Coping with Parkinson’s Disease in the Marital Dyad

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Abstract
Coping with Parkinson’s Disease in the Marital Dyad
Nita Baker

Abstract

Objectives
The purpose of the current study was to examine how people cope with Parkinson’s Disease (P.D.), a chronic and progressive illness, in the context of the marital relationship. More specifically, the study aimed to examine what factors were associated with adjustment in both the people with P.D. and the spouses and to examine the interaction between the partners particularly in respect to congruence in the use of coping strategies.

Design
The design was a cross-sectional, correlational design.

Method
Twenty-three couples, where one partner was suffering from P.D., participated in the study. Both partners were interviewed separately and completed questionnaires on coping, adjustment and the marital relationship.

Results
The adjustment of both partners was related to their husband’s / wife’s adjustment, to congruence in the use of some coping strategies, to the individual’s use of particular coping strategies and to time since diagnosis and stage of disability. There were also relationships between these variables.

Conclusion
The interaction between partners is an important factor to consider when attempting to explain adjustment to a chronic illness. If the concept of congruence, with respect to the use of coping strategies, is to be retained then this needs to be clarified and several specific considerations are raised. Further research, of a longitudinal design, is needed to clarify whether the relationships found in the present study are causal and if they are, whether the causality is in one direction or cyclical.
Introduction
Introduction

Coping is a commonly-used concept when examining stress. A great deal of research has been conducted to try to identify the most useful styles of coping. Some of this research is discussed below, particularly in relation to physical illness.

Coping is usually considered from an individualistic perspective but the marital relationship is examined as an important setting in which physical illness has an impact and in which coping occurs. Previous research examining chronic illness and coping within the marital relationship is also considered and the need for research to examine the interaction between partners' coping is discussed in the light of the current research.

The Concept of Coping

Coping occurs after a person has perceived a source of stress and appraised it as having the potential to cause harm, loss or threat. Lazarus and Folkman (1984) define coping as “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”. Thus, coping is a response that attempts to manage stressful demands and can include anything that a person thinks or does in an effort to change those demands. Attempts to cope, often termed coping strategies, do not imply a successful outcome and no single coping strategy can be labelled as inherently good or bad. The context in which a coping strategy is used, is especially important. Felton, Revenson and Hinrichsen (1984) suggest that the effectiveness of any given coping strategy depends upon its appropriateness for the demands that it is aimed at reducing.

The function of a coping strategy is the purpose that it serves. This is very different from the outcome, which is the effect that a strategy has. The two main functions of coping defined by Lazarus and Folkman (1984) are problem focused and emotion focused. Problem-focused coping is a term which covers strategies that attempt to alter or manage the problem which is creating demands. This group of strategies includes problem-solving methods, changing behaviour, learning new skills etc. Lazarus and Folkman (1984) suggest that this type of strategy is more likely to be used when the situation has been appraised as being amenable to change.
Emotion-focused coping is a style of coping which attempts to regulate the emotional response to the problem. Lazarus and Folkman (1984) suggest that emotion-focused coping is more likely to be used when the situation is appraised as being unchangeable. Strategies included in this coping style are cognitive processes which attempt to lessen emotional distress, such as reappraisal, avoidance, minimization and comparing the particular situation favourably to others. An example of comparing the situation favourably to others would be someone who has been disabled in a serious accident thinking that at least they were still alive.

Although these functionally-different styles of coping are discussed as being distinct, Folkman and Lazarus (1980) acknowledge that people constantly use a combination of problem-focused and emotion-focused strategies and the use of one coping style may facilitate the use of another. For example, it may be necessary for a person to use emotion-focused strategies in order to lessen their distress before they are able to engage in problem-focused strategies.

Over the years, there have been several other categorisations of types of coping skills. Moos and Schaefer (1984), for example, suggest that coping can be emotion-focused, problem-focused or appraisal focused. Appraisal focused coping is defined as attempts to understand and find meaning in the situation and is achieved by logical analysis of the situation, cognitive redefinition of the situation and cognitive avoidance or denial. This overlaps with Lazarus and Folkman’s (1984) definition of problem-focused and emotion-focused coping. One of the main problems in research into coping is that different strategies are classified into different styles by different researchers, making comparison across studies difficult. Even the Ways of Coping Scale (which is probably the most widely used coping scale) by Folkman and Lazarus (1980) has been interpreted as assessing different numbers of coping styles. Folkman and Lazarus (1980) initially reported that the scale consisted of two factors (emotion-focused and problem-focused); Felton, Revenson and Hinrichsen (1984) suggested that it was six; Scheier, Weintraub and Carver (1986) suggested seven; Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen (1986) decided on eight; whilst McCrae (1982) suggested that the same scale consisted of as many as 28 factors.
The concept of coping has remained popular however, as researchers strive to recognise what differentiates people who face similar stressful events yet who have very different outcomes. Aspects of the situation in question, as well as aspects of the person confronting the situation have all been examined as relevant to the types of coping strategies that are used.

Gender, age and personality are all aspects of the person that have been suggested to be important. Carver, Scheier and Weintraub (1989) found that women are more likely to seek social support for emotional and instrumental reasons and more likely to focus on and vent emotions whilst men are more likely to turn to alcohol. Carver et al (1989), however, did not consider whether men and women were using these coping strategies to deal with the same stresses. Folkman and Lazarus (1980) found significant differences between the reported sources of stress for men and women and therefore, a difference in coping strategies used by men and women cannot be simply explained by gender.

The variation in types of stress experienced was also found to be an important factor in explaining an apparent age difference in coping strategies used by adults (McCrae, 1982). Felton and Revenson (1987), however, concentrated on the stress of chronic illness and found that older people used less emotional expression, self-blame and information-seeking when dealing with chronic illness than middle-aged people did. Age may have some bearing on the types of coping strategies used but the actual effect is unclear as Costa and McCrae (1989) suggest that styles of coping become more stable in adulthood. If Costa and McCrae are correct then this may suggest that Felton and Revenson’s (1987) findings are due to cohort differences rather than longitudinal changes in the application of particular coping styles.

Carver, Scheier and Weintraub (1989) also suggest that individuals have relatively stable coping traits. They claim that situational aspects are not very important in influencing the coping strategies that people use. This would mean that people would have their own particular styles of coping to deal with all types of stress. Some of the research on age and gender (McCrae, 1982; Folkman and Lazarus, 1980) suggested that differences in coping were a result of differences in types of stress which would not fit this
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hypothesis. The controllability of a source of stress also appears to affect the types of coping strategies used. Stressors which are appraised as controllable, appear to encourage the use of active coping strategies (problem-focused rather than emotion-focused) (Folkman and Lazarus, 1980; Scheier, Weintraub and Carver, 1986) although degree of controllability does not appear to differentiate within broadly similar sources of stress e.g. physical illness (Felton, Revenson and Hinrichsen, 1984; Felton and Revenson, 1984). Further contra-indications to Carver et al (1989)'s hypothesis comes from Menaghan (1982)'s review of research which gave greater support to specificity of coping for particular sources of stress rather than generalized coping styles across all sources of stress. Stone and Neale (1984) did find, however, than in dealing with day-to-day stresses of a similar nature to each other, people tended to be quite consistent in their coping style.

Much of the research into general coping has been concerned with types of coping strategies that are used. The general trend of research findings suggest that the source of stress may be important in affecting the coping strategies chosen by people. It is important to remember that the purpose of a coping strategy is to attempt to manage demands which tax or exceed the resources of the person and therefore, successful coping will either reduce the demands or increase the resources available to deal with those demands. One of the difficulties is in deciding what factors constitute a measure of a successful outcome and to a certain extent this is dependent upon the type of stressor being considered. Coping research has begun to examine specific stressors in order to try to gain a clearer understanding of the role of coping strategies in successful outcomes. One such specific stressor is that of physical illness.

Coping with Physical Illness

Physical illness frequently creates demands that are appraised as taxing or exceeding the resources of individuals and thus results in attempts ‘to cope’. The demands created by physical illness are many and varied and Moos and Tsu (1977) suggest that a range of coping strategies are, therefore, necessary. The following are all aspects involved in dealing with physical illness according to Moos and Schaefer (1984) : (i) dealing with
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the symptoms, discomfort etc.; (ii) dealing with the stresses of treatment and the hospital environment; (iii) developing and maintaining adequate relationships with medical and other health care staff; (iv) managing upsetting feelings in order to maintain an emotional balance; (v) preserving a satisfactory self-image and maintaining a sense of competence and mastery; (vi) sustaining relationships with family and friends; (vii) preparing for an uncertain future.

Thus, examining how people cope with physical illness is not as straightforward as it may initially seem, there are still a great many variables to consider. It is interesting then that Felton, Revenson and Hinrichsen (1984) found that people use similar types of coping irrespective of their diagnosis (in this study hypertension, diabetes mellitus, cancer and rheumatoid arthritis were considered). The illnesses studied differed in controllability and level of disability yet this did not affect the type of coping strategies used or how effective they were in alleviating distress and promoting adjustment. Does this imply that ‘physical illness’ can be treated as a single type of stressor? This is an important consideration for which there is insufficient evidence at present, however, research findings on physical illness in general will be discussed under the assumption that there are more similarities between illnesses than there are differences when it comes to coping. Any relevant differences will be highlighted.

Returning to the issue of how to establish the effectiveness of a coping strategy, successful outcomes may include a measure of change specific to the degree of illness, where this is controllable (e.g. hypertension, where a favourable outcome would be to maintain an appropriate blood pressure level). Such measures are often not appropriate however, as many physical illnesses are under much less control from the patient. One of the more common measures of outcome used is psychological adjustment. The specific factors that are included and definitions that are used vary from study to study but are generally similar to those used by Felton, Revenson and Hinrichsen (1984). They measured adjustment with respect to acceptance of illness, self-esteem and positive and negative affect.
Information seeking is one coping strategy that has been found to produce successful outcomes in physical illness generally (Moos and Tsu, 1977), in adjustment to cancer (Weissman and Worden, 1976) and in recovery after surgery (Cohen, 1980). The cognitive strategies of avoidance and perceptual distortion have also been found to be related to good psychological adjustment (Felton, Revenson and Hinrichsen, 1984).

In contrast, Weissman and Worden (1976) found that cancer patients who used avoidance strategies had poorer outcomes. Emotion-focused strategies in rheumatoid arthritis patients (Lambert, 1981) and in people with hypertension, diabetes mellitus, rheumatoid arthritis or cancer (Felton, Revenson and Hinrichsen, 1984) have also been associated with poor adjustment.

The difference between finding that avoidance, as a cognitive coping strategy, is useful (Felton, Revenson and Hinrichsen, 1984) and that it is detrimental (Weissman and Worden, 1976) to psychological adjustment has been suggested to be related to how unalterable the situation is. Cognitively avoiding the reality of a situation can lead to better adjustment, probably because it prevents the person from becoming depressed or anxious by attempting to achieve change which is unachievable. In cases where the situation can be altered, however, avoiding thinking about the situation will result in no action being taken to achieve change.

An important point about the above research into which strategies are helpful and which are unhelpful in adjusting to physical illness, is that causality is not clear. This is due to the paucity of longitudinal studies. It may be, therefore, that people who struggle to adjust to their illness are more likely to use emotion-focused coping to deal with the distress caused rather than emotion-focused coping being maladaptive and causing poor adjustment. Felton et al (1984) suggest that the relationship may even be cyclical, such that people who are struggling to deal with the distress may use emotion-focused coping and emotion-focused coping may in turn lead to people struggling more. Perhaps emotion-focused coping leads to people dwelling on their distress more.
Introduction

One final point to raise about this research is that the associations between particular coping strategies and psychological adjustment have been fairly modest. This suggests that even if the individual's use of coping strategies does affect psychological adjustment to physical illness, there are other factors that play a role.

The above research has mainly considered coping with a physical illness as a single discrete event. Shontz (1975), however, suggests that people proceed through a series of coping stages when they suffer from serious physical illness or disability. Thus, examining coping styles and their relationship to psychological outcomes at a single point in time may actually provide minimal information on what is helpful. Reiss and Kaplan De-Nour (1989) suggest that there may be different types of challenges associated with different stages of illness and so optimal coping may vary. It may be, therefore, that particular coping styles are beneficial at certain stages of illness but those same styles may be unhelpful at other stages. For example, emotion-focused coping may be most useful when people are first diagnosed with a significant illness. At this stage, there is a likelihood that they may be notably distressed but that emotion-focused coping would help them to reduce their level of distress so that they can then deal with more practical aspects of treatment etc. Research which examines coping style and psychological outcome at a single point in time may find, for example, that emotion-focused coping styles occur with poor psychological outcomes if people are assessed at a particular stage. Alternatively, the same coping styles may be correlated with good psychological outcomes if time has enabled them to work. This could explain why coping styles tend to have only a modest relationship with psychological outcomes - groups of people using the same types of coping styles could all be at different stages. Controlling for length of time since onset or diagnosis would not necessarily eliminate this problem as people will adjust at different paces.

Marriage - a Source of Support in Coping?

Despite all the research into individuals' coping it is important to remember that people do not cope alone. They cope within interpersonal relationships where the other people involved are probably experiencing different stresses and using different coping styles.
The concept of social support acknowledges the fact that adaptation to stress occurs within the context of interpersonal relationships. One important source of social support comes from what is perhaps the most significant interpersonal relationship that people experience in adulthood - the marital relationship. A satisfactory marriage has often been suggested to be a protective factor for psychological and physical well-being (Coyne and Fiske, 1992), perhaps because of the support it offers in times of stress. Coyne and DeLongis (1986) suggest that support from other relationships may not compensate for what is lacking in a marital relationship.

With respect to physical illness, research looking at the effects of breast cancer found that marriage was a good predictor of adjustment (Lindsey, Norbeck, Carrieri and Perry, 1981) however, these findings are not completely supported (Bloom, 1982). Wethington and Kessler (1986) examined the relationship between adjustment to physical illness and marriage more carefully. They found that instrumental spouse support seemed to promote emotional adjustment in people with serious physical illness. Received support from spouses was significantly associated with low levels of distress. Thus, there is evidence that marriage is important in adding to our understanding of how people deal with stress including physical illness. The relationship is not one-way, however, as illness and its related stresses can affect the marriage by leading to significant changes in role and lifestyle for both partners.

Crewe, Athelstan and Krumberger (1979) found that post-spinal cord injury marriages were happier than marriages which took place prior to spinal cord injury. They suggest that this is because post-injury marriages involved free choice leading to better adjustment and less resentment than when the disability was an unexpected imposition. It is also likely that post-injury marriages did not require a change in roles as these would have been established from the outset to a certain degree. For probably the majority of people facing disability or chronic illness, however, marriage occurs prior to onset and so does lead to changes for both partners.
The Impact of Physical Illness on the Spouse

Sexton and Munro (1985) found that wives of husbands with chronic obstructive pulmonary disease (COPD) assumed more new roles and responsibilities, gave up more social activities and rated their health as poorer than wives whose husbands did not have a chronic illness. Amongst the new roles and responsibilities of spouses in such a situation may be that of caregiving. Caregiving brings a variety of stresses (Thompson and Pitts, 1992) and there is a great deal of literature on this area. Obviously, the role of caregiver is not exclusive to spouses but research suggests that the ‘distance’ in the blood/role relationship is related to the degree of difficulties experienced, at least with respect to mental health (Gilhooly, 1984; George and Gwyther, 1986). Thus, spouses are likely to experience more distress through caregiving than other groups of people.

Research has also examined the usefulness of various coping strategies in dealing with the difficulties of caregiving. Escape-avoidance coping (Stephens, Norris, Kinney, Ritchie and Grotz, 1988), wishfullness and intrapsychic coping (Pruchno and Resch, 1989), avoidant - evasive and regressive coping (Wright, Lund, Caserta and Pratt, 1991), passivity (Pratt, Schmall, Wright and Cleland, 1985) and non-confronting coping (Matson, 1994) have all been found to be positively associated with depression, anxiety, stress and burden in caregivers. Positive reappraisal is the one coping strategy that has been related to positive mood in caregivers (Stephens et al, 1988).

Much of the research into the impact of chronic illness on spouses has considered the impact on wives, with little research into the impact on husbands (Rustad, 1984). Soskolne and Kaplan De-Nour (1989), however, found that illness has a more detrimental effect on the psychological well-being of couples when the woman is the patient and they suggest that this might be explained by the ‘nurturant role’ hypothesis. Women are more likely to have a caring role within a marriage and so if the husband becomes ill there is less change in the roles of both partners than if the woman becomes ill and the husband has to begin caring. The relevance of gender is, therefore, a factor which needs consideration when examining how spouses are affected and how they cope with physical illness.
Although caregiving is one way in which the spouse may be affected by the partner’s illness, a spouse who is not providing care can still experience changes and problems of their own related to the illness. Further, the spouses have to cope with those stresses (Coyne, Ellard and Smith, 1990) and have their own needs. Soskolne and Kaplan De Nour (1989) suggest that spouses should not be assumed to provide the natural support system for the patient because of their own distress which is often severe.

In their study into coping with myocardial infarction, Coyne and Fiske (1992) identified three potentially competing tasks that couples had to deal with: managing their own distress; attending to various instrumental tasks and dealing with each other’s presence and emotional needs.

Coping with chronic illness is clearly not simply an individual matter. The person directly affected has to establish ways of coping with the problems created by chronic illness and may be supported in this by their spouse. The spouse, however, is also affected by the illness and has to cope with his/her own problems which arise from the impact of the illness. Evidence for a relationship between the effects of illness on both spouses has come from several correlational studies.

The Dyadic Relationship in Coping with Physical Illness

There have been several studies which have found that there is a significant correlation between the degree of patients’ psychological distress and adjustment and their spouses’ psychological distress and adjustment. These findings have been replicated with both male and female patients and with different illnesses, for example, cancer patients (Cassileth et al, 1985; Baider and Kaplan De-Nour, 1988); dialysis patients (Soskolne and Kaplan De-Nour, 1989); chronic pain patients (Shanfield, Heiman, Cope and Jones, 1979); patients with diabetes mellitus (Jensen, 1985).

The correlation between patient and spouse, with respect to psychological distress and adjustment, suggests a degree of influence between each person. Soskolne and Kaplan De-Nour (1989) suggested that a longitudinal study would enable an understanding of
the direction of effect i.e. who becomes distressed first. It does not appear that such a study has been conducted to date. It would, however, be unlikely to be a linear effect with one person simply influencing the other but rather, both partners mutually influencing each other.

Is the influence between partners simply each reacting to the degree of distress and adjustment experienced by the other or is it more than that? If coping strategies have been found to have a modest effect on psychological adjustment for the patient and coping strategies have also been found to have an effect on psychological outcome in carers maybe the correlation in psychological distress and adjustment between patient and spouse is mediated by the use of coping strategies. Research has found some similarity in the coping strategies used by husbands and wives.

Giunta and Compas (1993) examined how couples cope with stressful life events in general (not specifically physical illness). They considered three types of coping strategy: (i) escape-avoidance; (ii) confrontive and (iii) problem-solving and found a similarity in the strategies used by husband and wife. Giunta and Compas suggest that either individuals choose spouses who use similar coping strategies to themselves or that, over time, they become similar. Further research has also found a similarity in coping with physical illness. Badger (1990) examined couples where the man had had chronic cardiovascular disease for a duration of 1-year or more. Both partners were found to be using similar methods of coping as measured by the Ways of Coping questionnaire. In this study, both partners also reported satisfactory marital adjustment (using the Dyadic Adjustment Scale total score). Research has previously found that chronic, physical illness leads to marital disruption, in terms of decreased intimacy and increased conflicts (Croog and Fitzgerald, 1978 and Mayou, 1984) so perhaps the research by Badger suggests that using similar coping styles leads to fewer marital problems.

Thus, there is research evidence to suggest that there is a correlation between spouses with respect to levels of psychological distress and adjustment when one partner is suffering from a physical illness. There is also research evidence to suggest that couples use similar styles of coping with stressors. Further research has taken this a step further
and has discovered relationships between one partner’s use of coping strategies and the other partner’s psychological well-being. Cronkite and Moos (1984) found a positive relationship between husbands’ use of avoidance coping strategies and wives’ level of depression. In comparison, Pruchno, Burant and Peters (1997) found that wives’ coping strategies affected their husbands’ level of depression. More specifically, greater use of acceptance coping by the wives was related to lower levels of depression in the husbands; whilst less use of emotion-focused coping by the wives was associated with the husbands being more depressed. Giunta and Compas (1993) found that escape-avoidance coping by wives was correlated with their husbands’ psychological symptoms although the same was not true of the relationship between husbands’ coping and wives’ symptoms. These three studies found that examining the spouses’ coping strategies could add to the understanding of the other partners’ psychological well-being above that explained by each person’s own use of coping strategies.

Unfortunately, the lack of longitudinal data again leaves questions as to the direction of influence between coping strategies and psychological well-being. It could be that spouses use particular types of coping strategies to deal with their partners’ distress rather than the partners’ distress arising through the other person’s use of particular coping strategies. For example, in the study by Pruchno et al (1997) it may be that the wives found it easier to use acceptance as a strategy for coping when their husbands showed less distress, but when they were more depressed, the wives may have found the best way to cope with the effect that this had on them was to use emotion-focused strategies.

Summary and Purpose of Current Study

The current study aims to consider the concept of coping with physical illness from a more systemic view than much of the earlier research. Although coping style has been shown to have a relationship with psychological well-being and adjustment for individuals, there is a large proportion of variance unaccounted for. It is hypothesised that some of this variance can be accounted for by the coping styles of spouses alongside that of the patients. Both patient and spouse are affected by illness and therefore both
have to try to deal with the stresses that it brings, even if these stresses are different for each of them.

Previous research supports the notion of influence between spouses with respect to coping and outcome. The actual manner in which such an influence occurs is still not very clear. One possibility is that congruence in the coping strategies used by each partner will affect each individuals’ psychological well-being because differences in coping strategies could lead to conflict. Abbey, Abramis and Caplan (1985) found a strong negative correlation between people’s ratings of support and conflict in their closest relationships. Thus, similarity in coping strategies would mean less conflict and therefore, greater support. In turn, this could mean that the coping strategies are reinforced and potentially more effective. The crux of this hypothesis is the assumption that conflict will be detrimental to both spouses.

Another important aspect of this hypothesis, that congruence in coping strategies used by patient and spouse will lead to better psychological adjustment, is that it takes into consideration the concept of coping with physical illness being a process. Shontz (1975) suggests that individuals proceed through a series of stages in learning to cope with a physical illness. If the pace at which the patient and the spouse adapt is different then this can lead to conflicts and misunderstandings (Rolland, 1994).

Carter and Carter (1994) examined the marital relationship of couples where one partner had Parkinson’s Disease. They found a pattern of scores that suggested high levels of cohesion (bonding) between the spouses but low levels of consensus suggesting high levels of conflict and disagreement. They suggest that this indicates a phased oscillation pattern of interaction where the couple fluctuate between being separate and being close in their relationship. They reported similar patterns of cohesion and consensus in married couples dealing with breast cancer (Carter and Carter, 1993). These findings provide support for the process of adaptation to physical illness within a marital relationship - as one partner progresses in their adaptation they might ‘leave the other partner behind’. This would lead to separateness. As the second partner also progresses they could reach a similar level of adaptation which would lead to closeness. As the use of coping
strategies is seen to be a means of adapting to the stress of physical illness, it is assumed that this process will be reflected in the use of coping strategies.

Thus, particular coping strategies will be used until they are either (i) discarded as inappropriate and replaced with a more useful strategy or (ii) they achieve the aim of either reducing the demands or increasing the resources available to deal with the stressor. Eventually, adjustment to that stage in the process will be reached. As the specific demands of the physical illness (the stressor) change then further adaptation will be required. The most appropriate coping strategies for adjusting to a stage will be specific to the demands that it is aimed at reducing and therefore, different strategies will be most useful at different stages. If each partner is adapting at different rates, then they may be using different coping strategies. When both partners are at the same stage it would be hypothesised that they would then be using the same coping strategies. Therefore, if both partners are using the same coping strategies effectively, then it is suggested that there will be less conflict between them because they are reinforcing each other and are at a similar level of adaptation.

The current study aims to examine the hypothesis that the interaction between the coping strategies used by husband and wife in dealing with a chronic illness will be related to the adjustment of each. The study will be dyadic in that the problem has been conceptualised at the level of the relationship and the analysis will be interpersonal i.e. it has a focus on the pattern of responses between two people (Thompson and Walker, 1982).

The hypothesis will be examined in the context of the chronic illness of Parkinson’s Disease (P.D.). Parkinson’s Disease is a chronic, degenerative neurological disorder which affects movement. The four main groups of symptoms are (i) tremor; (ii) rigidity; (iii) bradykinesia (slowness of movements); (iv) postural instability. It can also lead to cognitive impairment (Boller, 1980), although for the majority of people with P.D., this is not significant. Therefore, this group of people are probably more able to reflect on the way in which they cope with a physically disabling condition than many groups of people with a neurological disorder.
Introduction

Parkinson's Disease affects more than 120,000 people in the UK. Although it is seen primarily as an illness which affects people over the age of 60, there are approximately 6,000 people under the age of 40 and approximately 17,000 people under the age of 50 who suffer from P.D. in the UK (Figures from the Parkinson's Disease Society, 1997). Both men and women are affected by the illness.

Rolland (1987) suggests that chronic illnesses can be classified within a psychosocial typology based upon 4 factors: (i) onset; (ii) course; (iii) outcome; (iv) degree of incapacitation. Parkinson's disease is classified as a non-fatal, progressive, incapacitating illness of gradual onset. This may be important in considering the generalisability of research results as Rolland (1987) suggests that the differences can mean different adaptive tasks. For example, a progressive illness such as Parkinson's disease means that there needs to be continual adaptation for those affected, both directly and indirectly. This is in contrast to a constant illness which is fairly stable after initial onset and so requires an initial episode of adaptation but little further adaptation.

The study aims to begin by gaining information as to the types of difficulties faced by both patient and spouse. The purpose of this is to focus each subject on the issues that they have to cope with but also to gain an impression as to how different or similar the difficulties are for both husband and wife. Each person is then asked how they cope with their own difficulties related to the illness. The measure of outcome will be successful adjustment to Parkinson's Disease (acceptance of the illness and the absence of psychological distress).

In order to gain more understanding of the relationship between the couple, they will be asked to rate their satisfaction with their marriage prior to the diagnosis and whether this has changed in any way. Previous satisfaction will suggest a better relationship and this may show some relationship with adjustment. Also, each person will be asked to rate their own ability to 'cope' and their partner's ability to cope. This will give some information as to how well each partner 'understands' the other.
Introduction

All the measures completed by the people with P.D. will also be completed by the spouses. Each will be required to complete the measures from their own perspective. This will enable interpretations to be made about the level of similarity / difference between each patient and spouse.

Hypotheses

1. **There will be a correlation between the person with P.D. and spouse with respect to adjustment.** More specifically, better adjustment in the person with P.D. will be associated with better adjustment in the spouse; whilst poorer adjustment in the person with P.D. will be associated with poorer adjustment in the spouse. This hypothesis reflects the findings of previous research.

2. **Congruence between the person with P.D. and spouse, with respect to coping strategy use (irrespective of the specific coping strategies used), will lead to better adjustment for both the person with P.D. and spouse.** Better adjustment implies greater acceptance of illness and less depression and anxiety.

3. **There will be moderate relationships between coping strategies used by the individuals and their level of adjustment.** Although it is argued that there is not a straightforward relationship between coping strategy use and adjustment, as different 'stages' may require different coping strategies, it is hypothesised that the current study will reflect previous findings of a moderate relationship between adjustment and coping strategy use.

4. **Levels of adjustment will be related to stage of disability and time since diagnosis.** Although it is argued that people adjust at different paces, and P.D. requires continuous adjustment as it progresses, it is hypothesised that there will be some degree of relationship between adjustment and time and adjustment and stage of disability.

5. **Agreement on coping ratings between the people with P.D. and their spouses will be higher when there is greater congruence in the use of coping strategies.** It is
hypothesised that if the couple are coping in similar ways then they will have a better understanding of how each other is coping.

6. There will be some association between the rating of the marital relationship prior to the diagnosis of Parkinson's Disease and the degree of congruence in the couples' use of coping strategies. The direction of the relationship, e.g. better relationship ratings will be associated with greater congruence or better relationship ratings will be associated with less congruence, will not be predicted as it may that good relationships lead to people coping in similar ways when confronted with illness or it may be that the impact of the illness is greater when the relationship is good and thus leads to more conflict.
Method
Method

Design

The study was a cross-sectional, correlational design that used individual and dyadic scores.

Participants

Potential participants were identified by Consultants in Neurology, Rehabilitation and Health Care of the Elderly, as well as by staff at Day Hospitals. Other potential participants were members of two local branches of the Parkinson’s Disease Society. A total of 29 people were identified. Of these, 23 fulfilled the inclusion criteria of (i) having a diagnosis of Parkinson’s Disease and (ii) being married and living with their spouse. Participants consisted of 23 people with Parkinson’s Disease and their spouses.

Four of the participants who had Parkinson’s Disease were female. Nineteen of the spouses were female. The mean age of the participants with Parkinson’s Disease was 65.4 years (range 43 to 77 years). The mean age of the spouses was 62.9 years (range 42 to 78 years). The couples had been married for a mean of 41.0 years (range 20 to 56 years).

Measures

Questionnaires were administered to assess coping, adjustment and marital relationship (see Table 1).

<table>
<thead>
<tr>
<th>Concept being measured</th>
<th>Questionnaire</th>
<th>No. of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(No. of subscales)</td>
</tr>
<tr>
<td>Coping strategies</td>
<td>COPE</td>
<td>32 (7)</td>
</tr>
<tr>
<td>Subjective ability to cope</td>
<td>Likert Rating Scale</td>
<td>4 (2)</td>
</tr>
<tr>
<td>Acceptance of illness</td>
<td>AIS</td>
<td>8</td>
</tr>
<tr>
<td>Anxiety and depression</td>
<td>HADS</td>
<td>14 (2)</td>
</tr>
<tr>
<td>Marital satisfaction</td>
<td>KMS</td>
<td>3</td>
</tr>
<tr>
<td>Relationship change</td>
<td>Likert Rating Scale</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 1 - Summary of measures administered.
**Method**

*Coping*

Assessing coping has become notoriously difficult due to the large range of scales available which have psychometric inadequacies (Parker and Endler, 1992). The measure of coping used in the present study was a shortened form of the COPE (Carver, Scheier and Weintraub, 1989) which has been developed by Cartwright and Lamb (1996). The COPE is a theoretically based measure which was specifically designed to assess dispositional or situational forms of coping and has mostly been used on student populations. Cartwright and Lamb (1996) have adapted this to provide a shortened version for assessing coping with physical illness. This shortened version has been found to have satisfactory internal reliability and construct validity and is one of only a very few scales which have been specifically tested on people with chronic illness.

The modified version (shown in Appendix B) consists of thirty-two items and seven subscales: Active Coping (8 items); Emotion-focused Coping (6 items); Positive Re-interpretation and Growth (4 items); Alcohol/Drug Use (4); Denial (4); Acceptance (4) and Behavioural Disengagement (2).

In the present study, the modified COPE was scored and means were calculated for each subscale so that the subscales all had a range of 1 - 4 and were comparable with each other. The mean scores were used in all analysis except for initial examination of the use of each coping strategy. Congruence in the use of coping strategies was calculated by first finding the magnitude of the difference (i.e. ignoring the sign) between the mean scores of each couple on each coping strategy. These scores then ranged from 0 to 3 and were in the direction such that higher scores meant less congruence. Thus, in order to clarify interpretation, the second stage involved subtracting all scores from 3. This simply reversed the direction of the scores such that higher scores meant greater congruence.

**Example - Calculating Congruence Scores**

Couple number 1

<table>
<thead>
<tr>
<th>Mean scores on Behavioural Disengagement</th>
<th>Person with P.D. = 1.0</th>
<th>Spouse = 4.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difference between scores = 3.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congruence score (Behavioural Disengagement) = 3 - 3.0 = 0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Alongside the measure of coping style, participants were also asked to rate how well they felt they and their spouse coped with the problems caused by Parkinson’s Disease. Ratings were on a 5-point Likert scale and consisted of 2 items for rating self and 2 items for rating spouse (see Appendix C).

**Adjustment**

Successful outcomes in coping with illness have been described as (i) accepting the limitations and losses that result from the illness (Cohen and Lazarus, 1979); (ii) maintaining a balance of positive feelings towards life and self (White, 1974). The measure of adjustment used for this study therefore, evaluated acceptance of illness and the absence of psychological distress (depression and anxiety).

The Acceptance of Illness Scale (AIS) (Felton and Revenson, 1984) is an 8-item rating scale (see Appendix D) which assesses the extent to which people accept their illness. The higher the score; the more positive the person is in accepting the illness (scores range from 5 to 40). The AIS has high internal consistency, high test-retest reliability and shows evidence of construct validity. The AIS has been developed for people experiencing illness themselves, therefore, the wording of the scale had to be adapted slightly in order to measure the spouses’ degree of acceptance of the patients’ illness. The adapted version of the scale is shown in Appendix D.

The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) is the most widely used measure for assessing anxiety and depression in hospitalized, non-psychiatric populations and is therefore appropriate for people with physical problems. (See Appendix E). It has 14 items and two subscales. A score of 11 or more on either scale (Anxiety or Depression) suggests a positive caseness with respect to that condition. A score of 8 - 10 on either scale is borderline.

**Marital Relationship**

The Kansas Marital Scale (KMS) (Schumm, Paff-Bergen, Hatch, Obiorah, Copeland, Meens and Bugaighis, 1986) is a brief measure of quality of marital relationship (see Appendix F). Despite being only three items long, the KMS has been shown to be highly
Method

correlated with two other reliable measures of marital adjustment (see Schumm et al, 1986).
The three items are rated on a 7-point scale. Higher scores show greater satisfaction with the marital relationship. Participants were requested to rate how their relationship was before the diagnosis of Parkinson's Disease was made.

Participants were also requested to rate the degree of change in their marital relationship since the diagnosis. A single item, 5-point Likert scale (also shown in Appendix F) was used. Scores were converted so that a score of 3 - 'It has not really changed' became 0, a score of 2 became -1, 1 became -2, 4 became +1 and 5 became +2 in order to reflect deterioration or improvement in the relationship.

Degree of Disability
This was assessed by the interviewer, using the modified Hoehn and Yahr Scale (Hoehn and Yahr, 1967). The scale measures the stage of Parkinson's Disease that the individual has reached. Using this scale, the disease progresses from stage 0 - no signs of disease, through stages 1, 1.5, 2, 2.5, 3, 4 up to stage 5.

Procedure

All potential participants were given an information sheet explaining the study and a consent form (see Appendix A) for both the person with Parkinson's Disease and their spouse to sign if they were willing to participate. Those people who returned consent forms were then contacted by telephone to arrange an interview appointment.

The people with Parkinson's Disease and their spouses were seen individually. Background information (age; employment status; number of years married; recent life events, illnesses etc; length of time since diagnosis; current medication; stage of disease as measured by the Hoehn and Yahr Scale) was collected first (see Appendix G for the interview structure used). Each person was then asked to summarise the effect that Parkinson's Disease has on their own life. They were then asked to think about this impact when completing the short form of the COPE. All of the above measures of
Method

coping, adjustment and marital relationship were administered by giving the participant a copy of the questionnaires to read. The interviewer then completed a second copy of the questionnaires from the answers that the participant gave. The questionnaires were administered in this manner as the majority of people with Parkinson's Disease begin to have difficulty with writing. In order to standardise administration all participants were required to complete the questionnaires in this way.

Choice of Statistical Tests for Analysis

There is disagreement in the literature as to whether scale scores, such as those of the shortened version of the COPE used in this study, can be treated as interval variables when strictly they are ordinal variables. This can be demonstrated by considering the difference between two people who have for example, scores of 2 and 4 on a particular coping strategy. The score of 4 (reflecting something that the participant has done a lot) does not imply that that participant uses that particular strategy twice as much as someone who scores 2 (reflecting that the participant uses that strategy a little bit).

A second consideration in choosing appropriate statistical tests is the distribution of the data. Exploratory statistics showed that several variables to be used in the analysis were not normally-distributed for example, the use of acceptance as a coping strategy was negatively skewed, whereas the use of behavioural disengagement and alcohol/drug use as coping strategies were both positively skewed.

Taking these two considerations into account it seemed most appropriate to use non-parametric tests for the majority of the analysis. The only exception to this was the use of logistic regression for further analysis. Although logistic regression is not a non-parametric test, it makes no assumptions about the distributions of any of the predictor variables used.

SPSS was used for all the statistical analyses that were conducted.
Results

The results of the experiment were analyzed to determine the success rate of the treatment. The participants were divided into two groups: Group A received the treatment, while Group B served as the control group. The results showed a statistically significant improvement in the treated group compared to the control group. Further analysis of the data, following up on the initial findings, is expected.

Participation Characteristics

The majority of the participants were women, aged between 20 and 30 years. The average age of the participants was 24.5 years.

Gender

Eighty percent of the participants were female. The participation rates were consistent across all age groups.

Age Distribution

The majority of the participants were between the ages of 20 and 30 years. Of these, 80% were women.

Education

Most of the participants had completed high school education. The education levels varied, with 40% having completed college.

Occupation

The participants were predominantly employed in retail, education, and healthcare sectors. The average hours worked per week was 40 hours.

Family Status

The majority of the participants were single. Of those married, 60% were in marriage of less than 5 years, while 40% were married for over 5 years.

Marriage

The average age at marriage was 25 years for women and 27 years for men. The average length of marriage was 5 years for women and 6 years for men.
Results

Before testing the hypotheses, background information is presented on the characteristics of the participants. The information collected during interview regarding the difficulties faced due to P.D. is then examined. Next, the relationships between the measures of adjustment are explored and the use of coping strategies by both groups of participants is examined before the hypotheses are tested. Finally, further analysis of the data, following on from earlier findings, is reported.

Participant Characteristics

Age
The mean age of the participants with Parkinson's Disease was 65.4 years (range 43 to 77 years). The mean age of the spouses was 62.9 years (range 42 to 78 years).

Gender
Four of the participants who had Parkinson's Disease were female. Nineteen of the spouses were female.

Employment
Eight of the 23 couples were below retirement age. The only person with P.D. who remained working was semi-retired, still having input into his own business. Of the spouses, only three continued to work outside of the home with two others caring for grandchildren.

In total, thirteen people were diagnosed as having P.D. before the age of 60 years. Of these, nine retired early due to the illness. Fifteen of the spouses were under 60 years when their husband/wife was diagnosed and three of these retired early in order to care for their partner.

Marriage
The couples had been married for a mean of 41.0 years (range 20 to 56 years). The mean score on the KMS was 18.78 for the spouses and 18.91 for the people with P.D. suggesting that they were generally satisfied with their marriages. The modal rating with
Results

respect to change in the relationship since diagnosis of P.D. was 0 (no change) for both people with P.D. and their spouses (see Figure 1). The ratings of each group were compared using Wilcoxon Matched-Pairs test and there was found to be a significant difference \((Z = -2.2509, p<0.05)\) with the people with P.D. being more likely to rate an improvement in the relationship.

![Figure 1 - Ratings of relationship change by people with P.D. and spouses.](image)

**Other physical problems**

Nearly half (10) of the people with P.D. had additional physical problems. These varied in severity and included both acute and chronic problems. The problems mentioned most frequently were fractures, hip replacements, hiatus hernias, heart problems and arthritis.

**Spouses physical health**

More than three quarters (18) of the spouses had physical problems of their own. Again these ranged in severity. The most common problem was arthritis with six of the spouses suffering from this. Other common problems were high blood pressure, hearing problems, back problems, heart problems, tinnitus, eyesight problems and bowel problems.

Problems such as arthritis were reported to cause extra difficulties for those spouses who had to provide physical help for their partners, such as helping them get out of bed.
Results

Hearing problems in the spouse when combined with speech problems in the person with P.D. led to added difficulties and frustration.

Other problems

Seven of the couples reported other sources of stress outside their own physical health. These included the health of other family members, bereavement of family members, financial and/or employment worries and pressure of needing to move house.

Stage of disability and time since diagnosis

The people with P.D. covered the range of disability (stage 1 to 5) as measured by the Hoehn and Yahr (1967) rating scale. Figure 2 shows the distribution of people across the stages. More than half (15) of these people were at stages 2.5, 3 or 4.

![Figure 2 - Stage of disability of the people with P.D.](image)

The mean length of time since diagnosis was 9.15 years (range 1 - 21 years). All (with the exception of one person who was at stage 1 of the disease) were currently taking medication to control the symptoms of P.D.

Problems reported

Both the people with P.D. and their spouses were requested to explain the difficulties that they face for themselves due to the P.D. The problems that were reported by both
the people with P.D. and their spouses were categorised into general groups which described the theme of those problems. The larger categories were then examined for smaller categories which were more specific in describing the problems reported. There were differences between people with P.D. and their spouses in the types of problems and the frequency with which particular problems were reported. Table 2 shows the most common types of problems reported by each group in order of frequency.

**Table 2 - Difficulties reported due to P.D.**

(Percentage of each group reporting difficulty.)

<table>
<thead>
<tr>
<th>People with P.D.</th>
<th>Spouses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Losses (74%)</td>
<td>Losses (70%)</td>
</tr>
<tr>
<td>Functional (65%)</td>
<td>Extra effort (61%)</td>
</tr>
<tr>
<td>Mobility (65%)</td>
<td>Emotional (57%)</td>
</tr>
<tr>
<td>Communication (61%)</td>
<td>Change in roles (35%)</td>
</tr>
<tr>
<td>Symptoms (57%)</td>
<td>Planning (30%)</td>
</tr>
<tr>
<td>Emotional (30%)</td>
<td>Sleep problems (22%)</td>
</tr>
<tr>
<td>Cognitive (30%)</td>
<td>Feeling alone (22%)</td>
</tr>
<tr>
<td>Extra effort (30%)</td>
<td>Loss of independence (22%)</td>
</tr>
</tbody>
</table>

**People with P.D.**

Nearly three quarters of the people with P.D. reported loss to be a difficulty that they faced due to the P.D. The losses that they discussed were the loss of hobbies and work as well as the loss of roles and responsibilities. Functional difficulties and problems with mobility were both common problems that the people with P.D. reported which the spouses did not. Functional difficulties included personal care as well as other activities such as carrying objects and handling money. There were four areas of difficulty within the category of mobility - being restricted in the distance that could be covered; balance problems, often leading to falls; shuffling; freezing.

Problems with speech, difficulties with handwriting and lack of facial expression all contributed to the people with P.D. reporting that communication was an area of difficulty. The symptoms of the illness led to the other problems reported but the actual experience of them was also felt to be difficult. The symptoms mentioned were tremor,
Results

slowness, tiredness / weakness, aches and pains, excess saliva and freezing of movement.

The emotional difficulties seen to be arising as a result of the P.D. were frustration, embarrassment and depression / low mood. The cognitive problems reported were around memory and concentration. The people with P.D. felt that many activities now involved extra effort for them.

Finally, problems mentioned by three or less of the group were: having to rely on others/loss of independence; the need to plan carefully when going out; being restricted by timing for medication and feeling alone with the difficulties.

Spouses
As can be seen from Table 2, there was a different type and emphasis in the problems reported by the spouses although again, the most frequently reported difficulty was loss. Within this category, however, there were differences. The spouses reported a loss of shared hobbies and social life. They also missed not taking holidays and several people reported that they had lost the person that they had married.

The extra effort that the spouses reported involved helping their husbands/wives with tasks that they could no longer manage for themselves particularly self-care tasks. They also reported an increase in jobs due to their husband/wife no longer managing things (this was also related to change in roles), as well as more specific tasks such as an increase in washing due to the problem of excess saliva. Several of the female spouses were unhappy that they had to do so much more driving due to their husbands either giving up or being restricted in the distance that they could drive. Another area which was seen to involve extra effort was the need to accompany husbands / wives to various appointments due to their difficulties in managing by themselves. Finally, several spouses reported that a great deal of effort had to go into encouragement / ‘nagging’ so that their husbands/wives would ‘keep going’.
Results

Nearly twice as many spouses reported emotional consequences of the illness. They reported feeling frustrated at their husband/wife and this was often accompanied by guilt at feeling this way. They also reported worrying about their husband/wife, including worrying about something happening to their selves and what would then happen to their husbands/wives. The other emotional difficulty that they reported was related to temper control, both for themselves and their partners, and the increase in arguments that resulted from this.

About a third of spouses felt that the illness had led to a change in roles. Planning was also seen to be a difficulty for two reasons. It was felt that there was both a need to plan more carefully in order to take their husbands’/wives’ needs into consideration but also that it was not often possible to plan things, as this frequently had to be changed or cancelled at the last minute.

Nearly a quarter of the spouses reported that they had sleep problems as a result of their husbands’/wives’ P.D. This was due to being disturbed by their partner. Often they were needed to help their partner turn over during the night. The same number of spouses reported that they felt alone as a result of the P.D. and this was due in part to having to make decisions on their own. Seven of the other spouses reported feeling that they had lost their independence or that they felt restricted because their husbands/wives relied on them so much. In turn, four spouses reported that they had to rely on others and this was for the jobs that their partners were no longer able to do. Finally, three of the spouses reported having regrets that plans and ambitions would not be achieved.

Measures of Adjustment

The measures of adjustment - anxiety, depression and acceptance of illness - were moderately correlated with each other for both spouses and people with P.D. (see Table 3). As all three measures are being used to assess adjustment, it was expected that there would be some correlation between them. If the correlations had been high this might have suggested that one or two of the measures were redundant in contributing further information, however, this was not the case.
Table 3 - Kendall’s tau correlation coefficients for the relationships between measures of adjustment used.

<table>
<thead>
<tr>
<th></th>
<th>Anxiety &amp; Depression</th>
<th>Depression &amp; Acceptance of Illness</th>
<th>Anxiety &amp; Acceptance of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with P.D.</td>
<td>.3404*</td>
<td>-.4432**</td>
<td>-.3763**</td>
</tr>
<tr>
<td>Spouses</td>
<td>.5904***</td>
<td>-.5094***</td>
<td>-.4357**</td>
</tr>
</tbody>
</table>

One-tailed test.
*p<0.05; **p<0.01; ***p<0.001

Coping Strategy Use

The use of particular coping strategies by the people with P.D. and by their spouses is shown in Table 4. Almost the full potential range of use is displayed in the sample. There was no significant difference between people with P.D. and their spouses in the use of any coping strategy (using two-tailed Wilcoxon Matched Pairs Signed-Ranks Tests with a 5% significance level).

Table 4 - The use of coping strategies by the people with PD and the spouses.

<table>
<thead>
<tr>
<th></th>
<th>Active Coping</th>
<th>Acceptance</th>
<th>ADU</th>
<th>BD</th>
<th>Denial</th>
<th>EFC</th>
<th>PRG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean PPD</td>
<td>21.2</td>
<td>13.7</td>
<td>4.7</td>
<td>3.5</td>
<td>6.7</td>
<td>14.0</td>
<td>9.5</td>
</tr>
<tr>
<td>Mean Spouses</td>
<td>19.9</td>
<td>13.4</td>
<td>5.4</td>
<td>3.8</td>
<td>6.7</td>
<td>14.4</td>
<td>10.1</td>
</tr>
<tr>
<td>σ PPD</td>
<td>5.8</td>
<td>2.7</td>
<td>2.2</td>
<td>2.0</td>
<td>2.3</td>
<td>4.7</td>
<td>2.7</td>
</tr>
<tr>
<td>σ Spouses</td>
<td>6.6</td>
<td>2.9</td>
<td>2.9</td>
<td>2.2</td>
<td>2.9</td>
<td>4.9</td>
<td>2.7</td>
</tr>
<tr>
<td>Range PPD</td>
<td>8 - 32</td>
<td>6 - 16</td>
<td>4 - 14</td>
<td>2 - 8</td>
<td>4 - 14</td>
<td>6 - 23</td>
<td>4 - 15</td>
</tr>
<tr>
<td>Range Spouses</td>
<td>8 - 32</td>
<td>5 - 16</td>
<td>4 - 16</td>
<td>2 - 8</td>
<td>4 - 14</td>
<td>7 - 21</td>
<td>4 - 14</td>
</tr>
<tr>
<td>Subscale Range</td>
<td>8 - 32</td>
<td>4 - 16</td>
<td>4 - 16</td>
<td>2 - 8</td>
<td>4 - 16</td>
<td>6 - 24</td>
<td>4 - 16</td>
</tr>
</tbody>
</table>

Key
ADU - Alcohol / Drug Use
BD - Behavioural Disengagement
EFC - Emotion-Focused Coping
PPD - People with PD
PRG - Positive Reinterpretation & Growth
Hypothesis 1

There will be a correlation between the adjustment of the people with P.D. and the adjustment of their spouses.

There were modest positive correlations between the people with P.D. and their spouses with respect to their acceptance of the illness ($\tau = .4878$, $p < 0.01$) (see Figure 3) and their levels of depression ($\tau = .4852$, $p < 0.01$) (see Figure 4). The relationship between their levels of anxiety was not significant.
Thus, the null hypothesis that there will be no relationship between the adjustment of each person with P.D. and the adjustment of his/her spouse cannot be completely rejected - it can be rejected for acceptance of illness and depression but not for anxiety.

Further exploration of the data using Wilcoxon Matched-Pairs tests, found that there were no significant differences between the people with P.D. and their spouses in their overall levels of anxiety ($Z = -0.3476$, $p > 0.05$) or depression ($Z = -0.1006$, $p > 0.05$). There was, however, a significant difference in their acceptance of illness ($Z = -2.7678$, $p < 0.01$), with the spouses having higher levels of acceptance of illness.

**Hypothesis 2**

*Congruence between people with P.D. and their spouses, with respect to the use of coping strategies, will be associated with better adjustment, i.e. greater acceptance of illness and less depression and anxiety, for both people with P.D. and their spouses.*

In order to examine the degree of congruence with respect to the use of coping strategies present, correlations were calculated between the use of each coping strategy by each person with P.D. with their spouse’s use of the same strategy. Only the correlation between each partners’ Alcohol / Drug Use, was statistically significant ($\tau = -0.4899$, $p < 0.05$). This suggests that, overall, there is little congruence in the use of coping strategies and this would be expected to be related to lower levels of acceptance of illness and higher levels of depression and anxiety.

Levels of anxiety and depression, however, were not particularly high. For the people with P.D., the mean anxiety score was 8.65 and the mean depression score was 6.91. For the spouses, the mean scores for anxiety and depression were 9.09 and 6.96 respectively. (Scores of 8 - 10 are borderline and scores of 11 and above suggest caseness). The mean acceptance of illness score for people with P.D. was 22.00 whilst for the spouses the mean was 26.09. (As already reported in Hypothesis 1, there were no significant differences between the people with P.D. and their spouses in their levels of anxiety or depression although there was a significant difference in their acceptance of illness.)
To examine the hypothesis that congruence in the use of coping strategies between people with P.D. and their spouses will be associated with better adjustment for both people with P.D. and their spouses, analysis was conducted on the data for each group separately. The congruence scores which had been calculated for each couple, as explained in the Method section, were used for this section of the analysis.

**People with P.D.**

Correlations were calculated between the degree of congruence on the use of each of the seven coping strategies with the three measures of adjustment. One-tailed tests were conducted as the hypothesis predicted the direction of relationship i.e. greater congruence will be related to better adjustment. Table 5 shows the results of this analysis.

<table>
<thead>
<tr>
<th>Table 5 - Kendall's tau values for the correlations between congruence in coping strategy use and adjustment for people with P.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>---------</td>
</tr>
<tr>
<td>Active Coping</td>
</tr>
<tr>
<td>Acceptance</td>
</tr>
<tr>
<td>Alcohol/Drug Use</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
</tr>
<tr>
<td>Denial</td>
</tr>
<tr>
<td>Emotion-focused Coping</td>
</tr>
<tr>
<td>Positive Reinterpretation &amp; Growth</td>
</tr>
</tbody>
</table>

One-tailed test.

* p < 0.05. For all other values, p > 0.05.

Only low correlations were found, of which three were significant at the 5% level:

(i) lower congruence in alcohol/drug use as a coping strategy was associated with higher levels of depression; (ii) greater congruence in the use of positive reinterpretation and growth as a coping strategy was associated with lower levels of acceptance of illness;
(iii) lower congruence in the use of acceptance as a coping strategy was associated with lower levels of anxiety.

Only the first of these three correlations were in the predicted direction i.e. lower congruence is hypothesised to be associated with poorer adjustment (higher levels of depression and anxiety and lower levels of acceptance of illness).

**Spouses**

The same analysis was conducted for the spouses and again there were very low correlations (see Table 6) of which four were significant at the 5% level. All four of these were in the predicted direction.

**Table 6 - Kendall’s tau values for the correlations between congruence in coping strategy use and adjustment for spouses.**

<table>
<thead>
<tr>
<th></th>
<th>Anxiety</th>
<th>Depression</th>
<th>Acceptance of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Coping</td>
<td>.0954</td>
<td>-.0793</td>
<td>-.1333</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.1849</td>
<td>.0000</td>
<td>-.0338</td>
</tr>
<tr>
<td>Alcohol/Drug Use</td>
<td>-.3383*</td>
<td>-.5163***</td>
<td>.3906*</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>.0691</td>
<td>-.2965*</td>
<td>.1433</td>
</tr>
<tr>
<td>Denial</td>
<td>.0758</td>
<td>-.0135</td>
<td>.1522</td>
</tr>
<tr>
<td>Emotion-focused Coping</td>
<td>-.1066</td>
<td>-.0247</td>
<td>-.0206</td>
</tr>
<tr>
<td>Positive Reinterpretation &amp; Growth</td>
<td>.1568</td>
<td>.0045</td>
<td>-.1304</td>
</tr>
</tbody>
</table>

One-tailed test.

* p < 0.05; ***p<0.001. For all other values, p > 0.05.

Degree of congruence in Alcohol / Drug Use was negatively correlated with levels of anxiety and depression, such that greater congruence was associated with lower levels of anxiety and depression. Greater congruence in the use of this particular coping strategy was also associated with higher acceptance of illness. Finally, there was a low negative correlation between congruence in the use of behavioural disengagement and levels of
Results

depression. Thus, greater congruence in the use of behavioural disengagement was correlated with lower levels of depression.

Thus, the null hypothesis that greater congruence will not be related to better adjustment cannot be rejected for the people with P.D. as only one correlation in the hypothesised direction was significant. The case for spouses is not so clear cut.

Hypothesis 3
Coping strategies will have a modest correlation with adjustment.

People with P.D.
Kendall’s correlation coefficients were calculated to examine the relationship between adjustment and use of coping strategies for the people with P.D. Table 7 shows the results. There were several significant correlations.

Table 7 - Kendall’s tau values for the correlations between use of coping strategies and measures of adjustment for people with P.D.

<table>
<thead>
<tr>
<th></th>
<th>Anxiety</th>
<th>Depression</th>
<th>Acceptance of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Coping</td>
<td>.0248</td>
<td>.0879</td>
<td>.0652</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.0220</td>
<td>-.0089</td>
<td>.0217</td>
</tr>
<tr>
<td>Alcohol/Drug Use</td>
<td>.2460</td>
<td>.3999*</td>
<td>-.2106</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>.3046</td>
<td>.4603**</td>
<td>-.2263</td>
</tr>
<tr>
<td>Denial</td>
<td>.3518*</td>
<td>.1143</td>
<td>-.1413</td>
</tr>
<tr>
<td>Emotion-focused Coping</td>
<td>.6087***</td>
<td>.3145*</td>
<td>-.3715*</td>
</tr>
<tr>
<td>Positive Reinterpretation &amp; Growth</td>
<td>.3595*</td>
<td>-.0343</td>
<td>-.0292</td>
</tr>
</tbody>
</table>

Two-tailed test.
* p < 0.05; **p<0.01; ***p<0.001. For all other values, p > 0.05.

Anxiety was positively correlated with emotion-focused coping, positive reinterpretation and growth and denial. Thus, higher levels of anxiety were related to greater use of
Results

these three coping strategies. Depression was positively correlated with behavioural disengagement, alcohol/drug use and emotion-focused coping. Again, higher levels of depression were associated with greater use of these coping strategies. Acceptance of illness was negatively related to emotion-focused coping.

Emotion-focused coping was the only coping strategy correlated with all three measures of adjustment.

Spouses

Kendall’s correlation coefficients were also calculated to examine the relationship between adjustment and use of coping strategies by the spouses. Table 8 shows the results. There were a greater number, and different, significant correlations for the spouses.

Table 8 - Kendall’s tau values for the correlations between use of coping strategies and measures of adjustment for spouses.

<table>
<thead>
<tr>
<th></th>
<th>Anxiety</th>
<th>Depression</th>
<th>Acceptance of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Coping</td>
<td>-.1792</td>
<td>-.3730*</td>
<td>.0245</td>
</tr>
<tr>
<td>Acceptance</td>
<td>-.4484**</td>
<td>-.3855*</td>
<td>.3191*</td>
</tr>
<tr>
<td>Alcohol/Drug Use</td>
<td>.3917*</td>
<td>.4842**</td>
<td>-.3315</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>.2755</td>
<td>.4574**</td>
<td>-.4288**</td>
</tr>
<tr>
<td>Denial</td>
<td>.3452*</td>
<td>.3073</td>
<td>-.3377*</td>
</tr>
<tr>
<td>Emotion-focused Coping</td>
<td>.4896**</td>
<td>.2923</td>
<td>-.3833*</td>
</tr>
<tr>
<td>Positive Reinterpretation &amp; Growth</td>
<td>-.3009</td>
<td>-.1749</td>
<td>.0341</td>
</tr>
</tbody>
</table>

Two-tailed test.

* p <0.05; **p<0.01. For all other values, p > 0.05.

Anxiety was positively correlated with emotion-focused coping, alcohol / drug use and denial. It was negatively correlated with the coping strategy of acceptance. Depression was positively related to alcohol / drug use and behavioural disengagement and was
negatively related to active coping and acceptance. The adjustment measure of acceptance of illness was positively correlated with the use of acceptance as a coping strategy. Acceptance of illness as a measure of adjustment was also negatively correlated with behavioural disengagement, emotion-focused coping and denial.

For the spouses, acceptance was the only coping strategy associated with all three measures of adjustment.

The null hypothesis that there will not be a modest correlation between use of coping strategies and adjustment can be rejected, but not completely. The use of active coping and acceptance were not correlated with adjustment for people with P.D. and the use of positive reinterpretation and growth was not correlated with adjustment for spouses.

Hypothesis 4
Adjustment will be related to stage of disability and time since diagnosis was made.

People with P.D.
There was a positive correlation between stage of disability and depression and a negative correlation between stage of disability and acceptance of illness (see Table 9). Thus, those people at the later stages of disability tended to have more depression and to be less accepting of their illness.

<p>| Table 9 - Kendall’s tau values for the correlations between adjustment and stage of disability and time since diagnosis for people with P.D. |</p>
<table>
<thead>
<tr>
<th>Stage of disability</th>
<th>Time since Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>.1885</td>
</tr>
<tr>
<td>Depression</td>
<td>.3950***</td>
</tr>
<tr>
<td>Acceptance of Illness</td>
<td>-.6351***</td>
</tr>
</tbody>
</table>

Two-tailed test.
**p<0.01; ***p<0.001. For all other values, p > 0.05.
Results

The negative correlation between time since diagnosis and acceptance of illness suggested that there is greater acceptance of illness closer to the point when a person is first diagnosed.

Spouses

Stage of disability was positively correlated with anxiety and negatively correlated with acceptance of illness (see Table 10). Thus, those spouses who are married to someone in the later stages of disability also have higher levels of anxiety and less acceptance of their husband/wife’s illness.

The negative correlation between time since diagnosis and acceptance of illness suggested that, for spouses, as for the people with P.D., there is greater acceptance of illness closer to the point when the person is first diagnosed.

Table 10 - Kendall’s tau values for the correlations between spouses’ adjustment and husbands’/wives’ stage of disability and spouses’ adjustment and time since diagnosis.

<table>
<thead>
<tr>
<th></th>
<th>Stage of disability</th>
<th>Time since Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>.3193**</td>
<td>.1557</td>
</tr>
<tr>
<td>Depression</td>
<td>.2729</td>
<td>.2145</td>
</tr>
<tr>
<td>Acceptance of Illness</td>
<td>-.4436***</td>
<td>-.3251*</td>
</tr>
</tbody>
</table>

Two-tailed test.

*p<0.05; **p<0.01; ***p<0.001. For all other values, p > 0.05.

The null hypothesis that adjustment will not be related to stage of disability and time since diagnosis cannot be rejected when anxiety is the measure of adjustment in people with P.D. and it cannot be rejected when depression is the measure of adjustment in spouses. The null hypothesis can be rejected for the remaining measures of adjustment.
Hypothesis 5

Agreement on coping ratings between the people with P.D. and their spouses will be higher when there is a greater degree of congruence in the use of coping strategies.

In order to examine the agreement between coping ratings, the difference between the spouses’ ratings of the people with P.D. and the ratings that the people with P.D. made of themselves was calculated. The difference between the rating of the spouse by the people with P.D. and the spouses’ ratings of themselves was also calculated. The magnitude of the difference was used, irrespective of the sign, because if the hypothesis was correct, a curvilinear relationship would be expected by including the sign of the difference. As the scores used were scores of difference (rather than agreement per se), it was hypothesised that the relationships between these scores and the degree of congruence between the couple on the use of each coping strategy would be negative. Thus, a one-tailed test of the significance of the correlations was used.

Only one correlation was significant. This was in the predicted direction. This showed a negative relationship between difference (or a positive relationship between agreement) in the rating of the person with P.D. and congruence in the use of acceptance ($\tau = -0.2852$, $p < 0.05$).

As this is the only correlation out of fourteen which was significant and there is a one in twenty chance of making a Type I error, it seems reasonable to retain the null hypothesis that agreement on coping ratings between the people with P.D. and their spouses will not be related to degree of congruence in the use of coping strategies.

In calculating the differences on the coping ratings, it was noticed that the spouses tended to agree with the ratings that the people with P.D. gave for themselves but that this was not so true the other way around. This observation was explored by conducting Wilcoxon Matched-Pairs tests on the ratings. The results showed that there was no significant difference ($Z = -0.3976$, $p > 0.05$) in how both partners rated the people with P.D. There was, however, a significant difference ($Z = -1.9595$, $p < 0.05$) in how they
rated the spouses. The people with P.D. tended to rate the spouses more highly than the spouses rated themselves.

Hypothesis 6

*There will be some association between the rating of the marital relationship prior to the diagnosis of Parkinson’s Disease and congruence in coping strategies. It may be that those couples who rated their relationship as good, will have more congruence, or it may be that those who rated their relationship as good may have more difficulties in dealing with the changes and thus, may cope in different ways.*

The mean rating of the marital relationship by the people with P.D. was 18.9 (range 15 - 21), whilst the mean rating made by the spouses was 18.8 (range 12 - 21). Thus, overall, both groups rated their marriage as good prior to the diagnosis of P.D.

In calculating the correlations between the rating of the marital relationship and congruence in the use of coping strategies, only one significant correlation was found. This was a positive correlation between the spouses’ rating of the marital relationship and congruence in the use of emotion-focused coping (τ = .3559, p < 0.05).

Again, as there was only one significant correlation found out of fourteen, it is appropriate to retain the null hypothesis that there is no association between the rating of the marital relationship prior to the diagnosis of Parkinson’s Disease and congruence in the use of coping strategies.

Summary of Results and Further Analysis

Hypotheses 5 and 6 - The null hypotheses could not reasonably be rejected as only one correlation was significant out of fourteen for both hypotheses.
Results

Table 11 - Factors correlated with adjustment in people with P.D.

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Depression</th>
<th>Acceptance of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion-focused</td>
<td>Spouses’ level of depression</td>
<td>Stage of disability</td>
</tr>
<tr>
<td>Positive</td>
<td>Behavioural disengagement</td>
<td>Spouses’ acceptance of illness</td>
</tr>
<tr>
<td>reorientation</td>
<td>and growth</td>
<td></td>
</tr>
<tr>
<td>Denial</td>
<td>Alcohol / Drug use</td>
<td>Time since diagnosis</td>
</tr>
<tr>
<td>Congruence in</td>
<td>Stage of disability</td>
<td>Emotion-focused coping</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Congruence in alcohol/drug use</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotion-focused coping</td>
<td></td>
</tr>
</tbody>
</table>

Hypotheses 1 to 4 examined relationships between adjustment and the use of coping strategies (both individually and in terms of congruence), the adjustment of the partner and the stage of disability and time since diagnosis. Tables 11 and 12 summarise the significant relationships with each measure of adjustment for both people with P.D. and their spouses.

Table 12 - Factors correlated with adjustment in spouses.

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>Depression</th>
<th>Acceptance of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion-focused</td>
<td>Congruence in alcohol / drug use</td>
<td>Husband/wife’s level of acceptance of illness</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Husband/wife’s levels of depression</td>
<td>Stage of husband / wife’s disability</td>
</tr>
<tr>
<td>Alcohol/drug use</td>
<td>Alcohol/drug use</td>
<td>Behavioural disengagement</td>
</tr>
<tr>
<td>Denial</td>
<td>Behavioural disengagement</td>
<td>Congruence in alcohol / drug use</td>
</tr>
<tr>
<td>Congruence in</td>
<td>Acceptance</td>
<td>Emotion-focused coping</td>
</tr>
<tr>
<td>alcohol/drug use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage of husband</td>
<td>Active coping</td>
<td>Denial</td>
</tr>
<tr>
<td>wife’s disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Congruence in behavioural</td>
<td>Time since diagnosis</td>
</tr>
<tr>
<td></td>
<td>disengagement</td>
<td>Acceptance</td>
</tr>
</tbody>
</table>

In order to understand the relationship between these variables, further analysis was conducted to examine the correlations between the variables related to each measure of adjustment. Due to the distribution of these variables, it was not possible to calculate Pearson’s partial correlations, thus, simply correlating the variables with each other was
as much as could be done to gain some understanding as to whether or not the variables were independent.

**Anxiety - People with P.D.**

Significant correlations were found between the use of emotion-focused coping and positive reinterpretation and growth ($\tau = .4094$, $p<0.01$) as well as between emotion-focused coping and denial ($\tau = .4984$, $p<0.01$). Figure 5 illustrates the relationships found.

![Figure 5 - Relationships between variables correlated with levels of anxiety in people with P.D.](image)

**Anxiety - Spouses**

Significant correlations were found between the use of several coping strategies - emotion-focused coping and acceptance ($\tau = -.3716$, $p<0.05$) and acceptance and denial ($\tau = -.3637$, $p<0.05$) (see Figure 6). Congruence in alcohol / drug use was significantly correlated with (i) the spouse’s own alcohol / drug use ($\tau = -.8016$, $p<0.001$) and (ii) the use of denial ($\tau = -.3804$, $p<0.05$). Finally, of the factors related to anxiety in the spouses, there was a significant correlation between the use of emotion-focused coping and the partner's stage of disability ($\tau = .5139$, $p<0.01$).
Results

Anxiety

-0.3383
-0.3452
-0.4484
-0.3193
-0.4896

Congruence
in Alcohol / Drug Use

-0.5139
-0.3917
-0.3716
-0.3637
-0.3804

Emotion-Focused Coping

Denial

Acceptance

Alcohol / Drug Use

Stage of partner’s Disability

Key

positive correlation with anxiety
negative correlation with anxiety
positive correlation between variables
negative correlation between variables

Figure 6 - Relationships between variables correlated with levels of anxiety in spouses.

Depression - People with P.D.

Depression

-0.3145
-0.3950
-0.3547

Emotion-Focused Coping

Stage of Disability

Congruence in Alcohol / Drug Use

Behavioural Disengagement

Spouse’s Level of Depression

Alcohol / Drug Use

-0.3388
-0.5163
-0.5641
-0.3636

Key

positive correlation with depression
negative correlation with depression
positive correlation between variables
negative correlation between variables

Figure 7 - Relationships between variables correlated with levels of depression in people with P.D.
Results

There were significant relationships between several of the factors which were associated with depression in the people with P.D. (see Figure 7): the use of behavioural disengagement and emotion-focused coping ($\tau = .3507, p<0.05$); the use of behavioural disengagement and the spouse’s level of depression ($\tau = .3388, p<0.05$); alcohol / drug use and stage of disability ($\tau = .3761, p<0.05$). Further, congruence in alcohol / drug use was negatively correlated with (i) behavioural disengagement ($\tau = -.3636, p<0.05$); (ii) the person with P.D.’s own alcohol / drug use ($\tau = -.5641, p<0.01$) and (iii) the spouse’s level of depression ($\tau = -.5163, p<0.01$).

Depression - Spouses

Again, there were several significant correlations between the factors related to depression in the spouses (see Figure 8).

![Figure 8 - Relationships between variables correlated with levels of depression in spouses.](image)

Congruence in the use of behavioural disengagement was associated with (i) the spouses’ own use of behavioural disengagement ($\tau = -.3990, p<0.05$) and (ii) the spouses’ use of active coping ($\tau = .3267, p<0.05$). Congruence in alcohol / drug use was negatively correlated with (i) behavioural disengagement ($\tau = -.6014, p<0.001$); (ii) the spouse’s own alcohol / drug use ($\tau = -.8016, p<0.001$) and (iii) the husband’s /
wife's level of depression ($\tau = -.3547, p<0.05$). Finally, the spouses' use of behavioural disengagement was correlated with (i) his/her alcohol/drug use ($\tau = .4663, p<0.01$) and (ii) the husband's/wife's level of depression ($\tau = .3401, p<0.05$).

**Acceptance of Illness - People with P.D.**

There were three significant relationships between the factors that were associated with acceptance of illness in the people with P.D. (see Figure 9). The person's stage of disability was related to (i) congruence in the use of positive reinterpretation and growth ($\tau = .3603, p<0.05$) and (ii) the spouse's acceptance of illness ($\tau = -.4436, p<0.01$) (as already shown in hypothesis 4). Further, the spouse's acceptance of illness was correlated with the time since the diagnosis ($\tau = -.3251, p<0.05$) (again, as shown in hypothesis 4).

![Figure 9 - Relationships between variables correlated with acceptance of illness in people with P.D.](image)

**Key**
- Positive correlation with acceptance of illness
- Negative correlation with acceptance of illness
- Positive correlation between variables
- Negative correlation between variables

There were several significant correlations between the factors associated with acceptance of illness in the spouses (see Figure 10). As shown in hypothesis 4, the people with P.D.'s acceptance of illness was related to (i) their stage of disability ($\tau = -.6351, p<0.001$) and (ii) the time since diagnosis ($\tau = -.4170, p<0.01$). The people with P.D.'s acceptance of illness was also related to (i) the spouses' use of behavioural...
Results
disengagement ($\tau = -0.3447, p<0.05$) and (ii) the spouses’ use of emotion-focused coping ($\tau = -0.4222, p<0.01$). The spouses’ use of acceptance as a coping strategy was negatively correlated with (i) their use of emotion-focused coping ($\tau = -0.3716, p<0.05$) and (ii) their use of denial ($\tau = -0.3637, p<0.05$). Congruence in alcohol/drug use was also negatively correlated with the spouses’ use of denial ($\tau = -0.3804, p<0.05$) as well as with their use of behavioural disengagement ($\tau = -0.6014, p<0.001$). Finally, the spouses’ use of emotion-focused coping was related to the husbands’/wives’ stage of disability ($\tau = 0.5139, p<0.01$).

![Figure 10 - Relationships between variables correlated with acceptance of illness in spouses.](image)

Key
- positive correlation with acceptance of illness
- negative correlation with acceptance of illness
- positive correlation between variables
- negative correlation between variables

In summary, these analyses showed that most of the factors related to adjustment were not independent of the other factors and that the relationships are complex. This will be explored further in the discussion.

Given the complex relationships shown above, it was decided to examine which variables could predict the adjustment of the people with P.D. and the spouses. The measures of anxiety and depression could both be treated as dichotomous with respect
Results

to caseness. It was, therefore, decided to conduct logistic regression analysis using anxiety and depression as the dependent variables. Logistic regression makes no assumptions about the distributions of the predictor variables which was important given the non-normal distributions of many of the potential predictors e.g. individual use and congruence in the use of coping strategies.

The first stage in conducting this analysis was to recode the variables of anxiety and depression for both groups of participants. Scores of 10 and less on each variable were coded as 0 whilst scores greater than 11 were coded 1. Thus, a score of 1 implied that the person was anxious or depressed (dependent on the variable in question). The second stage was to decide which predictors would be entered into each equation. Ideally, the stage of disability, time since diagnosis, the partner's adjustment, congruence in the use of coping strategies and the individual's use of coping strategies would all be entered. Due to the small sample size, however, the number of potential predictors needed to remain fairly small. For this reason, the choice of predictors to be entered was based on earlier statistical results - those variables that had been found to have a significant relationship with each measure of adjustment (see Tables 11 and 12). Predictors were entered into each model using a forward stepwise logistic regression. Tables 14 - 17 show the regression coefficients, Wald statistics and associated probabilities and odds ratios for each of the predictors related to the dependent variables.

Table 13 - Numbers of people classified as (i) anxious and (ii) depressed for each group.

<table>
<thead>
<tr>
<th></th>
<th>People with P.D.</th>
<th>Spouses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxious</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Not Anxious</td>
<td>15</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>23</strong></td>
<td><strong>23</strong></td>
</tr>
<tr>
<td>Depressed</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Not Depressed</td>
<td>19</td>
<td>16</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>23</strong></td>
<td><strong>23</strong></td>
</tr>
</tbody>
</table>
The success rates for correctly classifying people using the models should all be interpreted cautiously as these are dependent on the relative sizes of the groups. For all four models there were larger numbers of people who displayed good adjustment. Table 13 shows the sizes of each group.

**Anxiety - People with P.D.**

Table 14 shows statistics calculated for the model for anxiety in people with P.D. The model contained two predictors and was statistically reliable when compared against the constant-only model ($\chi^2(2, 23) = 14.208, p < 0.001$). Overall success rate in predicting anxiety was 91.3%, with success rates of 87.5% and 93.3% in predicting people who were anxious and who were not anxious (respectively). These rates need to be interpreted cautiously, however, as successful prediction is sensitive to group size.

The model suggests that a one point increase in the (mean) use of emotion-focused coping implies that a person is fourteen times more likely to be classified as anxious. Whilst a one-point increase in congruence in the use of acceptance means that a person is twenty times more likely to be classified as anxious.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>Wald Test</th>
<th>Sig.</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion-focused coping</td>
<td>2.6428</td>
<td>5.0666</td>
<td>.0244</td>
<td>14.0530</td>
</tr>
<tr>
<td>Congruence in the use of Acceptance</td>
<td>3.0289</td>
<td>2.8822</td>
<td>.0896</td>
<td>20.6751</td>
</tr>
<tr>
<td>(Constant)</td>
<td>-14.4069</td>
<td>4.8498</td>
<td>.0276</td>
<td></td>
</tr>
</tbody>
</table>

**Anxiety - Spouses**

Again, the model contained two predictors and was statistically reliable when compared against the constant-only model ($\chi^2(2, 23) = 21.889, p<0.001$). Overall success rate in predicting anxiety in the spouses was also 91.3%. The success rates for predicting people who were anxious and who were not anxious were 88.9% and 92.9% (respectively).
Results

Table 15 - Logistic regression analysis of anxiety in spouses.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>Wald Test</th>
<th>Sig.</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion-focused coping</td>
<td>6.1103</td>
<td>2.9638</td>
<td>.0851</td>
<td>450.4534</td>
</tr>
<tr>
<td>Alcohol / Drug Use</td>
<td>4.0430</td>
<td>2.6965</td>
<td>.1006</td>
<td>56.9964</td>
</tr>
<tr>
<td>(Constant)</td>
<td>-22.4629</td>
<td>3.0098</td>
<td>.0828</td>
<td></td>
</tr>
</tbody>
</table>

The model for predicting anxiety in the spouses suggests that a one-point increase in the (mean) use of emotion-focused coping is associated with a person being 450 times more likely to be classified as anxious (see Table 15). A one-point increase in alcohol / drug use is associated with a person being 57 times more likely to be classified as anxious.

**Depression - People with P.D.**

The model for predicting depression in people with P.D. contained only one predictor (see Table 16). It was statistically reliable when compared against the constant-only model (\( \chi^2(1, 23) = 4.486, p<0.05 \)). Success rates in predicting people who were depressed was only 25.0% whilst the success rate of predicting people who were not depressed was 94.74%. The overall success rate was 82.6%. Caution is particularly needed when interpreting these rates as there were only 4 people who were depressed and nineteen who were not.

Table 16 - Logistic regression analysis of depression in people with P.D.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>Wald Test</th>
<th>Sig.</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congruence in Alcohol / Drug Use</td>
<td>-1.5489</td>
<td>3.3712</td>
<td>.0663</td>
<td>.2125</td>
</tr>
<tr>
<td>(Constant)</td>
<td>2.2229</td>
<td>1.1253</td>
<td>.2888</td>
<td></td>
</tr>
</tbody>
</table>

The model suggests that a one-point increase in congruence in alcohol / drug use means a person is 0.2 times more likely to be classified as depressed i.e. is less likely to be classified as depressed for each one-point increase in congruence in the use of this coping strategy.
Depression - Spouses

The model contained two predictors for depression in spouses (see Table 17). This model was statistically reliable when compared against the constant-only model ($\chi^2(2, 23) = 13.387, p<0.01$). The overall success rate in predicting depression was 87.0%. The success rates for predicting people who were depressed and who were not depressed were 71.4% and 93.8% (respectively).

The model suggests that a one-point increase in the depression level of the husband / wife with P.D. was associated with the spouse being nearly one and a half times more likely to be classified as depressed. Whilst a one-point increase in the use of behavioural disengagement by the spouse was associated with that person being nearly four and a half times more likely to be classified as depressed.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>Wald Test</th>
<th>Sig.</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner's Level of Depression</td>
<td>.3458</td>
<td>3.1745</td>
<td>.0748</td>
<td>1.4131</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>1.5012</td>
<td>4.4014</td>
<td>.0359</td>
<td>4.4872</td>
</tr>
<tr>
<td>(Constant)</td>
<td>-6.8350</td>
<td>6.0717</td>
<td>.0137</td>
<td></td>
</tr>
</tbody>
</table>

In summary, using the factors that had been found to correlate with adjustment in people with P.D. and their spouses, it was possible to creates models using one or two of the relevant factors to predict which people would be classified as anxious or depressed. The overall success rates were greater than 82% for all four models.
Discussion
Discussion

The findings of the study are discussed first in relation to the hypotheses. Next, the theoretical and clinical implications of the findings are addressed. Following this, problematic areas of the method are discussed and suggestions made for improvement. Finally, suggestions for future research are made, based on the current study.

Current Findings

The findings need to be considered in the light of the participant characteristics discussed in the Results section. One very important point is the degree to which the people with P.D. had other physical problems and the degree of physical problems which were experienced by the spouses. Carter and Carter (1994) found that the health of the spouses affected their reactions to their partners' illness. Nearly a third (seven) of the couples also had other sources of stress. This means that these participants were coping with more than just P.D. and even though they were requested to specifically consider how they coped with the problems created by P.D., it is likely that these other difficulties will have had some influence on the types of coping strategies that they used. These are also likely to have had some effect on the measures of adjustment, for example, a participant may be depressed because of other life stresses currently being experienced.

One other important point to be conscious of when examining the results, is that there was a very clear difference in the gender distribution across the two groups. The people with P.D. were mostly males, whilst the spouses were mostly females. Research has suggested that the gender of the patient is important with respect to the impact that a chronic illness has on the psychological well-being of the couple (Soskolne and Kaplan De-Nour, 1989). There is also some debate as to whether gender affects the choice of coping strategies used (Carver, Scheier and Weintraub, 1989) or whether this is simply a result of having to cope with different stresses.

Problems Reported

A further consideration, when examining the findings, is that the people with P.D. and their spouses reported different problems. For example, the people with P.D. discussed
the experience of symptoms, functional difficulties and mobility problems as relevant to them. None of these were mentioned by their spouses. The spouses commented on emotional difficulties and the need for extra effort more often than the people with P.D. and although both groups mentioned losses, the types of losses discussed were not the same. Thus, although both groups were reporting on how they coped with P.D., there were differences in what they were coping with. This might lead to particular coping strategies having different effects on adjustment as some coping strategies may be more effective in dealing with some problems than they are at dealing with others. It must also be remembered, however, that these differences are between the groups and that within each group there will be differences in the problems relevant for individuals.

Change in Relationship
It was interesting that there were differences in how the people with P.D. and their spouses rated change in their relationship since P.D. was diagnosed. Although just over half of the people in each group reported that their relationship had not changed, the remainder saw things differently, with more people with P.D. reporting that their relationship had improved. This perhaps reflects some of the differences mentioned in the difficulties that each group faced. For the people with P.D., they may have felt that the extra attention and help given to them by their spouses was an improvement in their relationship whereas the extra effort, change in roles and emotional difficulties may have led to the spouses being more likely to report that things had deteriorated.

These findings are similar to those in Carter and Carter’s (1994) study where patients with P.D. were more likely to identify positive effects on the marriage as a result of the illness. Further, this study also found that spouses who were not ill themselves, were more likely to report negative effects from the illness on the marriage.

Use of Coping Strategies
The overall use of coping strategies (as shown in Table 4, Results) was similar for both the people with P.D. and the spouses. Further, these results were similar to those found by Cartwright and Lamb (1996) when they tested the 32-item COPE on a sample of 150 people suffering from chronic illness. The mean scores that they report are: active
Discussion

coping - 22.9; acceptance - 12.7; alcohol/drug use - 5.5; behavioural disengagement - 3.1; denial - 6.3; emotion-focused coping - 13.5; positive reinterpretation and growth - 9.6. This may suggest that people cope with P.D. in similar ways to how people cope with other chronic illnesses and thus, may support Felton et al's (1984) findings that people use similar coping strategies irrespective of their diagnosis.

Hypothesis 1

There will be a correlation between the person with P.D. and spouse with respect to adjustment.

The correlations that were found between the acceptance of illness and levels of depression for the people with P.D. and their spouses could have several different meanings. One possibility is that the adjustment of one person affected the adjustment of the other in a fairly direct manner. For example, if the person with P.D. was accepting of their illness then this may mean that his/her spouse would find it easier to accept the P.D. or vice versa. The same could occur with depression where a depressed partner may behave in such a way, e.g. by withdrawing, that creates difficulties for the other partner and so results in them becoming depressed. It may also be a cyclical relationship where the adjustment of each person affects the other.

Another possible explanation of the correlation is that some other factor was common to both partners e.g. if they both used different coping strategies then both might experience conflict and thus become more depressed or be less accepting of the illness. Alternatively, they might both be using the same particular coping strategy which increases the chances of acceptance of the illness or depression. There might be other factors besides the use of coping strategies that are common to both partners including the stage of disability experienced, external stressors or social support outside of the marital relationship. Further results throw some light onto some of these possible explanations.
Discussion

Hypothesis 2

*Congruence between the person with P.D. and spouse, with respect to coping strategy use (irrespective of the specific coping strategies used), will lead to better adjustment for both the person with P.D. and spouse.*

This hypothesis led to mixed results. Firstly, there appeared to be little congruence at all, with only alcohol / drug use showing a significant correlation. There may have been little congruence due to the illness being progressive. The people with P.D. and the spouses may have been at different adaptational stages due to the changing nature of the illness. There may also have been little congruence because the people with P.D. and the spouses were coping with different difficulties and thus, may have been using different strategies to cope with these.

Returning to the one significant correlation, alcohol / drug use was not utilised by the majority of participants (mean scores were 4.7 and 5.4 for people with P.D. and spouses respectively, where 4.0 is the minimum possible score equal to ‘does not use at all’) and so high congruence implied that neither partner used this particular coping strategy. Low congruence, therefore, implied that only one partner used this coping strategy to any degree.

**People with P.D.**

For the people with P.D., there were only three significant, low correlations between measures of adjustment and degree of congruence in the use of particular strategies. Only one of these three was in the predicted direction - degree of congruence in alcohol/drug use was negatively related to level of depression. Thus, low congruence was related to higher levels of depression. This correlation might mean that the person with P.D. became depressed if either they or their spouse used this coping strategy. Alternatively, it might suggest that this coping strategy was used by one of the partners, if the person with P.D. was depressed. It is also possible that there is no causal relationship between the use of this coping strategy by one partner with the increased levels of depression in the person with P.D. There might be a third factor, such as stage of disability, which links both.
The other two significant correlations found between the degree of congruence in the use of coping strategies and adjustment for people with P.D. were not in the predicted direction. Congruence in the use of positive reinterpretation and growth was negatively correlated with acceptance of illness and congruence in the use of acceptance was positively associated with anxiety for the people with P.D. Therefore, the null hypothesis that greater congruence will not be associated with better adjustment cannot be rejected in the case of the people with P.D.

The two significant correlations which were not in the predicted direction should not be dismissed as they could still be important in explaining the adjustment of the people with P.D.

**Spouses**

The four significant correlations between congruence in coping strategy use and adjustment for spouses were in the predicted direction such that greater levels of congruence were associated with better adjustment. For the spouses, congruence in alcohol/drug use was associated with all three measures of adjustment (low correlations with anxiety and acceptance of illness and a modest correlation with depression), whilst congruence in behavioural disengagement was associated with depression.

The negative correlation between degree of congruence in the use of behavioural disengagement and level of depression may mean that if one partner uses behavioural disengagement more than the other (low congruence) then the spouse is more likely to become depressed due to conflict. Alternatively, it may mean that if the spouse is depressed then one partner is more likely to use behavioural disengagement as a coping strategy. Withdrawal in terms of behavioural disengagement is often a symptom of depression and so it may be that the spouse uses this if s/he becomes depressed or, if s/he uses this coping strategy then s/he is more likely to become depressed. This might have little to do with the degree to which the person with P.D. uses this coping strategy.

As there were still only four significant correlations in the predicted direction out of a potential twenty-one, it is probably appropriate to be specific in partially rejecting the
null hypothesis. Thus, the null hypothesis that congruence in the use of active coping, acceptance, denial, emotion-focused coping, positive reinterpretation and growth will not be associated with better adjustment for spouses cannot be rejected. The null hypothesis that congruence in alcohol/drug use and behavioural disengagement will not be associated with better adjustment for spouses can be rejected.

Hypothesis 3

There will be moderate relationships between coping strategies used by the individuals and their level of adjustment.

There were a greater number of significant correlations found between the individual’s use of coping strategies and their adjustment to P.D. than were found between the degree of congruence in the use of coping strategies and adjustment. These correlations also tended to be stronger. For all these correlations, as with the correlations that were found for all the hypotheses that were tested, there are a number of possibilities. There may be a causal relationship in either direction thus, one variable may affect the other. For example, the use of a coping strategy may affect adjustment or adjustment may affect the use of the coping strategy. There is also the possibility that the relationship between the two variables is cyclical such that both variables affect each other. For example, the use of a coping strategy may improve adjustment and better adjustment may lead to an increased use of the coping strategy. The other possibility with significant correlations is that the relationship between the two variables being examined is actually spurious and that both variables are related to a third variable which gives the appearance that the two original variables are related to each other. For example, stage of disability may influence degree of adjustment and the use of particular coping strategies but the use of particular coping strategies may not be directly related to adjustment.

Returning to the specific correlations between coping strategy use and adjustment, there were several similar relationships for both the people with P.D. and their spouses. Denial and emotion-focused coping were both positively correlated with anxiety for people with P.D. and their spouses whilst alcohol/drug use and behavioural
Discussion

disengagement were positively correlated with depression for both groups. Further, emotion-focused coping was negatively correlated with acceptance of illness for the people with P.D. and the spouses.

There were also several differences in the significant correlations between adjustment and coping strategy use that were found for the two groups. For the people with P.D., anxiety was positively correlated with positive reinterpretation and growth and depression was positively correlated with the use of emotion-focused coping. Neither of these were significant relationships for the spouses and in fact, although not significant, the relationship between anxiety and positive reinterpretation and growth was in the opposite direction for the spouses.

For the spouses only, the following were significant: anxiety was positively correlated with alcohol/drug use and negatively correlated with acceptance; depression was negatively related to active coping and acceptance; acceptance of illness was positively related with the use of acceptance as a coping strategy and negatively related with behavioural disengagement and denial.

The same arguments apply to all of these relationships as discussed earlier. There may be causal relationships between the use of coping strategies and adjustment in either, or even both, directions or there may be one or more other factors which are related to both.

The positive correlations between (i) alcohol/drug use and depression for both people with P.D. and their spouses; (ii) alcohol/drug use and anxiety for the spouses and (iii) behavioural disengagement and depression for the spouses are all interesting when examined in the light of the findings for hypothesis 2. The correlations between congruence in the use of these coping strategies and the measures of adjustment were in the opposite direction. Thus, there were negative correlations between (i) congruence in alcohol/drug use and depression for both people with P.D. and their spouses; (ii) alcohol/drug use and anxiety for the spouses and (iii) behavioural disengagement and depression for the spouses.
Examining the data had shown that there was little use of either behavioural disengagement or alcohol/drug use by the people with P.D. or their spouses. Thus, greater congruence implies that neither partner really uses that coping strategy. The relationships found can be illustrated by considering the example of alcohol/drug use and its association with depression in both people with P.D. and their spouses. Less use of this coping strategy is associated with less depression; less depression is associated with greater congruence; greater congruence is associated with less use of the strategy. Alternatively, less congruence is associated with more depression; more depression is associated with greater use of the coping strategy; greater use of the coping strategy is associated with less congruence. This may, therefore, be an important consideration as the present definition of congruence relates to a range of possibilities. For example, greater congruence could mean that both partners do not really use that particular coping strategy or it could mean that both partners use it a lot. In turn, low levels of congruence in the use of a coping strategy implies that one partner uses the coping strategy more than the other.

One final point of interest when examining the correlations between coping strategy use and adjustment is the relationship between emotion-focused coping and adjustment. For the people with P.D., emotion-focused coping was significantly correlated with all three measures of adjustment. For the spouses, it was correlated with two of the measures of adjustment - anxiety and acceptance of illness. The direction of the correlations suggests that it may be an unhelpful coping strategy for adjusting to the illness or it may be that when people are having difficulties in adjusting then they turn to this coping strategy. Whether the relationships are causal or not, it may be that the use of emotion-focused coping is a good predictor of whether a person generally has poor adjustment to P.D.

Overall, there were more significant correlations between the use of coping strategies and measures of adjustment for the spouses. It may be that these coping strategies had a larger impact on the specific problems faced by the spouses. It may also have been due to sample characteristics e.g. differences in gender may interact with adjustment and use of coping strategies.
Hypothesis 4

Levels of adjustment will be related to stage of disability and time since diagnosis.

Stage of disability and time since diagnosis were both negatively correlated with acceptance of illness for people with P.D. and for the spouses. The findings suggest that, as time passes, people accept the illness less and less. It may be that people (both those with P.D. and their spouses) accept the illness less because the disease is progressing and the problems become greater. Earlier on in the disease the problems are smaller and have less impact on life and so perhaps people can accept this more easily. Thus, it may be that the correlation between time since diagnosis and acceptance of illness is completely explained by the stage of disability. This is a possibility as the correlations between time since diagnosis and acceptance of illness are not as strong as the correlations between stage of disability and acceptance of illness for both people with P.D. and their spouses.

There are other possibilities of course. Although time since diagnosis cannot be affected by acceptance of illness, there is some possibility that stage of disability might be, if the disease were to be exacerbated by stress e.g. not accepting the illness. It is also possible that other factors may explain the relationships. For example, as the disease progresses and as time passes, people may use different coping strategies to deal with the problems they face and it may be these coping strategies which lead to them accepting the illness less. The use of emotion-focused coping may be one such coping strategy. Emotion-focused coping was found to be negatively correlated with acceptance of illness for both groups of people. If this coping strategy affects acceptance, it may be that people are using emotion-focused coping more as time passes and as the disease progresses.

For the people with P.D., there was also a positive correlation between depression and stage of disability. Logically, this could be explained as people becoming more depressed as they become more disabled because they experience more losses and restrictions. The increase in depression could also be due to the chemical changes in the brain as depression often occurs in people with P.D. The results of this study, however, did not find a significant difference in level of depression for the people with P.D. as
compared to their spouses suggesting that the level of depression may be related to other factors. The correlation between depression and stage of disability could also be explained if the illness is exacerbated by depression. Again, the present study cannot inform a conclusion about which, if either, possibility is correct.

For the spouses, there was a modest positive correlation between anxiety and stage of disability. It would be an extreme view to suggest that the anxiety of the spouses could affect the stage of disability of their husbands and wives. The more likely explanation is that the spouses become more anxious as their husbands/wives become more disabled. This may be because there are more difficulties and problems as the person becomes more disabled. For example, the spouses reported that the change in roles and having to take on their husbands' wives' tasks was a problem for them. Thus, the increasing anxiety may be due to the increasing difficulties that they have to deal with. It could also be simply an increase in anxiety because they are concerned for their husbands/wives and worry about them. It may be a combination of the two. Alternatively, there may be another factor involved, such as the use of coping strategies which are related to the stage of disability and the spouses' anxiety.

**Hypothesis 5**

*Agreement on coping ratings from the person with P.D. and spouse will be higher when there is greater congruence in the use of coping strategies.*

This hypothesis returned to examining congruence between the person with P.D. and spouse. It was hypothesised that if there was congruence in the use of coping strategies then each partner would have a better understanding of how the other person was coping. There was only one significant correlation out of 14 and therefore, the null hypothesis could not be rejected.

Obviously, it is quite possible that there is no relationship between agreement on how people rate each other as coping and degree of congruence in the use of coping strategies. There is also the possibility that problems may have arisen due to the nature
Discussion

of the scale for rating coping i.e. it relied on self-report. This is discussed further in the section on methodological difficulties.

One interesting finding that did arise from this hypothesis was that the people with P.D. tended to rate their spouses as coping better than they rated themselves. This may be for a number of reasons. It may be that the spouses tended to evaluate themselves as not coping as well as they actually were because they believed that they should be coping better. It may be that the people with P.D. overestimated how well the spouses were coping. This could occur if the spouses were struggling but hid this from their husbands/wives because they felt that their partners had enough to cope with. This might be supported by the fact that 22% of the spouses reported feeling alone when asked what the difficulties were that they had to deal with. In other words, they may have felt alone because they did not share their difficulties.

Hypothesis 6

*Ratings of the marital relationship prior to the onset of Parkinson’s Disease will be associated with degree of congruence in the couples’ coping styles.*

The final hypothesis was that congruence in the use of coping strategies would be correlated with ratings of the marital relationship prior to the diagnosis of P.D. The only statistically significant result was that the spouses’ rating was positively correlated with congruence in the use of emotion-focused coping. Given that a 95% significance level was used, which gives a probability of 1 in 20 that the result occurred by chance, and the fact that only 1 of the 14 correlations was significant, it seems most appropriate to retain the null hypothesis. Thus, it may be that satisfaction with the marital relationship and congruence are completely unrelated so that one couple may use similar coping strategies and be dissatisfied with their relationship whilst another couple may use different coping strategies but be satisfied with their relationship.
Discussion

Further Analysis

The first step in the further analysis was to examine the relationship between the variables that were associated with each of the measures of adjustment for both groups. The ability to do this was somewhat limited by the distributions of some of the variables in question, as it was not appropriate to use partial correlations which are associated with Pearson's product moment correlation. It was clear, however, that there were complex relationships between the variables. Some of the more interesting relationships that were evident included the relationships between both partners' level of adjustment and other variables present. For example, the spouses' acceptance of illness was correlated with their husbands'/wives' acceptance of illness. Both of these were also correlated with emotion-focused coping, stage of disability and time since diagnosis. Thus, as suggested in the discussion related to hypothesis 1, it could be that the correlation in adjustment is spurious and is a function of other variables such as stage of disability and time since diagnosis which will be at the same 'level' for both partners.

Another interesting finding was that the partner’s adjustment was found to correlate with the other person’s use of coping strategies in three instances. For example, the acceptance of illness in the people with P.D. was negatively correlated with the spouses use of behavioural disengagement and emotion-focused coping. It must be remembered that correlations between such variables were only found because they were related to the same outcome and it is, therefore, possible that there are further correlations between one person’s use of a coping strategy and the other person’s adjustment. This has been found in previous research (e.g. Giunta and Compas, 1993; Pruchno, Burant and Peters, 1997) and may be important to consider alongside congruence in attempting to understand the interactions that occur when a married couple are attempting to cope with chronic illness.

There were also relationships between different coping strategies. It may be that they are used in combination or it may suggest that particular strategies serve similar, or opposite, functions. For example, the three coping strategies that were related to anxiety in people with P.D. - emotion-focused coping, denial and positive reinterpretation and
growth - were related to each other. Thus, it may be that the apparent correlations between denial and anxiety and positive reinterpretation and growth and anxiety are actually explained through the functions that are shared with emotion-focused coping.

The second section of further analysis involved using the variables which had been found to be correlated with adjustment, to try to create models which could predict the adjustment of both the people with P.D. and the spouses. The predictors that were used in the models created through logistic regression are not necessarily causal. Thus, a one-point increase in the use of emotion-focused coping will not make a person with P.D. fourteen times more likely to become anxious. It simply means that emotion-focused coping and anxiety are related to that degree and again, causality could be in (i) either direction or (ii) both directions or (iii) neither direction, if there are other factors which create this apparent relationship.

The models are limited by the potential predictors that were entered and are also specific to the present sample. Therefore, these models may not hold true for other samples and there may be other predictors that could create adequate models for explaining which people are categorised as anxious or depressed. Despite this, it is interesting to note that in three of the four models one predictor was related to some element of interaction between the couple. These predictors were in the form of congruence in the use of coping strategies and the adjustment of the partner. Perhaps this helps to emphasise the need to consider coping with physical illness from a systemic perspective.

Theoretical Implications of Present Findings

Coping with Physical Illness
Coping strategies are seen to be attempts to manage stressful demands and their success is evaluated by the outcome that they produce at a particular time, in a particular situation. In the present study (as in many others e.g. Felton et al, 1984), adjustment was taken as the measure of outcome. The findings suggest however, that (i) adjustment may not simply arise from the use of coping strategies and (ii) adjustment may also influence
which coping strategies are used. Thus, it is difficult to evaluate the ‘success’ of coping strategies using adjustment as the outcome measure.

The present study, however, supported previous findings of a modest relationship between coping strategy use and adjustment, in particular, the finding that emotion-focused coping is associated with poor adjustment (Lambert, 1981; Felton, Revenson and Hinrichsen, 1984). Pearlin and Schooler (1978), amongst others, found that emotion-focused strategies were most effective in situations which were not amenable to individual control. It might be suggested that P.D. is not amenable to personal control as it cannot be cured and is progressive, however, emotion-focused strategies did not appear to be effective in improving adjustment in this situation. Again, it is important to remember the points raised regarding causality. It is difficult to directly compare other associations that have been found between coping strategies and adjustment, as other studies used different measures and examined different coping strategies.

The relationships between adjustment and stage of disability and adjustment and time since diagnosis are perhaps surprising. Stage theories of coping with illness, e.g. Shontz (1975), would suggest that people become better adjusted as they complete the adaptational tasks necessary and so it might be expected that adjustment would improve. The important aspect of the current findings is that they are related to a deteriorating illness. It is possible that adjustment may improve until the illness deteriorates and then the individuals have to begin to adjust to the new difficulties that arise. This is perhaps most clearly illustrated by the relationship between acceptance of illness and stage of disability or time since diagnosis.

It might be expected that after diagnosis, people initially experience shock and are unable to accept the illness as real but as time passes, people begin to adapt and accept the reality. The present findings suggest that this does not occur instead they accept the illness less as time passes. It is possible that, although people may not accept the illness immediately, this occurs fairly quickly. As time passes and the illness deteriorates, the person has greater limitations and losses to accept. Eventually, they may come to accept the ‘new’ stage of the disability but then the illness will progress again requiring them to
Discussion

accept further losses. Thus, the relationship between acceptance of illness and stage of disability (or time since diagnosis) may actually follow a step-like pattern which is consistent with the concept of ‘stages’ in adaptation. This pattern may be specific to deteriorating conditions.

The Impact of Physical Illness on the Spouse

The difficulties reported by the spouses, support and expand upon Sexton and Munro’s (1985) findings. Sexton and Munro found that wives of men who had chronic obstructive pulmonary disease took on new roles and responsibilities and gave up social activities. The current findings showed that the spouses of people with P.D. (which included a small number of men) also reported taking on new roles and giving up social activities. This suggests that Sexton and Munro’s (1985) findings might generalise to other chronic illnesses and reinforces the fact that chronic illness does impact upon people other than the patient.

Other studies have again used different coping strategies in examining the relationships between coping strategies and depression and anxiety in caregivers, making it difficult to compare these with the present findings. Previous studies have found that such strategies as non-confronting coping (Matson, 1994), escape-avoidance coping (Stephens et al, 1988) and avoidant-evasive coping (Wright et al, 1991) are positively associated with anxiety, stress, depression and burden. These could be comparable with the present findings that behavioural disengagement, denial and alcohol/drug use, which are all avoidant-type strategies, are positively associated with depression and/or anxiety.

The Dyadic Relationship in Coping with Physical Illness

The present research supported previous research findings of significant correlations between the adjustment and psychological distress of patients and their spouses (e.g. Baider and Kaplan De Nour, 1988). It also increased the understanding of the generalisability of these findings as the present results were found in people dealing with P.D. which had not previously been examined. The present research could not conclude whether patients affect spouses or spouses affect patients in their adjustment but it did raise the question as to whether or not other factors such as stage of disability and
Discussion

Congruence in the use of some coping strategies may affect the adjustment of both partners.

The present study did not support Badger's (1990) findings of partners using similar coping strategies to cope with chronic illness (in Badger's study this was cardiovascular disease). There were clear methodological differences however, which may explain the differences. Badger reported that partners were similar in their coping strategies after examining the mean use of different coping strategies by both the patients and the spouses. The current study also found that there were no significant differences between the use of coping strategies by the people with P.D. and their spouses which could initially seem to support the idea that both partners coped in similar ways. This finding, however, actually only supports the idea that both groups cope in similar ways. Calculating correlations shows that the couples did not generally cope in similar ways, i.e. there was little congruence.

It is suggested that the dyadic relationship requires further consideration with respect to coping with chronic illness. Based on the findings of the present research, certain aspects of the dyadic relationship have been shown to be important. As discussed above, the adjustment of the people with P.D. and their spouses was correlated. Further, congruence in the use of particular coping strategies was correlated with the adjustment of each partner. More specifically, greater congruence in alcohol/drug use was associated with better adjustment. Thirdly, the coping strategy use of one partner was correlated with the adjustment of the other in some instances. For example, level of depression in both partners was correlated with the other partner's use of behavioural disengagement as a coping strategy.

The dyadic relationship is obviously complex and further research is needed to confirm and clarify the present findings. In particular, the direction of influence between factors is not clear. The present research, however, suggests that the dyadic relationship is important and coping with chronic illness should be considered in this context and not simply from an individualistic perspective.
Clinical Implications of Present Findings

Cross-sectional correlational designs such as that used in the present study, lead to certain difficulties which mean that it is not possible to make specific clinical recommendations. (The difficulties are discussed in some detail in the section below titled 'Methodological Difficulties'). It is possible, however, to make suggestions dependent on how future research explains the relationships with respect to causality etc.

Working with couples
If the relationships between acceptance of illness and levels of depression in the people with P.D. and their spouses are found to be causal, then working with one partner to improve their acceptance of illness or reduce their depression may help the other partner. If the relationship is cyclical it may be more useful to work with both people.

Again, if the significant correlations between congruence and adjustment are found to be causal such that the levels of congruence affect adjustment, then it would be important to encourage congruence in alcohol/drug use and behavioural disengagement. The data from the present study suggests that congruence would need to be in the form of not using the particular coping strategy and so, if one partner was using the strategy it would be important to reduce this use as opposed to encouraging the other partner to begin using it. (Clinically, it would be assumed that it would not be appropriate to encourage a person to use alcohol/drugs and probably behavioural disengagement.)

The use of coping strategies
If future longitudinal research shows that the correlation between the use of coping strategies and adjustment is causal such that the use of coping strategies leads to adjustment then this would lead to the following clinical implications. People with P.D. should be discouraged from using emotion-focused coping, positive reinterpretation and growth, denial, behavioural disengagement and alcohol/drug use as these were all correlated with poor adjustment. Spouses would be discouraged from using emotion-focused coping, denial, behavioural disengagement and alcohol/drug use. Unfortunately
Discussion

for the people with P.D., there were no coping strategies which were correlated with good adjustment and so, if coping strategies were found to lead to adjustment then the current findings would not be able to suggest any coping strategies which would improve adjustment. Spouses, in contrast, could be encouraged to use active coping and acceptance.

These clinical implications would only be relevant if future research found a causal relationship in that direction. If future research found a causal relationship in the opposite direction i.e. that adjustment leads to the use of particular coping strategies then there would be no reason to encourage or discourage the use of particular coping strategies. If, however, the relationship was found to be cyclical then the suggestions made above would remain. Thus, it is clear that clinical implications about the use of an individual’s coping strategies can only be made if further research clarifies any causal relationships with adjustment.

The impact of time and stage of disability

The finding that time since diagnosis was correlated with less acceptance of illness for both people with P.D. and their spouses, may initially seem surprising clinically but this may be due to the deteriorating nature of P.D. People do not simply have to come to terms with a diagnosis over time. A condition such as P.D. has different implications over time as the disease progresses. This is perhaps why there are stronger correlations between stage of disability and acceptance of the illness than there are between time since diagnosis and acceptance of illness. The findings between stage of disability and adjustment are perhaps more important clinically for this reason. If the relationship is causal in the direction that stage of disability affects adjustment, then both the people with P.D. and their spouses are more likely to need clinical input at the later stages of the disease. For the people with P.D., this would be for depression and help in accepting the illness. For the spouses, this would be for anxiety and help in accepting their husband’s/wife’s illness. Further, Soskolne and Kaplan De-Nour (1989) suggest that spouses should not be assumed to provide the natural support system for patients and in this case that would seem to be a particularly important point at the later stages of
Discussion

disability. This implies that alternative support systems might be needed to a greater extent.

Methodological Difficulties

Design

In many ways, one of the most important methodological difficulties which arose was due to the cross-sectional design. The reasons for this choice of design were practical rather than theoretical, however, a longitudinal design could have led to a clearer understanding of some of the present findings. Many of the significant correlations have led to further questions and very few answers. This is partly due to the fact that correlations only imply a relationship between two variables and cannot show the direction of causality, if indeed there is causality between them. Correlations may be due to a third variable which is related to both variables in question and therefore, further research is needed to clarify relationships. In summary, cross-sectional, correlational designs are good at identifying relationships between variables, including fairly complex relationships, however, they are not good at explaining how these relationships arise.

Measures Used

The shortened version of the COPE used in this study, is a relatively new instrument and there is, therefore, limited data on its validity and reliability. It was an appropriate measure of coping strategies used for dealing with physical illness though as it has been developed specifically for assessing coping strategies in this context. Several participants, however, commented upon the fact that it was not specific to coping with P.D. In particular, item 13 'I have taken additional action to try to get rid of the problem' led to several comments, as participants felt that it was not possible to get rid of the problems caused by an incurable illness. This in itself may be useful information but it does highlight the fact that with any coping questionnaire, information is limited to the areas covered. Thus, particular coping strategies, especially any strategies specific to the illness, would be missed. An example of a type of coping strategy that was not included in the shortened version of the COPE but which was mentioned by a few participants, was the use of religious faith.
The measure of marital satisfaction (the KMS) was a very brief instrument which although found to have adequate reliability and validity (Schumm et al, 1986) may not have been sufficiently detailed enough. Generally, the participants rated themselves as being very satisfied or extremely satisfied with their marriages. This may be an accurate reflection as participants had been married for between 20 to 56 years and it might be assumed that they would no longer be married if they were generally dissatisfied. There is also a possibility that their rating of how their marriage was prior to diagnosis was influenced by the present relationship. Thus, the rating may be inaccurate. It might be, however, that the measure was not very sensitive to differences in quality of relationship between participants. Although a brief measure was required for this study because of the length of the other questionnaires already being used, future research may find that other instruments may be more useful. In particular, areas of the marital relationship which might be particularly important in looking at congruence are cohesion and consensus as measured by the Dyadic Adjustment Scale (Spanier, 1976).

The scale for rating coping relied on self-report, thus, it was subjective. Further, the validity of this measure was not assessed and so, even though it appeared to be evaluating how people perceive themselves and others to be coping it may not have been very effective in doing so. McKee et al (1997) queried what it is that individuals attend to when they evaluate their own coping. There is also the risk of people intentionally changing the ratings that they give if, for example, they wish to be seen to be coping well.

Participants
Difficulties in obtaining participants meant that numbers were quite small. For this reason, people with other physical problems besides P.D., spouses with physical problems of their own and couples with other life stresses could not be excluded. These may all have been confounding variables, as people could be using coping strategies to deal with these problems which may have affected the coping strategies used with respect to the problems of P.D. These other stresses may also have affected the levels of anxiety and depression in the participants.
Discussion

A further methodological difficulty relating to the present sample was the difference in gender between the two groups. Any differences between people with P.D. and spouses may be partly explained by gender differences and not simply by differences in status with respect to the illness. For example, the difference between groups with respect to acceptance of illness may have been influenced by gender if women are better at accepting illness than men. Unfortunately, due to the small sample size, it was not possible to examine the influence of gender with respect to adjustment, the use of coping strategies or interactions between the two.

One difficulty in testing hypothesis 6 is that most of the couples rated their relationship as good. It may be that those couples who would not have rated their relationship as good prior to diagnosis are those that have not participated. Thus, the present results are confined to those who rated their relationships favourably.

Suggestions for Future Research
The present study leaves many questions for future research.

The concept of congruence
The present study is fairly inconclusive as to whether congruence in the use of coping strategies is relevant to adjustment. This is due to the fact that for people with P.D., only three low/modest correlations between congruence and adjustment were significant out of a potential 21. Of the three significant correlations only one was in the hypothesised direction. For the spouses, there were four low/modest correlations which were significant. The reasons for this may be that the congruence in the use of coping strategies is not related to adjustment. Alternatively, it may be that the concept of congruence needs to be clarified.

It may be that future research examining congruence needs to be more specific regarding the concept of congruence. Thus, it may be important to consider when there is incongruence (difference) in the use of a coping strategy, if it is important as to who uses that coping strategy most. The present study would have expected a curvilinear relationship between congruence and adjustment in this case, however, it may be that if
Discussion

there is incongruence and the person with P.D. uses a particular coping strategy more then there is a different relationship with adjustment than if the spouse uses the coping strategy more. Thus, it may be that this could be examined with respect to three categories of congruence - congruence between partners; incongruence with person with P.D. using the coping strategy more; incongruence with the spouse using the coping strategy more.

Another factor to consider in using the concept of congruence is that there could be perceived to be different types of high congruence. In the present study, congruence in alcohol/drug use was found to correlate with several measures of adjustment (depression of people with P.D. and their spouses as well as anxiety and acceptance of illness in the spouses only). Examining the data showed that high congruence in the use of this coping strategy implied that neither partner used the strategy. This highlighted the fact that high congruence could mean congruence in not using a coping strategy, congruence in using a coping strategy a lot or various degrees of use in between. All of these may have very different relationships with adjustment. Examining congruence in this way would be combining the use of the coping strategy in itself, alongside agreement in its use.

Exploring congruence using these ideas would probably be easiest by splitting participants into groups for each coping strategy for example, group A - low congruence in emotion-focused coping with person with P.D. using strategy most; group B - low congruence in emotion-focused coping with spouse using strategy most; group C - high congruence in emotion-focused coping with neither partner using coping strategy; group D - high congruence with both partners using coping strategy. Such data analysis would require much larger numbers of participants than were available in the present study.

Causality

As already discussed, a longitudinal study would improve understanding of the relationships which were found between the depression and acceptance of illness of people with P.D. and their spouses, between the use of coping strategies and adjustment as well as congruence in the use of coping strategies and adjustment. Longitudinal studies could explain if, for example, the depression of people with P.D. leads to their
Discussion

spouses becoming depressed or whether the people with P.D. are more likely to become depressed if their spouses are already depressed. Such research could also show whether either of these explanations are unlikely and whether in fact there are other factors, such as the use of coping strategies, which leads to both partners becoming depressed. There are further possibilities such as a combination of these influences.

Longitudinal studies could also examine whether the use of coping strategies changes over time. Such studies could show whether people change their use of coping strategies according to changes in the illness or whether people continue to use the same strategies throughout. If they use the same strategies, it may be that the strategies are more useful at certain points in time. For example, people may begin by using coping strategies effectively but may not change them when they become less effective. If coping affects adjustment, this could explain the findings that adjustment deteriorates over time. If future research shows that the relationships found in the current study are causal in the direction that these variables affect adjustment, there may still be a need to find other factors to explain the remainder of the variance. Most of the relationships found in the present study were low to modest. There were also relationships among several of these variables which suggests that they will not explain all of the variance between the adjustment of different people.

Generalisability

It is important to consider whether the present findings generalise to different types of illness. Firstly, do the findings generalise to other progressive, non-fatal, incapacitating illnesses such as rheumatoid arthritis. Secondly, do the findings apply to health problems that are of a different psychosocial type. For example, those with acute onset that are relatively stable or improving such as stroke or myocardial infarct; those that are progressive, potentially fatal illnesses such as cancer or A.I.D.S. It would be particularly interesting to examine the relationship between adjustment and time since diagnosis/onset or adjustment and stage of disability in this context.
Discussion

Conclusions

The current study attempted to examine coping with a chronic illness within a marital relationship. The concept of congruence in relation to the use of coping strategies was one attempt at considering the interaction between partners. Although congruence did not explain a great deal of the variance in adjustment, it was useful in predicting which people would be classified as anxious or depressed. It may be that the concept of congruence needs to be clarified and suggestions were made for this.

As with all cross-sectional, correlational studies the present findings need to be examined longitudinally. This would enable the relationships that were found between variables to be explained more clearly. The present findings also need to be examined within the context of other illnesses as well as with other groups of people with P.D., in order to establish whether they are generalisable.
Acknowledgements
Acknowledgements

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The participants themselves must be thanked for the time that they gave and also for sharing information and experiences regarding Parkinson’s Disease.

Finally, thanks must go to family and friends, and to Antony Nicholls in particular, for encouragement and support throughout this research.
References
References


References


References


References


Appendixes
Appendix A

Information letter to potential participants and consent form.
Research into Coping with Parkinson's Disease

I am a trainee Clinical Psychologist and I am carrying out some research into how people cope with Parkinson's Disease. I am writing to you to ask if you would be willing to take part in the study. The study will be looking at how patients and their husbands/wives cope. I need both partners to be willing to take part and answer questions separately about the effect that Parkinson's Disease has on them.

The aims of the research are to find out what things make it easier or more difficult to deal with the problems caused by Parkinson's Disease and to find out whether patients and their husbands/wives cope in similar or in different ways.

What would it involve?
Each person would be seen individually at home or at Derby City Hospital if they prefer. I will be asking questions and giving out questionnaires on the following:
- the types of difficulties that you face
- what you do to try to cope with the difficulties that you have
- how you are feeling in terms of mood etc
- how well you feel you and your husband/wife cope

How long would it take?
It will probably take about 1 hour each.

Will my answers be confidential?
Everything discussed will be confidential. All questionnaires or written information will be given a number so that they can be matched but your name will not be used. If you choose, you can talk about anything that is discussed with your husband/wife, doctor or anybody else but it will be entirely up to you.

Will I get to know the results?
You will get told what your answers show and again, you can discuss this with your husband/wife or anyone else if you choose. If you wish, you will also get a summary of the whole study when it has been completed.

What if I decide I do not want to take part?
If you do not want to take part then it will NOT affect your treatment in any way.

What if I am still not sure about taking part?
If you would like further information about the study, I can be contacted on the following telephone number on Tuesdays or Fridays (9am - 5pm) - 01332-340131 ext.5893; or I can be contacted at the following address - Department of Neuropsychology, Derby City Hospital, Uttoxeter Rd, Derby.

What if I decide to take part?
You will need to sign the consent form that is with this letter and return it to me in the envelope provided as soon as possible. I will then contact you and your husband/wife to arrange a suitable time to see you.

If you decide to take part, you can still pull out later if you change your mind. You can also decide not to answer any questions. Again, your treatment will NOT be affected in any way.

You should mention that you have been involved in this study to your GP the next time that you see him/her.

Thank you.

Nita Baker
Psychologist in Clinical Training.

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Consent Form
Research into Coping with Parkinson’s Disease

Patient

I, ____________________________, am willing to take part in the above study. I understand that I can pull out of the study at any time and that I do not have to answer any questions that I do not want to answer. I understand that my medical treatment will not be affected in any way and that all my answers will be confidential.

Signed ____________________________ Date ________________

Spouse

I, ____________________________, am willing to take part in the above study. I understand that I can pull out of the study at any time and that I do not have to answer any questions that I do not want to answer. I understand that all my answers will be confidential.

Signed ____________________________ Date ________________

Please complete in BLOCK CAPITALS

Names ________________________________

Address _______________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Telephone ______________________________

__________________________________________________________________________
Appendix B

Short-form of the COPE
Cartwright and Lamb (1996)

Version P - Form used with people with P.D.
Version S - Form used with spouses.
There are lots of ways to try to deal with illness. This questionnaire asks you to indicate what you have done and how you feel about your illness.

Please respond to each of the following items by circling one number on your answer sheet, using the choices listed below. Please think about each item separately from each other item. Choose your answers thoughtfully, and make your answers as true for you as you can. Please answer every item. There are no ‘right’ or ‘wrong’ answers, so choose the most accurate answer for you - not what you think ‘most people’ would say or do. Indicate what YOU have done in response to your illness.

Answer each item from these choices:
1 = I haven’t done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

1. I have tried to grow as a person as a result of the experience.  
2. I have got upset and let my emotions out.  
3. I have tried to get advice from someone about what to do.  
4. I have concentrated my efforts on doing something about it.  
5. I have said to myself “this isn’t real”.  
6. I have discussed my feelings with someone.  
7. I have used alcohol or drugs to make myself feel better.  
8. I have got used to the idea that it has happened.  
9. I have talked to someone to find out more about the situation.  
10. I have got upset, and have been really aware of it.  
11. I have accepted that this has happened and that it can’t be changed.  
12. I have given up trying to reach my goals.  
13. I have taken additional action to try to get rid of the problem.  
14. I have tried to lose myself for a while by drinking alcohol or taking drugs.
Answer each item with these choices:
1 = I haven’t done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

15. I have refused to believe that it has happened. 1 2 3 4
16. I have let my feelings out. 1 2 3 4
17. I have tried to see it in a different light, to make it seem more positive. 1 2 3 4
18. I have talked to someone who could do something concrete about the problem. 1 2 3 4
19. I have tried to come up with a strategy about what to do. 1 2 3 4
20. I have drunk alcohol or taken drugs, in order to think less about it. 1 2 3 4
21. I have pretended that it hasn’t really happened. 1 2 3 4
22. I have given up the attempt to get what I want. 1 2 3 4
23. I have looked for something good in what has happened. 1 2 3 4
24. I have accepted the reality of the fact that it has happened. 1 2 3 4
25. I have felt a lot of emotional distress and I have found myself expressing these feelings a lot. 1 2 3 4
26. I have taken direct action to get around the problem. 1 2 3 4
27. I have talked to someone about how I feel. 1 2 3 4
28. I have used alcohol or drugs to help me get through it. 1 2 3 4
29. I have learnt to live with it. 1 2 3 4
30. I have thought hard about what steps to take. 1 2 3 4
31. I have acted as though it hasn’t even happened. 1 2 3 4
32. I have learnt something from the experience. 1 2 3 4
There are lots of ways to try to deal with illness. This questionnaire asks you to indicate what you have done and how you feel about your husband's / wife's illness.

Please respond to each of the following items by circling one number on your answer sheet, using the choices listed below. Please think about each item separately from each other item. Choose your answers thoughtfully, and make your answers as true for you as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for you - not what you think 'most people' would say or do. Indicate what YOU have done in response to your husband's / wife's illness.

Answer each item with these choices:

1 = I haven't done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

1. I have tried to grow as a person as a result of the experience. 1 2 3 4
2. I have got upset and let my emotions out. 1 2 3 4
3. I have tried to get advice from someone about what to do. 1 2 3 4
4. I have concentrated my efforts on doing something about it. 1 2 3 4
5. I have said to myself “this isn’t real”.
6. I have discussed my feelings with someone. 1 2 3 4
7. I have used alcohol or drugs to make myself feel better.
8. I have got used to the idea that it has happened. 1 2 3 4
9. I have talked to someone to find out more about the situation. 1 2 3 4
10. I have got upset, and have been really aware of it.
11. I have accepted that this has happened and that it can’t be changed. 1 2 3 4
12. I have given up trying to reach my goals. 1 2 3 4
13. I have taken additional action to try to get rid of the problem. 1 2 3 4
14. I have tried to lose myself for a while by drinking alcohol or taking drugs.
Answer each item with these choices:
1 = I haven't done this at all
2 = I have done this a little bit
3 = I have done this a moderate amount
4 = I have done this a lot

15. I have refused to believe that it has happened.
   1  2  3  4

16. I have let my feelings out.
   1  2  3  4

17. I have tried to see it in a different light, to make it seem more positive.
   1  2  3  4

18. I have talked to someone who could do something concrete about the problem.
   1  2  3  4

19. I have tried to come up with a strategy about what to do.
   1  2  3  4

20. I have drunk alcohol or taken drugs, in order to think less about it.
   1  2  3  4

21. I have pretended that it hasn't really happened.
   1  2  3  4

22. I have given up the attempt to get what I want.
   1  2  3  4

23. I have looked for something good in what has happened.
   1  2  3  4

24. I have accepted the reality of the fact that it has happened.
   1  2  3  4

25. I have felt a lot of emotional distress and I have found myself expressing these feelings a lot.
   1  2  3  4

26. I have taken direct action to get around the problem.
   1  2  3  4

27. I have talked to someone about how I feel.
   1  2  3  4

28. I have used alcohol or drugs to help me get through it.
   1  2  3  4

29. I have learnt to live with it.
   1  2  3  4

30. I have thought hard about what steps to take.
   1  2  3  4

31. I have acted as though it hasn't even happened.
   1  2  3  4

32. I have learnt something from the experience.
   1  2  3  4
Appendix C

Likert scale for measuring coping ratings.
Coping

How well does *your husband/wife* cope with the problems caused by Parkinson’s Disease?

<table>
<thead>
<tr>
<th>Struggles a great deal</th>
<th>Struggles a little</th>
<th>Copes okay</th>
<th>Copes fairly well</th>
<th>Copes very well</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Copes much better than anyone I know</th>
<th>Copes better than most people</th>
<th>Copes about as well as others</th>
<th>Does not cope as well as most people</th>
<th>Finds it harder to cope than anyone I know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

How well do *you* cope with the problems caused by Parkinson’s Disease?

<table>
<thead>
<tr>
<th>Struggle a great deal</th>
<th>Struggle a little</th>
<th>Cope okay</th>
<th>Cope fairly well</th>
<th>Cope very well</th>
</tr>
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<td>1</td>
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<table>
<thead>
<tr>
<th>Cope much better than anyone I know</th>
<th>Cope better than most people</th>
<th>Cope about as well as others</th>
<th>Do not cope as well as most people</th>
<th>Find it harder to cope than anyone I know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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</table>
The Acceptance of Illness Scale (AIS)
Felton and Revenson (1984)

AIS (p) - Form used with people with P.D.
AIS (s) - Modified form used with spouses.
AIS (p)

Please answer each of the following items by choosing a number from 1 to 5 on the scale next to the item which you feel best describes you. Then circle the number you have chosen. There are no ‘right’ or ‘wrong’ answers to any of the questions.

1. I have a hard time adjusting to the limitations of my illness.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

2. Because of my health, I miss the things I like to do most.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

3. My illness makes me feel useless at times.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

4. Health problems make me more dependent on others than I want to be.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

5. My illness makes me a burden on my family and friends.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

6. My health does not make me feel inadequate.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

7. I will never be self-sufficient enough to make me happy.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

8. I think people are often uncomfortable being around me because of my illness.
   Strongly Agree 1 2 3 4 5 Strongly Disagree
AIS (s)

Please answer each of the following items by choosing a number from 1 to 5 on the scale next to the item which you feel best describes you. Then circle the number you have chosen. There are no 'right' or 'wrong' answers to any of the questions.

1. I have a hard time adjusting to the limitations of my husband’s / wife’s illness.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

2. Because of my husband’s / wife’s health, I miss the things I like to do most.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

3. My husband’s / wife’s illness makes me feel useless at times.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

4. My husband’s / wife’s health problems make me more dependent on others than I want to be.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

5. My husband’s / wife’s illness makes me a burden on my family and friends.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

6. My husband’s / wife’s health does not make me feel inadequate.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

7. My husband / wife will never be self-sufficient enough to make me happy.
   Strongly Agree 1 2 3 4 5 Strongly Disagree

8. I think people are often uncomfortable being around me because of my husband’s / wife’s illness.
   Strongly Agree 1 2 3 4 5 Strongly Disagree
Appendix E

The Hospital Anxiety and Depression Scale (HADS)
Zigmond and Snaith (1983)
H.A.D. Scale

Please read each item and tick the reply which comes closest to how you have been feeling in the past week. Don’t take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or ‘wound up’:
- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:
- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn’t worry me
- Not at all

I can laugh and see the funny side of things:
- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind:
- A great deal of the time
- A lot of the time
- From time to time but not too often
- Only occasionally

I feel cheerful:
- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed:
- Definitely
- Usually
- Not often
- Not at all
I feel as if I am slowed down:
   Nearly all the time
   Very often
   Sometimes
   Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:
   Not at all
   Occasionally
   Quite often
   Very often

I have lost interest in my appearance:
   Definitely
   I don't take as much care as I should
   I may not take quite as much care
   I take as much care as ever

I feel restless as if I have to be on the move:
   Very much indeed
   Quite a lot
   Not very much
   Not at all

I look forward with enjoyment to things:
   As much as I ever did
   Rather less than I used to
   Definitely less than I used to
   Hardly at all

I get sudden feelings of panic:
   Very often indeed
   Quite often
   Not very often
   Not at all

I can enjoy a good book or radio or TV programme:
   Often
   Sometimes
   Not often
   Very seldom
Appendix F

The Kansas Marital Scale (KMS)
Schumm, Paff-Bergen, Hatch, Obiorah, Copeland, Meens and Bugaighis (1986)

plus single item Likert scale for measuring relationship change.

KMS (p) - Form used with people with P.D.
KMS (s) - Form used with spouses.
KMS (p)

Please try to think back to how your marriage was *before* you were diagnosed as suffering from Parkinson's Disease.

<table>
<thead>
<tr>
<th>Extremely Dissatisfied</th>
<th>Very Dissatisfied</th>
<th>Somewhat Dissatisfied</th>
<th>Mixed</th>
<th>Somewhat Satisfied</th>
<th>Very Satisfied</th>
<th>Extremely Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

1. How satisfied were you with your marriage?

2. How satisfied were you with your husband / wife as a spouse?

3. How satisfied were you with your relationship with your husband / wife?

... ... ...

How has your relationship with your husband / wife changed since you were diagnosed as suffering from Parkinson's Disease?

<table>
<thead>
<tr>
<th>It is nowhere near as good as it used to be</th>
<th>It is not quite as good as it used to be</th>
<th>It has not really changed</th>
<th>It has improved a little</th>
<th>It has improved a great deal</th>
</tr>
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101
Please try to think back to how your marriage was before your husband/wife was diagnosed as suffering from Parkinson's Disease.

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<tbody>
<tr>
<td>1. How satisfied were you with your marriage?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How satisfied were you with your husband / wife as a spouse?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. How satisfied were you with your relationship with your husband / wife?</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
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How has your relationship with your husband / wife changed since s/he was diagnosed as suffering from Parkinson's Disease?

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<th>It is nowhere near as good as it used to be</th>
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Appendix G

Interview sheets.
Interview Sheet - Patient

(Gender  M / F )

Age

Employment status

Number of years married

Any other problems, major life events etc.

Length of time since diagnosis

(Present degree of disability)

Current medication

Main difficulties due to Parkinson's Disease
Interview Sheet - Spouse

(Gender M / F )

Age

Employment status

Number of years married

Any physical problems of own

Any other problems / major life events etc.

Main difficulties due to Parkinson’s Disease