PHYSICAL DISABILITY AND PSYCHOLOGICAL DISTRESS IN MULTIPLE SCLEROSIS: THE ROLE OF ILLNESS REPRESENTATIONS AND EXPERIENTIAL AVOIDANCE.

by

James Feeney

Clinical supervisor: Dr Phil Moore
Academic supervisor: Dr Andrew Vidgen

2012

Dissertation submitted in partial fulfillment of the requirements for the degree of D.Clin.Psy at Cardiff University and the South Wales doctoral programme in Clinical Psychology

DECLARATIONS:

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

Signed ..J.M. Feeney..... (candidate) Date ..7/09/12.....

STATEMENT 1

This thesis is being submitted in partial fulfillment of the requirements for the degree of D.Clin.Psy.

Signed ..J.M. Feeney..... (candidate) Date ..7/09/12...

STATEMENT 2

This thesis is the result of my own independent work/investigation, except where otherwise stated.
Other sources are acknowledged by explicit references.

Signed ..J.M. Feeney..... (candidate) Date ..7/09/12...

STATEMENT 3

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed ..J.M. Feeney..... (candidate) Date ..7/09/12.

STATEMENT 4: PREVIOUSLY APPROVED BAR ON ACCESS

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loans **after expiry of a bar on access previously approved by the Graduate Development Committee.**

Signed ..... (candidate) Date .....

ACKNOWLEDGEMENTS:

I would like to thank the participants who gave their time to complete this piece of research. I am so grateful to those who took the time to fill out my questionnaires; the research was all the more interesting for having responses in it!

Thanks to all the staff at the Helen Durham Centre who were so helpful and facilitating of this research project. Also, thanks to Katharine… you have been a massive help, and it's been a pleasure getting to know you.

I would also like to thank my supervisors, Phil Moore and Andrew Vidgen: their interest, feedback and positivity was invaluable in getting to this point. Andrew, you have officially earned "hero" status thanks to your constant openness, support and encouragement. A massive thank you.

I would also like to thank my supervisor Anne Johnson for all her help. Also thanks to all the supervisors (Estie, Julie, Rosemary & Gemma) and tutors on the course who have chatted and pep talked me through the whole training and research process.

Dr Holder: special thanks for being a mentor, friend and all round inspiration!

My cohort: I just don't know what I will do without you all. You have been amazing, and I can't believe that we still aren't living together on a boat yet. Good luck to you all, I've loved being a part of our (my) year.

Mum, Dad and all the Feeney clan, thanks for supporting me through all of this; for believing in me, or maybe just trusting in me. It's been a long road, and I couldn't have done it without your support and love.

Pam, Graham and all the Setters: six years ago we were sat in a restaurant in North Wales with our fingers and thumbs crossed implanting me with good vibes-Setter style. I just wanted to say thanks for being so supportive and understanding, interested and encouraging, all of the time. You've all been a wonderful influence.

Personally my gratitude goes most of all to Gareth. We're almost here. I couldn't have done it without you, I owe you so much (emotionally...the money's non-refundable), and I am so thankful to have you in my life. Thanks for keeping me sane and safe, and for constantly reminding me it's the effort, not necessarily the outcome that can be considered a result. Here's to Conran, Jo, a lack of 10cm, the songs, sometimes the dancing, and good fun all the time!

And lastly thanks to all my friends who have heard more about this research project than anyone else will ever do. You know who you are; thanks for being a part of my life, even though it is now just a boring ole life…have I told you about my thesis?

ABSTRACT:

Objectives: This study explores factors associated with psychological wellbeing and distress in people with Multiple Sclerosis (MS). The role of physical symptoms, illness representations and experiential avoidance in predicting psychological distress was assessed.

Design: Cross-sectional data was collected from 121 participants with a diagnosis of MS. Path analysis was used to test a hypothetical model of distress in MS that hypothesised that experiential avoidance would mediate the relationships between level of symptoms and distress, and between illness representations and distress.

Methods: Participants completed questionnaires assessing level of physical symptoms (EDSS), illness representations (BIPQ), experiential avoidance (AAQ-II), and psychological distress (GHQ-30). Path coefficients, allowing direct and indirect relationships to be evaluated, were obtained from a series of simultaneous multiple regression analyses; one for each endogenous variable (experiential avoidance, distress).

Results: Participants results highlighted significant positive associations between all the variables (symptoms, illness representations, experiential avoidance) and distress. Path analysis revealed that experiential avoidance did not mediate the relationships between level of symptoms and distress, nor illness representations and distress. Illness representations were the strongest predictor of psychological distress, while experiential avoidance was the strongest predictor when distress was conceptualised as depression.

Conclusions: Overall the study did not suggest that experiential avoidance mediates the relationship between illness representations and psychological distress; instead illness representations alone accounted for most of the variance in psychological distress. Experiential avoidance accounted for most of the depression experienced by participants. These results have a direct impact on how psychological interventions are delivered for people with MS, suggesting that disease factors, and beliefs about the illness, need to be taken account of and incorporated into treatment for presenting problems.

TABLE OF CONTENTS

Chapter One: Introduction

LIST OF FIGURES:

LIST OF TABLES:

LIST OF APPENDICES:

CHAPTER ONE: INTRODUCTION

1.1 THESIS OVERVIEW

Chapter One introduces key aspects of the research project. It will start by exploring the concept of experiential avoidance (EA). Before reviewing the relationship between EA and psychological distress by means of a systematic review, Multiple Sclerosis (MS) will be outlined. The chapter will also introduce the concept of illness representations, and the evidence to date of its relationship to psychological distress in MS. The chapter finishes by outlining the aims and objectives of this research including the research question, and clearly outlines the hypothesised path model indicating the proposed relationships between the variables in this study. The Methods chapter, Chapter Two, will introduce the procedures used to complete the research including what measures were used and how the sample was recruited. It will also provide a more in-depth account of path analysis. In Chapter three, the results are presented using path diagrams to consider the relationship between physical disability, illness representations, and EA and psychological distress in people with MS. Finally, Chapter Four, the discussion, concludes with a critical evaluation; as the implications of the results are considered. In this chapter the results are discussed in relation to the existing literature, clinical practice, future research and limitations of the current research.

1.2 INTRODUCTION TO THE STUDY

This research will explore factors that impact on psychological distress in people with MS. In particular the research will explore whether the construct of EA is useful when considering what mediates psychological distress in people with MS. EA has been explored within recent years as a potential mechanism that explains why distress occurs, and why psychological interventions that target EA lead to a decrease in psychological distress. The construct of EA is conceptualised as an unwillingness to remain in contact with private experiences such as painful thoughts and emotions and is often proposed to be critical to the development and maintenance of psychopathology (Hayes *et al.*, 1996).

Empirical evidence illustrates that EA is associated with decreased quality of life across both clinical and non-clinical populations, that it moderates the impact of treatment and

other external events, and that it mediates the impact of stressful life events on a variety of psychological variables including coping styles and emotion regulation strategies (Boulanger *et al.*, 2009). A meta-analysis by Hayes *et al.* (2006) showed that EA, as measured by the Acceptance and Action Questionnaire (AAQ-I, Hayes *et al.,* 2004), accounted for 16-28% of the variance in a range of behavioural health problems (Boulanage *et al.*, 2009). In a systematic review of the evidence for EA as a functional dimension in psychopathology Chawala and Ostafin (2007) highlighted that there is good evidence that EA predicts severity of symptoms in some psychiatric disorders and mediates the relationships between maladaptive coping and self regulatory strategies and psychological distress.

In light of the vast quantities of research emerging in the last ten years (e.g. that has explored EA and its association with psychopathology and maladaptive behaviours), updated research is necessary to help determine the relevance and applicability of this construct to different populations and psychological conditions. While EA has been studied in some clinical health populations (pain: Feldner *et al.*, 2006, Zettle *et al.*, 2005, HIV: Batten *et al.*, 1997) it has not been applied to the MS population.

MS is the most common neurological disease of young adults and implies multiple psychosocial challenges including uncertainty, lack of control, interpersonal difficulties, stigma, visibility of disease and disability. Chronically ill individuals must strive to regain a feeling of normalcy, develop and maintain a positive self-image, control their physical symptoms, and make adjustments to their life roles (Minden & Schiffer, 1990). The amount of stress associated with making these adjustments is argued by Jean *et al.* (1997) to be directly related to the number and severity of disease related symptoms present, interference with work, social, and family environments, the availability and utilization of support systems and the patient's personal assessment of the disease.

Past research has indicated a positive association between the level of disability and psychological distress (e.g. depression) for people with MS, however this finding has not always been upheld in the literature, with equal numbers of studies finding this association, and others not (Arnett *et al.*, 2008). This would suggest the presence of moderators and mediators, for example, use of coping strategies, social support, and perceptions of the illness itself (ibid).

This study is concerned with whether the level of disability explains the levels of psychological distress people with MS experience, or whether this relationship is mediated by illness representations and/or EA.

1.3 THE CONCEPT OF EXPERIENTIAL AVOIDANCE

1.3.1 OVERVIEW

Providing an introduction to EA, the following section provides definitions of, and the theoretical underpinnings of EA.

1.3.2 DEFINITION OF EXPERIENTIAL AVOIDANCE

The idea that avoiding negative affect influences psychological distress is as old as the various schools of psychotherapy (Chawla & Ostafin, 2007). This idea, Chawala and Ostafin (2007) state, has recently been presented in a new way, as the construct of EA. Hayes *et al.* (1996) define EA as consisting of two analogous parts: the unwillingness to remain in contact with aversive private events (including bodily sensations, emotions, thoughts, memories, and behavioural predispositions), and secondly, the action taken to alter the aversive experiences or the events that elicit them.

Historically, EA has been incorporated by many psychological research fields, but in recent years, third wave cognitive and behavioural therapies have put EA as one of the main underlying tenets of their psychological model of mental health and wellbeing, such as dialectical behaviour therapy (DBT; Linehan, 1993), and Acceptance and Commitment Therapy (ACT; Hayes *et al.*, 1999). While other therapies have long held the view that avoidance may lead to distress, ACT has been the first therapy that held EA as the central tenant that underpins psychological wellbeing, and more importantly that started to measure it.

1.3.3 ACCEPTANCE AND COMMITMENT THERAPY

ACT is an empirically supported treatment that combines acceptance and mindfulness strategies, and commitment and behaviour change strategies, with an emphasis on increasing psychological flexibility (Strosahl & Robinson, 2009). ACT has been evaluated in over 30 randomised clinical trials, and demonstrates a medium effect size (Cohen's *d* of around 0.6) in comparison to other active treatments known to be helpful for various psychological difficulties or disorders (Strosahl & Robinson, 2009). Research suggests that ACT is an effective intervention for depression, addictions, anxiety, smoking cessation, chronic pain, psychosis, diabetes management and job stress (Hayes *et al.*, 2006). Meditational analyses have provided evidence for the possible causal role of core ACT processes (acceptance/EA, defusion and values) in producing beneficial clinical outcomes, while deficit levels of these core processes have been shown to correlate with psychopathology (Strosahl & Robinson, 2009).

ACT assumes that all distress is partially uncontrollable. Human beings are "hard-wired" so that anxiety and fear are essential in evolutionary terms, and as such it is unlikely that human beings could ever be free of these emotions (Gauntlett-Gilbert & Connell, 2012). From an ACT perspective, psychological suffering is caused by EA and an over-identification with the content of private experience, both of which it is argued, act as barriers to acting in ways that promote living a life that has purpose and meaning (Strosahl & Robinson, 2009). ACT also states that psychological distress predominately emerges from normal rather than pathological processes (Hayes *et al.*, 2012), and distress originates not from biomedical or psychiatric syndromes, but rather from culturally supported attempts to escape from or avoid the experience of pain per se (Strosahl & Robinson, 2009). It is the attempt to avoid, escape and control unwanted private experiences that traps people in the cycle of human suffering (ibid).

When ACT was originally conceived, the overarching term for its model of psychological ill-health was *EA*; acceptance was the term used to positively describe this model and was defined as the willingness to experience unwanted private events in order to pursue one's values and goals (Bond *et al.*, 2011). Over the last few years the underlying model of ACT has emphasised psychological flexibility rather than EA, and the underlying model of ACT is increasingly referred to as *psychological flexibility*; defined as the ability to fully contact the present moment and the thoughts and feelings it contains without needless defense,

and depending upon the context, persisting in or changing behaviour in pursuit of goals and values (Hayes *et al.*, 2006).

Contributing to levels of psychological flexibility are six inter-connected processes: contact with the present moment, acceptance, values, defusion, committed action, and self as context (Thompson & McCracken, 2011). All six processes are considered to interrelate and interact (Strosahl & Robinson, 2009); all combine to promote psychological flexibility (Hayes *et al.*, 2006). EA is an example of psychological flexibility/inflexibility, and refers to psychological stances and actions that people take when the present moment contains thoughts and feelings that people may not wish to contact (Bond *et al.*, 2011). ACT consequently views and operationalises EA and acceptance as two endpoints on a single continuum (Hayes *et al.*, 2006), whereby the amount of time and energy deliberately spent employing EA strategies is suggested to diminish contact with present experiences and interfere with progress towards valued goals. Psychological acceptance, conversely, is based on flexible and efficient response styles that enable individuals to stay in contact with their thoughts and emotions whilst attending to the information they provide (Kashdan *et al.*, 2009).

1.4 MULTIPLE SCLEROSIS

Before considering the evidence to support examining EA within the MS population, the following sections introduce MS including a definition of MS, epidemiology, types and stages of MS, and the symptoms of MS. This section then explores the links between MS and the high prevalence rates of psychological distress in this population. Although MS has many psychological and psychiatric consequences and co-morbidities, such as stress, anxiety, depression, and psychosis (Haussleiter *et al.,* 2009); depression has been the most researched form of distress in the MS population, as it is the most common psychiatric diagnosis for this client group (Uguz *et al.*, 2007). As such the focus of the following section focuses largely on depression. This section also highlights what has been proposed to cause distress in MS, and argues that EA and, illness representations, are worthy of further investigation within this clinical population.

1.4.1 DEFINITION OF MULTIPLE SCLEROSIS

MS literally means multiple scars (Eeltink & Duffy, 2004). MS is a chronic, often disabling, autoimmune disease that affects the central nervous system (CNS), including the brain, spinal cord and optic nerves (Kalb, 2008). In MS, the autoimmune attack involves inflammation directed against the myelin, which is the protective insulation surrounding the axons, and the cells that make myelin, in a process called demyelination (ibid). Demyelination results in plaques (often called lesions) along the myelin sheath that interferes with nerve conduction. When the myelin is damaged, neurological messages may either slowed down or be completely blocked, which can lead to a reduction or loss of functioning (Arnett, 2003). Because these lesions can form anywhere in the CNS, MS can produce a wide variety of symptoms (Mohr *et al.,* 1999).

The course of MS is uncertain, but is a deteriorating condition marked by periodic attacks or exacerbations that remit partially or fully (Mohr *et al.*, 1999). The overall prognosis of MS is well documented, with irreversible limitations in ambulation, a unilateral aid required for walking, and patients becoming wheelchair bound after approximately 8, 20, and 30 years of evaluation, respectively (Confavreux *et al.*, 2003).

1.4.2 EPIDEMIOLOGY

Although MS appears most commonly in young adulthood, it has been known to develop in early childhood or long after age 60 (Kalb, 2008). With onset occurring during young adulthood, MS often strikes individuals who have not previously dealt with significant health concerns. According to the World Health Organization, MS affects more than 1.3 million people worldwide (Dua & Romani, 2008), and is the most common disease of the central nervous system to cause permanent disability in young adults (Ramagopalan *et al.*, 2010).

MS is two times more common in people of Caucasian ethnicity than other ethnicities (McNulty, 2007). The proportion of women with MS is increasing, with a ratio of 3:1, women to men (Fowler *et al.,* 2008) and there are thought to be approximately 85,000 people with the disease in the UK (Vaughan *et al.*, 2003).

The precise factors that contribute to the development of MS are unknown, but it is generally believed that it is caused by environmental factors in a genetically susceptible person that trigger an autoimmune response against the CNS (Weiner, 2009). Factors supporting genetic effects include excess occurrence in Northern Europeans relative to indigenous populations from the same geographic location, familial aggregation, and lack of excess of MS in adopted relatives of patients with MS (Kantarci & Wingerchuk, 2006). The environmental epidemiology of MS is poorly understood but research implicates factors such as viral exposure, dietary fatty acids, vitamin D, solar ultraviolet radiation exposure, organic solvent exposure, and cigarette smoking (ibid).

1.4.3 TYPES AND STAGES OF MULTIPLE SCLEROSIS

There are four commonly accepted clinical courses that MS tends to take: benign MS, relapsing remitting MS (RRMS), primary progressive MS (PPMS) and secondary progressive MS (SPMS). Most patients are diagnosed with RRMS, which commonly develops into SPMS, while benign and PPMS are less commonly seen in the clinical population, as outlined below.

The first clinical course of MS is a benign sensory form, where attacks are characterised by sensory symptoms and/or inflammation of the optic nerve (optic neuritis). Benign MS is identified by disease duration, but also by level of disability (National Multiple Sclerosis Society (NMSS), 2011). Disability is commonly measured using the Expanded Disability Status Scale (EDSS; Kurtzke, 1983), and a low EDSS score coupled with lengthy disease duration has become synonymous with benign MS (Hviid *et al.*, 2011). Benign MS patients have a mild course of disease and show no or minimal accumulation of disability over time, although little is known about patient reported outcomes such as quality of life, fatigue, depression and cognitive function (ibid).

RRMS is the most common form of the disease (Bramow *et al*., 2010), characterised by clearly defined acute attacks with full recovery or with residual deficit upon recovery (Arnett, 2003). Approximately 85% of people with MS begin with a RRMS course (NMSS, 2011), but the vast majority develop SPMS over time, characterised by gradual accumulation of irreversible impairment (Bramow *et al.*, 2010).

SPMS begins initially as RRMS, followed by progression of disability. It is characterised by less functional recovery following attacks, persistently worsening functioning during or between attacks, and/or fewer and fewer attacks accompanied by progressive disability (NMSS, 2011). According to some studies more than 50% of people with RRMS will develop SPMS within ten years (ibid).

PPMS is characterised by progression of disability from onset and the symptoms generally do not subside or plateau (Arnett, 2003). Of people with MS, only 10% have PPMS (NMSS, 2011). People with PPMS steadily lose function over time, without experiencing remission from symptoms (Thompson *et al.*, 1991). People with PPMS report higher perceived MS severity, more mental health problems and lower physical functioning than those with RRMS (Lerdal *et al.*, 2009). Although patients with PPMS typically have a later disease onset and a more equal male: female ratio, they reach major disability milestones at similar ages as patients with SPMS (Bramow *et al.*, 2010). By contrast, several studies indicate that patients with PPMS remain cognitively better preserved than those with SPMS (ibid).

1.4.4 SYMPTOMS OF MULTIPLE SCLEROSIS

There are many symptoms of MS that occur, some more debilitating than others and can include problems with urinary and bowel function, pain and changes in sensation and dizziness, tiredness, depression and cognitive or memory impairment, mobility, speech and eating difficulties, problems with eyesight and hearing (Robinson *et al.*, 2000). More than 50% of MS patients experience problems with memory, executive functioning, attention, or speed of information processing (Bruce *et al.*, 2010).

However, one of the characteristics of MS is the variability of symptoms that result from the many different parts of the CNS affected (Bruce *et al.*, 2010). Rao *et al.*, (1992) have suggested that because the etiology of MS remains largely unknown, there exists no cure for the disease and limited symptomatic relief. The question of whether there is a prodrome in MS has so far not been extensively studied (Ramagopalan *et al.*, 2010), but many people who are diagnosed with MS recall earlier symptoms that could be attributable to a demyelinating event (ibid).

Although MS is a progressive neurological disease, patient's experience of their disease extends beyond neurological disability to many other aspects of suffering, notably symptoms of fatigue, depression or pain (Ziemssen, 2009). As such Mitchell *et al.* (2005) argue that traditional medical models of impairment and disability are an incomplete summary of disease burden (Mitchell *et al.*, 2005). For instance, in a study of quality of life in MS, physicians considered physical functioning and role limitations due to physical problems as the most important dimensions impacting on patient's quality of life; however patients identified the mental health and role limitations due to emotional problems as the most important dimensions limiting their quality of life (Rothwell *et al.*, 1997).

1.5 MULTIPLE SCLEROSIS, PSYCHIATRIC CO-MORBIDITY AND PSYCHOLOGICAL WELLBEING

Since the majority of MS patients are diagnosed between the ages of 20 and 40, they are often dealing with multiple issues: including raising a family, or starting their career (Dupont, 1997). Given its often unpredictable and progressive nature, widespread symptoms and neurological basis, Dyer and Ehde (2012) state that it is perhaps unsurprising that depression is a common co-morbid condition. Depression associated with MS is described by Gay *et al.* (2010) as usually moderate in severity, affecting between 15 to 47% of the MS population, with lifetime prevalence estimates of around 50%. Depressive symptoms emerge early in the course of MS, with scores on the Beck Depression Inventory (BDI, Beck, 1961) being over four times higher in patients with a mean disease duration of 17 months compared to age and gender matched controls (Kern *et al.*, 2009, Sadovnik *et al.*, 1996). Even though medium levels of intensity characterise this depression, the risk of suicide is 5-10 times higher in the MS population than in the general population (Gay *et al.*, 2010, Sadovnik *et al.*, 1996).

Other psychiatric symptoms such as anxiety, social anxiety (Poder *et al.*, 2009) or irritability/emotional lability, are also common but have attracted far less attention when compared with depressive symptoms (Kern *et al.*, 2009). Apart from clinical psychiatric diagnosis, sub-threshold psychiatric symptoms and psychological distress are also frequently present. In a study of 100 MS outpatients, 48% reported symptoms of emotional difficulties without meeting the criteria for a diagnostic disorder (Feinstein & Feinstein, 2001). Approximately 35% of patients endorse chronic worry (Bruce & Arnett, 2009). Personality changes, including decreased empathy, increased neuroticism, decreased

agreeableness and conscientiousness have also been noted in the literature (Bruce *et al.*, 2010). Emotional difficulties that are MS related are known to be associated with problems managing activities of daily living, poorer vocational status, and reduced quality of life (ibid). Despite this, psychological distress is most often only conceptualised as depression within the MS literature (Kern *et al.*, 2009) and has been the predominant focus of research into psychiatric co-morbidity (Poder *et al.*, 2009).

1.5.1 CAUSES OF PSYCHOLOGICAL DISTRESS IN MULTIPLE SCLEROSIS

The relationship between psychological and psychiatric disorders within MS is complex and the extent to which they might be reactive to numerous psychosocial factors or even be symptoms of the neuropathological process itself remains unclear (Haussleiter *et al.*, 2009). While depression is a major psychological symptom, it has yet to be determined whether depressive episodes are psychosocial reactions to its progressive nature, or clinical manifestations of neurological impairment, or as highlighted by Siegert and Abernethy (2005) a combination of both. Some hypotheses put forth to date include that overlapping somatic symptoms such as fatigue may lead to inflated estimates of depression (Siegert & Abernethy, 2005); it could be related to an underlying disease process such as lesion load or brain atrophy (Feinstein *et al.*, 2004), or it could be explained by psychosocial factors such as social support, coping, conceptions of the self and illness and stress (Arnett *et al.*, 2008).

1.5.1.1 PHYSICAL DISABILITY

There is significant evidence that physical and neurological disability are directly associated with depression and psychological distress in MS; for example higher levels of disability are associated with more severe depressive symptoms (Chwastiak *et al.*, 2002). As well as psychological wellbeing, health related quality of life (HRQoL) has been widely examined as an outcome measure in MS, and over 90 studies have highlighted that many patients with MS have notable decrements in HRQoL, which is often due to the effect of disability in daily living (Mitchell *et al.*, 2005).

Although widely investigated, the relationship between depression and functional disability in MS remains unclear (Millefiorini *et al.*, 1992; Janssens *et al.*, 2003). Some studies suggest that patients with greater disability are more likely to experience psychological

distress (Chwastiak *et al.*, 2002) with correlations between EDSS scores and measures of depression in a recent meta-analysis (Arnett *et al*., 2008) ranging from *r*=.30 (Zorzon *et al.*, 2001) to .39 (McIvor *et al.*, 1984).

Other authors claim that the frequency or severity of psychological distress among MS patients is independent of the severity of MS, as reflected by the patients score on the EDSS (Beatty *et al.*, 1990, Fassbender *et al.*, 1998, Moller *et al.*, 1994, Pujol *et al.*, 1997). Such mixed findings suggest the presence of moderators or mediators (Arnett *et al.*, 2008). Arnett *et al.* (2008) recommend focusing on what may interact with physical disability in order to establish a clearer understanding of the relationship between disability and distress in this client group. What follows is a discussion of some constructs that have been proposed to interact with physical disability and distress in this client group, with a focus on illness representations. As will be discussed, EA has not been looked at in this population to date, however it has shown to be a mediator of distress for many other populations and psychological problems.

1.5.1.2 PAIN, FATIGUE AND COGNITIVE IMPAIRMENT

Pain can be a serious problem affecting between 44% and 80% of people with MS (Hirsh *et al.*, 2009). According to Arnett *et al.* (2008) studies examining the relationship between pain and depression have been mixed, with roughly equal numbers of studies showing a positive versus null relationship (Arnett *et al.*, 2008). Although less extensively studied pain frequently causes interference in a variety of functional domains including sleep, recreation and occupational activities (Hirsh *et al.*, 2009).

Up to 40% of MS patients name fatigue as their most disabling symptom, and it has been reported to cause profound disruption of quality of life in MS patients (Shah, 2009), for example fatigue has been identified as the one symptom most responsible for having to cut back on work hours (Smith & Arnett, 2005). Many MS patients with fatigue also complain of sleep disturbance, which may be secondary to neuropathic pain, spasticity, and restless leg movement. Shah (2009) recommends that further research is needed to gain a better understanding of the underlying mechanisms associated with MS sleep disturbance and fatigue.

Cognitive impairment has been detected in 40-60% of patients (Rao *et al.*, 1991). Arnett *et al.* (2008) report that existing studies are evenly divided between studies that report null effects (although those reporting null effects tend to be earlier studies (Siegert & Abernethy, 2005)) and those that report significant associations. Of course one of the primary issues in the research on depression and MS is that many of the somatic symptoms of depression (fatigue and cognitive impairment) are also common features of MS (Minden & Schiffer, 1990).

1.5.1.3 COPING STRESS AND SOCIAL SUPPORT

Coping and stress are commonly linked within the empirical literature on coping, because coping strategies are typically used in response to stressful events (Arnett *et al.*, 2008). Arnett *et al.* (2008) found that emotion-focused and avoidant coping strategies are consistently positively associated with psychological distress (e.g., depression), whereas problem focused and active coping strategies are inversely related to depression. Reviewing outcomes other than depression, Pakenham (1999) demonstrates that less reliance on emotion focused coping was associated with improvements in depression but also in global distress, social adjustment, and subjective health status.

Arnett *et al.* (2008) also highlight that the relationship between social support and depression in MS is very consistent; those with better social support are less likely to be depressed than patients with poorer social support. However, there are many coping researchers that agree that social support is a critical element of a comprehensive model of stress and coping (Lazarus & Folkman, 1984; Schreurs & deRidder, 1997; Valentiner *et al.*, 1994).

According to the Levanthal's self regulation model (Levethal *et al.*, 1980; Leventhal *et al.*, 1984) illness representations are also related to coping, and via coping, to outcomes (Vaughan *et al.*, 2003). Coping is seen as a mediating factor between illness representations and outcome, although there is evidence to suggest that illness representations may be better predictors of outcome than coping strategies (Moss-Morris *et al.*, 1996).

1.6 ILLNESS REPRESENTATIONS AND MULTIPLE SCLEROSIS

According to the self-regulation model cognitive representations of illness play an important role in influencing patient's strategies for coping with an illness and associated emotional responses. Illness representations are of interest in the MS research field, as MS is marked by a lack of clarity about prognosis and a fluctuating physical condition which can create powerful challenges for psychological wellbeing (Boss & Couden, 2002). An individual's perception of their circumstances is critical to their overall quality of life; an individual's perception of their future, whether accurate or inaccurate, has a substantial influence (Mitchell *et al.*, 2005).

Research on a number of medical illnesses has identified a generic structure of illness representations consisting of five dimensions (Vaughan *et al.*, 2003, p 288):

- Identity (the label attributed to the illness and symptoms associated with it)
- Time-line (the expected duration and course of the illness)
- Consequences (the short and long term effects of the illness, and it's physical social, economic, and emotional effects)
- Cause (the factors considered to have led to the development and onset of the illness)
- Cure/controllability (what the individual believes they or medical professionals can do to control or bring about recovery from the illness) .

The overall sense that an individual makes of their illness is based on the interplay between all the illness representation components (Vaughan *et al.*, 2003).

To date there have only been three studies published in the literature that look at the role of illness representations in MS. Using outcome measures of illness intrusiveness, activities of daily living, anxiety, depression and self esteem Vaughan *et al.* (2003) investigated the nature of illness representations in a sample of people with MS in the UK. Their sample consisted of 99 adults who had a formal diagnosis of MS (77 females, mean age 44.8 years). Using the Illness Perception Questionnaire (IPQ) (Weinman *et al.*, 1996) they found that beliefs about MS along the identity, time-line, cause, and cure dimensions were found to be consistent with the general medical nature and understanding of MS, indicating that participants had developed beliefs about their illness that were accurate and

realistic in terms of conventional clinical views. Namely, participants reported that MS was associated with a wide range of symptoms, that it would last a long time, and there was no specific cause and an unlikely cure. Identity, consequences and cure/controllability components of illness representations demonstrated the greatest number of relationships with outcome measures (Vaughan *et al.*, 2003). The belief that MS had serious consequences was related to greater difficulty in each of the outcome variables, suggesting that individuals who consider their MS to have many negative effects on their life will be more likely to encounter a range of difficulties, including increased emotional distress. Vaughan *et al.* (2003) state that compared to other illnesses, the illness representations of MS demonstrated a generally stronger illness identity, a more chronic timeline, and in particular, a lower sense of control.

It should be noted that in this study the type of MS experienced by the participants was not reported, and there was no indication of MS severity (e.g. EDSS scores). These two limitations reduce the generalisability of these findings. Also the majority of the participants (*N*=96) had received psychological input either by attendance at a psycho-education group for newly diagnosed MS or for individual input, which may have contributed to the accuracy of the participants beliefs.

Spain *et al.* (2007) examined the role of illness representations of people with MS in relation to quality of life. Using a large sample of 580 patients with MS in Australia, they demonstrated that illness representations were an independent factor contributing to health related quality of life. In this study, EDSS scores were a significant determinant in all domains (information processing speed, fatigue, pain, illness perceptions), except mental health (anxiety, depression). Essentially this study highlighted that while symptom severity (EDSS scores) can reduce quality of life; illness representations also have a significant role.

Jopson and Moss-Morris (2003) found that illness representations, utilizing Leventhal's five component illness representations model (Leventhal *et al.*, 1980), predicted adjustment to MS over and above the effects of the severity of the illness. Using hierarchical multiple regression they demonstrated that illness severity accounted for the majority of the variance in physical and role dysfunction, while patients' illness representations were the most significant predictors of social dysfunction, fatigue, anxiety, depression and self esteem. While the sample of 168 patients had all four subtypes of MS well represented,

the sample was accessed from a support group and so may not be representative of the wider MS population.

These are important findings, as Jopson and Moss-Morris (2003) highlight that illness representations are rarely the focus of psychological interventions. While each of these studies have some limitations, the findings suggest that illness representations are worthy of further study as a cause of psychological distress in people with MS.

1.7 EXPERIENTIAL AVOIDANCE AND DISTRESS: THE EVIDENCE

EA has never been studied in relation to an MS population; however it has shown in previous research to have a significant impact on the distress experienced by different populations and psychiatric disorders (Hayes ***et al.***, 2006). In order to explore the relationship between EA and psychological distress, and elicit whether it is worthy of further investigation in a sample of MS participants, a systematic review of the literature relating to EA was undertaken as part of the current study.

Previously Chawala and Ostafin (2007) published an empirical review of the evidence for EA as a functional dimension in psychopathology. This review focused on research evidence published between 1999 and 2006, using the search terms “EA” and “ACT”, to identify 28 studies that specifically addressed EA. Some of the findings from this systematic review suggested that EA: (a) influences the likelihood of substance use relapse, (b) mediates the relation between traumatic events and general psychological distress, (c) predicts severity of symptoms in some specific disorders such as Generalised Anxiety Disorder (GAD) and trichotillomania, and (d) mediates the relationship between maladaptive coping and self-regulatory strategies, and psychological distress. Ruiz (2010) also conducted a review of ACT looking at correlational, experimental psychopathology, component and outcome studies; although not systematic, it also found that EA is related with a wide range of psychological disorders and mediates the relationship between different types of symptoms and psychological constructs.

1.7.1 AIMS AND SCOPE OF THE CURRENT LITERATURE REVIEW

The present systematic review of the literature aims to critique and synthesise new empirical research that both strengthens and updates the studies presented by Chawala and Ostafin (2007).

1.7.2 SYSTEMATIC REVIEW QUESTION

What is the relationship between EA and psychological distress?

1.7.3 METHOD

1.7.3.1 LITERATURE SEARCH STRATEGY

To locate relevant studies the following electronic bibliographic databases were searched: PsychINFO, PsycARTICLES, Web of Knowledge, Medline, Science Direct, and CINAHL.

1.7.3.2 SEARCH TERMS

The search terms used by Chawala and Ostafin (2007) were “EA” and “ACT”. For this systematic review the search term used was “experiential avoidance”. This approach to searching the databases was taken as using the search term ACT (as conducted by Chawala and Ostafin, 2007) (and ACT+EA, EA and distress/wellbeing) generated a smaller number of abstracts to check. As such, using just “experiential avoidance”, produced the greatest number of articles to search, that would address the systematic review question posed: what is the relationship between EA and psychological distress.

1.7.3.3 INCLUSION AND EXCLUSION CRITERIA

Of the 28 articles identified by Chawala and Ostafin, 3 had non clinical samples, and 16 were undergraduate samples. To address issues of generalisability and validity this review is concerned with looking specifically at clinical samples. Articles were collected from the time period 2006-2011, and the full inclusion and exclusion criteria are presented below.

1.7.3.4 Inclusion criteria:

- Articles must be about distress/psychopathology
- Articles must be empirical studies
- Articles must include clinical samples
- Articles must be reported in English

1.7.3.5 Exclusion criteria:

- Articles linking EA to a behaviour (e.g. smoking cessation, disease management, weight loss, self harm etc) will not be included, as this is not necessarily about distress
- Articles must be about EA and not a similar concept (i.e. avoidant coping)
- Articles about EA, and it's relationships to behaviours (test performance etc) will be excluded
- Articles must be about individual EA (i.e. not the effect of parents EA on adolescents OCD)
- Conceptual reviews will be excluded
- Studies comparing interventions, e.g., CBT with ACT
- Single Cases/Case Series

1.7.4 SYSTEMATIC REVIEW PROCESS

A total of 1034 articles were identified and reviewed by title and abstract for relevance to the topic of EA. Any article that clearly met one of the exclusion criteria was eliminated from the review at this stage. This process left 212 abstracts that were examined in more detail to ensure that they were eligible for inclusion in the study. The clinical supervisor of the study acted as an independent rater, examining the 212 abstracts, and inter-rater agreement was 85% (include) and 90% (exclude). Since the inclusion/exclusion criteria were used to judge inter-rater agreement, each of the articles, not agreed on by both parties, were discussed in a consensus building process until agreement was reached.

Of the 212 abstracts reviewed 34 full text articles were retrieved, and from these 34, 14 studies were eligible to be included in the systematic review. The process of article

extraction is detailed in full in Appendix 1. A protocol developed by Vandenbrouke *et al.* (The STROBE checklist, 2007, Appendix 2) was used to assess the quality of the studies, and the use of such a protocol has been recommended as essential for the rigorous implementation of a systematic review (Schlosser, 2007). The strengthening the reporting of observational studies in epidemiology (STROBE) checklist consists of a checklist of 22 items and facilitates critical appraisal and interpretation of studies (Vandenbrouke *et al.*, 2007). Table 1 (Appendix 3) summarises alphabetically the demographics, research design, variables studied, and effect sizes or statistics reported for each study.

1.7.5 RESULTS

1.7.5.1 OVERVIEW OF THE NARRATIVE LITERATURE REVIEW

The 14 articles that met the inclusion and exclusion criteria were reviewed considering the study design, aims and objectives, how EA was measured, the role of EA in psychopathology/psychological distress, limitations of the research, and summary highlighting implications for future research and clinical practice.

1.7.5.2 STUDY DESIGN

Of the 14 articles included in the review, 12 were cross sectional and 2 were longitudinal. The two longitudinal studies assessed patients at 2 (Manos *et al.*, 2010) and 4 (Berking *et al.*, 2009) time points.

1.7.5.3 AIMS OF THE STUDIES

Of the 12 cross sectional studies, 6 examined the role of EA in a number of diagnoses (e.g Generalised Anxiety Disorder (GAD; Lee *et al.,* 2010), anxiety (Berman *et al.*, 2010), depression (Bohlmeijer *et al.*, 2011), borderline personality disorder (Iverson *et al.*, 2011), and Post Traumatic Stress Disorder (PTSD; Morina *et al.*, 2008; Morina *et al.*, 2010).

5 of the cross sectional studies looked at EA as a mediator: mediating between coping and psychopathology in chronic pain (Costa & Pinto-Gouveia, 2009), between maladaptive coping styles and psychopathology (Fledderus *et al.*, 2010), between life hassles and delusions (Goldstone *et al.*, 2011), between anxiety sensitivity and borderline personality

disorder (Gratz *et al.*, 2008), and between social anxiety disorder and post traumatic stress disorder on quality of life (Kashdan *et al.*, 2009). One of the cross sectional studies (Andrew & Dulin, 2007) examined the moderating role of EA between physical health and depression and anxiety.

Of the two longitudinal studies included in the review, one examined whether EA impedes the reduction of depression during treatment for borderline personality disorder (BPD; Berking *et al.*, 2009), while the other examined whether EA or obsessive beliefs predicted the severity of OCD symptoms (Manos *et al.*, 2010).

1.7.5.4 SAMPLES INCLUDED IN THE STUDIES

The samples sizes in these studies ranged from 20 (Gratz *et al.*, 2008) to 208 (Andrew & Dulin, 2007). 12 of the 14 studies used convenience sampling, either recruiting samples from clinics or university departments, or using adverts in newspapers, or social media sites. One of the studies used a type of random sampling, called the random walk sampling strategy (Kashdan *et al.*, 2009). This included choosing 6 out of 30 regions, then choosing a list of towns and villages within these regions to sample from. The authors state that this was done randomly. Then a street was randomly chosen to begin recruiting from. Morina *et al.* (2008) also used this sampling strategy; however the other study completed by Morina *et al.* (2010) did not give details of how participants were chosen but merely stated that “participants were contacted”, suggesting a convenience sample was used.

Three studies (Andrew & Dulin, 2007; Bohlmeijer *et al.*, 2011; Fledderus *et al.*, 2010) included adults over 65 within their samples. Andrew and Dulin (2007) looked specifically at an older adult population (age range 70-90+), while the other two studies indicated a fairly representative age range (aged between 24-71). The age range was not reported for two studies: Kashdan *et al.*, (2009) gave the standard deviation (SD) while Costa and Pinto-Gouveia (2011) gave the mean age for each gender, and the SD for each gender (see Table 1, Appendix 3).

There was a marked difference in the male to female ratio in almost all of the studies. One study looked only at female participants (Berking *et al.,* 2009). Only one study had more

males than females (Goldstone *et al.,* 2011), while the rest ranged from participants being 55-90% female.

1.7.5.5 THE MEASUREMENT OF EXPERIENTIAL AVOIDANCE

EA as measured by the Acceptance and Action Questionnaire (AAQ-I, Hayes *et al.*, 2004) or the AAQ-II (Bond *et al.*, 2011), was the main measure of EA within each of the 14 studies reviewed.

Six of the 14 studies reviewed used the most up to date version of the AAQ scale, the AAQ-II. However these six studies used the 10 item version of the AAQ-II rather than the current seven item version (Bond *et al*., 2011). Five studies used the nine item AAQ-I, while three used the 16 item version of the scale.

One of the important things to note is the direction of scoring in the different versions and that the AAQ measures the continuum from EA to acceptance. In the 16 item version of the AAQ-I, high scores indicate EA (low scores indicate acceptance), which the three studies using the 16 item version followed. Unlike the 16 item version, low scores on the nine item version indicate EA (so high scores indicate acceptance). Only Gratz *et al.* (2008) recoded the items, on the nine item AAQ-I, so that high scores indicate greater EA.

The most up to date version of the AAQ, the AAQ-II, used by six of the studies, states that like the nine item version, low scores indicate EA. However, Costa and Pinto-Gouveia (2011) stated that higher scores on the AAQ-II equate to EA, and is the only one of the six studies, using the AAQ-II to state this. Apart from differences in the direction of scoring; one important thing to note is that the AAQ-I, and the ten item AAQ-II are not single factor measures (i.e. studies highlight that they measure more than one factor) (Bond et al., 2011), which will be discussed in more detail in the critical review.

Although the words “high EA” is used throughout this study, it is important to note that the AAQ-II is measuring the continuum between EA and acceptance, so when studies report a relationship between EA and (for example) depression, it can be assumed that the study is expressly stating that the findings report that there was EA being used by participants.

1.7.6 THE RELATIONSHIP BETWEEN EXPERIENTIAL AVOIDANCE AND PSYCHOPATHOLOGY

Nine of the 14 studies explored the relationship using correlations between EA and psychological distress. These relationships are reviewed according to the type of psychiatric disorder or symptoms the review studies looked at.

1.7.6.1 DEPRESSION

Three of the studies explored correlations between EA and depression (Andrew & Dulin, 2007; Berking *et al.*, 2009; Costa & Pinto-Gouveia, 2011). These three studies reported positive linear correlation ranging from r=.34, p<0.001 using the Beck Depression Inventory (BDI, Berking *et al.*, 2009) to r=.67, p <0.001, using the Depression, Anxiety and Stress Scale (DASS-21 (Lovibond & Lovibond, 1995); Costa & Pinto-Gouveia, 2011; Berking *et al.*, 2009).

1.7.6.2 ANXIETY

Six of the 14 studies explored the relationship between EA and anxiety (Andrew & Dulin, 2007; Berman *et al.*, 2009; Costa & Pinto-Gouveia, 2011; Fledderus *et al.*, 2010; Gratz *et al.* , 2008, Lee *et al.*, 2010). Four studies reported significant linear correlations ranging from r=.43, p <0.01, using the Geriatric Anxiety Inventory (GAI (Pachana et al., 2007); Andrew & Dulin, 2007) to r= -.47, p <0.01, using the Hospital Anxiety and Depression Scale (HADS (Zigmond & Snaith, 1983); Fledderus *et al.*, 2010). It should be noted that the negative correlation noted in the study by Fledderus *et al.* (2010) represents the direction of scoring of the version of AAQ used in the study, but this negative correlation still represents EA. The remaining two studies did not report the correlation between EA and anxiety.

1.7.6.3 PSYCHOLOGICAL WELLBEING/STRESS/PSYCHIATRIC SEVERITY

Two studies reported on psychological wellbeing/psychiatric distress. Fledderus *et al.* (2010) reported on the relationship between EA and emotional wellbeing, and found that higher acceptance (low EA) was strongly related to better emotional wellbeing (r=.38, p

<0.01). Related to the concept of wellbeing, Costa & Pinto-Gouveia (2011) reported a positive correlation between EA and stress (r=.7, p< 0.001). Morina *et al.* (2008) also reported that EA correlated significantly with psychiatric severity, as measured by the Brief Symptom Inventory (BSI, (Derogatis, 1975); r=.39, p <0.01).

1.7.6.4 DELUSIONS/PARANOIA

One study looked at the relationship between EA and delusions. Goldstone *et al.* (2011) reported that EA was strongly associated with delusions and delusional distress (r= -.49 & -.61 in a non-clinical sample, and r= -.40 & -.48 in a clinical sample, i.e. lower EA >delusions and delusional distress).

1.7.6.5 POST TRAUMATIC STRESS DISORDER

Two of the studies (Kashdan *et al.*, 2009; Morina *et al.*, 2008) looked at the role of EA in PTSD, but only Kashdan reported on the correlation between EA and PTSD, reporting a significant correlation between EA and posttraumatic symptoms (r=.47, p < 0.01).

1.7.6.6 BORDERLINE PERSONALITY DISORDER

One study reported on the relationship between EA and Borderline Personality Disorder (BPD). Iverson *et al.* (2011) report that EA was significantly associated with BPD symptom severity, measured using the Personality Assessment Inventory-Borderline Features Scale (PAI-BOR, Morey (1991)) after accounting for depression (r= -.68, p <0.01, i.e lower EA > BPD).

1.7.6.7 OBSESSIVE COMPULSIVE DISORDER

One study reported on the relationship between EA and OCD, and this was the only study to find no relationship between EA and the construct under study. Manos *et al.* (2010) reported that that EA was generally not related to the severity of OCD symptoms, as measured by the Obsessive Compulsive Inventory-Revised (OCI-R, (Fao et al., (2002); r= -0.051-.153).

1.7.6.8 SUMMARY

Nine of the 14 studies reported on the correlations between EA as measured by the AAQ-I and AAQ-II. As can be seen, some of the studies reported on the relationship between one or more outcomes including depression, anxiety, and wellbeing/stress/psychiatric severity, PTSD, BPD and OCD. Eight of these nine studies reported correlations between EA ranging from r= .34, p < 0.001 (Berking *et al.*, 2009) to r= .7, p <0.001 (Costa & Pinto-Gouveia, 2011). These relationships are in line with ACT's underlying theoretical model; that increased EA is shown to correlate with psychological difficulties.

One of the studies (Manos *et al.,* 2010), reported no correlation between EA and the severity of OCD symptoms (r= -.051-.153). However, this study only included one measure of distress the OCI-R, and on closer inspection they did not calculate a total score, but only looked at some of the subscales by selecting relevant items.

1.7.7 EXPERIENTIAL AVOIDANCE AS A MEDIATOR

ACT has build an evidence base by studying the mechanisms purported to promote psychological change (e.g defusion, values, acceptance); these processes, through which psychological changes are thought to occur, are called mediators of change (Kazdin, 2008). Statistical mediation is thought to be more meaningful than correlation analysis as it considers a potential mechanism of change (Hayes, 2009). In terms of the studies in this review, seven of the 14 articles conducted formal meditational analysis, and one study (Andrew & Dulin, 2007) carried out moderation rather than mediation analysis.

Three of the seven mediation studies (Fledderus *et al.*, 2010, Morina *et al.*, 2010, Costa & Pinto-Gouveia, 2011) used procedures for meditational analysis outlined by Baron and Kenny (1986) while three of the studies (Bohlmeijer *et al.*, 2011; Kashdan *et al.*, 2009; Goldstone *et al.*, 2011) carried out meditational analysis with bootstrapping procedures as outlined by Preacher and Hayes (2008). One of the studies (Gratz *et al.*, 2008) also used the method outlined by Baron and Kenny (1986), but while the other three studies used Sobel's statistic to confirm whether the mediation was full or partial, Gratz *et al.* (2008) did not.

1.7.7.1 BARON AND KENNY METHOD OF MODERATION

Andrew and Dulin (2007) examined the relationship between self reported health and mental health problems in older adults. After the other three variables of interest in the study (social support, functional impairment, self reported health) were added to a regression equation, EA contributed 4% of the unique variance in depression (β=0.22; p<0.01). In line with the procedures outlined by Baron and Kenny (1986) when an interaction term (self reported health x AAQ scores) was added, this contributed a further 8% of the variance of depression. With anxiety as the dependent variable, EA contributed to 11% of the unique variance of anxiety, but the interaction term (self reported health x AAQ scores) contributed a further 20% of the variance of anxiety, indicating a large moderating effect of EA on self reported health and anxiety.

1.7.7.2 BARON AND KENNY METHOD OF MEDIATION

Three of the four studies using the Baron and Kenny (1986) method used the Sobel test. The mediation is partial if Sobel z is p<0.05, and full if Sobel z is p= 0.00 (Costa & Pinto-Gouveia, 2011).

Only one of the studies suggested that EA was a full mediator between the effect of detached/emotional coping in depression (Costa & Pinto-Gouveia, 2011), reporting that z=-3.08; p=0.00. Also within this study, EA partially mediated between rational coping and depression (z= -2.16; p = 0.003), and between rational coping and stress (z= - 2.20, p = 0.03).

EA fully mediated the effects of passive coping on depression (z= 2.79, p =0.01), and anxiety (z= 4.36, p=0.01), and it partially mediated the effects of passive coping on emotional wellbeing (z= -.26, p= 0.05), and psychological wellbeing (z= -2.05, p = 0.05) in the study by Fledderus *et al.* (2010). However it should be noted that Fledderus *et al.* (2010) state that EA fully mediates all of the four variables mentioned above, which is a detour from the guidance about p values followed by Costa and Pinto-Gouveia (2011).

Morina *et al.* (2010) found that EA partially mediated the relationship between somatic distress and quality of life (z= -3.20, p= 0.02), and also partially mediated the relationship between somatic distress and psychological distress (z= 2.38, p = 0.02).

While Gratz *et al.* (2008) did follow the procedures outlined by Baron and Kenny (1986) they used a hierarchical logistic regression analysis to determine if EA mediated the relationship between anxiety sensitivity and BPD. They found that the model including EA was reliably different to the model with only anxiety sensitivity, and that anxiety sensitivity did not remain a significant predictor when controlling for EA.

1.7.7.3 PREACHER AND HAYES BOOTSTRAPPING METHOD OF MEDIATION

While Goldstone *et al.* (2011) used the guidance by Baron and Kenny (1986) to determine whether EA mediated the relationship between life hassles and two measures of delusions in a clinical and a non-clinical sample, in order to test the significance of the mediation relationships, they used the bootstrapping method used by Preacher and Hayes (2004). The Preacher and Hayes (2004) method uses nonparametric bootstrapping with 5000 samples to derive a 95% confidence interval for the impact of a mediator. An indirect (meditational) effect is considered significant if zero is not contained in the 95% confidence interval (ibid).

They estimated the indirect effect of EA upon delusions to lie between .0133, and .5562, and between .1687 and .4275 for the indirect effect of EA on delusional distress in the non-clinical sample. For the clinical sample, bootstrapping values were between .0817 and .4538 for delusions, and between .0500 and .2072 for delusional distress. As zero was not in any of the intervals (Goldstone *et al*., 2011), this indicated a significant indirect effect of EA in the relationship between life hassles and both measures of delusions.

Many researchers have emphasised the importance of paying more attention to the mechanisms of change in effective treatments (e.g Kazdin, 2007), and Bohlmeijer *et al.* (2011) have done just that by showing that improvements in acceptance during their intervention for adults with depressive symptomatology mediated the effects of the intervention on symptoms at follow up. They highlight bootstrapping values between -4.10 and -.67 to evidence that the mediating effect of improvement of AAQ-II scores from baseline to post-treatment were significant.

Using the bootstrapping techniques advocated by Preacher and Hayes (2004), Kashdan *et al.* (2009) also used Sobel's test of mediation. Using Sobel's test they highlighted that EA

partially mediated the effects of social anxiety (*z*= 2.48, *p* =0.01), and PTSD (*z*= 2.70, *p*= .007) on quality of life scores. Bootstrapping means, also confirming the mediating effect of EA, were .66 and .61, for social anxiety disorder and PTSD respectively.

1.7.8 THE PREDICTIVE VALUE OF EXPERIENTIAL AVOIDANCE

Six studies that did not look at meditational analysis instead focused on the predictive value of EA, which is more a test of the underlying model of ACT, and its utility in providing interventions from an ACT perspective.

Two of these studies (Berman *et al.*, 2010, Manos *et al.*, 2010) found that EA did not predict anxiety symptom severity (Berman *et al.*, 2010), and OCD symptom severity (Manos *et al.*, 2010). Berman *et al.* (2010) report that when EA is added to a hierarchical regression analysis it added no additional variance in anxiety scores (as measured by the Beck Anxiety Inventory (BAI; Beck *et al.*, 1988), and that the physical concerns subscale of the anxiety sensitivity index (ASI-3; Taylor *et al.*, 2007) was the only significant unique predictor of anxiety scores (β =.49, p <0.01). However, given that the BAI has been noted to assess physiological correlates of anxiety, it is not surprising that the physical symptoms subscale of the ASI-3 was significantly associated with it.

As discussed earlier, Manos *et al.* (2010) results indicated that EA had limited association with measures of OCD severity and did not add significantly to prediction of OCD symptom dimensions above and beyond obsessive beliefs and depression.

Providing support for the causal effect of EA on depression (that is that EA is a cause rather than a consequence of depression) Berking *et al.* (2009) looked to a sample of women with BPD. Their results demonstrate that the AAQ-I was significantly associated with changes in both the outcome measures of depression the BDI, and the Hamilton Rating Scale for Depression (HRSD, Hamilton, 1960) (the HRSD β = 12.858, p <0.05, and the BDI β = 9.568, p <0.05), but neither the HRSD nor the BDI scores were significantly associated with subsequent changes in the AAQ (HRSD, β =-0.002, BDI, β = 0.011).

Highlighting that EA may be a central process in BPD, Iverson *et al.* (2011) looked at EA and two other domains of emotional functioning: emotion dysregulation and distress tolerance. While emotion dysregulation was significantly associated with BPD symptom

severity (r=.55, p<0.01), only EA was significantly associated with BPD symptom severity after controlling for depression (β = -.51, p<0.05).

Testing the assumption that EA is the main underlying process in Generalised Anxiety Disorder (GAD) Lee *et al.* (2010) looked at a clinical and a non-clinical sample. The individuals with GAD reported higher rates of EA, and greater distress about anxious, depressive, angry and positive emotions. Also the AAQ was able to significantly classify GAD status.

In order to assess the role EA plays in the maintenance of PTSD symptoms Morina *et al.* (2008) compared three groups, a current PTSD group, a recovered PTSD group, and a non PTSD group. There was a significant group difference in EA between groups (F (2,81)= 8.40, p <0.01), and subsequent post-hoc comparisons of means revealed that participants in the current PTSD group contained significantly higher AAQ scores (M= 43.4, SD= 5.6) than those in the recovered PTSD group and the non PTSD group (M=38.8, SD= 5.4 and M =35.9, SD= 7.7). The recovered PTSD and non PTSD groups did not differ significantly in EA, which has led Morina *et al.* (2008) to suggest that EA may also be an aetiological factor for PTSD.

1.7.9 SUMMARY

For this review, 14 articles were sourced that met the inclusion and exclusion criteria. Each of the 14 studies were reviewed considering their design, aims and objectives, how EA was measured, and its relationship to psychological distress.

Of the 14 articles that were reviewed 12 used a cross sectional design, and two used a longitudinal design. The samples sizes in these studies ranged from 20 (Gratz *et al.*, 2008) to 208 (Andrew & Dulin, 2007). The mean age of participants ranged from 27 (Berman *et al.*, 2010) to 80-84 (Andrew & Dulin, 2007). The gender ratio ranged from 44% (Goldstone *et al.*, 2010) to 100% (Berking *et al.*, 2010) female.

EA was measured by using the Acceptance and Action Questionnaire (AAQ), but eight used the older version (either the nine or 16 item AAQ-I). The remaining six used the 10 item AAQ-II; however the current version of the AAQ-II is actually a seven item version (Bond *et al.*, 2011).

Nine of the 14 studies explored correlations between EA and psychological distress (depression, anxiety, psychological wellbeing, stress, psychiatric severity, delusions, PTSD, BPD and OCD). Eight of these studies reported positive correlations between EA ranging from $r = .34$, $p < 0.001$ (Berking *et al.*, 2009) to $r = .7$, $p < 0.001$ (Costa & Pinto-Gouveia, 2011). Only one of the studies (Manos *et al.,* 2010), reported no correlation between EA and the severity of OCD symptoms ($r = -.051$-$.153$).

Seven of the articles carried out meditational analysis and one a moderation analysis, with EA as the key mediator/moderator. All of these studies reported good evidence that EA is a mediating/moderating variable between a range of measures of distress.

Two studies found that EA did not predict either OCD symptoms severity, or anxiety symptom severity. However the remaining four studies looking at the predictive value of EA found good support that it predicts depression, BPD symptom severity, GAD, and PTSD symptoms.

1.7.10 CRITICAL REVIEW AND DISCUSSION

Based on the narrative review of the 14 studies, a critical review will be undertaken regarding issues of sampling, methods, measures and theoretical issues, before a summary of the issues is considered and the role of EA is weighed as to whether it should be investigated in MS populations.

1.7.10.1 SAMPLES

In terms of the populations sampled, the 14 studies considered in the systematic review consist only of mental health populations. As such this review highlights that many physical health conditions have not been studied in terms of the role of EA, despite some authors stating that ACT is suited to long term conditions (Hayes *et al.*, 1999; Ruiz, 2010). This finding is similar to the results generated by Chawala & Ostafin (2007) whose systematic review did not highlight any studies looking at EA in clinical health populations. A cursory glance at the official website for the Association for Contextual Behavioural Psychology (http://contextualpsychology.org) highlights that there have been Acceptance and Action Questionnaires (AAQ) developed for diabetes, epilepsy, substance abuse,

weight, smoking, body image, chronic pain, irritable bowel syndrome, tinnitus and auditory hallucinations. It may have been a limitation of the systematic review to exclude papers that were about behaviours (for example a paper by Gregg *et al*., (2007) was about diabetes *self management*), however it also highlights that many of these studies did not meet other requirements of the systematic review, for example using undergraduate samples, or not including measures of distress.

1.7.10.2 METHODS

In keeping with the results of the systematic review conducted by Chawala and Ostafin (2007), and that by Ruiz (2010) the review of the correlational analysis provides additional support that EA is significantly involved with a wide range of psychological disorders. In addition its status as a mediator of distress is growing within the literature.

Chawala and Ostafin (2007) stated that little research had been conducted on EA as a mediator of distress. This systematic review addresses this issue identifying eight studies that highlight that EA does act as a mediating variable. The importance of research on EA as a mediator of psychological distress is so evidence accumulates to suggest that focusing treatment on reducing EA may lead to improvements in a particular problem/disorder. As such these eight studies provide support to suggest that ACT is working through one of their main hypothesised processes (EA).

It should be noted that all of these meditational analyses were cross sectional designs. True tests of mediation require longitudinal designs where the change in the hypothesised mediator is measured temporally before the outcome measure (Hayes, 2009, Selig & Preacher, 2009). Also mediation itself does not show causation, but rather the functional importance of an intervention's impact on a process, and that process' effect on an outcome (Hayes, 2009). It may have been important then, considering this view of mediation by Hayes, to have included intervention studies within the review, although Ruiz (2010) has highlighted that the results in this field of ACT enquiry (mediation) are still preliminary, and so would benefit from using longitudinal designs.

Despite these shortcomings, the mediation analysis used strict criteria for mediation and moderation pulling from the guidelines outlined by Baron and Kenny (1986), and also by Preacher and Hayes (2004). Baron and Kenny's methods for meditational analysis have

been the most influential in the literature with Zhao *et al.* (2010) highlighting that their 1986 paper has been cited by 11,480 journal articles, and are now so well known they are used by authors and requested by journal reviewers almost reflexively (ibid). However, the methods developed by Preacher and Hayes (2004) have arisen due to certain criticisms of the Baron and Kenny method, which is argued to have low power in comparison to newer bootstrap tests (Zhao *et al.*, 2010). To date though, none of the studies have engaged with using their variables under study to move beyond mediation analysis to propose a model of psychological distress in the areas of psychopathology studied, with the role of EA clearly outlined and included.

1.7.10.3 MEASURES

One of the major limitations of all of the studies incorporated in this systematic review is their use of measures of EA. The Acceptance and Action Questionnaire-I (AAQ; Hayes *et al.*, 2004) is the most widely used measure of EA in the literature to date, consisting of nine to 16 items depending on the version (Bond *et al.,* 2011). A meta-analysis of 27 studies that used this measure found that it predicted a wide range of quality of life outcomes (depression, anxiety, job satisfaction) with an average effect size of r=.42 (Hayes *et al.*, 2006). Due to unnecessary item complexity (e.g. “When I evaluate something negatively, I usually recognise that this is just a reaction, not an objective fact”) and the subtlety of the concepts addressed, the internal consistency of the AAQ-I has often been a problem (Bond *et al.*, 2011) with alpha coefficients of .70, and test-retest reliability of .64 over four months (Hayes *et al.*, 2004). Alpha levels have sometimes been lower, especially with community samples and certain subpopulations (lower levels of education) (Bond *et al.*, 2011). As such the factor structure of the AAQ has been unstable, with the original validation study identifying nine and 16 item single factor versions, but other research identifying a two factor 16 item version (Bond *et al.*, 2011).

These issues were addressed in developing the AAQ-II, but the AAQ-II started out as a 10 item scale, which is the one used in all of the studies included in the review, but after final psychometric analysis was reduced to a seven item scale (Bond *et al.*, 2011). The AAQ-I and AAQ-II correlate at .97, but the AAQ-II has better psychometric consistency.

In the review conducted by Chawla and Ostafin (2007) they queried the conceptualization of EA, as they stated it was unclear whether EA should be viewed as a broad and

univariate construct, or a multifaceted construct with several dimensions. This confusion is only fuelled then, by the use of various measures of the AAQ.

1.7.10.4 THEORETICAL ISSUES

Chawala and Ostafin's (2007) major criticism of the EA literature revolved around whether EA was a separate construct from the construct of coping. Dennison *et al.* (2009, p. 144) state that coping strategies are "the conscious efforts an individual makes to manage internal or external stressors that they perceive as taxing their existing resources". The use of certain emotion-focused strategies (e.g. wishful thinking (hoping for a miracle), and escape-avoidance coping (e.g. forgetting the whole thing) are reported by Dennison *et al.* (2009) to be strong and consistent predictors of worse adjustment across studies in the MS literature. While the relationships between avoidant coping and poor outcomes seem well established in empirical studies, what is less clear is whether EA is distinct from emotional and avoidant coping strategies (Chawala & Ostafin, 2007; Karekla & Panayiotou, 2011).

EA does share some commonalities with other concepts in the literature such as emotion dysregulation, distress intolerance, intolerance of uncertainty, cognitive and emotional suppression, and mindfulness (Boulanger *et al.*, 2009). However, EA has never been described as a form of coping and in general not related to the coping literature (Karekla & Panayioutou, 2011). Though coping models include the broader concept of avoidance and factors that can be thought of as EA (mental disengagement, denial), to date these factors have not been clustered together or investigated as EA (ibid).

Karekla and Panayiotou (2011) highlight that while the process of EA looks like the avoidant coping strategies (described above, i.e. wishful thinking, escape-avoidance), Fledderus *et al.* (2010) state that an important difference is revealed when looking at the way these constructs are operationalised. EA assess whether a person engages in attempts to change the form, frequency, or situational sensitivity of unwanted private events, while coping styles are measured in terms of how often a strategy is used and what the content of the actual behaviour is to cope with the stressful situation (Fledderus *et al.*, 2010). EA is more focused on the function and context of behaviour, whereas coping styles are focused on the frequency and content of the behaviour (Hayes *et al.*, 1996, cited in Fledderus *et al.*, 2010).

In a recent attempt to empirically address this question, Karekla & Panayiotou (2011) showed that the more participants report high levels of EA (as measured by the 10 item AAQ-II), the more they tend to use emotion focused and avoidant types of coping. They also state that both EA and coping predicted psychological distress and wellbeing, with most variance explained by coping but some additional variance explained by EA. Their study concludes that coping styles and EA are largely overlapping but not identical constructs. It should be noted that this study used the 10 item AAQ-II, rather than the current 7 item AAQ-II, and the 10 item AAQ-II is likely to be a two factor structure (Bond *et al.*, 2011). Of interest in this study, the authors noted that individuals who were high in EA also used coping styles not typically considered avoidant such as seeking emotional support, venting and self-blame; suggesting that individuals high in EA not only suppress and dampen affect but also process and express it in a maladaptive way.

As has been considered in the systematic review, EA has been shown to fully mediate the relationship between detached/emotional coping and depression, and to partially mediate between rational coping and depression and stress (Costa & Pinto-Gouveia, 2011); EA also mediated the effects of passive coping on depression, anxiety, emotional wellbeing and psychological wellbeing (Fledderus *et al.*, 2010). However, the limitations highlighted in the measurement of EA are likely to have added to the lack of clarity that has dogged the literature to date.

1.7.10.5 SUMMARY

Two of the fourteen studies (Berman *et al.*, 2010; Manos *et al.*, 2010) did not provide any support for the role of EA in psychological distress, while the other 12 studies provide good support for the role of EA in psychological distress. These positive associations generally accord with the wider literature on EA, for example Ruiz (2010), incorporating the correlations from 22 studies, suggested a weighted correlation of r=.55 between some version of the AAQ and standard measures of depression, and a weighted correlation of r= .52 between some version of the AAQ and standard measures of anxiety. These relationships provide a rationale for investigating the role of EA in different populations. Although EA has been investigated as a mediator of distress, these studies may have limited generalisability due to the use of cross sectional designs. Despite this, the evidence is growing that EA may play a role in mediating distress in psychopathology, and as such it

is worthy of investigating the mediating role of EA in other populations. A major limitation of the literature has been the inadequate definition of EA which is underpinned by the less than adequate measurement of EA using previous versions of the AAQ; the AAQ-I.

It should be noted that although the review was systematic, it cannot be considered to be exhaustive due to the narrow search terms used. For example, a search of the MS literature identified a paper examining the role of acceptance (rather than EA) in adjusting to MS over time (Pakenham & Fleming, 2011), and this paper, due to its relevance, will be discussed below.

ACCEPTANCE & MS:

Pakenham and Fleming (2011) developed an MS specific measure of the AAQ, the MS Acceptance Questionnaire (MSAQ) to investigate the relationship between MS and adjustment (lower distress, higher positive affect, life satisfaction, marital adjustment and better subjective health status). They based the MSAQ on the 16 item AAQ. The MSAQ, also a 16 item questionnaire, yielded a two factor structure: ability to take action despite MS and a need for control, or a lack of willingness to experience MS symptoms and unwanted internal events related to MS.

Of interest to the current study, the MSAQ was stated to be a stronger predictor of adjustment to MS than the AAQ (16 item version), however only the action dimension of acceptance emerged as a consistent predictor of adjustment including lower distress. The willingness factor, while related to lower positive affect, was unrelated to three of the adjustment outcomes including distress. As such, and in consideration of the wider debate about measurement issues within the field of EA considered earlier, Pakenham and Fleming (2011) concluded that while there is some evidence that acceptance plays a role in adjusting to MS over time, further investigation is needed to examine the factor structure of the MSAQ across other MS samples to refine its applicability to this population. It is likely that the use of the AAQ-I, rather than the more psychometrically sound AAQ-II may have impacted on the results garnered using the MSAQ.

1.8 CHAPTER SUMMARY

MS is the most common neurological disease of young adults and implies multiple psychosocial challenges, with prevalence estimates for depression of around 50% affecting between 15 to 47% of the MS population (Gay *et al.,* 2010). Other psychiatric symptoms such as anxiety, social anxiety (Poder *et al.,* 2009) irritability, and emotional lability are also common (Kern *et al.*, 2009). Apart from clinical psychiatric diagnosis, sub-threshold psychiatric symptoms and psychological distress are frequently present (Feinstein & Fienstein, 2001).

While other psychological constructs have been investigated in relation to distress in MS, such as coping and social support, EA is one construct that has not been investigated in this population. EA is defined as the unwillingness to remain in contact with aversive private events and the action taken to alter the aversive experiences or events that elicit them (Hayes *et al.*, 1996). EA is one of six processes that underpin the model of mental health as outlined by ACT (Strosahl & Robinson, 2009). To date there is good evidence that EA is related to several forms of psychopathology (Boulanage *et al.*, 2009, Chawala & Ostafin, 2007). A systematic review of the literature identified 14 studies, eight of which reported positive correlations between EA and various forms of psychological distress: depression, anxiety, psychological wellbeing, delusions, BPD, OCD, PTSD. Six studies focused on the causal role of EA. Four of these studies highlighted that EA is a cause of, rather than a consequence of, depression (Berking *et al.*, 2009); that it plays a central role in BPD (Iverson *et al.*, 2011); that it is one of the main underlying processes in GAD (Lee *et al.*, 2010); and that it plays a role in maintaining PTSD symptoms (Morina *et al.*, 2008).

The systematic review also identified 7 studies that highlighted that EA acted as either a full or partial mediator between various constructs (self reported health, detached emotional coping, rational coping, passive coping, somatic distress, anxiety sensitivity, life hassles, social anxiety) and outcome measures of distress (quality of life, depression, anxiety, emotional wellbeing, BPD symptom severity, delusional distress). In addition Pakenham and Fleming (2011) developed a MS specific measure of acceptance, the MSAQ, which, despite the preliminary design, highlighted that the action part of the MSAQ, predicted distress in MS.

In trying to understand what causes psychological distress in the MS client group, one of the most researched hypotheses has been that level of disability causes the level of psychological distress, and there is significant evidence that physical and neurological disability is associated with depression and psychological distress in MS (Chwastiak *et al.,* 2002). However there is an equal number of studies that highlight no relationship between disability and distress, which suggests that other factors are moderating or mediating the relationship (Arnett *et al.,* 2008). Given the evidence for the mediating role of EA in psychopathology (such as depression, anxiety, social anxiety disorder which are common psychological problems faced by people with MS); it is hypothesised that EA may mediate between disability and distress in MS; however this has not been tested to date. Authors have suggested that ACT is well suited to long term health conditions (Hayes *et al.*, 1999; Ruiz, 2010) such as chronic pain and diabetes (Hayes *et al.*, 2006). Using a small sample (n=15) Sheppard *et al.* (2010) found that depression decreased over time following a 5 hour ACT workshop for people with MS. However, despite this evidence that ACT might be a helpful intervention, and the study conducted by Pakenham and Fleming (2011) looking at acceptance and adjustment in MS, there has been no research exploring the role of EA and psychological distress with MS populations.

Illness representations of MS may also operate as a mediator between physical disability and forms of psychological distress (e.g depression, Arnett *et al.*, 2008). The overall sense that an individual makes of their illness is based on the interplay between the components of illness representations: identity, time-line, consequences, cause, and cure/controllability. Although research on the role illness representations play in distress experienced by people with MS is in its infancy, to date researchers have shown that individuals who consider their MS to have many negative effects on their life will be more likely to encounter a range of difficulties, including increased emotional distress (Vaughan *et al.,* 2003, Jopson & Moss-Morris, 2003). No study to date has examined how illness representations may moderate or mediate the relationship between psychological distress (e.g. depression) and physical disability (Arnett *et al.*, 2008).

1.9 INTRODUCTION TO THE CURRENT STUDY

1.9.1 AIM

The aim of this study is to explore factors associated with psychological distress in a sample of participants who have MS. It aims to explore the relationships between level of

symptoms, illness representations, and EA, and to investigate the influence of each of these factors on psychological distress. It is hypothesised that EA will mediate the relationship between level of symptoms and distress, and between illness representations and distress, which if confirmed may support the use of interventions addressing illness beliefs and avoidance, such as those outlined by ACT, with clients with MS. The psychological factors under study (illness representations and EA), unlike illness factors (physical symptoms) are potentially modifiable through psychological interventions (Dennison *et al.*, 2009).

1.9.2 RESEARH QUESTION

How are severity of symptoms, illness beliefs and EA related to psychological distress in participants with MS?

1.9.3 PATH ANALYSIS APPROACH

Path analysis is a subset of Structural Equation Modeling (SEM) (Stoelting, 2002) and is a statistical technique for analysing relationships among a set of variables to reveal the relative effect of each variable on another variable (Schumacker & Lomax, 2004). Path analysis starts with outlining the proposed relationships between a set of variables based on theory, research and logic (Klem, 1995). Along with a path analysis, a path model provides a pictorial representation of hypothesised relationships among variables (Stage *et al.*, 2004).

In path models, there are two types of variables: endogenous and exogenous (Klem, 1995). The values of endogenous variables are explained by one of more of the variables in the model, while the values of exogenous variables are taken as given; the model does not try to explain them (Klem, 1995). The distinction is similar to that between dependent (endogenous) and independent variables (exogenous) (ibid). However in a path model a variable can be both independent and dependent. An endogenous variable has arrows coming towards it, and can be both a dependent and independent variable. This is represented when there are both incoming and outgoing arrows in the path model (ibid). Exogenous variables have no arrow links towards them from other variables in the model (Klem, 1995, Inan & Lowther, 2010).

1.9.4 HYPOTHESISED PATH MODEL

In order to explore factors impacting on psychological distress in MS a proposed model is presented in Figure 1.1. This model has been proposed based on the theory and research reviewed in the previous sections. The path model consists of one exogenous variable: level of disability (EDSS) and three endogenous variables: experiential avoidance (AAQ-II), illness representations (BIPQ), and psychological wellbeing (GHQ-30).

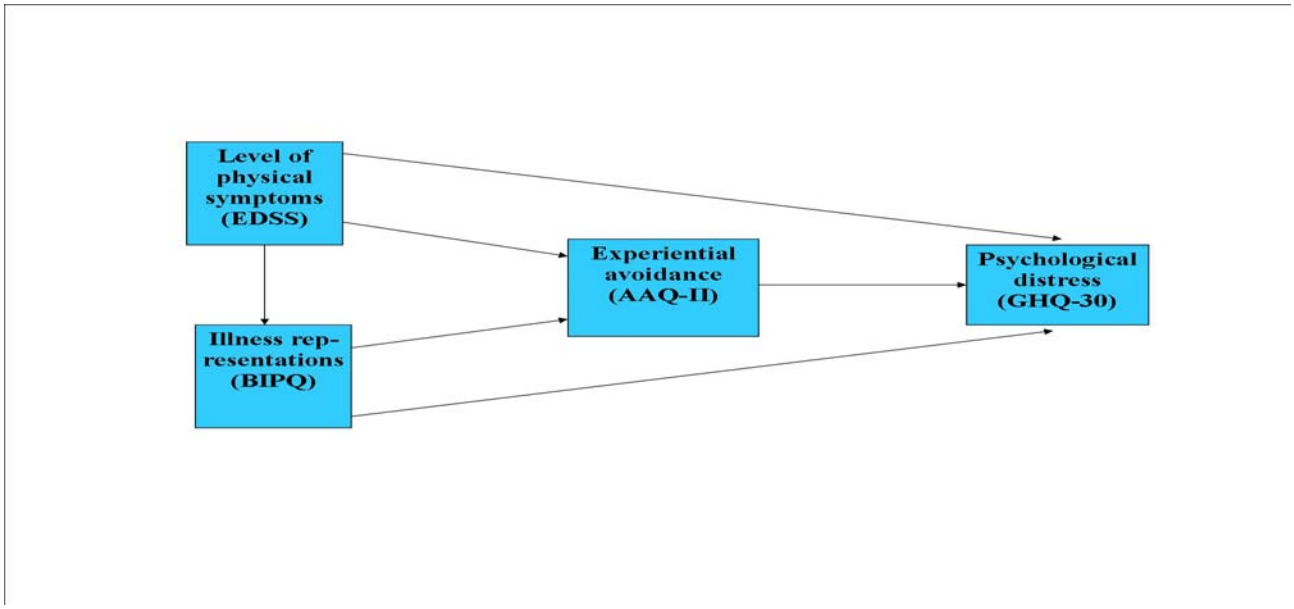


Figure 1.1: Hypothesised model of psychological distress based on theory and research

1.9.5 PURPOSE OF STUDY

Considering the path models in Figure 1.1 as a research framework, the study examined the following hypotheses:

1) There will be a positive relationship between physical symptoms and psychological distress
2) There will be a positive relationship between illness representations and psychological distress
3) There will be a positive relationship between experiential avoidance and psychological distress

4) The relationship between disability and psychological distress will be mediated by experiential avoidance
5) The relationship between illness representations and psychological distress will be mediated by experiential avoidance
6) The relationship between disability and psychological distress will be mediated by illness representations

A secondary aim of the research is to highlight the difference that may occur if distress is conceptualised as depression.

CHAPTER TWO: METHODS

2.1 INTRODUCTION

This chapter will describe the methods used for this research study considering the design, sample, measures used, the procedure for gathering the data, and ethical considerations.

2.2 DESIGN

A cross sectional, within subjects design was used. The analysis then examined the theoretical model that has been outlined in Figure 1.1 in section 1.9.4. Path analysis is viewed by many as an extension of multiple regression, but instead of predicting to one single dependent variable, is concerned with the predictive ordering of variables and allows researchers to test a theory of casual order among a set of variables (Klem, 1995). The starting point for such an analysis is the theory of the causal relationships among a set of variables which is expressed as a path model (ibid).

Each variable in a path analysis should be measured on an interval scale, or an ordinal scale where the data can be treated as interval (Klem, 1995). Path analysis allows the magnitude of hypothesised effects to be estimated, and also allows researchers to test whether the model is consistent with the observed data (ibid). If the model is not consistent with the data, it can be rejected as unlikely; however it cannot be proved that a path model is correct as different models can be consistent with the same observed data (Klem, 1995).

Simultaneous multiple regression analyses were used to assess predictors of distress, as outlined by the path model in section 1.9.4. In simultaneous multiple regression all independent variables (IV) are entered into the regression at the same time, and so each IV is evaluated in terms of what it adds to predicting the dependent or outcome variable, that is different from the predictability afforded by all the other IVs (Tabachnick & Fidell, 2007). One simultaneous regression analysis is needed for each endogenous variable (Klem, 1995).

This method of carrying out path analysis has been outlined by a number of authors (Judd & Kenny, 1981; Kenny *et al.*, 1998) but the guidelines by Klem (1995) have been used for

this study, as they provide the clearest account of how to conduct path analysis using multiple regression, when it is not possible to use more sophisticated computer packages designed for path analysis (eg AMOS for SEM). Although SEM was considered to test the overall model's adequacy of fit, this approach was not used due to sample size limitations (Thompson, 2000).

2.3 POWER ANALYSIS

There is little consensus about how to estimate sample size for path analysis (Hoe, 2008), however path analysis involves a series of multiple regression analyses to test the predicted relationships between variables (Klem, 1995). As such methods for determining the number of participants in multiple regression were consulted.

Kline (1998) recommends that the sample size should be 10 times (or ideally 20 times) as many cases as parameters. In path analysis, each measured variable usually has three parameters: its path coefficient, its variance, and the disturbance term (so 30 participants for each variable) (ibid). Harris (1985) recommends that the number of subjects be $N+m>50$ (m= the number of predictors (3)) (N=53), while Green (1991) suggests a rule of thumb for multiple correlations whereby $N>50+8m$ (N=74), or $N>104+m$ (N=107) for a partial correlation suggesting that the sample size should be between 53 participants and 107. These sample sizes are similar to those suggested by Cohen (1992), in order to detect a medium effect size (N=76), using three predicators. Considering the above information, it appears that a sample size of 53 is the lowest recommended number, and 107 the largest.

2.4 SAMPLE

The study population comprised adults over the age of 18 with a current diagnosis of MS (MS) who were known to a centre for neuroinflammatory diseases covering a large geographical area in South Wales.

2.4.1 INCLUSION CRITERIA

The ability to speak fluent English was prerequisite to participation as valid and reliable versions of each measure were not available in other languages (e.g Welsh). Having a

confirmed diagnosis of MS was also a prerequisite of the study. Participants were included if they were able to give informed consent to take part in the study (indicated by response or non-response).

Although the questionnaire battery was designed for anonymous completion, participants were invited to ask a carer/family member to assist them to complete the battery of research questionnaires.

2.5 MEASURES

The variables under examination in this study were physical disability (level of symptoms), illness representations, EA and psychological distress. In addition to a background information questionnaire, four established questionnaires were used to measure these variables and these five components comprised the questionnaire battery. To reduce any potential burden on participants measures were selected that had suitable psychometric properties, while also being relatively quick to complete. Also due to the cognitive impairments that individuals with MS can experience it was considered important to choose measures that were clear and simple.

The battery was printed over 10 sides of A4 paper. Pages were stapled together, with the consent form, and instructions were provided to encourage completion in order of presentation. The battery, in order that measures were presented, comprised the following five measures:

1) A background information questionnaire (Demographic Questionnaire)
2) The Expanded Disability Status Scale: self report (EDSS)
3) The Acceptance and Action Questionnaire-II (AAQ-II)
4) The Brief Illness Perception Questionnaire (BIPQ)
5) The General Health Questionnaire (GHQ-30)

2.5.1 Demographic Questionnaire

Demographic information collected included the participants age, gender, length of time since experiencing the symptoms of MS, the year when they were diagnosed, and the type of MS they have (Appendix 4). It was made clear to participants in the information sheet that if they did not provide this information it would be accessed from their file, however they also had to give their consent for this.

2.5.2 The Expanded Disability Status Scale (EDSS): self report

Levels of symptoms were measured using the expanded disability status scale-self report measure (Ingram *et al.*, 2010). This measure is based on the expanded disability status scale (EDSS) (Kurtzke, 1983), a measure used in most clinical trials, and accepted as the gold standard (Ingram *et al.*, 2010).

The EDSS, an ordinal measure, is the standard measure of disease progression and the degree of neurological impairment in MS clinical practice and clinical trials (Chwastiak *et al.*, 2002). The EDSS divides functioning into eight systems, pyramidal, cerebellar, brainstem, cerebral, bowel and bladder, sensory, visual, and other; impairment in each system is graded and then summed across the eight systems. Scores for the total scale can range from 0 (no neurological abnormality) to 10 (death from MS). As a shorthand, Chwastiak *et al.* (2002) highlight that someone with a score lower than four is ambulatory, a patient with a score between 4.5 and 6.5 has disability severe enough to limit daily activity, and a patient with a score of 7 is essentially restricted to a wheelchair.

Current functioning was determined by the EDSS self report (EDSS-SR), as developed by Ingram *et al.* (2010) (Appendix 5). The EDSS-SR, asks patients to select from a series of statements describing walking ability as specified by the EDSS with reference distance between well recognised local landmarks; for example 500m equated to the length of one of the well-known city centre shopping streets. Patients who could walk at least 500m without rest or aid were scored at EDSS equal or less than four. The EDSS-SR is unable to score any EDSS score below 4 (as this would require an individual neurological examination). As such, a review of patient records was conducted to identify neurologist derived scores below 4. The mean EDSS score from 2399 neurological examinations on

MS patients not currently in relapse where a score of less than four was recorded was 2.18. As such, any value under four was entered as 2.18 as their EDSS score.

EDSS scores derived from questionnaires have good levels of correlation (intraclass correlation coefficients of 0.69 to 0.89) with clinician-derived data with perfect agreement noted in 75.9% and 88.6% allowing for accepted intra-observer variation of +0.5 EDSS points (Ingram *et al.*, 2010).

2.5.3 The Acceptance and Action Questionnaire-II

The Acceptance and Action Questionnaire (AAQ-I; Hayes *et al.*, 2004) is the most widely used measure of EA (Bond *et al.*, 2011). The AAQ-I was developed in order to establish an internally consistent measure of ACT's model of mental health and behavioural effectiveness.

The original item pool for this short (nine to 16 items) Likert style scale was generated by Acceptance and Commitment Therapy (ACT) therapists and researchers to represent the phenomena that constitute EA. The final scale contained items on negative evaluation of feelings, avoidance of thoughts and feelings, distinguishing a thought from it referent, and behavioural adjustment in the presence of difficult thoughts and feelings.

The AAQ-II was developed by Bond *et al.* (2011) to address the shortcomings of the AAQ-I. Findings indicate that the reliability of the AAQ-II is consistently above the AAQ-I, with a mean alpha coefficient across samples of .84, with 3 and 12 month test-retest reliability .81 and .79, respectively (Bond *et al.*, 2011). The AAQ-II was designed to assess the same construct as the AAQ-I and the two scales correlate at .97, but the AAQ-II has better psychometric consistency. Most importantly factor analytic findings suggest the AAQ-II is a unidimensional measure (Bond *et al.*, 2011).

The current version of the AAQ-II (Appendix 6) requires participants to answer seven items with a seven point Likert type response scale, responses range from never true to always true. Higher scores on the AAQ-II indicate greater EA (less acceptance). It should be noted that the version of the AAQ-II sent to participants, and in Appendix 6, is the 10 item AAQ-II; however items 1, 6 and 10 were omitted from scoring the AAQ-II, in line with current recommendations.

2.5.4 *The Brief Illness Perception Questionnaire*

The Brief Illness Perception Questionnaire (BIPQ, Broadbent *et al.*, 2006) is a nine item scale designed to rapidly assess the cognitive and emotional representations of illness. The BIPQ was used to assess patient's illness perceptions along the dimensions of consequences, timeline, identity, personal control, treatment control, emotional representation, concern and coherence (Appendix 7). Each dimension is measured by a single item scored on an 11 point Likert scale, with higher scores indicating stronger endorsement of that item (e.g high identity scores indicate that the participant experiences more symptoms, Broadbent *et al.*, 2006). In order to ensure data could be treated as interval level data, the composite score was calculated.

A composite BIPQ score, with higher scores indicating a more negative perception of the illness (Wilson *et al.*, 2011), was derived in accordance with the authors instructions (Broadbent et al., 2006). Broadbent describes that the composite score represents the degree to which the illness is perceived as threatening or benign. The composite score reflects the overall positivity (low total BIPQ= a benign view of the illness) or negativity (high total BIPQ= a more threatening view of the illness) of individual's illness perceptions. The BIPQ evaluates the quantity or strength of illness perceptions, not the content of these specific beliefs (van Oort *et al.*, 2011). This approach (taking the composite score) is consistent with the current approach taken by illness representations research, when investigating its relationship to, or ability to predict, other constructs (e.g Knowles *et al.*, 2011; Wilson *et al.*, 2011). In addition, using the composite score is necessary for the statistical analysis used; path analysis, that requires data that can be treated as interval. The causal scale (asking participants to list what they felt caused their MS) was not incorporated into this study, and only the summary score was of interest for this study.

The BIPQ was chosen over the longer version IPQ-R, primarily due to its brevity; however there are moderate to good associations between the BIPQ and the IPQ-R on all the equivalent dimensions (Broadbent *et al.*, 2006). Research demonstrates that the BIPQ items, have very good test-retest reliability (from an r value of .48 (coherence) to .71 (consequences) with p values <0.001), and when compared to the IPQ-R, good concurrent (from an r value of .32 (treatment control) to .63 (emotional response), p values <0.001), predicative and discriminate validity (Broadbent *et al.*, 2006).

2.5.5 The General Health Questionnaire 30

The General Health Questionnaire-30 (GHQ-30, Goldberg & Hillier, 1972), which can be viewed in Appendix 8, was designed as a self-administered questionnaire to detect undifferentiated emotional distress in community settings rather than psychiatric populations (Nicholson *et al.*, 2005). It acts as a screening instrument for minor psychiatric disorder, especially anxiety and depressive illness (ibid). Questions ask whether a range of symptoms have recently been worse or better than usual. The GHQ-30 was prepared from the full 60 item version using the best discriminators for psychiatric caseness, but removing somatic items, making it especially useful in research in clinical health populations.

In the GHQ-30, the four response categories of the positively worded items are labelled "better than usual/more so than usual", "same as usual", "less than usual", and "much than usual", whereas response categories for the negatively worded items are "not at all", "no more than usual", "more than usual", and "much more than usual". Each GHQ item was scored with a Likert format where subject's responses can take a value of 0 to 3. From this a summary score was calculated, ranging from 0 to 90, which was used in the final analysis.

The factor structure of the GHQ-30 has been extensively investigated. There are five robust factors in the GHQ-30 corresponding to symptoms of anxiety, feelings of incompetence, depression, difficulty in coping and social dysfunction (Huppert & Garcia, 1991). Five subscales can be derived by summing participant's scores on each item that contributed to a particular factor, based on the factor structure as outlined by Huppert *et al.*, (1989) (Appendix 9), for example the depression subscale of the GHQ-30 can be calculated using items 24, 25, 26, 29, 30 (ibid).

2.6 PROCEDURE

2.6.1 RECRUITMENT

Participants were recruited from a centre for neuroinflammatory diseases covering a large geographical area in South Wales. Recruitment was planned to occur in two waves, by postal methods of data collection, and during client's clinic appointments. This second

strategy, accessing potential participants at clinic, would only be employed if there was a low return rate from the first sampling strategy, postal methods.

A list of clients was generated at the centre for neuroinflammatory diseases. In accordance with the terms of the ethics approval and data protection guidelines, a member of the neurological diseases centre was responsible for sending potential participants a letter of invitation authored by the clinical psychologist in the service (Appendix 10), the information sheet (Appendix 11), the consent form (Appendix 12), the questionnaire battery (Appendix 4-8), and a stamped addressed envelope for returns.

A total of 800 potential participants were identified to be sent the research packs by the clinical supervisor at the neurological department. It was ensured that all participants had a confirmed diagnosis of MS before including them in the study, and that also these participants were alive (by cross referencing with the existing patient management system of the health board). This process reduced the potential sample to 399 participants who were sent an invitation letter, information sheet, consent form and the five questionnaires.

The questionnaire battery was coded for each participant. Each code would enable accessing demographic information (e.g. EDSS score) if participants did not want, or could not provide this. Participants were made aware that their patient files would be accessed if they did not provide this information, and consent was gained for this action.

A total of 117 participants responded to this phase of data collection; a response rate of 29%. In order to ensure an adequate sample size a second sampling strategy was employed. Research packs (including the invitation letter, information sheet, consent form, five questionnaires, and stamped addressed envelope) were provided to the multidisciplinary team, who would ask patients at their inpatient appointment whether they would be interested in partaking in the research. The team ensured that patients had not been previously approached about this research. This second stage of sampling generated a further 10 participants for inclusion in the study. Thus the two sampling strategies generated a potential sample of 127 participants. However on inspection six participants had returned the research pack unanswered, and so the final sample consisted of 121 participants.

2.7 ETHICAL CONSIDERATIONS

The main ethical considerations have been adequately addressed by the research and discussed in clinical supervision and with the ethics panel at review. Although it was deemed that this study did not pose a great risk to potential participants the following areas of ethical practice were considered in the design of this study. Voluntary participation, gaining informed consent, anonymity and the provision of contact details for further questions or concerns (emotional or with the research design itself) are considerations which have been addressed.

Information sheets were provided alongside consent forms to be read prior to deciding on consent. The voluntary nature of participation in the study was clearly outlined in the information sheet (see patient information sheet in Appendix 11), and that declining to take part would not affect their care in any way. In addition to the information sheet the consent form (see Appendix 12) reminded participants that participation was voluntary and that declining to take part would not affect their care in any way. The consent form also specifically asked potential participants to highlight that they had read and understood the information sheet, understood that participation was voluntary, that data would be treated anonymously and that they would not be identified in any report of the research project, and finally that their file would be accessed to gain demographic information (such as type of MS) if they did not or were not able to provide it.

In order to protect the confidentiality and anonymity of the participants each participant was assigned an identification number. Each of the measures sent to potential participants used this identification number so that no identifying information needed to be attached to any of their questionnaire responses. All participant information, consent forms and questionnaires were stored in a locked filing cabinet within Cardiff and Vale UHB premises.

Due to the nature of this research question and the measures used, which require participants to reflect on their mood and wellbeing, it was considered possible that some individuals might become distressed as a result of taking part in the study. This was highlighted to participants in the information sheet, and participants were advised that they could refuse to answer questions they found upsetting, and could withdraw from the study at any point of completion. While all of the questionnaires used have been established in

the literature and have not been reported to cause adverse experiences or distress, in order to address any concerns potential participants may have had, the researcher also provided phone and e-mail details to answer any questions that prospective participants had.

2.8 ETHICAL APPROVAL

Authorisation to conduct the research was obtained through application to the NHS Research and Development Department of the Local Health Board. After reviewing the proposal, this committee grated approval for the study to be completed (see Appendix 13 & 14), Approval was also granted from the Local Research Ethics committee (see Appendix 15).

CHAPTER THREE: RESULTS:

3.1 INTRODUCTION

This chapter will describe the results that have been garnered for this research project. After providing descriptive statistics for the sample and measures used, the chapter outlines how missing values were handled. The chapter next outlines how the data met the assumptions for conducting path analysis using multiple regression analysis. This includes considering normality and data transformation and includes tests of multivariate assumptions including multicollinearity, independent errors, linearity and homoscedaciety. The chapter then goes on to test the main hypotheses.

3.2 DESCRIPTIVE DATA

3.2.1 PARTICIPANTS

Data were collected from 121 participants, 98 of whom were female and 23 male. All demographic information collected can be viewed in Table 3.1 below. Information in the table has been rounded up to the nearest whole number.

The age range of participants was 21 to 87 years, and the mean age was 46.92 (SD= 12.74). Participants reported experiencing the symptoms of MS for a mean of 12.82 (SD= 11.02) years before receiving a diagnosis, ranging between 1 and 59 years. Participants also reported that they had received a diagnosis ranging between 0 and 43 years ago (prior to participation in study), with the mean being 8.76 years (SD 8.54).

On the self report measures 23% reported that they did not know what type of MS they had. As such only these participants medical files were accessed (*N*=28) to ascertain their type of MS diagnosis, although due to incomplete records, for these 28 participants, this was only possible for 24 participants. Therefore, using both self report and checking patient files, the type of MS for each participant was only known for 117 of the total sample.

53% of the participants reported having relapsing remitting MS, 27% reported having secondary progressive MS, 14% reported having primary progressive MS, while 7% reported having benign MS.

Table 3.1: Characteristics of participants in the study

Variable	N	Mean (SD)	Median	Percentages
Gender Male Female	121 23 98			 19% 81%
Age	121	47 (13)	46	
Length of symptoms before diagnosis	121	13 (11)	10	
No of years since diagnosis	121	9 (9)	7	
Type of MS Relapsing remitting Benign Secondary progress. Primary progress.	117 62 07 32 16			97% 51% 6% 26% 13%

3.2.2 MEASURES

Descriptive data for the four variables, the EDSS, the BIPQ, the AAQ-II and the GHQ-30 are included in Table 3.2. The mean scores, standard deviations, and minimum and maximum scores obtained from the sample are presented for each variable. The possible range of scores that could be obtained on each of the measures is also included. It should be noted that the data presented in these tables is the untransformed data to enhance clarity.

Table 3.2: Descriptive data for EDSS, AAQ-II, BIPQ and GHQ-30.

Variable	Mean	Standard deviation	Minimum Score	Maximum Score	Range of measure
Expanded Disability Status Scale (EDSS)	4.75	1.96	2.18	8	2.18-8
Acceptance and Action Questionnaire (AAQ-II)	19.41	10.9	7	49	7-49
Brief Illness Perception Questionnaire (BIPQ)	45.63	13.15	11	75	0-80
The General Health Questionnaire (GHQ-30)	32.65	16.88	7.15	84.38	0-90

Table 3.3 provides a breakdown of the mean, median and mode for each of the separate items on the BIPQ. The participants in this study rated timeline as the most negative representation of MS (M=9), while the least negative was their emotional concern about MS (3).

Table 3.3: Mean, median and mode for each of the items on the BIPQ

BIPQ item	Mean	Median	Mode
Consequences	5.4	5	7
Timeline	8.9	10	10
Personal Control	6.1	6	8
Treatment Control	5.5	6	8
Identity	5.5	6	7
Coherence	5.7	6	7
Emotional Concern	3	2	2
Illness Concern	5.6	6	8

3.3 STATISTICAL ANALYSIS

Data were analysed using the Statistical Package for the Social Sciences (SPSS, Versions 16 and 19 for Windows and Mac, respectively).

3.4 DATA SCREENING

3.4.1 MISSING DATA IMPUTATION

The GHQ recommends treating incomplete answers as low scores, and so this procedure was followed when creating the dataset. Beyond this, the complete dataset was screened for missing values, and the following section outlines how missing values were handled.

Missing Values Analysis (MVA) was conducted on the resulting dataset (*N*=121), which showed that less than 5% of the data was missing across the study variables. Tabachnick and Fidell (2009) have stated that if 5% or less data points are missing in a random pattern from a data set almost any procedure for handling missing values yields similar results.

Data were largely missing at random (MAR) as is the case in most social science research (Acock, 2005). Although Little's MCAR statistic was significant, indicating that the data were not completely missing at random, further investigation illustrated that there was no systematic pattern to the missingness, and so it can be assumed that the data were MAR.

Missing data were imputed using Expected Maximisation (EM) in SPSS. This approach assumes the missing data meets MAR assumptions and uses an iterative procedure to create a single data set with no missing values. This process is based on observed relationships between variables and produces a less biased estimate of parameters when the data is MAR than deletion methods or other forms of single imputation such as mean substitution (Fox-Wasylshyn & El-Masri, 2005).

3.4.2 OUTLIERS

Extreme values analysis, on SPSS, was used to check for outliers, and indicated the presence of 1 outlier on the AAQ-II (a score of 49), and 6 outliers on the GHQ-30 (ranging

from 73-84). Data had been accurately entered into the database, and these scores are within the range expected of the measures used. Inspection of these scores also indicated that these extreme scores were representative of the participants scores on other measures (i.e. they also scored highly on other measures) and so these outliers were not considered suitable for deletion, as they are considered to be sampled from the target population.

3.5 TESTS OF MULTIVARIATE ASSUMPTIONS

The path analysis was carried out in two phases: assumption testing and path estimates. In order to draw conclusions about a population based on a regression analysis done on a sample, several assumptions must be met (Field, 2009). When the assumptions of regression are met, the model for a sample can be accurately applied to the population of interest with some confidence (ibid). The assumptions that must be met include normally distributed data, no perfect multicollinaerity, homoscedasticity, independent errors, and linearity, and these are discussed below. The procedures to examine these assumptions followed the guidance provided by Field (2009) and by (Tabachnick & Fidell, 2007).

3.5.1 NORMALITY

The statistics employed require assumptions of normality to be met and therefore normality of the variables was assessed through examination of histograms and also using the Kolmogorov-Smirnov statistical test (K-S test) (Appendix 16). The K-S test revealed that two of the predictors variables (the EDSS scores and the AAQ-II scores) and the outcome variable (GHQ-30) were non-normally distributed ($p<0.05$).

Field (2009) recommends analyzing normality by analyzing the skewness and kurtosis of the data, in addition to using the K-S statistic, to make a more informed decision about the normality of data. In order to standardise the reported values for skewness and kurtosis (Appendix 17), they were converted into *z*-scores by subtracting the mean of the distribution (in this case 0) and then divided by the standard error of skewness or kurtosis, as recommended by Field (ibid).

Field (2009) suggests that z-scores greater than 1.96 for both skewness and kurtosis should be considered significant at the $p<0.05$ level, greater than 2.58, significant at the $p<0.01$ level, and scores greater than 3.29, significant at the $p<0.001$ level.

An analysis of skewness and kurtosis indicated that the EDSS scores were not significantly skewed ($z=1.1689$), however they were significantly negatively kurtotic ($z=3.30$, $p<0.001$). Consonant with the K-S test, the AAQ-II ($z=3.5286$), and the GHQ-30 ($z=5.5479$) were both found to be skewed at the $p<0.001$ level, indicating significant positive skewness. The AAQ-II was not significantly kurtotic ($z=0.767$), however the GHQ was significanlty positively kurtotic ($z=2.89$, $p<0.01$).

3.5.2 DATA TRANSFORMATION

Field (2009) recommends data transformations to correct problems with normality, but can also reduce the impact of outliers (Tabachnick & Fidell, 2007). Relationships between scores are not altered as a result of data transformation, since the same transformation is applied to each of the values in a given variable (Field, 2009).

The three most common types of data transformation are log transformation, square root transformation and reciprocal transformation. Log transformation is useful to reduce positive skew, as taking the logarithm of a set of numbers compresses the right tail of the distribution more than the left (Field, 2009). Square root transformations are also a useful way to reduce positive skew by taking the square root of each score. By transforming data in this way, large scores are brought closer to the centre of the distribution (ibid). Reciprocal transformation involves dividing 1 by each score, which effectively reverses scores, so that what were large values originally, become small values after transformation, and vice versa (Field, 2009).

Log, square root and reciprocal transformations were carried out on the three variables found to have a non-normal distribution (the EDSS, AAQ-II and GHQ-30). Log transformations resulted in the best improvements to normality; the AAQ-II and GHQ-30 were no longer significantly skewed ($p>0.05$), and the log transformation also reduced the impact of the negative kurtosis on the GHQ-30 ($p>0.05$).

Log transformation did not address the level of kurtosis in the EDSS, however Allison (1999) states that the assumption of normality is the least important of all assumptions in multiple regression, and given a moderate sample size can be dispensed with entirely. Arbukle (1997, p 239) also states that “a departure from normality that is big enough to be significant could still be small enough to be harmless”. Given the adequate sample size of 121 it is considered that the data would be robust enough to this violation of assumption. However, given that the log transformation in this study produced significant improvements in the normality of two variables, it was decided that the transformed data, for each of the three non-normally distributed variables, would be reported in the statistical analysis.

3.5.3 MULTICOLLINEARITY

Multicollinearity exists when there is a strong correlation between two or more predictors in a regression model (Field, 2009). Multicollinearity poses a problem because when highly correlated variables are included in the same analysis there is much redundancy in the statistical analysis; multicollinearity suggests that two variables measure essentially the same thing (ibid).

There was no evidence of the presence of multicollinearity amongst the variables. This assumption was validated by the Variance Inflation Factor (VIF) values (the recommended guidance is below ten) and tolerance values (tolerance below 0.2 indicates a potential problem) (Field, 2009). The average VIF values were all well below ten, and tolerance statistics all well above 0.2, confirming that multicollinearity was not considered a problem (Field, 2009). Also, in terms of multicollinearity there were no substantial (r >.9) correlations between variables (Field, 2009) (these correlations can be seen in Table 3.4).

3.5.4 INDEPENDENT ERRORS

For any two observations the residual terms (prediction errors from a regression analysis) should be uncorrelated (Field, 2009). To check whether the residuals in the model are independent the Durbin-Watson statistic for autocorrelation, which tests for serial correlations between errors (whether adjacent errors are correlated) (Field, 2009) was used. A value of two suggests that the residuals are uncorrelated; a value below two indicates a positive correlation, a value above two indicates a negative correlation. In this

case the values were all close to two (1.67-2.25), indicating that the assumption of independent errors was met.

3.5.5 LINEARITY AND HOMOSCEDACITY

In regression it is assumed that the relationship being modeled is a linear one (Field, 2009), and as such linearity was assessed through examination of scatterplots for each pair of variables when the multiple regression analysis was run. As recommended by Field (2009) plots for *ZRESID against *ZPRED, a histogram and normal probability plots of the residuals was requested when running the regression analyses. Also, Tabachnick and Fidell (2007) recommend that if scatterplots appear oval-shaped or near oval-shaped, then it can be assumed that they are linear and homoscedatic. As can be seen in the plots (Appendixes 18 and 19), there was no evidence of the graphs funneling out, indicating that hetroscedactiy was not an issue (Field, 2009). Also there were no curves in the data, indicating that the assumption of linearity had been met (ibid).

3.5.6 SUMMARY

The first stage of the path analysis: assumption testing has indicated that the data were suitable for estimating the path coefficients through use of multiple regression analysis. The previous section highlighted that missing values were imputed using expected maximization in SPSS. To address that three of the variables, the EDSS, the AAQ-II, and the GHQ-30 were not normally distributed, log transformations were completed. Finally further tests such as the Durbin-Watson statistic, the Variance Inflation Factor (VIF) values, and examining scatterplots indicated that there were no problems arising from linearity, homoscedacity, multicollinearity and indendepent errors, and that the data were suitable for tests of multivariate statistics.

The next section outlines the process of estimating the path coefficients. Before this, establishing that there is a relationship between the variables of interest in the study will be assessed through bivariate correlations.

3.6 BIVARIATE CORRELATIONS

Hypotheses 1 to 3 were investigated using Pearson product moment correlations. Table 3.4 presents a correlation matrix, with Pearson correlation coefficients (*r*) reported for each pair of variables, along with significance levels. In these and all further statistical analyses, the log transformed data for the variables EDSS, AAQ-II, and GHQ-30 have been used.

Table 3.4: Correlation matrix of variables EDSS, BIPQ, AAQ-II, GHQ-30 and the depression subscale from the GHQ-30.

Variable	EDSS	BIPQ	AAQ-II	GHQ-30	GHQ-Depression
EDSS		.57 P<0.01	.18 P<0.05	.29 P<0.01	.24 P<0.01
BIPQ			.52 P<0.01	.70 P<0.01	.60 P<0.01
AAQ-II				.67 P>0.01	.65 P<0.01
GHQ-30					.86 P<0.01
GHQ-Depression					

Hypothesis 1: There will be a positive relationship between physical symptoms and psychological distress

Table 3.4 shows that a significant positive relationship exists between the EDSS scores and the GHQ-30 (r=0.29, p (one tailed) <0.01), therefore hypothesis 1 is supported.

Hypothesis 2: There will be a positive relationship between illness representations and psychological distress

As can be seen from table 3.4, a significant positive relationship exists between the BIPQ and the GHQ-30 (r=.70, p (one tailed) <0.01), and therefore hypothesis two is supported.

Hypothesis 3: There will be a positive relationship between experiential avoidance and psychological distress

Examination of Table 3.4 indicates that when investigating the relationship between the AAQ-II and the GHQ-30, hypothesis 3 is supported as the data shows a significant positive relationship exists (r=.67, p (one tailed) <0.01).

3.7 PATH ANALYSIS

Path analysis using a series of simultaneous regression analyses (Appendix 18-19) in SPSS was used to test hypotheses 4, 5 and 6. Hypothesis 4 stated that EA would mediate between disability and distress, hypothesis 5 stated that EA would mediate between illness representations and distress, and hypothesis 6 stated that illness representations would mediate between disability and distress.

Figure 3.1 shows the path model used to assess hypotheses 4, 5 and 6. The path coefficients along each pathway are the standardised beta coefficients obtained from the multiple regression analyses (Appendix 18-19). A regression was not necessary to obtain the path between level of physical symptoms (EDSS) and illness representations (BIPQ), but in the path model is represented by the bivariate correlation (Klem, 1995).

The path coefficients represent the strength of the relationship between each pair of variables. Direct effects are shown in the path diagram by straight arrows from one variable to another (Klem, 1995). Statistical significance of each of the path coefficients is indicated by use of asterisks.

Error terms (E) were also determined for each regression analysis within the path model, and these were calculated by taking the variance of the errors (1-R^2) from the regression equation for the corresponding dependent variable (Bryman & Cramer, 1990, Klem, 1995). Error terms provide an indication of the success of the model, as they represent how much variance within the model remains unexplained (Klem, 1995) after the regression analyses have been carried out.

Also, in path analysis, the indirect pathways between variables are of interest. Indirect effects involve chains of straight arrows, where the path along the arrows is always

forward, and in the direction of the arrow (ibid). Klem (1995) highlights that in order to estimate the magnitude of an indirect effect of one variable on another, you must locate all the routes, and for each route multiply the path coefficients to obtain their product, and (if necessary) then add the products to get their direct effect.

Hypotheses 4 and 5 predicted that EA would act as a mediator variable within the model. Hypothesis 6 proposes that illness representations would act as a mediator variable within the model. Frazier *et al.* (2004) describe a mediator as a variable that explains the relation between a predictor and an outcome, and so it influences the outcome variable. Therefore to examine hypotheses 4 to 6, the strength of the indirect pathways through EA were calculated and compared to the strength of direct relationships within the model.

Hypothesis 4: The relationship between physical symptoms (EDSS) and psychological distress (GHQ-30) will be mediated by experiential avoidance (AAQ-II).

In order to assess support for this hypothesis, the strength of the direct pathway between physical symptoms and psychological distress was compared to the indirect pathway via EA. Klem (1995) advises calculating this indirect pathway by multiplying the path coefficient between physical symptoms and EA (-.17) by the path coefficient between EA and psychological distress (.42). Thus the strength of this pathway was calculated as **-.07**. The direct pathway between physical symptoms and EA and psychological distress is -**.09**. Therefore the hypothesis that EA mediates the relationship between physical symptoms and psychological distress is not supported by this data, since the strength of the direct pathway is greater than the strength of the indirect pathway. Also, the direct pathway between disability and distress is not significant, indicating that there is no relationship for EA to mediate.

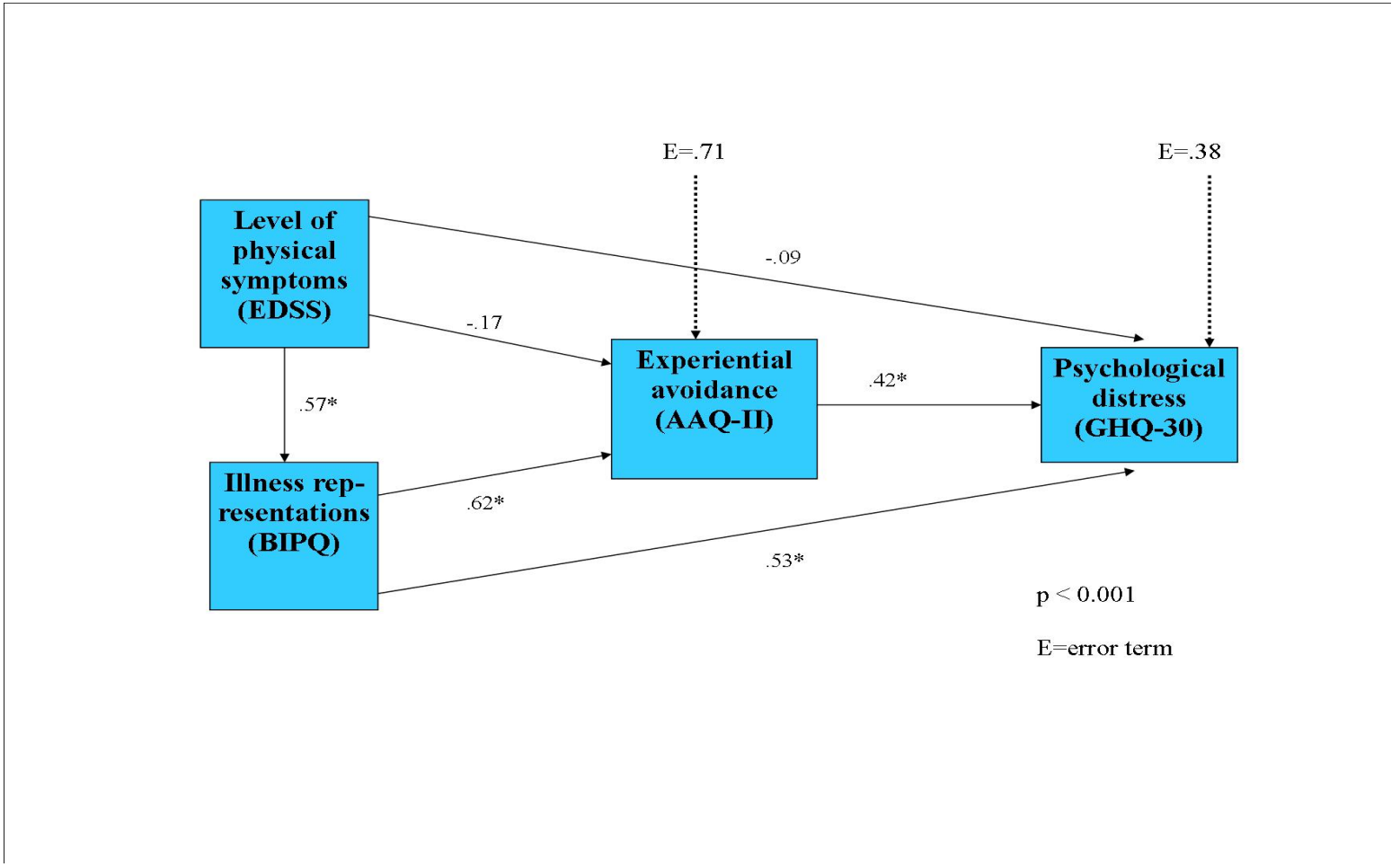


Figure 3.1: Path diagram of the relationships between level of symptoms, illness beliefs, experiential avoidance, and psychological distress, showing path coefficients and error terms

Hypothesis 5: The relationship between illness representations and psychological distress will be mediated by experiential avoidance

The strength of the direct pathway between illness representations and psychological distress was compared to the indirect pathway through EA. The indirect pathway was calculated by multiplying the path coefficient between illness beliefs and EA (.62), and the path coefficient between EA and psychological distress (.42). Thus the strength of the indirect pathway was calculated as .**26.** The strength of the direct pathway between illness beliefs and psychological distress is .**53**. Therefore the hypothesis that EA mediates the relationship between illness beliefs and psychological distress is not supported by the data, since the direct pathway is greater than the strength of the indirect pathway.

Hypothesis 6: The relationship between physical symptoms and distress will be mediated by illness representations.

The strength of the direct pathway between physical symptoms and psychological distress was compared to the indirect pathway via illness representations. The indirect pathway was calculated by multiplying the path coefficient between symptoms and distress (.57) and the path coefficient between illness representations and distress (.53). The strength of this indirect pathway was calculated as .**30**. The strength of the direct pathway is **-.09**. Therefore the hypothesis that illness representations mediate the relationship between physical symptoms and distress is supported. However, the direct pathway between disability and distress is not significant, indicating that there is no relationship for EA to mediate, and therefore this hypothesis was rejected.

3.7.1 SUCCESS OF THE PSYCHOLOGICAL DISTRESS PATH MODEL

By examining the error variance within the path model, the overall success of the model can be assessed. As outlined previously, error terms provide an indication of how much variance within the variables remains unexplained by the hypothesised relationships in the model (Bramwell, 1996). The error term may represent different types of error arising from measurement or general model error, such as omission of relevant variables or incorrect ordering of factors within the model (ibid). Bramwell (1996) suggests that error variance can be considered high if it is above .80.

Figure 3.1 highlights two error terms (AAQ-II & GHQ-30), both below .80. The error term is lowest for the regression analysis of physical symptoms, illness beliefs, EA and distress (.38). This indicates that these three variables can be considered to account for 62% of the variance in distress within this sample.

3.8 PSYCHOLOGICAL DISTRESS CONCEPTUALISED AS DEPRESSION

Given the amount of research that has been devoted to depression as the main measure of psychological distress in the literature, the results also consider depression as an outcome measure, using the depression subscale from the GHQ-30. This model is not presented as an alternative model to the psychological distress model, but to investigate the impact of conceptualising distress as depression. As such, the same 6 hypotheses are used to investigate the relationship between disability, EA, illness representations and distress, but conceptualised as depression.

The depression subscale, like the GHQ-30, was not normally distributed according to the K-S test ($p<0.05$), and was found to be positive skewed ($z=5.39$, $p<0.001$), but not kurtotic ($z= 1.61$). As such, it was also transformed using log transformation, which addressed the problems with normality.

Hypotheses 1 to 3 were investigated using Pearson product moment correlations, which were presented in table 3.4. As can be seen from Table 3.4 significant positive correlations exist between EDSS scores and depression ($r=.24$, p (one tailed) <0.01), between illness representations and depression ($r=.60$, p (one tailed) <0.01), and between EA and depression ($r=.65$, p (one tailed) <0.01). These correlations indicate that hypotheses 1 to 3 are supported when conceptualising distress as depression.

Figure 3.2 shows the path model used to assess hypothesis 4, 5 and 6, when conceptualising distress as depression. As previously discussed, the path coefficients along each pathway are the standardised beta coefficients contained from the multiple regression analysis. Only one new regression was needed to calculate the path coefficients for this model (Appendix 20). The coefficients indicate the strengths of the relationships between each of the variables, with statistical significance being indicated by use of an asterisk. Error terms were determined within the path model by taking the

variance of errors from the regression equation (Klem, 1995). To examine hypotheses 4 to 6, conceptualising distress as depression, the strength of the indirect pathways through EA were calculated and compared to the strength of the direct relationships within the model.

Hypothesis 4: *The relationship between physical symptoms and depression will be mediated by experiential avoidance:*

The strength of the direct pathway between physical symptoms and depression was compared to the indirect pathway via EA. The indirect pathway was calculated by multiplying the path coefficient between physical symptoms (EDSS) and EA (AAQ-II) (-.17), by the coefficient between EA and depression (.46). Thus, the strength of the indirect pathway was calculated as **-.08**. The strength of the direct pathway between physical symptoms and depression is **-.05**. Therefore the hypothesis that EA mediates the relationship between level of physical symptoms and depression is supported by the data. However, as the path model shows, there is no significant relationship between physical symptoms and depression, and so this hypothesis that EA acts as a mediating variable between physical symptoms and depression is rejected, as the model indicates that there is no relationship to mediate.

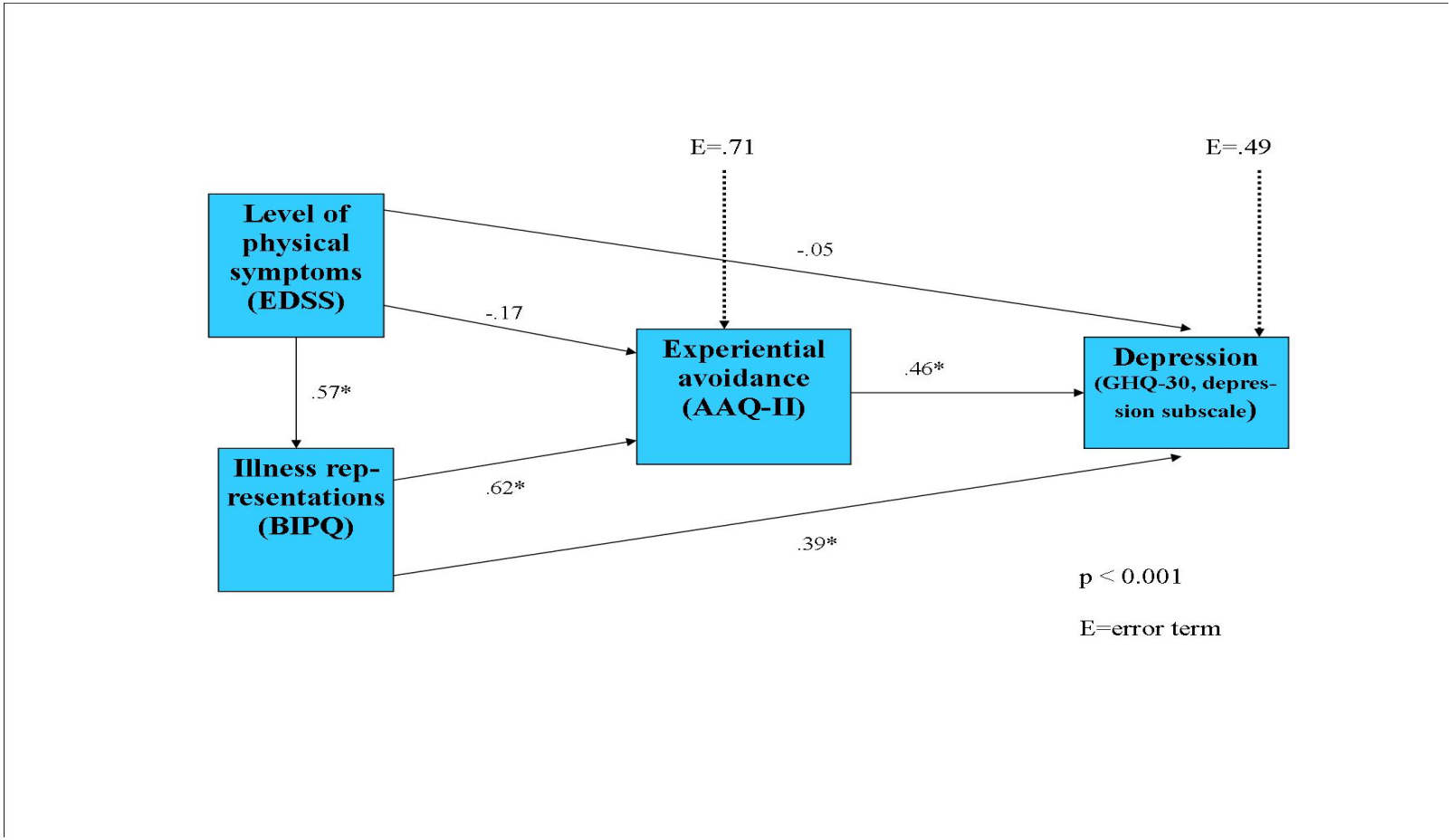


Figure 3.2: Path diagram of the relationships between level of symptoms, illness beliefs, experiential avoidance, and depression, showing path coefficients and error terms.

Hypothesis 5: *The relationship between illness representations and depression will be mediated by experiential avoidance:*

To assess support for this hypothesis, the strength of the direct pathway between illness representations and depression was compared to the indirect pathway via EA. The indirect pathway was calculated by multiplying the path coefficient between illness representations and EA (.62), and the path coefficient between EA and depression (.46). This indicated that the strength of the indirect pathway was .**29**. The strength of the direct pathway between illness representations and depression is **.39**. Therefore the hypothesis that EA mediates the relationship between illness representations and depression is not supported as the strength of the direct pathway is greater than the strength of the indirect pathway.

Hypothesis 6: *Illness representations will mediate the relationship between physical symptoms and depression.*

In order to test this hypothesis, the strength of the direct pathway between EDSS scores and depression was compared to the indirect pathway through illness representations. The indirect pathway was calculated by multiplying the path coefficient between physical symptoms and illness representations (.57), and the path coefficient between illness representations and depression (.39). Thus the strength of the indirect pathway was calculated as **.22**. The strength of the direct pathway between physical symptoms and depression is **-.05**. Therefore the hypothesis that illness representations mediate the relationship between level of physical symptoms and depression is supported by the data. However, as in Hypothesis 4, the path model shows that there is no significant relationship between physical symptoms and depression, and so this hypothesis, that illness representations acts as a mediating variable between physical symptoms and depression is rejected, as the model indicates that there is no relationship to mediate.

CHAPTER FOUR: DISCUSSION:

4.1 OVERVIEW

This chapter will reflect on how the results obtained during this study contribute to theory and knowledge about psychological distress in Multiple Sclerosis (MS). The results will be discussed with reference to current literature. Before discussing the clinical implications of the research, the strengths and limitations of the study will be considered. In addition recommendations for future research will be outlined.

4.2 SUMMARY AND INTERPRETATION OF THE FINDINGS

The aim of the present study was to explore factors associated with psychological distress in a sample of participants with MS. The factors explored were level of disability as measured by the EDSS, illness representations and EA. As one of the limitations of the literature on psychological wellbeing in MS to date has been that psychological distress has mainly been conceptualised as depression, this study looked at a broader conceptualization of psychological distress, using the 30 item General Health Questionnaire (GHQ-30) as the outcome measure. The association with each of these factors on psychological distress, and the inter-relationships between them were examined using path analysis. Path analysis allowed the explicit display of hypothesised relationships that were expected to occur. In addition, due to the amount of literature that exists in relation to rates of depression in MS populations, the variables under study were also investigated when conceptualizing distress as depression, to highlight any differences that might occur in the results.

Pearson product moment correlations showed that there were significant positive correlations between all four of the variables under study: level of physical symptoms (EDSS), illness representations (BIPQ), EA (AAQ-II), and psychological distress (GHQ-30). Each of the variables were positively scored, with high scores indicating higher rates of disability, higher illness representations (negativity of individuals illness representations), EA (as opposed to acceptance), and increased levels of psychological distress. The significant positive correlations indicate that a high score on any of the variables of interest is likely to be associated with a high score on another of the variables of interest.

The current study hypothesised that level of physical symptoms, illness representations and EA would all be associated with increased psychological distress. The significant, positive correlations found between variables therefore provide support for each of these first three hypotheses.

Indirect and direct relationships between all four variables were tested using the method of path analysis. A model of the hypothesised relationships was presented and then tested as to its goodness of fit with the data, by examining the error terms (amount of variance left unexplained in the model). The model presented was based on theory and research findings. This study hypothesised that there would be indirect effects within the data; that EA would mediate between level of physical symptoms (EDSS) and distress, and between illness representations and distress. However as will be discussed below, the data demonstrated a number of significant direct relationships between the variables, and there was little evidence to support the hypothesised indirect relationships.

4.2.1 THE PSYCHOLOGICAL DISTRESS MODEL

Overall the model was considered to be relatively successful in accounting for variance in predicting distress, as indicated by the error terms. Specifically the three variables: level of symptoms (EDSS), illness representations (BIPQ) and EA (AAQ-II) were found to account for a significant proportion of the variance in psychological distress (62%). This suggests that the model was successful in highlighting three important variables in explaining distress amongst individuals with MS. It should be noted that, two of the paths; the path from the EDSS scores to EA and the path from EDSS scores to distress, have negative values, and, as they were not significant, indicate no relationship with the outcome variables of interest. This is of note as the bivariate correlation indicated a significant positive correlation (e.g. r=.29, p<0.01 between EDSS scores and GHQ-30 scores).

If the beta coefficients of these two aforementioned paths were positive they would suggest that the model is not plausible (Duffy, 1991), because two of the hypothesised relationships fail to meet one of the conditions for a casual relationship; covariance (ibid). However, the model was not rejected based on these grounds, as it is believed that these negative values indicate suppressor effects.

If variables are positively correlated (bivariate correlations), then develop a negative regression weight after inclusion in a regression equation, then it is likely that one of the variables is a suppressor (Massen & Bakker, 2001). As defined by Pedhazur (1982, p. 104) “a possible suppressor variable is a [predictor] variable that has a zero, or close to zero correlation with the criterion (outcome or dependent variable) but is correlated with one or more than one of the predictor variables”.

It would seem that the EDSS variable may be the suppressor variable, in that, it has no relation to the outcome variables within regression: psychological distress or EA, but it has a strong relationship to illness representations (they would not exist without the physical symptoms/illness). Suppressors improve prediction indirectly by making other predictors better; they make the R^2 effect size larger, even though the suppressor has little or no correlation with the dependent variable (Thompson, 2006). For example, post hoc analysis (Appendix 21) showed that omitting the EDSS variable, and regressing psychological distress on illness representations and EA, did not change the R^2 value, but did change the standardised beta coefficient, presented in the results section, from .53 to .47 for the path from illness representations to psychological distress. This path was significant at $p<0.001$. These post hoc analyses provide support to suggest that the EDSS variable may have been causing suppressor effects, and as such the model is regarded as plausible.

The strongest direct pathway to distress was from illness representations. This suggests that illness beliefs may have a central role in predicting psychological distress in individuals with MS, which is consistent with the findings from previous research (Vaughan *et al.*, 2003; Jopson and Moss-Morris , 2003). There was also a strong relationship between illness representations and EA, suggesting that the more negative a participant’s illness representation, the more EA was employed by participants. There was also a strong positive relationship between EA and psychological distress, however illness representations alone had a more direct influence on distress than did EA, and explained more of the unique variance in distress. Therefore, it appears that when participants with MS hold more negative illness representations (high BIPQ summary scores) they engage more with EA (i.e avoiding thoughts about the illness).

The current study hypothesised that EA would act as a mediator between level of physical symptoms and distress, and between illness representations and distress. A mediator variable is one that accounts for a relationship between a predictor and an outcome, and

so it rests on the assumption that there must be a relationship to mediate (Frazier *et al.*, 2004). Thus within the proposed model, the indirect pathways through EA were hypothesised to be more strongly associated with distress than the direct pathways between level of physical symptoms and distress, and/or between illness representations and distress.

Findings did not support the hypothesised role of EA as a mediator between physical symptoms and psychological distress. However since the direct pathway from physical symptoms to level of distress did not highlight a statistically significant relationship to mediate, this is not a surprising finding.

Findings did not support the hypothesised role of EA as a mediator between illness representations and psychological distress. The direct relationship between illness representations and distress was found to be stronger than the indirect relationship via EA. Therefore, data suggests that illness representations is best conceptualised as providing a direct contribution to variation in distress within this population, as well as being a predictor of greater EA. Illness representations are said to be directly related to coping, and via coping to outcomes (Vaughan *et al.*, 2003). As highlighted by Karekla and Panayiotou (2011) coping styles and EA are largely overlapping but not identical constructs. The findings of this research suggest that illness representations may be better predictors of outcome than coping or related constructs (EA), which is in keeping with previous findings (Moss-Morris *et al.*, 1996).

Findings partially supported the hypothesis that illness representations would mediate the relationship between the level of physical symptoms and distress. However the strength of the direct path from illness representations to distress was stronger than the indirect pathway from level of symptoms through illness representations to distress. As has been discussed earlier, the EDSS path to psychological distress was not significant, indicating no relationship to psychological distress; however it may have acted as a suppressor variable. As such this may suggest that illness representations are a moderator (under what conditions) rather than a mediator.

4.2.2 DISTRESS CONCEPTUALISED AS DEPRESSION

Given the amount of research that has been conducted within this population about depression, the depression subscale of the GHQ-30 was used to run a secondary analysis, using the same six hypotheses. As such, it was hypothesised that level of physical symptoms, illness representations and EA would be associated with increased depression. Again, support for each of these three hypotheses was found by the significant positive correlations between EDSS scores, BIPQ scores, EA scores and the depression subscale of the GHQ-30.

When conceptualizing distress as depression, similar findings were highlighted. Again, the two paths from level of physical symptoms (EDSS) to EA and from level of physical symptoms to depression have negative values; which at face value indicates that an increase in disability equates to a decrease in EA and a decrease in depression. However, given that the bivariate correlations between the level of physical symptoms and both EA and depression were both positive, this negative relationship is again considered to be an example of a suppression effect caused by the EDSS scores.

The strongest direct pathway to depression was from EA, which is a different finding when distress is conceptualised in a broader sense (using the GHQ-30), which indicated that illness representations were a stronger predictor of psychological distress. This suggests that for depression in MS populations, EA may have a central role, although further research is required. Illness representations also had a significant relationship to depression, but did not account for as much variance as EA did.

The findings did not support the hypothesised role of EA as a mediator between either level of physical symptoms or illness representations, and the direct pathways provided a greater contribution to the variance in depression within this population.

This model is only presented for exploratory purposes, to highlight that conceptualizing distress in different ways suggest different findings; and the relationship of the variables in relation to depression in MS requires much further research.

4.3 STRENGTHS AND LIMITATIONS OF THIS RESEARCH

4.3.1 STRENGTHS

One of the most important strengths of the present study is the empirical support it provides for what may account for the high rates of psychological distress in a UK MS sample. As such the findings of this study contribute to a psychological understanding of the complex pathways that can lead to psychological distress in this population. The objective of the current study was to further knowledge and understanding of the psychological factors associated with psychological distress in individuals who have MS. As has been suggested in this research the effects of MS on patient quality of life including mental health, has often been neglected, for example Foley and Brandes (2009) state that it is commonly neglected in MS assessment and clinical trial designs. The relationship of psychological distress with MS status is complex (Arnett *et al.*, 2008) but the model presented in this study was shown to be relatively successful in accounting for the variance in distress (as measured by the GHQ-30) and the findings are considered an important addition to the knowledge base in this area.

Due to the limitations in psychometric properties in previous versions of the AAQ-I, it is a strength of the current study that it has used the most up to date version of the AAQ, the AAQ-II, which has shown to have good psychometric properties, and evidence states that it measures a single construct (Bond *et al.*, 2011). Given that all of the research incorporated in the introduction (e.g. systematic review) used measures of EA with less than acceptable psychometric properties, this stands as a clear strength of the research.

Despite increasing attention within the empirical literature, research on EA can be regarded to be in its infancy, and so exploring the concept further, with sound psychometric measures, and with different populations is of significant theoretical interest. While EA has been shown to mediate between certain variables and outcomes, such as detached coping and depression (Costa & Pinto-Gouveia, 2011), passive coping and depression and anxiety (Fledderus *et al.*, 2010), and between social anxiety and PTSD on quality of life (Kashdan *et al.* (2009), this study has highlighted that EA does not mediate between disability and distress, nor between illness representations and distress. Despite this, the research did indicate that there is a relationship between EA and depression in the MS populations, and so warrants further investigation.

Also, to date psychological distress has mostly been conceptualised as depression within the empirical literature, and so the use of the GHQ-30 which provides a broader measure of psychological health and wellbeing, is considered as a strength of the study. In addition, the GHQ-30 was able to provide a measure of depression, and so the research was able to conceptualise distress as depression, and to consider the implications of this. For example, given that the three variables: physical symptoms, illness representations and EA accounted for 62% of the variance of distress, but only 50% of the variance in depression, this analysis highlights that conceptualizing psychological distress only as depression is a limited view on the experience of distress in MS, and this should be addressed in future research and service provision.

The sample size in this study is also considered a strength of the research. Using estimates for multivariate statistics as outlined by Harris (1985) and Green (1991), it was estimated that the sample size would be between 53 and 107; sample sizes similar to those suggested by Cohen (1992) in order to detect a medium effect size (n=76), using three predictor variables. Thus the final sample size of 121 is considered to be a strength of the study, and reduces the probability of Type 2 errors (Lachin, 1981).

4.3.2 LIMITATIONS

Certain limitations of the study need to be noted. The limitations will be discussed in the areas of design, the use of self report measures, and sampling, and the implications of these limitations will be considered.

4.3.2.1 DESIGN

As the study is cross sectional the direction of relationships cannot be clarified. Further research using longitudinal designs would allow for investigation of the direction of the relationships between the variables in the model. Longitudinal research would also be better able to establish the nature of mediation relationships (Goldstone *et al.*, 2011), and Hayes *et al.* (2006) argue that true mediation analysis requires longitudinal designs.

In addition, path analysis cannot establish the direction of causality (Stage *et al.*, 2004). However, direction has been ascribed to the variables within the model on the basis of

theory, and as such the results provide support for the relationships expressed within the model. Future research on EA and illness representations in MS may provide a clearer account of the relationships and direction of these, for MS populations.

4.3.2.2 USE OF SELF REPORT MEASURES

All of the data for this study were collected through the use of self report measures. In addition, some of the self report measures used require further consideration.

Self report measures are now receiving increasing recognition as secondary outcome measures in MS research (Gold *et al.*, 2003). As can be seen there was a range of disability experienced by the participants included in the study, from participants scoring two on the EDSS (minimal disability) to eight (essentially restricted to bed or chair, maintains many self care functions) on the EDSS (Kurtzke, 1983), and each of the types of MS were fairly well represented, with 39% of the sample representing the more severe forms of MS: secondary progressive (26%) and primary progressive (13%) types of MS. So one particular limitation of using self report measures in this population is that cognitive impairment associated with MS may have affected the response provided. Pakenham and Fleming (2011) found that participants with less cognitive impairment reported higher MSAQ action, suggesting that participant's ability to engage in EA, or acceptance, might be affected by their cognitive functioning. The prevalence of cognitive impairment in MS is estimated to be between 54% and 65% across all stages of the disease (Amato *et al.*, 2006). However as cognitive impairment was not assessed it cannot be accounted for in the responses provided and subsequent analysis. In addition, the role of cognitive impairment and its impact on cognitive flexibility requires further research.

As with all self report measures, the measures used, may be subject to various forms of response bias and/or socially desirable responding (van de Mortel, 2008). A social desirability scale could have been used to minimise the effect of this on the research, however a review of questionnaire based research studies listed on CINAHL between 2004-2005, found that of 14275 articles, only 31 used a social desirability scale (van de Mortel, 2008).

4.3.2.3 MEASURES USED

This study included an analysis of the relationships between the EDSS and three other variables: illness representations, EA and psychological distress as measured by the GHQ-30. The EDSS is a widely used measure within the literature, but has nonetheless attracted criticism.

The EDSS remains as the most widely used disability measure in clinical trials of MS (Hobart *et al.*, 2000). While the EDSS has been described as the gold standard in MS research, it has also been called the “tarnished gold standard”, however all other available measures of disability in MS also have some limitations (Thompson & Hobart, 1998, p. 192). One of the main limitations of the EDSS for this study was that it is, in effect, an ordinal scale (McGuigan & Hutchinson, 2004). The EDSS was developed before the acceptance of psychometric methods of scale development and has a number of problems such as rater variability, poor reliability, insensitivity to change at certain levels (e.g the higher levels of disability), and too much emphasis on mobility status (ibid).

In most studies, the distribution of scores on the EDSS forms, similar to the distribution found in this study, a bimodal distribution with peaks in the lower and upper ranges and a trough in the middle (Hohol *et al.*, 1995). However, the EDSS is a familiar and widely used measure and so it’s inclusion in the study is justified. However, it may have been more helpful to include another measure of disability and treat both measures as one latent variable, suitable for analyzing within SEM. However this may have been problematic given the sample size needed for SEM, which increases, as variables are added to the model (Cohen, 1992).

Previous research highlights that the EDSS correlates with depression using the BDI as a measure of depression (McIvor *et al.*, 1984, Mohr *et al.*, 1997; Pujol *et al.*, 2000), however other research suggests that no relationship is apparent using the BDI (Minden *et al.*, 1987; Beatty *et al.*, 1990; Sabatini *et al.*, 1996, Pujol *et al.*, 1997). Thompson and Hobart, (1998) highlighted that EDSS scores have poor correlations with the GHQ-28 item version, and the GHQ-depression subscale (Rabins *et al.*, 1986). Therefore it may have been erroneous to predict a relationship to occur between the EDSS and psychological distress. Despite this, bivariate correlations did provide support for a relationship between EDSS scores and distress ($p<0.01$), and the use of it in the path model indicated that EDSS

scores may act as a suppressor variable, increasing the prediction of other variables. As such, the use of the EDSS as a measure of physical symptoms added to the plausibility of the models presented here.

Conceptualizing distress as depression was used to compare how distress is conceptualised and how this might impact on results, rather than to compare the two models. While, when conceptualizing distress as depression, the results suggested that EA explains most of the variance, this finding requires replication using more robust measures of depression, rather than a subscale of a measure, as used in this study.

The BIPQ was chosen over the longer version of the IPQ for its brevity; and the composite score from the BIPQ was used to indicate the overall positivity or negativity of participant's illness perceptions of MS. This approach; using the composite score, was about the strength of illness perceptions, rather than the content of illness perceptions. While this approach was meaningful in addressing the research question posed in this thesis, and consonant with similar research investigating the relationship between the concept of illness representations and other constructs, the significance of the content of illness representations has been lost to some extent by using the total score from the BIPQ. This issue will be addressed further when considering future research.

4.3.2.4 SAMPLE

Convenience sampling can often lead to highly unrepresentative samples. 81% of the sample was female, which is slightly under representative of men, as the ratio of women: men is 3:1 (Fowler *et al.*, 2008). In terms of the distribution of types of MS, as we saw earlier, approximately 15% of the total MS population has primary progressive MS, and 65% to 85% of people with relapsing remitting develop secondary progressive MS about 15 years after diagnosis. These figures would suggest that the current sample is representative of the primary progressive population; however the numbers of participants reporting having relapsing remitting (51%), and secondary progressive (26%) do not seem representative. Considering that 65% of people with relapsing remitting MS, develop secondary progressive MS, 15 years after diagnosis, this sample can be considered representative of the MS population in general, considering the mean of 8.76 years of diagnosis. Finally, convenience sampling is representative of much of the research with MS populations and the field of psychology in general (Sheppard *et al.*, 2010).

4.4 CLINICAL IMPLICATIONS

The results indicated that EA does not act as a mediator in the psychological distress people with MS experience. Illness representations accounted for most of the variance in psychological distress, while EA accounted for more of the variance when conceptualizing distress as depression. The main clinical implication of this research is that it increases our understanding about the processes that contribute to psychological distress within this population, and as such, this may inform therapeutic interventions and consequently, improve outcomes and the quality of life of people with MS experience.

The impact of illness representations on psychological distress evidenced by this study suggests that assisting clients to develop some sense of control over their illness and symptoms might improve their psychological wellbeing. Emotional problems are one of the most significant influences on the wellbeing and quality of life of people with MS (Rothwell *et al.*, 1997) and may have at least as much impact as ambulatory and physical health issues (Foley *et al.*, 2009). MS has an unpredictable course, making future disability difficult to anticipate; this uncertainty makes it hard for people with MS to maintain a sense of control over their disease. The distinct role played by illness representations suggests that cognitive factors are important in determining psychological wellbeing in this population.

Given that the strongest direct route to distress was through illness representations, targeting illness beliefs in interventions seems logical. In other areas of physical health, such as cardiac medicine and surgery, illness representation interventions have shown to be effective. Petrie *et al.* (2002) highlight a brief intervention designed to alter patient's perceptions about their myocardial infarction that resulted in improved functional outcomes, in comparison to a control group. However, this intervention was designed to change inaccurate and negative illness beliefs.

How controllable, amendable to change, or inaccurate illness representations of MS actually are remains to be seen, for example in the study by Vaughan *et al.* (2003) the participants illness representations of MS were accurate and realistic in terms of conventional clinical views. The belief that MS had serious consequences was related to greater difficulty in each of the outcome measures (anxiety, depression and self esteem)

(ibid). To believe that MS does not have serious consequences may not be a realistic assumption. Stafford (2007, p.94) wrote a recent paper entitled “Isn’t it all just obvious?”, stating “[illness representations are] all just common sense, but dressed up in big words to confuse people”. However, unlike researchers and academics, patients may not be consciously aware that their illness representations are guiding behaviour (Hale *et al.*, 2007).

As such, illness representations may be amenable to intervention in the MS population. One therapeutic model with potential to address illness representations, whether they be accurate or inaccurate, is of course cognitive behavioural therapy (CBT). The use of CBT is recommended by the NICE guidelines for MS (NICE, 2003), suggesting that psychological treatments such as CBT should be considered for depression in the MS population. Although there is a significant amount of evidence on the efficacy of CBT as an intervention for anxiety and depressive disorders, many of these studies have been conducted with patients without significant medical problems (White & Trief, 2005). To date, CBT has been the main model used to treat depression in the MS population (Mohr, 2011), however there is a dearth of literature on the subject area and as such is ripe for future research.

The illness representations model has been used explicitly to tailor CBT interventions in pilot studies for people with systemic lupus erthematosus (Goodman *et al.*, 2005). This intervention was found to change participant’s perceptions of treatment control and emotional representations, and perceived stress was reduced following the intervention. This is a potentially important study which may be influential for tailoring CBT treatments with MS populations, as systemic lupus erthematosus has, like MS, an unpredictable disease course with periods of illness varying widely in severity, alternating with remissions (Stoll *et al.*, 2001). There are also high prevalence rates of mental health problems (e.g depression), in the lupus population (ibid).

To date, CBT for MS has not explicitly incorporated illness representations into a therapeutic intervention. Mohr *et al.* (2001) described individual CBT sessions with MS patients that included teaching specific skills for the management of MS related symptoms and problems, such as fatigue management, management of mild cognitive impairment, pain management, stress management, skills for intimacy, communication and sexual dysfunction, and management of social difficulties. As such this intervention may have

inadvertently addressed illness representations. The findings of this study concluded that CBT and anti-depressant medication were more effective than an emotional expression group. This is an interesting finding from the general non-medical psychotherapy literature, that all treatments are generally equal (Mohr *et al.*, 2001). It seems that concerns related to the disease (Mohr, 2011), as well as the management of symptoms of distress/depression, are important to consider within psychological interventions for people with MS.

This current study also highlighted that EA is the strongest predictor of distress, when conceptualised as depression, in this population. Although this finding needs to be interpreted with caution due to measurement issues. Despite this, while EA was not the strongest predictor of distress using the GHQ-30, it did account for some of the variance in distress reported by the participants (using the GHQ-30). These findings support the application of psychotherapies that seek to reduce EA in the treatment of distress in MS populations. Given the strong relationship between illness representations and EA (.62), the results also suggest that interventions aimed at decreasing EA may limit the potential negative consequences of illness representations; however this would require further research.

This current study highlights that EA, as measured by the AAQ-II accounts for some of the variance in psychological distress, and when distress is conceptualised as depression, most of the variance in depression for people with MS however there is very little empirical literature about depression and the use of ACT, and even less about the use of ACT in the MS population.

Sheppard *et al.* (2010) found that a 5 hour ACT workshop for 15 participants with MS effected a statistically significant reduction in depression, as measured by the BDI, over time ($p<0.05$, 3 month follow up). This is the only study to apply ACT with an MS client group. This intervention used psychoeducation about MS, identifying the costs associated with the struggle to control unwanted thoughts, feelings and physiological reactions linked with MS, the importance of balancing acceptance and behaviour change strategies, values clarification exercises, using mindfulness and acceptance strategies to foster psychological flexibility when faced with MS related barriers, and using cognitive defusion techniques to reduce the behavioural impact of negative thoughts and feeling. As can be seen from the topics discussed, depression was not targeted explicitly during the

intervention, so the reduction in depression is a noteworthy finding. For example, Mindfulness was targeted explicitly but there was no change in mindfulness at 3 month follow up, which the authors suggest could represent demand characteristics such as social desirability. As such, future research is needed to further understand how ACT can be adapted for MS populations. It also may be that some of the aspects of the aforementioned ACT intervention targeted or impacted on illness representations of MS, through the use of topics such as psychoeducation about MS, identifying the costs associated with the struggle to control unwanted thoughts, feelings and physiological reactions linked with MS, or using mindfulness and acceptance strategies to foster psychological flexibility when faced with MS related barriers.

Presently two studies have investigated the effectiveness of ACT for depression (Zettle & Hayes, 1986; Zettle & Rains, 1989). Zettle and Hayes (1986) compared ACT to two forms of Cognitive Therapy (CT), and found that ACT was better than CT in reducing depressive symptoms at the 2 month follow up. However rather than focusing on EA as the mediatior of change, Zettle and Hayes (1986) looked at a measure of cognitive fusion (the Automatic Thoughts Believability Questionnaire, Hollen & Kendall, 1980). Cognitive fusion is the tendency to take thoughts literally and to believe that they describe reality, rather than what they are-"just thoughts" (Spiegler & Guevremont, 2003), whereas EA involves the effort to avoid unpleasant private events (ibid). Zettle and Hayes (1986) found that cognitive fusion mediated between the other two measures of depression, the BDI and the Hamilton Depression Scale (HRSD): basically the higher the believability of the depressive thoughts at mid-treatment, the higher the effect in scores of BDI and HRSD were at post-treatment (Ruiz, 2010). Again the study by Zettle and Rains (1989) used a measure of cognitive defusion, and so future studies about depression or distress in MS populations may be interested in using a measure of EA and cognitive fusion. Given the importance of beliefs that was highlighted by this study, cognitive fusion may play a key role in furthering our understanding of distress in this population.

The finding that each of the psychological variables, illness representations and EA may uniquely contribute to the variance in psychological distress, would seem to provide support for both acceptance based interventions and cognitive therapy. While there are differences between cognitive and acceptance based interventions, especially with regard to the mechanisms of change, there are also similarities between cognitive and acceptance approaches (Arch & Craske, 2008). Given the finding that beliefs (illness

representations) have a strong direct relationship to distress both ACT and CBT offer explicit methods for dealing with thoughts or beliefs: in ACT cognitive fusion and acceptance are advocated, whereas in CBT cognitive restructuring is endorsed (ibid). What does seem clear is that whichever method is used to help clients experiencing distress, concerns related to the disease are clearly important to address.

4.5 SERVICE IMPLICATIONS

In addition to the implications for direct clinical interventions for this client group this study has some broader implications for the services that provide support for individuals with MS. Given the high levels of psychological distress in this population it is surprising that the NICE guidelines for MS (NICE, 2003), and the guidelines for commissioning MS services (Wade, 2006) have paid little attention to the mental health needs of the MS community. The 2011 audit of MS services (Wade *et al.*, 2011) has recommended that clinical staff in primary and secondary care should be asked to use structured assessments of mood and daily activities and to refer to specialist services as appropriate.

The development of the new mental health measure in Wales (The Mental Health (Wales) Measure, 2010), which strengthens primary care psychological wellbeing services, means that this is an opportune time for the mental health needs of MS patients to be adequately addressed in Wales. However, the British Psychological Society's response to the new measure (National Assembly for Wales, NAW, n.d) critiques the Measure and seems to suggest that it has been outlined only for mental health problems but recommends that it needs to be "for those living with other chronic conditions...likely to impact on their mental health and wellbeing". In addition, the success of the Measure will in part depend on the availability of appropriately trained staff to offer services to individuals, and appropriately trained staff to clinically supervise those in primary care mental health (ibid). This piece of research highlights that knowledge of psychological theories such as illness representations theory may be crucial for effective psychological interventions in the MS population, and that problem based formulations (e.g. CBT for depression) are unlikely to meet the needs of clients with MS, who may require individualised formulations incorporating aspects about the illness that impact on their psychological health and wellbeing.

4.6 FUTURE RESEARCH

A bigger sample would have allowed the use of SEM, and this method of estimating path coefficients has many advantages over using multiple regression to estimate path coefficients (Klem, 1995). The first advantage is that programmes for conducting SEM (AMOS, LISREL or EQS) provide additional results such as all the implied correlations, all total effects, and the standard errors for indirect effects.

Most important, these programs calculate and reports several measures of overall fit of the model (e.g model chi-square, root mean square error of approximation (RMSEA), goodness of fit statistic (GFI) and adjusted goodness of fit statistic (AGIF) Hooper *et al.*, 2008). As such, it is recommended that further data be gathered from the existing population base to build an adequate sample from which to conduct SEM analysis, as this will allow estimates of model fit to be garnered. The model should be tested against other competing models using this data set (i.e. the full model, versus the direct path model, versus, the indirect paths model); comparing the fit indices to predict the most accurate model for this dataset, and subsequently population. The use of SEM has another advantage, as it allows the use of latent variables rather than manifest variables, which would overcome some of the difficulties in measurement by using the EDSS. Future studies might wish to complement the use of the EDSS with other measures of functional disability in MS to reduce any possibility of measurement error. Similarly this study highlighted the importance of beliefs (illness representations), so future research may wish to focus on cognitive fusion, another component of ACT, to assess its role in mediating between beliefs and distress. In the same way that the EDSS and another measure of disability in MS might be taken together as a latent variable, a measure of EA and cognitive fusion may also be utilised to create a latent variable considered to represent psychological flexibility. That is, items from these measures (manifest variables) could be used in future research to produce latent variables, suitable for more advanced SEM statistical techniques.

In this study the BIPQ was chosen over the longer Illness Perception Questionnaire (IPQ; Weinman *et al.*, 1996) or the IPQ-R (revised, Moss-Morris *et al.*, 2002). The BIPQ was chosen over the IPQ, and IPQ-R as these two measures consist of between 63 to 73 items respectively, which may have impacted on participation in the study. This study was not looking at which particular parts of illness representations (identity, timeline, consequences

etc.) had the strongest relationship with distress, as this has been covered by the three studies investigating illness representations and psychological distress to date. Considering the findings of this research which highlights the role of illness representations in psychological distress for this population, future research may wish to use the longer version of the IPQ to assess the content and not just the overall strength of illness perceptions. The IPQ-R for example offers advantages over the BIPQ when researchers want to perform a more detailed analysis of participant's identity beliefs (Broadbent et al., 2006).

As discussed in the introduction, three studies found specific parts of illness representations (identity, consequences & cure/controllability) demonstrated the greatest number of relationships with anxiety, depression and self esteem (Vaughan *et al.*, 2003). As such incorporating just these three variables in future models may account for more of the variance in distress, than measuring illness representations in general, or using the composite score. However, more research confirming that these are the most important parts of illness representations (Vaughan *et al.*, 2003) would be a necessary first step towards this. It is likely that illness representations are unique to the individual, but also, as Vaughan *et al.* (2003) did not account for MS type, it could be that certain illness representations have more prominence for certain types of MS. These questions would be very amenable to future research.

Qualitative research about illness representations may also be an important next step in order to develop an insight into how interventions can be tailored for this client group. In particular exploring how the illness representations of MS are incorporated into the lived experiences of this client group, as while illness representations are said to predict health behaviours (Leventhal *et al.*, 1980, Leventhal *et al.*, 1984) how they impact on the behaviours of people with MS, has not been outlined.

As has been discussed illness representations are related to coping, so future research may wish to investigate the relationship between illness representations and coping, and to further elucidate the difference between coping and EA, as to date this has not been studied using the (seven item) AAQ-II. In the ongoing debate about whether EA is a separate construct to coping, and based on the findings that illness representations influence an individual's coping response (Turner *et al.*, 2000), it might be worthy to

conduct a study comparing EA to coping using a similar design to this one, and see which of these paths is the strongest predictor of distress in MS.

Another future area of research is to investigate how illness representations integrate with existing schemata, for example castrophising is thought to be an important type of cognition that, in addition to illness representations and coping, independently predict depression in a sample of participants experiencing chronic pain (Turner *et al.*, 2000). Again, this is something that would be amenable to developing a model for use with path analysis/SEM.

The role played by EA in predicting depression in this sample opens up avenues for future research on ACT and EA in MS. While Sheppard *et al.* (2010) have highlighted that a short ACT intervention for MS resulted in a statistically significant reduction in depression, this was an open trial and as such has many limitations. Future research may wish to investigate what parts of ACT may be effective for MS populations, in particular concentrating on ACT's emphasis on beliefs (e.g cognitive fusion).

4.7 CONCLUSION

This study found that each of the variables: level of physical symptoms, illness representations and EA were positively associated with psychological distress in a sample of participants with MS. When these variables were subjected to a path analysis based on theory and research, the relationship between physical symptoms, as measured by the EDSS, disappeared, but acted as a suppresser variable making the relationship between illness representations, EA and distress stronger. Together these three variables accounted for 62% of the variance in distress experienced by the participants. It was found that illness representations were the strongest predictor of distress in this population. It was hypothesised that EA would act as a mediator variable between illness representations and distress, but there was no evidence to support this, and illness representations had more of a direct impact on distress. While EA did not mediate the relationship between either physical symptoms or illness representations in relation to depression, it was the strongest predictor of depression in this population.

As such the findings have implications for psychological interventions for this clinical population. In short, the findings suggest that beliefs about the illness are important to

incorporate into interventions for psychological difficulties experienced by this client group, and that both acceptance and cognitive therapies have much to offer this client group in meeting their psychological needs. However more research is needed in terms of how illness representations impact on behaviours in this client group, and whether other parts of ACT (e.g cognitive defusion) may impact on the distress this client group experiences.

The findings of the study contribute to a psychological understanding of the complex pathways that can lead to psychological distress in this population. The relationship between psychological distress with MS status is complex (Arnett *et al.*, 2008) but the model of distress presented in this study, has been successful in accounting for 62% of the variance in distress experienced by this population of MS participants. The study also provided preliminary evidence for the role of EA in the MS population. EA has been shown to play a key role in psychopathology and as a mediator of distress in other research. However this study showed that while it may have a relationship to depression, it does not mediate between level of symptoms nor illness representations and the resulting distress experienced by participants in this study.

The findings of the study should be interpreted with some caution as both path analysis and cross sectional designs do not allow for making generalizations about the direction of relationships between the variables under study. Longitudinal studies may be able to address this limitation and provide a truer test of mediation than is possible with cross sectional designs. Also this research only used self report measures; which may be problematic due to response bias (social desirability) and also as cognitive impairments may have impacted on the reliability of the responses provided, as there are high rates of cognitive impairment in MS populations. The use of the EDSS to measure physical symptoms is less than adequate, and it could be argued that it is an ordinal scale rather than an interval scale required for the analysis used. However it is the most widely used measure in MS research, and future studies replicating or building on the model presented here are recommended to use SEM, where EDSS scores can be complimented by using other scales to compose a latent variable measuring disability. Finally although the current study used a convenience sample, which may have lead to an unrepresentative sample, convenience sampling is representative of much of the research in MS populations and psychology (Sheppard *et al.*, 2010).

As mentioned future research would benefit from using a method such as SEM which has many advantages over using regression for assessing the goodness of fit of models, although this method does require quite big samples in general. Future research about the nature and impact of illness representations on distress is also recommended; how they impact on behaviour and how they integrate with existing schemata being two possible areas of interest. As has been noted psychological interventions that incorporate illness representations components (CBT) have proven effective to date, and further research on illness representations will increase our understanding of how interventions can be most effectively tailored for this population. Also the relationship between illness representations, coping and EA is another area ripe for exploration. The preliminary finding that EA is the strongest predictor of depression, also suggests that researching ACT as an intervention for depression in MS would be useful, as this has not been researched to date with rigorous and controlled methods and designs.

REFERENCES:

Acock, A.C. (2005). Working with missing values, *Journal of Marriage and Family*, 67, 1012-1028.

Allison, P.D. (1999). *Multiple Regression: A Primer*, Pine Forge Press: California.

Andrew, D.H. & Dulin, P.L. (2007). The relationship between self-reported health and mental health problems among older adults in New Zealand: Experiential avoidance as a moderator, *Aging and Mental Health*, 11 (5), 596-603.

Arbuckle, J. (1997). *Amos users' guide: Version 3.6*. Small Waters Corporation: Chicago.

Arch, J.J., & Craske, M.G. (2008). Acceptance and Commitment Therapy and Cognitive Behavioural Therapy for anxiety disorders: Different treatments, similar mechanisms? *Clinical Psychology: Science and Practice*, 15 (4), 263-279.

Arnett, P.A. (2003). Neuropsychological presentation and treatment of demyelinating disorders. In P. Halligan, U. Kischka, & J. Marshall (Eds.), *Handbook of Clinical Neuropsychology*. Oxford University Press: Oxford.

Arnett, P.A., Barwick, F.H. & Beeney, J.E. (2008). Depression in Multiple Sclerosis: Review and theoretical proposal, *Journal of the International Neuropsychological Society*, 14, 691-724.

Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual strategic, and statistical considerations, *Journal of Personality and Social Psychology*, 51, 1173-1182.

Batten, S. V., Follette, V. M., & Hayes, S. C. (1997). Experiential avoidance as a model for understanding psychological correlates of HIV and AIDS: Review, theory, and treatment implications, *The Behaviour Therapist*, 20, 99-103.

Beatty,W.W., Goodkin, D.E., Hersgaard, D., & Monson, N. (1990). Clinical and demographic predictors of cognitive performance in Multiple Sclerosis. *Archives of Neurology*, *47*, 305–308.

Beck, A.T. (1961). An inventory for measuring depression, *Archives of General Psychiatry*, 4, 561-571.

Beck, A.T., Epstein, N., Brown, G., & Steer, R.A. (1988). An inventory for measuring clinical anxiety: Psychometric properties, *Journal of Consulting and Clinical Psychology*, 56: 893-897.

Berking, M., Neacsiu, A., Comtois, K.A. & Linehan, M.M. (2009). The impact of experiential avoidance on the reduction of depression in treatment for borderline personality disorder, *Behaviour Research and Therapy*, 663-670.

Berman, N.C., Wheaton, M. G., McGrath, P. & Abramowitz, J.S. (2010), Predicting anxiety: The role of experiential avoidance and anxiety sensitivity, *Journal of Anxiety Disorders*, 24, 109-113.

Bohlmeijer, E.T., Fledderus, M., Rokx, T.A.J.J. & Pieterse, M.E (2011), Efficacy of an early intervention based on acceptance and commitment therapy for adults with depressive symptomatology: Evaluation in a randomized controlled trial, *Behaviour Research and Therapy*, 49, 62-67.

Bond, F.W., Hayes, S.C., Baer, R.A., Carpenter, K.M., Guenole, N., Orcutt, H.K., *et al.* (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire-II: A revised measure of psychological inflexibility and experiential avoidance, *Behaviour Therapy*, 42 (4), 676-688.

Boss, P., & Couden, B.A. (2002). Ambiguous loss from chronic physical illness: Clinical interventions with individuals, couples and families, *Journal of Clinical Psychology*, 58 (11), 1351-1360.

Boulanger, J.L., Hayes, S.C. & Pistorello, J. (2009). Experiential avoidance as a functional contextual concept, In A.M. Kring & D.M. Sloan (Eds.), *Emotion regulation and*

Psychopathology: A transdiagnostic approach to etiology and treatment, The Guilford Press: New York.

Bramwell, R. (1996). Advanced use of multiple regression: Modeling mediated and moderated effects, in J. Haworth (Ed.), *Psychological research: Innovative methods and strategies*, Routledge: London.

Bramow, S., Frischer, J.M., Lassmann, H., Koch-Henriksen, N., Lucchinetti, C.F., Sorensen, P.S., *et al.* (2010). Demyelination versus remyelination in progressive Multiple Sclerosis, *Brain*, 133 (10), 2983-2998.

Broadbent, E., Petrie, K.J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire, *Journal of Psychosomatic Research*, 60, 631-637.

Bruce, J. M. & Arnett, P. (2009). Clinical correlates of generalised worry in Multiple Sclerosis. *Journal of Clinical and Experimental Neuropsychology*, 31(6), 698–705

Bruce, J.M., Hancock, L.M., Arnett, P. & Lynch, S (2010). Treatment adherence in Multiple Sclerosis: Association with emotional status, personality and cognition. *Journal of Behavioural Medicine*, 33, 219-227.

Bryman, A., & Carter, D. (1990). *Quantitative data analysis for Social Scientists*, Routledge: London

Chawla, N. & Ostafin, B. (2007). Experiential avoidance as a functional dimensional approach to psychopathology: An empirical review, *Journal of Clinical Psychology*, 63 (9), 871-890.

Chwastiak, L., Ehde, D., Gibbons, L., Sullivan, M., Bowne, J.D. & Kraft, G.H. (2002). Depressive symptoms and severity of illness in Multiple Sclerosis: Epidemiological study of a large community sample, *American Journal of Psychiatry*, 159, 1862-1868.

Cohen, J. (1992). A power primer, *Psychological Bulletin*, 112, 155-159.

Confavreux, C., Vukusic, S. & Adeleine, P. (2003). Early clinical predictors and progression of irreversible disability in Multiple Sclerosis: An amnesic process, *Brain*, 126, 770-782.

Costa, J. & Pinto-Gouveia, J. (2011). The mediation effect of experiential avoidance between coping and psychopathology in chronic pain, *Clinical Psychology and Psychotherapy*, 18, 34-47.

Dennison, L., Moss-Morris, R., & Chalder, T. (2009). A review of psychological correlates of adjustment in patients with Multiple Sclerosis, *Clinical Psychology Review*, 29, 141-153.

Derogatis, L. (1975). *Brief Symptom Inventory*, Clinical Psychometric Research: Baltimore.

Dua, T. & Romani, P., (2008). *Atlas of Multiple Sclerosis Resources in the World*., retrieved on the 26th of November 2010 from http://www.who.int/mental_health/neurology/Atlas_Multiple Sclerosis_WEB.pdf

Duffy, J. R. (1991). *Path analysis*, retrieved on the 19th April 2012 from http://aphasiology.pitt.edu/archive/00001436/01/21-05.pdf

Dupont, S. (1997). Multiple Sclerosis. In A. Baum, S. Newman, J. Weinman, R. West, & C. McManus (Eds.) *Cambridge handbook of Psychology Health and Medicine*. Cambridge: Cambridge University Press.

Dyer, J., Ehde, D.M (2012). Multiple Sclerosis: depression, In J.H. Stone, M Blouin, M. (Eds.) *International Encyclopedia of Rehabilitation*, retrieved on the 10th of September 2012 from http://cirrie.buffalo.edu/encyclopedia/en/article/292/

Eeltink, C., & Duffy, M. (2004). Restorying the illness experience in Multiple Sclerosis, *The Family Journal: Counseling and Therapy for Couples and Families*, 12, 282-286.

Fao, E.B, Huppert, J.D., Leiberg, S., Langner, R., Kichic, R., Hajcak, G., et al. (2002). The Obsessive Compulsive Inventory: Development and validation of a short version, *Psychological Assessment*, 14, 485-596.

Fassbender, K., Schmidt, R., Mofsner, R., Kischka, U., Kuhnen, J., Schwartz, A., *et al.* (1998). Mood disorders and dysfunction of the hypothalamic-pituitary-adrenal axis in Multiple Sclerosis, *Archives of Neurology*, *55*, 66–72.

Feinstein, A., & Feinstein, K. (2001). Depression associated with Multiple Sclerosis: Looking beyond diagnosis to symptom expression, *Journal of Affective Disorders*, 66, 193–198.

Feinstein, A., Roy, N., Lobaugh, N., Feinstein, K., O'Connor, P & Black, S. (2004). Structural brain abnormalities in Multiple Sclerosis patients with major depression, *Neurology*, 62, 586-590.

Feldner, M. T., Hekmat, H., Zvolensky, M. J., Vowles, K., E., Secrist, Z. & Leen-Feldner, E. W. (2006). The role of experiential avoidance in acute pain tolerance: A laboratory test. *Journal of Behaviour Therapy & Experimental Psychiatry*, 37, 146-158.

Field, A. (2010). *Discovering Statistics using SPSS, Third edition*, Sage publications: London.

Fledderus, M., Bohlmeijer, E.T., Pieterse, M.E. (2010). Does experiential avoidance mediate the effects of maladaptive coping styles on psychopathology and mental health? *Behaviour Modification*, 34, 503-519.

Foley, J.F., & Brandes, D.W (2009). Redefining functionality and treatment efficacy in Multiple Sclerosis, *Neurology*, 72, S1-S11.

Fowler, C.J., Panicker, J.N., Crake, M., Harris, C., Harrison, S.C.W., Kirby, M., *et al.* (2008). A UK consensus on the management of the bladder in Multiple Sclerosis, *Journal of Neurology, Neurosurgery & Psychiatry*, 80, 470-477.

Fox-Wasylyshyn, S.M., El-Masri, M.M. (2005). Handling missing data in self report measures, *Research in Nursing and Health*, 28, 488-495.

Frazier, P.A., Tix, A.P., & Barron., K.E. (2004). Testing moderator and mediator effects in counseling psychology research, *Journal of Counselling Psychology*, 51, 115-134.

Gauntlett-Gilbert, J., & Connell, H. (2012). Coping and acceptance in chronic childhood conditions, *The Psychologist*, 25, 198-201.

Gay, M-C., Vrignaud, P., Garitte, C., & Meunier, C. (2010). Predictors of depression in Multiple Sclerosis patients, *Acta Neurological Scandinavica*, 121, 161-170.

Gold, S.M., Schulz, H., Monach, A., Schulz, K-H., & Heesen, C. (2003). Cognitive impairment in Multiple Sclerosis does not affect reliability and validity of self-report health measures, *Multiple Sclerosis*, 9, 404-410.

Goldberg, D.P., & Hillier, V.F. (1979). A scaled version of the General Health Questionnaire, *Psychological Medicine*, 9, 139-45.

Goldstone, E., Farhall, J., Ong, B. (2011). Life hassles, experiential avoidance and distressing delusional experiences, *Behaviour research and therapy*, 49, 260-266.

Goodman, D., Morrissey, S., Graham, D., & Bossingham, D. (2005). The application of cognitive behaviour therapy in altering illness representations of systemic lupus erthematosus, *Behaviour change*, 22, 156-171.

Gratz, K.L., Tull, M.T., Gunderson, J.G. (2008). Preliminary data on the relationship between anxiety sensitivity and borderline personality disorder: The role of experiential avoidance, *Journal of Psychiatric Research*, 42, 550-559.

Gregg, J. A., Callaghan, G. M., Hayes, S. C., & Glenn-Lawson, J. L. (2007). Improving diabetes self-management through acceptance, mindfulness, and values: A randomised controlled trial. *Journal of Consulting and Clinical Psychology*, 75, 336-343.

Green, S.B. (1991). How many subjects does it take to do a regression analysis? *Multivariate Behavioural Research*, 26, 499-510.

Hale, E.D., Treharne, G.J., Kitas, G.D. (2007). The common-sense model of self regulation of health and illness: How we can use it to understand and respond to our patient's needs, *Rheumatology*, 46, 904-906.

Hamilton, M. (1960). A rating scale for depression, *Journal of neurology, neurosurgery and psychiatry*, 23, 56-62.

Hampson, S.E., Glasgow, R.E., & Toobert, D.J. (1990). Personal models of diabetes and their relations to self-care activities, *Health Psychology*, 9, 632-646.

Harris, R.J. (1985). *A primer of multivariate statistics: 2nd edition*, Academic Press: New York.

Hayes, A.F. (2009). Beyond baron and Kenny: Statistical mediation analysis in the new millennium, *Communication Monographs*, 76, 408-420.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A. & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes, *Behaviour Research and Therapy*, 44, 1-25.

Hayes, S.C., Strosahl, K., & Wilson, K.G., Bissett, R.T., Pistorello, Toarmino, D., *et al.* (2004). Measuring experiential avoidance: A preliminary test of a working model, *The Psychological Record*, 54, 553-578.

Hayes, S.C., Strosahl, K., & Wilson, K.G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behaviour change*, The Guilford Press: New York.

Hayes, S.C., Strosahl, K.D. & Wilson, K.G. (2012). *Acceptance and Commitment Therapy, the process and practice of mindful change*, Guilford Press: New York.

Hayes, S.C., Wilson, K.G., Gifford, E.V., Follette, V.M. & Strosahl, K. (1996). Experiential avoidance and behavioural disorders: A functional dimensional approach to diagnosis and treatment, *Journal of Consulting and Clinical Psychology*, 64, 1152-1168.

Haussleiter, I.S., Brune, M., & Juckel, G. (2009). Psychopathology in Multiple Sclerosis: Diagnosis, prevalence and treatment, *Therapeutic Advances in Neurological Disorders*, 2, 13-29.

Hirsh, A.T., Turner, A.P., Ehde, D.M., & Haselkorn, J.E. (2009). Prevalence and impact of pain in Multiple Sclerosis: Physical and psychological contributors, *Archives of Physical Medical rehabilitation*, 90, 646- 651.

Hobart, J., Freeman, J., Thompson, A. (2000). Kurtzke scales revisited: The application of psychometric methods to clinical intuition, *Brain*, 123, 1027-1040.

Hoe, S.L. (2008). Issues and procedures in adopting structural equation modeling technique, *Journal of Applied Quantitative Methods*, 3, 76-83.

Hohal, M.J., Orav, E.j., & Weiner, H.L. (1995). Disease steps in Multiple Sclerosis: a simple approach to evaluate disease progression, *Neurology*, 45, 251-255.

Hollen, S.D., & Kendall, P.C. (1980). Cognitive self-statements in depression: Development of an automatic thoughts questionnaire, *Cognitive Therapy and Research*, 4, 383-396.

Hooper, D., Coughlan, J., & Mullen, M.R. (2008). Structural Equation Modeling: Guidelines for determining model fit, *Electronic Journal of Business Research Methods*, 6, 53-60.

Huppert, F.A., Walters, D.E., Day, N.E., & Elliott, B.J. (1989). The factor structure of the General health Questionnaire (GHQ-30): A reliability study on 6317 community residents, *British Journal of Psychiatry*, 155, 178-185.

Huppert, F.A., & Garcia, W. A. (1991). Qualitative differences in psychiatric symptoms between high risk groups assessed on a screening test, *Social Psychiatry and Psychiatric Epidemiology*, 26, 252-258

Hviid, L., Healy, B.C., Rintell, D.J., Chitnis, T., Weiner, H.L., & Glanz, B.I (2011). Patient reported outcomes in benign Multiple Sclerosis, *Multiple Sclerosis Journal*, 17, 876-884.

Inan, F.A., & Lowther, D.L. (2010). Factors affecting technology integration in K-12 classrooms: A path model, *Educational Technology Research and Development*, 58, 137-154.

Ingram, G., Colley, E., Ben-Shlomo, Y., Crossburn, M., Hirst, C.L., Pikersgill, T.P., *et al.* (2010)., Validity of patient derived disability and clinical data in Multiple Sclerosis, *Multiple Sclerosis*, 16, 472-479.

Iverson, K.M., Follette, V.M., Pistorello, J., Fruzetti, A.E. (2011). An investigation of experiential avoidance, emotion dysregulation, and distress tolerance in young adult outpatients with borderline personality disorder symptoms, *Personality Disorders: Theory, Research and Treatment*, Jul 4, no pagination given

Janssens, A., van Doorn, P.A., de Boer, J.B., Kalkers, N.F., van der Meche, F., Passchier, J., *et al.* (2003). Anxiety and depression influence the relation between disability status and quality of life in Multiple Sclerosis, *Multiple Sclerosis*, 9, 397-403.

Jean, V.M., Beatty, WW., Paul, R.H., & Mullins, L. (1997). Coping with general and disease-related stressors by patients with Multiple Sclerosis: Relationships to psychological distress, *Multiple Sclerosis*, 3, 191-196.

Jopson, N.M., & Moss-Morris, R. (2003). The role of illness severity and illness representations in adjusting to Multiple Sclerosis, *Journal of Psychosomatic Research*, 54, 503-511.

Judd, C.M., Kenny, D.A. (1981). Process analysis: Estimating mediation in treatment evaluations, *Evaluation Review*, 5, 602-619.

Kalb, R.C. (2008). Multiple Sclerosis*: The questions you have, the answers you need*, Demos Medical Publishing, New York.

Kantarci, O., & Wingerchuk, D. (2006). Epidemiology and natural history of Multiple Sclerosis: New insights, *Current opinion in Neurology*, 19, 248-254.

Karekla, M., & Panayiotou, G. (2011). Coping and experiential avoidance: Unique or overlapping constructs, *Journal of Behaviour Therapy and Experimental Psychiatry*, 42 , 163-170.

Kashdan, T.B., Morina, N., & Priebe, S.(2009). Post-traumatic stress disorder, social anxiety disorder, and depression in survivors of the Kosovo war: Experiential avoidance as a contributor to distress and quality of life, *Journal of Anxiety Disorders*, 23, 185-196.

Kazdin, A.E. (2008). Evidence based treatment and practice: new opportunities to bridge clinical research and practice, enhance the knowledge base, and improve patient care, *American Psychologist*, 63, 146-159.

Kenny, D.A., Kashy, D., & Bolger, N. (1998). Data analysis in social psychology, In D. Gilberts, S. Fiske., & G. Lindzey (Eds.) *Handbook of Social Psychology: 4th edition,* McGraw-Hill: New York.

Kern, S., Schrempf, W., Schneider, H., Schultheiss, T., Reichmann, H., & Ziemssen, T. (2009). Neurological disability, psychological distress and health-related quality of life in Multiple Sclerosis patients within the first three years after diagnosis, *Multiple Sclerosis*, 16, 752-758.

Klem, L. (1995). Path analysis, In L.G. Grimm & P.R. Yarnold, (Eds.) *Reading and understanding multivariate statistics*, American Psychological Association, Washington.

Kline, R.B. (1998). *Principles and practice of structural equation modeling*, The Guildford Press: New York.

Knowles, S.R., Wilson, J.L., Connell, W.R., & Kamm, M.A (2011). Preliminary examination of the relations between disease activity, illness perceptions, coping strategies, and psychological morbidity in Chron's disease guided by the common sense model of illness, *Inflammatory Bowel Diseases*, 17, 2551-2557.

Kurtzke, J.F. (1983) Rating neurologic impairment in Multiple Sclerosis: an expanded disability status scale (EDSS), *Neurology*, 33, 1444-1452

Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*, Springer Publishing Company: New York.

Lee, J.K., Orsillo, S.M., Roemer, L., Allen, L.B. (2010). Distress and avoidance in generalised anxiety disorder: Exploring the relationships with intolerance of uncertainty and worry, *Cognitive Behaviour Therapy*, 39, 126-136.

Lerdal, A., Celius, E. G., & Moum, T. (2009). Perceptions of illness and its development in patients with Multiple Sclerosis: A prospective cohort study. *Journal of Advanced Nursing*, 65, 184-192.

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger, In S. Rachman (Eds.), *Contributions to Medical Psychology, Volume 2*, Pergamon Press: Oxford.

Leventhal., H., Nerenz, D.R., & steele, D.J. (1984). Illness representations and coping with health threats, In A. Baum, S.E. Taylor, & J.E. Singer (Eds.)., *Handbook of Psychology and Health*, Lawrence Erlbaum associates: Hillsdale, NJ.

Linehan, M.M. (1993). *Cognitive Behavioural Treatment of Borderline Personality Disorder*, The Guilford Press, New York.

Lovibond, S.H., & Lovidbond, P.F. (1995). *Manual for the Depression Anxiety and Stress Scales: 2nd edition*, Psychology Foundation: Sydney.

Massen, G.H., & Bakker, A.B (2001). Suppressor variables in path models, *Sociological Methods and Research*, 30, 241-270.

Manos, R.C., Cahill, S.P., Wetterneck, C.T., Conelea, C.A., Ross, A.R., Riemann, B.C. (2010), The impact of experiential avoidance and obsessive beliefs on obsessive-compulsive symptoms in a severe clinical sample, *Journal of Anxiety Disorders*, 24, 700-708.

McGuigan, C., & Hutchinson, M. (2004). The Multiple Sclerosis impact scale (MSIS-29) is a reliable and sensitive measure, *Journal of Neurology, Neurosurgery & Psychiatry*, 75, 266-269.

McIvor, G.P., Riklan, M., & Reznikoff, M. (1984). Depression in Multiple Sclerosis as a function of length and severity of illness, age, remissions, and perceived social support, *Journal of Clinical Psychology*, 40, 1028-1033.

McNulty, K. (2007). Coping with Multiple Sclerosis: Considerations and interventions. In E. Martz & L. Hanock (Eds.) *Coping with Chronic Illness and Disability*, New York: Springer.

Mental Health (Wales) Measure. (2010), retrieved on the 19th April 2012 from http://www.assemblywales.org

Millefiorini, E., Padovani, A., Pozzilli, C., Loriedo, C., Bastianello, S., Buttinelli, C., *et al.*(1992). Depression in the early phase of Multiple Sclerosis: Influence of functional disability, cognitive impairment and brain abnormalities, *Acta Neurologica Scandinavica*, 86, 354-358

Minden, S.L., Orav, J., & Reich, P. (1987). Depression in Multiple Sclerosis. *General Hospital Psychiatry*, *9*, 426–434.

Minden, S. L, & Schiffer, R.B. (1990). Affective disorders in Multiple Sclerosis, *Archives of Neurology*, 47, 98-104.

Mitchell, A.J., Benito-Leon, J., Morales Gonzalez, J-M., & Rivera-Navarro, J. (2005). Quality of life and its assessment in Multiple Sclerosis: Integrating physical and psychological components of wellbeing, *The Lancet Neurology*, 4, 556-566.

Mohr, D.C., Dick, L.P., Russo, D., Pinn, J., Boudewyn, Likosky, W., Goodkin, D.E. (1999). The psychosocial impact of Multiple Sclerosis: exploring the patient's perspective, *Health Psychology*, 18, 376-382.

Mohr, D.C. (2011). Psychiatric disorder, stress and their treatment among people with Myltiple sclerosis, in S., Pagoto (Ed.), *Psychological co-morbidities of physical illness: A behavioural medicine perspective*, Springer Science and Business Media: New York.

Mohr, D.C., Boudewyn, A.C., Goodkin, D.E., Bostrom, A., & Epstein, L. (2001). Comparative outcomes for individual cognitive behaviour therapy, supportive expressive

group psychotherapy, and sertraline for the treatment of depression in Multiple Sclerosis, *Journal of Consulting and Clinical Psychology*, 69, 942-949.

Mohr, D.C., Goodkin, D.E., Gatto., N., & van der Wende, J. (1997). Depression, coping, and level of neurological impairment in Multiple Sclerosis, *Multiple Sclerosis*, 3, 254-258.

Moller, A.,Wiedemann, G., Rohde, U., Backmund, H., & Sonntag, A. (1994). Correlates of cognitive impairment and depressive mood disorder in Multiple Sclerosis, *Acta Psychiatrica Scandinavica*, *89*, 117–121.

Morey, L.C. (1991). *Personality Assessment Inventory: Professional manual*, Psychological Assessment Resources: Florida

Morina, N., Ford, J.D., Risch, A.K., Morina, B., Stangier, U. (2010). Somatic distress among Kosovar civilian war survivors: relationship to trauma exposure and the mediating role of experiential avoidance, *Social Psychiatry and Psychiatric Epidemiology*, 45, 1167-1177.

Morina, N., Stangier, U., Risch, A.K. (2008). Experiential avoidance in civilian war survivors with current versus recovered posttraumatic stress disorder: A pilot study, *Behaviour Change*, 25, 15-22.

Moss-Morris, R., Petrie, K.J., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1, 15-25.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., Buick, D. (2002). The revised illness perception questionnaire (IPQ-R), *Psychology and Health*, 17, 1-16.

National Multiple Sclerosis Trust. (2009). *Prevalence of Multiple Sclerosis in the UK revised*, MS Trust news item-12 June 2009, retrieved on the 19th September 2011 from http://www.mstrust.org.uk/atoz/prevalence_incidence.jsp

National Assembly Wales (n.d). *Mh45: legislation committee No.3. Proposed Mental Health (Wales) measure. Response from the Welsh Branch of the British Psychological Society*, retrieved on the 19th April 2012 from www.assemblywales.org

National Multiple Sclerosis Society. (2011). *Four disease courses of Multiple Sclerosis*, retrieved on 19th September 2011 from http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/what-is-ms/four-disease-courses-of-ms/index.aspx

NICE (2003). *Management of Multiple Sclerosis in primary and secondary care, NICE clinical guidelines, CG8*, retrieved on the 22nd of April 2012 from http://www.nice.org.uk/CG8

Nicholson, A., Fuhrer, R., Marmot, M. (2005). Psychological distress as a predictor of CHD events in men: The effect of persistence and components of risk, *Psychosomatic Medicine*, 67, 522-530.

Pachana, N.A., Byrne, G.J., Siddle, H., Koloski, N., Harley, E, & Arnold, E. (2007). Development and validation of the Geriatric Anxiety Inventory, *International Psychogeriatrics*, 19, 103-114.

Pakenham, K.I. (1999). Adjustment to Multiple Sclerosis: Application of a stress and coping model, *Health Psychology*, 18, 383-392.

Pakenham, K.I., & Fleming, M. (2011). Relations between acceptance of multiple sclerosis and positive and negative adjustments, Psychology and Health, 26, 1292-1309.

Petrie, K. J., Cameron, L.D., Ellis, C.J., Buick, D., & Weinman, J. (2002). Changing illness perceptions after myocardial infarction: an early intervention randomised controlled trial, *Psychosomatic Medicine*, 64, 580-586.

Poder, K., Ghatavi, K., Campbell, T.L., Kisely, S., Sarty, I., Stadnyk, K., *et al.* (2009). Social anxiety in a Multiple Sclerosis clinic population, *Multiple Sclerosis*, 15, 393-398.

Preacher, K.J., Hayes, A.F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models, *Behaviour Research Methods*, 40: 879-891.

Pugol, J., Bello., J., Dues, J., Marti-Vilalta, J.L., & Capevila, A. (1997). Lesions in the left arcuate fasciculus region and depressive symptoms in Multiple Sclerosis, *Neurology*, 49, 1105-1110.

Pugol, J., Bello., J., Dues, J., Marti-Vilalta, J.L., & Capevila, A. (2000). Beck depression inventory factors related to demyelinating lesions of the arcuate fasciculus region, *Psychiatry Research*, 99, 151-159.

Rabins, P.V., Brooks, B.R., O'Donnell, P., Pearlson, G.D., Moberg, P., Jubelt, B *et al.* (1986). Structural brain correlates of emotional disorder in Multiple Sclerosis, *Brain*, *109*, 585–597.

Ramagopalan, S.V., Dobson, R., & Giovannoni, G. (2010). Multiple Sclerosis: Risk factors, prodromes, and potential causal pathways, *The Lancet Neurology*, 9, 727-739.

Rao, S. M., Huber, S. J., & Bornstein, R. A. (1992). Emotional changes with Multiple Sclerosis and Parkinson's disease. *Journal of Consulting & Clinical Psychology*, 60, 369-378.

Robinson, I., Neilson, S., & Clifford Rose, F. (2000). *Multiple Sclerosis at your fingertips guide*. Class Publishing, London.

Rothwell, P.M, McDowell, Z., Wong, C.K, & Dorman, P.J.(1997). Doctors and patients don't agree: Cross sectional study of patients' and doctors' perceptions and assessments of disability in Multiple Sclerosis. *British Medical Journal*, 314, 1580- 1583.

Ruiz, F.J. (2010). A review of acceptance and commitment therapy (ACT) empirical evidence: Correlational, experimental, psychopathology, component and outcome studies, *International Journal of Psychology and Psychological therapy*, 10, 125-162.

Sabatini, U., Pozzilli, C., Pantano, P., Koudriavtseva, T., Padovani, A., Millefiorini, E., *et al.* (1996). Involvement of the limbic system in Multiple Sclerosis patients with depressive disorders. *Biological Psychology*, *39*, 970–975.

Sadovnick, A.D., Remick, R.A., Allen, J., Swartz, E., Yee, I.M.L., Eisen, K., *et al.* (1996). Depression and Multiple Sclerosis. *Neurology*, 46(3), 628-632.

Schlosser, R.W. (2007). Appraising the quality of systematic reviews, *Focus, Technical Brief No. 2007*, retrieved on 13th of April 2012 from www.ncddr.org/kt/products/focus/focus17/

Schreurs, K., & de Ridder, D. (1997). Integration of coping and social support perspectives: Implications for the study of adaption to chronic diseases, *Clinical Psychology Review*, 17, 89-112.

Schumacker, R.E., & Lomax, R.G. (2004). *A beginner's guide to structural equation modeling*, Lawrence Erlbaum Associates: New Jersey.

Selig, J.P., & Preacher, K.J. (2009). Mediation models for longitudinal data in developmental research, *Research in Human Development*, 6, 144-164.

Shah, A (2009). Fatigue in Multiple Sclerosis, *Physical Medicine and Rehabilitation clinics of North America*, 20, 363-372.

Sheppard, S.C., Forsyth, J.P., Hickling, E.J., & Cianchi, J. (2010). A novel application of acceptance and commitment therapy for psychological problems associated with Multiple Sclerosis: Results from a half-day workshop intervention, *International Journal of Multiple Sclerosis Care*, 12: 200-206.

Siegert, R. J., & Abernethy, D. A. (2005). Depression in Multiple Sclerosis: A review. Journal of Neurology, *Neurosurgery & Psychiatry*, 76, 469-475.

Smith, M.M., & Arnett, P.A. (2005). Factors related to employment status change in individuals with Multiple Sclerosis, *Multiple Sclerosis*, 11, 602-609.

Spain, L.A., Tubridy, N., Kilpatrick, T.J., Adams, S.J., & Holmes, C.C.N., (2007). Illness perception and health related quality of life in Multiple Sclerosis, *Acta Neurlogica Scandinavia*, 116, 293-299.

Spiegler, D.C & Guevremont. (2003). *Contemporary Behaviour Therapy*, Wadsworth Cengage Learning: CA, USA.

Stafford, T. (2007). Isn't it all just obvious? *The Psychologist*, 20, 94-95.

Stage, F.K., Carter, H., & Nora, A. (2004). Path analysis: An introduction and analysis of a decade of research, *Journal of Educational Research*, 98, 5-12.

Stoelting, R. (2002). *Structural equation modeling/Path analysis*, retrieved on 12th of January 2012 from http://userwww.sfsu.edu/~efc/classes/biol710/path/SEMwebpage.htm

Stoll, T., Kauer, Y., Buchi, S., Klaghofer, R., Sensky, T., & Villiger, P.M. (2001). Prediction of depression in systemic lupus erthematosus patients using SF-36 mental health scores, *Rheumatology*, 40, 695-698.

Strosahl, K.D. & Robinson, P.J. (2009). Teaching ACT to whom, why and how, In J., Ciarrochi, J.T, Blackledge, F.P., Deane (Eds.), *Acceptance and Commitment Therapy: Contemporary Theory Research and Practice*, Australian Academic Press, Sydney, Australia.

Tabachnick, B.G., & Fidell, L.S. (2007). *Using Multivariate Statistics, Fifth edition*, Pearson International Edition, Pearson education: Boston

Tarnopolsky, A., Hand., D.J., McLean., E.K., Roberts, H., & Wiggins., R.D. (1979). Validity and use of a screening questionnaire (GHQ) in the community, *British Journal of Psychiatry*, 134, 508-515.

Taylor, S., Zvolensky, M.J., Cox., B.J., Deacon, B., Heimberg, R.G., Ledley, D., *et al.* (2007). Robust dimensions of anxiety sensitivity: Development and initial validation of the Anxiety Sensitivity Index-3, *Psychological Assessment*, 19, 176-188.

Thompson, B. (2000). Ten commandments of Structural Equation Modeling, in L. Grimm & P. Yarnell (Eds.) *Reading and understanding more multivariate statistics*, American Psychological Association, Washington.

Thompson, B. (2006). *Foundation of behavioural statistics: An insight based approach*, The Guilford Press: New York.

Thompson, A.J., & Hobart, J.C. (1998). Multiple Sclerosis: Assessment of disability and disability scales, *Journal of Neurology*, 245, 189-196.

Thompson, A., Kermode, A., Wicks, D., MacManus, D., Kendall, B., Kingsley, D., *et al.* (1991). Major differences in the dynamics of primary and secondary progressive Multiple Sclerosis, *Annals of Neurology*, 29, 53-62.

Thompson, M., & McCracken, L.M. (2011). Acceptance and related processes in adjustment to chronic pain, *Chronic Pain and Headache Reports*, 15, 144-151.

Turner, J.A., Jensen, M.P., & Romano, J.M. (2000). Do beliefs, coping, and catastrophising independently predict functioning in patients with chronic pain? *Pain*, 85, 115-125.

Uguz, F., Akpinar, Z., Ozkan, I., & Tokgoz. (2008). Mood and anxiety disorders in patients with Multiple Sclerosis, *International Journal of Psychiatry in Clinical Practice*, 12, 19-24.

Wade, D. (2006). *NHS services for people with* Multiple Sclerosis*: a national survey, An audit of commissioning, provision and experience of services used by people with* Multiple Sclerosis *in 2005-6, against recommendation from NICE clinical guideline 8*, The royal college of physicians and the Multiple Sclerosis Trust, retrieved on the 18th of April 2012 from http://bookshop.rcplondon.ac.uk/details.aspx?e=186

Wade, D., Besford, J., Lowe, D. (2011). *The national audit of services for people with Multiple Sclerosis 2011*, September 2011, retrieved on the 18th of April 2012 from http://www.rcplondon.ac.uk/sites/default/files/ms_audit_national_report_2011_0.pdf

Weiner, H.L. (2009). The challenge of Multiple Sclerosis: How do we cure a chronic heterogeneous disease? *Annals of Neurology*, 65, 239-248.

Weinman, J., Petrie, K.J., Moss-Morris, R., & Horne, R. (1996). The illness perception Questionnaire: A new method for assessing the cognitive representations of illness, *Psychology and Health*, 11, 431-445.

White, C.A. & Trief, P.M. (2005). Psychotherapy for medical patients, In G.O., Gabbard, J.S, Beck, & J., Holmes (Eds.), *Oxford textbook of psychotherapy*, Oxford University Press, New York.

Wilson, E.R.H., Wisely, J.A., Wearden, A.J., Dunn, K.W., Edwards, J., Tarrier, N. (2011). Do illness perceptions and mood predict healing time for burn wounds? A prospective, preliminary study, *Journal of Psychosomatic Research*, 71, 364-366.

Valentiner, D.P., Holahan, C.J., & Moos, R.H. (1994). Social support, appraisals of event controllability and coping: an integrative model, *Journal of Personality and Social psychology*, 66 (6), 1094-1102.

Van de Mortel, T.F. (2008). Faking it: Social desirability response bias in self report research, *Australian journal of Advanced Nursing*, 25, 40- 48.

Van Oort, L., Schroder, C & French, D.P. (2011). What do people think about when they answer the Brief Illness Perception Questionnaire? A “think-aloud” study, British Journal of Health Psychology, 16, 231-245.

Vandenbrouke, J.P., von Elm, E., Altman, D.G., Gotzsche, P.C., Mulrow, C.D., Pocock, S.J., *et al.* (2007). Strengthening the reporting of observational studies in epidemiology (STROBE): Explanation and elaboration, *Annals of Internal Medicine*, 147, 163-194

Vaughan, R., Morrison, L., & Miller, E. (2003). The illness representations of Multiple Sclerosis and their relations to outcome, *British Journal of Health Psychology*, 8, 287-301.

Zettle, R.D., & Hayes., S.C. (1986). Dysfunctional control by client verbal behaviour: The context for reason giving, *The Analysis of Verbal Behaviour*, 4, 30-38.

Zettle, R.D., & Rains., J.C. (1989). Group cognitive and contextual therapies in treatment of depression, *Journal of Clinical Psychology*, 45, 438-445.

Zettle, R. D., Hocker, T. R., Mick, K. A., Scofield, B. E., Petersen, C. L., Hyunsung S., *et al.*(2005). Differential strategies in coping with pain as a function of level of experiential avoidance, *The Psychological Record*, 55, 511-524.

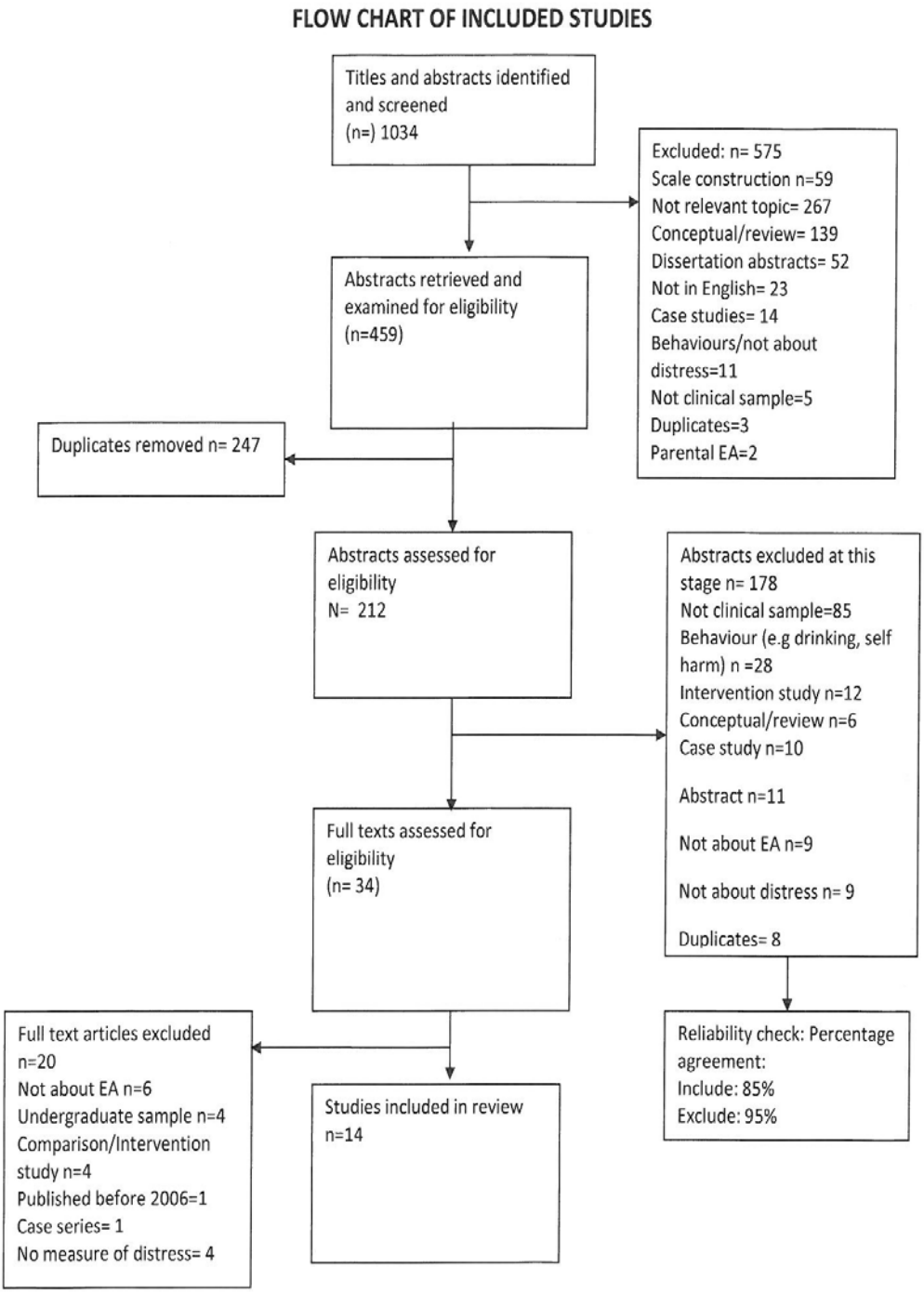
Zhao, X., Lynch, J.G., & Chen, Q. (2010). Reconsidering Baron and Kenny: Myths and truths about mediation analysis, *Journal of Consumer Research*, 37, 197-206.

Ziemssen, T. (2009). Multiple Sclerosis beyond EDSS: Depression and fatigue, *Journal of the neurological sciences*, 277, 537-541.

Zigmond, A.S., Snaith, R.P. (1983). The hospital anxiety and depression scale, *Acta Psychiatrica Scandinavica*, 67, 361-370.

Zorzon, M., de Masi, R., Nasuelli, D., Ukmar, J., Mucelli, R.P., Cazzato, G., *et al.* (2001). Depression and anxiety in Multiple Sclerosis: A clinical and MRI study in 95 subjects. *Journal of Neurology*, *248*, 416–421.

APPENDIX 1: SYSTEMATIC REVIEW PROCESS:



APPENDIX 2: THE STROBE CHECKLIST

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

1

Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Andrew & Dulin 2007	Cross sectional (within subjects)	GDS-SF (Geriatric Depression Scale Short Form) GAI (Geriatric Anxiety Inventory)	AAQ-16 item High scores represent experiential avoidance	Individuals over 70 living in their own home or in a retirement village in New Zealand	208	67%	70 to 90+ (80-84)	Hierarchical multiple regression analyses	There was a significant positive correlation between depression and experiential avoidance (r=0.37, p<0.01), and anxiety and experiential avoidance (r=0.43; p<0.01). Experiential avoidance explained 8% of the unique variance in depression (β=1.96; p <.0.01), 20% in anxiety (β =3.12; p =<0.01), and moderated the relationships between self reported health and both depression and anxiety.	Generalisability of findings: sample was healthy, community dwelling older adults, with low levels of depression. AAQ 16 item, not a unidimensional measure of experiential avoidance. Baron and Kenny (1986) procedures used to test moderation.
Berking, Neacsiu, Comtois & Linehan (2009)	Longitudinal (within subjects)	HRS (Hamilton Rating Scale 25 item version) BDI (Beck depression Inventory)	16 item AAQ High scores=more experiential avoidance	Outpatient females during 1 year of treatment for BPD	81	100%	28.9 (11-44)	Pearson's correlation Hierarchical linear modeling Structural equation modeling	Experiential avoidance was positively associated with greater severity of depression at all points of assessment (range between (BDI) r =0.44-0.61, (HRSD) r =0.34-0.67). Reductions of experiential avoidance during treatment was significantly associated with a greater reduction of depression (r =0.85) experiential avoidance predicted subsequent reduction of depression whereas the level of depression did not predict subsequent changes in experiential avoidance	AAQ 16 not a unidimensional measure of experiential avoidance Sample size was small for use with structural equation modeling Only female sample, reducing the generalisability of the studies

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Berman, Wheaton, McGrath & Abramowitz (2010)	Cross sectional (within subjects)	BAI (Beck Anxiety Inventory) ASI (Anxiety Sensitivity Index) BDI (Beck depression Index)	10 item AAQ-II High scores= greater psychological flexibility/less experiential avoidance	Primary diagnosis of an anxiety disorder (e.g. OCD, panic disorder, social phobia, GAD)	42	86%	27.21 (18-63)	Hierarchical regression analyses	Correlational analyses indicated associations between anxiety sensitivity and experiential avoidance (r =-.48, p <0.001) and AI and experiential avoidance are correlated with anxiety (r =.52, p <0.001; r =-.43, p <0.001). The physical concerns dimensions of AS predicted anxiety symptom severity independently of experiential avoidance (R^2=.36, p <0.01)	BAI may measure panic symptoms rather than anxiety per se AAQ-II ten item not a unidimensional measure of experiential avoidance
Bohlmeijer, Fleddderus, Rokx, Pieterse (2011)	Cross sectional study (between subjects)	Center for Epidemiologic Studies Depression Scale (CES-D) Hospital Depression and Anxiety Scale-Anxiety Subscale Checklist Individual Strength	10 item AAQ-II Dutch version High score indicates higher acceptance and less experiential avoidance	Adults with mild to moderate psychological distress	49	86%	49 (24-71)	t-tests Chi square tests Group comparisons	ACT intervention led to statistically significant reduction in depressive symptoms (CES-D= F=9.19 (post treatment, and 9.30 (follow-up), p <0.03; HADS= F=7.97 (p <0.006) & 4.23 (p <0.043) CIS= F= 8.24 (p <0.005) & 7.84 (p <0.006). Results for Cohen's d showed medium effect sizes at post tx and follow up (CES-D= .60 & .63; HADS= .67 & .56). Meditational analysis shows that the improvement of AAQ-II from baseline to post-treatment significantly predicted scores on the CES-D at follow up (bootstrapping values between -4.10 and -.67 (adjusted R^2 values).	Control group (n=44) waiting list, randomly assigned to the ACT intervention, or waiting list. Groups stratified on gender and age. Mental health relied on self report ratings rather than clinician ratings Number of participants using medication longer than three months prior to starting group, and changes to medication was not assessed AAQ-II ten item not a unidimensional measure of experiential avoidance Mediation analysis used guidelines by Preacher & Hayes (2004)

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Costa & Pinto-Gouveia (2011)	Cross sectional (within subjects)	CSQ Coping Styles Questionnaire) DASS-21 (Depression, Anxiety and Stress Scale)	AAQ-ten item Higher results=higher experiential avoidance	Adults recruited from Primary care settings in Portugal With a specific chronic pain condition, e.g. rheumatoid arthritis	70	90%	Male 61 (SD 16.81) Female 59 (SD 14.68)	Pearson correlation matrix Linear regression models	Experiential avoidance was highly and positively correlated with depression (r =0.67; p <0.001) and stress (r = 0.693; p <0.001), and moderately with anxiety (r = 0.0314; p <0.05). Experiential avoidance partially mediated the relationship between rational coping and depression (z=-2.16; p = 0.003). Experiential avoidance fully mediated the effect of detached/emotional coping in depression (z= -3.08; p = 0.00). Experiential avoidance partially mediated the effect of rational coping on stress (z= -2.20; p = 0.03). Rational coping was negatively correlated with depression (r = -0.4; p <0.001), anxiety (r = -0.301; p <0.05), and stress (r = -0.439; p <0.001). Detached/emotional coping was negatively correlated with depression (r = -0.28; p <0.05) and stress (r = -0.74; p < 0.01).	Excluded severe psychopathology in the sample which limits the generalisabiliy of the findings. AAQ ten item not a unidimensonal measure of experiential avoidance Baron and Kenny (1986) procedures used to test mediation

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Fledderus, Bohlmeijer & Pieterse (2010)	Cross sectional study (within subjects)	UCL (Utrecht coping list) CES-D (Centre for epidemiologic studies depression scale) HADS-A (Hospital anxiety and depression scale-anxiety subscale) MHC-SF (Mental Health continuum: short form)	AAQ-II 10 item Higher scores= more acceptance	Dutch participants with Mild to moderate anxiety or depressive symptoms Excluded those with severe pathology, and those who recently started pharmacological treatment	93	82%	49 (24-71)	Pearson correlations and multiple regression analyses	Lower levels of experiential avoidance (high acceptance) strongly related to reduced passive coping (*r*.= -0.56, *p* <0.01). Higher acceptance strongly related to decreased anxiety (*r* = -.47, *p* <0.01), and better emotional wellbeing (*r* = 0.38, *p* <0.01). Experiential avoidance mediates the effects of passive coping on both increased anxiety (z= 4.36, *p* = .01) and depression (z= 2.79, *p* =.01)and decreased emotional (z= -2.26, *p* = .05) and psychological wellbeing (z= -2.05, *p* =.05). Results suggest that a person who is prone to use experiential avoidance or has learned experiential avoidance strategies has a higher risk of developing psychopathology and lower mental health. Early interventions may be useful.	Control: Half the sample was randomised to waiting list Sample was predominately male, but was a diversity of age, education and psychological distress. AAQ-II ten item not a unidimensional measure of experiential avoidance Baron and Kenny (1986) procedures used to test mediation

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Goldstone, Farhall, Ong (2011)	Cross sectional study (within subjects)	PDI (Peters Delusions Inventory) SRLE (Survey of recent life events)	AAQ-II 10 item High scores= more acceptance	N=100 With a diagnosed psychotic disorder through clinical and disability support services in Melbourne Australia	100	44%	26-35 (mean not given)	Pearson product-moment correlations Bootstrapping (method prescribed by Preacher & Hayes, 2004)	Both life hassles and experiential avoidance were strongly associated with each of the delusions measures (-.49 & -.61 in the non-clinical sample; - .40 & -.48 in the clinical sample; *p*'s in the <0.01). Life stress was a significant predictor of experiential avoidance (*t* (131) = -8.46, *p* <0.001) as were delusions (*t* (131) = 6.81, *p* <0.001). Thereafter in the presence of life hassles, experiential avoidance was found to be a significant predictor of both delusions (*t* (130) = -3.09, *p* <0.001) and delusional distress (*t* (130) = -5.06, *p* <0.001). Although still significant the impact of life stress upon delusions (*t* (130) = 3.82, *p* <0.001, and delusional distress (*t* (130) = 3.92, *p* <0.001) was markedly diminished when the influence of experiential avoidance was controlled for. The findings suggest that individuals with a tendency to use experiential avoidance to suppress or avoid unwanted thoughts (clinical and nonclinical samples)are significantly more likely to experience delusions in response to stressful life events	Diagnosis was not confirmed, but self reported AAQ-II ten item not a unidimensional measure of experiential avoidance Used a non-clinical sample of 133. This non matched sample limits the appropriateness of comparing findings across the 2 samples. Mediation analysis used guidelines by Preacher & Hayes (2004)

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Gratz, Tull & Gunderson (2008)	Cross sectional study (within subjects)	SCID (Structured Clinical Interview for DSM-IV Axis I disorders) DIPD-IV (Diagnostic interview for DSM-IV Personality Disorders ASI BSI (Brief symptom inventory) AIM (Affect Intensity List) BIS (Barratt Impulsivity Scale)	AAQ-nine item Items recoded so high scores indicate greater experiential avoidance	Adults meeting five or more criteria for borderline personality disorder (BPD) using the DIPD-IV and the SCID	40	87%	32.25 (18-52)	One way Anova's Logisitc regression analysis	Anxiety sensitivity predicts experiential avoidance (F (1, 39) = 5.30, adjusted R^2=.10, p <0.05). The relationship between anxiety sensitivity and borderline personality disorder was mediated by experiential avoidance (x^2 = 37.36, p <0.01). AS and experiential avoidance as mediator accounted for a significant amount of additional variance (81%) in BPD above and beyond negative effect (x^2 = 5.33, p <0.05), affect intensity/reactivity and impulsivity (x^2 =5.29, p <0.05)	Control consisted of n=20 who did not meet full criteria for any personality disorder, and not meet more than three criteria for BPD. Small and predominantly female sample (approx 85% in each condition) AAQ nine item not a unidimensional measure of experiential avoidance

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Iverson, Follette, Pistorello & Fruzzetti (2011)	Cross sectional study (within subjects)	SCID SASI-II (Suicide attempt self-injury Interview) DERS (Difficulties in Emotion Regulation Scale) DTS (Distress Tolerance Scale) PAI-BOR (Personality Assessment Inventory-Borderline features scale) BDI-II PASAT-C (The Paced auditory serial addition task-computerised version)	AAQ-II 10 item High scores= more acceptance	Adults with BPD or sub threshold BPD (3/4 symptoms) US sample 32 women 8 men	40	80%	20.8 (18-25)	Pearson's correlation Hierarchical regression analysis	Emotion dysregulation (r =.55, p <0.01) and experiential avoidance (r = -.68, p <0.01) were significantly associated with BPD symptom severity after accounting for depression. Only experiential avoidance was significantly associated with BPD symptom severity after controlling for depression symptoms (β = -.51, p <0.05).	Small sample for statistical analysis used. AAQ-II ten item not a unidimensional measure of experiential avoidance

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Kashdan, Morina & Priebe (2009)	Cross sectional study (within subjects)	MINI (MINI International Neuropsychiatric Interview) LSL (Life stressor Checklist-revised) BSI MANSA (Manchester short assessment of quality of life)	AAQ-nine item Higher scores on the AAQ 9 represent greater experiential avoidance	Albanian civilian survivors of the Kosovo war. At least 23 years of age (indicative of being at least 16 years old during the war) having experienced a war related stressor (match the stressor criterion 1A of PTSD described by DSM-IV)	174	62%	39.52 (SD: 11.17)	Hierarchical regression analyses	Presence of PTSD (partial n^2p=.16), SAD (partial n^2p=.21), or MDD (partial n^2p=.30) was associated with greater experiential avoidance and global distress and lower QoL (*p*s<0.005). (n^2p) is the partial eta squared n2p, and is a measure of variance like *r*-squared). It tells us what proportion of the variance in the dependent variable is attributable to the factor in question. Experiential avoidance was a partial mediator of the effects of social anxiety disorder (SAD) and post-traumatic stress disorder (PTSD) on quality of life (QOL). Only war survivors without SAD and low experiential avoidance reported elevated QOL; people with either SAD or high reliance on experiential avoidance reported compromised low QOL.	Measures were translated to Albanian, then back translated, suggesting possible limitations, suggesting limitations with construct validity. AAQ-9 item not a unidimensional measure of experiential avoidance Baron and Kenny (1986) procedures used to test mediation

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Lee, Orsillo, Roemer & Allen (2010)	Cross sectional study (within subjects)	ADIS-IV (Anxiety Disorders Interview Schedule for DSM-IV) PSWQ (Penn state worry questionnaire) DASS-21 IUS (Intolerance of uncertainty scale) ACS (Affective Control Scale)	AAQ- 16 item High scores equal to high experiential avoidance	Adults recruited in Boston, with a principal diagnosis of GAD with a ADIS severity rating of at least 4.	66	61%	33.58 (19-66)	MANCOVA Discriminant Function Analysis	The generalised anxiety group reported increased experiential avoidance about distress about emotions compared to the non-GAD group [F (5, 58) = 22.80, p <0.0005; n2p=.66). Participants with generalised anxiety disorder reported significantly higher levels of experiential avoidance (n^2p=.51) and distress about anxious (n^2p=.61), depressive (n^2p=.25), angry (n^2p=.17), and positive (n^2p=.11) emotions, compared to non-clinical controls. Measures of experiential avoidance (r =.80) and distress about emotions (r =.85 & .52) significantly predicted GAD status.	Control: n= 33 Demographically matched controls Recruitment of control group only focused on current diagnosis of anxiety and did not enquire about past experiences of mental health (non-clinical group may also use experiential avoidance etc), also secondary diagnosis were high in the clinical group, so observed differences may not be due to GAD. AAQ- 16 item not a unidimensional measure of experiential avoidance
Manos, Cahill, Wetterneck *et al.* (2010)	Longitudinal (within subjects)	Y-BOCS-SR (Yale-Brown Obsessive Compulsive Scale) OCI-R (Obsessive Compulsive Inventory-Revised) OBQ44 (Obsessive beliefs questionaire-44) BDI BAI	AAQ-nine item High scores=greater experiential avoidance	Adults from Wisconsin US, with a primary diagnosis of OCD	108	55%	32.1 (18-65)	Pearson correlations and multiple regression analyses	Experiential avoidance was not generally related to the severity of obsessive compulsive symptoms (r = -0.051-.153) and experiential avoidance did not add significantly to the prediction of OCD symptom domains (β =.206, t=1.960, p <=.053) above and beyond depression or general anxiety. experiential avoidance as currently measured may not play a role in OCD symptom severity or changes in OC severity across treatment	AAQ 9 item not a unidimensional measure of experiential avoidance (in this study had an internal consistency of alpha=.58) Intervention was CBT led with exposure and response prevention and cognitive restructuring as main interventions (so experiential avoidance not targeted as a process of change) Most (54%) had at least one additional diagnosis. Only affective disorder (which accounted for 36% of second diagnosis) was mentioned.

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Morina, Stangier & Risch (2008)	Cross sectional study (within subjects)	MINI IES-R (Impact of events scale-revised) BSI	AAQ-nine item Higher scores on the AAQ represent greater experiential avoidance	Albanian civilian survivors of the Kosovo war. At least 23 years of age (indicative of being at least 16 years old during the war) having experienced a war related stressor (match the stressor criterion 1A of PTSD described by DSM-IV)	84	56%	38.4 (22-60)	ANOVA ANCOVA	Experiential avoidance correlated significantly with PTSD (r =.47, p <0.01), and psychiatric severity (r =.39, p= <0.01). Significantly higher rates of experiential avoidance and psychological distress in current PTSD group as compared with a recovered PTSD group and a non-PTSD group (F(2,81)= 8.40, p <0.01)	Control group included n=25 recovered PTSD group n= 31 non PTSD group, leaving only 28 in the PTSD group so a small sample to generalise from. Not all three groups were well matched, for example there were more females in the current PTSD and recovered PTSD groups, and more males in the non PTSD groups. Also the groups differed in terms of length of education, but not age. AAQ nine item not a unidimensional measure of experiential avoidance

Study	Design	Psychological distress measures	Experiential avoidance measure	Participants	N	Female %	Mean Age (Range)	Methodology	Key findings	Limitations/Comments
Morina, Ford, Risch, Morina & Stangier (2010)	Cross sectional study (within subjects)	MINI PHQ (Patient Health Questionnaire) IES-R GHQ-12 (General health questionaire -12 item) EQOLS (Eurohis Quality of Life Scale)	AAQ-nine item Higher scores on the AAQ represent greater experiential avoidance	Albanian civilian survivors of the Kosovo war At least 23 years of age (indicative of being at least 16 years old during the war) having experienced a war related stressor (match the stressor criterion 1A of PTSD described by DSM-IV)	163	61%	45 (24-63)	Chi-square analyses T tests Multiple regression analysis	Experiential avoidance partially mediates the relationship between SD and quality of life (z= -3.20, *p* - 0.02) and SD and psychological distress (z=2.38, *p* =0.02). After accounting for the effects of war related variables, demographic variables, as well as posttraumatic stress disorder and major depressive episodes, somatic distress (SD) was associated with greater psychological distress, experiential avoidance, and lower quality of life.	The classification of somatic distress based on a questionnaire not yet validated for use among Kosovar participants Baron and Kenny (1986) procedures used to test mediation

APPENDIX 4: BACKGROUND INFORMATION QUESTIONNAIRE:

V1.1 18/03/11

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

BACKGROUND INFORMATION QUESTIONNAIRE

1: Age: _____

2: Gender Male: ☐ Female: ☐

3: How long have you experienced the symptoms of Multiple Sclerosis?

For _____ years

4: When were you diagnosed with Multiple Sclerosis?

In _____(e.g 1980 etc)

5: What type of Multiple Sclerosis do you have?

Relapsing remitting: ☐

Benign Multiple Sclerosis: ☐

Secondary progressive Multiple Sclerosis: ☐

Primary progressive Multiple Sclerosis: ☐

Don't know: ☐

1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff CF14 5DX
Ty Archway, 77 Ty Glas Avenue, Llanishen, Caerdydd CF14 5DX
Tel/Ffon 029 2020 6464 Fax/Ffacs 029 2019 0106
Email/Ebost deborah.robinson2@wales.nhs.uk

APPENDIX 5: EXPANDED DISABILITY STATUS SCALE- SELF REPORT

V1.2 16/06/11

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

THE EXPANDED DISABILITY STATUS SCALE: SELF REPORT

Question 1: Are you able to walk independently-without the use of a walking stick or frame or person to hold or FES machine or other support? (please tick)

☐ Yes- **Please go to Question 2**

☐ No- **Please go to Question 3 on the next page**

Question 2: At your best, how far can you walk without a rest or help from a stick or frame or person or FES or other walking aid? (please tick)

☐ Unrestricted (I can walk for 2-3 hours with no problem)

☐ Clearly more than 500 metres/550 yards

☐ About 500 metres/550 yards
(about the length of Queens Street in Cardiff)

☐ About 300 metres/330 yards
(the length of 3 football pitches)

☐ About 200 metres/220 yards
(half of Queens Streets in Cardiff or 2 football pitches)

☐ About 100 metres/110 yards
(the length of one football pitch or the outpatients Corridor in the UHW hospital)

☐ Less than 100 metres/110 yards

If you can walk without the aid of a walking aid such as a stick, you have finished this questionnaire, and can move onto the next questionnaire overleaf.

If you need help to walk or use a wheelchair, please continue to Question 3

Question 3: Please tick the box below that best describes your walking ability.

- ☐ I can walk more than, or about, 100 metres/110 yards (the length of a Football pitch) with 1 stick or person or support
- ☐ I use an FES machine to walk (on **one** leg/on **both** legs-please ring)
- ☐ I need support on both sides to walk, such as 2 sticks or a Walker/frame
- ☐ I can only walk about 10 metres (just about across a room)
- ☐ I can only walk a few steps even with help and normally use a wheelchair
- ☐ I use a wheelchair all of the time and can't take even a few steps

Question 4: If you are bed or chair bound, do you have trouble using your hands for writing and eating, etc.

Yes ☐

No ☐

Question 5: Are you totally confined to bed and need help with all daily tasks?

Yes ☐

No ☐

APPENDIX 6: ACCEPTANCE AND ACTION QUESTIONNAIRE-II

V1.1 18/03/11

AAQ-II

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

It's OK if I remember something unpleasant.	1	2	3	4	5	6	7
My painful experiences and memories make it difficult for me to live a life that I would value.	1	2	3	4	5	6	7
I'm afraid of my feelings.	1	2	3	4	5	6	7
I worry about not being able to control my worries and feelings.	1	2	3	4	5	6	7
My painful memories prevent me from having a fulfilling life.	1	2	3	4	5	6	7
I am in control of my life.	1	2	3	4	5	6	7
Emotions cause problems in my life.	1	2	3	4	5	6	7
It seems like most people are handling their lives better than I am.	1	2	3	4	5	6	7
Worries get in the way of my success.	1	2	3	4	5	6	7
My thoughts and feelings do not get in the way of how I want to live my life.	1	2	3	4	5	6	7

APPENDIX 7: THE BRIEF ILLNESS PERCEPTION QUESTIONAIRE

V1.1 15/06/11

The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your Multiple Sclerosis (MS) affect your life?

0 1 2 3 4 5 6 7 8 9 10

No affect at all — Severely affects my life

How long do you think your MS will continue?

0 1 2 3 4 5 6 7 8 9 10

A very short time — Forever

How much control do you feel you have over your MS?

0 1 2 3 4 5 6 7 8 9 10

Absolutely no control — Extreme amount of control

How much do you think your treatment can help your MS?

0 1 2 3 4 5 6 7 8 9 10

Not at all — Extremely helpful

How much do you experience symptoms from your MS?

0 1 2 3 4 5 6 7 8 9 10

No symptoms at all — Many severe symptoms

How concerned are you about your MS?

0 1 2 3 4 5 6 7 8 9 10

Not at all concerned — Extremely concerned

How well do you feel you understand your MS?

0 1 2 3 4 5 6 7 8 9 10

Don't understand at all — Understand very clearly

How much does your MS affect you emotionally? (e.g. Does it make you angry, scared, upset or depressed?

0 1 2 3 4 5 6 7 8 9 10

Not at all affected emotionally — Extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your MS. The most important causes for me:-

1._____

2._____

3._____

GENERAL HEALTH QUESTIONNAIRE

GHQ-30

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

HAVE YOU RECENTLY:

1 — been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2 — lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3 — been having restless, disturbed nights?	Not at all	No more than usual	Rather more than usual	Much more than usual
4 — been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
5 — been getting out of the house as much as usual?	More so than usual	Same as usual	Less than usual	Much less than usual
6 — been managing as well as most people would in your shoes?	Better than most	About the same	Rather less well	Much less well
7 — felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
8 — been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
9 — been able to feel warmth and affection for those near to you?	Better than usual	About same as usual	Less well than usual	Much less well
10 — been finding it easy to get on with other people?	Better than usual	About same as usual	Less well than usual	Much less well
11 — spent much time chatting with people?	More time than usual	About same as usual	Less time than usual	Much less than usual
12 — felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
13 — felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable

PLEASE TURN OVER

HAVE YOU RECENTLY:

14 — felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
15 — felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
16 — been finding life a struggle all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
17 — been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
18 — been taking things hard?	Not at all	No more than usual	Rather more than usual	Much more than usual
19 — been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
20 — been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
21 — found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
22 — been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
23 — been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
24 — been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
25 — felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
26 — been feeling hopeful about your own future?	More so than usual	About same as usual	Less so than usual	Much less hopeful
27 — been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual
28 — been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
29 — felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
30 — found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual

---

Published by GL Assessment Limited
The Chiswick Centre, 414 Chiswick High Road, London W4 5TF.
GL Assessment is part of the Granada Learning Group

First published 1978.

GL assessment
the measure of potential

Code 0090000395
4(1.08)

APPENDIX 9: FACTOR STRUCTURE OF THE GENERAL HEALTH QUESTIONAIRE

Factor A – Anxiety

2 Lost much sleep over worry?
14 Felt constantly under strain?
15 Felt you couldn't overcome your difficulties?
18 Been taking things hard?
21 Found everything getting on top of you?
22 Been feeling unhappy and depressed?
23 Been losing confidence in yourself?
28 Been feeling nervous and strung-up?

Factor B – Feelings of incompetence

4 Been managing to keep yourself busy and occupied?
6 Been managing as well as most people would in your shoes?
7 Felt on the whole you were doing things well?
8 Been satisfied with the way you've carried out your task?

Factor C – Depression

24 Been thinking of yourself as a worthless person?
25 Felt that life is entirely hopeless?
26 been feeling hopeful about your own future?
29 Felt that life isn't worth living?
30 Found at times you couldn't do anything because your nerves were too bad?

Factor D – Difficulty in coping

13 Felt capable of making decisions about things?
16 Been finding life a struggle all the time?
17 Been able to enjoy your normal day-to-day activities?
19 Been getting scared or panicky for no good reason?
27 Been feeling reasonably happy, all things considered?

Factor E – Social dysfunction

5 Been getting out of the house as much as usual?
10 Been finding it easy to get on with other people?
11 Spent much time chatting with people?

APPENDIX 10: INVITATION LETTER

The Helen Durham Centre

NEUROSCIENCES DIRECTORATE
Neuro-Inflammatory Unit
Department of Neurology
University Hospital of Wales
Heath Park, Cardiff, CF14 4XW

Tel: 029 2074 8161 (Administrator)
Tel: 029 2074 5403 / 5564 (Secretaries)
Tel: 029 2074 5018 (Multidisciplinary Team)
Fax: 029 2074 4015

V2.1 26.04.11

Dear XXXX

I am collaborating with James Feeney from Cardiff University on a research project investigating different factors that may influence how well people adjust to and cope with having multiple sclerosis. Understanding more about the different factors that may influence how well people adjust to and cope with MS will help us in developing new approaches to helping people who experience difficulties with this.

We would like to invite you to take part in the research. The study involves asking people to complete some questionnaires about themselves and their symptoms, then returning them to us. It will take approximately 20-30 minutes to fill them in. I have included information about the study that James is conducting as well as the questionnaires that we would like people who agree to take part to fill in and return to us at the Helen Durham Centre (we have enclosed a stamp addressed envelope for this).

It is up to you whether you take part or not and if you do not wish to take part in the study then you do not need to do anything further. If you do not wish to take part in the study then it will not affect the care you receive from the Helen Durham Centre for Neuroinflammatory Diseases in any way.

If after reading the information you have any further questions then please feel free to contact James on the details provided.

Yours sincerely,

Dr Phil Moore
Clinical Psychologist in Neuropsychology, University Hospital for Wales
Honorary Research Fellow, Cardiff University Medical School

Cardiff and Vale NHS Trust,
University Hospital of Wales,
Heath Park, Cardiff,
CF14 4XW
Phone 029 2074 7747

NHS WALES GIG

Ymddiriedolaeth GIG Caerdydd a'r Fr
Ysbyty Athrofaol Cymru,
Parc Y Mynydd, Caerdydd
CF14 4XW
Phone 029 2074 7747

V2.1 26.04.11

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Level of symptoms, illness perception and experiential avoidance as predictors of distress in multiple sclerosis

INFORMATION SHEET

You are being invited to take part in a research study that is being carried out by Dr Phil Moore (Clinical Psychologist), Dr Andrew Vidgen (Clinical Psychologist, and James Feeney (Trainee Clinical psychologist). Before you make a decision about taking part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Take time to decide whether you wish to take part. If you have any questions or there is something further that you are unsure about, please feel free to contact James Feeney to discuss it further.

What is the research?
We are looking at some of the factors that can cause people with Multiple Sclerosis (MS) to experience psychological distress or that can affect their quality of life. In particular we are looking at factors such as coping and emotional difficulties, but also the physical difficulties people with MS may experience, and how these three ideas relate to each other. The study aims to involve individuals who are experiencing difficulties in these areas, and those who are not, so that we can develop a better understanding of the types of difficulties that different people experience, and why that might occur.

Why have I been invited to participate?
The study aims to involve as many people as possible who have been diagnosed with a neuroinflammatory condition such as MS; whether or not they have experienced any significant or noticeable cognitive, physical, social or emotional difficulties. We are hoping to contact over 200 people to take part in the study.

Do I have to take part?
No. You do not have to take part in this research if you do not want to, and you do not have to give a reason why you do not want to take part. This decision will not affect the service you receive in any way. This information sheet describes the study, however if you have any further questions about the study please contact the researcher and they will talk through any questions you have.

If you agree to take part in the study then we will ask you to sign a consent form.

What will taking part in the study involve?
If you consent to participating in the research, we will ask you to complete 5 questionnaires. The details of the questionnaires are listed below:

1) A Background Information sheet: This asks you for some information about yourself, your age, your gender, how long you have experienced symptoms of MS, when you were diagnosed with MS, and what subtype of MS you have.
2) The Expanded Disability Status Scale: this will ask you some questions about the physical symptoms you experience as a result of MS. Most of the questions ask about walking, and the distances you walk.
3) The Brief Illness Perception Questionnaire: This is a series of 10 questions asking for your views about your illness
4) The Acceptance and Action Questionnaire-II: This will ask 10 questions about how you deal with emotions and emotional problems in general
5) The General Health Questionnaire (GHQ-30): This has 30 questions that ask about your psychological wellbeing (sadness, anxiety, depression, social life, confidence) at this present time.

In total completion of the questionnaires will take between 25 and 45 minutes. You will have no obligation to complete all this information and can decide not to complete any of these, when you are undertaking these. For instance, you may wish to complete some parts of the questionnaires, but not all of it.

You may wish to have a friend or relative help you to fill out some of the questionnaires, especially if you have difficulty reading or concentrating for long periods.

If you have difficulty filling out the Background Information questionnaire, the consent form asks your permission to access your file at the Helen Durham Centre if any of this information is missing. This will be done by a member of the team, and passed onto me, so I would not access your file directly.

If you choose to complete the questionnaires we have provided you with a pre-paid addressed envelope in order for you to return the questionnaires.

What are the possible benefits of taking part?
While there will be no direct benefit to you, it is hoped the information you provide will help clinicians to gain a better understanding of what may or may not cause emotional difficulties, and thus help us support people better. There is currently little research that helps to inform our understanding of the social and emotional wellbeing of individuals with MS. Understanding more about this can then help in the management of these conditions.

What are the disadvantages of taking part?
It is possible that some of the questionnaires may make you feel uncomfortable or distressed. However if at any point during the completion of

If you agree to take part in the study then we will ask you to sign a consent form.

What will taking part in the study involve?
If you consent to participating in the research, we will ask you to complete 5 questionnaires. The details of the questionnaires are listed below:

1) A Background Information sheet: This asks you for some information about yourself, your age, your gender, how long you have experienced symptoms of MS, when you were diagnosed with MS, and what subtype of MS you have.
2) The Expanded Disability Status Scale: this will ask you some questions about the physical symptoms you experience as a result of MS. Most of the questions ask about walking, and the distances you walk.
3) The Brief Illness Perception Questionnaire: This is a series of 10 questions asking for your views about your illness
4) The Acceptance and Action Questionnaire-II: This will ask 10 questions about how you deal with emotions and emotional problems in general
5) The General Health Questionnaire (GHQ-30): This has 30 questions that ask about your psychological wellbeing (sadness, anxiety, depression, social life, confidence) at this present time.

In total completion of the questionnaires will take between 25 and 45 minutes. You will have no obligation to complete all this information and can decide not to complete any of these, when you are undertaking these. For instance, you may wish to complete some parts of the questionnaires, but not all of it.

You may wish to have a friend or relative help you to fill out some of the questionnaires, especially if you have difficulty reading or concentrating for long periods.

If you have difficulty filling out the Background Information questionnaire, the consent form asks your permission to access your file at the Helen Durham Centre if any of this information is missing. This will be done by a member of the team, and passed onto me, so I would not access your file directly.

If you choose to complete the questionnaires we have provided you with a pre-paid addressed envelope in order for you to return the questionnaires.

What are the possible benefits of taking part?
While there will be no direct benefit to you, it is hoped the information you provide will help clinicians to gain a better understanding of what may or may not cause emotional difficulties, and thus help us support people better. There is currently little research that helps to inform our understanding of the social and emotional wellbeing of individuals with MS. Understanding more about this can then help in the management of these conditions.

What are the disadvantages of taking part?
It is possible that some of the questionnaires may make you feel uncomfortable or distressed. However if at any point during the completion of

All research in the NHS is looked at by an independent group of people, called a research ethics committee, whose job it is to protect your safety, rights and wellbeing and dignity. This study has been reviewed and given favourable opinion by the local research ethics committee.

Finding out more before deciding
Please do ask any questions that you have. I can be contacted by e-mail, letter or telephone. I am very happy to discuss the study with you further, and answer any questions you have.

James Feeney (in collaboration with Dr Phil Moore)
Doctoral Programme in Clinical Psychology
1st floor, Archway House,
77 Ty Glas Avenue, Llanishen,
Cardiff,
CF145DX

Telephone: 02920 206464
E-mail: James.Feeney@wales.nhs.uk

The Helen Durham Centre
Neuro-Inflamatory Unit
Department of Neurology
University Hospital of Wales
Heath Park
Cardiff
Cf14 4XW

Telephone: 02920 74 5018

1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff CF14 5DX
Ty Archway, 77 Ty Glas Avenue, Llanishen, Caerdydd CF14 5DX
Tel/Ffon 029 2020 6464 Fax/Ffacs 029 2019 0106
Email/Ebost deborah.robinson2@wales.nhs.uk

APPENDIX 12: CONSENT FORM

V1.1 18/03/11

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

CONSENT FORM:

Title of Research Study: **Level of symptoms, illness perception and experiential avoidance as predictors of distress in multiple sclerosis**

Principle Researcher: **James Feeney**

Participant name:.....

Please put your initials in the box if you consent--

1) I confirm that I have read and understood the information sheet for the above study or that the study has been explained to me ☐

2) I understand that participation is voluntary and that I am free to decline participation in the study, without giving any reason and without my care being affected in any way ☐

3) I understand that the data collected in this study will be used anonymously by the researcher as part of the research study, and that I will not be identified in any report of the research project ☐

4) I understand that my file will be accessed at the Helen Durham Centre to access basic demographic information, such as my age, gender, year diagnosed with Multiple Sclerosis (MS), and type of MS, if I have not provided this ☐

5) I agree to take part in the study ☐

Please turn over

V1.1

If you agree with all the above items, please sign, date and print your name in the space provided below.

Name of participant ..... Date..... Sign.....

Name of researcher ..... Date..... Sign.....

1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff CF14 5DX
Ty Archway, 77 Ty Glas Avenue, Llanishen, Caerdydd CF14 5DX

Tel/Ffon 029 2020 6464 Fax/Ffacs 029 2019 0106
Email/Ebost deborah.robinson2@wales.nhs.uk

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

24 May 2011

Mr James Feeney
Trainee Clinical Psychologist
Cardiff and Vale University Health Board
77 Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

Dear Mr Feeney

Project ID : 11/MEH/5067 : Level Of Symptoms, Illness Perception And Experiential Avoidance As Predictors Of Distress In Multiple Sclerosis

Further to recent correspondence regarding the above project, I am now happy to confirm receipt of:

- Evidence of favourable opinion from the relevant NHS Research Ethics Committee
- Revised documentation as required by the REC in order to obtain favourable opinion
- Evidence of appropriate informed consent training for the CI

The following amended documentation is approved for use with this study:

Document	Version	Date
Invitation Letter	2.1	26/04/11
Participant Information Sheet	2.1	26/04/11

Please accept this letter as confirmation of sponsorship by Cardiff and Vale UHB and permission for the project to begin.

May I take this opportunity to wish you success with the project, and to remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D Office if any external or additional funding is awarded for this project in the future
- Inform the R&D Office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D Office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the Data Protection Act 1998
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the Human Tissue Act, 2004 (for further information please contact Sharon Orton, HTA Coordinator OrtonS@cf.ac.uk).

If you require any further information or assistance, please do not hesitate to contact staff in the R&D Office.

Yours sincerely,

Professor Jonathan I Bisson
Cardiff and Vale University Local Health Board R&D Director

CC R&D Lead, Prof Nick Craddock

APPENDIX 14: AMMENDED R&D DOCUMENTS:

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

17 June 2011

Mr James Feeney
Trainee Clinical Psychologist
Cardiff and Vale University Health Board
77 Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

Dear Mr Feeney

Project ID : 11/MEH/5067 : Level Of Symptoms, Illness Perception And Experiential Avoidance As Predictors Of Distress In Multiple Sclerosis

Amendment Date: 16 June 2011

Thank you for notifying the Cardiff and Vale Research Review Service (CaRRS) of this non-substantial amendment.

The documents reviewed were:-

Document	Version	Date
Expanded disability status scale: self report	1.2	16/06/11
Brief illness perception questionnaire	1.1	15/06/11

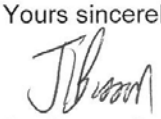
I can confirm that you may continue with this study accordingly.

Non-substantial amendments do not require approval from a Research Ethics Committee, however please ensure that the appropriate Research Ethics Committee has a copy of this letter for information.

May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Inform the R&D Office if any external or additional funding is awarded for this project in the future.
- Inform the R&D Office of any further amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start / end dates.
- Complete any documentation sent to you by the R&D Office regarding this project.
- Adhere to the protocol as approved by the Research Ethics Committee.
- Ensure the research complies with the Data Protection Act 1998.

Yours sincerely,



Professor Jonathan I Bisson
Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC R&D Lead Prof Nick Craddock

APPENDIX 15: ETHICAL APPROVAL:

NISCHR

Uned Cydlynu Caniatâd | PCU | Permissions Co-ordinating Unit

South East Wales Research Ethics Committee
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6823

South East Wales Research Ethics Committee - Panel D

Telephone: 02920 376822/6823

12 May 2011

Mr James Feeney
Trainee Clinical Psychologist
Cardiff and Vale UHB
Archway House
77 Ty Glas Avenue
Llanishen
CF145DX

Dear Mr Feeney

Study title: **Level of symptoms, illness perception and Experiential Avoidance as predictors of distress in multiple sclerosis**

REC reference: **11/WA/0082**

Thank you for your letter of 27 April 2011, 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, Dr K Craig.

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], subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see _3Conditions of the favourable opinion_4 below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission (_3R&D approval_4) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites (_3participant identification centre_4), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Investigator CV	P Moore	18 March 2011
Investigator CV	A Vidgen	18 March 2011
Investigator CV	J Feeney	18 March 2011
Letter of invitation to participant	2.1	26 April 2011
Participant Consent Form	1.1	18 March 2011
Participant Information Sheet	2.1	26 April 2011
Protocol	1.1	18 March 2011
Questionnaire: Background Information Questionnaire	1.1	18 March 2011
Questionnaire: The Expanded Disability Status Scale: Self Report	1.1	18 March 2011
Questionnaire: The Brief Illness Perception Questionnaire		

Questionnaire: General Health Questionnaire		
Questionnaire: AAQ-II	1.1	18 March 2011
REC application	IRAS 3.1	11 February 2011
Referees or other scientific critique report	CaRRS	25 February 2011
Response to Request for Further Information	J Feeney	27 April 2011

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.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

Notifying substantial amendments
Adding new sites and investigators
Progress and safety reports
Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/WA/0082	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

pp.

Dr K J Craig
Chair

Email: jagit.sidhu@bsc.wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: *R&D Office for Cardiff and Vale ULHB*

APPENDIX 16: K-S STATISTIC AND HISTOGRAMS

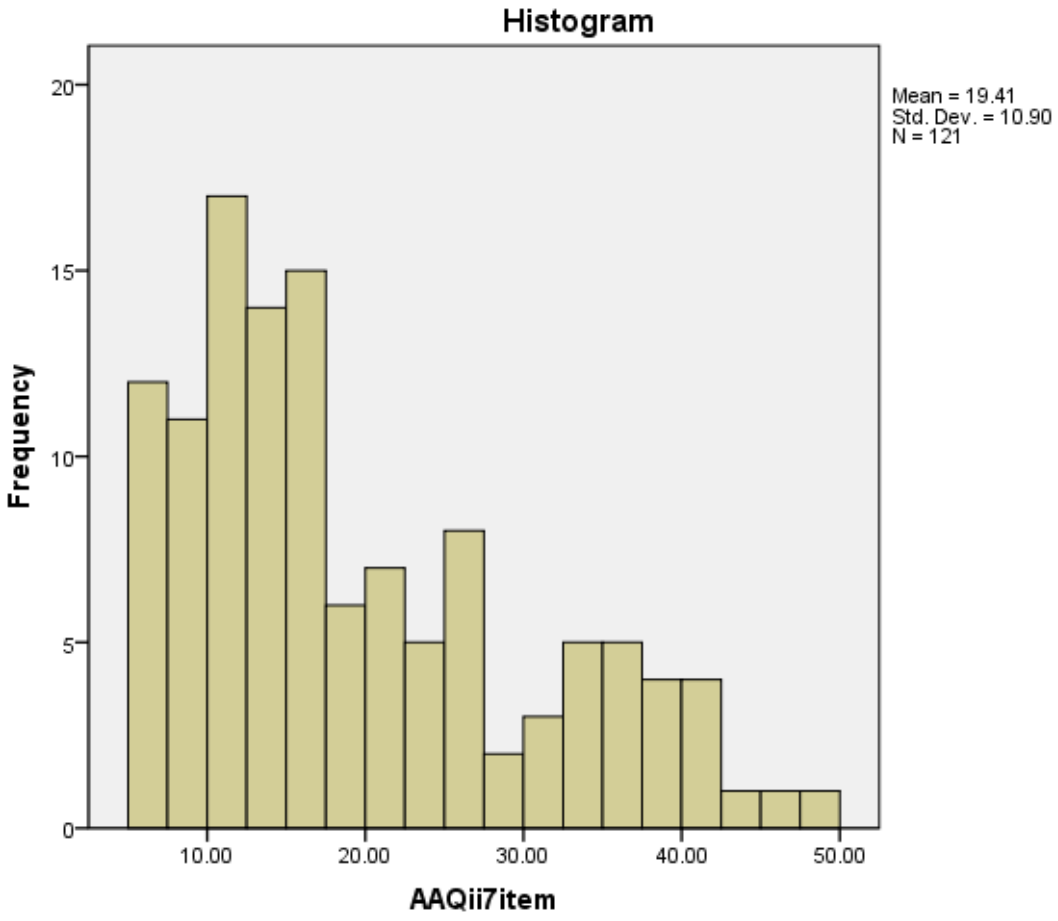
Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
EDSS	.240	118	.000	.852	118	.000
AAQii7item	.159	118	.000	.897	118	.000
BIPQtotal	.065	118	.200*	.985	118	.215
GHQtotal	.126	118	.000	.897	118	.000
Depression	.218	118	.000	.845	118	.000

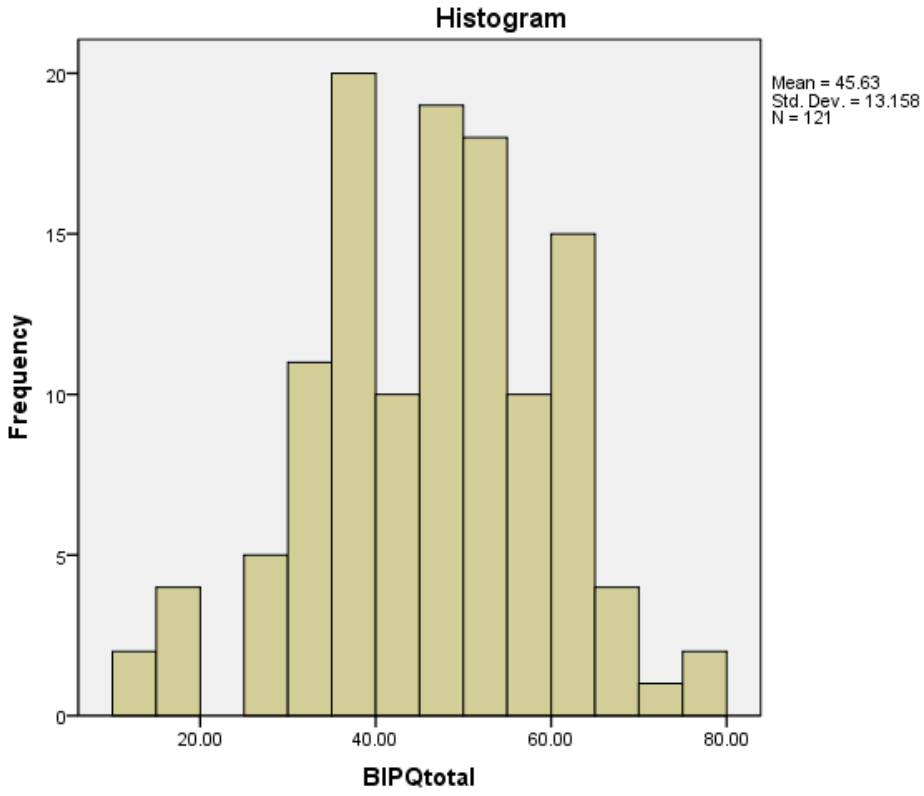
a. Lilliefors Significance Correction

*. This is a lower bound of the true significance.

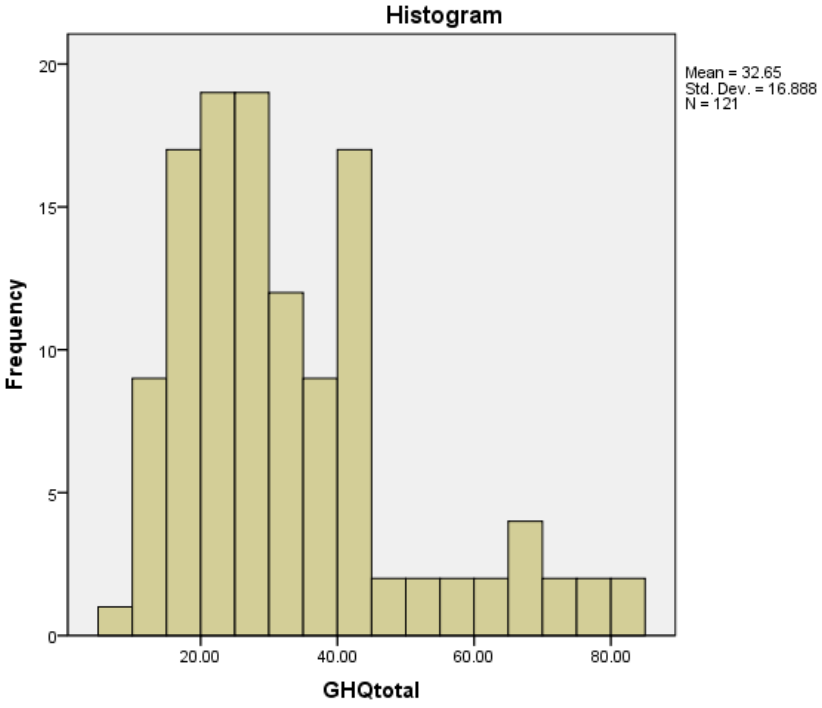
AAQii7item



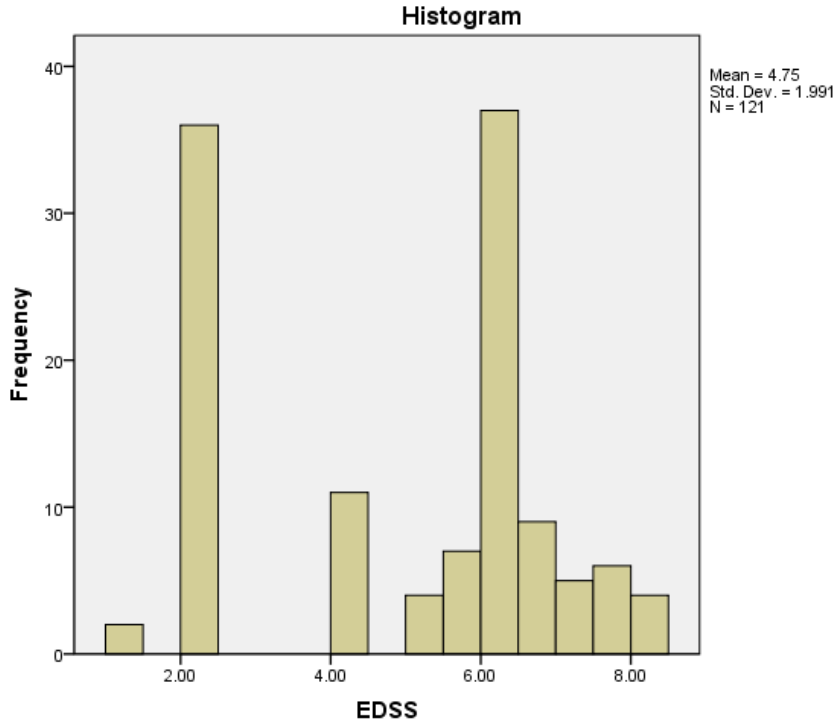
BIPQtotal



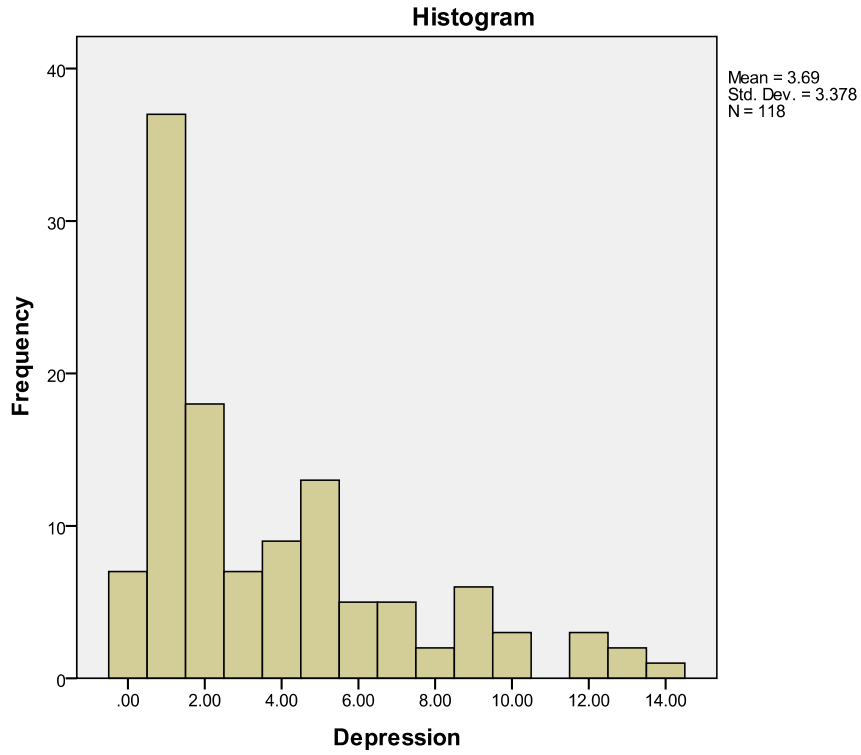
GHQtotal



EDSS



Depression subscale:



APPENDIX 17: SKEWNESS AND KURTOSIS STATISTICS

Statistics

		AAQii7item	BIPQtotal	GHQtotal	EDSS	Depression
N	Valid	121	121	121	121	118
	Missing	0	0	0	0	3
Mean		19.4120	45.6313	32.6550	4.7545	3.6949
Std. Error of Mean		.99095	1.19616	1.53531	.18097	.31096
Median		16.0000	46.0000	29.0000	6.0000	2.0000
Mode		7.00	36.00	14.00	6.00	1.00
Std. Deviation		10.90042	13.15775	16.88836	1.99070	3.37793
Variance		118.819	173.126	285.217	3.963	11.410
Skewness		.876	-.244	1.169	-.310	1.203
Std. Error of Skewness		.220	.220	.220	.220	.223
Kurtosis		-.256	-.151	.956	-1.357	.716
Std. Error of Kurtosis		.437	.437	.437	.437	.442
Range		42.00	64.00	77.23	7.00	14.00
Minimum		7.00	11.00	7.15	1.00	.00
Maximum		49.00	75.00	84.38	8.00	14.00
Percentiles	25	10.5000	36.0000	20.0000	2.1800	1.0000
	50	16.0000	46.0000	29.0000	6.0000	2.0000
	75	26.0000	55.0000	40.5000	6.0000	5.0000

APPENDIX 18: 1ST SIMULTANEOUS REGRESSION: EDSS, BIPQ, AAQ7, ONTO GHQ-30

Descriptive Statistics

	Mean	Std. Deviation	N
GHQtotallog	1.4773	.20775	121
EDSSlog	.7325	.16594	121
BIPQtotal	45.6313	13.15775	121
AAQ7log	1.2510	.22656	121

Variables Entered/Removed[b]

Model	Variables Entered	Variables Removed	Method
1	AAQ7log, EDSSlog, BIPQtotal	.	Enter

a. All requested variables entered.

b. Dependent Variable: GHQtotallog

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.788[a]	.621	.611	.12950	.621	63.938	3	117	.000	1.667

a. Predictors: (Constant), AAQ7log, EDSSlog, BIPQtotal

b. Dependent Variable: GHQtotallog

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3.217	3	1.072	63.938	.000[a]
	Residual	1.962	117	.017		
	Total	5.179	120			

a. Predictors: (Constant), AAQ7log, EDSSlog, BIPQtotal

b. Dependent Variable: GHQtotallog

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	.701	.080		8.745	.000	.542	.859					
	EDSSlog	-.110	.088	-.088	-1.252	.213	-.284	.064	.287	-.115	-.071	.658	1.519
	BIPQtotal	.008	.001	.529	6.557	.000	.006	.011	.694	.518	.373	.498	2.009
	AAQ7log	.381	.062	.415	6.157	.000	.258	.503	.673	.495	.350	.712	1.404

a. Dependent Variable: GHQtotallog

Collinearity Diagnostics[a]

Model	Dimension	Eigenvalue	Condition Index	Variance Proportions			
				(Constant)	EDSSlog	BIPQtotal	AAQ7log
1	1	3.916	1.000	.00	.00	.00	.00
	2	.042	9.656	.16	.04	.44	.07
	3	.032	11.121	.02	.57	.19	.18
	4	.011	19.081	.82	.39	.37	.74

a. Dependent Variable: GHQtotallog

Casewise Diagnostics[a]

Case Number	Std. Residual	GHQtotallog	Predicted Value	Residual
57	3.164	1.73	1.3226	.40977

a. Dependent Variable: GHQtotallog

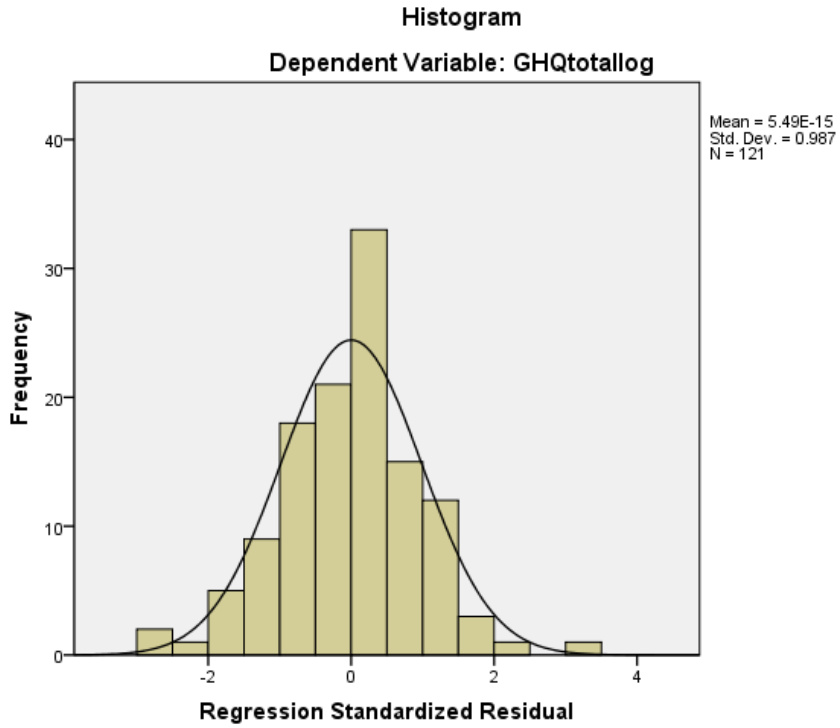
Residuals Statistics[a]

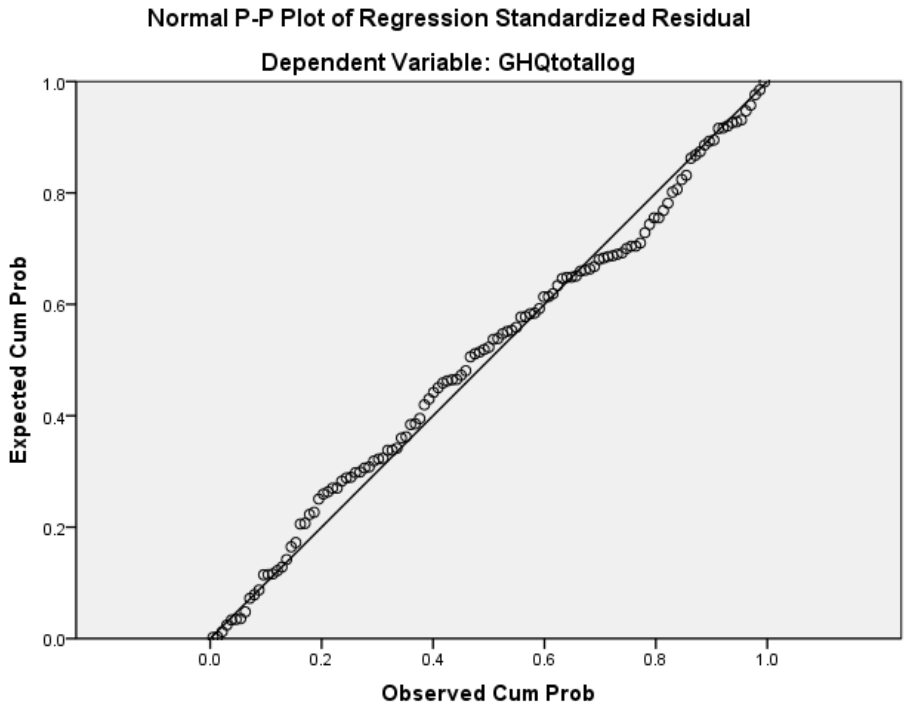
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	1.1005	1.8774	1.4773	.16373	121
Std. Predicted Value	-2.302	2.443	.000	1.000	121
Standard Error of Predicted Value	.012	.049	.023	.006	121
Adjusted Predicted Value	1.0879	1.8850	1.4773	.16391	121
Residual	-.37132	.40977	.00000	.12787	121
Std. Residual	-2.867	3.164	.000	.987	121
Stud. Residual	-2.917	3.228	.000	1.005	121

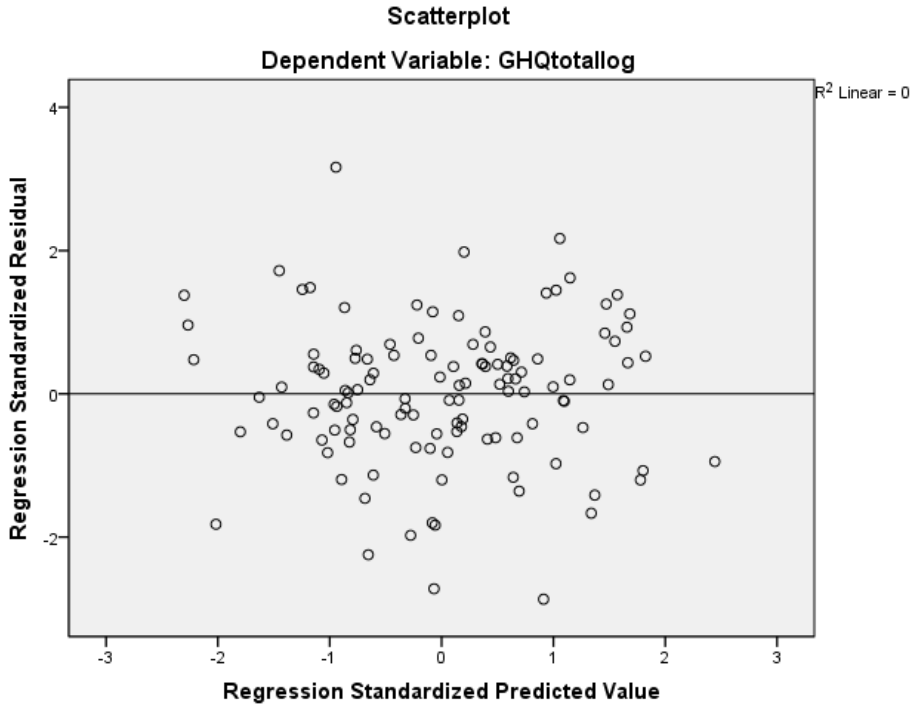
Deleted Residual	-.38433	.42644	.00000	.13249	121
Stud. Deleted Residual	-3.016	3.367	-.001	1.018	121
Mahal. Distance	.093	15.938	2.975	2.269	121
Cook's Distance	.000	.106	.009	.017	121
Centered Leverage Value	.001	.133	.025	.019	121

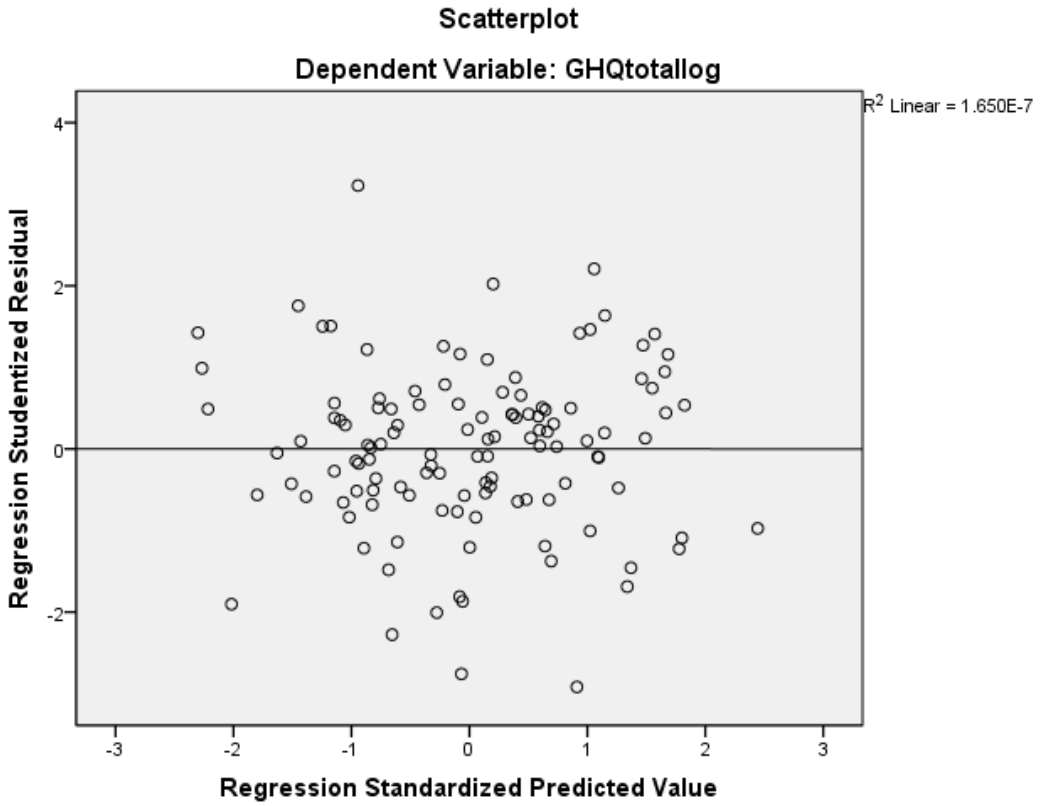
a. Dependent Variable: GHQtotallog

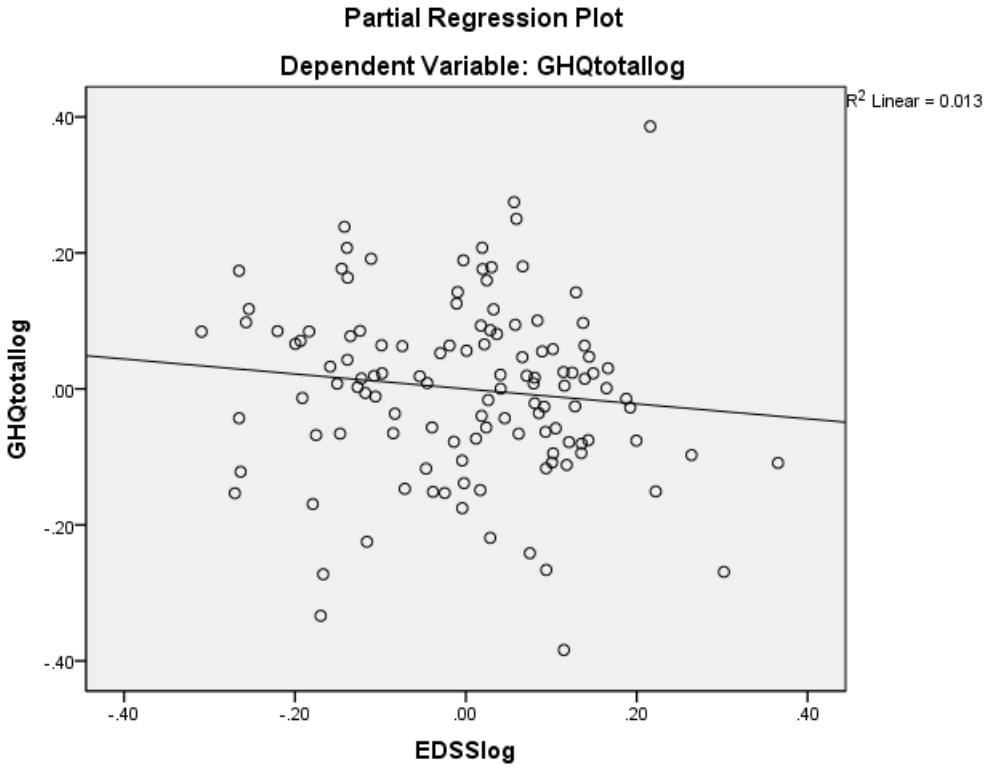
Charts

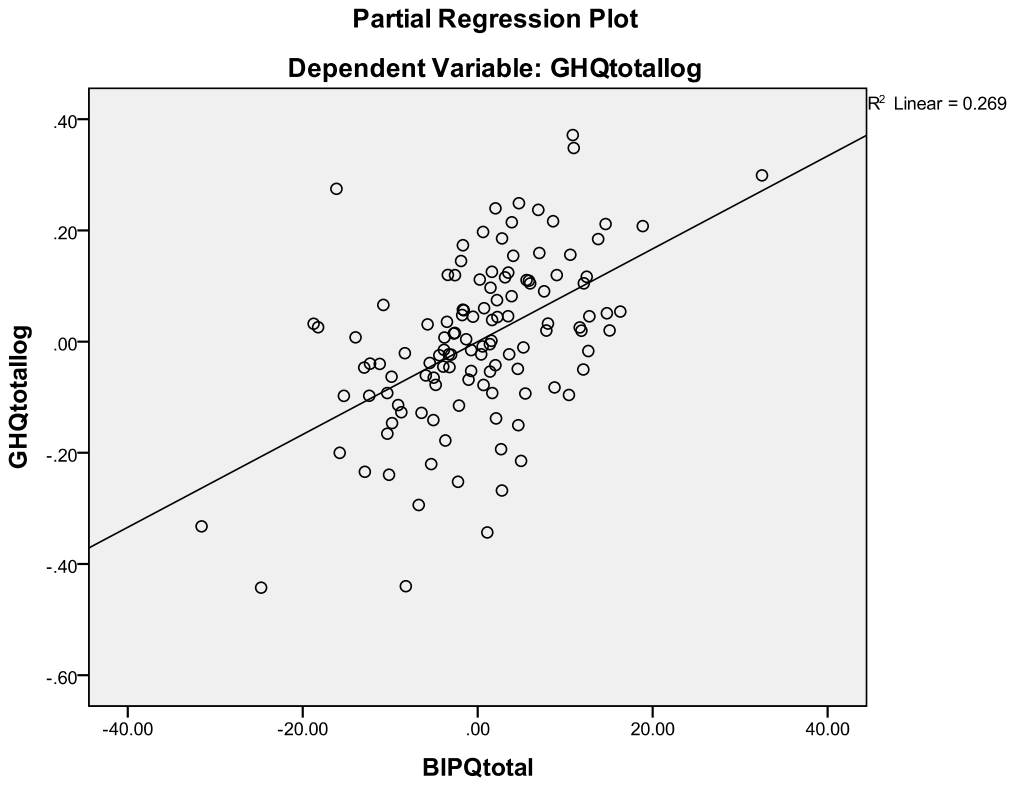


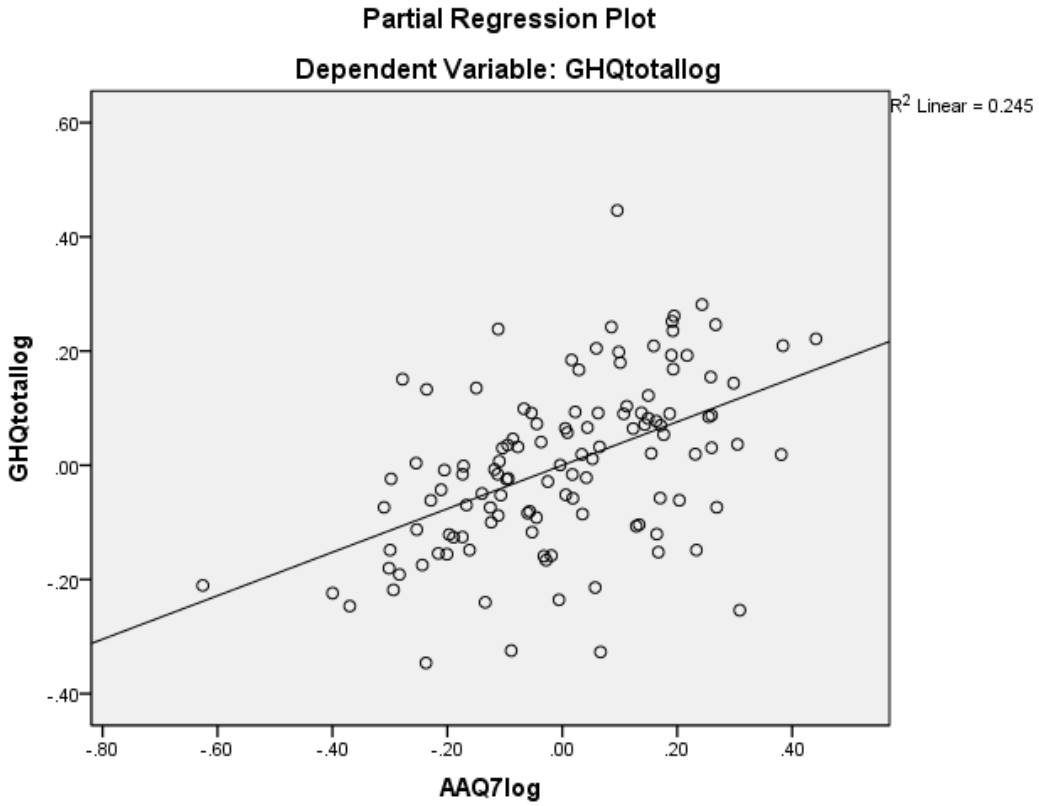

Normal P-P Plot of Regression Standardized Residual
Dependent Variable: GHQtotallog
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0


Scatterplot
Dependent Variable: GHQtotallog
R² Linear = 0
Regression Standardized Residual
Regression Standardized Predicted Value
4
2
0
-2
-3
-2
-1
0
1
2
3


Scatterplot
Dependent Variable: GHQtotallog
R² Linear = 1.650E-7
Regression Studentized Residual
Regression Standardized Predicted Value
4
2
0
-2
-3
-2
-1
0
1
2
3


Partial Regression Plot
Dependent Variable: GHQtotallog
R² Linear = 0.013
GHQtotallog
EDSSlog
.40
.20
.00
-.20
-.40
-.40
-.20
.00
.20
.40


Partial Regression Plot
Dependent Variable: GHQtotallog
R² Linear = 0.269
GHQtotallog
.40
.20
.00
-.20
-.40
-.60
-40.00
-20.00
.00
20.00
40.00
BIPQtotal


Partial Regression Plot
Dependent Variable: GHQtotallog
R² Linear = 0.245
GHQtotallog
.60
.40
.20
.00
-.20
-.40
-.80
-.60
-.40
-.20
.00
.20
.40
AAQ7log

APPENDIX 19: REGRESSION: EDSS AND BIPQ ONTO AAQ7-II

Descriptive Statistics

	Mean	Std. Deviation	N
AAQ7log	1.2510	.22656	121
EDSSlog	.7325	.16594	121
BIPQtotal	45.6313	13.15775	121

Correlations

		AAQ7log	EDSSlog	BIPQtotal
Pearson Correlation	AAQ7log	1.000	.179	.518
	EDSSlog	.179	1.000	.569
	BIPQtotal	.518	.569	1.000
Sig. (1-tailed)	AAQ7log	.	.025	.000
	EDSSlog	.025	.	.000
	BIPQtotal	.000	.000	.
N	AAQ7log	121	121	121
	EDSSlog	121	121	121
	BIPQtotal	121	121	121

Variables Entered/Removed[b]

Model	Variables Entered	Variables Removed	Method
1	BIPQtotal, EDSSlog	.	Enter

a. All requested variables entered.

b. Dependent Variable: AAQ7log

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.536[a]	.288	.276	.19282	.288	23.835	2	118	.000	2.050

a. Predictors: (Constant), BIPQtotal, EDSSlog

b. Dependent Variable: AAQ7log

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1.772	2	.886	23.835	.000[a]
	Residual	4.387	118	.037		
	Total	6.159	120			

a. Predictors: (Constant), BIPQtotal, EDSSlog

b. Dependent Variable: AAQ7log

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	.939	.082		11.414	.000	.776	1.102					
	EDSSlog	-.233	.129	-.171	-1.807	.073	-.488	.022	.179	-.164	-.140	.676	1.478
	BIPQtotal	.011	.002	.615	6.509	.000	.007	.014	.518	.514	.506	.676	1.478

a. Dependent Variable: AAQ7log

Collinearity Diagnostics[a]

Model	Dimension	Eigenvalue	Condition Index	Variance Proportions		
				(Constant)	EDSSlog	BIPQtotal
1	1	2.939	1.000	.01	.00	.01
	2	.039	8.675	.50	.01	.74
	3	.022	11.628	.49	.99	.25

a. Dependent Variable: AAQ7log

Casewise Diagnostics[a]

Case Number	Std. Residual	AAQ7log	Predicted Value	Residual
1	-3.245	.90	1.5287	-.62563

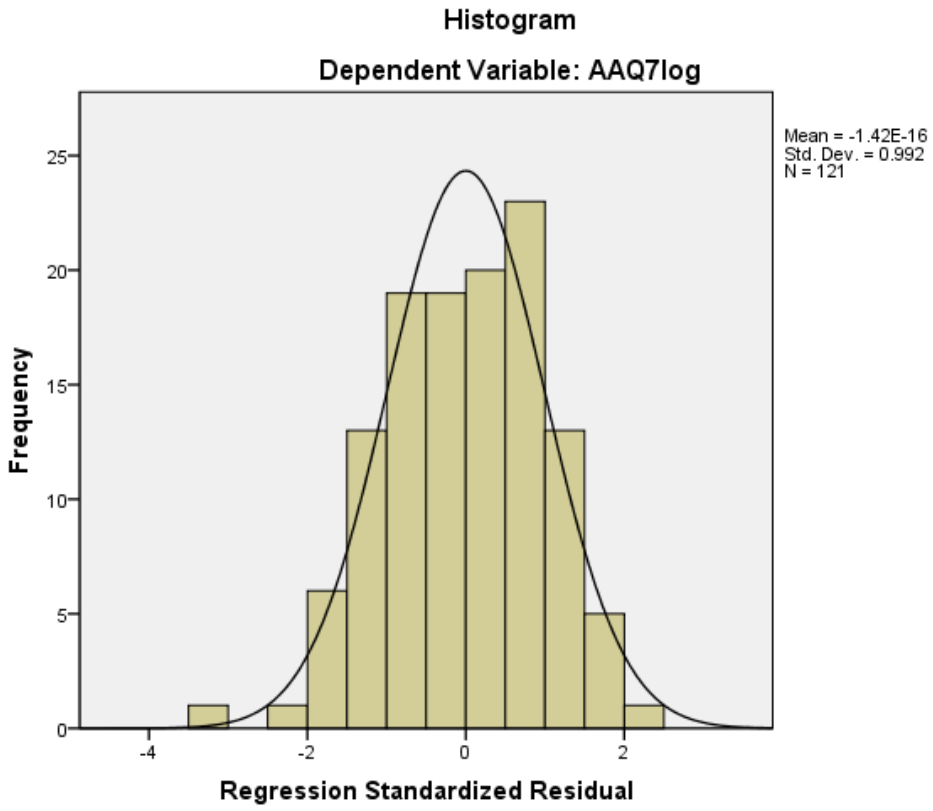
a. Dependent Variable: AAQ7log

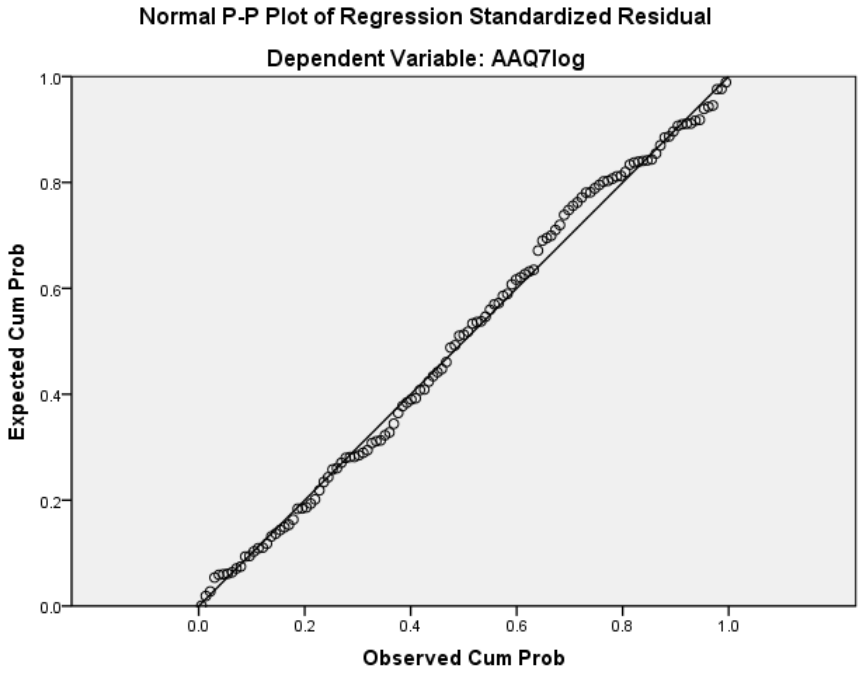
Residuals Statistics[a]

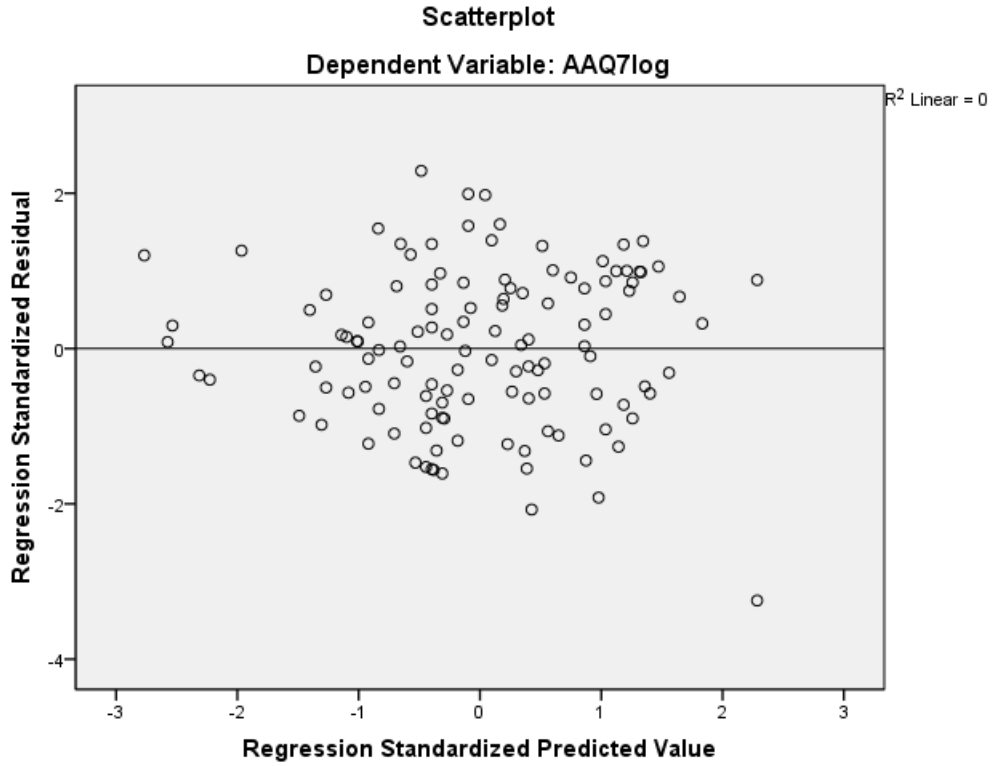
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	.9147	1.5287	1.2510	.12153	121
Std. Predicted Value	-2.767	2.285	.000	1.000	121
Standard Error of Predicted Value	.018	.062	.029	.008	121
Adjusted Predicted Value	.8885	1.5629	1.2510	.12241	121
Residual	-.62563	.44134	.00000	.19120	121
Std. Residual	-3.245	2.289	.000	.992	121
Stud. Residual	-3.332	2.317	.000	1.005	121
Deleted Residual	-.65984	.45233	.00005	.19637	121
Stud. Deleted Residual	-3.486	2.362	-.001	1.013	121
Mahal. Distance	.041	11.233	1.983	1.740	121
Cook's Distance	.000	.202	.009	.020	121
Centered Leverage Value	.000	.094	.017	.014	121

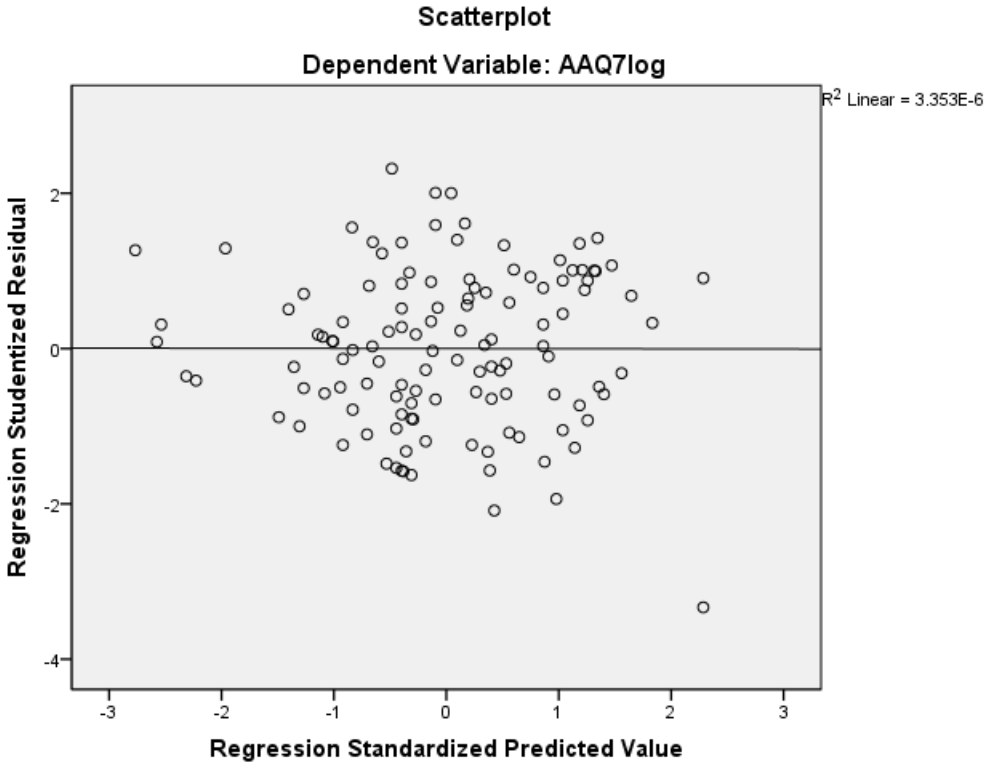
a. Dependent Variable: AAQ7log

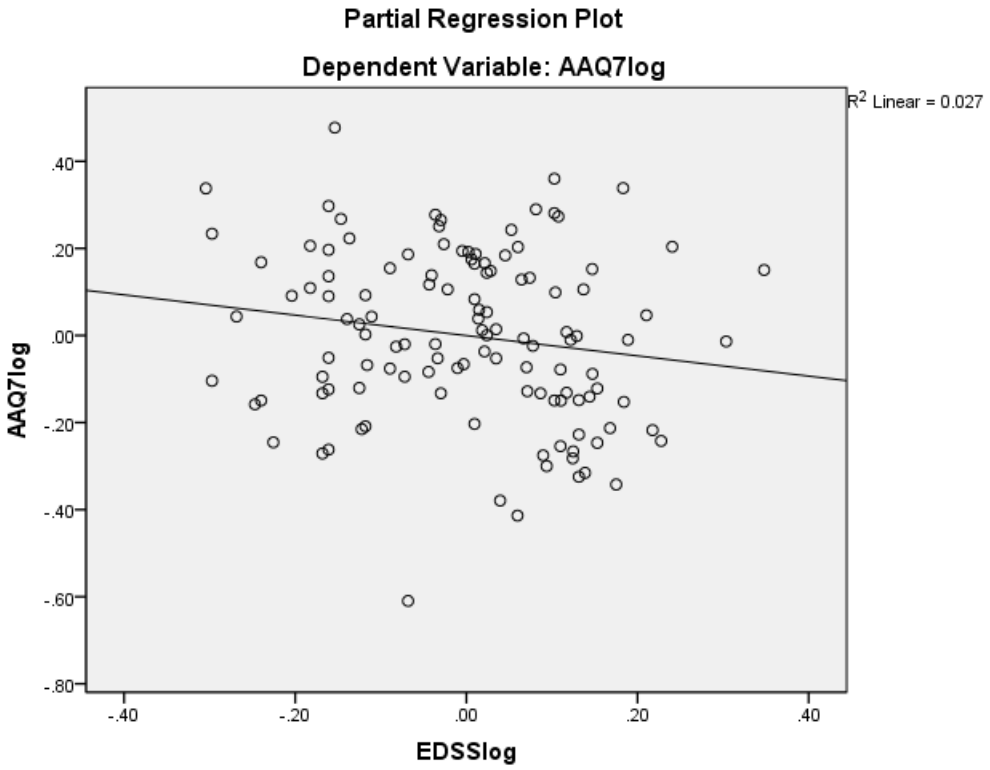
Charts

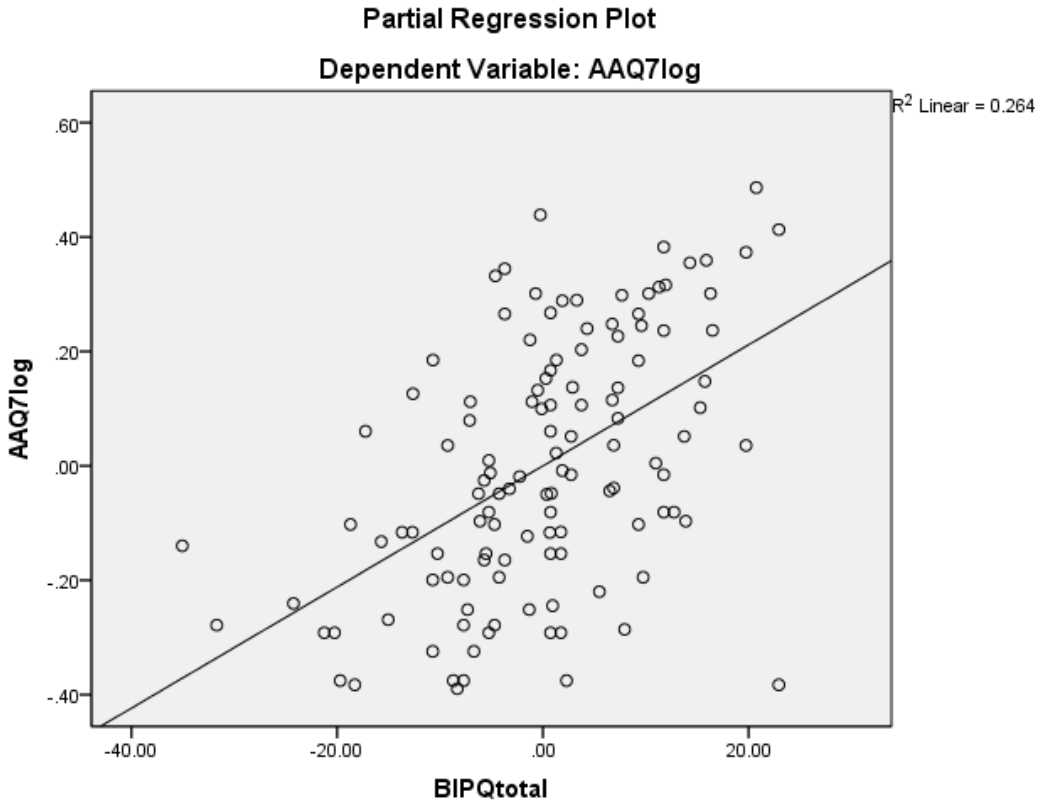



Normal P-P Plot of Regression Standardized Residual
Dependent Variable: AAQ7log
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0


Scatterplot
Dependent Variable: AAQ7log
R2 Linear = 0
Regression Standardized Residual
Regression Standardized Predicted Value
2
0
-2
-4
-3
-2
-1
0
1
2
3


Scatterplot
Dependent Variable: AAQ7log
R² Linear = 3.353E-6
Regression Studentized Residual
Regression Standardized Predicted Value
2
0
-2
-4
-3
-2
-1
0
1
2
3


Partial Regression Plot
Dependent Variable: AAQ7log
R² Linear = 0.027
AAQ7log
EDSSlog
.40
.20
.00
-.20
-.40
-.60
-.80
-.40
-.20
.00
.20
.40


Partial Regression Plot
Dependent Variable: AAQ7log
R2 Linear = 0.264
AAQ7log
.60
.40
.20
.00
-.20
-.40
-40.00
-20.00
.00
20.00
BIPQtotal

APPENDIX 20: REGRESSION FOR DEPRESSION MODEL

Correlations

		depression log	EDSSlog	AAQ7log	BIPQtotal
Pearson Correlation	depression log	1.000	.238	.645	.595
	EDSSlog	.238	1.000	.149	.558
	AAQ7log	.645	.149	1.000	.502
	BIPQtotal	.595	.558	.502	1.000
Sig. (1-tailed)	depression log	.	.005	.000	.000
	EDSSlog	.005	.	.054	.000
	AAQ7log	.000	.054	.	.000
	BIPQtotal	.000	.000	.000	.
N	depression log	118	118	118	118
	EDSSlog	118	118	118	118
	AAQ7log	118	118	118	118
	BIPQtotal	118	118	118	118

Variables Entered/Removed[b]

Model	Variables Entered	Variables Removed	Method
1	BIPQtotal, AAQ7log, EDSSlog	.	Enter

a. All requested variables entered.

b. Dependent Variable: depression log

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.719[a]	.517	.504	.21351	.517	40.600	3	114	.000	1.681

a. Predictors: (Constant), BIPQtotal, AAQ7log, EDSSlog

b. Dependent Variable: depression log

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	5.552	3	1.851	40.600	.000[a]
	Residual	5.197	114	.046		
	Total	10.749	117			

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	5.552	3	1.851	40.600	.000[a]
	Residual	5.197	114	.046		
	Total	10.749	117			

a. Predictors: (Constant), BIPQtotal, AAQ7log, EDSSlog

b. Dependent Variable: depression log

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	-.556	.136		-4.086	.000					
	EDSSlog	-.091	.147	-.050	-.620	.536	.238	-.058	-.040	.666	1.502
	AAQ7log	.620	.104	.455	5.944	.000	.645	.486	.387	.724	1.382
	BIPQtotal	.009	.002	.394	4.323	.000	.595	.375	.282	.510	1.962

a. Dependent Variable: depression log

Collinearity Diagnostics[a]

Model	Dimension	Eigenvalue	Condition Index	Variance Proportions			
				(Constant)	EDSSlog	AAQ7log	BIPQtotal
1	1	3.915	1.000	.00	.00	.00	.00
	2	.042	9.683	.15	.06	.09	.41
	3	.032	11.025	.02	.54	.15	.24
	4	.011	19.265	.83	.39	.75	.35

a. Dependent Variable: depression log

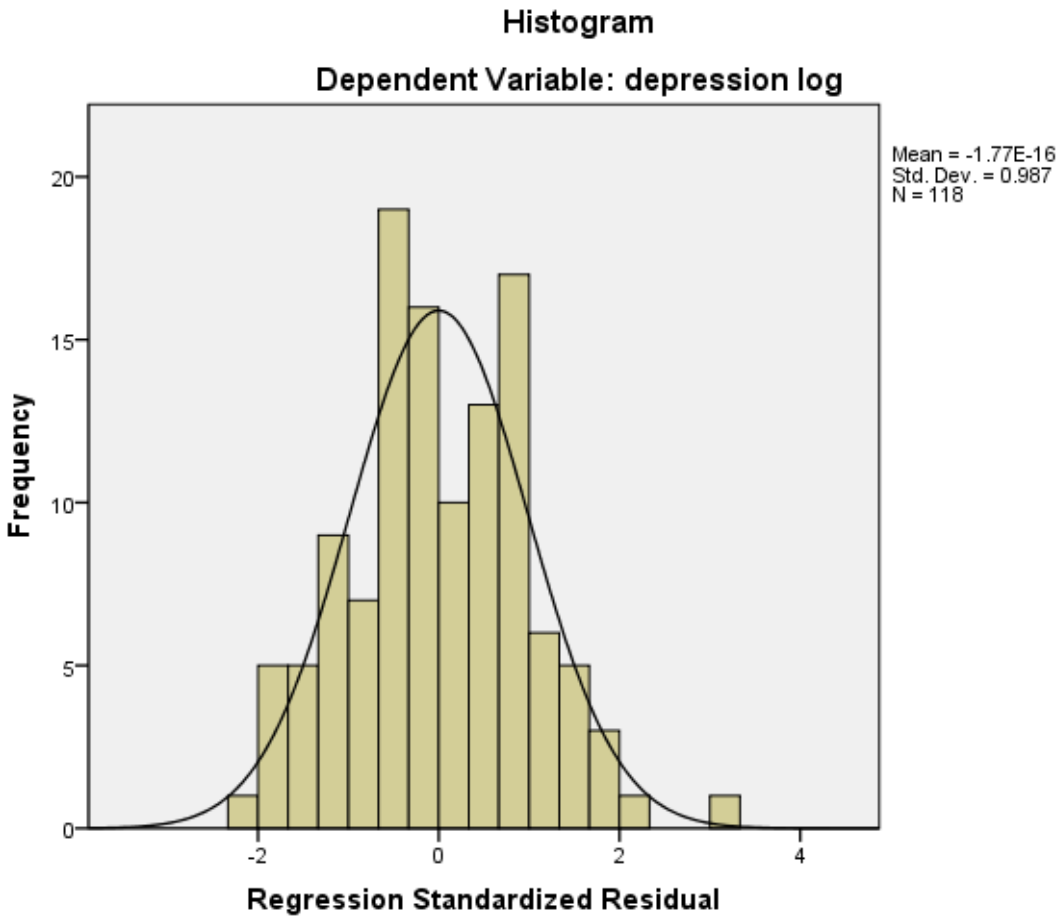
Residuals Statistics[a]

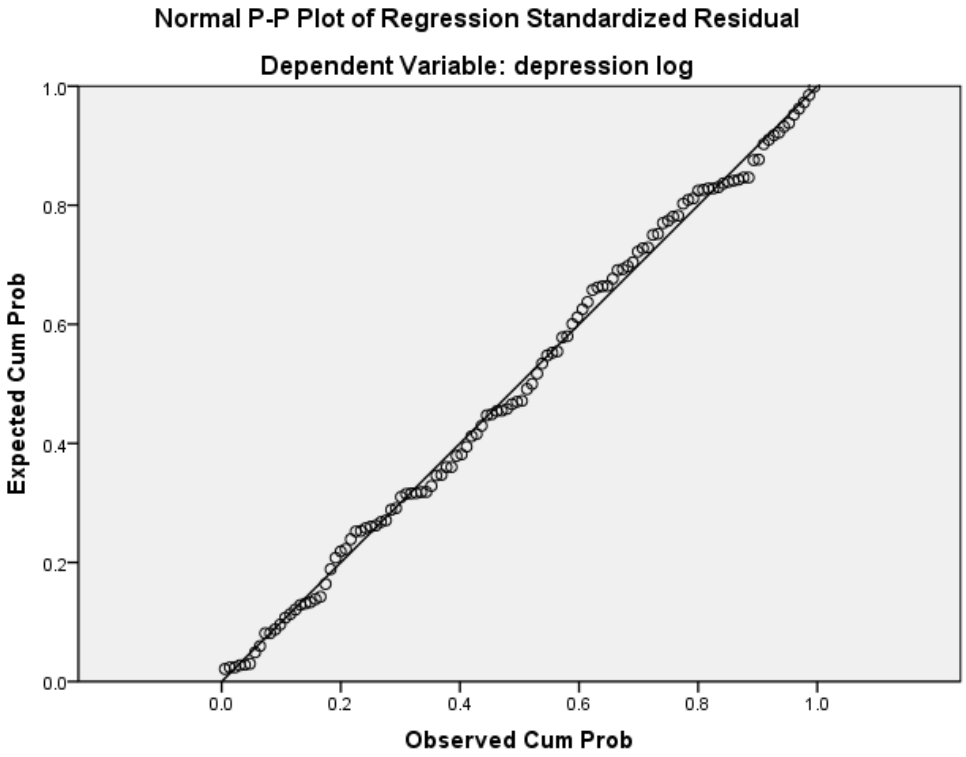
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	.0877	.9822	.5672	.21784	118
Std. Predicted Value	-2.201	1.905	.000	1.000	118
Standard Error of Predicted Value	.020	.082	.038	.010	118
Adjusted Predicted Value	.0742	.9879	.5672	.21808	118
Residual	-.43386	.64870	.00000	.21075	118
Std. Residual	-2.032	3.038	.000	.987	118
Stud. Residual	-2.061	3.101	.000	1.004	118

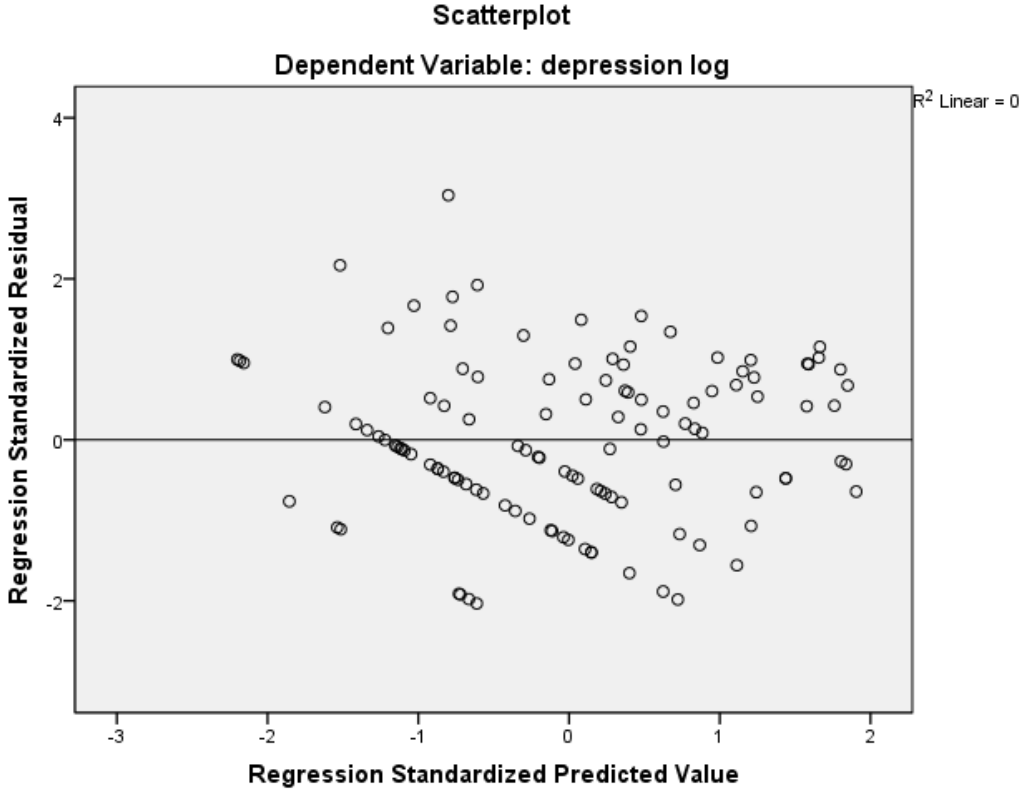
Deleted Residual	-.44644	.67590	-.00002	.21796	118
Stud. Deleted Residual	-2.092	3.227	.000	1.012	118
Mahal. Distance	.086	16.171	2.975	2.279	118
Cook's Distance	.000	.101	.009	.013	118
Centered Leverage Value	.001	.138	.025	.019	118

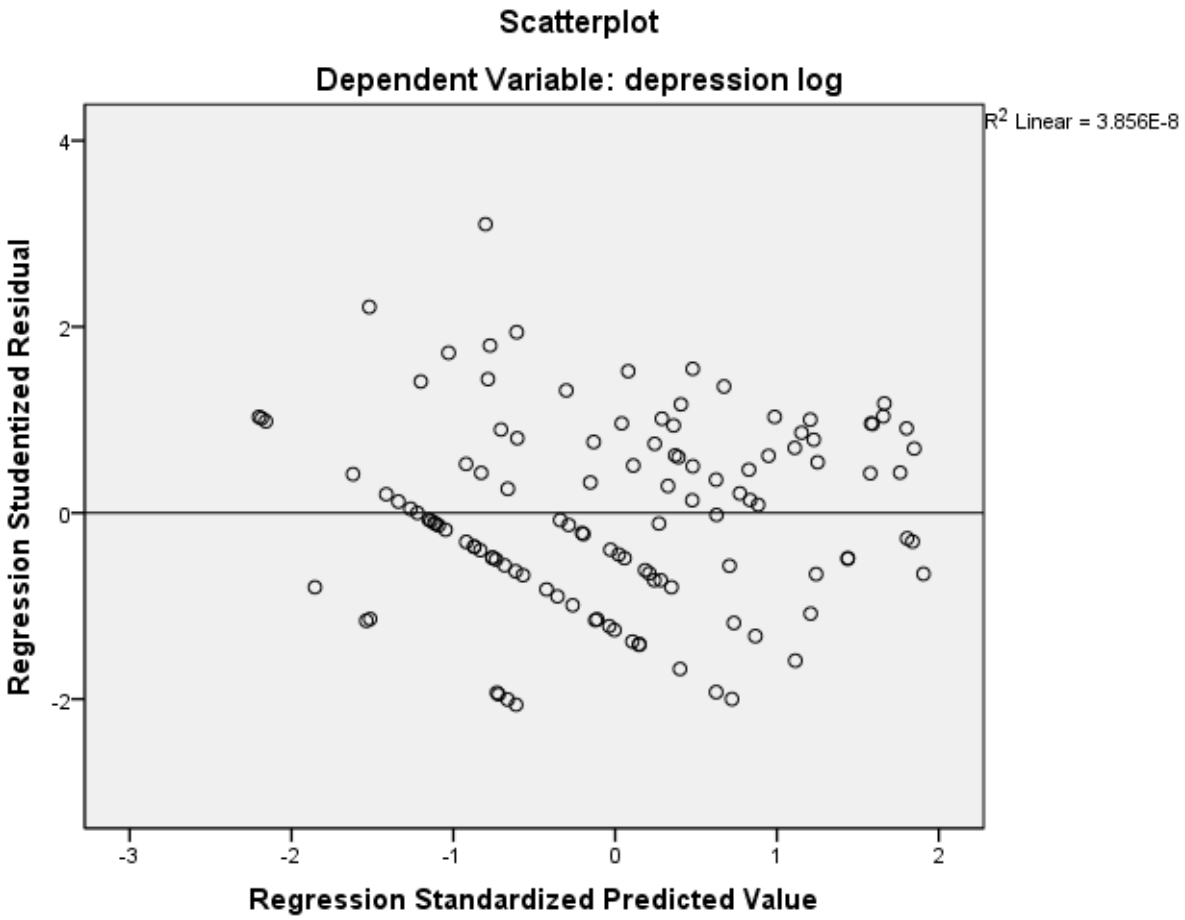
a. Dependent Variable: depression log

Charts




Normal P-P Plot of Regression Standardized Residual
Dependent Variable: depression log
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0


Scatterplot
Dependent Variable: depression log
R2 Linear = 0
Regression Standardized Residual
Regression Standardized Predicted Value
4
2
0
-2
-3
-2
-1
0
1
2


Scatterplot
Dependent Variable: depression log
R2 Linear = 3.856E-8
Regression Studentized Residual
Regression Standardized Predicted Value
4
2
0
-2
-3
-2
-1
0
1
2

APPENDIX 21: POST HOC ANALYSIS:

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.785[a]	.616	.610	.12982	.616	94.667	2	118	.000	1.650

a. Predictors: (Constant), BIPQtotal, AAQ7log

b. Dependent Variable: GHQtotallog

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3.191	2	1.595	94.667	.000[a]
	Residual	1.989	118	.017		
	Total	5.179	120			

a. Predictors: (Constant), BIPQtotal, AAQ7log

b. Dependent Variable: GHQtotallog

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	.645	.067		9.629	.000					
	AAQ7log	.393	.061	.429	6.434	.000	.673	.510	.367	.732	1.366
	BIPQtotal	.007	.001	.472	7.075	.000	.694	.546	.404	.732	1.366

a. Dependent Variable: GHQtotallog