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HELEN UNDERWOOD BSc Hons MSc

**INVESTIGATING THE RELATIONSHIP BETWEEN STRESSFUL LIFE EVENTS,
COPING STYLE AND PARKINSON'S DISEASE**

**Section A: The Relationship between Parkinson's Disease, Stressful Life Events and
Coping Style: Laying the Ground Work**

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SEPTEMBER 2011

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY

DECLARATION FOR MAJOR RESEARCH PROJECT

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DECLARATION

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Date

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Signed (supervisor)

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STATEMENT 2

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SUMMARY OF PORTFOLIO

Section A gives an overview of Parkinson's disease, followed by a review of physiological and psychological literature suggestive of a relationship between stress and illness, with special consideration given to neurological disorders, including PD. Literature suggestive of direct and moderating relationships of coping style in relation to illness is then given. Finally, implications of the literature and directions for future research are considered.

Section B describes an empirical study investigating the direct relationships between stressful life events, coping style and Parkinson's disease, and of coping style as a moderator in the former relationship. Relationships were tested using correlation or logistic regression. Stressful life events and emotion-oriented coping style were found to have a direct relationship with PD. Coping style did not moderate the relationship between stressful life events and PD.

Section C provides a critical appraisal of the study described in Section B. It addresses four questions posed with regard to: research skills and abilities learned, what could be done differently and why, clinical implications, and future research ideas. This section also includes personal reflection by the author of the process of carrying out the study, and of several learning points that occurred throughout the process.

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Running Head: ARE PARKINSON'S DISEASE, STRESSFUL LIFE EVENTS AND
COPING STYLE RELATED?

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Major Research Project

SECTION A

Literature Review

**The Relationship between Parkinson's Disease, Stressful Life Events and
Coping Style: Laying the Ground Work**

Word Count: 5499 (plus 193 additional words)

Abstract

Historically, Parkinson's disease has been understood in terms of biological and environmental risk factors. However, the current review focuses on evidence that highlights the possible contribution that psychological factors may have in its aetiology, specifically stressful life events and coping style. To place the review in context, it opens with a description of Parkinson's disease and currently acknowledged risk factors. An overview is then given of the theories of stress and illness, and of the physiological basis for a relationship between stress and illness, including Parkinson's disease. It then reviews the research evidence that has focussed on the relationship between stressful life events and illness in general, particularly the impact of the severity and number of events. Particular consideration is then given to the relationship between stressful life events and neurological disorders. Discussion then moves to the theoretical relationship between coping and illness, and research pertaining to the direct effects of coping on illness, and coping as a moderator between stressful life events and illness, is examined. The review concludes by highlighting possible directions for future research, and the theoretical and clinical implications this may have.

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Introduction

Researchers have long been interested in the association between psychologically stressful life events, such as bereavement, and the impact of these on health and well-being. Much of the literature to date has focussed on physical illnesses such as breast cancer and coronary heart disease. With recent advances in the field of psychoneuroimmunology, it is recognised that there may also be an association between stressful life events and neurological conditions. It is also generally recognised that coping with stressful events may have an impact on health outcomes, although there is debate as to the role coping may have. The primary focus of this review will be to consider the effects of stressful life events and coping style in relation to the neurological condition Parkinson's disease. To place the issue in context, a brief description of Parkinson's disease and its currently known aetiological factors will be discussed. The theoretical and empirical literature regarding the relationship between psychological stress and illness, specifically neurological disorders, will then be described and evaluated, followed by consideration of the literature on coping in relation to health outcomes and Parkinson's disease. The paper will conclude with suggestions for possible directions for future research. The search strategy used for this review is contained in Appendix A.

Parkinson's disease

Description and prevalence

Idiopathic parkinsonism, or Parkinson's disease (PD), is a progressive neurodegenerative movement disorder. People with PD initially present with mild

symptoms, such as a slight stiffness or tremor, which increases in severity over the years to a pronounced tremor, rigid muscles, and slowed movement, which often cause extensive disability. Sixty-five per cent of those who develop PD are male (Shulman, 2007), with symptoms typically starting after the age of 40 (Soukup & Adams, 1996). It is estimated that PD currently affects around 120,000 people in the UK (Parkinson's UK, 2010), and the risk of developing the condition increases with age (The National Institute for Clinical Excellence; NICE, 2006). Therefore as the proportion of adults over 65 years-old in the population is set to increase, questions as to the development and cause of disorders associated with older age, such as PD, become increasingly pertinent.

Aetiology and risk factors

There is currently a limited understanding of the aetiology of PD (Sellbach, Boyle, Silburn & Mellick, 2006). Traditionally researchers have focussed on genetic and environmental risk factors, finding evidence to suggest that a number of factors may increase a person's risk of developing PD. In a review of family history research, Sellbach et al (2006) found that estimates of hereditary risk of PD varied widely, by between 2 to 40 times higher amongst relatives of those with PD. Ethnicity has been found to be a risk factor, with PD being 50% more common amongst White than Black or Asian populations (Willis, Evanoff, Lian, Criswell & Racette, 2010), as has exposure to chemicals, such as pesticides, which has been found to increase a person's likelihood of developing PD by 1.1 to 1.4 times (Dick et al., 2007). Certain lifestyle factors have also been associated with PD; smoking cigarettes has consistently been found to reduce the risk of PD by around 50% (Checkoway et

al., 2002; Miller & O'Callaghan, 2008), and higher level of education has also been found to be a risk factor with an increasing risk for increasing years of education (Frigerio et al, 2005).

The literature suggests that genetic and environmental factors are likely to play a role in the development of PD; however, these do not in themselves explain PD, and the variation of results has sparked considerable debate as to the extent of the role of these factors (Sellbach et al., 2006). There is a growing recognition in the literature that PD may be associated with a combination of factors, although genetic and environmental factors remain a focus (Guttman, Kish & Furukawa, 2003; Sellbach et al., 2006). Sulzer (2007) proposed a multiple hit hypothesis of PD, theorising that the disease develops through an interaction between multiple genetic and environmental risk factors. Others have likewise suggested it to be a multifactorial process, determined by a culmination of biological, environmental and life-style factors (Sellbach et al., 2006). The biopsychosocial model (Engel, 1977) has been used extensively as a framework for understanding factors related to illness; however, only comparatively recently has research interest turned to the psychological aspects of PD (Macniven, 2009). This is supported by unpublished anecdotal evidence from PD Nurse Specialists who report that patients commonly describe a history of stressful or traumatic events.

Psychological stress and illness

Theoretical frameworks of stress and ill-health

Researchers have long been interested in the relationship between stress and its detrimental impact on health and well-being. Early theorists conceptualised stress as an

automatic response to external stressors, proposing that stressors resulted in disequilibrium in the individual that required a period of readjustment, which in turn depleted the individual's resources leaving them vulnerable to disease (Cannon, 1932; Selye, 1956). Engel (1977) challenged such biomedical approaches, proposing a biopsychosocial framework of stress and illness which acknowledged and incorporated the role of individual attributes, resources and social context in understanding the determinants of illness. However, despite the weight of evidence over the last 30 years supporting the biopsychosocial model, the dominant model of illness today remains a biomedical one (Fava & Sonino, 2007). This paradigm continues to be challenged, perhaps most strongly by the increasing evidence-base from the field of psychoneuroimmunology (PNI), from which researchers are finding that a variety of somatic disorders are related to a complex biopsychosocial reaction to stress (Tosevski & Milovancevic, 2006).

There has been much debate in the literature as to the extent to which stress directly influences physical and psychological health. Cohen and Rodriguez (1995) proposed a heuristic framework in which biological responses to psychological disturbances may be a primary pathway to physical disorder. Consistent with such a hypothesis, Clements and Turpin (1996) report finding a significant direct effect of stressful events on physical health outcomes. In contrast, in their review of the literature on life stress, Kessler, Price and Wortman (1985) describe only a small direct effect of stressful life events on health outcomes. Lazarus (1991) proposed a transactional theory of stress, in which stress is seen as an active process in relation to health, and is comprised of causal antecedents (e.g. personal variables such as life events) and mediating or moderating processes (e.g. coping). The consequential effects of these transactions are hypothesised to create both immediate

effects, such as mood and physiological changes, and more long-term effects, in terms of somatic and psychological health (Lazarus, 1991).

Definitions of stress

A wide variety of definitions of stress exist in the literature. Cohen, Kessler and Gordon (1997) noted a commonality amongst approaches to defining stress and the role of stress in disease, and offered a definition of stress as “a process in which environmental demands tax or exceed the adaptive capacity of an organism, resulting in psychological and biological changes that may place persons at risk for disease.” (p.3). A commonly cited definition is that given by Lazarus and Folkman (1984) who define psychological stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her wellbeing.” (p.19).

Physiological response to psychological stress

A wide range of literature has emerged over last few decades investigating the association between stress and health conditions, such as coronary heart disease (Greenwood, Muir, Packham & Madeley, 1996) and fibromyalgia (Cleare, 2004). Researchers considering the effects of psychological stress on health outcome have traditionally focussed on the effects of stress on the neuroendocrine system (Lovallo, 1997), and the interaction between behaviour, the central nervous system and immune systems (Glaser, 2005). In terms

of the neuroendocrine system, stress has been found to activate the hypothalamic-pituitary-adrenal axis (HPA), creating elevated levels of cortisol. This is in part an adaptive response to stress facilitating the body's readiness for a 'fight or flight' response to the stressor; however, excess or prolonged cortisol excretion can have a suppressive effect on the immune system (Dallman et al., 2004).

Stress and PD: A neurophysiological theory

It has been argued that without a basis for biological plausibility of a mechanism through which stress may affect neurological conditions, as exists for other health conditions, epidemiological evidence of such an association would need to be large to enable any conclusions to be drawn (Goodin et al., 1999). PNI researchers have in recent years proposed a possible neural pathway through which such a relationship might exist. PD occurs when there is a loss of cells in the brain (in the substantia nigra) that produce the neurotransmitter dopamine, which is involved in movement control. As a result, messages regarding movement cannot be transmitted from the basal ganglia to the parts of the brain responsible for carrying out that movement (Huot, Levesque & Parent, 2007). Smith (2002) stated that there is increasing evidence that stress is implicated in cell damage and loss in some brain regions (including the basal ganglia), as studies have found that stress increases the concentration of certain chemicals in the brain (glucocorticoids, dopamine and glutamate) which in combination have the capacity to be neurotoxic and promote cell loss. It has therefore been proposed that stressful experiences may be a key factor in the loss of cells that underlies PD (Smith, 2002). Furthermore, Smith (2002) suggested that the increased levels of neurotransmitters, such as dopamine, produced during stress may also be implicated in the

exacerbation of PD symptoms, as it may be that if this creates neurotoxicity, it could continue to further affect the individuals existing movement abilities during stress.

The literature relating to stress and illness suggests that there is a theoretical and physiological basis for a relationship between stress and a broad range of physical disorders, including PD. It remains unclear, however, whether this is a direct effect or whether it is moderated by a process such as coping. The current review will therefore firstly consider in more detail the literature pertaining to the direct relationship between stressful life events and illness, followed by a review the literature relating to the role of coping in illness. Within this, evidence relating to both the aetiology and progression of illness will be considered, as it has been suggested that these may have a common physiological basis (Smith, 2002); however, as this basis is a theoretical and not an empirical one, it must be borne in mind that these may have different underlying mechanisms.

The relationship between stressful life events and illness

Stressful and adverse life events

There is a large evidence-base to suggest that individuals who have experienced potentially stressful life events are at greater risk of physical and psychological ill-health (Turner & Wheaton, 1997). Much literature has focussed on the impact of stress caused by daily hassles (e.g. home maintenance, rising prices) on health outcomes. However, in recent years there has been an increased interest in the impact of events that require significant or major adjustment by the individual, in the literature most often termed as stressful life events (SLE's) or adverse life events (ALE's). SLE's can be divided into more common events,

such as loss of a loved one, or potentially traumatic events (PTE's), such as sexual assault (Kessler et al., 1985) which are defined by the DSM-IV as having experienced or witnessed an event(s) that "involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others" (p.467) (American Psychiatric Association, 1994).

There has been debate in the literature as to what constitutes an SLE. Consistent with early theory, Holmes and Rahe (1967) hypothesised that both positive and negative life events are stressful, arguing that both types of event require adaptation and adjustment to a new situation, and thus can lead to health difficulties. As such, they incorporated both types of event into their widely used Social Readjustment Rating Scale (SRRS; Holmes & Rahe, 1967). This assumption of life transitions as inherently stressful has been challenged for not taking account of individual differences in distinguishing between events that may be desirable or undesirable, given that some life events may offer escape from a stressful situation, such as divorce in the context of an abusive marriage (Sarafino, 2008; Wheaton, 1990). This critique is supported by research findings that undesirable negative events and not positive desirable events are correlated with illness (Sarason, Sarason, Potter & Antoni, 1985).

The level of stress experienced following an event is generally accepted to vary due to the characteristics of the event, such as controllability, desirability, predictability and magnitude (Thoits, 1983; Wheaton, 1990). A common distinction is also made in the literature between the effects of normative events, those that are expected or are a part of the life-span (e.g. marriage, childbirth, widowhood), and non-normative events, those seen as rare or unexpected (e.g. disasters and diseases). Ryff and Heidrich (1997) hypothesised that normative events promote health and wellbeing, arguing that these contribute to the

perception of personal growth, mastery and development over time; whereas non-normative events are hypothesised to undermine these key features of wellbeing (Dohrenwood & Dohrenwood, 1974; Wheaton, 1990), and therefore may have a deleterious impact on health and wellbeing.

Type and severity of events

Aldwin (2007) stated the importance of differentiating between daily hassles, more common SLE's and PTE's, highlighting the qualitative difference between these types of event and the impact that these may have on the individual. Supporting this, Lazarus and Folkman (1984) found that SLE's and daily hassles showed only a modest correlation ($r = 0.20$), concluding that hassles and SLE's are independent of each other. With the increasing interest in field of post-traumatic stress disorder (PTSD), it has been proposed that more severe and possibly traumatic early life events, such as physical and sexual abuse, may have an effect on health in adulthood (Tosevski & Milovancevic, 2006). Consistent with this, Leserman et al. (2005) found that that life-time trauma (e.g. domestic violence or death of close family member) and recent severe SLE's (e.g. major financial problems, physical or sexual assault) were associated with worse health related outcomes, higher risk of disability and increased use of health services, explaining 12% to 27% of variance in health-related functioning.

In general, the evidence from breast cancer literature also suggests that more severe SLE's are associated with a higher risk of developing illness (Chen et al., 1995; Geyer, 1991; Lillberg et al., 2003). Chen et al. (1995) prospectively studied women referred for

examination of possible breast cancer and found both severe and threatening events experienced in the previous 5 years to be associated with an increased risk of breast cancer. In their prospective study of patients prior to diagnosis, Geyer (1991) similarly found a correlation between breast cancer and number of severe SLE's (those relating to loss) over the past 8 years ($r = 0.28$). Lillberg et al. (2003) investigated the effects of more common events (e.g. moving house) and more severe events (e.g. death of a spouse), although a cumulative risk of cancer for all events was found, analysis of individual items revealed that three severe events were independently associated with increased risk of breast cancer; separation / divorce, death of a spouse, and death of a close friend or relative.

Number of events

The cumulative effect of SLE's in relation to negative health outcome has often been emphasised in the literature (Wheaton, 1990; Resick, 2001; Tosevski & Milovancevic, 2006). More specifically, it has been argued that major SLE's (e.g. death of a loved one) may have a cumulative effect over the life span that serves as a risk factor for the development of physical disorders (Tosevski & Milovancevic, 2006). Research findings support this assertion, for example Felitti et al. (1998) found that compared to those with no reported adverse events, adults who had experienced four or more adverse life events in childhood, such as physical and sexual abuse, were significantly more likely to suffer from a number of health conditions in later life, such as; ischemic heart disease, diabetes, cancer, stroke, and hepatitis. Furthermore, Wirtz and Harrell (1987) found that those who had previously experienced a potentially traumatic event that represented a threat to life (e.g. a major illness or death of a friend) experienced a greater level of stress following a further SLE than those

who had previously experienced a non life-threatening past event (e.g. divorce). In contrast, Michael et al. (2009) reported an increased risk of breast cancer for one SLE but a decreased risk for each additional SLE; however, when adjustment was made for confounding variables this decrease was not significant.

The relationship between SLEs and neurological disorders

The purpose of the current review is to examine the literature pertaining to the relationship between Parkinson's disease and SLE's; however, only one recent study was found to address this relationship. Therefore to consider the broader context for the possibility of such an association, the existing literature pertaining to the association between SLE's and multiple sclerosis (the most studied neurological disorder in terms of SLE's) will firstly be reviewed, followed by a review of the PD study.

Multiple Sclerosis

The majority of studies investigating the relationship between MS and SLE's have focussed on relapse or exacerbation of symptomatology. Consistent with the idea that an accumulation of SLE's may be deleterious for health, the literature has generally found that increased frequency of events is associated with a higher risk of relapse in MS. Ackerman et al. (2002) report finding increased risk of relapse was associated with increased frequency of SLE's in their cohort study of MS participants. Mitsonis et al.'s (2008) cohort study found that three or more events, over a 4-week period, were associated with an increased risk of

relapse in the following 4 weeks. In contrast, Buljevac et al.'s (2003) cohort study found that a single stressor significantly increased risk of symptom exacerbation over the following 4 weeks, but multiple stressors did not. It must be noted however, that Ackerman et al. (2002) and Mitsonis et al. (2008) used small sample sizes (26 and 26 participants respectively) and did not control for disease-related stressors, therefore limiting and potentially confounding results; whereas Buljevac et al. (2003) did not use a standardised measure of stressful events, therefore limiting comparison and generalisability of results.

Research findings as to the differential effect of the severity of stressful events in terms of MS relapse have been varied. Mitsonis et al (2008) investigated more common SLE's, such as work/financial difficulties and more severe SLE's, such as death / illness and did not find that type or severity of SLE's were associated with an increased risk of relapse in MS. In contrast, Ackerman et al. (2003) found that the severity of the threat was associated with increased risk of symptom relapse. Also, Mohr et al. (2000) in their small scale cohort study, found that moderately stressful life events, characterised as disrupted daily routines and conflict, were associated with the appearance of new Gd+ brain lesions 4 to 8 weeks later, but did not find an association between major negative life events and disease exacerbation of MS. This may in part be due to removal of items from the standardised measure used, which would also limit the comparison to other studies.

Only four studies were found to investigate the aetiological relationship between SLE's and onset of MS, three of which found evidence suggestive of an association (Warren, Greenhill and Warren, 1982; Grant et al., 1989; Li et al., 2004). Warren et al. (1982) conducted a retrospective case-control study of 100 people with MS and 100 people with other neurological or rheumatological conditions. MS participants reported significantly

more unwanted stress than controls in the 2 years prior to MS onset (79% vs 54%, $p < 0.001$), and had experienced three times the number of SLE's over the same period; however, the use of an un-validated measure of stress limits interpretation of the findings. Grant et al. (1989) did use validated measures in their case-control study, and found that compared to 40 healthy control participants, 39 participants with MS had experienced more severely threatening life events in the preceding 6 months to onset (62% vs 15%, $p < 0.001$). More recently, a retrospective cohort study by Li et al (2004) found that parents who had a child die before the age of 18 had a greater risk of MS than parents who had not; notably the risk was higher if the child had died unexpectedly, which is consistent with the theory that non-normative events may have a greater impact on health and wellbeing than normative events (Ryff & Heidrich, 1997).

In contrast, a case-control study by Palumbo, Fontanillas, Salmaggi, Mantia and Milanese (1998) found that although a higher proportion of MS participants than those with chronic polyneuropathies reported more SLE's (especially death of a relative or partner; 24.6% vs 14.8%) in the year before onset, the finding was non-significant. However, the study did not adequately control for disease-related factors that may have confounded results. Overall, the quality of these studies varied, and the use of different measures in each limits comparability, and therefore conclusions that can be drawn. In addition, it must be noted that although the above studies generally support a relationship between SLE's and both the onset and exacerbation of symptoms in MS, it cannot be concluded that the underlying mechanisms of aetiology and disease progression in MS are the same.

Parkinson's Disease

To date, only one study has investigated the relationship between SLE's and PD. Rod, Hansen, Schernhammer and Ritz (2010) conducted a population-based study in Denmark to investigate the role of major life events in the aetiology of PD. PD cases (N = 13,695) identified from the National Hospital Register were matched with 68,445 control cases identified from the Central Population Register. Life event data obtained from national registries comprised of: divorce, death of a child, death of a spouse, and long-term unemployment. The authors report finding an inverse association between number of life events and the risk of PD for men, with an odds ratio (OR) of 0.58 (95% CI: 0.34 – 0.99) for three or more life events compared to those who experienced no major life events. Life events were not found to be associated with PD in women. These results indicate that certain major but common life events are not associated with a causal role in the aetiology of PD, therefore not consistent with hypothesis that cumulative effect of SLE's increases risk of illness (Tosevski & Milovancevic, 2006). However, PD is primarily an outpatient condition and only those hospitalised could be identified and included in the study. Also information on major life events was limited to those available from national registries, thus not a comprehensive assessment of major or traumatic SLE's. Therefore, interpretations based on the findings of this study are potentially limited and may not accurately represent the PD population or life events that may be associated with PD.

The relationship between coping and illness

Stressful life events and coping

As discussed above, there is a growing evidence base suggesting that exposure to stressful life events may precipitate the onset of ill-health (Theorell and Rahe, 1971). However, although adverse events in life are inevitable and it is probable that most individuals will experience at least one PTE during their life (Kessler et al., 1985), not all those who experience such events do become ill. Therefore how individuals respond to and manage life's adversities has been of great interest to researchers, specifically in terms of vulnerability factors and personal characteristics that may render individuals more or less resilient to stress induced ill-health (Cohen et al., 1997). One factor that has generated a great amount of interest in its influence on individual reactivity to stress and adverse life events is coping style (Kessler et al., 1985).

Definitions of coping and coping strategies

Two broad theories of coping have been proposed in the literature, an environmental approach and a person-based approach (Aldwin, 2007). The environmental approach posits that coping is a flexible process that responds to environmental demands, and as such an individual's coping behaviour will vary depending upon situational aspects of a particular stressor (Lazarus & Folkman, 1984). Others have proposed a person-based approach (Endler & Parker, 1990; Miller, Brody & Summerton, 1988), arguing that individuals use specific and characteristic behaviours or strategies to cope when faced with a stressful situation.

Reflective of this difference in perspective, definitions of coping have also varied. Lazarus

and Folkman (1984) defined coping as the “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141); whereas Aldwin (2007) has defined coping as “the use of strategies for dealing with actual or anticipated problems and their attendant negative emotions” (p.125).

Despite theoretical differences in perspective, there exists a general agreement regarding the types of coping style that individuals use in their attempts to manage or respond to situations perceived as stressful (Aldwin & Yancura, 2004). Traditionally, coping styles have been understood in terms of two general domains; problem-focussed and emotion-focussed coping (Lazarus & Folkman, 1984). Problem-focussed coping involves task oriented strategies, aimed at analysing and solving the problem. In addition to using traditional problem solving strategies, efforts directed at changing the environment, a problem-focussed approach encompasses efforts directed inwards at changing the self (Lazarus & Folkman, 1984; Kahn, Wolfe, Quinn, Snoek, & Rosenthal, 1964). Emotion-focussed coping involves strategies that are directed towards reducing the emotional distress of an event without necessarily changing the situation itself, for example; minimisation, avoidance, distancing, denial, positive comparisons, self-blame and discharging emotions (Lazarus and Folkman, 1984). Subsequently, studies have found avoidance to be a distinct third dimension of coping (Folkman & Lazarus, 1988; Endler and Parker, 1990), which includes avoiding the problem through distraction or social diversion through denying, minimising or ignoring a stressful situation (Moos & Holahan, 2003).

The role of coping in relation to health outcomes

According to the general literature on coping, specific coping styles either promote physical health or exacerbate illness (Endler & Parker, 1990). More specifically problem-focussed strategies have been thought to lessen the impact of the stressor, and have therefore been associated with better health outcomes than emotion-focussed coping, which is generally thought to deplete personal resources (Lovallo, 1997; Holahan & Moos, 1987). However, coping style in relation to adverse life events may be a complex one, as it is proposed that in uncontrollable situations, conversely, problem-focussed coping may have an adverse effect whereas emotion-focussed coping may have a positive effect on physical health (Aldwin, 2007).

Aldwin and Revenson (1987) proposed two possible theoretical models of this complex relationship; a direct effects model and moderator "buffering" effects model. Lazarus (1999) supported the latter model, arguing that as coping style can affect how stressful events are perceived and managed, they therefore may mitigate the relationship between stressful life events and physical functioning. However, it has also been proposed that different coping styles may apply to different models, with emotion-focussed and avoidant coping hypothesised to have a negative direct effect on health regardless of the level of event stress, and problem-focussed coping to have a buffering effect in mitigating the negative effects of stress on health (Aldwin & Revenson, 1987; Wilkinson, Walford, & Espnes, 2000; Cohen & Rodriguez, 1995; Ogden, 1996).

Direct effects of coping on health outcome

A limited number of studies have investigated the direct effect of coping style in relation to the progression and onset illness. Avoidant coping has generally been positively correlated with greater progression of cancer and HIV symptoms compared to problem-focussed coping styles (Epping-Jordan, Compas & Howell, 1994; Vassend, Eskild, & Halvorsen, 1997; Mulder, Vroome, van Griensven, Antoni & Sandfort, 1999; Mulder, Antoni, Duivenvoorden & Kauffmann, 1995). Epping-Jordan et al. (1994) conducted a cross-sectional, longitudinal study and, in terms of aetiology reported that avoidant coping predicted positive cancer status a year later. They hypothesised that avoidance had contributed to continued experience of distress and emotional arousal which in turn contributed to worsened health status. The study did not measure effects of other coping styles therefore limiting the conclusions that can be drawn in this regard.

Moderating effects of coping on health outcome

Only one study was found to examine the interaction between SLE's and coping on disease, specifically in terms of disease progression. Mohr et al. (2002) examined the hypothesis that coping moderates the relationship between stressful events and the development of new Gd+ brain lesions in MS. The study found that distraction, as a way of coping, was a significant moderator associated with a decrease in this relationship, whilst instrumental problem-focussed coping marginally decreased and emotional coping marginally increased the relationship. Limitations of the study included small sample size

and the exclusion of individuals who did not develop new Gd+ lesions during the study; however, findings are noted to be generally consistent with existing coping literature.

Coping and Parkinson's disease

A small number of studies have shown a direct effect of coping on health related quality of life (HRQoL) in individuals with PD. Bucks et al. (2011) conducted a cross-sectional study with 85 participants, and found that problem-focussed coping was significantly associated with better HRQoL in terms of cognitive ability, communication and bodily discomfort, in contrast to emotion-focussed coping which was significantly associated with poor HRQoL in terms of emotional well-being and mood. Montel, Bonnet and Bungener (2009) similarly report emotion-focussed coping and diversion strategies as being associated with poor HRQoL. Individuals with PD have also been found to use significantly fewer problem-focussed coping strategies compared to comparably disabled controls (Ehmann, Beninger, Gawel, & Riopelle, 1990), and in terms of disease-related stressors, individuals with PD have been shown to most commonly use emotional coping (Frazier, 2000). However, no studies have so far investigated the direct effect of coping on the presence of PD, or the interaction between stress and coping in relation to PD.

Summary

There are approximately 120,000 people in the UK with Parkinson's disease, a figure that is set to rise with a predicted increase in the older adult population. Understanding of the

aetiology of PD is currently limited, and has focussed primarily on the study of biological and environmental risk factors. A number of theories have proposed that psychological stress, as experienced through adverse life events, may be associated with physical health outcomes. This review has provided a brief overview of research into the physiological effects of stress and the emerging evidence-base that has examined the effects of psychological stress, through adverse life events on a variety of health outcomes. In general the literature suggests that severe or traumatic life events are more often associated with increased risk of illness onset or exacerbation of existing illness, and that these may have a cumulative effect in relation to health problems, including neurological disorders. However, it is noted that the physiological basis for the onset and exacerbation of illness may differ.

With reference to the increased interest in the literature regarding individual differences that may influence resilience to stress, the current review has also given an overview of the literature on coping. There is currently insufficient evidence to draw firm conclusions with regard to the relationship that coping style may have with stress and illness; however, the literature is suggestive of a direct effect of avoidant coping on disease onset and progression, and of a possible moderating effect of coping style between stress and brain lesions in an existing neurological disorder.

The development of an interest in the literature with regard to a relationship between stress and Parkinson's disease is evidenced by a recent neurophysiological theory proposed for the existence of such a relationship. However, only one population-based study has empirically investigated this relationship to date, and therefore there is insufficient evidence to draw conclusions. The literature regarding coping and PD suggests that coping style is related to health related quality of life in PD, with problem-focussed coping being related to

better outcome and emotion-focussed coping being related to poor outcome; however, no studies have investigated the direct relationship between coping style and PD or the moderator effects that coping may have in relation to stress and PD.

Conclusions and future research

Despite anecdotal evidence of a relationship between PD and the experience of psychologically stressful or traumatic events, there is a paucity of research investigating this relationship. The current literature review has demonstrated that research evidence does suggest a relationship between stressful life events and illness, albeit a complex one that may be moderated by how the individual copes with the event. It may also be that coping has a direct effect itself on illness. However, no field of study has produced what could be considered conclusive results in respect of any of these relationships, in terms of PD or general health outcomes.

The primary role for future research would therefore be to firstly empirically explore the relationship between the experience of stressful life events and PD. It would also be useful for the research to be conducted with a community sample of people with PD, given that PD is primarily an outpatient disorder. Given the possible complexity of this relationship, empirical research would also have a role in investigating the differences that may render individuals more or less resilient to stress induced ill-health. In the first instance, future research should investigate the possible direct effect of coping on PD, as well as investigating coping as a moderator of stressful events in the relationship with PD, as this is a novel hypothesis which is yet to be tested empirically.

Such research could potentially increase our understanding of the possible aetiological risk factors for PD, provide a new theoretical insight into the role of coping in terms of PD and build on the wider health outcomes evidence-base. Given the prospective rise expected in those diagnosed with PD, gaining knowledge of the associated risk factors, in particular the role of coping strategies, would be important in terms of considering preventative interventions that might enhance health and well-being (Aldwin, 2007). This would therefore have implications for health service policy and planning, especially given the current provision of dedicated PD clinical psychology services in the UK are scarce (Macniven, 2009).

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HELEN UNDERWOOD BSc Hons MSc

Major Research Project

SECTION B

Journal Paper

**Investigation of the Relationship between Parkinson's Disease, Stressful
Life Events and Coping Style: A Pilot Study**

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Abstract

Objectives. Literature suggests that a relationship exists between stressful life events (SLE's), coping style and illness. The present study aimed to investigate the direct relationships between both SLE's and coping style, and Parkinson's disease (PD), and coping style as a moderator between SLE's and PD.

Design. A retrospective, correlational design was employed in the current pilot study, using correlational and multivariate methods of analysis.

Methods. Life-time experience of SLE's and coping style were measured using self-report questionnaires, and were completed by a group of people with PD (N = 19) and a group of people without PD (N = 20).

Results. Significant relationships were found between SLE's and PD, and emotion-oriented coping and PD. People who reported a higher number of SLE's were associated with a 2.6 times higher risk of having PD (OR = 2.60; 95% CI, 1.35 – 4.99) and those who reported a higher level of emotion-oriented coping had an 8% increased chance of having PD (OR = 1.08; 95% CI, 1.00 – 1.17), compared to those with fewer reported SLE's. No other significant direct effects or moderator effects were found.

Conclusions. These findings suggest an association between stressful life events and PD, and to a lesser degree between emotion-oriented coping and PD. Further research is needed to replicate and clarify findings.

Introduction

What is known about Parkinson's disease?

Idiopathic Parkinson's disease (PD) is a progressive movement disorder, characterised by a resting tremor, muscle rigidity, and slowed movement, which can cause extensive disability and distress for the person. It is the second most common neurological disorder after Alzheimer's disease (Ishihara & Brayne, 2006), and currently affects an estimated 120,000 people in the UK (Parkinson's UK, 2010). PD is also an age related condition (The National Institute for Clinical Excellence; NICE, 2006), and given that the older adult population is set to increase in the coming decades, it is surprising how little is known about its aetiology.

The literature suggests that environmental and genetic factors, such as exposure to pesticides (Dick et al., 2007) and family history of PD (Sellbach, Boyle, Silburn & Mellick, 2006), may increase a person's likelihood of developing PD. However, these factors do not fully account for the development of PD, and as such interest has now turned to possible psychological determinants of the disease (Macniver, 2009). Existing literature suggests that psychological factors, specifically stress and coping style, may have a relationship with both the onset and exacerbation of neurological disorders. Within this, evidence relating to PD is sparse, but is an area to which the current research paper contributes; therefore, evidence for the relationship between stress, coping style and PD will be reviewed below within the wider context of literature pertaining to Multiple Sclerosis (MS), the most studied neurological disorder in this area.

The potential role of stressful life events

There is a large evidence-base suggesting that those who have experienced potentially stressful events are at an increased risk of developing a physical illness (Turner & Wheaton, 1997), and psychoneuroimmunology (PNI) research has supported a physiological basis for such a relationship in a variety of somatic disorders (Tosevski & Milovancevic, 2006). The following basis for a causal relationship between stressful life events (SLE's) and PD has also been proposed by Smith (2002). When under stress, the body responds by activating the hypothalamic-pituitary-adrenal axis (HPA), which results in elevated release of glucocorticoids (e.g. cortisol), dopamine, and glutamate, in readiness for a 'fight-or-flight' response. However, in combination these neurotransmitters have the capacity to be neurotoxic; therefore it has been argued that this could potentially be related to the loss of dopamine producing neurons that underlie the aetiology PD (Smith, 2002).

Smith (2002) also stated that evidence implicates stress in symptom progression in PD, and proposed that the underlying mechanism for this may be similar to that possibly underpinning the aetiology of PD. For example, the elevated levels of neurotransmitters produced during stress remain neurotoxic and may therefore affect the individuals existing movement abilities during stress. The evidence relating to the relationship between stressful life events and neurological disorders will therefore be considered below in terms of both onset and illness progression, although it is acknowledged that these remain separate constructs which may or may not have a similar physiological basis.

In the literature, it is generally accepted that SLE's can be conceptualised in two ways; as normative, more common events (e.g. divorce), or as non-normative, potentially traumatic events (e.g. sexual assault; Ryff & Heidrich, 1997; Kessler, Price & Wortman,

1985). It has also been argued that the level of stress experienced following an event varies according to event characteristics, such as controllability and predictability (Wheaton, 1990). Consistent with this, it has been proposed that non-normative events are those most associated with a deleterious impact on health, as they undermine the individual's perception of personal growth over time (Ryff & Heidrich, 1997). The evidence pertaining to the relationship between SLE's and MS will firstly now be considered, followed by evidence relating to PD.

In terms of symptom progression, findings of longitudinal cohort studies examining the relationship between SLE's and the exacerbation of MS symptoms are generally suggestive of a relationship. Ackerman et al. (2002) longitudinally measured stressful life events and exacerbation of symptoms in twenty-three women with MS over the period of one year. Survival analysis revealed that an increase in the number of severe (e.g. physical assault) and non-severe (e.g. vehicle accident) stressful life events were associated with a greater likelihood of experiencing MS exacerbations. More recently, Mitsonis et al. (2008) longitudinally examined the relationship between stressful life events and relapses in twenty-six women with MS, for an average of 53.6 weeks. Regression analysis found that women who experienced three or more stressful events over a period of four weeks were five times more likely to experience a relapse. The severity of the stressful events was not found to be significantly associated with the risk of relapse.

However, the above two studies are limited in that both used small sample sizes, did not clinically confirm exacerbations, and did not control for MS related stressors, which may have confounded results. A study by Buljevac et al. (2003) longitudinally investigated self-reported experience of stressful life events that were not related to MS in a sample of seventy-three patients. Exacerbations were confirmed through neurological examination.

Regression analysis found that experiencing at least one stressful life event doubled the likelihood of MS exacerbation in the following four weeks. Therefore, evidence suggests that an increased number of SLE's experienced is related to increased likelihood of exacerbation or relapse in MS.

With respect to aetiological factors, two recent studies were found to investigate the relationship between stressful life events and the onset of MS (Palumbo, Fontanillas, Salmaggi, La Mantia & Milanese, 1998; Li et al, 2004). Palumbo et al. (1998) retrospectively explored the frequency of stressful life events that occurred in the year prior to MS onset, in a case-control study of 65 people with MS and 27 people with Polyneuropathy. Frequency analysis revealed that although those with MS reported a higher number of stressful events occurring in the year prior to illness onset than those with Polyneuropathy, the difference was not significant. Interpretation of the results may be limited however, as an un-validated questionnaire was used, therefore limiting assessment of reliability or validity of results. It also seems that they used a combination of both normative and non-normative events in the analysis, which may have confounded the results. A more recent study by Li et al. (2004) partially addressed these limitations. They conducted a large-scale, retrospective cohort study in Denmark, examining the relationship between the death of a child and the onset of MS. Regression analysis found that parents who had lost a child were at a significantly increased risk of MS compared to those who had not. Furthermore, the overall risk of MS was nearly twice as high for those who had unexpectedly lost their child. However, due to the paucity and disparity of evidence, further research would be needed to clarify the relationship between SLE's and MS onset.

To date, only one study has been found to explore the relationship between SLE's and PD. Rod, Hansen, Schernhammer and Ritz (2010) conducted a large, population-based, case-

control study in Denmark, investigating the aetiological relationship between major life events and PD. Major life events were those attainable through National Registries: divorce, death of a child, death of a spouse, and long-term unemployment. Data was collected for 13,695 people with PD and 68,445 controls. Regression analysis revealed an inverse association between number of life events and the risk of PD for men (odds ratio = 0.58; 95% CI: 0.34 – 0.99), with three or more events decreasing the likelihood of having PD compared to controls. No significant effect was found for women. It is important to note that the use of National Registries introduced two main limitations for the study; it restricted major life events to those available through registries, and only those hospitalised with PD were identifiable for inclusion in the study. As PD is predominantly an out-patient disorder, it would be important to investigate this relationship further in a more representative sample of the PD population.

The potential role of coping

Although evidence suggests that SLE's may be associated with a negative impact on health, it is also acknowledged that not everyone who experiences such events becomes ill. Therefore, individual characteristics that may play a role in a person's level of resiliency to stress, such as coping style, have been of much interest to researchers (Cohen, Kessler & Gordon, 1997). Coping has been conceptualised in terms of three main domains or styles (Folkman & Lazarus, 1988; Endler & Parker, 1990b): problem-focused (or task oriented) coping, emotion-focused (or emotion-oriented) coping and avoidant (or avoidance-oriented) coping. It has been proposed that coping style may be related to health outcome in two

conceptually different ways; through a direct effect on health outcome, or by moderating or 'buffering' the relationship between SLE's and health outcome (Aldwin & Revenson, 1987).

In terms of the direct effect of coping, it has been proposed that problem-focused coping ameliorates the impact of the stressor, leading to better health outcomes; whereas emotion-focussed and avoidant coping are proposed to deplete an individual's resources, and are therefore associated with poor health outcomes (Lovallo, 1997; Cohen & Rodriguez, 1995). No studies have so far investigated the direct relationship between coping and presence of MS or PD, in terms of aetiology or illness progression; however, evidence from the wider health literature is generally supportive of these effects. For example, a longitudinal cohort study of 104 people with HIV (Vassend, Eskild, & Halvorsen, 1997) found a positive correlation between avoidant coping and symptom progression, and a negative correlation between problem-focussed coping and symptom progression. It is noted that findings may be limited by the short follow-up period of two years, and that it cannot be assumed the same relationship exists in terms of neurological disorders.

A small number of studies have explored the relationship between coping and health related quality of life (HRQoL) in those with PD, perhaps the most salient of which to the current study is that of Frasier (2000), who investigated coping style in relation to disease-related stressors (cognitive, physical and psychosocial) in 145 people with PD. Regression analyses found that emotional coping was the most commonly used style of coping in relation to all types of stressors. Given that it has been argued that coping styles are characteristic and stable behaviours over time (Endler & Parker, 1990b), this study highlights the possibility that emotion-focussed coping may be a prominent coping style of those with PD.

Only one study has directly investigated coping as a moderator between SLE's and neurological disorder. Mohr et al.'s (2002) cohort study investigated coping as a moderator in the relationship between stress and the subsequent appearance of new brain lesions in a sample of thirty-six people with MS. Over a period of between 28 to 100 weeks, monthly measures were taken of brain lesions, using MRI scanning, and stressful life events and coping style, using a modified standardised questionnaire measure. Regression analysis revealed that distraction (a form of avoidant coping; Endler & Parker, 1990b) significantly moderated the relationship between stress and new brain lesions. Although non-significant, the authors also report that higher levels of instrumental (problem-focussed) coping were marginally associated with a decreased relationship between stress and new brain lesions, and higher levels of emotional coping were marginally associated with an increased relationship between the same factors. The study is strong in terms of controlling for potentially confounding variables, such as MS related stressors, but is limited in terms of sample size and exclusion of those who did not develop new brain lesions. However, it does highlight the possibility that coping style may moderate the relationship between stressful events and the progression of disease activity in a neurological disorder, and that the effect may vary between coping styles.

Summary and implications

Previous research suggests that there is evidence of a relationship between SLE's and both the aetiology and symptom progression of neurological disorders, and although it has been suggested that the underlying physiological mechanisms of these may be similar, the possibility remains that they may differ in this respect. However, there is a paucity of

research investigating these relationships in terms of PD, and given that the one study exploring the aetiological relationship was limited in terms of sample population and range of SLE's, it is a relationship worthy of further investigation. Coping style has been theorised to have a differential effect in relation to positive or negative health outcome. Evidence from the general health literature supports this; however, little investigation has been undertaken in this area in terms of neurological disorder. Furthermore there has been no investigation of either a direct relationship between coping and PD, or of coping as moderator of the relationship between SLE's and PD. The current research study was developed in order to address these limitations and gaps in the evidence-base.

There are important theoretical and clinical implications of undertaking this research. For example, existing theory could be built on in terms of the relationship between psychological risk factors and PD. There is also the potential to provide new insight into the role of coping in relation to PD, thus potentially contributing to further knowledge as to direct and / or moderator effects of the different coping styles. Clinically, furthering our knowledge of these relationships could support the consideration of preventative interventions being more widely available; which is especially pertinent given the aging population and therefore the likely rise in coming years of disorders such as PD.

Current research aim and hypotheses

Due to the complexity of identifying the exact physiological onset of PD, the aim of the current research was to conduct an exploratory pilot study to investigate the relationship between the presence of Parkinson's disease, the life time experience of stressful life events,

and coping style within a community sample of people with PD. With regard to this aim, and based on existing theory and research, the following hypotheses were proposed:

1. There is a significant relationship between number of stressful life events experienced and the presence or absence of PD.
2. There is a significant relationship between problem-focused coping and the presence or absence of PD.
3. There is a significant relationship between emotion-focused coping and the presence or absence of PD.
4. There is a significant relationship between avoidant coping and the presence or absence of PD.
5. Psychological factors (experience of stressful life events and coping style) will have a direct effect in predicting of presence or absence of PD.
6. Coping style will have a moderator or "buffering" effect between the number of stressful life events experienced and the presence or absence of PD.

Method

Participants

Sample

Participants were 39 adults, aged between 60 and 86 years old (mean = 73 yrs, standard deviation = 6.8). This comprised of 19 participants who were diagnosed with Parkinson's disease (age range 60-78, mean = 70, standard deviation = 5.2), and a control group of 20 participants without Parkinson's disease (age range 65-86, mean = 75, standard deviation = 7.5). Participants with Parkinson's disease were recruited through Parkinson's disease Nurse Specialists in an NHS Trust based in the south east of England. Control group participants were recruited by the researcher from older adult organisations in the same geographical area, via presentations and poster advertisement (Appendix B). Table 1 displays demographic characteristics of the participants in both groups.

Table 1

Demographic characteristics of both groups of research participants

	Parkinson's disease group Number (% of N=19)	Control group Number (% of N=20)
Gender		
Male	9 (47%)	5 (25%)
Female	10 (53%)	15 (75%)
Ethnicity		
White British	15 (79%)	13 (65%)
White English	4 (21%)	7 (35%)
Smoker		
Yes	3 (16%)	6 (30%)
No	16 (84%)	14 (70%)
Family history of PD		
None	14 (74%)	16 (80%)
Parent	2 (11%)	1 (5%)
Aunt or Uncle	1 (5%)	2 (10%)
Grandparent	2 (11%)	1 (5%)
Highest level of education		
No formal qualifications	7 (37%)	9 (45%)
GCSE / CSE / O' Level	3 (16%)	2 (10%)
Vocational qualification	4 (21%)	7 (35%)
A' Level	1 (5%)	1 (5%)
Undergraduate Degree	2 (11%)	1 (5%)
Postgraduate degree	2 (11%)	0 (0%)

Inclusion criteria

Participants with Parkinson's disease were invited to take part in the research if they: (1) had a diagnosis of idiopathic Parkinson's disease; (2) were able to give informed consent to participate in the research; and (3) did not meet any of the exclusion criteria as described below. Participants without Parkinson's disease were invited to take part if they: (1) were able to give informed consent to take part in the research; and (2) did not meet any of the exclusion criteria described below.

Those with non-idiopathic forms of Parkinson's disease or Parkinsonism were not considered for inclusion in the current study. These forms of the disease are usually associated with an identifiable aetiological basis, such as a tumour or stroke, and therefore represent a clinically different sample to those with idiopathic Parkinson's disease (Soukup & Adams, 1996).

Exclusion criteria

Participants with Parkinson's disease were excluded if they: (1) had a diagnosis of dementia; (2) had a co-morbid neurological disorder (e.g. Multiple Sclerosis); and (3) if they had any additional severely debilitating chronic health condition. Participants without Parkinson's disease were excluded if they met the same exclusion criteria as the Parkinson's group, with the additional exclusion criteria that they must not have a diagnosis of Parkinson's disease.

Design

A quantitative, retrospective, correlational design was used in the current study. This was chosen due to its previous use in similar areas of research, and its ability to analyse measures of multiple risk factors using multivariate statistical methods.

Measures

Stressful life events

Stressful life events were measured using the Trauma History Questionnaire (THQ; Green, 1996; Appendix C). The THQ is a self-report, 24-item scale that measures life time history of exposure to events that were potentially traumatic, and that may meet the DSM-IV stressor criterion (Criterion A) for post-traumatic stress disorder (APA, 1994). Events are divided into three areas; crime-related events, general disaster and trauma, and physical and sexual experiences. Respondents are asked to state whether 'yes' they have or 'no' they have not experienced each item, and if so, how many times it occurred and approximate age at the time. The THQ has been shown to have good test-retest reliability ($r = .76$; Mueser et al., 2001), and moderate construct validity with the Clinician-Administered Posttraumatic Stress Disorder Scale (CAPS; Blake et al., 1990; r 's between .48 to .85, $p < .05$; Mueser et al., 2001). For use in the current analysis, all item 'yes' responses were summed to calculate a total score for Criterion A traumatic events experienced, yielding a score between 0 and 24 for each participant, as this total score is the most commonly used in previous research (Resnick, Bond, & Mueser, 2003). The THQ was chosen for use in this study due to the wide

range of traumatic and severely stressful events that are measured, its self-report nature, and inclusion of events that have occurred across the life span.

Coping style.

Coping style was measured using the Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1990a; Appendix D). The CISS is a self-report, 48-item questionnaire. It asks respondents to rate the extent to which they engage in certain types of activities when they encounter stressful situations, using a 5 point Likert scale (0 not at all - 5 very much). The CISS is scored according to three main coping sub-scales: task-oriented coping (e.g. Focus on the problem and see how I can solve it), emotion-oriented coping (e.g. Become very upset), and avoidance-oriented coping (e.g. See a movie). Each sub-scale is comprised of 16 items, and yields a score of between 16 and 80. Avoidance is further divided in to two sub-components, distraction and social diversion. Previously well used coping scales, such as the Ways of Coping Questionnaire (WCQ; Folkman & Lazarus, 1988) have measured only two styles of coping; problem-focussed and emotion-focussed. However, as factor analysis has been shown to support the validity of three main sub-scales of coping (Cosway, Endler, Sadler & Deary, 2000), the CISS, and more specifically the three main scales, were chosen for use in the current study.

Psychometric examination of the CISS has shown that the task-oriented coping sub-scale has good internal consistency (Cronbach's α between .87 and .9), test re-test reliability ($r = .73$ for males and $r = .72$ for females; $p < .001$), and high construct validity compared to the problem-focussed subscale of the WCQ ($r = .65$, $p < .001$; Endler & Parker, 1990b). The emotion-oriented coping sub-scale has been shown to have good internal consistency

(Cronbach's α between .89 and .9), high test re-test reliability ($r = .68$ for males and $r = .71$ for females; $p < .001$), and moderate to high construct validity compared to the six emotion-focussed subscales of the WCQ (r 's between .27 and .77, $p < .05$; Endler & Parker, 1990b). Finally, the avoidance-oriented coping sub-scale has also been shown to have good internal consistency (Cronbach's α between .81 and .82), and high test re-test reliability ($r = .55$ for males and $r = .60$ for females; $p < .001$). Although avoidance does not have a direct counterpart on the WCQ, the CISS avoidance-oriented sub-scale demonstrated high construct validity with the social diversion scale on the WCQ ($r = .48$, $p < .001$; Endler & Parker, 1990b).

Procedure and ethical considerations

Ethical approval for the current study was obtained from the Kent National Research Ethics Committee (Appendix E); in addition, permission to conduct the study was approved by the appropriate NHS Trust research and development department (Appendix F). All procedures described in the current study were carried out according to the guidelines stipulated by these organisations. Given the physical difficulties often experienced by people with Parkinson's, provision was made for participants to choose whether they would wish to be visited in their home by the researcher, in accordance with Trust guidelines for lone-working, or whether they would like to arrange to meet the researcher in a local NHS clinic site. A participant information sheet (Appendices G and H) was given, or sent in the post, to all potential participants during the recruitment stage. This described the purpose and procedure of the study, data handling information, and gave contact details for the purposes of requesting more information about the study or making a complaint. It was asked that this

information be read before meeting with the researcher, at which point informed consent would be requested.

Three participants were met at an NHS clinic site (two participants with Parkinson's disease and one control group participant); the remaining thirty-six participants were visited in their home. Firstly, the opportunity to ask questions about the research project in general or specific procedures was given to all participants. Given the potentially distressing nature of the study and the questions asked, participants were also reminded of their right to withdraw from the study at any time, without this having an effect on any current or future treatment. Contact numbers of local NHS and charitable organisations who could provide further support were available if needed; however, this was not deemed necessary for, or by, any participant during the course of the current study. Following this, informed consent was given in writing (Appendix I). At this time, participants were also asked if they would like to receive a summary of the research findings following completion of the study. Brief demographic information was then obtained from participants (Appendix J). For all participants, the THQ was then administered, following which the CISS was completed. All data were anonymous, through assignation and use of participant numbers, and kept confidential in a locked cabinet and password protected database.

At the completion of the study, a summary of the results was sent to all participants who requested this (Appendix K and L). A summary of the results was also sent to the relevant NHS Trust research and development department and ethics committee (Appendices M, N and O); an end of study form was also sent to the latter (Appendix P).

Data analysis

Power calculation

A priori power calculations suggested that for correlation analysis, a sample size of 30 would be adequate to achieve a high level of power (using Cohen's, 1988, .8 level) in detecting a significant ($p < .05$) relationship between stressful life events and health outcome, based on the average correlation coefficient found for a similar population (Mohr, Hart, Julian, Cox, & Pelletier, 2004). Calculations also showed that to achieve a high level of power (.8, as above) in detecting a significant ($p < .05$) relationship between coping style and health outcome, an adequate sample size would be between 23 and 39. Literature regarding multivariate regression analysis suggested that a minimum of 10 – 15 participants per predictor variable would be needed to achieve sufficient power to test a regression model (Field, 2009). Given that the current study was to have four predictor variables, and that as a pilot study it would not be ethical to use a larger sample than the minimum, it was hoped to achieve 40 participants in total. Consideration will be given in the discussion as to the possible impact of recruiting fewer participants than suggested by the above power calculation.

Planned analysis

Results are presented in the following sections. Firstly, inspection of the data is presented, followed by examination of the relationship between each of the demographic variables and the outcome variable (presence or absence of PD). Hypothesis testing is then

presented; for clarity, planned analysis for each hypothesis is set out prior to the findings for each respective analysis.

Results

Inspection of data

Analyses were conducted using the software program SPSS (Version 17.0). Prior to analysis, the data were checked to determine whether variables met the assumptions for parametric statistics. Shapiro-Wilk's test was used to examine normality of distribution. The predictors of task-oriented coping style and avoidance-oriented coping style were found to be normally distributed for both outcome variable groups; however, the predictor of stressful life events was found to be positively skewed for both the PD group and the non-PD group, and the predictor of emotion-oriented coping style was found to be positively skewed for the non-PD group (see Appendix Q for histograms). The data associated with these predictors was therefore transformed by centring scores through calculating the square root of each (Field, 2009). This transformation of data achieved a normal distribution of data for both transformed predictors, therefore allowing use of parametric tests. A small number of outliers were identified in the distributions prior to transformation; however, transformation of data reduced the skew of the distributions and therefore the impact of the outliers. Remaining outliers were retained as the mean values and 5% Trimmed Mean values were very similar, indicating the outlier values were not too different from the normal distribution (Pallant, 2010).

In order to examine direct relationships, a series of Pearson's correlations were conducted between predictor variables. Data were examined to determine whether they met

the assumptions for the regression analysis to follow. As normality of distribution is not an assumption required for regression, these analyses were conducted using untransformed data. Collinearity was examined between variables; Variance Inflation Factor (VIF) values were all substantially below 10, and tolerance values all above 0.1, indicating that collinearity did not exist between predictor variables (Pallant, 2010). Linearity of the logit was examined; interactions between each predictor variable and its log transformation were all found to be non-significant, therefore indicating the assumption was met and a linear relationship exists between predictors and the outcome variable (Field, 2009).

Examination of demographic variables

The effects of demographic variables on the outcome variable (presence or absence of PD) were explored in order to examine their relationships. Pearson correlations and Chi-square goodness of fit tests were used. Chi-squared tests indicated that the following factors were not found to be significantly associated with the presence or absence of PD: sex of the participant, $\chi^2(1, N = 39) = 2.12, p = 0.15$, and ethnicity, $\chi^2(1, N = 39) = 0.94, p = 0.33$. Having a family history of PD, smoking, and level of education had categories with expected frequencies of less than 5; therefore Fisher's Exact test was used. No significant association was found between the presence or absence of PD and the following factors: family history of PD, $\chi^2(1, N = 39) = 1.12, p = 0.82$, whether the person was a smoker, $\chi^2(1, N = 39) = 1.12, p = 0.45$, or level of education, $\chi^2(1, N = 39) = 3.58, p = 0.70$. This suggests that the two groups of participants were similar with regard to these factors. However, on average, control group participants were found to be older ($M = 75.00, SE = 1.69$) than PD participants

($M = 70.47$, $SE = 1.19$). This difference was significant $t(37) = 2.19$, $p < 0.05$, which represents a medium effect size.

Hypotheses 1-4

Planned analysis:

It was hypothesised that there would be a relationship between the presence or absence of PD and the following variables: number of stressful life events (hypothesis 1), task-oriented coping (hypothesis 2), emotion-oriented coping (hypothesis 3), and avoidance-oriented coping (hypothesis 4). Hypothesised relationships were investigated through conducting a series of point-biserial correlations between the outcome variable (presence or absence of PD) and totals on the following scales: THQ, CISS task-oriented coping, CISS emotion-oriented coping, and CISS avoidance-oriented coping. Due to the exploratory nature of hypotheses, correlations were calculated based on a two-tailed test of significance.

Findings of analysis:

Table 2 presents a correlation matrix of the results of the analyses. Number of stressful life events was shown to have a statistically significant relationship to the presence or absence of PD, $r_{pb} = .60$, $p < .01$ (hypothesis 1). As the correlation coefficient represents effect size (Field, 2009), this relationship had an effect size of .60, indicating a large effect size for this relationship according to Cohen (1988). Emotion-oriented coping was also shown to have a statistically significant relationship to the presence or absence of PD, $r_{pb} = .38$, $p < .05$ (hypothesis 3), with an effect size of .38 indicating a medium effect size for this

relationship (Cohen, 1988). However, as shown in Table 2, there was no statistically significant relationship between either task-oriented coping ($r_{pb} = .25$, $p = .13$) or avoidance-oriented coping ($r_{pb} = .13$, $p = .44$) and the presence or absence of PD (hypotheses 2 & 4).

Table 2

Correlation matrix between all predictor variables and outcome variable (presence or absence of PD)

	THQ	CISS TOC	CISS EOC	CISS AOC
Outcome grp ^a	.60**	.25	.38*	.13

Note. THQ = Trauma History Questionnaire Total score; CISS TOC = CISS Task Oriented Coping subscale; CISS EOC = CISS Emotion Oriented Coping subscale; CISS AOC = CISS Avoidance Oriented Coping subscale; Outcome grp = Outcome group, whether PD is present or absent.

^a All correlations associated with Outcome grp were analysed using Point-Biserial correlations due to this being a discrete dichotomous variable.

* $p < .05$. ** $p < .01$.

Hypothesis 5

Planned analysis

It was hypothesised that psychological factors (experience of stressful life events and coping style) will have a direct effect in predicting of presence or absence of PD. This was tested by entering variables found to be significantly correlated with the outcome group into a binary logistic regression analysis. These variables were stressful life events, as measured by the THQ, and emotion-oriented coping, as measured by the CISS EOC sub-scale. Regression

analysis was conducted using the forced entry method, with the demographic variable of age added as a covariate into step one to control for its effect, and the predictor variables added at step two.

Findings of analysis

Results indicated that the direct effects model containing the two predictor variables of number of stressful life events and emotion-focused coping was statistically significant, omnibus $\chi^2 (1, N = 39) = 20.32, p < .01$. The model was shown to explain between 47.2% (Cox and Snell, R squared) and 62.9% (Nagelkerke, R squared) of the variance in whether participants would have PD or not. Analysis suggested that the model correctly classified 74.4% of cases, indicating the model was sensitive (Pallant, 2010). Table 3 shows that both predictor variables tested were significant direct predictors of presence or absence of PD. Number of stressful life events was the strongest predictor, with an odds ratio of 2.60 indicating that as the number of stressful life events increases, the likelihood of having PD increases by 2.6 times. Emotion-oriented coping recorded an odds ratio of 1.08, indicating that those who had PD were 1.08 times more likely to report using emotion-oriented coping than those without PD.

Table 3

Logistic regression analysis for psychological factors predicting the presence or absence of PD

Predictor	B	SE	Wald	p	Exp(B)	95% CI for Exp(B)	
						Lower	Upper
Constant	2.41	6.39	.14	.71	-	-	-
THQ	.96	.33	8.22	.004**	2.60	1.353	4.993
CISS EOC	.08	.039	4.11	.043*	1.08	1.003	1.169

Note. Age controlled for but omitted from Table; THQ = Trauma History Questionnaire Total score; CISS EOC = CISS Emotion Oriented Coping subscale

*p < .05. **p < .01.

Hypothesis 6

Planned analysis

It was hypothesised that coping style will have a moderator or “buffering” effect between number of stressful life events experienced and the presence or absence of PD.

Tests of moderation were performed using a logistic regression analysis. The method used was that described by Baron and Kenny (1986), which states that when regressed on the dependent variable, moderator effects are demonstrated when a significant interaction effect is found between the predictor and moderator variable, whilst the direct effects of the moderator and predictor variable are controlled.

Although no significant direct relationship was found between number of stressful life events and the variables of task-oriented coping and avoidant coping (hypotheses 2 & 4), it remains possible that the interaction between these variables is significant (Aldwin, 2007); therefore, moderation analysis included these variables. Separate analyses were conducted for each moderator variable. Again, as in analysis for hypothesis 5, regression analysis was conducted using the forced entry method, with the demographic variable of age added as a covariate into step one to control for its effect. The variables of number of stressful life events (predictor variable) and coping style sub-scale (moderator variable; task-oriented coping, emotion-focused coping or avoidant coping) were added to step two to control for the direct effects of these, then the interaction term was added at step three.

Findings of analysis

Tables 4, 5, and 6 display the results of individual logistic regression analyses for the moderating effect of each coping sub-scale between number of stressful life events and presence or absence of PD. Results show that there were no statistically significant interactions between number of stressful events and either task-oriented coping (Table 4), emotion-oriented coping (Table 5), or avoidance-oriented coping (Table 6). This therefore indicates that coping style does not have a moderator or “buffering” effect between number of stressful life events experienced and the presence or absence of PD.

Table 4

Logistic regression analysis for the moderator effect of task-oriented coping style between stressful life events and the presence or absence of PD

Predictor	B	SE	Wald	p	Exp(B)
THQ	.96	.33	8.22	.004	2.60
CISS TOC	.04	.049	.675	.411	1.04
THQ x CISS TOC	-.001	.03	.002	.968	.99

Note. Age controlled for but omitted from Table; THQ = Trauma History Questionnaire Total score; CISS TOC = CISS Task Oriented Coping subscale

Table 5

Logistic regression analysis for the moderator effect of emotion-oriented coping style between stressful life events and the presence or absence of PD

Predictor	B	SE	Wald	p	Exp(B)
THQ	.96	.33	8.22	.004	2.60
CISS EOC	.079	.039	4.11	.043	1.08
THQ x CISS EOC	.036	.021	2.78	.095	1.04

Note. Age controlled for but omitted from Table; THQ = Trauma History Questionnaire Total score; CISS EOC = CISS Emotion Oriented Coping subscale.

Table 6

Logistic regression analysis for the moderator effect of avoidance-oriented coping style between stressful life events and the presence or absence of PD

Predictor	B	SE	Wald	p	Exp(B)
THQ	.80	.272	8.69	.003	2.23
CISS AOC	.02	.041	.324	.569	1.02
THQ x CISS AOC	.016	.020	.649	.421	1.02

Note. Age controlled for but omitted from Table; THQ = Trauma History Questionnaire Total score; CISS AOC = CISS Avoidance Oriented Coping subscale.

Discussion

The purpose of the current study was to investigate the relationship between Parkinson's disease, the experience of stressful life events and coping style. It was hypothesised that there would be significant relationships between the presence or absence of PD and the variables of stressful life events, problem-focused coping, emotion-focused coping and avoidant coping, and that these psychological factors would have a direct effect in predicting the likelihood of PD. It was also hypothesised that coping style would moderate the relationship between stressful life events and coping.

Three of the above hypotheses were supported by the findings of this study; that there is a significant relationship between stressful life events and the presence of PD, a significant relationship between emotion-focused coping and the presence of PD, and that these were

both significant predictors of PD. These results will be reviewed below, alongside potential reasons for the non-significance of results for the remaining hypotheses.

Stressful life events and Parkinson's disease

Firstly, it is important to acknowledge that the retrospective design used here may be considered by some to be a limitation of the study of life-time events. However, although in their review of the validity of retrospective reports of adverse life events, Hardt and Rutter (2004) note that there is some bias towards reporting false-negatives in such studies, they conclude that this does not invalidate results of studies relating to major adversities that can be easily defined. Therefore, as the current study measures non-normative, potentially traumatic life events, and there is no reason to believe that any bias in reporting would affect one group over another, the current results are considered to be a valid representation of events experienced.

Findings of the current study indicate that there is a relationship between life time experiences of non-normative, stressful life events and the presence of PD. This is an interesting finding, given this is the first study to investigate this relationship with regard to PD in a community sample, and it is consistent with previous neurological studies relating to MS (i.e. Li et al, 2004). However, generalisability of this finding is limited to those who have experienced non-normative and possibly traumatic life-events, as measured by the THQ. Limited conclusions can also only be drawn from this initial finding due to an inherent limitation of the correlational design used to establish this relationship, which does not allow conclusions to be drawn with regard to the direction of the effect, therefore limiting comparison with previous research. It does, however, enable calculation of the effect size of

the finding, which indicates that the relationship between non-normative stressful life events and PD is a strong one. It is worthwhile treating this finding with a degree of caution, as although the sample size indicated there was adequate statistical power for identifying a significant effect, this is the first study to investigate this relationship, and therefore further research using a larger sample would be recommended to replicate the finding before drawing firm conclusions.

When both predictors found to be significantly related to the presence of PD were entered into the logistic regression model in a single step, the variable of stressful life events was found to be the most significant predictor of PD. This result provides information regarding the direction of the relationship found above, as the odds of having PD are 2.6 times higher for a person who reports having experienced a higher number of non-normative stressful life events than for a person who reports having experienced a lower number of non-normative stressful life events. The current findings are therefore consistent with previous MS studies that found an increased risk of illness in those who had experienced stressful events (i.e. Buljevac et al., 2003). It also goes some way to supporting the argument that non-normative events can have a deleterious impact on a person's health (Ryff & Heidrich, 1997). However, it is also notable that this finding is in direct contrast with the one other PD study (Rod et al., 2010) to investigate this relationship, which found an inverse relationship between the experience of stressful life events and PD in men, and no relationship with regard to women. One possible reason for this disparity could be the difference in events measured in each study. Rod et al. (2010) measured a limited number of both normative and non-normative events for use in their analysis, whereas the THQ used in the current study focussed on a wider range of specifically non-normative, potentially traumatic events. Therefore, given that non-normative events are associated with deleterious impact on health,

whereas normative events are associated with promoting well-being (Ryff & Heidrich, 1997), this could potentially explain the difference found.

Given that Rod et al.'s (2010) research is the only other example of a study to have tested the hypothesis of a relationship between stressful life events and PD, it is also possible that either the findings from that study, or the findings from this study, may represent a chance result. This possibility makes replication of the current research important in order to clarify this point. If the current research findings do indicate the 'true' nature in terms of the relationship between stressful life events and the presence of PD, this would indicate a need to consider possible interventions for individuals identified as having experienced a number of non-normative and possibly traumatic stressful events in their life, such as those measured by the THQ. Given that the current findings represent the presence of PD and not specifically the onset or progression of the disease, such interventions would need to be inclusive of both those without a diagnosis of PD, taking a preventative approach, and those with PD, to ameliorate the impact of such events in terms of disease progression, in order to address the possible associated health implications.

Methodologically, the current study did not meet the minimum numbers needed for regression analysis, therefore was limited in this regard. However, it is interesting that despite an underpowered sample, a significant result has been found in relation to the psychological predictors of PD, particularly in terms of stressful life events, which may in part reflect the above finding of a strong relationship between the two. Findings from the regression analysis may also have been influenced by the use of untransformed data to test the model, as it is possible that outliers in the data had an impact on the predictive ability of the model. Further examination of the data revealed one outlier to be present, but that its residual value did not indicate this to be a clear outlier (Pallant, 2010); therefore, is unlikely

to have influenced the model to a great degree. However, due to the small sample size, it is unclear whether this outlier was simply an unusual result, or a case representative of a different part of the population; caution must therefore be taken in interpreting this result, and a larger scale study would be necessary to clarify this. None the less, this is an important finding as it is the first time an increase in the experience of stressful life events has been associated with an increased likelihood of having PD, and therefore future research would be warranted to further investigate this relationship.

Coping style and Parkinson's disease

Research findings support the hypothesis of a direct relationship between emotion-oriented coping and the presence of PD. Although this is the first study to investigate the direct relationship between coping and PD, it extends findings of previous research by Frasier (2000) who found that emotional coping is the most commonly employed style of coping in those with PD in relation to disease related stressors. Given the premise that coping style is a stable personality factor over time, independent of type of stressor (Endler & Parker, 1990b), this is perhaps not a surprising result. Sample size indicated adequate statistical power for identifying a significant relationship, and a medium effect size was found, indicating the relationship between emotion-oriented coping and PD is of moderate strength. However, as this was the first time this relationship has been investigated, findings should be interpreted with caution until replicated by further research. As above, it is also acknowledged that findings are limited due to the correlational design used, which does not enable conclusions to be drawn with regard to direction of the relationship.

When entered into the logistic regression model and tested as a predictor of PD, the emotion-oriented coping was found to be a statistically significant predictor, indicating that individuals who reported increased levels of emotion-oriented coping had an 8% increased chance of having PD. This is consistent with the general coping literature that proposes emotion-focused coping is associated with poor health outcomes (Lovullo, 1997), and does not support the proposal that emotion-focussed coping has a positive effect on health in relation to adverse life events (Aldwin, 2007). However, this finding accounts for a relatively small (8%) variability between groups. Therefore, although results were significant, it is difficult to draw firm conclusions about the relationship with any certainty, especially given the obvious limitation of the small sample size in the current study. Again, as the sample size did not meet statistical power needed for regression, it is interesting that a significant effect was found. It could be that this was a chance result, amplified due to the small sample size, or it may be that the finding is a true, but small, representation of the relationship between emotion-oriented coping and PD. The finding from hypothesis three of a medium effect size of this relationship supports the latter explanation; however, a larger scale study is warranted to clarify this finding. The finding that emotion-focussed coping is a significant predictor of PD should therefore be considered tentative until further research has replicated the result.

Neither problem-focused coping nor avoidant coping were found to have a significant relationship with PD in the current study. Given previous research in the field of coping and illness this is somewhat surprising. For example, previously, avoidant coping has been significantly positively correlated, and problem-focused coping significantly negatively correlated, with the progression of illnesses such as HIV (Vassend, et al., 1997). As the sample size for these correlations suggested there was adequate statistical power to identify any significant findings if there were any, it is likely that these findings are indicative of no

relationship between these variables and PD in the current sample. As this is the first study to investigate the direct relationship between coping and PD, it may be this disparity in results indicates that coping styles are associated with a differential impact in relation to different illnesses or disorders. Another potentially influential factor that may account for this discrepancy between findings is a difference in the measures used to evaluate style of coping in relation to health outcome; a variety of measures have been previously used to investigate such relationships, however this is the first example found of the use of the CISS, therefore limiting comparison between findings.

The findings of this study also indicate that coping style does not have a moderator or “buffering” effect in the relationship between stressful life events and PD. Although no previous studies have investigated this relationship in relation to PD, this finding is partially in contrast to the previous neurological disorder study that investigated coping as a moderator between stress and exacerbation of MS (Mohr et al., 2002), which found distraction (one aspect of avoidant coping) to be a significant moderator of the relationship. There are several possible reasons why this finding was not replicated in the current study. Firstly, it is important to recognise that although MS and PD are both neurological conditions, they remain two distinct disorders, and as such may be associated with interactions between different predictive factors. Secondly, methodological reasons, such as the lack of statistical power for regression analysis as discussed above, may have influenced findings in the current study. Mohr et al. (2002), who also had a small sample size, report a non-significant, marginal trend towards emotional coping as a moderator between stress and exacerbations in MS. A similar trend was also seen in the current study. Conclusions obviously cannot be drawn on this due to the non-significance of the finding; however, as the current sample size was underpowered to find a significant effect, a future larger scale study would be warranted

to investigate the possibility of this relationship further. Given the finding of a significant relationship between non-normative stressful life events and PD, as well as the progressive nature of PD, it is clinically important in terms of future approaches to care to identify factors that may moderate this relationship.

Conclusion

In conclusion, findings from the current research suggest that there is a relationship between number of non-normative stressful life events experienced and the presence of PD, and to a lesser extent that emotion-oriented coping is also related to the presence of PD; both findings are consistent with existing research relating to stress, coping and illness. Findings do not suggest a relationship between problem-focused or avoidant oriented coping and PD, or that coping style moderates the relationship between stressful life events and PD. Finally, the current finding, that non-normative stressful life events and emotion-oriented coping are significant predictors of PD, supports the importance and contribution of psychological factors in relation to PD. However, due to methodological limitations of the current research, and paucity of other empirical evidence in the field, replication of the current findings would be essential.

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Major Research Project

SECTION C

Critical Appraisal

Word Count: 1986 (plus 1 additional word)

Contents

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Critical Appraisal

The research study presented in this portfolio aimed to investigate the relationship between stressful life events, coping style and Parkinson's disease (PD). The current paper will present a critical appraisal of this research study. This will be done by addressing four questions asked by the course for this purpose.

Question 1: What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

In carrying out this research I have learned a great deal about how to conduct a project of this scale within the NHS, something I have not previously done. The prospect of conducting a study in an area in which very little has been written was initially both exciting and daunting. Meeting with my external supervisor, a Clinical Health Psychologist, and the Parkinson's disease Nurses, hearing of their observations and experiences, and seeing their enthusiasm for the project was therefore valuable in the early stages of designing the project. From this I learned the importance of linking in with a wider network of professionals who have in-depth knowledge of the research area of interest. Although it was tempting to take these early ideas and enthusiasm and rush into the design phase of the research, I learned the importance of grounding the research in the context of an existing evidence-base. This was challenging due to the paucity of specific evidence relating to PD, but needing to widen my focus at this point enabled me to familiarise myself with the wider theoretical and empirical literature, which in turn helped to develop meaningful hypotheses.

The use of a retrospective design for the study presented some challenges, for example in how to measure the variables of interest, especially in terms of how to retrospectively measure stressful events that had occurred across the life span. A number of studies in this area had used a prospective design, and could therefore utilise more well established standardised questionnaires asking about recent events; however, given the time frame, a prospective design was beyond the scope of the current study. From this I learned the value of taking the time to conduct a thorough search of previous literature that had retrospectively studied events across the life-span, especially the literature pertaining to the reliability and validity of the measures in terms of clinical samples, prior to choosing a measure for the current project.

In terms of gaining approval from appropriate organisations to conduct research in an NHS context, I have developed a keen awareness of the time that this can take, and the sometimes unanticipated parts of the process that might be involved, for example the requirement to attend a Trust Good Clinical Practice training day. I have learned the value of starting the processes as early as feasibly possible, whilst keeping in constant communication and liaising between different organisations to ensure all relevant documentation has been provided. I have also learned the benefits of using a clear and direct style of communication to convey time scales involved.

In terms of conducting the research, at times the research visits exceeded the expected maximum of 45 minutes, as some participants talked in more detail about their experiences than anticipated given the requirements of the study. I found it difficult at times not to respond as a clinician to the past distress that was being conveyed at times, but feel that I learned how to adopt the role of researcher, whilst also being aware of my ethical responsibilities and duty of care should someone become actively distressed in the room.

However, on reflection I think I need to further improve my skills in terms of being time-boundaried within this context. On a practical note with regard to carrying out future research, I would also need to learn more about the process of securing funding. I am aware that this is one aspect of the research process I have no firsthand experience of as yet, and that beyond the course it would be a vital part of any future research.

Question 2: If you were able to do this project again, what would you do differently and why?

I failed to anticipate the length of time that the recruitment stage of the project would take; therefore, if I were to do the project again, I would do a few things differently in order to maximise the recruitment potential, and to achieve the number of participants needed for statistical power at an earlier stage of the project. Firstly, I would be more pro-active and direct earlier on in liaising with the relevant Research and Development department to ensure the process of approval was as swift as possible. Secondly, although I approached the Parkinson's disease Nurse Specialists very early on in the process to plan recruitment, I underestimated how long the process would actually take, given that they are very busy professionals whose first priority was not recruitment to the research, despite their enthusiasm. I would also approach older adult organisations earlier on to facilitate recruitment of control participants, as again this part of the study took longer than anticipated. Finally, I would also consider widening the recruitment area, and having a secondary area to approach if needed. In terms of PD participants, this would involve forward planning in applying to more than one NHS Trust Research and Development Department.

During the design phase of the study, a great deal of consideration was given ethically to the possible impact on participants of being asked about stressful and potentially traumatic life events, and plans were made for accessing further support if needed. Detailed information about events was not a requirement of the study, and this was emphasised to participants during our meetings; however, a number of people did talk in more detail about the events they had experienced. On reflection, I had not fully appreciated the possible impact that hearing such events might have on me as a researcher. I valued supervision and support given in respect of this; however, if I were to do the project again, I would schedule more regular research supervision for this purpose.

Question 3: Clinically, as a consequence of doing this study, would you do anything differently and why?

I have very little clinical experience of working psychologically with people with physical health conditions, and I feel I have learned a lot through the process of conducting this study, in terms of the wide ranging impact that psychological factors such as stress and coping can have on a person in terms of their physical health. In my clinical practice, I ordinarily ask during assessment about significant life events that the client feels may have contributed to their difficulties. In conducting this study I have learned that people, especially those of an older generation, may have experienced events during their life that potentially have had, or could have, an impact on their health. From participant responses, I have also realised that people may not always recall these events, or consider them relevant or important enough to report until asked. This is consistent with an observation made by Golden-Kreutz et al. (2005), who stated that although those who have experienced violent or

traumatic events make more use of health care services, the consequences of previous events are not always visible and often hidden from health services.

Having had this experience, I will be try to sensitively but explicitly ask clients about any potentially stressful or traumatic life events, even those that do not seem relevant, with a view to incorporating these into the client's clinical formulation, especially as evidence suggests that stress can increase the risk of both physical and psychological health difficulties (Turner & Wheaton, 1997). As a consequence of doing this project, I now also have a greater understanding of different coping styles, and the differential impact these may have in relation to health. Clinically, this understanding will enable me to be more focused in my assessment of how a person copes with adversity, and to understand more fully the role that this might be playing in their difficulties, therefore helping inform appropriate interventions where necessary.

On a service level, PD is most often seen within a medical model framework, for which solely medical interventions are provided. Given that the findings of the current study suggest psychological factors are also related to PD, clinically I feel it would be important where possible to actively recommend that PD services invest in the provision to either offer psychological services to their clients, or to put people in touch with identified external organisations that can provide such support if identified as a need. In conducting this study, my own observation of the availability of psychological services for people with PD is that it is very limited, with only one of the two PD teams in the research locality having albeit limited access to a clinical psychologist. This is consistent with Macniver (2009) who noted that clinical psychology service provision in the UK for those with PD is scarce.

Question 4: If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

This was the first study to investigate the relationship between these particular variables and PD in a community out-patient sample. Therefore, due to the encouraging findings from the current pilot study, I would firstly seek to extend and build on this in order to further explore and replicate the findings of the current project and work towards developing the evidence-base. I would initially do this by using the same design and method to undertake a larger scale study of the current research project. I would increase the sample size to a minimum of 15 cases per predictor variable. If number of participants allowed, I might also want to do a post hoc analysis to investigate whether there was a differential effect of coping style on PD in relation to the different types of stressful event (i.e. crime related, natural disaster). In doing this, I would seek to further explore the potential complexity of the relationship between coping style and adverse life events as proposed by Aldwin (2007), who suggested that the effect of coping style in relation to physical health varies according to the perceived controllability of the stressful event. It would be important to build on the evidence base in this way before further conclusions are drawn with regard to the relationships between stressful life events, coping style and PD.

I would then also be interested in extending research in this area, by again using a similar design, in order to explore other variables that might have direct or moderating effects in relation to PD. I would initially focus on the variable of cognitive hardiness, as this, like coping style, has long been proposed as a protective mechanism in relation to health (Nowack, 1989), and has also been found to mitigate the relationship between stress and illness (Kobasa, 1979). More recent research has also found that cognitive hardiness has a direct impact on somatic distress and in moderating the effects of both stressful life events

and emotional coping on psychological distress (Beasley, Thompson, & Davidson, 2003). Thus, it might be that cognitive hardiness has a direct relationship with PD, and that it may also moderate the effects of stressful life events and emotion-oriented coping on PD, which might further explain relationships found between variables in the current study. The study would use the same measures of stressful life events and coping style as the current project to enable comparison between studies, and could use the Cognitive Hardiness Scale (CHS; Nowack, 1990), a standardised self-report questionnaire, to measure cognitive hardiness. Given that this would increase the number of predictor variables in the analysis, I would again increase the number of participants needed to establish statistical power and increase the strength of any results.

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SECTION D

Appendix of Supporting Material

Appendix A

Literature review search strategy

An electronic search was conducted initially to identify relevant literature, using the following databases: PsychINFO, Medline, EBM Reviews and NINDS Parkinson's disease research web (maintained by the National Institute of Neurological Disorders and Stroke).

An advanced search was conducted using the search terms *Parkinson's* disease, neurological disorder, physical illness, in combination with the terms stress, stressful life events, adverse life events, psychological trauma, psychological stress, and the terms coping style, coping strategies, aetiology, physiopathology, risk factor and moderator. All published literature to date was included (final search conducted May 2011), and terms were 'exploded' where possible to maximise and expand the search.

The initial search generated a large number of results; therefore the search was limited to peer reviewed journal articles and book chapters, published in English. Abstracts were then screened to determine appropriateness for the review; empirical and theoretical publications regarding the relationships of interest were sought. A manual search of references was also undertaken of the appropriate publications.

PARTICIPANTS NEEDED FOR RESEARCH

I am looking for volunteers to take part in a study investigating the relationship between stressful life events, coping style and Parkinson's disease.

Volunteers will be part of a control group for the study, and I hope you will consider participating if you:

- Are aged 65 or over,
- Are not diagnosed with Parkinson's disease or any other neurological disorder (such as Multiple Sclerosis or dementia)
- Do not have a severe and debilitating chronic health condition

As a participant, you would be asked to complete two 'tick box' questionnaires: one asking if you have experienced certain stressful life events (e.g. crime or physical assault related events), and one regarding how you cope in stressful or difficult situations. Responses will remain completely anonymous and you will not be identifiable in any published research articles.

Participation would involve one meeting with the researcher, lasting approximately 45 minutes at a location convenient to you (at home or local NHS building). Travel costs will be reimbursed.

To volunteer for this study, or if you would like to find out more, please contact:

Helen Underwood
Trainee Clinical Psychologist

on

 hu8@canterbury.ac.uk

or

 **01892 507 673** (please give my name when leaving a message)

*This study has been reviewed and approved by an NHS Research Ethics Committee,
REC Reference Number: 10-H1101-49*

Appendix C

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Appendix G

[NHS Trust Header]



Salomons Campus at Tunbridge Wells

PARTICIPANT INFORMATION SHEET

Research study: Investigating the relationship between stressful life events, coping style and Parkinson's disease.

I would like to invite you to take part in a research study. Before you decide to take part, it is important that you understand why this research is being done and what it will involve.

Please take time to read the following information carefully and feel free to discuss it with other people if you wish.

If anything is not clear, or you would like more information, please contact me on the number or email at the bottom of this sheet.

What is the purpose of the study?

I am a trainee clinical psychologist and I am carrying out this study as part of my doctoral degree.

Parkinson's disease is the second most common neurological disorder after Alzheimer's disease; however, we currently do not know the cause of the disease. Researchers have found that certain risk factors may increase a person's chances of developing the disease, such as family history of Parkinson's disease and exposure to pesticides.

I aim to find out if the number of stressful life events a person has experienced, and their style of coping in difficult situations, are also factors that may contribute to a person's chances of having Parkinson's disease.

Why have I been invited?

You have been chosen to participate in this study because you have been diagnosed with Parkinson's disease. I will be inviting people with Parkinson's disease and people who do not have Parkinson's disease to take part.

Do I have to take part?

It is up to you to decide. If you do decide to take part, you will be asked to sign a consent form; however you will be free to withdraw at any time from the study and do not need to give a reason. This will have no effect on health services you receive now or in the future.

What would taking part involve?

I would arrange a time to meet with you on one occasion for an interview, either at a local NHS site or a location convenient to you such as your home. Any travel costs incurred would be repaid. The interview should take approximately 45 minutes, and would involve firstly answering any questions you have about the study and asking you to read and sign a consent form to take part. I would then ask you to complete two questionnaires:

- The first requires you to indicate whether or not you have experienced particular stressful or possibly traumatic life events (with regard to crime, general disaster and physical and sexual assault) and if so how many times and age at the time.
- The second is a 'tick box' questionnaire that requires you to rate how much you use certain types of activities to cope in stressful or difficult situations.

I would offer to sit with you and read out the questions, although as some questions are quite personal you may wish to complete the questionnaires on your own or with the help of a friend or partner. Once the interview has ended you will not be asked to do anything else and your involvement in the study will be finished.

Are there any disadvantages of taking part?

In the interview, questions will be asked about past life events that some people may find distressing. However, both questionnaires ask for limited information, as described earlier, and detailed information about experiences will not be required. Anyone who becomes distressed will be given the chance to take a break before deciding whether to continue. If further support is needed, contact details will be given of people or organisations that may provide this support. Parkinson's disease nurses may also be informed in order to provide additional support.

What are the possible benefits of the taking part?

Whilst there are no immediate benefits for those taking part in this study, it is hoped that this work will help us to develop a greater understanding of the psychological risk factors that may increase the chances of developing Parkinson's disease.

What about confidentiality?

All information collected as part of this project will be anonymous and kept strictly confidential in accordance with the Data Protection Act (1998). To assure this, those who take part will be assigned a participant number and anonymous information will only be accessible to me and my supervisors. I will not be informing your GP that you are taking part.

What will happen to the results of the study?

The results of the study will be written up and submitted as part of my doctorate degree. The results will also be given to the NHS trust, and it is hoped that the results will be published in a professional journal. In these reports it will not be possible to identify any individual who has taken part. Everyone who participates will be given the option to receive a written summary of the results.

All data relating to this study will be kept for ten years, in accordance with the Data Protection Act (1998). It will be stored securely and you will not be identifiable as names will not be recorded.

Who is funding the study?

Canterbury Christ Church University is funding the study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, well-being, rights and dignity. This study has been reviewed and approved by the Kent Research Ethics Committee. Approval has also been given by the Research and Development Department of [NHS Trust].

What if I want to make a complaint about the study?

If you wish to complain or have concerns about how you were treated during the study, please contact Dr Paul Camic (Clinical Research Director) by writing to him at the Department of Applied Psychology, Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent, TN3 0TG, or by calling **01892 507 773**. Alternatively, if you would like independent advice, you can contact your local Patient Advice and Liaison Service (PALS) on [XXX] for the [XXX] area, and [XXX] for the [XXX] area.

Contact details for further information

If you have any questions or concerns about the study, please contact me by either emailing hu8@canterbury.ac.uk, or by leaving a message on the following answering service and I will contact you as soon as possible: **01892 507 673**. If leaving a message, please state that it is for Helen Underwood and also leave your name and contact number.

Thank you for taking the time to read this and for considering taking part in this study.

PARTICIPANT INFORMATION SHEET

Research study: Investigating the relationship between stressful life events, coping style and Parkinson's disease.

I would like to invite you to take part in a research study. Before you decide to take part, it is important that you understand why this research is being done and what it will involve. Please take time to read the following information carefully and feel free to discuss it with other people if you wish.

If anything is not clear, or you would like more information, please contact me on the number or email at the bottom of this sheet.

What is the purpose of the study?

I am a trainee clinical psychologist and I am carrying out this study as part of my doctoral degree.

Parkinson's disease is the second most common neurological disorder after Alzheimer's disease; however, we currently do not know the cause of the disease. Researchers have found that certain risk factors may increase a person's chances of developing the disease, such as family history of Parkinson's disease and exposure to pesticides.

I aim to find out if the number of stressful life events a person has experienced, and their style of coping in difficult situations, are also factors that may contribute to a person's chances of having Parkinson's disease.

Why have I been invited?

To establish whether stressful life events and coping style may contribute to the risk of having Parkinson's disease, it is important to find out about the life events and coping styles

of those who do not have Parkinson's disease, to see if these differ from those with the disease. You have been chosen to participate in this study because you do not have a diagnosis of Parkinson's disease. I will be inviting people with Parkinson's disease and people who do not have Parkinson's disease to take part.

Do I have to take part?

It is up to you to decide. If you do decide to take part, you will be asked to sign a consent form; however you will be free to withdraw at any time from the study and do not need to give a reason.

What would taking part involve?

I would arrange a time to meet with you on one occasion for an interview, either at a local NHS site or a location convenient to you such as your home. Any travel costs incurred would be repaid. The interview should take approximately 45 minutes, and would involve firstly answering any questions you have about the study and asking you to read and sign a consent form to take part. I would then ask you to complete two questionnaires:

- The first requires you to indicate whether or not you have experienced particular stressful or possibly traumatic life events (with regard to crime, general disaster and physical and sexual assault) and if so how many times and age at the time.
- The second is a 'tick box' questionnaire that requires you to rate how much you use certain types of activities to cope in stressful or difficult situations.

I would offer to sit with you and read out the questions, although as some questions are quite personal you may wish to complete the questionnaires on your own or with the help of a friend or partner. Once the interview has ended you will not be asked to do anything else and your involvement in the study will be finished.

Are there any disadvantages of taking part?

In the interview, questions will be asked about past life events that some people may find distressing. However, both questionnaires ask for limited information, as described earlier, and detailed information about experiences will not be required. Anyone who becomes distressed will be given the chance to take a break before deciding whether to continue. If

further support is needed, contact details will be given of people or organisations that may provide this support.

What are the possible benefits of the taking part?

Whilst there are no immediate benefits for those taking part in this study, it is hoped that this work will help us to develop a greater understanding of the psychological risk factors that may increase the chances of developing Parkinson's disease.

What about confidentiality?

All information collected as part of this project will be anonymous and kept strictly confidential in accordance with the Data Protection Act (1998). To assure this, those who take part will be assigned a participant number and anonymous information will only be accessible to me and my supervisors. I will not be informing your GP that you are taking part.

What will happen to the results of the study?

The results of the study will be written up and submitted as part of my doctorate degree. The results will also be given to the NHS trust, and it is hoped that the results will be published in a professional journal. In these reports it will not be possible to identify any individual who has taken part. Everyone who participates will be given the option to receive a written summary of the results.

All data relating to this study will be kept for ten years, in accordance with the Data Protection Act (1998). It will be stored securely and you will not be identifiable as names will not be recorded.

Who is funding the study?

Canterbury Christ Church University is funding the study.

Who has reviewed the study?

All research involving NHS patients is looked at by an independent group of people called a Research Ethics Committee to protect your safety, well-being, rights and dignity. As this study involves Parkinson's disease patients from within the NHS, it has been reviewed and

approved by the Kent Research Ethics Committee. Approval has also been given by the Research and Development Department of [NHS Trust].

What if I want to make a complaint about the study?

If you wish to complain or have concerns about how you were treated during the study, please contact Dr Paul Camic (Clinical Research Director) by writing to him at the Department of Applied Psychology, Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent, TN3 0TG, or by calling **01892 507 773**.

Contact details for further information

If you have any questions or concerns about the study, please contact me by either emailing hu8@canterbury.ac.uk, or by leaving a message on the following answering service and I will contact you as soon as possible: **01892 507 673**. If leaving a message, please state that it is for Helen Underwood and also leave your name and contact number.

Thank you for taking the time to read this and for considering taking part in this study.

Appendix I

[NHS Trust Header]



Centre Number:

Salomons Campus at Tunbridge Wells

Participant Identification Number:

CONSENT FORM

Title of Study:

Investigating the relationship between stressful life events, coping style and Parkinson’s disease.

Name of Researcher:

Helen Underwood, Trainee Clinical Psychologist

Please initial box

- 1. I confirm that I have read and understood the information sheet for the above study (dated 31 August 2010, version 4). I have had the opportunity to ask questions, and these have been answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and this will not affect any current or future care.
- 3. I understand that my responses will be anonymised, and that I will not be identifiable in the write-up of Helen Underwood’s research or any paper that is submitted for publication.
- 4. I agree to take part in this study.
- 5. I understand that the research data collected during the study may be looked at by other individuals from the research team, sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

Please circle

- 6. I would like to receive a summary of the findings of this study. Yes / No

Name (please print): Date: Signature:

Researcher: Date: Signature:

Appendix J

[NHS Trust Header]



Salomons Campus at Tunbridge Wells

Centre Number:

Participant Identification Number:

Demographic Information:

Sex: male / female

Age:

Ethnicity:

Family history of PD: yes / no - if yes, participants relationship to person (s)

.....

Highest educational qualification:

Smoker: yes / no

Appendix K

Template cover letter to participants: Summary of research findings



Salomons Campus at Tunbridge Wells

Canterbury Christ Church University
Broomhill Road
Tunbridge Wells
Kent
TN3 0TG

[Name of participant]

[Address of participant]

July 2011

Dear Mr / Mrs [participant's surname],

Re. Feedback from your participation my research project entitled 'Investigating the relationship between stressful life events, coping style and Parkinson's disease'.

Thank you again for participating in my research project, I very much appreciated and valued your participation and it was lovely to meet you.

On the consent form, you indicated that you would like to receive a summary of the research findings. I have recently completed the research, and therefore I enclose with this letter a summary of the research findings. The summary contains a description of how I analysed the responses that you and other participants gave to the questionnaires, and what I found out from this.

Many thanks again and best wishes for the future.

Yours sincerely,

Helen Underwood
Trainee Clinical Psychologist

Appendix L

Summary of research findings for participants

Investigating the relationship between stressful life events, coping style and Parkinson's disease: Summary of the research findings

Researcher : Helen Underwood, Trainee Clinical Psychologist,
Canterbury Christ Church University
Supervisors: Dr Jan Rich, Professor Paul Camic

The relationships I was interested in:

Previous research has suggested that there is a relationship between stressful life events and illness, and between coping style and illness. I was interested in investigating whether both stressful life events and coping style were related to Parkinson's disease.

More specifically, I was interested in whether stressful life events are directly related to Parkinson's disease, and whether different styles of coping are directly related to Parkinson's disease. If they are, I was interested to know if they could be used to predict whether a person is likely to have Parkinson's disease or not. Finally, I was also interested in whether a person's style of coping either increases or decreases the impact of stressful events in their relationship with Parkinson's disease.

Participants:

All together, 39 people took part in the project, 19 people with Parkinson's disease and 20 people without Parkinson's disease. Everyone was asked to complete the two questionnaires in the same order that you did.

Analysing the information gathered:

I added up the number of stressful life events that you indicated you had experienced to give a total score. I then added up the numbers you had circled on the coping questionnaire, which gave three scores; one score for task-oriented coping, indicating how much you cope by analysing and solving a problem, a score for emotion-oriented coping, indicating how much you experience and try to reduce emotional distress, and a score for avoidance-oriented coping, indicating how much you avoid or distract yourself from a problem.

I did this for each person's responses to the questionnaires, and the statistical tests I used to investigate the relationships I was interested in were based on *everyone's combined total* scores. This means that your own experiences and ways of coping may not seem to be the same as the results described below. Please be assured, however, that your responses to each questionnaire were included in the analysis.

Findings:

Findings from the research were that:

(1) There is a direct relationship between the number of stressful life events experienced and Parkinson's disease.

(2) There is a direct relationship between using an emotion-oriented style of coping and Parkinson's disease. Neither of the other ways of coping were directly associated with Parkinson's disease.

(3) The likelihood of having Parkinson's disease is 2.6 times higher for people who report having experienced a higher number of stressful life events than those who have experienced fewer stressful life events. Also, people who use higher levels of emotion-oriented coping are 8% more likely to have Parkinson's disease than those who use lower levels of emotion-oriented coping.

(5) None of the coping styles had an effect on the relationship between stressful life events and Parkinson's disease.

As this is the first study to investigate these relationships with people who have Parkinson's disease these are important findings, as they highlight for the first time that psychological factors, specifically stress through the experience of stressful life events and emotion-oriented style of coping, are related to Parkinson's disease. However, further research will need to be done before we can be more certain about these findings, and before firm conclusions are made.

I hope that this summary is helpful, and I would also like to thank you again for taking part in this study and helping me to uncover these findings.

Helen Underwood
Trainee Clinical Psychologist

Appendix M

Cover Letter to Research Ethics Committee: Summary of research findings



Salomons Campus at Tunbridge Wells
Department of Applied Psychology
Canterbury Christ Church University
Broomhill Road
Tunbridge Wells
Kent
TN3 0TG

Ms Sharon Busbridge
Committee Coordinator
Kent Research Ethics Committee
South East Coast Strategic Health Authority
Preston Hall
Aylesford
Kent
ME20 7NJ

11th July 2011

Dear Ms Busbridge,

REC reference number: 10/H1101/49

Study Title: Investigating the relationship between stressful life events, coping style and Parkinson's disease.

Thank you for granting ethical approval for the above research study on 8th December 2010. I am writing to inform you that I have now concluded data collection for the above study. Please find enclosed an end of study form, and a summary report of the research.

Please do contact me if you require any further information.

Yours sincerely,

Helen Underwood
Trainee Clinical Psychologist
Email: hu8@canterbury.ac.uk

Appendix N

Cover Letter to NHS R&D Department: Summary of research findings



Department of Applied Psychology
Canterbury Christ Church University
Broomhill Road
Tunbridge Wells
Kent
TN3 0TG

[R&D Contact]

[R&D Department NHS Trust address]

11th July 2011

Dear [R&D contact],

Study Title: Investigating the relationship between stressful life events, coping style and Parkinson's disease.

R&D Ref No.: TN11-001

Thank you for granting R&D approval for the above research study on 6th January 2011. I am writing to inform you that I have now concluded data collection for the above study. Please find enclosed a summary report of the research.

Please do contact me if you require any further information.

Yours sincerely,

Helen Underwood
Trainee Clinical Psychologist
Email: hu8@canterbury.ac.uk

Appendix O

Summary of research findings for Research Ethics Committee and NHS Trust R&D

Investigating the relationship between stressful life events, coping style and Parkinson's disease: Summary of the research findings

Helen Underwood, Trainee Clinical Psychologist, Canterbury Christ Church University

Supervisors: Dr Jan Rich, Professor Paul Camic

REC Ref: 10/H1101/49

R&D Ref: TN11-001

Background and aims:

Previous theoretical and empirical literature have suggested that there is a direct relationship between the number of stressful life events a person has experienced, and their style of coping, and illness. Evidence also suggests that coping style may moderate the relationship between stressful life events and illness. There has been very little research to see whether psychological factors are related to Parkinson's disease (PD); one study has investigated the relationship between stressful life events and PD, but used a sample that was not representative of the general PD population. Therefore this study aimed to investigate the direct relationship between stressful life events, coping style and PD, and coping style as a moderator in the relationship between stressful life events and PD, in a community based, out-patient sample.

Design:

This study had a quantitative, retrospective, correlational design, and used multivariate statistical methods of analysis.

Participants:

Thirty-nine participants were recruited in the current study. Nineteen participants with PD were recruited through Parkinson's disease Nurse Specialists in one NHS Trust, 9 were male and 10 were female, with an average age of 70. Twenty control group participants were recruited by the researcher through older adult organisations in the same geographical area, of whom 5 were male and 15 were female, with an average age of 75. The groups were found to be similar in terms of gender, but different in terms of age. All participants classed themselves as either White British or White English.

Procedure:

Participants completed two questionnaires; one that measured the number of stressful or possibly traumatic events that they had experienced in their life, and one that measured their style of coping with stressful events. The total scores for number of stressful life events and for each of the three coping styles sub-scales (task-oriented, emotion-oriented, and avoidance-oriented coping) for each participant were then statistically analysed.

Results:

A direct relationship was found between stressful life events and PD, and between emotion-oriented coping and PD. Of these, stressful life events was found to be most predictive of a person's likelihood of having PD, with the odds of having PD found to be 2.6 times higher for a person who reports a higher number of stressful life events than a person who reports a lower number of stressful events. Emotion-oriented coping style was also found to predict whether a person is likely to have PD, although those who reported a higher use of this style of coping were found to be only 8% more likely to have PD than those who used this style of coping less. Coping style was not found to moderate the relationship between stressful life events and PD.

Conclusions:

The current research found that there is a relationship between stressful life events and, to a lesser extent, emotion-oriented coping style and PD. It also found that these factors can successfully contribute to predicting a person's likelihood of having PD. This is an important finding in terms of recognising the contribution that psychological factors can have in relation to PD, although as the first study of its type, it will be important that future research extends and replicates these findings before firm conclusions are drawn. However, these findings may have important implications at a clinical and service level in terms of future approaches to care.

The findings also suggest that coping style does not moderate the relationship between stressful life events and PD. Given the small sample size in the current study, and that it is the first to investigate this relationship in people with PD, it would again be important for future research to further explore and replicate this finding before more firm conclusions can be drawn.

Helen Underwood
Trainee Clinical Psychologist

Appendix P

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Appendix Q

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Appendix R

Inspection of normality of data

The distributions of each scale for each group of participants were inspected through examination of histograms, created using the software programme SPSS (Version 17.0). These are presented below for each scale and sub-scale, each with a comment with regard to their distribution in terms of normality.

Figure Q1 shows the histogram of the Trauma History Questionnaire scale for the non-Parkinson's group, showing that this is positively skewed and therefore not normally distributed. Data for this scale was therefore transformed through a square root transformation (Field, 2009). The histogram of transformed data (Figure Q2) shows that transformed data is normally distributed; therefore parametric tests were used with transformed THQ scores.

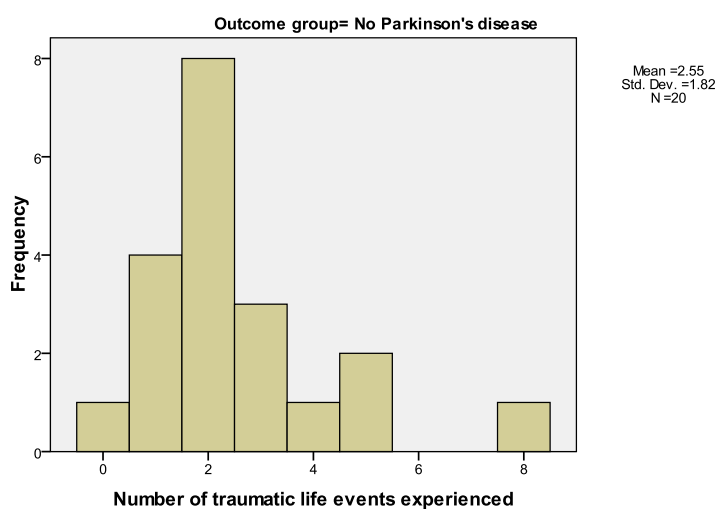


Figure Q1. Histogram of THQ scores for the non-Parkinson's group

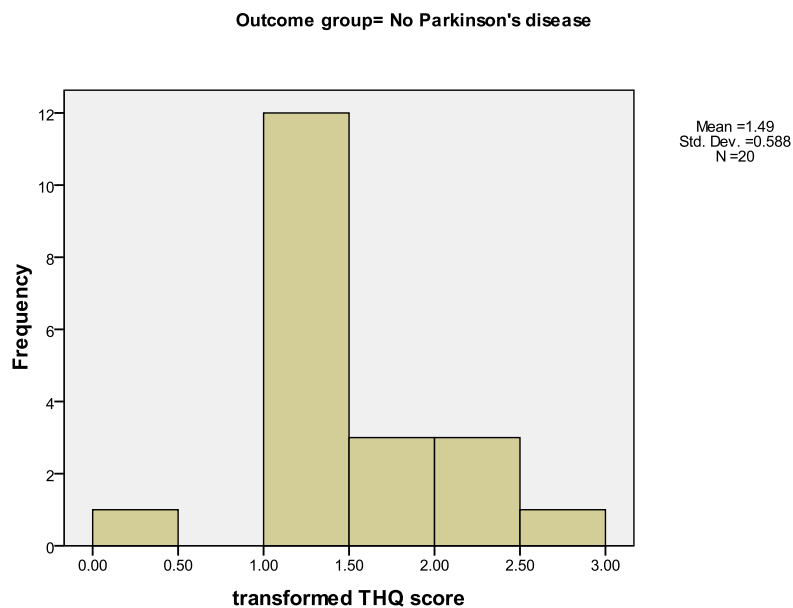


Figure Q2. Histogram of transformed THQ scores for the non-Parkinson's group

Figure Q3 shows the histogram of the Trauma History Questionnaire scale for the Parkinson's group, showing that this is positively skewed and therefore not normally distributed. Data for this scale was therefore transformed through a square root transformation (Field, 2009). The histogram of transformed data (Figure Q4) shows that transformed data is normally distributed, therefore parametric tests were used with transformed THQ scores

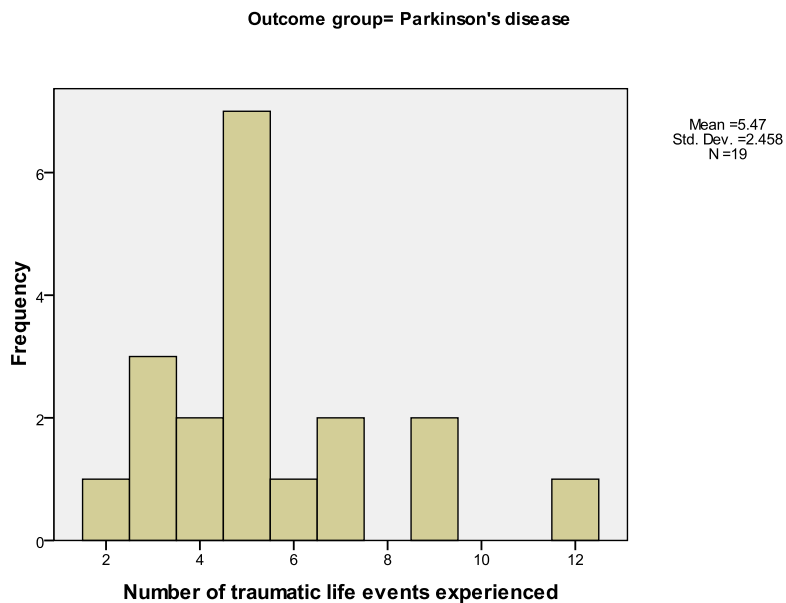


Figure Q3. Histogram of THQ score for non-Parkinson's group

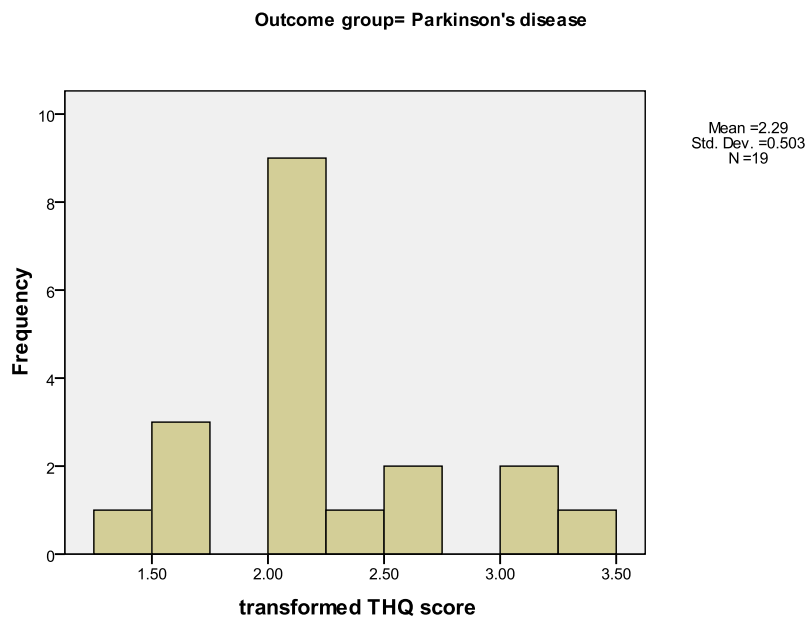


Figure Q4. Histogram of the transformed THQ score for non-Parkinson's group

Figure Q5 shows the histogram of the task-oriented coping subscale of the Coping Inventory for Stressful situations for the non-Parkinson's group, showing that this is normally distributed. Parametric tests were therefore used for this scale.

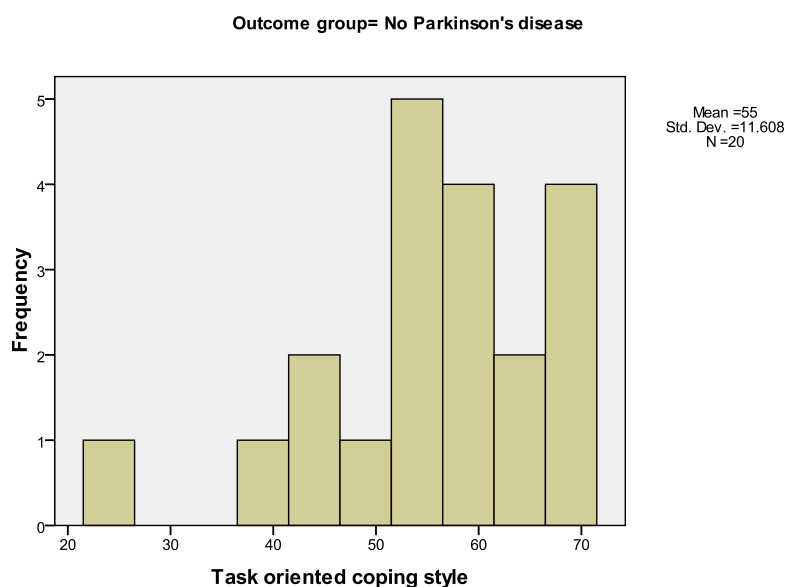


Figure Q5. Histogram of CISS task-oriented coping sub-scale score for the non-Parkinson's group.

Figure Q6 shows the histogram of the task-oriented coping subscale of the Coping Inventory for Stressful situations for the Parkinson's group, showing that this is normally distributed. Parametric tests were therefore used for this scale.

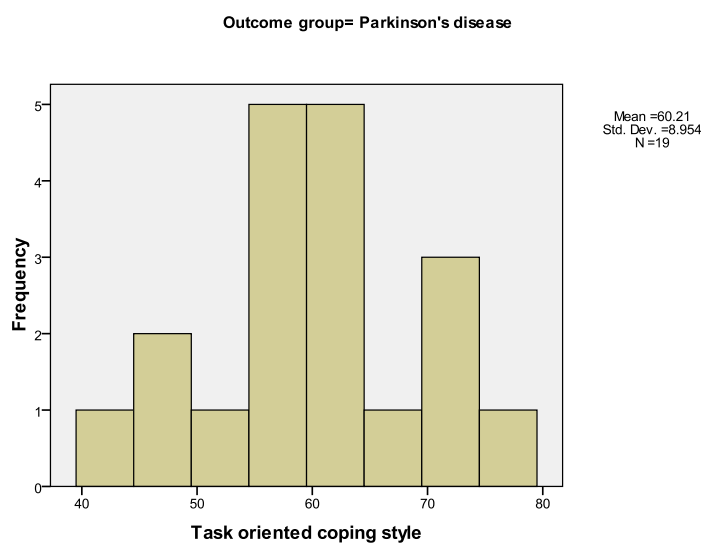


Figure Q6. Histogram of CISS task-oriented coping sub-scale score for the Parkinson's disease group.

Figure Q7 shows the histogram of the emotion-oriented coping subscale of the Coping Inventory for Stressful situations for the non-Parkinson's group, showing that this is positively skewed and therefore not normally distributed. Data for this scale was therefore transformed through a square root transformation (Field, 2009). The histogram of transformed data (Figure Q8) shows that transformed data is normally distributed, therefore parametric tests were used with transformed CISS emotion-focussed scores

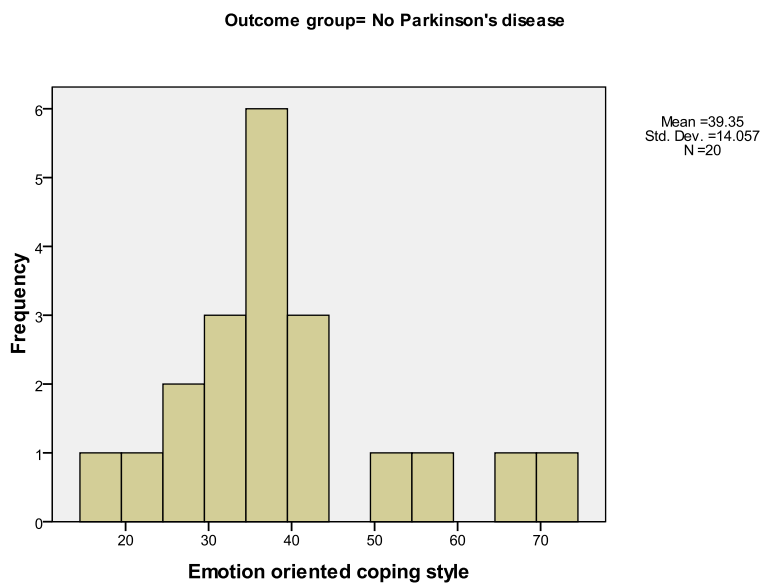


Figure Q7. Histogram of CISS emotion-oriented coping sub-scale score for the non-Parkinson's group.

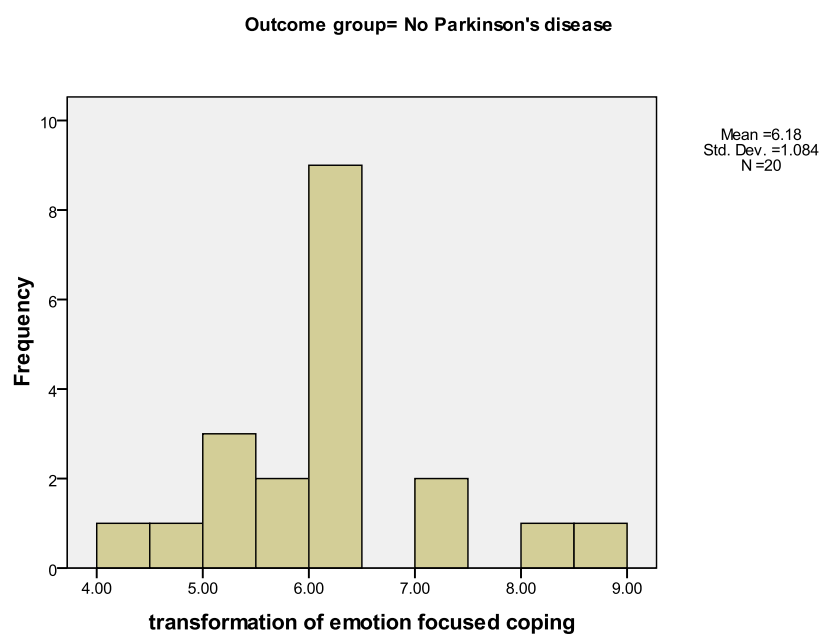


Figure Q8. Histogram of the transformed CISS emotion-oriented coping sub-scale score for the non-Parkinson's group.

Figure Q9 shows the histogram of the emotion-oriented coping subscale of the Coping Inventory for Stressful situations for the Parkinson's group, showing that this is normally distributed. However, as the CISS emotion-oriented sub-scale for the non-Parkinson's group was transformed to achieve a normal distribution, the scores of the Parkinson's group were also transformed, thus allowing comparison of the two scales (Field, 2009). Figure Q10 shows the histogram of the transformed emotion-oriented coping subscale for the Parkinson's group.

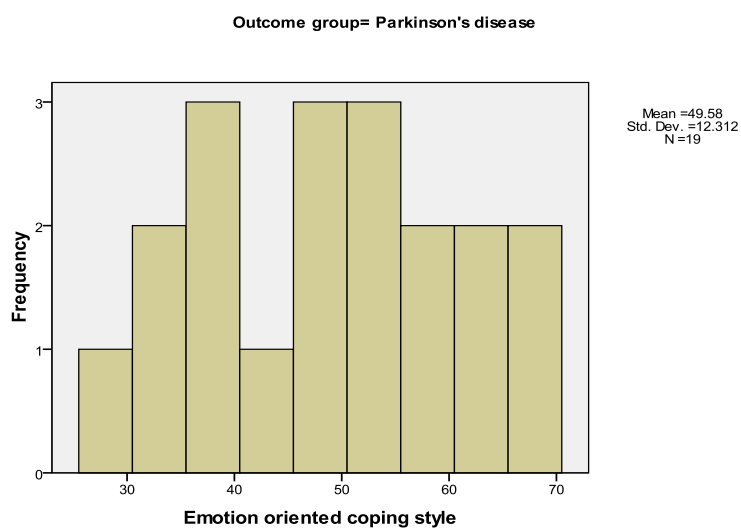


Figure Q9. Histogram of CISS emotion-oriented coping sub-scale score for the Parkinson's group.

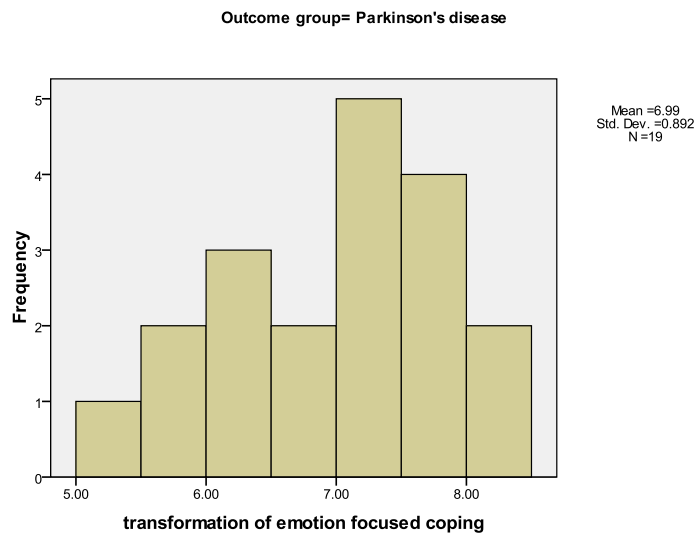


Figure Q10. Histogram of the transformed CISS emotion-oriented coping sub-scale score for the Parkinson's group.

Figure Q11 shows the histogram of the avoidance-oriented coping subscale of the Coping Inventory for Stressful situations for the non-Parkinson's group, showing that this is normally distributed. Parametric tests were therefore used for this scale.

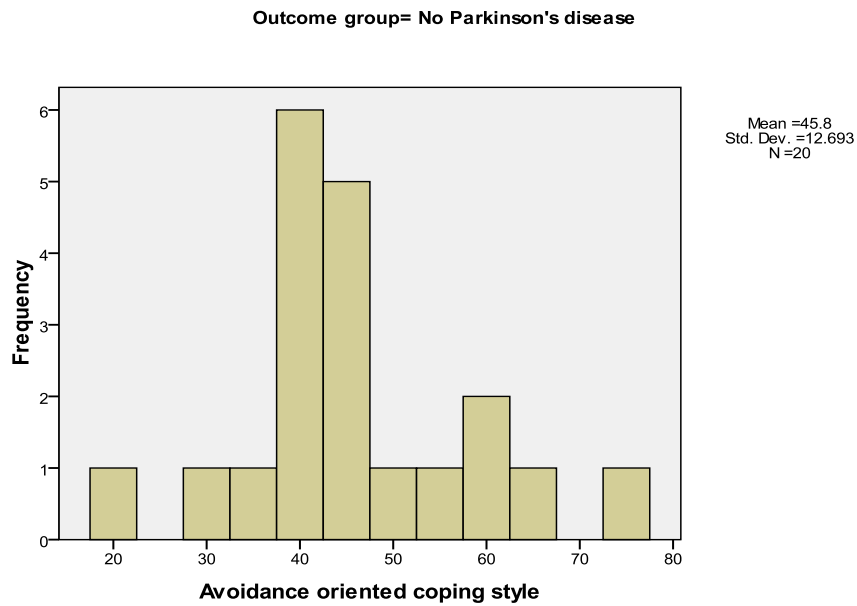


Figure Q11. Histogram of CISS avoidance-oriented coping sub-scale score for the non-Parkinson's group.

Figure Q12 shows the histogram of the avoidance-oriented coping subscale of the Coping Inventory for Stressful situations for the Parkinson's group, showing that this is normally distributed. Parametric tests were therefore used for this scale.

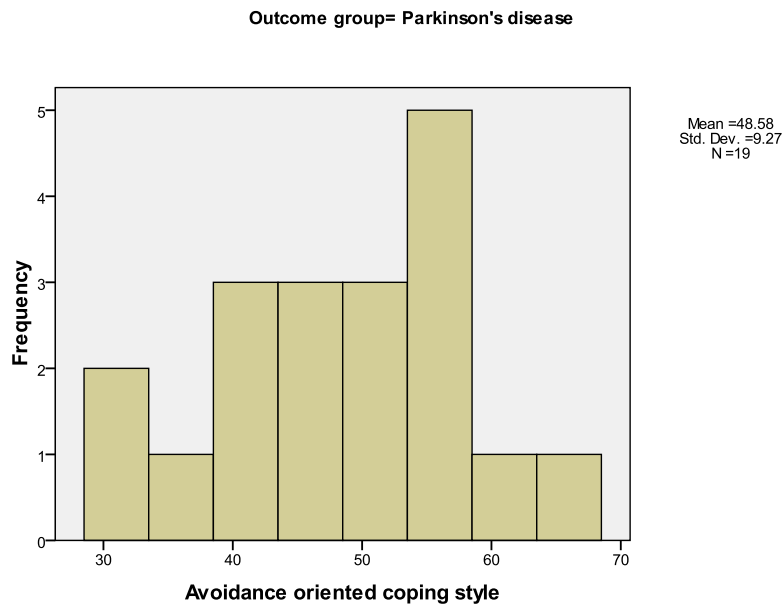


Figure Q12. Histogram of CISS avoidance-oriented coping sub-scale score for the Parkinson's group.

Appendix S

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