with MS patients could contribute to anger and have given researchers an insight into possible reasons why HCPs may become angry in clinical situations. This data also highlighted that HCPs

identified that through their own personal experiences they felt equipped in managing anger, although they did report extra training could be useful.

Further research could further explore HCPs' views on anger in MS by using unstructured interviews. Further research could investigate particular groups of HCPs and their views on what could contribute to MS patients' anger. Using unstructured interviews and using a thematic analysis could be appropriate methods to explore this. Further research could also use observational methods to explore real life episodes of patient's and HCP's anger in a bid to uncover further possible triggers.

Chapter Six: Study 5- MS Patients' Perceptions of Anger

6.1. Summary of Study 5

This study was conducted, as study four was, to build on and complement the results obtained in the quantitative studies one, two and three. The main purpose of study five was to explore anger from MS patients' perspectives and understand their views of what factors could contribute to their levels of anger. A qualitative approach, using structured questionnaires, was used to collect data.

Structured questionnaires were used as participants were given the option of filling in the questionnaire in their own homes without the researcher present. Thus, it was felt that structured questionnaires would guide responses and facilitate the largest amount of responses. Furthermore, as one purpose of this study was to complement previous studies in the thesis, it was felt that structured questions were preferable.

Content analysis was used to analyse the data gathered as for study four (see section 5.1 for more details).

The main research questions were:

- How often do MS patients experience anger?
- What triggers and causes will MS patients identify as contributing to their levels of anger? What are the consequences of this anger on MS patients and their families?
- Will triggers and consequences identified by MS patients be similar to those identified by HCPs?

6.1.1 Design for Study Four

Study five adopted a qualitative approach design using a structured interview. Fifty three MS participants consented and completed this study. MS participants were asked six questions about the frequency of the anger they experienced, what the possible triggers were and how this effected their health and families health (see section 6.2). Participants were asked to provide as much information as possible when answering the questions. The questionnaire was constructed by the main researcher and had not been used in previous studies.

Data were analysed using a content analysis to categorise data and provide a frequency count of the data in each category (see section 5.6). The number of participants contributing to each category was given alongside quotations illustrating that category. At each stage of the analysis process an independent researcher with expertise in qualitative methods carried out an audit trail and assessed whether AP's judgements were sound. Quality measures were considered to judge whether credibility, dependability and transferability had been achieved (see section 6.5.1.).

6.2 Participants, Procedures and Method

Ninety five MS patients were approached from an MS clinic and a self help centre for people with MS. Patients from the MS clinic were introduced to the researcher after their appointment with the specialist MS team, where the neurologist gave patients a letter explaining the nature of AP's work. In the self help centre, AP was introduced to all potential volunteers in an informal announcement. In both cases, the researcher took patients to a separate room and provided them with a letter and an information sheet about the study to take away. Potential participants were given two weeks to decide if they would like to take part in the study. The researcher telephoned potential participants after two weeks and organised a convenient time and venue for the study to commence with the researcher's

presence or agreed to have the questionnaire sent to them in the post. If patients did not wish to take part, they contacted the researcher and all further contact was ceased (information sheets and letters can be found in appendix 2). The inclusion criteria for MS patients were identical to those of studies one, two and three (refer to section 2.2.2). Full ethical approval was given by the East Kent Research Ethics Committee and Royal Holloway Ethics Committee. The information sheets explained that direct quotes may be used in this study.

Fifty three MS patients completed this study (43 had completed the vignette studies two and three). Forty-six were female. The mean age was 44.6 years old. All participants were British born and nationality varied. Three were Indian, one was Australian and the rest were English. Thirty-eight were diagnosed with RRMS, five with PPMS, nine with SPMS and one with benign MS. In terms of DMTs, 21 were receiving Copaxone, six were receiving Rebif, three were receiving Avonex, one was receiving LDN and 22 were not on any medication for MS. Twenty participants were unemployed, 25 were employed and eight were retired (see table 6.1).

Table 6.1
MS Patient Demographics

Characteristic	n	%
Age at time of survey (years)		
25-35	2	4
36-45	24	45
44-55	22	42
56-65	4	7
66-75	1	2
Age at time of Diagnosis (years)		
14-24	8	15
25-34	20	38
35-44	19	36
45-54	4	7
55-64	2	4

Duration of MS (years)		
1-10	29	55
11-20	16	30
21-30	6	11
31-40	2	4
Type of MS		
RRMS	38	72
PPMS	5	9
SPMS	9	17
Benign	1	2
Disease modifying therapy		
Copaxone	21	40
Rebif	6	11
Avonex	3	6
LDN	1	2
No medication	22	41
Employment status		
Unemployed	20	38
Employed	25	47
Retired	8	15

All participants took part in this study in their own homes with the researcher present. All participants were given a paper copy of the questionnaire; however AP conducted a structured interview and read each question aloud to each participant and wrote down their responses to ensure that any physical disabilities associated with MS did not impact on responses. AP did not deviate from the questions presented and did not provide participants with any additional prompts. One word was excluded for participant 402 for his/her response to question three as it was felt that it may breach confidentiality.

Questionnaire

The questionnaire was constructed by the researcher and Professor D Langdon to specifically gather information about MS patients' perspectives of anger. The questionnaire consisted of

six structured questions and an additional question which asked participants to leave any further comments. The questions were (see appendix 7):

- 1) *How often do you become angry/frustrated because of your MS? (e.g. every day, one a week, once a month).*
- 2) *Was there any point during the course of your MS (from diagnosis to currently) that you became angrier than you are now?*
- 3) *Why do you become angry/frustrated with MS?*
- 4) *Do you get or have you ever got angry at health professionals like doctors and nurses? If so why?*
- 5) *Do you feel that anger can affect your healthcare or health?*
- 6) *Do you feel that your anger/frustrations affect your family members? If so how?*
- 7) *Please add any further comments on your personal experience of anger and frustration with living with MS.*

MS patients were asked to provide as much information as possible to these questions. Content analysis was used to analyse the data following the same steps as for study four (see section 5.2 and table 5.1). As with study 4, although codes in the data were not pre-determined the nature of the questions asked meant that participants answers were inevitably primed e.g. ‘do you feel anger can affect your healthcare and health?’ Therefore the resulting codes that emerged from data were essentially deductive. All data was coded and no parts of the units had more than one central meaning and therefore were not assigned more than one two code.

All codes were placed into categories and no data was excluded. Categories in this study were essentially pre-determined and deductive due to the structured questions which were asked, e.g. 'do you feel that your anger/frustrations affect your family members?' Such questions inevitably primed the answers given by participants. Once the main categories were developed they were divided into sub components to help to clarify and summarise the complex data that was engulfed by the main category. The sub components were decided by the main researcher and Dr Eatough.

At each stage, an independent researcher with expertise in qualitative methods carried out an audit trail and assessed whether AP's judgements were sound. The independent researcher was not blind to AP's judgements. If there were discrepancies between the researchers on how data should be coded or categorised this was resolved by in-depth discussion. If discrepancies were not resolved after this a third independent researcher would be asked for their opinion (Professor D. Langdon) and their opinion would be taken as final. However the former or latter situations did not occur and Dr Eatough and AP agreed on all judgements made.

The number of participants contributing to each category is given alongside quotations illustrating that category in the results section (see section 6.3).

6.3 Results

Content analysis revealed four main categories that MS patients identified as contributing to their levels of anger and possible consequences. The main categories were:

- Anger frequency
- Unpredictability of MS

- HCPs' behaviour
- Effect on health

Each of these was divided into components and sub components.

6.3.1 Anger Frequency

MS patients commented on the frequency of their levels of anger since the diagnosis of MS.

This category was divided into five components (see table 6.2):

- Daily
- Weekly
- Monthly
- Near diagnosis
- No anger/hardly ever due to MS

Table 6.2
Number of MS participants endorsing components of Anger Frequency Category

Components of Anger Frequency Category	Number of MS participants contributing to each category (% of total sample)	Example Quotations
Daily occurrence	24 (45%)	<i>"On a daily basis" (427, q1).</i> <i>"Most days if I want to perform a task such as gardening or house work" (425, q1).</i>
Weekly occurrence	7 (13%)	<i>"When my ms challenges or interferes with normal life about once a week" (415, q1).</i>
Monthly	5 (9%)	<i>"Probably around once a month" (413, q1).</i> <i>"Once or twice a month." (404, q1).</i>
Near diagnosis	8 (15%)	<i>"When I was first diagnosed" (449, q2).</i> <i>"Yes at diagnosis" (437, q2).</i>
No anger due to MS/hardly at all	9 (17%)	<i>"Almost never" (442, q1).</i> <i>"MS does not make me angry" (411, q8).</i> <i>"Yes (anger) but it has nothing to do with MS" (424, q5).</i>

6.3.1.1 Daily, Weekly or Monthly Frequency

Just under half of patients (24) reported that anger was a daily regular experience since the onset of MS. Although patients were not asked to comment specifically on the types of anger that were expressed, half of the 24 patients reported that their daily expression of anger was usually expressed in milder forms of anger such as frustration:

“Everyday-mostly frustration- Some days better than others” (446, q1).

*“Not so much anger but frustration, everyday at little things that I can't do like cooking”
(426, q1).*

The data indicated that daily anger in MS patients is expressed in subtler forms of the emotion. Ten MS patients additionally reported that they attributed daily frustrations due to the interference of MS on their daily lives or if they were having a relapse:

“Everyday frustrated because cannot do things I want to and because get so tired if I try to do something” (401, q1).

*“Daily if I am relapsing or having enhanced symptoms but generally maybe a month”
(453,q1).*

It seems apparent that anger may be in response to specific barriers or situations rather than a constant stable emotion. A smaller minority of patients reported that anger was a weekly (7) or monthly occurrence (5), highlighting that the frequency of anger varied amongst participants.

6.3.1.2 Anger Near Diagnosis

A small amount of patients (8) recalled that anger was often more prevalent at the time of their diagnosis. Three patients explained that diagnosis and the start of the MS disease course was particularly an anger provoking time as they contemplated what a future with MS would look like:

“Initial diagnosis and realising what the future may bring with a disease like MS” (435, q2).

The same number of patients (3) explained that it was previous to a confirmed diagnosis of MS which caused them to experience anger as they had no explanation for painful symptoms:

“Angry when I had not been diagnosed but had painful symptoms” (444, q2).

Interestingly, it should be noted that two patients specifically wrote additional comments reporting that their anger expression experienced once they had been diagnosed with MS was different to the anger they that experienced before a diagnosis of MS:

“Never use to be an really angry person but I can see a difference in my behaviour and I don’t like myself” (444, q7).

However, as no additional information was sought it is unclear what these participants meant and if their anger was more frequent or more explosive since the diagnosis of MS, or ‘different’ in another way.

6.3.1.3 No Anger

A small number of patients (9) reported that they did not experience anger due to MS, which is important to consider in this study. Rather, they identified that their levels or frequency of anger were not different since the diagnosis of MS. This could allude to the theory that anger in MS may be triggered by the same factors as in healthy individuals, rather than specific factors associated with MS. These results highlight that anger experienced in MS may not be any different from anger experienced in healthy populations. However, as more data were not gathered on this point no further interpretations can be made.

One patient reported that she/he actively tries to stop him/herself from becoming angry:

“Not that much as I try to think of ways around problems- anger is a waste” (439, q1).

Therefore, this patient seemed to believe that anger is a negative emotion that needs to be avoided.

6.3.2 Unpredictability of MS

Unpredictability emerged as a main category. This was divided into three components which additionally had sub components (see table 6.3):

- Disease course
- Restrictions of MS
- Symptoms/disabilities

Table 6.3
Number of MS participants endorsing components and sub components of Unpredictability of MS

Components and Sub Components of Unpredictability of MS Category	Number of MS participants contributing to each category (% of total sample)	Example Quotations
Disease Course	10 (19%)	
Relapses	4 (8%)	<i>"Although I have RRMS it never remits" (413, q3).</i> <i>When I am having a relapse, when I am not ill I don't feel as angry" (428, q1).</i>
Restrictions of MS	31 (58%)	
Limitations on life	20 (38%)	<i>"Because it restricts so much of my life" (410, q3).</i> <i>"Because of the limitations it places on my life" (435, q3).</i>
Not normal	2 (4%)	<i>"When my MS challenges or interferes with normal life about once a week" (415, q1).</i>
Restricts daily tasks	3 (6%)	<i>"Most days if I want to perform a task such as gardening or house work" (425, q2).</i>
Restricts social life	4 (8%)	<i>"Because it restricts so much of my life. Socialising, walking, driving, working" (410, q3).</i>
Restricts family life	2 (4%)	<i>"Having daughter highlights my restrictions" (418, q2).</i>
Symptoms/disabilities	14 (26%)	
New symptoms	3 (6%)	<i>"New symptoms developed that made changes in lifestyle necessary" (408, q2).</i>
Progression in disability	5 (9%)	<i>"Yes when became more disabled" (401, q2).</i>
Bladder or bowel dysfunction	3 (6%)	<i>"Bladder embarrassment" (445, q3).</i>
Cognitive function	3 (6%)	<i>"Cognitive slowness is also upsetting and frustrating." (404, q3).</i>

6.3.2.1 Disease Course

Seven MS patients reported that the unpredictability of the actual disease course contributed to their levels of anger:

“Because I don't know what happens next and when, can anything be done about it or not”
(424, q3).

As MS is unpredictable, it may be difficult for patients to prepare for the next attack. Consequently MS patients may be unable to plan for future events possibly contributing to angry feelings. A smaller number of patients (4) specifically commented that it was the relapses and remissions in their disease course which contributed to their arousal of anger:

“I seem only to be frustrated during a relapse. I am never angry when I feel well, I am happy and thankful that I feel great” (403, q3).

Again, it could be speculated that relapses which do not have a defined time period cause uncertainty and consequently contribute to anger levels.

6.3.2.2 Restriction of MS

The majority of patients (31) reported that their anger was aroused due to the restricting nature of MS. Twenty patients reported that MS restricts their lives and therefore they have to adapt their lifestyles which could provoke anger:

“Moved to a bungalow and had to change my lifestyle” (426, q3).

Three patients reported that their anger levels were associated with the impact that MS has on their daily domestic tasks. Additionally, four patients commented that MS leads to restrictions in their social lives and a few patients (2) commented that they become angry as MS prevents them from attending to their families:

“Finding it very difficult to come to terms with not being able to do what I used to and can't keep up with the kids” (401, q1).

It appears that MS restricts most domains of life thus it is unsurprising that this could trigger angry feelings.

A minority of patients (2) commented that MS takes away their feelings of normality:

“After 30 years of MS I am now angry of how my life has been altered. I think of the things I could have achieved and am comparing myself to 'normal' women my age” (410, q8).

These patients explained the struggle in attempting to remain ‘normal’ in comparison to similar individuals in their social networks. Thus, it could be that these patients feel angry as they feel as if they have been ‘robbed’ of their right to remain ‘normal.’

6.3.2.3 Symptoms/Disabilities

Participants reported that it was the appearance of new symptoms (3) and progression of current disabilities (5) which could contribute to their anger levels. It could be that such symptoms and disabilities make MS patients aware that their lives with MS will be ‘different’, as they have to learn to adapt to resulting disabilities.

Three participants specifically singled out that losing bowel and bladder functions could arouse their anger:

“I try not to let it affect me but certain faculties fail it becomes increasingly more difficult especially if you have always been very independent and don't like asking for help” (434, q7).

The loss of basic functions could cause embarrassment and rob patients of their independence, possibly causing frustration and anger.

Three patients additionally highlighted that deterioration in cognitive functions contributed to their anger. Non-physical symptoms are hard for outsiders to identify; thus it could be

speculated that MS patients might find these invisible symptoms more frustrating, as they have to spend time explaining their difficulties to others.

6.3.3 HCPs' Behaviour

MS patients identified HCPs' behaviour as contributing to anger. This main category was divided into three components which also had sub components (see table 6.4):

- Access to HCPs
- Attitudes of HCPs
- Information provided

Table 6.4
Number of MS participants endorsing components and sub components of HCPs' behaviour Category

Components and Sub Components of HCPs' Behaviour Category	Number of MS participants contributing to each category (% of total sample)	Example Quotations
Access to HCP	6 (11%)	
Difficulties in getting an appointment with specialist	3 (6%)	<i>"Can't get to speak to specialist doctor so become angry" (426, q4).</i>
Appointments too short	2 (4%)	<i>"Yes but not openly to them. Consultations are too short" (401, q4).</i>
Monitoring of symptoms by HCPs	1 (2%)	<i>"I feel irritated by the system with the lack of structured regular monitoring." (435, q4).</i>
Attitudes of HCPs	14 (26%)	
Dismissive/patronizing attitudes	7 (13%)	<i>Attitude is dismissive; do not take feelings into consideration" (401, q4). "Rarely- as sometimes they treat me as stupid, they can be patronizing" (436, q4).</i>
Not listening to patient's subjective accounts	5 (9%)	<i>"Frustrated towards neurologist as did not pay attention to subjective account of things" (429, q4).</i>
Lack of empathy	2 (4%)	<i>"Yes a few times for not being empathetic to certain problems" (434, q4).</i>

Information provided	14 (26%)	
Little specialist knowledge	4 (8%)	<i>“Too little understanding of the condition in the medical profession” (451, q8).</i>
Lack of explanations	6 (11%)	<i>“Yes, ‘you have MS, no time to talk now.’ No literature given” (445, q4).</i>
Not providing extra information	4 (8%)	<i>“Do not give me any extra information about treatments on offer” (439, q4).</i>

6.3.3.1 Access to HCPs

A small number of patients (3) reported that they had difficulty in obtaining appointments with GPs and specialists:

“Yes, ‘you have ms, no time to talk now.’ no literature given appointment made for 6 months time.”(46, q4).

As specialist MS clinics usually operate on a monthly basis, patients may often have lengthy waits before specialist appointments. Additionally two patients commented that appointments were too short, which could provoke anger especially if compounded by an already lengthy wait to see a specialist. One patient also felt that a lack of regular monitoring from HCPs contributed to their anger levels as they felt that it is left up to them to decide if a particular symptom needed attention, rather than receiving regular appointments from specialists to monitor their symptoms. While some patients may be happy with this level of autonomy, other patients may see it as a lack of support and thus possibly contributing to the arousal of their anger.

6.3.3.2 Attitudes and Communication Styles

A number of patients (14) reported that HCPs’ attitudes could contribute to the arousal of their anger. Patients commented that it was specifically dismissive and patronising attitudes which could provoke anger possibly as such attitudes could cause patients to feel belittled and undervalued:

“I've got angry with nurses because I feel they do not listen to me or appear dismissive”

(433, q4).

A similar amount of patients (5) commented that HCPs who did not listen to them could provoke anger. A few patients (2) reported that communication styles and attitudes which were low in empathy could also provoke anger. One of these patients reported that they felt that HCPs who used non empathetic styles did not convey ‘real communication.’ The potential danger of such styles could be that they may contribute to anger arousal, but additionally they could also cause patients to avoid HCPs:

“Yes because I avoid HCPs now because I cannot take the stress” (408, q4).

Thus, this quote highlights the extreme importance of communication and attitude styles.

6.3.3.3 Information Provided

Approximately a quarter of patients (14) identified that another factor which could contribute to anger was lack of information. Four MS patients felt that within the medical profession there was little understanding of MS and a lack of specialist knowledge:

“Yes most don't understand the condition especially GPs” (451, q4).

It could be possible that if MS patients feel that HCPs do not have a good understanding of MS it may not only contribute to levels of anger but could also lead to patients not taking onboard their advice. Further, if MS patients feel that GPs and non-specialists have little understanding of MS they may seek to see a specialist neurologist each time a symptom appears. Consequently, MS patients may be waiting a long period of time to see a specialist, when perhaps a quicker appointment with a GP could have resolved their concerns.

Six MS patients also reported that they felt that HCPs did not provide them with adequate amounts of information or explanations. A smaller number of patients (4) reported that HCPs who did not readily provide them with extra information caused them frustration and anger.

These patients felt that they had to take the initiative and ask for extra information, which could be perceived as a HCPs being secretive and purposely withholding important information from patient perspectives.

6.3.4 Effects on Health

MS patients identified that consistently high levels of anger could have detrimental effects on their own health and their family’s health. Interestingly patients also reported that it could have both positive and negative effects on their family’s behaviour. This main category of effects on health had three components which were further dived into sub components (see table 6.5):

- Patient health
- Family’s health
- Family’s behaviour

Table 6.5
Number of MS participants endorsing components and sub components of effects on health category

Components of Effects on Health Category	Number of MS participants contributing to each category (% of total sample)	Example Quotations
Patient health	28 (53%)	
Tiring	5(9%)	<i>“Yes makes me feel drained/lack of energy” (417, q6).</i>
Induces stress	11 (21%)	<i>“Yes because it makes me stressed” (406, q6).</i>
Depressive symptoms	7 (13%)	<i>“Health- yes as can lead to depression” (435, q6)</i>
Physical symptoms	4 (8%)	<i>“Yes-anger raises my blood pressure” (446, q6).</i>
Cognitive dysfunction	1 (2%)	<i>“Yes-not good for me and it hinders/affects decision making as anger blinds me” (439, q6).</i>
Family’s health	18 (34%)	
Conceal anger	3 (6%)	<i>“I try to conceal my frustrations” (403, q6). “Yes they would do if I told them of all my frustrations” (410, q6).</i>

Emotional effects	12 (23%)	<i>"Sometimes as it makes them feel hopeless" (437, q6). "Yes- they get upset" (436, q6).</i>
Anger/irritation	3 (6%)	<i>"I can make them angry at me!" (447, q6).</i>
Effect on family's behaviour	12 (23%)	
Children's behaviour	4 (8%)	<i>"Yes children unsettled- behavioural issues" (401, q6).</i>
Communication	4 (8%)	<i>"Yes they never know what to do or say" (451, q6). "Only when I have flared into anger- that's when they started to listen more" (408, q6).</i>
Tension	3 (6%)	<i>"Causes arguments" (435, q6). "Yes because it causes unrest for silly reasons" (434, q6).</i>
Separation	1 (2%)	<i>"Yes husband left me" (416, qu6).</i>

6.3.4.1 Patient Health

Twenty percent of patients (11) identified that anger caused them stress which they believed could have negative consequences for their health:

"Yes I have always thought anger produces stress which is bad." (11, q6).

One patient additionally believed that the stress could cause a relapse. Some patients (7) reported that anger caused them to display symptoms of depression, while four reported that it physically affected their health by increasing their blood pressure. Five patients explained that anger caused tiredness. A small number of patients explained that anger was physically draining and increased their levels of fatigue.

As well as commenting that anger affects emotional and physical symptoms, one MS patient highlighted that anger could affect cognitive skills, specifically the decision making process. While this may not directly affect health, it could result in poor decision making which could have negative effects on healthcare in the long run.

6.3.4.2 Family Health

A number of patients (12) believed that their levels of anger affected their family's emotional states, causing them to feel upset, hopeless and sad:

“Yes it makes them sad and feel sorry for me” (424, q6).

Although none of the patients reported that family members became depressed, it could be that if these feelings were prolonged and then were coupled with other life stressors or internal factors, it could lead to the emergence of depression.

Three MS patients further reported that they believed that their anger expression could also stimulate anger expression in their family members and cause them to become angry. Three patients were worried about the impact of their anger and frustrations and therefore chose to conceal their anger from family members, highlighting the importance these patients placed on the emotion of anger.

6.3.4.3 Family Behaviour

Overall 12 MS patients reported that they believed that their anger had or could have a negative effect on their family's behaviour. Four MS patients specifically explained that their displays of anger unsettled and confused their children:

“It makes my kids confused by my outbursts” (449, q6).

A smaller number of patients (3) reported that their angry outbursts negatively affected their communication between themselves and family members:

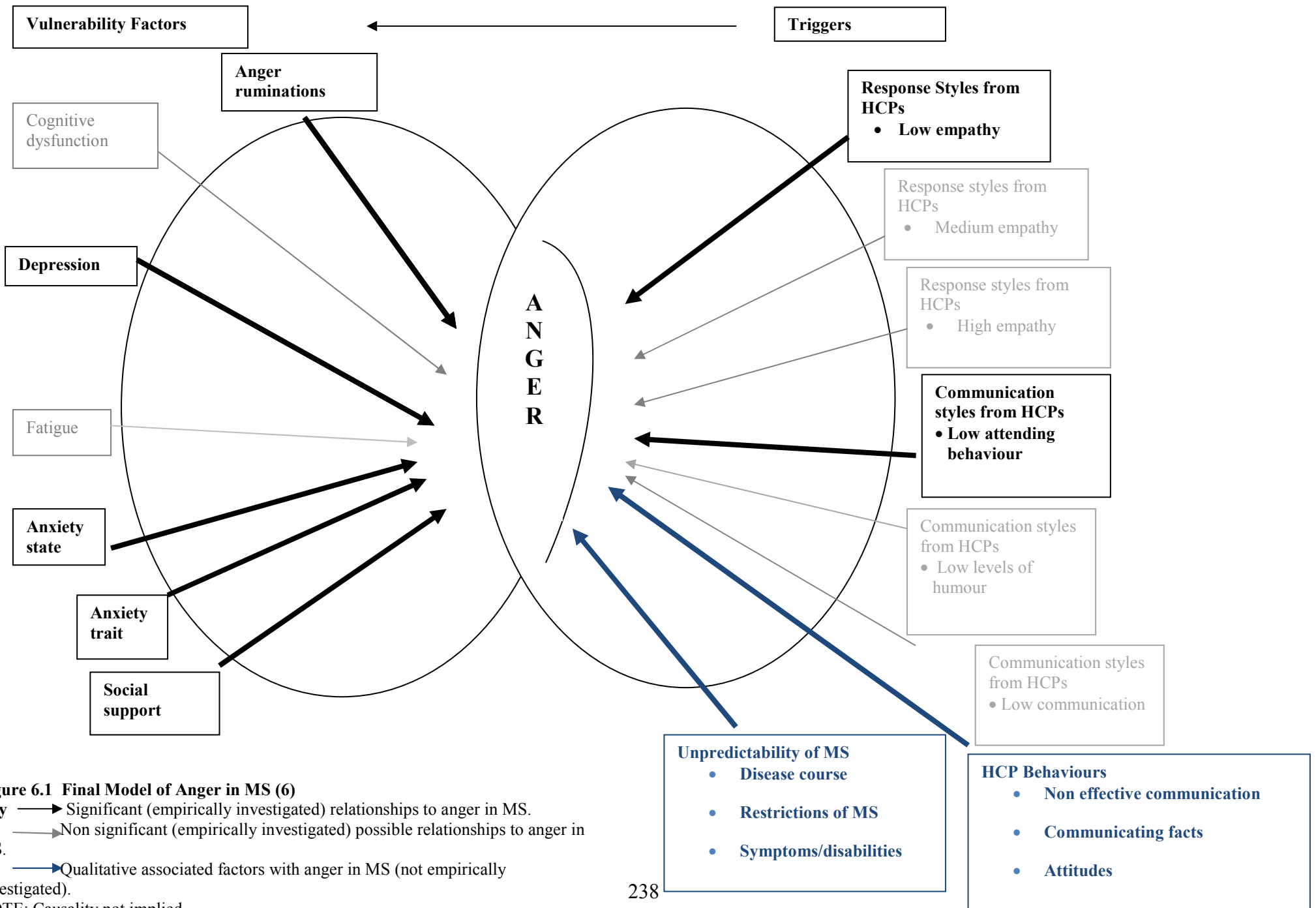
“Because I know they do not know how to speak to me” (432, q6).

Three patients also reported that their anger expression caused tension within the household and one patient believed that her husband was specifically unable to cope with her angry outbursts which resulted in the end of their marriage. This highlights the potential negative effects patient anger can have on family dynamics.

However, surprisingly one patient reported that anger actually contributed to positive communication as his/her anger made family members acknowledge his/her feelings and listen. Thus, anger could have a positive effect on communication from the patient's point of view.

6.4 Model of Anger

These qualitative findings can be placed into the Model of Anger in MS patients to create a Final Model of Anger in MS (see figure 6.2). MS patients identified, similar to HCPs (see chapter 5), that it was HCPs' behaviours, attitudes and information provided, which could contribute to the arousal of their anger. MS patients reported the unpredictability of MS in the form of symptoms, restrictions of MS and the disease course could contribute to anger. These findings can be hypothetically placed into the model as these associations and direction of causality have not been tested empirically.



6.5 Discussion

The qualitative data revealed that MS patients had some insight into possible causes and consequences of their anger. Patients commented that anger could potentially cause problems for their health and healthcare, and for their family's health and behaviour. MS patients identified possible factors that could contribute to their anger as being the actual disease course of MS, the restrictions of MS, the unpredictability of MS, as well as factors displayed by HCPs. Categories that were identified by the majority of patients will be discussed here.

Just under half of the patients commented that anger was a frequent daily occurrence since the diagnosis of MS, providing evidence for clinical observations that MS patients do display angry behaviours (Feinstein & Feinstein, 2001). However, of the patients who commented on the type of anger experienced, participants mostly alluded to mild to moderate levels of anger in the form of frustration. Only 16% of patients noted that these levels of anger often had no relation to their levels of anger previous to the diagnosis of MS, perhaps indicating that anger experienced in MS populations might not be unique to MS. However, as the data were not rich enough, we are unable to assess whether the anger that patients experienced since a diagnosis of MS was substantially different to the anger experienced previously.

The majority of patients reported that it was the restrictions that MS placed on their lives which played an important role in anger expression. Such constraints extended to all areas of life including domestic tasks, socialising, leisure activities and attending to family members. Two patients felt that such restrictions caused them to feel not 'normal' as they no longer had control of their lives. This provides support for Kalb (2005) who suggests that MS patients' anger is due to the loss of control they have over their lives. As patients lose this control, they could grieve for a past life that they had, potentially causing anger and frustration.

While some of the factors identified complement previous studies in this thesis, one particular factor did not. Some MS patients identified the actual disease course, disabilities and physical symptoms associated with MS as a possible contributor to anger levels. The quantitative study one did not find an association between physical disability and anger levels, in line with previous studies (Nocentini et al., 2009). Perhaps quantitative measures are assessing for the association between actual levels of physical deterioration e.g. not being able to walk a specific distance, while MS participants in this study are commenting that it is not only these physical disabilities which could impact onto their anger but the resulting consequences such as becoming dependent on other people. Thus each study could have captured a different component of disability. Either way clinicians and researchers should be mindful of the role that the actual disease course of MS and physical disabilities could play in levels of anger.

Interestingly, a minority of MS patients identified that various factors displayed by HCPs contributed to their anger levels. This suggests that while past literature in psychiatric in-patients has concentrated on HCPs roles in anger expression in patients, the focus of research in MS may need to focus on other factors.

Some MS patients identified that HCPs' attitudes which were dismissive, patronising and non-empathetic, as possibly contributing to the arousal of anger. These attitudes were similar to the attitudes that were identified by HCP participants in study 4 (see chapter 5), as possibly contributing to MS patients' arousal of anger. These results complement studies two and three which looked at communication and response styles from HCPs and the potential association with the arousal of anger in MS patients. Past literature has additionally found that empathetic behaviours from HCPs are preventative of anger in patients with preventable problems (Elder et al., 2005). Lancee et al. (1995) similarly found that non-empathetic

behaviours of HCPs were associated with anger in psychiatric patients. These results indicate that some of the factors which MS patients identify as contributing to their anger are not specifically associated with MS, but may also arouse anger in other illnesses.

MS patients identified the importance of anger by reporting that they believed that anger could have detrimental effects on health by contributing to stress, depression and additionally their cognitive functions. These views complement empirical literature which has found that anger can have detrimental effects on health (Gardner & Moore, 2008). These results highlight that while anger may not take violent forms in MS populations, MS patients do still view continual subtle levels of anger expression as a problem. Additionally, a small proportion of MS patients reported that their anger levels could negatively affect their family member's health, perhaps causing family members to display depressive symptoms. MS patients' beliefs are in line with past literature which has found that levels of anxiety, depression and distress are elevated in MS partners after their partners have been diagnosed with MS (Janssens et al., 2003). However, one patient emphasised that his/her anger actually caused his/her family to listen to him/her, therefore having a positive effect on relationships in the household. There is little empirical work on the effects that MS patient anger has on family relationships. Future research could consider investigating this area further.

6.5.1 Quality Measures

For a detailed description of quality measures please refer to section 5.5.1. Credibility was adhered to by recruiting MS patients who had variations in disease course, type and length of MS. Additionally data was of reasonable length and categories and components were checked by an independent researcher. Dependability was adhered to by asking all participants the same set of questions. To aid transferability meaningful quotations and demographics have

been presented. However, it should be noted that the sample may have been unrepresentative as participants were only recruited from two clinics.

6.5.2 Strengths and Limitations

This study shares the same methodological strengths as study four (see section 5.5.2). Additionally a real strength of this study was that it provided insightful data on MS patients' perceptions of anger. The categories which emerged provide evidence for past literature and have complemented the previous studies one, two, three and four. Interestingly both HCPs and MS patients identified in the qualitative studies that communication, attitudes and nursing styles could contribute to MS patients' anger expression and consequently affect patients' health and relationships.

In relation to the proposed model of anger in MS (figure 6.2), this study allowed for the identification of an additional HCP behaviour (attitudes) and unpredictability of MS to be added to the model, contributing to further understanding of possible factors which could arouse anger in MS patients.

Limitations of this study must be considered. As with study four (see section 5.5.2) it must be acknowledged that categories in the content analysis were not allowed to emerge inductively and the structured interview constrained responses. A large proportion of participants in this study also took part in studies two and three. Participation in these studies may have primed responses and thus categories which emerged from this study may not have been truly inductive. It would be interesting to investigate which categories would emerge if unstructured interviews were performed with a different set of participants. Additionally, as in study four (see section 5.5.2) a considerable limitation is that the researcher did not manage to bracket her views adequately. The researcher asked closed questions which

assumed that MS patients were angry. In hindsight, it would have been preferable to ask patients what types of emotions they experienced and explore if anger was one of them. However it must be noted that while the questions assumed that MS patients experienced anger, some patients did actually respond that they did not experience anger and therefore were able to answer in an appropriate way regardless of the closed question approach. Further research could consider interviewing participants using open ended questions and investigate if similar concepts found in this study arise.

While this study allowed for insightful responses for possible consequences and potential causes of the arousal of anger, it did not gather much data on the types of anger that patients expressed. Only a few patients commented on the mild levels of anger that they felt. With hindsight this information would have aided in assessing how much of a problem anger was in MS patient populations and helped researchers and professionals to be aware of the nature of anger in such populations.

There was an unequal split of men and women respondents, with only two men responding to the questionnaire. However, this is unsurprising considering that MS affects more women than men. It is not known if the same categories would have emerged if more men had participated in this study, as past literature does note that there is a difference in how men and women perceive anger (Thomas, 2003). Some patients also commented that anger was more prevalent if they were experiencing a relapse. In hindsight, it would have been preferable to either divide patients into groups, defined by their diagnosis or if they were currently experiencing a relapse, to gather richer data on the experience and contributors of anger at different points on the disease course. This would have aided interpretations. However, as the sample size was small and due to the unequal number of MS patients falling into the different

sub-categories of MS, it was felt that it would not have been appropriate to analyse data in that way.

The sample of MS patients was drawn from two particular MS clinics. Therefore, their views of HCPs' behaviours, long wait times and information provided could reflect just the practice of these specific clinics. It must be considered that MS patients from differing samples may have differing views on possible factors which could contribute to arousal of anger.

Further research could continue to investigate MS patients' perspectives on anger by using an unstructured interview technique to gather richer data. The contributors which were identified by MS patients could also be studied empirically. Additionally further research could address the gender imbalance in the current sample and seek to investigate community samples of MS patients' views of anger.

Chapter Seven: Final Discussion

The aim of this thesis was to build a descriptive model of possible vulnerability factors and triggers that could contribute to anger levels in MS populations (see figure 6.2). The next section will discuss the main findings from all the studies and conceptualise these in terms of theoretical models of anger (see section 1.4). Overall main limitations, strengths and suggestions for further work will be considered. In-depth discussions of each study can be found in previous chapters.

7.1 Main Conclusions

This thesis concluded that anger expressed in MS patients was not found to be characterised as unusually severe or violent forms of anger and that their anger expression may be not be unusually disturbing or demanding on HCPs' time. Several factors were identified which could contribute to the arousal of anger in MS patients. These factors may not be unique to MS as disease factors were not empirically associated with the arousal of anger. Rather, it is emotional and social factors (depression, anxiety, social support and anger ruminations) which contributed to anger along with communication and response styles in health care contexts.

However, as the studies in this thesis did not directly compare MS participants with other neurological populations, it is unclear if these factors are somehow different in MS patients or are general factors which are related to anger and thus would also be associated with anger expression in other neurological populations.

The results of study one suggested a trend towards significance in terms of MS patients having higher levels of some vulnerability factors such as emotional factors

(depression and anxiety trait) and lower levels of social support compared to the healthy control sample; although it must be noted that the results fall short of formal significance when a conservative adjustment is applied. MS affects emotional processing and MS patients are often characterised by emotional dysregulation (Krause et al., 2009). Therefore, it could be concluded that due to higher levels of some vulnerability factors and lower levels of social support and deficits in emotional processing, MS patients may have a lower threshold for anger expression. Additionally the demands of MS including physical disabilities, neurological cognitive deficits, constraints that MS places on patients' daily lives (Freal, Kraft & Coryell, 1984), and clinical situational factors could also affect the threshold for anger expression.

Data from the studies in this thesis help to support this conclusion. Study one reported that the MS group had a trend towards significance with higher levels of depression and anxiety trait (significance level of 0.01 & 0.05, but not significant after Bonferroni's correction was applied) and lower levels of social support, compared to healthy control participants (at a significance level of 0.01, but not significant after Bonferroni's correction was applied). Therefore, it could be the case that these high levels of emotional factors make anger expression more likely to occur at a lower threshold compared to healthy populations, who are generally unlikely to have emotional dysregulation and have 'normal' levels of other emotional factors.

Studies two and three indicate that MS patients' anger is also triggered by some communication and interaction styles from HCPs. Importantly, HCPs underestimated the levels of provoked anger in MS patients in healthcare contexts. This could be

interpreted as MS patients having a lower threshold for anger expression, as even HCPs who work so closely with MS patients failed to appreciate the high levels of anger expression that some situations could trigger. Viewed in the context of study one, higher levels of depression and anxiety trait could partly explain the higher levels of anger expression estimated by the MS patients. In terms of uniqueness of factors, the same styles of interaction and communication that produced high estimates of anger expression in MS patients have also been associated with arousal of anger in psychiatric in-patient populations and patients who need palliative care (Heaven & Maguire, 2003; Lancee et al., 1995). Thus, factors that are associated with anger expression in MS populations also instigate anger expression in other clinical populations.

The qualitative studies complemented the quantitative studies; MS patients identified that interaction and communication styles with HCPs might contribute to high levels of anger expression. Additionally MS patients identified that the unpredictability of MS contributed to their anger expression. Thus, although disease factors measured on nominal scales were not statistically significant in study one, it is interesting to note that unpredictability, an overarching impact of the disease, emerged as a contributing factor in anger expression. Importantly 46% of patients reported that anger expression was a daily occurrence, suggesting some insight into the importance and frequency of anger in the MS sample population. However, it must be noted that some MS patients qualitatively reported that anger experienced in MS was not specifically due to MS. This indicates that factors which lead to the arousal of anger, might not be wholly unique to MS or possibly that anger might not be experienced differently in all MS

participants. Rather, MS patients could have a lower threshold for experiencing anger due to the symptomatology of MS.

7.1.2 Additional Conclusions

The sample of MS patients did not display very high levels of intense anger expression as measured on STAXI, which would usually be associated with explosive and aggressive acts. Additionally just under half of the sample identified that they frequently displayed anger on a daily basis in the qualitative studies. Thus, the data does not suggest that anger levels in MS patients are linked to violence and extreme behaviours, but that anger arousal is quite frequent. However, raised levels of anger, even in subtler forms, does disrupt relationships and communication. This is particularly important in a long term disease such as MS, where the unpredictability of the disease course will result in important and long standing relationships with HCPs. Also in family situations even infrequent episodes of anger expression which are outside the 'norm' can fracture relationship dynamics and reduce carers' motivations. In a chronic disease which can last up to forty years, MS patients who 'snap' and display anger, even at a relatively low level, to caregivers are likely to wear down carers' resilience and possibly impact onto their carers' health.

In terms of severity of anger reported by HCPs, a standardised measure was not taken on the STAXI. However, in chapter 5 (see section 5.3) the majority of HCPs (66%) reported that they 'hardly ever' felt anger at work. The majority of HCPs reported that when they did it was in relation to organisational structures rather than MS patients. Therefore our studies do not conclude that HCPs who work with MS patients have excessive amounts of anger; however it is also unknown if the anger they do report is

typical of other HCPs who work with other patient populations as no comparisons were made.

Whilst there are similar factors contributing to anger in healthy people, other clinical populations and MS, some differences exist. Fatigue contributed to anger arousal in the healthy population, but did not contribute to anger arousal in the MS population. Depression, anxiety state and social support were associated with MS patients' arousal of anger but not that of the healthy populations (possible reasons for these differences have been discussed in detail in chapter 2 section 2.8). Anger ruminations and anxiety trait contributed to anger arousal in both populations. Depression, anxiety trait and social support were marginally significantly different in the MS population; therefore, these levels could change the threshold for anger expression. Anger ruminations and anxiety state levels did not differ between MS and normal populations and were contributors to anger expression in both groups. Interestingly fatigue, which was marginally significantly higher (at a significance level of 0.01 but not significant once a conservative adjustment was applied) in the MS population, only contributed to anger expression in the normal population. This may be due to fatigue being a chronic aspect of MS, which impacts on other symptoms and therefore is not perceived as influencing anger by MS patients.

7.2 Models of Anger

As has been mentioned, the possible factors which have been associated with anger in MS may not be unique to MS; therefore the results are discussed in the general context of theoretical models of anger in an attempt to understand the process and possible causal pathways of arousal of anger in MS populations.

7.2.1 Anger Determinant and Consequences Model

Novaco's (1994) Anger Determinant and Consequences theoretical model proposes that dysfunctional anger is triggered by environmental events, which in turn impinge on emotional cognitive processing, behaviour and physiological arousal. The results from the studies suggest that anger in MS can be triggered by environmental events such as interaction and communication styles from HCPs. Such environmental triggers could affect MS patient's cognitive processing which could be further affected by the neurological cognitive deficits that MS patients have (Rao, 1997). Additionally emotional dysregulation could further affect MS patients' cognitive processing. MS patients qualitatively reported a change in their behaviour and health due to anger, and many explained that this consequently affected their family's behaviours (see sections 6.3.4). Such changes in behaviour could then feed back into environmental triggers such as HCPs' interactive and communication styles, which again would impinge on MS patients' cognitive processing, physiological arousal and expression of anger. Therefore, MS patients' anger, although not highly dysfunctional as this model proposes, can be accommodated in Novaco's model. These results of the studies in this thesis allow researchers to shed light on possible environmental triggers which could arouse anger.

7.2.2 The Anger Avoidance Model

The Anger Avoidance Model (Gardner & Moore, 2008) of clinical anger suggests that clinical anger is triggered due to biological vulnerability and aversive life events. Such experiences and predispositions cause individuals to scan environments for situations that are likely to cause anger, which then contributes to the experience of

anger. Cognitive misinterpretations and emotional dysregulation further lead to the external or internal expression of anger.

It could be theorised that symptoms of MS impose vulnerability factors which are associated with anger (study one) and that MS patients also have a low threshold for anger expression. This then coupled with experiences of MS (in the qualitative studies MS patients note that they were more angry around the time of diagnosis) and interaction and communication styles with HCPs which are associated with anger (studies two and three), could cause MS patients to scan their environment for potential anger provoking experiences. Additionally, MS patients have difficulties in emotional processing (Krause et al., 2009) which could lead to arousal of anger which could be then internalised or externalised (see figure 7.1).

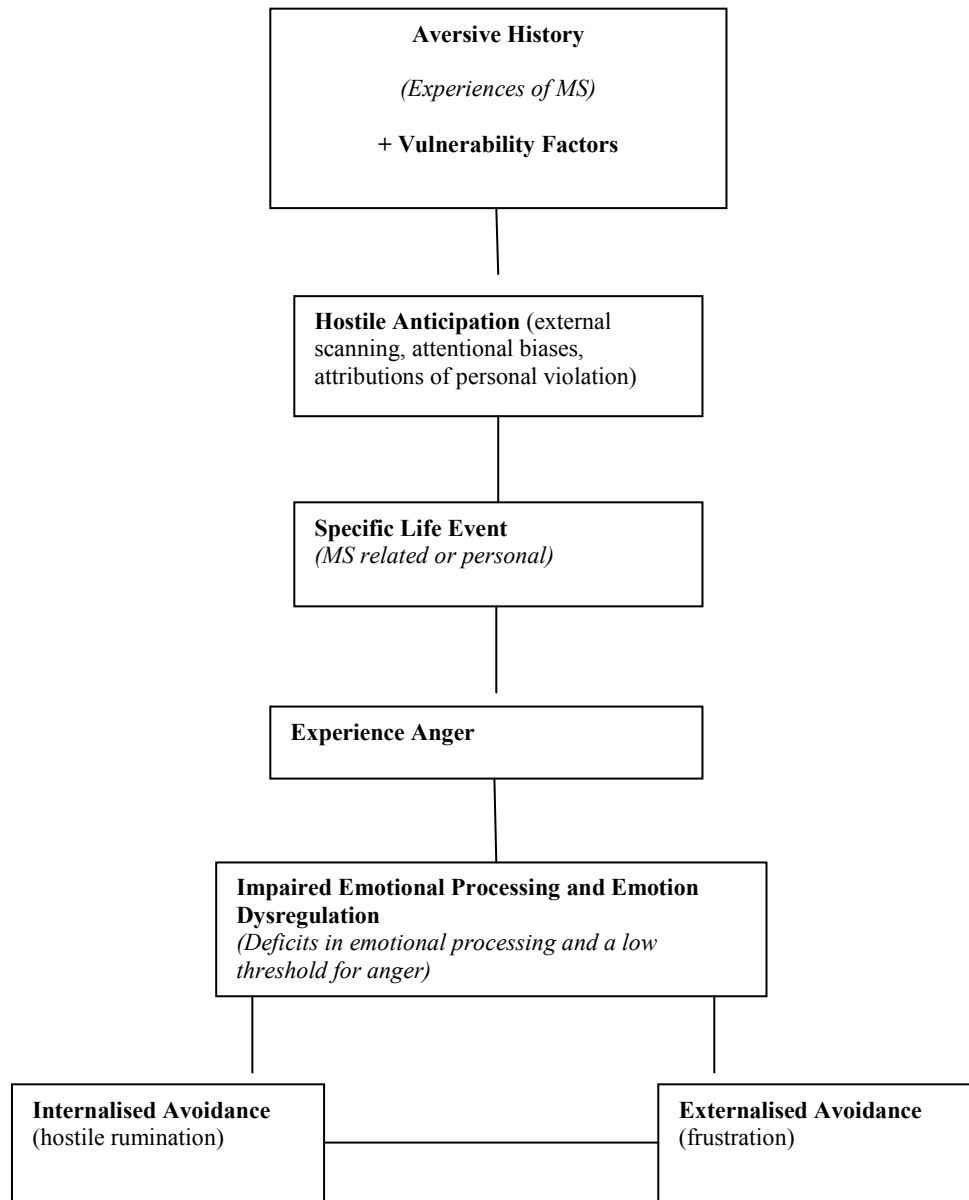


Figure 7.1 A Reconceptualised Model of The Anger Avoidance Model (Gardner & Moore, 2008) Specific to MS Patients.

7.2.3 The General Aggression Model

The General Aggression Model (Anderson & Bushman, 2004; Anderson & Carnagey, 2004) fundamentally explains that aggression is due to individual differences and situational factors. Vulnerability factors found to be associated with MS patients' levels of anger in study one could be conceptualised as individual differences in MS patients. Situational factors could be conceptualised as communication and interactive

styles from HCPs. Such factors could consequently increase aggression through affect, cognition and arousal. The model theorises that once these pathways are activated individuals appraise situations. If cognitive resources are not available immediate appraisal leads to aggression and anger. Study one found that anger ruminations are high in MS patients (although not significantly higher than healthy control participants). Individuals who ruminate are less able to problem solve, because ruminations prevent individuals from allocating cognitive resources to other specific domains (Larsen & Diener, 1992). Additionally neurological cognitive deficits that are associated with MS patients could affect the cognitive resources available, making it more likely for MS patients to make immediate appraisals. However, it must be noted that this is purely speculative as no measures were taken of MS patients' appraisals of anger provoking situations.

This model also proposes that social interaction can affect aggressive displays. For example, anger can provoke higher levels of provocation from the target, which will facilitate another angry or aggressive response by the individual. Aggressive responses may also be reinforced by a target backing down. High levels of social support were significantly associated with anger in MS suggesting that social interactions do contribute to anger as this model suggests, perhaps indicating that angry displays from MS patients provoke high levels of social responses which encourage MS patients to elicit angry responses. Furthermore, one MS patient did report that his/her anger did cause family members to listen to her (see section 6.3.4).

7.2.4 Summary of Models

In summary, MS patients' anger expression can be conceptualised using theoretical models of anger. Previous models of anger are typically modelled on aggression and dysfunctional anger; therefore it is unsurprising that contributors to anger in MS patients do not fit seamlessly with such models. Importantly these models indicate that the process of anger expression in MS may not be unique, and cognition, contextual, individual and behavioural factors all contribute to expression of anger in MS. However, the studies in this thesis shed light on which individual and contextual factors could be associated with anger expression in MS patients.

7.3 General Limitations

7.3.1 Sample

A prominent limitation of all the studies was the sample. Sample sizes were relatively small. Problems in recruiting made it difficult to recruit extra participants in a narrow time frame. MS clinics were only run once a month, and often had a maximum of 16 patients. Of these 16 patients, only a minority met the inclusion criteria. Furthermore, often MS patients had to wait a long time for these specialist appointments, which often meant they were anxious at the appointment time. Such MS patients were not approached, as it was felt that asking such patients to take part in research would have overwhelmed them. On reflection, specialist MS clinics may not have been the optimum place to recruit participants. From this learning experience, AP did approach a self help charitable organisation for people with MS and found recruitment in this centre very productive. However, this centre only had a maximum of approximately 30 members, some of whom did not fit the inclusion criteria.

Once participants did agree to take part in the study, the next challenge to overcome was finding a convenient time and venue. While AP did offer a choice of venues and did remind participants of the test session before the appointment by telephone, often AP would travel to the venue to find that participants had forgotten the appointment or due to the unpredictability of MS were no longer able to keep to the appointment. Due to these challenges, many participants were lost. As AP was present for every single test session in study one and the majority of test sessions in studies two, three and five, patients used test sessions as an opportunity to generally talk to a researcher about MS. Consequently, test sessions could last a whole morning or afternoon. On reflection, the time limit for each test session should have been reinforced to participants so they were aware that they only had time to take part in the questionnaires rather than reflect on the course of their MS. However, when patients did openly reflect and talk about their MS it allowed AP to reflect on her own research and understand the complexities of MS more fully which was an invaluable experience.

The sample of participants was drawn from the County of Surrey in the South East of the UK where the majority of the population are Caucasian. Due to the nature of the measures used all participants had to be native English speakers. Therefore, the participants in this study were not representative of the whole of the UK or reflective of a diverse ethnic background. These results therefore cannot be generalised to other cultures or societies without caution. This is especially important given that accepted communication and interaction styles with HCPs are culturally influenced (Takayama, Yamazakia, & Katsumatab, 2001). Therefore, it is not known if similar results would have been found if the samples were ethnically diverse.

The sample of MS patients was mixed, but analysis did not use a categorical approach. Therefore, it is not known if anger arousal would have been triggered by different vulnerability factors or triggers depending on the subtype of MS or whether MS patients were at different points on the disease course.

MS participants were also only taken from two MS clinics and one Charity Organisation. These results therefore cannot be generalised to populations of MS patients from other clinics or to community samples of MS patients. Additionally patients who display very high levels of aggression may actually not attend MS clinics within the NHS if they had been identified as being too aggressive or disruptive to treat in clinical settings.

In hindsight it was noted that MS patients in the qualitative studies may have been hesitant in expressing their true feeling about HCPs even though confidentiality was assured. Also due to the nature of MS and NHS systems, patients are often likely to have lengthy contact with the same neurologist and MS nurses who co-ordinate their care. Therefore, patients may not have thought that their interaction or communication styles contributed to anger as they may not have had anything to compare styles against (Brown, Dunn, & Butow, 1997).

7.3.2 Gender Ratio

As MS has a higher incidence in females, the sample reflects this unequal gender ratio. However, the male MS experience of anger may have been underrepresented. Similarly, most HCPs are female but it is unclear why only female staff responded to these studies. Anger expression is affected by gender. Women express and experience

anger differently to men (Collier, 1982; Sharkin, 1993; Thomas, 2003). Women feel less free to directly express their frustrations (Thomas, 2003) where as men report more aggressive and physical reactions in response to anger (Harris, 1992). Contrary to this Milovchevich, Howells, Drew and Day (2001) found no gender differences in anger and anger expression in a community sample of healthy participants. It is unknown if different vulnerability or situational factors would have been identified if the thesis sample was more equal. Additionally, it would have been interesting to investigate in the qualitative studies men's perceptions of anger whether they were HCPs or patients.

7.3.3 Personality Traits

Personality traits and pre-morbid anger measurements were not available for any of the participants. Therefore it is unknown how much of the anger variance was attributed to pre-morbid personality and temperament rather than the factors specifically investigated in these studies. Models of anger suggest that the arousal of anger is linked to past life experiences and individual differences; however participant's past experiences and personalities were not taken into account in this thesis.

7.3.4 Structure of Studies

The qualitative and quantitative data complemented each other, but they were unable to validate each other due to the methodological limitations and the very fact that the same participants took part in more than one study. However, qualitative data did allow for both HCPs and MS patients to express their feelings and thoughts and provide differing perspectives. This is important as literature specific to anger in MS

populations is limited. On reflection, it would have been favourable to conduct in-depth interviews with HCPs and MS patients to gather richer data. Additionally such participants should have been independent of participation in previous studies.

In hindsight, it was felt that studies two and three overlapped in their concepts of response and communication styles. Perhaps these studies should have been collapsed into one or vignettes should have been drafted in such a way to make sure there was a clearer distinction between the concepts of response and communication styles.

7.3.5 Understanding Anger

The nature of the studies did not enable us to comment on how typical MS anger is of other neurological or chronic conditions. Therefore, it is not known if anger is qualitatively different in MS populations compared to other patient populations. The majority of MS patients did not score in the maladaptive range of anger, thus our data suggests that anger expression in MS populations is not usually very severe. Clinical opinions do still indicate that anger is an issue in MS (Feinstein 2004; Langdon & Thompson, 1999; Nocentini et al., 2009). Additionally, it should be noted that even a few patients expressing maladaptive anger in clinical settings is personally upsetting and would take up disproportionate amounts of clinical time.

7.4 General Strengths

7.4.1 Exploratory Study

As this was essentially an exploratory study which drew on information on anger from a variety of populations, it was possible to investigate a number of factors without being bound specifically to any one previous model of anger. This allowed

many factors to be investigated within the constraints of a small sample size, which can be seen as a positive aspect.

As this was a new area to be researched, there was a concern to establish that it would be recognised by the wider academic community as important. However, through contact with MS patients and presenting preliminary findings on anger at various international conferences, AP had personal feedback and communications from MS patients and HCPs who saw this as a worthwhile study and were appreciative of the research.

7.4.2 Model of Anger

A descriptive model of anger was constructed to incorporate the overall results from these studies (see figure 6.2). This is the first attempt to begin to develop a descriptive model of anger in MS. These preliminary ideas can be taken forward and expanded to identify other variables and their potential association with anger in MS.

7.5. Clinical Implications and Further Research

Clinical implications of this study include that HCPs could be trained in identifying the subtle interactions of the combination of factors which could lead to anger expression in MS patients. HCPs could be encouraged to use their communication and interactive styles to portray empathy and be attentive to individual needs to reduce arousal of anger in healthcare contexts.

Further research is needed to validate the results of these studies and to extend the findings. Further research could firstly involve identifying other factors which could contribute to anger in MS patients such as personality factors and pre-morbid anger levels. Once a complete set of factors have been identified, research could investigate whether these factors trigger the same amount of anger variance in all subtypes and stages of MS or whether a unique set of factors is associated with different subtypes and stages of MS.

Current studies investigated response and communication styles that HCPs have been found to use in different sets of patient groups (i.e. psychiatric and non specified in-patients). While the findings in these studies found that MS patients and HCPs identified similar communication and response styles as other patient populations, it is not known if HCPs who work with MS patients do use these particular response/communication styles in clinical settings with MS patients. Observational studies need to gather this type of information.

Further work could use qualitative unstructured interviews with MS patients and HCPs to investigate which other causes of anger they identify and additional perceptions of anger. Not only will this help to obtain richer data in this field but it may help to further validate the empirical results from the studies presented here.

Additional research could investigate family caregivers in MS. MS patients did qualitatively identify that their aroused anger can affect family members behaviours and health. It would be interesting to investigate if MS family members also identify

this to be true and if they identify similar causes and consequences of anger in MS populations as MS patients and HCPs.

Further research could use the proposed Model of Anger to set up anger management workshops for HCPs to help them to manage patient anger. HCPs did express the usefulness of such training days and development of their skills to help to support the management of MS patient anger.

The research in these studies looked at aroused anger in health care contexts, research needs to extend investigations to community contexts and investigate if a similar set of factors arouse anger in these situations. Additionally because MS patients were taken from clinic populations, it needs to be investigated whether MS patients taken from a community sample have similar levels of anger and whether contributors to their anger arousal are similar to MS clinic populations. Further research is needed to address the sample limitations in these studies.

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Appendix 1



East Kent Local Research Ethics Committee

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Miss Anisha Paddam
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23 February 2007

Dear Miss Paddam

Full title of study: A Model of Anger in Multiple Sclerosis Patients.
REC reference number: 07/Q1803/5

Thank you for your letter of 12 February 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1803/5**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Roger Wheeldon
Chair

Email: Julie.Knowles@nhs.net

Enclosures: Standard approval conditions

Copy to: Dr Hitesh Patel
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04 July 2007

Miss. Anisha Paddam
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Royal Holloway University of London
Psychology Department, Egham Hill
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Dear Miss. Paddam

Study title: A Model of Anger in Multiple Sclerosis Patients.
REC reference: 07/Q1803/5
Amendment number: 02.
Amendment date: 25 May 2007

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 08 June 2007.

Ethical opinion

The sub committee approved the amendment. The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	2	25 June 2007
Notice of Substantial Amendment (non-CTIMPs)		25 May 2007

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to South East Coast Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

R&D approval

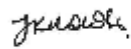
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1803/5:	Please quote this number on all correspondence
-------------	--

Yours sincerely



Julie Knowles
Committee Co-ordinator

E-mail: Julie.Knowles@nhs.net

Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to: Dr Hitesh Patel, This is a Royal Holloway University of London studentship



National Research Ethics Service

East Kent Local Research Ethics Committee

Kent & Medway SHA
Freslon Hall
Aylesford
Kent
ME20 7NJ

Telephone: 01622 710010
Facsimile: 01622 713168

28 May 2008

Miss Anisha Paddam
PhD full time student
Royal Holloway University of London
Royal Holloway University of London
Psychology Department, Egham Hill
Egham, Surrey
TW20 0EX

Dear Miss Paddam

Full title of study: A Model of Anger in Multiple Sclerosis Patients.
REC reference number: 07/Q1803/5

The REC gave a favourable ethical opinion to this study on 23 February 2007.

Further notification(s) have been received from local site assessor(s) following site-specific assessment. On behalf of the Committee, I am pleased to confirm the extension of the favourable opinion to the new site(s). I attach an updated version of the site approval form, listing all sites with a favourable ethical opinion to conduct the research.

R&D approval

The Chief Investigator or sponsor should inform the local Principal Investigator at each site of the favourable opinion by sending a copy of this letter and the attached form. The research should not commence at any NHS site until approval from the R&D office for the relevant NHS care organisation has been confirmed.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1803/5

Please quote this number on all correspondence

Yours sincerely

Mrs Yvonne Roper
Committee Co-ordinator

This Research Ethics Committee is an advisory committee to South East Coast Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England.

Email: yroper@nhs.net


Enclosure: Site approval form

Copy to: Dr Hitesh Patel, This is a Royal Holloway University of London studentship

East Kent Local Research Ethics Committee

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	07/021803/5	Issue number:	0	Date of issue:	28 May 2008
Chief Investigator:	Miss Anisha Paddam				
Full title of study:	A Model of Anger in Multiple Sclerosis Patients.				
This study was given a favourable ethical opinion by East Kent Local Research Ethics Committee on 23 February 2007. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.					
Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes (7)
Miss Anisha Paddam	Psychology PhD Student Researcher	St George's NHS Healthcare Trust	Wandsworth Research Ethics Committee	28/05/2008	
Approved by the Chair on behalf of the REC:  (delete as applicable) (Signature of Chair/Co-ordinator) Yvonne Ridd (Name)					

7: The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension or termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.

Paddam A

From: Blackman Carol
Sent: 23 October 2007 13:13
To: Langdon D; Paddam A
Subject: Ethics Proposals 2007/008 and 2007/007

Dear Dawn and Anisha,

Thank you for conducting the pilot as requested by DEC and for your feedback. We note that questionnaire completion took as much as 90 minutes, which is very long, but we note that you will be present during every data collection session, to monitor for fatigue and irritation, and to curtail data collection as appropriate. DEC therefore approves your submissions for 36 months as requested, on the condition that any ill effects of lengthy questionnaire completion (particularly in the vulnerable clinical population) will be monitored closely. Good luck with your study.

Regards

Carol

*Miss Carol Blackman
Administrative Assistant
Psychology Department
Royal Holloway University of London
Egham
Surrey TW20 0EX*

*Tel: +44 (0)1784 443529
Fax: +44 (0)1784 434347
E-mail: Carol.Blackman@rhul.ac.uk*

No virus found in this incoming message.
Checked by AVG Free Edition
Version: 7.5.488 / Virus Database: 209.15.0/1086 - Release Date: 22/10/2007 19:57

13/10/2007

Ashford and St. Peter's Hospitals



NHS Trust

Research & Development Office

Reference: 2006AP01

02 March 2007

Miss Anisha Paddam
Psychology Dept. RHUL
Egham, Surrey TW20 0EX

Dear Miss Paddam

St Peter's Hospital
Gauldford Road
Chertsey
Surrey
KT16 9PZ

Tel: 0193-272-2901
Fax: 0193-272-2554

Re: A Model of Anger in Multiple Sclerosis Patients. REC Ref: 07/Q1803/5

I am very pleased to inform you that Director R&D has approved your study and the R&D office has no objection in your proceeding with this study. However, the R&D Office would highly appreciate to receive final report of your study and any dissemination (s) from this work.

Best wishes,

Yours sincerely,

Dr Isaac John
Clinical Effectiveness and R&D Manager
E-Mail: isaac.john@spnhs.uk

St George's Research Office
Ground Floor, Hunter Wing, St George's University of London,
Granger Terrace, Tooting, London SW17 0RE

Direct Line: 020 8725 1012
Direct Fax: 020 8725 0794
Email: awithers@sgul.ac.uk

30 October 2008

Miss Anisha Paddam
Royal Holloway, University of London
Psychology Department, Egham Hill
Egham, Surrey
TW20 0EX

Dear Miss Paddam

PROJECT TITLE: A model of anger in multiple sclerosis patients
Protocol version #: 1
Protocol date: 08/01/2007
REC Reference: 07/Q1803/5
SSA Reference: 08/H0803/115
RO Reference: 08.0105
Sponsor: Royal Holloway, University of London
Host site: St George's Healthcare NHS Trust
Principal Investigator: Miss Anisha Paddam

The research approval process for the above named study has been completed successfully.

The conditions for host site approval are as follows:

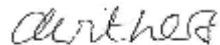
- The PI must ensure compliance with protocol and advise the host of any change(s) to the protocol. Failure of notification may affect host approval status.
- Under the terms of the Research Governance Framework, the PI is obliged to report any adverse events to the Research Office, as well as the REC, in line with the protocol and sponsor requirements. Adverse events must also be reported in accordance with the Trust Adverse Incident Reporting Policy & Procedures.
- The PI must ensure appropriate procedures are in place to action urgent safety measures
- The PI must ensure the maintenance of a Trial Master File (TMF)
- The PI must ensure that all named staff are compliant with the Data Protection Act, Human Tissue Act 2005, Mental Capacity Act 2005 and all other statutory guidance and legislation (where applicable)
- The PI must be compliant with monitoring and auditing by the Research Office
- The PI must report any cases of suspected research misconduct and fraud to the Research Office.
- The PI must provide an annual report to the Research Office for all research involving NHS patients, Trust or SGUL staff and/or resources. The PI must notify the Research Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care.
- All non-Trust members of the research team who will have direct contact with participants must obtain an honorary research contract prior to project commencement.

All research carried out within St George's Healthcare NHS Trust and St George's, University of London, must be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (2005, second edition, Department of Health).

Failure to comply with the above conditions and regulations will result in the termination of the research project.

Please contact the Research Office if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely



Ailsa Withers
Research & Development Manager
St George's Healthcare NHS Trust

Copy to: John Morley, Senior Finance Manager, St George's Healthcare NHS Trust

Appendix 2



If you have any queries please call
Anisha Paddam
01784443703 or
07903216 386

Dear Sir/Madam,

Request to participate in a study looking at experience of anger in MS patients

One of My PhD students is carrying out a research project in conjunction with Royal Holloway University and St George's University. Her name is Anisha Paddam. She is interested in looking at the experience of anger, specifically what factors can contribute to anger in Multiple Sclerosis patients. Enclosed with this letter is an information sheet and letter from Anisha Paddam which explains what would be involved in this study should you wish to take part.

Participation is entirely voluntary and even if you decide to take part in the study you can still withdraw at any time. All results gathered from this study are confidential.

Anisha Paddam will contact you within two weeks to ask if you would like to take part in the study. If you do not wish to be contacted, please contact Anisha Paddam and leave a message, and she will not contact you. Please feel free to contact Anisha Paddam if you have any queries.

Thank you for taking the time to read this letter. I hope you will find this project interesting.

Yours Sincerely,

Dr David Barnes
Consultant Neurologist
St Peter's Hospital
Guilford Road
Surrey



If you have any queries please call
Anisha Paddam
01784443703 or
07903216 386
e-mail a.paddam@rhul.ac.uk

Dear Sir/Madam,

Request to participate in a study looking at experience of anger in MS

My Name is Anisha Paddam, I am a PhD student at Royal Holloway University. I am being supervised by Dr Dawn Langdon. I am looking at anger in multiple sclerosis patients. I am specifically looking at which factors could contribute to anger in MS patients.

Please take the time to read the information sheet provided. If you would like to take part in the experiment please fill in the consent form and then fill in the vignettes provided.

The experiment consists of 18 questionnaires. Your task is to answer the questionnaires on emotions, mood and take part in some memory questionnaires.

Participation is entirely voluntary and even if you decide to take part in the study you can still withdraw at any time. All results gathered from this study are confidential.

I would very grateful if you did decide to take part in this experiment.

Your time is very much appreciated. I will contact you within two weeks about participation in the study. If you do not wish to be contacted please contact me. Please do not hesitate to contact me, if you have any questions or queries.

Yours Sincerely,
Anisha Paddam
PhD researcher
Royal Holloway University



May 29th 2007

email: a.paddam@rhul.ac.uk
Direct line- 01784443703
07903216386

Dear Sir/Madam,

Volunteers needed for research into Multiple Sclerosis

We have a number of ongoing studies that look at memory, concentration and other psychological aspects of multiple sclerosis (MS). We need to compare how people with MS do on various tasks with how healthy people do on the same tasks.

Would your company be interested in supporting our work? Usually, it would involve the healthy volunteers from your company spending an hour or so with one of our researchers. The interview generally takes place at the workplace, for your convenience.

If you feel that some of your employees would like to volunteer, please contact us for more information.

Best Wishes

Yours Sincerely,

Anisha Paddam (BSc Hons.)
PhD Researcher



If you have any queries please call
Anisha Paddam
01784443703 or
07903216 386
e-mail a.paddam@rhul.ac.uk

Dear Sir/Madam,

Request to participate in a study looking at experience of anger in MS

My Name is Anisha Paddam, I am a PhD student at Royal Holloway University. I am being supervised by Dr Dawn Langdon. I am looking at anger in multiple sclerosis patients. I am specifically looking at communication between health professionals and patients, and how this can contribute to anger.

Please take the time to read the information sheet provided. If you would like to take part in the experiment please fill in the consent form and then fill in the vignettes provided.

The experiment consists of two sets of vignettes. I am asking you to read each one and then rate how angry that vignette would make you feel, if you were in that situation. **Please answer the vignettes in the order that they come, as they have been randomised they are not necessarily in sequential order.**

If you are receiving this by post then, after you have finished, please return the vignettes, one copy of the consent form and the demographic details questionnaire, back to me in the freepost envelope provided.

Participation is entirely voluntary and even if you decide to take part in the study you can still withdraw at any time. All results gathered from this study are confidential.

I would very grateful if you did decide to take part in this experiment.

Your time is very much appreciated. Please do not hesitate to contact me on the details above, if you have any questions or queries.

Yours Sincerely,
Anisha Paddam
PhD researcher
Royal Holloway University



If you have any queries please call
Anisha Paddam
01784443703 or
07903216 386
e-mail a.paddam@rhul.ac.uk

Dear Sir/Madam,

Request to participate in a study looking at experience of anger in MS caregivers

My Name is Anisha Paddam, I am a PhD student at Royal Holloway University. I am being supervised by Dr Dawn Langdon. I am looking at anger in multiple sclerosis patients. I am specifically looking at what factors in health professionals could contribute to anger in Multiple Sclerosis patients.

The MS Trust has sent you this letter, on my behalf, along with my study, as they felt you would be suitable for my study.

Please take the time to read the information sheet provided. If you would like to take part in the experiment please fill in the consent form and then fill in the vignettes provided.

The experiment consists of two sets of vignettes and a short questionnaire on anger. I am asking you to read each one and then rate how angry that vignette would make you feel, if you were in that situation. **Please answer the vignettes in the order that they come, as they have been randomised they are not necessarily in sequential order.**

There is also a short questionnaire after this which asks you about your personal experiences of anger.

After you have finished, please return the vignettes and questionnaire back to me in the freepost envelopes provided.

Participation is entirely voluntary and even if you decide to take part in the study you can still withdraw at any time. All results gathered from this study are confidential.

I would very grateful if you did decide to take part in this experiment.

Your time is very much appreciated. Please do not hesitate to contact me on the details above, if you have any questions or queries.

Yours Sincerely,

Anisha Paddam
PhD researcher
Royal Holloway University



If you have any queries please call
Anisha Paddam
01784443703 or
07903216 386
e-mail a.paddam@rhul.ac.uk

Dear Sir/Madam,

Request to participate in a study looking at experience of anger in MS

My Name is Anisha Paddam, I am a PhD student at Royal Holloway University. I am being supervised by Dr Dawn Langdon. I am looking at anger in multiple sclerosis patients. I am specifically looking at communication between health professionals and patients, and how this can contribute to anger.

Please take the time to read the information sheet provided. If you would like to take part in the experiment please contact the researcher for further information.

The experiment consists of a short questionnaire on your personal experiences of anger. I am asking you answer these questions and share your experiences with me.

Participation is entirely voluntary and even if you decide to take part in the study you can still withdraw at any time. All results gathered from this study are confidential.

I would very grateful if you did decide to take part in this experiment.

Your time is very much appreciated. I will contact you within two weeks about participation in the study. If you do not wish to be contacted please contact me. Please do not hesitate to contact me, if you have any questions or queries.

Yours Sincerely,

Anisha Paddam
PhD researcher
Royal Holloway University



Information Sheet (Study 1 Patient)

Project: A Model of Anger in Multiple Sclerosis

My name is Anisha Paddam and I am a PhD student at Royal Holloway University of London. I am carrying out a research project to find out which factors in Multiple Sclerosis patients contribute to anger levels. I am inviting you to take part in this. Before you decide it is important to understand why the research is being done and what it will involve for you, if you wish to take part. Please take time to read the following information carefully and discuss it with others if you wish. The first half of this information sheet explains the purpose of the study and what will happen to you if you decide to take part. The second half of this information sheet gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Past literature has shown anger to be an important emotion which can affect well being in patients. The purpose of this study is to investigate which factors in Multiple Sclerosis patients contribute to anger levels.

Why have I been chosen?

You have been chosen to be invited to take part in this study as factors that may link to anger in Multiple Sclerosis patients, like yourself, is to be investigated. In total 100 patients will be tested.

Do I have to take part?

No. Taking part in this research study is entirely voluntary. If you do, you will be given this information sheet to keep and be asked to sign a consent form. Even if you do participate in the study you are still free to withdraw at any time and without giving a reason. A decision not to take part or to withdraw at any time will not, in anyway, affect the standard of care you receive.

What will happen to me if I take part?

You will complete questionnaires about factors that may contribute to levels of anger. These questionnaires will measure, anxiety, depression, pain, social support, memory difficulties, fatigue, coping, adjustment to Multiple Sclerosis, illness representations and how often you think about past anger provoking events. Therefore you will have to answer 18 questionnaires as instructed the best that you can. Each questionnaire comes with instructions and I will be there when you complete them, so that I can answer any questions you may have. I would visit you at home, in St Peters/St George's Hospital or at Royal Holloway University if you preferred.

What do I have to do?

You will have to answer the questionnaires as best as you can.

What are the possible risks of taking part?

Very, occasionally, people may find the questionnaires more difficult to complete than they had expected and this can be off putting. However I do understand this and I do not expect people to perform perfectly, I am happy for you to guess if you are not sure what to write down in the questionnaires.

What are the possible benefits of taking part?

You may not receive any direct benefit from taking part in the study. However, the information obtained during the study may help us to gain a better understanding of why Multiple Sclerosis patients become angry, this may help us to develop ways of treating such anger.

What happens after the research study stops?

After you have completed the study, you are free to contact me at any time should you have any queries.

Will my taking part in the study be kept confidential?

All information collected during the course of the research will be kept strictly confidential. The results of this study will be marked with a number and not any of your personal details.

Contact details

If you wish to obtain further information on this study or have any questions or queries, either now, during or after the study please contact me;

Royal Holloway, University of London,

Psychology department,

Egham Hill

Egham

Surrey

TW20 0EX

Telephone 01784 443 703

07903 216 386

E-mail A.Paddam@rhul.ac.uk

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making your decision.

Part 2**What will happen if I don't want to carry on with the study?**

If you withdrawn from the study, I will destroy all of the data collected up to that point, and your data will not be used.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Complaints

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (01784 443 703, or 07903 216 386.) If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Harm

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action against St Peters Hospital/ Royal Holloway University of London, however you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part be kept confidential?

If you join the study, some parts of your medical records and data collected for the study will be looked at by authorised persons, these being Anisha Paddam (primary investigator) Dr Dawn Langdon (primary supervisor of investigator) and Dr David Barnes (NHS consultant at St Peters hospital and secondary supervisor). Nothing that could identify you will be disclosed outside the research site. All of your data will be held on secure PC's or locked filing cabinets where only the three persons above can access them.

What will happen to the results of the study?

A report of the study will be written and you can ask to receive a summary of the results if you wish.

Who is organising and funding the research?

The study is being conducted as part of my PhD at Royal Holloway University of London.

Who has reviewed this study?

The Local Research Ethics Committee has reviewed this study.

Thank you for reading this information sheet. I hope that you will decide to take part in my project and that you will find it interesting.



Information Sheet (Control participants Study 1)

Project: A Model of Anger

My name is Anisha Paddam and I am a PhD student at Royal Holloway University of London. I am carrying out a research project to find out which factors in persons contribute to anger levels. I am inviting you to take part in this. Before you decide it is important to understand why the research is being done and what it will involve for you, if you wish to take part. Please take time to read the following information carefully and discuss it with others if you wish. The first half of this information sheet explains the purpose of the study and what will happen to you if you decide to take part. The second half of this information sheet gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Past literature has shown anger to be an important emotion which can affect well being. The purpose of this study is to investigate which factors contribute to anger levels.

Why have I been chosen?

You have been chosen to be invited to take part in this study as factors that may link to anger, in healthy participants like yourself, is to be investigated. In total 100 participants will be tested.

Do I have to take part?

No. Taking part in this research study is entirely voluntary. If you do, you will be given this information sheet to keep and be asked to sign a consent form. Even if you do participate in the study you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

You will complete questionnaires about factors that may contribute to levels of anger. These questionnaires will measure, anxiety, depression, pain, social support, memory difficulties, fatigue, coping, and how often you think about past anger provoking events. Each questionnaire comes with instructions and I will be there when you complete them so that I can answer any questions you may have. I would visit you at your place or work, your home or you may prefer to come to my office at Royal Holloway University of London.

What do I have to do?

You will have to answer the questionnaires as best as you can.

What are the possible risks of taking part?

Very, occasionally, people may find the questionnaires more difficult to complete than they had expected and this can be off putting. However I do understand this and I do not expect people to perform perfectly, I am happy for you to guess if you are not sure what to write down in the questionnaires.

What are the possible benefits of taking part?

You may not receive any direct benefit from taking part in the study. However, the information obtained during the study may help us to gain a better understanding of why people become angry, this may help us to develop ways of treating anger.

What happens after the research study stops?

After you have completed the study, you are free to contact me at any time should you have any queries.

Will my taking part in the study be kept confidential?

All information collected during the course of the research will be kept strictly confidential. The results of this study will be marked with a number and none of your personal details.

Contact details

If you wish to obtain further information on this study or have any questions or queries, either now, during or after the study please contact me;

Anisha Paddam

Royal Holloway, University of London,

Psychology department,

Egham Hill

Egham

Surrey

TW20 0EX

Telephone 01784 443 703

07903 216 386

E-mail A.Paddam@rhul.ac.uk

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making your decision.

Part 2

What will happen if I don't want to carry on with the study?

If you withdrawn from the study, I will destroy all of the data collected up to that point, and your data will not be used.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Complaints

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (01784 443 703, or 07903 216 386.) If you remain unhappy and wish to complain formally, you can do this through the Royal Holloway University of London complaints procedure. Details can be obtained from the university.

Harm

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action against Royal Holloway University of London, however you may have to pay your legal costs.

Will my taking part be kept confidential?

If you join the study, data collected for the study will be looked at by authorised persons, these being Anisha Paddam (primary investigator) Dr Dawn Langdon (primary supervisor of investigator) and Dr David Barnes (NHS consultant at St Peters hospital and secondary supervisor). Nothing that could identify you will be disclosed outside the research site. All of your data will be held on secure PC's or locked filing cabinets where only the three persons above can access them.

What will happen to the results of the study?

A report of the study will be written and you can ask to receive a summary of the results if you wish.

Who is organising and funding the research?

The study is being conducted as part of my PhD at Royal Holloway University of London.

Who has reviewed this study?

The Local Research Ethics Committee has reviewed this study.

Thank you for reading this information sheet. I hope that you will decide to take part in my project and that you will find it interesting.



Information Sheet (Patient Studies 2 and 3)

Project: A Model of Anger in Multiple Sclerosis

My name is Anisha Paddam and I am a PhD student at Royal Holloway University of London. I am carrying out a research project to find out which factors in Multiple Sclerosis patients contribute to anger levels. I am inviting you to take part in this. Before you decide it is important to understand why the research is being done and what it will involve for you, if you wish to take part. Please take time to read the following information carefully and discuss it with others if you wish. The first half of this information sheet explains the purpose of the study and what will happen to you if you decide to take part. The second half of this information sheet gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Past literature has shown anger to be an important emotion which can affect well being in patients. The purpose of this study is to investigate which factors in Multiple Sclerosis patients contribute to anger levels.

Why have I been chosen?

You have been chosen to be invited to take part in this study as factors that may link to anger in Multiple Sclerosis patients, like yourself, is to be investigated. In total 100 patients will be tested.

Do I have to take part?

No. Taking part in this research study is entirely voluntary. If you do, you will be given this information sheet to keep and be asked to sign a consent form. Even if you do participate in the study you are still free to withdraw at any time and without giving a reason. A decision not to take part or to withdraw at any time will not, in anyway, affect the standard of care you receive.

What will happen to me if I take part?

You will be asked to read 32 scenarios, which are investigating communication and nursing styles between patients and caregivers. After you have read them you will be asked to rate your anger level in response to these. Each scenario comes with instructions and I will be there if you would like me to be, when you complete them, so that I can answer any questions you may have. I would visit you at home, in St Peters/St Georges Hospital or Royal Holloway University if you preferred. If it is more convenient I can post the questionnaires to you and you can complete them in your own time.

What do I have to do?

You will have to imagine that you are in that scenario then afterwards rate how angry that scenario would make you feel.

What are the possible risks of taking part?

Very, occasionally, people may find it hard to imagine themselves in the scenarios and this can be off putting. However I do understand this and I do not expect people to perform perfectly, I am happy for you to guess if you are not sure how to rate your anger in response to the scenarios.

What are the possible benefits of taking part?

You may not receive any direct benefit from taking part in the study. However, the information obtained during the study may help us to gain a better understanding of why Multiple Sclerosis patients and caregivers become angry, this may help us to develop ways of treating such anger.

What happens after the research study stops?

After you have completed the study, you are free to contact me at any time should you have any queries.

Will my taking part in the study be kept confidential?

All information collected during the course of the research will be kept strictly confidential. The results of this study will be marked with a number and not any of your personal details.

Contact details

If you wish to obtain further information on this study or have any questions or queries, either now, during or after the study please contact me;

Royal Holloway, University of London,

Psychology department,

Egham Hill

Egham

Surrey

TW20 0EX

Telephone 01784 443 703

07903 216 386

E-mail A.Paddam@rhul.ac.uk

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making your decision.

Part 2**What will happen if I don't want to carry on with the study?**

If you withdrawn from the study, I will destroy all of the data collected up to that point, and your data will not be used.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Complaints

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (01784 443 703, or 07903 216 386.) If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Harm

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action against St Peters Hospital/ Royal Holloway University of London, however you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part be kept confidential?

If you join the study, some parts of your medical records and data collected for the study will be looked at by authorised persons, these being Anisha Paddam (primary investigator) Dr Dawn Langdon (primary supervisor of investigator) and Dr David Barnes (NHS consultant at St Peters hospital and secondary supervisor). Nothing that could identify you will be disclosed outside the research site. All of your data will be held on secure PC's or locked filing cabinets where only the three persons above can access them.

What will happen to the results of the study?

A report of the study will be written and you can ask to receive a summary of the results if you wish.

Who is organising and funding the research?

The study is being conducted as part of my PhD at Royal Holloway University of London.

Who has reviewed this study?

The Local Research Ethics Committee has reviewed this study.

Thank you for reading this information sheet. I hope that you will decide to take part in my project and that you will find it interesting.



Information Sheet (Health Care Professionals Study 2, 3 and 4)

Project: A Model of Anger in Multiple Sclerosis

My name is Anisha Paddam and I am a PhD student at Royal Holloway University of London. I am carrying out a research project to find out which factors in Multiple Sclerosis Caregivers contribute to anger levels not only in caregivers but also Multiple Sclerosis patients. I am inviting you to take part in this. Before you decide it is important to understand why the research is being done and what it will involve for you, if you wish to take part. Please take time to read the following information carefully and discuss it with others if you wish. The first half of this information sheet explains the purpose of the study and what will happen to you if you decide to take part. The second half of this information sheet gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Past literature has shown anger to be an important emotion which can affect well being. The purpose of this study is to investigate which factors in Multiple Sclerosis Caregivers contribute to anger levels in both carers and patients.

Why have I been chosen?

You have been chosen to be invited to take part in this study as factors that may link to anger, in Multiple Sclerosis health care professionals like yourself, is to be investigated. You have also been chosen as you have been a professional care in MS for at least a year. In total 50 participants will be tested.

Do I have to take part?

No. Taking part in this research study is entirely voluntary. If you do, you will be given this information sheet to keep and be asked to sign a consent form. Even if you do participate in the study you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

You will read 32 scenarios of situations detailing an imaginary episode between a caregiver and a Multiple Sclerosis patient. You will be asked to imagine yourself in these scenarios and then rate your anger level in response to this. Each scenario comes with instructions. You will take part in this in your own time and any convenient quiet venue. Additionally you will be asked to complete a questionnaire on your experiences of anger from multiple sclerosis patients. Direct quotes may be used from this additional questionnaire.

What do I have to do?

You will have to imagine the scenario as if you were a part of it and then rate your anger in response to these scales. You will also be asked to relay your own personal experiences of anger.

What are the possible risks of taking part?

Very, occasionally, people may find the scenarios more difficult to complete than they had expected and this can be off putting. However I do understand this and I do not expect people to perform perfectly, I am happy for you to guess if you are not sure how to rate your anger after having read the scenarios.

What are the possible benefits of taking part?

You may not receive any direct benefit from taking part in the study. However, the information obtained during the study may help us to gain a better understanding of why caregivers and Multiple Sclerosis patients become angry, this may help us to develop ways of treating anger.

What happens after the research study stops?

After you have completed the study, you are free to contact me at any time should you have any queries.

Will my taking part in the study be kept confidential?

All information collected during the course of the research will be kept strictly confidential. The results of this study will be marked with a number and not any of your personal details. If quotes are directly published they will not identify any personal information and the source of the quote will remain anonymous.

Contact details

If you wish to obtain further information on this study or have any questions or queries, either now, during or after the study please contact me;

Anisha Paddam

Royal Holloway, University of London,

Psychology department,

Egham Hill

Egham

Surrey

TW20 0EX

Telephone 01784 443 703

07903 216 386

E-mail A.Paddam@rhul.ac.uk

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making your decision.

Part 2

What will happen if I don't want to carry on with the study?

If you withdrawn from the study, I will destroy all of the data collected up to that point, and your data will not be used.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Complaints

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (01784 443 703, or 07903 216 386.) If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Harm

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action against St Peters/ Royal Holloway University of London, however you may have to pay your legal costs. The normal National Health Service Complaints mechanisms will still be available to you.

Will my taking part be kept confidential?

If you join the study, data collected for the study will be looked at by authorised persons, these being Anisha Paddam (primary investigator) Dr Dawn Langdon (primary supervisor of investigator) and Dr David Barnes (NHS consultant at St Peters hospital and secondary supervisor). Nothing that could identify you will be disclosed outside the research site. All of your data will be held on secure PC's or locked filing cabinets where only the three persons above can access them.

What will happen to the results of the study?

A report of the study will be written and you can ask to receive a summary of the results if you wish.

Who is organising and funding the research?

The study is being conducted as part of my PhD at Royal Holloway University of London.

Who has reviewed this study?

The Local Research Ethics Committee has reviewed this study.

Thank you for reading this information sheet. I hope that you will decide to take part in my project and that you will find it interesting.



Information Sheet (Study 5 Patient)

Project: A Model of Anger in Multiple Sclerosis

My name is Anisha Paddam and I am a PhD student at Royal Holloway University of London. I am carrying out a research project to find out which factors in Multiple Sclerosis patients contribute to anger levels. I am inviting you to take part in this. Before you decide it is important to understand why the research is being done and what it will involve for you, if you wish to take part. Please take time to read the following information carefully and discuss it with others if you wish. The first half of this information sheet explains the purpose of the study and what will happen to you if you decide to take part. The second half of this information sheet gives you more detailed information about the conduct of the study.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Past literature has shown anger to be an important emotion which can affect well being in patients. The purpose of this study is to investigate which factors in Multiple Sclerosis patients contribute to anger levels.

Why have I been chosen?

You have been chosen to be invited to take part in this study as factors that may link to anger in Multiple Sclerosis patients, like yourself, is to be investigated. In total 100 patients will be tested.

Do I have to take part?

No. Taking part in this research study is entirely voluntary. If you do, you will be given this information sheet to keep and be asked to sign a consent form. Even if you do participate in the study you are still free to withdraw at any time and without giving a reason. A decision not to take part or to withdraw at any time will not, in anyway, affect the standard of care you receive.

What will happen to me if I take part?

You will complete a short questionnaire on your own experiences of anger. You will answer 8 questions in total. Direct quotes may be taken from your answers and used in my research, although you will not be identified. I will be there when you complete them, so that I can answer any questions you may have or if you prefer you can answer them without me present. I would visit you at home, in St Peters/St George's Hospital or at royal Holloway University if you preferred.

What do I have to do?

You will have to answer the questionnaires as best as you can.

What are the possible risks of taking part?

Very, occasionally, people may find the questionnaires more difficult to complete than they had expected and this can be off putting. However I do understand this and I do not expect people to perform perfectly, I am happy for you to guess if you are not sure what to write down in the questionnaires.

What are the possible benefits of taking part?

You may not receive any direct benefit from taking part in the study. However, the information obtained during the study may help us to gain a better understanding of why Multiple Sclerosis patients become angry, this may help us to develop ways of treating such anger.

What happens after the research study stops?

After you have completed the study, you are free to contact me at any time should you have any queries.

Will my taking part in the study be kept confidential?

All information collected during the course of the research will be kept strictly confidential. The results of this study will be marked with a number and not any of your personal details. Direct quotes may be used but they will not identify any personal information and the source of the quote will be kept anonymous.

Contact details

If you wish to obtain further information on this study or have any questions or queries, either now, during or after the study please contact me;

Royal Holloway, University of London,

Psychology department,

Egham Hill

Egham

Surrey

TW20 0EX

Telephone 01784 443 703

07903 216 386

E-mail A.Paddam@rhul.ac.uk

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making your decision.

Part 2

What will happen if I don't want to carry on with the study?

If you withdrawn from the study, I will destroy all of the data collected up to that point, and your data will not be used.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Complaints

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (01784 443 703, or 07903 216 386.) If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Harm

In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action against St Peters Hospital/ Royal Holloway University of London, however you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part be kept confidential?

If you join the study, some parts of your medical records and data collected for the study will be looked at by authorised persons, these being Anisha Paddam (primary investigator) Dr Dawn Langdon (primary supervisor of investigator) and Dr David Barnes (NHS consultant at St Peters hospital and secondary supervisor). Nothing that could identify you will be disclosed outside the research site. All of your data will be held on secure PC's or locked filing cabinets where only the three persons above can access them.

What will happen to the results of the study?

A report of the study will be written and you can ask to receive a summary of the results if you wish.

Who is organising and funding the research?

The study is being conducted as part of my PhD at Royal Holloway University of London.

Who has reviewed this study?

The Local Research Ethics Committee has reviewed this study.

Thank you for reading this information sheet. I hope that you will decide to take part in my project and that you will find it interesting.



Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM (Patients)

Title of Project: Model of Anger in Multiple Sclerosis

Name of Researcher: Miss Anisha Paddam

Please initial box

1. I confirm that I have read and understand the information sheet
for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from Royal Holloway University, and St Peter's Hospital from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research.
I give permission for these individuals to have access to my records.
4. I agree to take part in the above study.

_____ Name of Patient	_____ Date	Signature
_____ Name of Person taking consent (if different from researcher)	_____ Date	Signature
_____ Researcher	_____ Date	Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Please note data collected on this consent form will be stored separately from data.

When completed, 1 for participant; 1 for researcher site file;

Please note data collected on this consent form will be stored separately from data.



Centre Number:
Study Number:
Participant Identification Number for this trial:

CONSENT FORM (HCP's)

Title of Project: Model of Anger in Multiple Sclerosis

Name of Researcher: Miss Anisha Paddam

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.
3. I understand that relevant sections of any of my data collected during the study, may be looked at by responsible individuals from Royal Holloway University, and St Peter's Hospital from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

When completed, 1 for participant; 1 for researcher site file;

Please note data collected on this consent form will be stored separately from data.

Appendix 3

Demographic Information for Patients

Age _____

Gender _____

Ethnicity _____

Marital status _____

Employment status _____

Medication _____

Type of MS _____

Year diagnosed _____

Year of first symptom _____

Demographic Information for Controls

Age _____

Gender _____

Ethnicity _____

Marital status _____

Employment status _____

How long have you been in your current job? _____

Are you currently on any Medication? _____

Do you have any history of mental illness? _____

Do you have any physical disabilities? _____

Hauser Ambulation Scale

0. Asymptomatic; fully active
1. Walks normally, but reports fatigue with athletic or other demanding activities.
2. Abnormal gait or episodic imbalance; gait disorder is noticed by family and friends; able to walk 25ft. in 10 sec. or less.
3. Walks independently.
4. Requires unilateral support (cane or single crutch) to walk; walks 25ft. in 20 sec. or less.
5. Requires bilateral support (canes, crutches or walker) and walks 25ft. in 25 sec. or less; or requires unilateral support but needs more than 20 sec. to walk 25 ft.
6. Requires bilateral support and more than 20 sec. to walk 25 ft., may use wheelchair on occasion.
7. Walking limited to several steps with bilateral support; unable to walk 25 ft., may use wheelchair for most activities.
8. Restricted to wheelchair; able to transfer self independently.
9. Restricted to wheelchair; unable to transfer independently.

Test Description: Selective Reminding Test

Objective:

The Selective Reminding Test (SRT) consists of 12 words that are presented orally and then written on a list. The test is designed to measure the ability to recall words that were presented orally and then written on a list.

Administration:

The subject sits:

"This is a test of memory. I'm going to read you a list of 12 words.

After I do each I want you to tell me, as many words as you can remember in my order.

After that I will tell you the words that you missed and ask you again to recall the whole list, even ones that you might have said before."

The experimenter reads 12 words at the rate of one word per second. It is the test of the subject's ability to recall the words. (Gardner, 1970, p. 104)

"These are the words you missed."

and the experimenter asks:

"Now try to tell me the whole list of 12 words, even if you told me before."

Through a series of repetitions of this procedure, the subject's memory is gradually improved. The use of the previously mentioned procedure is to guide the subject through the test. The experimenter should not be allowed to read the words out loud.

After the administration of the Selective Reminding Test, the experimenter should record the number of words that were recalled.

Scoring:

The SRT is scored according to the rules of Gardner (1970, p. 104).

A word is counted as recalled if it is recalled on any trial.

The number of words recalled is the number of words recalled.

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Selective Reminding Test (English)

B	Words	1	2	3	4	5	6
	Bottle						
	Fields						
	Gir						
	Temple						
	Star						
	Animal						
	Forest						
	Lake						
	Clock						
	Office						
	Summer						
	Mountain						

	1	2	3	4	5	6
Long Term Storage						
Consistent Long Term Retrieval						

Test Description: 10/36 Spatial Recall Test

Objective:

The subject will be able to recognize a checkerboard design after a 10-second delay.

Material:

Construction and development of a checkerboard.

Administration:

Place the empty checkerboard in front of the subject. Introduce the checkerboard to the subject as follows: "This checkerboard is blank."

"This is a test of visual memory."

"In a moment I will show you a checkerboard that is like the one in front of you, except that I will have a design on it that is not on it."

"I'm going to let you look at it for ten seconds, then I'm going to take it away and have you make another one as nearly like it as you can."

Display the checkerboard for ten seconds. The checkerboard will appear as follows: (The checkerboard is a 4x4 grid of squares. The top row has 3 squares, the second row has 4 squares, the third row has 3 squares, and the fourth row has 4 squares. The checkerboard is shown in a perspective view.) The subject is asked to make another checkerboard as nearly like the checkerboard in front of him as he can. The checkerboard is shown as follows:

When the checkerboard is removed, the subject is asked to make another checkerboard as nearly like the checkerboard in front of him as he can.

"I'm going to show you that same design."

"After you look at it for ten seconds, I'll ask you to try to make it again."

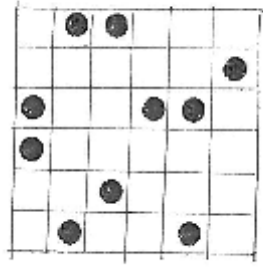
Remove the checkerboard as instructed. The checkerboard is shown as follows:

After the delayed recall of the Selective Reminding Test The subject will be able to recognize a checkerboard after a 10-second delay.

Scoring:

Record the number of checkerboards that the subject makes that are as nearly like the checkerboard in front of him as he can. The checkerboard is shown as follows:

Spatial Recall Test / B



Serial position
Serial position



Serial position
Serial position



Serial position
Serial position

Test Description: Symbol Digit Modalities Test

Objective:

The Symbol Digit Modalities Test is a visual perceptual and motor memory test that is used to measure attention, processing speed, and visual-motor coordination.

Material:

See code
Practice Test Form 1000-0

Administration:

15 to 20 minutes

*"Look at these boxes (point to 4).
Notice that each has a mark in the upper part and a number in the lower part.
Each mark has a different number."*

"Now look down here (point) where the boxes have marks in the top part but the lower part of the boxes is blank. I'll tell you in what number the dot goes in each box. Like this."

Demonstrate with the test table.

"Now, when I say 'BEGIN' you tell me which number should go in each of these boxes, up to this double line (point to double line)."

"If it is a right number, the number goes in the box. If not, the number is marked as

incorrect and you can't use it again."

"When I say 'BEGIN', work as quickly as you can, telling me what number should go in each box."

Begin here, and do as many as you can, without skipping any.

You may want to keep track of where you are with your finger.

When you finish one row, just go on to the next.

Keep working as quickly as you can, without making any mistakes, until I say 'STOP'."

After subject finishes 30 seconds.

Scoring:

Count the number of correct responses in the 30-second period.

+	┌	└	◌	┌)	>	(◌
1	2	3	4	5	6	7	8	9

(┌ ◌ (┌ > ◌ ┌ (> ◌ (> (◌)

┌ > (◌ ┌ > ┌ ┌ (◌ > ◌ ┌ ┌)

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◌ ┌ ┌ (> ┌ (┌ > + ◌) ┌ > ┌

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Test Description: Paced Auditory Serial Addition Test (PASAT)

Objective:

The Paced Auditory Serial Addition Test (PASAT) is a measure of auditory attention and working memory. It is a serial task that requires the examinee to listen to a series of numbers and add them together to produce a running total. The test is designed to measure the ability to process and store information in memory while performing a task.

Material:

The test material consists of a series of numbers that are spoken at a rate of 1 every 3 seconds.

Instructions:

Read the examiner's test:

On this test you are going to hear a series of single digit numbers that will be presented at the rate of 1 every 3 seconds.

Listen for the first 2 digits, add them up, and tell me the answer.

When you hear the next number, add it to the sum you heard right before this.

Continue to add the next number to the preceding one.

Remember, you are not being asked to give me a cumulative total, but rather the sum of the 2 numbers spoken in a row.

For example, if you were given the numbers 6, 7, 5, and 2, you would say 13, 12, and 5.

It is very important that you do not give me a cumulative total, but rather the sum of the 2 numbers spoken in a row.

This is a difficult task. If you should lose your place, just jump right back to the last 2 numbers in a row and add them up.

There are some practice items in the beginning of the test.

Let's try these:

Try the numbers 6, 7, 5, and 2. The examiner says:

6, 7, 5, and 2. The examiner says:

6, 7, 5, and 2. The examiner says:

6, 7, 5, and 2. The examiner says:

6, 7, 5, and 2. The examiner says:

6, 7, 5, and 2. The examiner says:

For part 2, the examiner says

There is a second part to this test, identical to the first, except now the numbers are coming a little faster, one every 2 seconds.

Let's try the practice items:

Try the numbers 6, 7, 5, and 2. The examiner says:

Scoring:

The test is scored by counting the number of correct answers. The maximum score is 10.

Sample Item 1 _____ Correct _____ Wrong _____ Blank _____ Missed _____

Number correct _____ Number wrong _____ Number blank _____ Number missed _____

Paced Auditory Serial Addition Test (PASAT) - B

3 seconds rate

Start	2	6	7	8	6	4	1	3	4
4	10	12	10	11	19	12	8	2	2
3	8	2	0	3	5	1	2	7	0
4	9	5	10	12	10	10	7	19	2
3	1	8	0	2	0	7	4	2	0
0	3	0	10	19	17	19	0	8	13
1	2	8	0	6	0	5	0	1	0
17	2	7	13	12	14	10	10	6	8
4	2	2	0	1	7	3	0	3	0
8	0	7	9	7	3	10	12	10	10
1	0	3	2	0	4	6	7	1	4
10	2	8	7	8	10	13	14	2	0

Test completed

2 seconds rate

7-2	0	2	7	0	0	1	2	3	0
10	14	1	19	12	11	10	0	5	14
0	0	0	0	0	0	1	0	0	0
10	0	8	7	14	10	0	0	11	0
7	4	2	8	0	3	0	0	3	7
10	3	0	3	0	1	14	0	2	10
0	0	0	0	0	3	7	2	1	0
10	8	7	10	10	5	10	11	0	0
0	0	1	0	0	0	7	1	0	0
0	0	0	0	0	10	10	0	0	10
0	0	0	0	1	0	1	0	0	0
10	0	0	10	0	10	10	0	10	10

Test completed

Page 10

Selective Reminding Test (English)

Instruction:

*"Now try to tell me the whole list of 12 words again.
Be sure we worked on several times."*

B

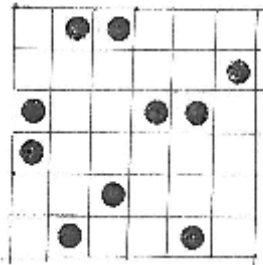
Delayed Recall	
Words	Delay
Bottle	
Fogate	
Girl	
Temple	
Star	
Animal	
Forest	
Lake	
Object	
Officer	
Summer	
Mountain	

Total Delay:
Number of recalled words:

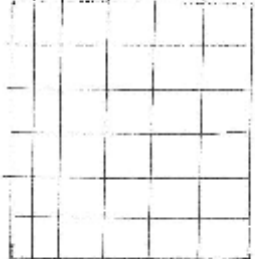
Spatial Recall Test / B

Delayed Recall

- Write the name for the design in front of the subject for the design on the design card and on the design card.
- The design is the top.
- "I would like you to make that design again the way you worked on the first page."
- Record the number of correct designs as correct.



Delayed Recall



WISC-III-R Manual
 WISC-III-R Manual

Test Description: Word List Generation / B

Objective:

Word List Generation tests your ability to generate words that correspond to a given semantic category and produce a list of words.

Material:

Word List

Administration:

15-20 minutes per trial

I'm going to give you a category name and I want you to tell me as many words as you can that are associated with this category.

For example, if the category was "fish", you could say "sea", "tuna", "shrimp", "fish", etc.

I do not want you to use the same word over again by adding a different ending and saying "hammer", "hammering", etc.

Just tell me as many words as you can. You'll have 90 seconds to do this. I'll tell you when to start and stop.

The participant is then told to begin and the test is administered using the word list.

90 seconds is allowed for seconds are up, the test is done, and the list of words is done.

For example, the following words could be used:

The words are listed in the word list.

The category is "animals".

You may begin.

Scoring:

During the test, the participant is asked to generate as many words as possible that are associated with the category. The words are then listed in the word list.

Chicago Multiscale Depression Inventory

Rate, using scale, how much you have felt like the words on the left in the past week including today. 1 indicates never feeling this emotion during the week and 5 indicates extremely feeling this emotion during the week.

	Not at all	A little	Moderately	Quite a bit	Extremely
	1	2	3	4	5
Sad	1	2	3	4	5
Joyful	1	2	3	4	5
Easily awakened	1	2	3	4	5
Inferior	1	2	3	4	5
Unable to pay attention	1	2	3	4	5
Glum	1	2	3	4	5
Exhausted	1	2	3	4	5
Woeful	1	2	3	4	5
Blue	1	2	3	4	5
Worthless	1	2	3	4	5
Unhappy	1	2	3	4	5
Punished	1	2	3	4	5
Tired	1	2	3	4	5
Sluggish	1	2	3	4	5

	Not at all	A little	Moderately	Quite a bit	Extremely
	1	2	3	4	5
Cheerless	1	2	3	4	5
Energetic	1	2	3	4	5
A failure	1	2	3	4	5
Low	1	2	3	4	5
Loved	1	2	3	4	5
Unable to concentrate	1	2	3	4	5
Poor appetite	1	2	3	4	5
Despised	1	2	3	4	5
Hated	1	2	3	4	5
Fitful sleep	1	2	3	4	5
Criticised	1	2	3	4	5
Fatigued	1	2	3	4	5
Forgetful	1	2	3	4	5
Capable	1	2	3	4	5
Dreary	1	2	3	4	5
Trouble falling asleep	1	2	3	4	5
Rejected	1	2	3	4	5
Despairing	1	2	3	4	5

	Not at all	A little	Moderately	Quite a bit	Extremely
	1	2	3	4	5
Happy	1	2	3	4	5
Weak	1	2	3	4	5
Gloomy	1	2	3	4	5
Forgotten	1	2	3	4	5
Active	1	2	3	4	5
Sorrowful	1	2	3	4	5
Somber	1	2	3	4	5
Useless	1	2	3	4	5
Miserable	1	2	3	4	5
Alert	1	2	3	4	5
Resented	1	2	3	4	5
Uninterested in sex	1	2	3	4	5
Unwanted	1	2	3	4	5
Peaceful	1	2	3	4	5
Restless	1	2	3	4	5
Deserted	1	2	3	4	5
Grim	1	2	3	4	5
Unworthy	1	2	3	4	5

**Self – Evaluation Questionnaire.
STA1 Form Y-1**

A number of statements which people have used to describe themselves are given below. Read each statement and then choose the appropriate number to indicate how you *feel right now*, that is at *this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately so	Very much so
	1	2	3	4
1. I feel calm.	1	2	3	4
2. I feel secure.	1	2	3	4
3. I am tense.	1	2	3	4
4. I feel strained.	1	2	3	4
5. I feel at ease.	1	2	3	4
6. I feel upset.	1	2	3	4
7. I am presently worrying over misfortunes.	1	2	3	4
8. I feel satisfied.	1	2	3	4
9. I feel frightened	1	2	3	4
10. I feel comfortable.	1	2	3	4
11. I feel self confident.	1	2	3	4

	Not at all	Somewhat so	Moderately so	Very much so
	1	2	3	4
12. I feel nervous.	1	2	3	4
13. I am jittery.	1	2	3	4
14. I feel indecisive.	1	2	3	4
15. I am relaxed.	1	2	3	4
16. I feel content.	1	2	3	4
17. I am worried.	1	2	3	4
18. I feel confused.	1	2	3	4
19. I feel steady.	1	2	3	4
20. I feel pleasant.	1	2	3	4

A number of statements which people have used to describe themselves are given below. Read each statement and then choose the appropriate number to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	Almost never	Sometimes	Often	Almost always
	1	2	3	4
21. I feel pleasant.	1	2	3	4
22. I feel nervous and restless.	1	2	3	4
23. I feel satisfied.	1	2	3	4
24. I wish I could be as happy as others seem to be.	1	2	3	4

25. I feel like a failure.	1	2	3	4
26. I feel rested.	1	2	3	4
27. I am 'calm, cool and collected.'	1	2	3	4
28. I feel that difficulties are piling up so that I cannot overcome them.	1	2	3	4
29. I worry too much over something that doesn't really matter.	1	2	3	4
30. I am happy.	1	2	3	4
31. I have disturbing thoughts.	1	2	3	4
32. I lack self confidence.	1	2	3	4
33. I feel secure.	1	2	3	4
34. I make decisions easily.	1	2	3	4
35. I feel inadequate.	1	2	3	4
36. I am content.	1	2	3	4
37. Some unimportant thought runs through my mind and bothers me.	1	2	3	4
38. I take disappointments so keenly that I can't put them out of my mind.	1	2	3	4
39. I am a steady person.	1	2	3	4
40. I get in a state of				

tension or turmoil as I think over my recent concerns and interests.	1	2	3	4
--	---	---	---	---

Anger Rumination Scale

This questionnaire looks at how people think about anger. We are not expecting that everyone feels/or has felt like all of the statements below, but MS does provoke some extreme emotions and we just want to check this out.

Please rate on the scale how likely each statement is of you, with 1= almost never, and 4 = almost always.

	Almost never			Almost always
	1	2	3	4
I re-enact the anger episode in my mind after it has happened.	1	2	3	4
When something makes me angry, I turn this matter over and over again in my mind.	1	2	3	4
Memories of even minor annoyances bother me for a while.	1	2	3	4
After an argument is over, I keep fighting with this person in my imagination.	1	2	3	4
Memories of being aggravated pop into my mind before I fall asleep.	1	2	3	4
I have long living fantasies of revenge after the conflict is over.	1	2	3	4
When someone makes me angry I can't stop thinking about how to get this person back.	1	2	3	4
I have day dreams and fantasies of violent nature.	1	2	3	4

I have difficulty forgiving people who have hurt me.	1	2	3	4
I ponder about the injustices that have been done to me.	1	2	3	4
I keep thinking about events that angered me for a long time.	1	2	3	4
I feel angry about certain things in my life.	1	2	3	4
I ruminate about my past anger experiences.	1	2	3	4
I think about certain events from a long time ago and they still make me angry.	1	2	3	4
I think about the reasons people treat me badly.	1	2	3	4
When someone provokes me, I keep wondering why this should happen to me.	1	2	3	4
I analyse events that make me angry.	1	2	3	4
I have had times when I could not stop being preoccupied with a particular conflict.	1	2	3	4

Anger Scale

A number of statements that people use to describe themselves are given below. Read each statement and then using the 1-4 scale below, indicate how you *feel right now*. Remember that there are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to best describe your present feelings. The 1-4 scale is;

1= Not at all

2= Somewhat

3= Moderately

4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

A number of statements that people use to describe themselves are given below. Read each statement and then using the 1-4 scale below, indicate how you *generally feel*. Remember that there are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to best describe how you generally feel. The 1-4 scale is;

1= Almost never

2= Sometimes

3= Often

4= Almost always

11. I am quick tempered.

12. I have a fiery temper.

13. I am a hotheaded person.

14. I get angry when I'm slowed down by others mistakes.

15. I feel annoyed when I am not given recognition for my work.

16. I fly off the handle.

17. When I get mad I say nasty things.

18. It makes me furious when I am criticized in front of others.

19. When I get frustrated, I feel like hitting someone.

20. I feel infuriated when I do a good job and get a poor evaluation.

Everyone feels angry or furious from time to time, but people differ in the ways that they react when they are angry. A number of statements are listed below which people use to describe their reactions when they feel angry or furious. Read each statement and then using the 1-4 scale below, indicate how often you generally react or behave in the manner described when you are feeling angry or furious. Remember that there are no right or wrong answers. Do not spend too much time on any one statement. The 1-4 scale is;

1= Almost never

2= Sometimes

3= Often

4= Almost always

21. I control my temper. _____

22. I express my anger. _____

23. I keep things in. _____

24. I am patient with others. _____

25. I pout or sulk. _____

26. I withdraw from people. _____

27. I make sarcastic remarks to others. _____

28. I keep my cool. _____

29. I do things like slam doors. _____

30. I boil inside but I don't show it. _____

31. I control my behaviour. _____

32. I argue with others. _____

33. I tend to harbor grudges that I don't tell anyone about. _____

1= Almost never

2= Sometimes

3= Often

4= Almost always

34. I strike out at whatever infuriates me. _____

35. I can stop myself from losing my temper. _____

36. I am secretly quite critical of others. _____

37. I am angrier than I am willing to admit. _____

38. I calm down faster than most other people. _____

39. I say nasty things. _____

40. I try to be tolerant and understanding. _____

41. I'm irritated a great deal more than people are aware of. _____

42. I lose my temper. _____

43. If someone annoys me, I'm able to tell him or her how I feel. _____

44. I control my angry feelings. _____

WTAR Word List

We don't expect people to read all these words, so don't worry if you find it difficult. Please pronounce the words below. Beginning with the first word on the list, pronounce each word aloud. Start with the first word 'again,' and go down this column, one after the other, without skipping any. When you finish this column, go to the next column. Pronounce each word even if you are unsure.

Again	Amphitheatre	Exigency
Address	Lieu	Xenophobia
Cough	Grotesque	Ogre
Preview	Iridescent	Scurrilous
Although	Ballet	Ethereal
Most	Equestrian	Paradigm
Excitement	Porpoise	Perspicuity
Know	Aesthetic	Plethora
Plumb	Conscientious	Lugubrious
Decorate	Homily	Treatise
Fierce	Malady	Dilettante
Knead	Subtle	Vertiginous
Aisle	Fecund	Ubiquitous
Vengeance	Palatable	Hyperbole
Prestigious	Menagerie	Insouciant
Wreath	Obfuscate	Hegemony
Gnat	Liaison	

The Perceived Social Support Scale

We are interested in how you feel about the following statements. Read each statement carefully; indicate how you feel about each statement by choosing the appropriate number from the 1-7.

Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly Agree	Very strongly agree
1	2	3	4	5	6	7

1. There is a special person who is around when I am in need.

2. There is a special person with whom I can share joys and sorrows.

3. My family really tries to help me.

4. I get emotional help and support I need from my family.

5. I have a special person who is a real source of comfort for me.

6. My friends really try to help me.

7. I can count on my friends when things go wrong.

8. I can talk about my problems with my family.

9. I have friends with whom I can share my joys and sorrows.

10. There is a special person in my life who cares about my feelings.

11. My family is willing to help me make decisions.

12. I can talk about my problems with friends.

Fatigue Severity Scale

We are interested in the types of fatigue you experience, what impact this has on you and how often. Read each statement below and choose the appropriate number, using the 1-7 scale below, which accurately describes each statement. The 7- point scale is as follows:

1= Strongly disagree

2= Disagree

3= Slightly disagree

4= Neither agree or disagree

5= slightly agree

6= Agree

7= Strongly agree

1. My motivation is lower when I am fatigued.

2. Exercise brings on my fatigue.

3. I am easily fatigued.

4. Fatigue interferes with my physical functioning.

5. Fatigue causes frequent problems for me.

6. My fatigue prevents sustained physical functioning.

7. Fatigue interferes with carrying out certain duties and responsibilities.

8. Fatigue is among my three most disabling symptoms.

9. Fatigue interferes with work, family, or social life.

Appendix 4

Demographic Information for HCP's

Age _____

Gender _____

Ethnicity _____

Marital status _____

Employment status _____

How long have you been in your current job? _____

Are you currently on any Medication? _____

Do you have any history of mental illness? _____

Do you have any physical disabilities? _____

Demographic Information for Patients

Age _____

Gender _____

Ethnicity _____

Marital status _____

Employment status _____

Medication _____

Type of MS _____

Year diagnosed _____

Year of first symptom _____

Vignettes (Response Styles)

Vignette One

Scenario Ahmed has been prescribed a new type of medication for his MS. However he feels that it is not working and is now refusing to take it. He is at the MS clinic visiting his MS nurse George discussing medication.

Nurse Response ‘Look Ahmed, you have to take your medication otherwise you won’t know if it works or not. We all have to do things we don’t like, so come on hurry up and take it, there’s a good boy.’

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse to Ahmed* makes you feel, *not* how angry Ahmed’s refusal to take the medication makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Two

Scenario Ahmed has been prescribed a new type of medication for his MS. However he feels that it is not working and is now refusing to take it. He is at the MS clinic visiting his MS nurse George discussing medication.

Nurse Response ‘You need to take your medication to see if it working. Take your medication until the end of the week, if you still feel it is not working then we will have a chat to the doctors.’

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse to Ahmed* makes you feel, *not* how angry Ahmed’s refusal to take the medication makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Three

Scenario Ahmed has been prescribed a new type of medication for his MS. However he feels that it is not working and is now refusing to take it. He is at the MS clinic visiting his MS nurse George discussing medication.

Nurse Response ‘Hey I understand that you must be sick of trying new drugs all the time, and I expect you just want them to start working straight away. Unfortunately you need to take them just a little bit longer to see what affect they do have. I know it must be hard having to take these drugs and then not seeing any immediate affect. So let’s see if we can work this out. You can either take them until the end of the week and we can see what happens? Or you can stop taking them and have another chat with the doctor, see if there is anything else he can recommend? What do you think? How do you feel about this Ahmed?’

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse to Ahmed* makes you feel, *not* how angry Ahmed’s refusal to take the medication makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Four

Scenario Roberto is wheelchair bound and is visiting the MS clinic and has an appointment with his nurse, he is waiting for his nurse in the outpatients room. Roberto needs to go to the toilet but needs some help out of his wheelchair. He asks a nearby busy nurse to help him.

Nurse Response 'Everyone can wait five minutes, or so they say.'

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse* to Roberto makes you feel, *not* how angry Roberto's incontinence makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Five

Scenario Roberto is wheelchair bound and is visiting the MS clinic and has an appointment with his nurse, he is waiting for his nurse in the outpatient's room. Roberto needs to go to the toilet but needs some help out of his wheelchair. He asks a nearby busy nurse to help him.

Nurse Response 'Hi there Roberto. Ok, I will be with you in a couple of minutes; I've just got to finish this paper work. Then I will help you out of that wheelchair to go to the toilet.'

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse* to Roberto makes you feel, *not* how angry Roberto's incontinence makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Six

Scenario Roberto is wheelchair bound and is visiting the MS clinic and has an appointment with his nurse, he is waiting for his nurse in the outpatients room. Roberto needs to go to the toilet but needs some help out of his wheelchair. He asks a nearby busy nurse to help him.

Nurse Response ‘Roberto, good to see you again! I can see that you need to use the toilet. I know you need a little bit of help getting out your wheelchair. But I am just attending another patient right now. I will be with you in a couple of minutes is that okay? Or would you like me to get someone else to help you?’ Your choice, which is best?

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse to Roberto* makes you feel, *not* how angry Roberto’s incontinence makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Seven

Scenario Hardeep is feeling low and depressed because her partner of five years is leaving her. Her partner said that he cannot cope with the demands of Hardeep's MS anymore. Her MS nurse is visiting her.

Nurse Response 'Cheer up Hardeep; it's not the end of the world. You shouldn't cry over spilt milk. Imagine what state you would be in, if it was some major crisis happening!'

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse to Hardeep* makes you feel, *not* how angry it makes you feel that Hardeep's partner is leaving her. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Eight

Scenario Hardeep is feeling low and depressed because her partner of five years is leaving her. Her partner said that he cannot cope with the demands of Hardeep’s MS anymore. Her MS nurse is visiting her.

Nurse Response ‘Ah Hardeep, why don’t I make us a cup of tea, that will make things better.’

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse to Hardeep* makes you feel, *not* how angry it makes you feel that Hardeep’s partner is leaving her. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

- 1. I am furious. _____
- 2. I feel irritated. _____
- 3. I feel angry. _____
- 4. I feel like yelling at somebody. _____
- 5. I feel like breaking things. _____
- 6. I am mad. _____
- 7. I feel like banging on the table. _____
- 8. I feel like hitting someone. _____
- 9. I am burned up. _____
- 10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Vignette Nine

Scenario Hardeep is feeling low and depressed because her partner of five years is leaving her. Her partner said that he cannot cope with the demands of Hardeep's MS anymore. Her MS nurse is visiting her.

Nurse Response 'I am very sorry to hear that Hardeep, I know how close you two were. I understand you are going to need a lot of support and I will help you as much as I can. It' Now you freshen up and we'll have a chat.'

Please now rate your anger levels of the anger scale. I am interested in how angry the *behaviour and statements made by the nurse* to Hardeep makes you feel, *not* how angry it makes you feel that Hardeep's partner is leaving her. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____
9. I am burned up. _____
10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Appendix 5

Demographic Information for HCPs

Age_____

Gender_____

Ethnicity_____

Marital status_____

Employment status_____

How long have you been in your current job?_____

Are you currently on any Medication?_____

Do you have any history of mental illness?_____

Do you have any physical disabilities?_____

Demographic Information for Patients

Age _____

Gender _____

Ethnicity _____

Marital status _____

Employment status _____

Medication _____

Type of MS _____

Year diagnosed _____

Year of first symptom _____

Vignettes (Communication)

Here are some scenarios. Please read each scenario carefully. After reading a scenario, please use the anger rating scale below, to rate how angry each situation would make you feel.

Scenario 1

Phyllis, an MS Nurse arrives on a morning visit to Jane, a 41 year old woman with MS. Jane has been using a wheelchair for the last few months. Phyllis greets Jane and asks Jane how she is feeling and how things are going for her. Jane says that her back has been bothering her and she has been getting some pain. Phyllis asks if Jane has been able to manage the pain and Jane says she has got some pain killers from her GP which help a bit. Phyllis says it is good that Jane was able to manage the situation. Phyllis asks if anything else is bothering Jane. Jane says she has noticed some constipation, which has been a bit uncomfortable. Phyllis mentions that this might be linked to the pain killers and suggest some things that might improve things. Jane is pleased to hear that this is likely to be a secondary effect of her pain drugs and not a symptom of her MS advancing. Jane says she will call Phyllis in a week or two to let Phyllis know whether her constipation has settled.

Please now rate how angry this scenario would make you feel if you were Jane. I am interested in how angry the *behaviour and statements made by the nurse* to Jane makes you feel, *not* how angry Jane's pain or constipation makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____

6. I am mad. _____

7. I feel like banging on the table. _____

8. I feel like hitting someone. _____

9. I am burned up. _____

10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Scenario 2

Naomi, an MS nurse is visiting Kirsten, a 39 year old woman with MS who is finding it increasingly difficult to walk, even with a walking stick. After a quick greeting, Naomi asks Kirsten if she has been able to walk the whole distance to the local shop this week. Kirsten says no and that a neighbour has been doing her shopping. Naomi asks Kirsten if she's been able to manage her bladder without accidents for the last few weeks. Kirsten says that it has been hard to get to the loo in time, but at least she only has to rush to pee. Naomi asks if Kirsten is constipated and if it is getting worse. Kirsten says it is, and is worried it may signal that her MS is progressing. Naomi says that she will keep the situation under review and call again in a few weeks.

Please now rate how angry this scenario would make you feel if you were Kirsten. I am interested in how angry the *behaviour and statements made by the nurse* to Kirsten makes you feel, *not* how angry Kirsten's disability or constipation makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____
8. I feel like hitting someone. _____

9. I am burned up. _____

10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Scenario 3

Priya has MS and is a married 35 year old woman with two young children. She has asked Sonia, her MS Nurse, to visit her at short notice. Sonia could hear the strain in Priya's voice when she telephoned and asked if Priya wanted to talk over the phone immediately. Priya preferred to speak face to face and so Sonia visited the next day. Priya looked pale and tired and Sonia noticed her eyes were red. Sonia made small talk with Priya while she made two coffees and sat calmly on a kitchen stool, letting the small talk die away. She waited for Priya to open up. There was a pause, and then Priya began to sob. Sonia gently lifted Priya's coffee out of her grasp and put it down, as she placed an arm round her shoulders and waited for her to speak. Priya choked out that her husband was leaving her. He could no longer cope with her increasing disability, chronic fatigue and the childcare demands placed on him as a result. Sonia said she was sorry that Priya was in this situation, on top of her MS. Priya could understand how Sonia must feel and offered her support to help her through this crisis. Priya was grateful that Sonia didn't offer false cheer. They both knew that this was a searing loss for Priya, but Priya felt she could rely on Sonia for help at this difficult time. Sonia offered to come back at the start of next week to check on Priya. Priya happily agreed to this and said goodbye to Sonia with a gentle hug.

Please now rate how angry this scenario would make you feel if you were Priya. I am interested in how angry the *behaviour and statements made by the nurse* to Priya makes you feel, *not* how angry it makes you feel that Priya's husband has left her. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____

6. I am mad. _____

7. I feel like banging on the table. _____

8. I feel like hitting someone. _____

9. I am burned up. _____

10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Scenario 4

Tara is 40 years old and has been with her partner for 10 years. Tara has MS and one young child. She telephoned her MS nurse Joyce, and asked her to come and see her as soon as possible as she was going through a personal crisis and needed support. Joyce gave her an appointment in two weeks time and is visiting her this morning. Joyce greets Tara and follows her through to the lounge. Tara strikes up conversation about the weather and how cold it has been lately. Joyce nods her head and agrees. Joyce then asks why she rang and asked to see her. Tara begins to break down and sobs that her partner has left her. Joyce shakes her head and asks if he said why he was leaving. Tara says that he says he finds the disabilities that MS causes too hard to deal with. Joyce tells Tara to cheer up and that this does not mean that she will be alone forever. Tara sobs that he is the only man she has ever loved. Joyce says that she is bound to feel like this but in time she will find someone else. Tara nods her head disappointedly and wipes her tears away. Joyce then looks at her watch and gets up to leave, she says goodbye to Tara and as she is leaving shouts that she will be in touch in a couple of weeks.

Please now rate how angry this scenario would make you feel if you were Tara. I am interested in how angry the *behaviour and statements made by the nurse* to Tara makes you feel, *not* how angry it makes you feel that Tara's partner has left her. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____

7. I feel like banging on the table. _____

8. I feel like hitting someone. _____

9. I am burned up. _____

10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Scenario 5

Anita an MS nurse is visiting Fred her 52 year old patient, who is now practically bed bound with MS. His wife Lillian is very devoted, but inevitable feels the strain at times and is particularly saddened that Fred's spasms and sleep disturbance now mean they sleep in separate rooms. Lillian greets Anita at the door with a cheerful smile, and Anita marvels at her resilience. Once in Fred's bedroom, Anita breaks the ice by joking that Lillian has at last got Fred to take some rest (his over activity in more mobile days had exacerbated his fatigue). Fred and Lillian smile at this and are grateful to be seen by an MS nurse who knows their history and always manages to cheer them up. Fred explains that his leg spasms have been troublesome and just on cue, his right leg shoots out from under the bedcovers. Anita chuckles and says that Fred could be playing for England but Fred says it is all own goals these days. Anita feels the increased tone in Fred's legs and suggests that they get a physio to visit for further advice. Lillian accompanies Anita to the door. Lillian says that it's hard to sleep apart from Fred; she never thought she'd miss his snoring, but she does. Anita says that Lillian could always leave the doors open, so she can still hear him, and at least Lillian's not at risk of being kicked out of bed. Both women smile their goodbyes and Anita makes a note to visit them again soon to check the physio visit has been successful.

Please now rate how angry this scenario would make you feel if you were Fred. I am interested in how angry the *behaviour and statements made by the nurse* to Fred makes you feel, *not* how angry Fred being bed bound makes you feel. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____

6. I am mad. _____

7. I feel like banging on the table. _____

8. I feel like hitting someone. _____

9. I am burned up. _____

10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Scenario 6

Rita an MS nurse is visiting Nelson, her 50 year old MS patient. Nelson has been bed bound for the last 6 months. His wife Janet cares for him full time. Janet is deeply upset that Nelson has now moved to the spare room, due to his increasing disturbed sleep and spasms in his arms. Janet greets Rita at the door with a smile and takes her up to Nelson's room. After greeting each other Nelson explains that he now tends to get spasms in his arm. Rita nods her head and examines Nelson's arm, just then a spasm causes Nelson's right arm to punch out toward the nurse. Janet jokes that Nelson could be a boxer, Janet and Nelson both laugh lightly as Rita continues assessing the arm. Rita suggests that they ask a physio to come out and suggest what types of exercises Nelson could do to help his spasms. Rita checks her watch a few times and then Janet walks Rita to the door. Janet says jokingly that she does not miss sharing the same bed as him and fighting for her half of the duvet. Rita checks her watch again and says goodbye. Rita wonders how Janet and Nelson can stay so cheerful.

Please now rate how angry this scenario would make you feel if you were Nelson. I am interested in how angry the *behaviour and statements made by the nurse* to Nelson makes you feel, *not* how angry it makes you feel that Nelson is bed bound of having spasms. Please use the scale below:

1= Not at all, 2= Somewhat, 3= Moderately, 4= Very much so

How I Feel Right Now

1. I am furious. _____
2. I feel irritated. _____
3. I feel angry. _____
4. I feel like yelling at somebody. _____
5. I feel like breaking things. _____
6. I am mad. _____
7. I feel like banging on the table. _____

8. I feel like hitting someone. _____

9. I am burned up. _____

10. I feel like swearing. _____

Please feel free to add any extra comments about why this scenario is anger provoking. However you are not obliged to.

Appendix 6

Demographic Information for HCPs

Age_____

Gender_____

Ethnicity_____

Marital status_____

Employment status_____

How long have you been in your current job?_____

Are you currently on any Medication?_____

Do you have any history of mental illness?_____

Do you have any physical disabilities?_____

**Experience Reflective Survey
Part 1**

A. Professional anger

1. How often do you find yourself feeling angry at work?
 - a) Hardly ever
 - b) Quite often
 - c) Frequently
 - d) Almost all the time

2. What makes you angry? (rank in order of importance)
 - e) Repetitive questions by patients
 - f) Other patient demands
 - g) Carer demands
 - h) Other professionals
 - i) Limited resources
 - j) NHS policies/admin

2. Do you feel that you can manage your anger and are adequately supported?
 - a) Almost all the time
 - b) Frequently
 - c) Quite often
 - d) Hardly ever

4. Have you experienced displays of anger from other professionals?
 - a) Hardly ever
 - b) Quite often
 - c) Frequently
 - d) Almost all the time

5. Do you feel that you can manage their anger and are adequately supported?
 - a) Almost all the time
 - b) Frequently
 - c) Quite often
 - d) Hardly ever

Any further comments?

B Patient anger

6. Have you experienced displays of anger from patients?
 - a) Hardly ever
 - b) Quite often
 - c) Frequently
 - d) Almost all the time

7. What makes them angry? (rank in order of importance)
 - e) your actions
 - f) actions of other professionals
 - g) limited healthcare resources
 - h) physical restrictions of MS
 - i) low mood increasing their irritability
 - j) cognitive impairment leading to disinhibition
 - k) financial pressures

8. How much of your patient contact time is spent managing patient anger?
 - a) less than a quarter
 - b) less than half
 - c) three quarters
 - d) almost all
 - e) hours per week

9. Does patient anger interfere with (rank in order of importance)
 - a) communication with you
 - b) access to other professionals
 - c) appropriate use of medication
 - d) self management of MS symptoms
 - e) patient's family relationships

10. Do you feel that you can manage their anger and are adequately supported?
 - l) Almost all the time
 - m) Frequently
 - n) Quite often
 - o) Hardly ever

Any further comments?

Part 2

Drawing on your own personal experience as a health professional, please answer the following questions, in as much detail as possible on anger which you have encountered in your professional role. Thank you for your time.

1) From your own experiences, please highlight practices or types of ‘nursing styles’ you have used when dealing with patients, which have evoked an angry response from a patient.

2) In the situations above, do you feel that there was anything you could have done to stop the anger arising from the patient?

3) Which situations/interactions causes you to have anger towards a patient?

4) Do you feel that you have sufficient training and awareness of why anger arises in MS patients and health professionals like yourself?

5) If not, what sorts of training would be useful to you?

Appendix 7

Demographic Information for Patients

Age _____

Gender _____

Ethnicity _____

Marital status _____

Employment status _____

Medication _____

Type of MS _____

Year diagnosed _____

Year of first symptom _____

Anger Questionnaire

Please answer the following questions in as much detail as possible on anger and frustrations of living with MS. Even if you do not find yourself to be an angry person your comments will very much be appreciated.

Please post this back along with the consent form and background questions in the free post envelope provided.

- 1) How often do you become angry/frustrated because of your MS? (e.g. every day, one a week, once a month).

- 2) Was there any point during the course of your MS (from diagnosis to currently) that you became angrier than you are now?

- 3) Why do you become angry/frustrated with MS?

- 4) Do you get or have you ever got angry at health professionals like doctors and nurses? If so why?

- 5) Do you feel that anger can affect your healthcare or health?

- 6) Do you feel that your anger/frustrations affect your family members? If so how?

- 7) Please add any further comments on your personal experience of anger and frustration with living with MS.