PSYCHOLOGICAL ADJUSTMENT TO THE DIAGNOSIS OF PARKINSON'S DISEASE:
A QUALITATIVE ANALYSIS

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ABSTRACT

Parkinson's Disease (PD) is a progressive and incurable neurological disorder which affects approximately 1% of people over 65. Despite the relatively high prevalence of PD, there has been very little research exploring the lived experience of people who suffer from this illness. In this study 9 people with PD were interviewed with their partner about their experiences of being diagnosed with PD. The qualitative methodology of grounded theory was then used to produce an analytical version of their accounts. The transitional model of psychological adjustment to PD developed from the analysis consisted of four phases: pre-diagnosis, diagnosis, initial adjustment and transition to the chronic phase. The individual experience of this model was mediated by five sets of factors: age-related issues, professional support, family and social context, past and current health status and the context of daily life.

The pre-diagnosis phase consisted of four stages: noticing and discounting or rationalising; suspecting; deciding to seek medical help and searching for a medical diagnosis. Receiving a diagnosis was, most commonly, responded to with intense emotional shock related to the uncertainty of what the diagnosis meant for future life.

The aim of the initial adjustment phase was to reduce uncertainty, re-establish a sense of control and cope with the emotional response to the diagnosis. Analysis suggested that participants engaged in three major tasks of adjustment to achieve these aims: information seeking, resolving identity dilemmas and coping with symptoms and treatment demands. Each person's approach to these tasks was determined by the way in which they conceptualised PD within the context of daily life. Four patterns of conceptualisation were identified: PD as irrelevant, an interruption, something to be integrated into current lifestyle or an intrusion.

Transition to the chronic phase of illness was characterised by the person having found ways to live with continued uncertainty, having found personal meaning in the diagnosis and a reduction in emotional distress. The theoretical and clinical implications of the findings are discussed and limitations of the study considered.
1.0 INTRODUCTION

1.1 General Introduction

Over recent decades, advances in preventative measures and medical care have seen a decline in previously life threatening infectious diseases, such as typhoid or TB, and an increased prevalence of chronic illnesses, such as heart disease and diabetes (Sarafino, 1990). Increasingly, the challenge for health services is to help people to manage chronic illness within the context of their daily lives. In response to this challenge clinical psychologists are becoming increasingly involved in what have been traditionally medical settings (Rozensky, 1994).

A major reason for the current prominence of chronic illness is the greater life expectancy of people today. Many illnesses are more common in later life and, as people live longer, they are more at risk of suffering ill health. Parkinson's Disease (PD) affects approximately 1% of people over 65 with its prevalence increasing along with the increasing aged population. There has been very little exploration in the research literature to date of people's experiences of living with PD and yet understanding of this is essential if services are to meet the challenge of helping people to manage this illness in their daily lives (Habermann, 1996; Marr, 1991).

1.2 Physical and Psychological Characteristics of Parkinson's Disease

1.2.1 Physical Characteristics of PD

PD is a disabling, progressive neurological disorder. Progression is usually slow and life expectancy is reported to be only slightly less than normal (Dimond & Markham, 1979). There is strong evidence against hereditary factors (Duvoisin, 1986). There is no definitive biological marker to confirm the diagnosis of PD which is made upon the basis of clinical findings, medical history and physical examination. There are significant problems in diagnostic accuracy due, in part, to variations in diagnostic criteria.

The classic triad of symptoms in PD is tremor, muscle rigidity and bradykinesia. The tremor is intermittent, generally being present when limbs are at rest, and can be exacerbated by emotional states such as anxiety or excitement. Muscle rigidity is experienced as muscle stiffness, soreness or cramping. Because the muscles are constantly contracted they may shorten, particularly in the back, resulting in postural changes (stoop), back pain, poor balance and propulsion and
falling. Bradykinesia is characterised by slowness and poverty of movement. Examples of bradykinesia include fatigue, diminution in automatic movements (e.g. eye blinking, swallowing), a soft monotonous voice, festinating gait (shuffle), 'freezing' (difficulty resuming walking after suddenly stopping) and an immobile 'masked' facial expression. Like the tremor, these symptoms are intermittent. In addition to the primary symptoms of PD there are many other problems associated with the disease. These include decreased sexual libido, excessive sweating and salivation and cognitive impairments. People vary widely in the degree to which they experience any of the above symptoms and also in how symptoms progress over time (Duvoisin, 1991).

Although the specific cause of PD remains unknown, the underlying neuropathological changes have become increasingly well understood in recent years. Aetiologically the disorder stems from the loss of neurones in the substantia nigra, the basal ganglia and other brainstem dopaminergic cell groups, leading to a depletion of the neurotransmitter dopamine in these groups. This has led to the use of palliative treatments using dopamine replacement therapy. Whilst effective in alleviating symptomatology, however, the value of such treatments is limited by the emergence of drug-related side effects. Long-term effectiveness is further limited by the underlying disease progression.

1.2.2 Psychological Characteristics of PD

Rolland argues that chronic illnesses can be categorised by psychosocial type (e.g. Rolland, 1987). The typology he suggests conceptualises four broad distinctions of onset (acute versus gradual), course (progressive, constant or episodic), outcome (extent to which a disease is life threatening) and degree of incapacitation. Different illnesses are hypothesised to pose different psychosocial demands depending on their position along each of the above dimensions. Within Rolland's classification, PD is as a disease of gradual onset which, although non-fatal, is progressive and causes gradually increasing levels of incapacitation. The major psychological challenge arising from PD lies in its progressiveness and incapacitation. Continual adaptation is required and people have to cope with the knowledge that further decline is unavoidable. This challenges the amount of choice and control that individuals and their families feel they have over their future and ways have to be found of living in conditions of continued uncertainty (Wallhagen & Brod, 1997).
1.3 **Overview of Psychosocial Research in PD**

Current psychosocial research in PD can be considered within three broad categories: identification of specific psychological concomitants of PD, psychological adjustment or adaptation to PD and, less frequently, explorations of a person's experience of living with PD. Research within each of these areas is now briefly reviewed.

1.3.1 **Psychological Con-comitants of Parkinson's Disease**

The predominant focus of psychosocial research has been on identifying and explaining the occurrence of specific psychological concomitants of PD, primarily depression. Although prevalence estimates of depression in PD vary widely (from 4% to 90%), there is a general consensus that rates of depression in this population are elevated compared to age matched controls (e.g. Cummings, 1993). An ongoing debate concerns the aetiology of depression in PD; is it an understandable reaction to the disease and its consequences or a clinical manifestation of the underlying neuropathological changes? From this latter, biomedical, position, depression is considered a 'symptom' of PD and is generally treated using anti-depressant medication.

Research aimed at resolving the aetiological debate has generally been interpreted as supporting a biomedical model of depression. It has been argued, however, that when considered in more detail, the findings fit better with psychosocial explanations (see Brown & Jahanshahi, 1995 for a review). In many ways this aetiological debate is a sterile one and has detracted research efforts from a more likely interactionist perspective which acknowledges the contribution of both psychosocial and neurobiological factors to depression (e.g. Dakof & Mendelsohn, 1986). The relative contribution of each set of factors is likely to vary for any individual.

To understand the potentially important and distinct contributions of individual psychological and wider social factors to psychological outcome in PD, it has been argued (e.g. Brown & Jahanshahi, 1995) that greater emphasis is needed on understanding differences in individual experience; why does one person become depressed and another not? Discussions also need to be broadened to include psychological con-comitants of PD other than depression. Anxiety in particular, has been reported as a more common, specific and clinically relevant psychological
feature of PD (e.g. Starkstein, Robinson, Leiguarda & Preziosi, 1993) but has received minimal research attention.

1.3.2 Psychological Adjustment or Adaptation to PD

Consistent with current approaches in other areas of health psychology, transactional models of stress and coping (e.g. Lazarus & Folkman, 1984) have been the primary theoretical framework within which psychological adjustment to PD has been explored. Within this model, PD is viewed as a source of stress to which the person responds with a range of responses and coping behaviours. Stress is not inevitable but occurs when there is a perceived mismatch between the nature of the demand(s) and the person's ability to respond. The emphasis is therefore on understanding resiliency as well as risk factors. Relative to other areas of health psychology, there have been very few studies examining variations in psychological adjustment to PD. The majority of studies available (e.g. Brod, Mendelsohn & Roberts, 1998; MacCarthy & Brown, 1989) have taken a 'top-down' approach whereby the variables to be examined have been selected by extrapolating from research on other chronic illnesses. Narrowing the focus to a set of imported variables, however, runs the risk of neglecting unforeseen factors of critical significance.

A notable exception to this 'top-down' approach is a study by Dakof and Mendelsohn (1989) who interviewed 44 people in relatively advanced stages of PD and their carers, both alone and together, to identify variables significant in adaptation. Four qualitatively different patterns of adjustment were identified: sanguine and engaged (cluster I), depressed and worried (cluster II), depressed and misunderstood (cluster III) and passive and resigned (cluster IV). This study is significant in that it identifies qualitatively different patterns of adaptation only some of which involve depression. It therefore places greater emphasis on resiliency and highlights anxiety as an important characteristic of adjustment for some people. Marked anxiety about the future was the key characteristic distinguishing cluster II participants from cluster III.

Taken together, studies of psychological adjustment to PD have considered a wide variety of psycho-social variables, as well as demographic and disease variables (e.g. disability, severity, duration). Variables found to be significantly associated with adjustment can be grouped into four broad categories: disability, coping style, perceptions of control, and interpersonal relationships.
Disability and Psychosocial Adjustment

Consistent with many univariate studies (e.g. Starkstein, Mayberg, Preziosi et al., 1992), multivariate studies have consistently shown disability (functional capacity) to be the best predictor of psychological well-being. In a comprehensive study by MacCarthy and Brown (1989), for example, disability explained 16% of the variance in psychological well-being. Disability characteristics were also found to be important in the observed variations in patterns of adaptation identified by Dakof & Mendelsohn (1989). Cluster III people, who were depressed and misunderstood, showed the greatest level of disability. Longitudinal studies have also found a significant association between changes in depression and disability over time (Brown, MacCarthy, Gotham & Marsden, 1988). More detailed examination of the pattern of changes in depression and disability over time, suggested the need to consider not only absolute level of disability but also the rate of change of disability. On this basis, Brown and Jahanshahi (1995) concluded that the rate of disease progression may be important in psychological adjustment; slow progression enabling people to adapt more easily than when progression is more rapid.

The consistent link between disability and psychological well-being suggests that the emotional experience of PD is closely linked to the everyday realities of managing daily routines and functions that others take for granted (Brod, Mendelsohn & Roberts, 1998). This highlights the potential importance of considering a person's 'lived experience' of PD.

Coping style and Psychosocial Adjustment

With regard to coping style, unproductive distraction (e.g. smoking, eating), "acting out" (e.g. self-blame, taking it out on others) and avoidance strategies (e.g. avoidance of negative thoughts, denial, wishful thinking) have been identified as potentially adverse coping strategies (e.g. MacCarthy & Brown, 1989). Avoidance of negative thoughts is not necessarily an adverse coping strategy, however, and Brod, Mendelsohn and Roberts (1998) have highlighted the need to distinguish between using a coping strategy and realising one's aim in doing so. Their data suggested that people who not only tried but succeeded in putting distressing thoughts out of mind had significantly higher levels of psychological well-being. Consistent with this, a distinguishing feature of the 'sanguine and engaged' group in the study by Dakof and Mendelsohn (1989) was their ability to put negative thoughts out of mind. This group was also characterised by having a positive attitudinal stance (e.g. believing that things could be worse). MacCarthy and Brown (1989) also found coping
strategies such as active problem solving (e.g. looking for others with the same problem) and positive distancing (e.g. turn attention to other tasks) to be associated with an independent measure of positive well-being, although these were unrelated to depression.

Perceptions of Control and Psychosocial Adjustment

Having a sense of personal control has been linked with positive health outcomes in many areas of health psychology (e.g. Seeman & Lewis, 1995) but has been only moderately associated with psychological well-being in PD (e.g. Brod, Mendelsohn & Roberts, 1998; MacCarthy & Brown, 1989). In understanding these findings, Wallhagen and Brod (1997) make an important distinction between perceived control over symptoms and perceived control over disease progression. Their research suggests that only the former of these is associated with psychological well-being (Wallhagen & Brod, 1997). Conversely, in Dakof and Mendelsohn's (1989) study, the 'sanguine and engaged' group believed that their actions and attitudes could affect at least some aspects of the disease course of PD. For conditions such as PD, where disease progression is ultimately not controllable, it may not be psychologically beneficial to have overly high levels of perceived control. This is consistent with Tennen and Affleck's (1987) observation that when outcomes are not controllable, believing oneself to have a high level of personal control can have costs as well as benefits. With regards to PD, it may be of more relevance to examine ways in which people cope with the lack of control over disease progression to prevent feelings of helplessness (Seligman, 1975). One such way may be to derive a sense of personal control in the 'here and now' through symptom management.

Interpersonal Relationships and Psychosocial Adjustment

Brod, Mendelsohn and Roberts concluded that "the psychological problems of Parkinson's patients are fundamentally in the area of interpersonal relations" (Brod, Mendelsohn & Roberts, 1998, p.220). This conclusion was based on the associations found between psychological well being and satisfaction with social support, feelings of being a burden and social isolation. Consistent with this conclusion, a distinguishing feature of the 'depressed and misunderstood' group in Dakof & Mendelsohn's (1989) study was their feelings of social isolation (which related to feeling misunderstood) and the marked reduction in participation in personal, family and social roles. Associated with this, self esteem has also been positively linked with psychological well-being (MacCarthy & Brown, 1989).
Limitations of 'Adjustment' Research

Whilst studies of psychological adjustment to PD have identified variables which may potentially contribute to psychological outcome, they do not explicitly address the question of why these are influential; what are the underlying processes involved? Research within this framework has also been criticised for its implicit assumption that there is an "effective" way to adapt (Habermann, 1996). Habermann argues that "what this sets up is a judgement of coping patterns that is not only decontextualised from the demands faced by the person but risks the person being viewed as having failed" (Habermann, 1996, pp. 411). Studies of psychological adjustment have also failed to consider adjustment as a dynamic process which changes in relation to disease status and illness phase. The study by Dakof & Mendelsohn (1989), for example, focused on people in the advanced stages of PD for whom the issues may be very different to those faced by people in the acute stages immediately following diagnosis. Dakof and Mendelsohn's study also fails to address the issue of how coping strategies may change over time in response to changing illness demands and how earlier coping strategies may determine subsequent adjustment (Brown & Jahanshahi, 1995). Thus, for example, a coping strategy used in the later stages of illness (e.g. carrying on as normal or not dwelling on the problem) may not be the most effective during the early stages following diagnosis when active attempts to resolve problems and find meaning are required (Habermann, 1996).

1.3.3 The Experience of Living with PD

An "experience-of-illness" framework has been widely advocated within chronic illness research (e.g. Conrad, 1990) but has received little attention with regards to PD. Accounts have been largely anecdotal (e.g. Peace, 1995) or speculative (e.g. Brown & Jahanshahi, 1995) with only a handful of empirical studies available (e.g. Habermann, 1996, Marr, 1991). These studies have used qualitative methodologies, such as interpretative phenomenology, which are more suited to exploring the complexities of lived experience. These methods place greater emphasis on understanding the role of personal meanings in explaining individual variations in how people live and cope with PD.

To consider this further, studies which have explored the experience of PD are now considered within a temporal framework of chronic illness advocated by Rolland (1987). This framework has not been empirically validated, nor is it explicit
in the studies of current concern, but it nevertheless provides a useful framework for synthesising the findings of studies available. Rolland's framework is summarised in figure 1.

**Figure 1**: Rolland's (1987) temporal framework of chronic illness

![Rolland's framework of chronic illness](image)

Within this model, illnesses are conceptualised as having three time phases: crisis, chronic and terminal. Each phase is hypothesised to have distinct psychosocial tasks that require significantly different strengths, attitudes or change from the person. As PD is not a life threatening condition and the current research is concerned with the early stages of the illness, only the crisis and chronic phases will be considered in the following discussion.

**Experiences of PD in the 'Crisis' Phase of Illness**

Diagnosis of a chronic illness has been shown to disrupt the assumed predictability of life to create a situation of uncertainty which demands an urgent response to life's fundamental questions (e.g. Bury, 1982). As such it can be considered a time of 'crisis' which requires the individual to find meaning in the diagnosis and a way of living with a new reality. Broadly consistent with Rolland's (1987) description of the crisis phase, Habermann (1996), in an exploratory study of people diagnosed with PD in middle life, makes a distinction between illness related demands and demands relating to roles and relationships. Each set of demands will now be considered in more detail.

**Illness Related Demands**

Of relevance to the pre-diagnosis period, Habermann (1996) identified the tasks of 'acknowledging symptoms' and 'seeking medical advice'. In both this study,
and an exploratory study of older people's experiences of PD by Marr (1991), obtaining a diagnosis of PD was problematic. Consistent with research in the wider chronic illness literature (e.g. Charmaz, 1991), receiving a definitive diagnosis was essential to legitimise and validate ambiguous bodily complaints and to enable people to 'move on' and make sense of their experience. 'Moving on' also required an acceptance of the reality of the diagnosis once received (Habermann, 1996; Marr, 1991).

Identified illness related demands relevant to the period of initial adjustment include information seeking, coping with bodily changes and medications and coping with the emotional response to the diagnosis (Habermann, 1996; Marr, 1991; Pinder, 1995). Information seeking has been most extensively studied by Pinder (1995) who identified three broad patterns of seeking information: seekers, who actively sought information; weavers, who were more cautious about having information and avoiders, who deliberately chose not to find out about PD. Pinder (1995) also examined the process of information seeking from the perspective of the GP. Comparing GP's and patients in this way provided valuable information on how difficulties may arise in establishing working relationships with health professionals; a task of initial adjustment identified by Rolland (1987). What emerged was the danger of GP's ignoring the personal meaning of the clinical facts within the context of patients daily lives. Patients' dissatisfaction with health professionals lack of attention to the human significance of PD has also been noted by Lindgren (1996) and Habermann (1996) and is consistent with research within the wider chronic illness literature (e.g. Thorne, 1993).

Demands Relating to Roles and Relationships

It is in this context that the personal meaning and individual experience of PD can best be understood and an underlying theme in all studies was the threat PD posed to self identity. Even in Pinder's exploration of the 'practical' task of information seeking, she concluded that patients "sought to find in the clinical facts a way of sustaining their sense of self - of managing potential and actual threats to their identity - so that the facts themselves had different meanings within the framework of patient's lives" (Pinder, 1995, p. 84).

Definitions of Identity

Identity has been variously defined in the literature and is often used interchangeably with the term self-concept (Breakwell, 1986). From a symbolic
interactionist perspective (e.g. Thoits, 1991), identities are negotiated performances of role prescriptions attached to the occupancy of a social position (e.g. husband, father, provider). As such, any person can have many identities depending on the number of roles adopted. Thus a person can have separate role identities, for example, as a father, brother, husband and provider, although greater subjective importance may be attributed to some identities over others.

**PD as a Threat to Identity**

The potential, or actual, loss of work role and disruption in family and social relationships have been identified as significant demands in living with PD (Habermann, 1996; Marr, 1991). Bodily changes created situations in which the role prescriptions attached to specific roles were unable to be achieved. This loss of unity between body and self has been coherently described by Charmaz in her extensive writings within the chronic illness literature (e.g. Charmaz, 1995a). According to Charmaz, adapting to chronic illness means altering life and self in socially and personally acceptable ways to accommodate bodily losses and limits and resolving lost unity between body and self.

**An Integrative Theoretical Framework for Understanding Threatened Identities**

Further understanding of PD as a threat to identity can potentially be achieved by broadening the discussion to include theoretical frameworks which are not unique to chronic illness but which seek to explain the nature and effects of a threat to identity regardless of it's source. In an integrative model proposed by Breakwell (1986), identity is said to be determined by the operation of two identity processes: assimilation-accommodation and evaluation. Assimilation refers to the absorption of new components into the identity structure and accommodation to the adjustment that occurs in the existing structure so as to find a place into which to fit the new elements. The process of evaluation entails allocation of meaning and value to identity content of both old and new elements.

Breakwell (1986) suggests that the operation of these identity processes can be predicted from three identity principles which specify desirable end states: uniqueness or distinctiveness for the person, continuity across time and situation and a feeling of personal worth or social value (self esteem). Threat to identity occurs when "the processes of identity, assimilation-accommodation and evaluation are, for some reason, unable to comply with the principles of continuity, distinctiveness and self-esteem which habitually guide their operation" (Breakwell, 1986, p. 47). The
reason for this obstruction - in the context of the current discussion PD - constitutes a threat. Breakwell (1986) suggests that when identity is threatened people respond with a variety of coping strategies that seek to maintain the principles of continuity, distinctiveness and self-esteem. General research into chronic illness would support the prediction that people often actively engage in coping efforts to maintain identity (e.g. Charmaz, 1995a).

A central concept in Breakwell's (1986) model is the assertion that threats to identity can only be studied meaningfully within a social and historical context. Social meanings provide the backdrop against which personal meanings develop. This draws attention to concepts such as stigma which have been implicated in some studies on PD (e.g. Dakof & Mendelsohn, 1989; Singer, 1976) but which have not been widely studied. Consideration of societal attitudes to ill health in general and attitudes towards situations that may arise from PD, such as unemployment, may also be required.

**Grieving for a Lost Identity**

In many illnesses there will inevitably be aspects of identity which cannot be maintained because of the physical limitations imposed by the disease. Whilst people may engage in active efforts to compensate for these 'lost' aspects of identity (e.g. by focusing on other roles and identities or developing new roles), Rolland (1987) also identifies a 'task' of the crisis phase as 'grieving' for a pre-illness identity. Grief is a normal reaction to any major loss, not just bereavement and Parkes (1972) used the term "psychosocial transition" to describe events which alter lifestyle in some way as to produce a similar emotional response. Grief is characterised by feelings of denial, shock, anger, depression and ultimately acceptance and is part of a natural healing process (e.g. Bowlby, 1973; Kubler-Ross, 1969).

Marr (1991) used the theme of loss to describe the impact of PD on the lives of older people, but, otherwise, concepts of loss and grieving have remained largely implicit in studies relating to PD. A notable exception to this is a study by Lindgren (1996) which explored the presence and nature of chronic sorrow in PD. Historically, the term chronic sorrow was first used by Olshanky (1962) to describe the reoccurrence of feelings of grief experienced by parents of children with learning disabilities as their child continually failed to meet developmental norms. In relation to chronic illness, chronic sorrow has been defined as the 'normal' grief experienced from continual losses during the trajectory of an illness or disability (Lindgren, 1996). This may have particular relevance to conditions such as PD which are
progressive. Lindgren (1996) found that all 10 people in her study experienced, at various points during the illness course, a variety of emotions such as anger, denial, fear, frustration, despair, guilt and depression (which collectively she called sorrow). These were particularly intense at diagnosis but all participants experienced re-occurring feelings of sorrow in response to "tragic things" experienced during the illness course. Furthermore, for some people these feelings were re-experienced not only in response to an actual event, but when previous losses were remembered. Only these people were described by Lindgren (1996) as suffering from chronic sorrow.

Although there are similarities between grief and clinical depression, (e.g. feelings of sadness, reduced appetite, early wakening), it is important to distinguish the two (e.g. Lindgren, 1996). Parkes (1997) suggests that grief can be distinguished from depression by its transient nature (even within an hour people who allow themselves to grieve will usually begin to feel better), the absence of self-deprecatory feelings (e.g. feelings of guilt and worthlessness) and the incapacity of people to engage in activities which would alleviate depression. The failure of most studies to distinguish between clinical depression and grief has implications for interpreting research examining the prevalence of depression in PD patients. 'Caseness' scores on a depression scale (e.g. the Beck Depression Inventory) may not necessarily be indicative of clinical depression but of grief and thus rates of depression in PD may actually be lower than reported.

Experience of PD in the 'Chronic' Phase of Illness

Rolland describes the chronic phase of illness as the "day-to-day living with a chronic illness" (Rolland, 1987, p. 207). The key task of this phase is to maintain the resemblance of a 'normal' life under the 'abnormal' presence of a chronic illness and heightened uncertainty. The distinction between the initial adjustment and chronic phases of illness is blurred in the current literature on PD, but, following Rolland's (1987) definition, it can be surmised that living with the increasing symptoms of PD requires the development of strategies to cope with the demands of daily living. The following discussion will therefore focus on issues of coping in PD.

Coping with PD

Coping has already been briefly discussed in relation to research on adjustment to PD but there is an important conceptual difference when this is considered within a temporal framework such as Rolland's (1987). From this
perspective, rather than being seen as a static variable, coping is conceptualised as an ongoing, dynamic process. This is consistent with Lazarus' theory of coping as process, the essential features of which are that the nature and adaptational effectiveness of coping will change in relation to the nature of: (i) a specific demand or encounter (ii) the changing context of any given stressful encounter and (iii) in relation to individual coping style (see Lazarus, 1993, for a review). Lazarus makes a functional distinction between problem-focused and emotion-focused coping. The function of problem-focused coping is to change the person-environment relationship by acting on the environment or oneself. The function of emotion-focused coping is to change either (a) the way the stressful relationship with the environment is attended to (as in vigilance or avoidance) or (b) the relational meaning of what is happening. Emotion focused strategies tend to be used when people believe that they can do nothing to change the situation and mitigate the stress even though the actual conditions of the relationship have not changed (Lazarus & Folkman, 1984).

The implications of conceptualising coping as a process are that there may be no universally good or bad coping strategies and that the specific demands created by the diagnosis of PD have to be identified rather than considering PD as an overall stress. Unfortunately, research within an experience of illness framework has not significantly advanced understanding of the processes which people use to cope with the demands of PD. Habermann (1996) focused on identifying and describing the specific demands associated with PD, but devoted relatively little attention to understanding how people coped with these. Conversely, Marr (1991) identified coping strategies but presented these in isolation from the specific demands. It was therefore difficult to conclude which coping strategies were used in response to which demand. A further limitation of these studies is their failure explicitly to consider the outcome of coping. Consistent with Brod, Mendelsohn and Roberts' (1998) assertion that using a coping strategy needs to be distinguished from realising one's aim in doing so, Lazarus (1993) has highlighted the need to consider coping effort and coping outcome independently. In failing to do this studies, such as that by Marr (1991), provide only a description of the coping process.

Despite the above limitations, it is interesting that many of the coping strategies identified in 'experience' research are consistent with those identified as significant in 'adjustment' studies. These include both problem-focused strategies (e.g. learning new ways to adapt to the changes imposed) and emotion-focused strategies (e.g. having a positive outlook, for example, by making comparisons to people "worse off" and putting negative thoughts out of mind by "not dwelling on the problems"). An identified coping strategy which seemed to be specific to
avoiding worries about the future was deliberately narrowing the attentional focus by "coping with a day at a time" (Habermann, 1996; Marr, 1991). Marr (1991) identifies the desire to maintain independence and normality as the main 'driving force' behind efforts to cope with day to day living.

1.4 PD: A lifespan Perspective

A limitation of existing research in PD is the general neglect of lifespan issues. Within the context of health psychology, lifespan theorising predicts that the experience of an illness will differ according to the stage of life in which it occurs (Penny, Bennet & Herbert, 1994). Theoretical models within lifespan psychology differ in the extent to which they emphasise change and stability over the lifecycle, but there is an underlying philosophy that different stages in the lifecycle pose unique developmental tasks and challenges and are typically associated with different life events (e.g. retirement in old age, marriage in young adulthood).

Whilst there is an awareness of the potential influence of a person's stage of development on their experience of PD, this has generally only been acknowledged by focusing studies on people within particular age groups. The potential interactions between lifespan issues and the individual experience of PD requires more attention, however, especially in the light of claims that PD "presents what may be a model case for studying the interconnections of chronic disease and ageing" (Brod, Mendelsohn & Roberts, 1998, p. 214). PD has been hypothesised to have a unique relationship with ageing by virtue of the fact that, at a biological level, it can be interpreted as a speeding up of the normal process of overall loss of dopaminergic tone with age (Morgan, 1992). Thus, it has been suggested that "by it's very nature the symptomatology of PD is bound to complicate and intensify those issues and problems, like physical decline and changing social identity that are normally part of ageing" (Brod, Mendelsohn & Roberts, 1998, p. 213). To explore this possibility further, consideration needs to be given to what constitutes 'normal' ageing.

1.4.1 The 'Normal' Process of Ageing

Although definitions of 'old age' have traditionally been made on the basis of chronological age (i.e. over 65), current gerontological thinking stresses the importance of subjective experience in ageing (e.g. Thompson, 1992). Early theories of ageing such as "disengagement" theory (Cummings & Henry, 1961) have been rejected in favour of models which emphasise the resiliency of older people in adapting to their changing circumstances (e.g. Baltes & Baltes, 1990). Far from
being helpless 'victims' of a predetermined natural order of events, individuals are recognised as being active, competent and creative in responding to the challenges they face (e.g. Atchley, 1989).

Key identity management tasks in later life relate to achieving continuity of self identity and maintaining individuality and positive self-esteem (Coleman, 1996). These tasks are strikingly similar to those described earlier in Breakwell's (1986) integrative model of threatened identity. Indeed, in a culture where 'old age' generally has many negative associations, one might even conceptualise age in itself as a threat to identity. Older persons frequent denial of feeling old can be seen as a defiance of a spoiled identity (Thompson, 1992). Many older people successfully maintain self-esteem, self-image and individuality using a variety of interpretative processes and adaptive strategies (e.g. Coleman, 1996). Thus the assertion that PD intensifies identity changes that are 'normally' part of ageing can be challenged on the grounds that such changes are not 'normal'. An alternative position is that it is ill health in general (rather than PD specifically) which threatens the processes by which identity as a 'young' person is maintained. The dominant meaning of ageing in modern society is one of illness and incapacitation (Frank, 1993) and thus, actual physical decline, may require greater efforts to resist taking on the identity of an 'old person'.

1.4.2 The Impact of Ill Health on the Process of 'Normal' Ageing

Ageing is directly linked to health status. Increased survival rates would seem to be accompanied by increased morbidity with greater numbers of health problems and more chronic illnesses (e.g. Briggs, 1998). Although illness is more common in later life, older people are not by virtue of their age expert at dealing with disability. Furthermore, they are more likely to be coping with multiple health problems which may pose unique challenges. The interactive effects of multiple health problems has received scant attention in the literature and, in fact, people with co-morbid health problems have been actively excluded from studies on PD (e.g. Brod, Mendelsohn & Roberts, 1998) even though this may be an important factor in understanding individual experience.

The impact of specific illnesses on the psychological experience of ageing has received very little direct attention in the literature and discussions have tended to draw upon studies of the frail 'very old' (e.g. Johnson, 1993). This research suggests that, for the 'oldest old', continuity and stability may not be as desirable as adapting by accepting change. Internal control over meanings and interpretations
(e.g. emphasising previous life themes, manipulating perception of present reality, making social comparisons) may be more important than control over circumstances. As noted earlier, these strategies have also been identified as important features of coping with the demands of PD (e.g. Marr, 1991). The similarities between the coping strategies used by people with PD and the 'oldest old' is interesting given descriptions of PD as "premature ageing" (Singer, 1973). It could be hypothesised that as PD accelerates biological development into the later stages of life, the coping strategies more relevant to this biological stage become applicable. It is important, however, that the meaning of being artificially 'forced' into a later stage of physical development that may be inconsistent with psychosocial development, is not overlooked. The discrepancy between subjective feelings of age and the physical experience acquires importance here. This has more traditionally been considered in relation to people in middle life, for whom diagnosis of an illness like PD is considered a non-normative event. It could also be applied, however, to older people for whom ill health has not been normative in relation to their own experience. This again raises the possibility of the potentially different experiences of people suffering from multiple health problems for whom ill health may be more normative. Furthermore, it is also important to be aware of the immense variation in people conventionally considered 'old' (i.e. over 65). People over 65 are often heard to make distinctions between themselves and their chronologically older peers.

1.5 The Current Study

Research on PD has been dominated by studies addressing the biomedical-reactive debate concerning the aetiology of depression in PD. Whilst the contribution of neurobiological factors is acknowledged by the author, this study specifically aims to explore the potential contributions of psychosocial factors to the emotional experience of PD in the 'crisis' phase of illness identified in Rolland's (1987) conceptual framework. Current psychosocial studies relating to PD have largely been concerned with documenting outcome and identifying psychosocial variables significant in this (i.e. adjustment and con-comitant research) or categorising and describing experience. No study has attempted to understand the processes underlying the overall experience of being diagnosed with PD or suggested inductive theory which could explain it. These were the aims of the current study. Such a theory could provide a framework for future investigations through the identification of variables not previously considered and the generation of hypotheses. It could also suggest important ways in which health services can ensure that appropriate care and support is provided for people with PD.
The research questions can be summarised as follows:

1. What are the processes by which people decide to seek medical help and subsequently receive a diagnosis of PD?

2. What are the processes which people use in their adjustment to the diagnosis of PD?

3. What is the emotional experience of being diagnosed with PD and how does this interact with the processes of relevance to research questions 1 and 2?
2.0 **METHOD**

2.1 **Research Design**

Since this was an exploratory study in a poorly researched area, it was decided to use a qualitative research method which emphasises the importance of understanding the multiplicities, variations and complexities of participants' personal experiences. Grounded Theory (Glaser & Strauss, 1967) is a qualitative research method which has been widely advocated as particularly suited to research within the field of health psychology (e.g., Chamberlain, 1999) and was selected as appropriate to the current research questions. A brief overview of this approach is now given before describing how it was operationalised in relation to the current research questions.

2.2 **Overview of the Grounded Theory Approach**

Grounded theory is a research methodology originally devised by Glaser and Strauss (1967) in response to their concerns that research in social sciences at that time focused mainly on the verification of a relatively small number of theories and that such research had become largely irrelevant to the people it was intended to help. They argued that an important prior step was being neglected; the discovery of concepts and hypotheses relevant to the area being researched. Similar concerns have been subsequently expressed in the field of psychology (e.g., Rennie, Phillips & Quartaro, 1988).

The essential features of grounded theory are that it is theoretical and 'grounded'. By theoretical it is meant that a theory of the phenomenon in question must be developed and that this must extend beyond a descriptive account. The researcher moves from a descriptive classification of events and facts to an abstract theory of the phenomenon that accounts for relationships and processes. By 'grounded' it is meant that a theory must emerge or be developed from the data and not from pre-determined hypotheses or formulations. For this reason a detailed literature search is often delayed until after analysis and subsequent theory formation. It is acknowledged that some prior understanding of the research area is required, for example, to select and develop a question to research, but grounded theory emphasises that the researcher must be alert to the potential influence of this on the analytic process and confirm all ideas, intuitions and hypotheses against the data gathered.
There is no one agreed method for conducting grounded theory analyses. Rather, grounded theory provides a set of strategies for conducting rigorous qualitative research (Charmaz, 1995b). 'Data' in grounded theory can take a number of forms (e.g. observations, clinical notes) but is typically generated through interviewing. The process of analysing data therefore begins with attempts to make sense of a usually large amount of unstructured data by coding it according to participants' descriptions of phenomena. The codes can represent concepts and themes which emerge in participants' accounts of their experiences and are sorted into an open ended indexing system. In order to generate theory, however, analysis needs to extend beyond coding, otherwise it would constitute a form of content analysis. Two fundamental analytic commitments distinguish grounded theory from content analysis; the method of constant comparison and theoretical sampling. A third process, theoretical sensitivity, is also encouraged although it is not usually discussed directly in published studies. Each of these strategies is now briefly reviewed.

(1) The method of constant comparison

This requires the researcher to continually sift through the data and systematically compare basic data instances, different participants and emerging categories for similarities and differences between them. This is intended to promote the identification of the properties of categories (e.g. when does a category apply and not apply) and also of the links and relationships between categories.

(2) Theoretical Sampling

This involves the researcher actively sampling new cases for their potential for generating new theory, by extending or deepening the researcher's emergent understanding, rather than for population representativeness. One consideration in theoretical sampling is negative case analysis (Kidder, 1981) where the researcher deliberately explores instances or cases that do not seem to fit the concept that has been emerging. Negative case analysis is invaluable as it serves to challenge initial assumptions and categories and hence can work as a check against the danger of building indefensible arguments from a corpus of data (Pidgeon, 1996).
(3) Theoretical Sensitivity

Within a grounded theory approach researchers are also encouraged to use their knowledge of the field, both professional and personal, to inform, clarify and substantiate theory in the later stages of its development. This process is referred to as theoretical sensitivity and is facilitated by keeping theoretical memos. Memos are simply notes of ideas, interpretations and hypotheses written up throughout the analysis and which can be explored through collecting and examining other data. It is pertinent to mention here that the researcher has a long-standing clinical interest in understanding the interactions between chronic illness and psychological well-being and has had substantial clinical experience of this area both as an assistant and trainee psychologist. To help gain further 'sensitivity' within the field of PD, the researcher spent time informally observing activities within a specialist clinic for people with PD.

Employing the above strategies together involves the researcher in a highly interactive and iterative (i.e. cyclical) process in which the traditional distinction between the data collection and data analysis phases of a research project are broken down. Data analysis proceeds as soon as sufficient material has been collected and feeds back into the sampling of new data. The dynamic relation between data analysis and data collection is a critical characteristic of the grounded theory approach.

2.3 Operationalisation of the Grounded Theory Approach in the Current Study

2.3.1 Ethical Considerations

Ethical approval was received from the School of Psychology Ethics Committee and the North Clwyd Ethics Committee (see Appendix 1). Careful consideration needed to be given to the possibility that asking people to recall their accounts of being diagnosed with PD could potentially cause distress. This influenced decisions made about the recruitment and interview procedures.

(1) Recruitment

All participants recruited either attended a specialist PD clinic which had access to psychology services or were currently seeing a clinical psychologist for therapy.
(2) Interview procedure

The decision to use a participant led approach to interviewing allowed participants to structure their accounts in the way they felt most comfortable. Relevant literature relating to interviewing about sensitive topics was also consulted in advance of the interviews (Coyle & Wright, 1996; King, 1996).

Additionally, issues of confidentiality were addressed in the written information given to participants prior to the interview (see appendix 2) and again in the interview setting. The opportunity for participants to withdraw at any point during the research process without having to give a reason and without it affecting their future care was emphasised. Consent to participate was obtained (see appendix 3).

2.3.2 Participants

Recruitment Procedures

Although theoretical sampling dictates that recruitment of participants should be guided by the emerging analysis, participants in the current study had to be 'theoretically sampled' in advance of the interview. This was necessitated by both the time limitations of the study and also the need to give colleagues clear criteria for the recruitment of participants. The recruitment criteria were developed to maximise the likelihood of participants' experiences conceptually fitting the phenomena under study (i.e. the experience of PD in the early stages of adjustment) and were therefore that participants should have a confirmed diagnosis of PD and have been diagnosed within the last 18 months. Due to difficulties in recruitment, however, many of the final participants had been diagnosed for longer than 18 months. The implications of this are discussed later (see discussion section 4.3.4).

Participants were primarily recruited from a specialist, multi-disciplinary movement disorders clinic located within the older adult services of a local district hospital. These participants were recommended by the medical consultant and nursing sister at the clinic. One participant (Mr H) was recommended by a clinical psychologist whom he had been seeing for several months. This participant did not attend a specialist movement disorders clinic but was receiving treatment from a neurology consultant. The study was initially introduced to participants by the nursing sister, medical consultant or clinical psychologist. If verbal agreement to participate was obtained then participants were contacted by telephone to answer any
further questions and arrange an initial interview. All participants were given written information about the study prior to the first interview.

Participant Characteristics

A detailed sample profile is provided in table 1.

Table 1: Profile of participant characteristics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Age at diagnosis</th>
<th>Years since diagnosis</th>
<th>marital status</th>
<th>work status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr A</td>
<td>M</td>
<td>75</td>
<td>74</td>
<td>0.5</td>
<td>Married retired</td>
</tr>
<tr>
<td>Mr B</td>
<td>M</td>
<td>77</td>
<td>75</td>
<td>1.5</td>
<td>Widowed self-</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(lived with friend)</td>
<td>employed</td>
</tr>
<tr>
<td>Mrs C</td>
<td>F</td>
<td>76</td>
<td>69</td>
<td>7</td>
<td>Married retired</td>
</tr>
<tr>
<td>Mr D</td>
<td>M</td>
<td>68</td>
<td>66</td>
<td>2.5</td>
<td>Married retired</td>
</tr>
<tr>
<td>Mrs E</td>
<td>F</td>
<td>66</td>
<td>64</td>
<td>2</td>
<td>Married retired</td>
</tr>
<tr>
<td>Mr F</td>
<td>M</td>
<td>68</td>
<td>61</td>
<td>7</td>
<td>Married retired</td>
</tr>
<tr>
<td>Mr G</td>
<td>M</td>
<td>50</td>
<td>42</td>
<td>8</td>
<td>Married employed</td>
</tr>
<tr>
<td>Mr H</td>
<td>M</td>
<td>69</td>
<td>65</td>
<td>3.5</td>
<td>Married retired due</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>to PD</td>
</tr>
<tr>
<td>Mrs I</td>
<td>F</td>
<td>69</td>
<td>67</td>
<td>1.5</td>
<td>Married retired</td>
</tr>
</tbody>
</table>

2.3.3 Interview Procedure

Although interviewing is the most common method of data collection in grounded theory, there are no clear guidelines as to how this should be approached (e.g. Melia, 1996). Approaches to interviewing can be distinguished by the degree of structure. Within a semi-structured framework the interviewer has an idea of the broad areas of interest but encourages participants to talk freely within these areas and uses their responses as a guide to further questioning. This approach was adopted in the current study. Interviews were loosely structured but aimed to cover a number of areas of concern to the research questions (see appendix 4). After being briefly introduced to the study and interview procedures, participants were asked to tell their story of how they came to find out that they had PD. Their account of this

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1 Although not married, for reasons of convenience, the friend living with Mr P will be referred to as Mrs P.
was used as a guide for further questioning and exploration. Consistent with the iterative nature of grounded theory, as themes and concepts emerged from the ongoing data analysis, these were explored with subsequent participants. Many of these themes arose naturally in participants' accounts but, if this did not occur, an open ended question was asked to direct them to the relevant issue. Throughout, a balance was sought between exploring themes emerging from previous interviews whilst being open to the emergence of new themes.

All participants were interviewed at home, with the exception of Mr G and Mr F who preferred to be interviewed at the movement disorders clinic. Participants were given the choice of being interviewed either alone or with a friend or family member. The reasons for this were two fold: firstly, it was felt that having somebody else present may help to reduce any feelings of anxiety on the part of the person with PD. Secondly, drawing upon data from multiple sources often enables a richer, fuller story to be obtained and strengthens the conclusions made (Smith, 1996). All participants chose to be interviewed with their spouse or partner, although Mrs A was not present for all of the interview with her husband. Mrs E's daughter was also present for some of the interview.

Interviews were flexible in length, lasting for between 1 and 2 hours and were audiotaped so that they could later be transcribed. All participants were interviewed once except Mr A who requested the opportunity to read through a transcript of his initial interview. A second interview was subsequently arranged to explore and discuss any emerging issues. This provided a valuable opportunity to check the validity of the researchers interpretations. After completion of the analyses, four participants (Mr D, Mr H, Mrs C and Mr G) were asked to review a summary of the overall findings of the research. This is a recommended method of assessing validity in qualitative research (e.g. Smith, 1996) and is particularly relevant to grounded theory where the comprehensibility of the findings to the people who took part in the study has been specifically identified as an evaluation criteria (Strauss & Corbin, 1990).

2.3.4 Transcription

All interviews were transcribed in full by the researcher and this was felt to be an extremely important factor in gaining familiarity with the text. Of particular use was a familiarity with how participants spoke, in terms of intonation and emphasis. This had an impact on the analysis and interpretation process and helped the researcher become theoretically sensitive to the data. Interviews were transcribed
as soon as possible following the interview and all names were changed to maintain confidentiality.

2.3.5 Data Analysis

Generation of Categories

Each interview transcript was coded by sticking as closely as possible to the information given by the participants. As recommended by Pidgeon and Henwood (1996), for each paragraph or line, the question was asked 'what categories, concepts or labels do I need to account for what is of importance to me in this paragraph?'. Emerging categories were documented on an index card and specific instances of where this category occurred in the data were logged. In this way multiple examples of each category were built up both within and between participants. Potential links with other categories were also noted on the index card. The coding process was iterative so that as new categories emerged from subsequent interviews, previous transcripts were examined for instances of these. As data accumulated and categories became more developed, greater differentiation within categories was possible and subcategories were identified. An example of this was the category of 'information seeking' which ultimately produced four subcategories of active seeking, selective seeking and active and passive avoidance.

Theory Generation

By continually examining the index cards it was possible to identify categories which were universal across participants, those which only applied to a select few, and categories which were central to the experience of a particular individual. This formed the basis for using the method of constant comparison to explore the reasons why differences and similarities occurred. In this way more abstract themes and categories were developed and links between categories clarified. This process was aided by the process of questioning which involved continually asking questions of the data, for example, 'to whom does this category apply?'; 'how does it relate to other instances'; 'does it apply to all informants?'. To maintain the 'groundedness' of the developing theory, interpretations and emerging themes were related back to the data continually by asking the question 'is this interpretation/theme justified by the data available?'.

Identifying negative case examples was an important feature of the method of constant comparison. Exploring why cases did not fit the emerging conceptual system was critical in ensuring that the emergent theory was valid to all participants' experiences. As the theory emerged, the question was continually asked 'is this theory able to explain every person's experience?'. An example of negative case analysis was exploring why one participant (Mr A) did not react to the diagnosis of PD with the same reaction of shock and disbelief reported by all the other participants. Theoretical memos and field notes were kept at all stages of the research process (e.g. immediately after the interview, during transcription, during analysis).
3.0 **RESULTS**

Emerging from the analysis was a transitional model of participants' experience of PD. This is summarised diagrammatically in figure 2.

**Figure 2:** A model of participants' experiences of being diagnosed with PD developed from the analysis.
This model indicates a sequential process which consists of four phases: pre-diagnosis, diagnosis, initial adjustment and transition to the chronic phase. Analysis suggested that the individual experience of the process outlined in figure 2 was mediated by a number of factors which could be grouped into five broad categories: age-related issues, professional support, family and social context, past and current health status and the context of daily life. These are summarised in figure 3.

**Figure 3:** Summary of the factors shown to mediate the individual experience of PD

- **AGE RELATED ISSUES**
  - Life circumstances
  - Association between age, PD and ill health
  - Closer proximity to death with age

- **PROFESSIONAL SUPPORT**
  - Chronic versus acute models of care
  - Attention to the human significance
  - Access to a specialist service

- **FAMILY AND SOCIAL CONTEXT**
  - Family context
    - Changes in family relationships
    - Issues of dependency
    - Responding to emotional needs
  - Social Context

- **CURRENT AND PAST HEALTH STATUS**

- **PD IN THE CONTEXT OF DAILY LIFE**

**INDIVIDUAL EXPERIENCE OF PD**
Each phase of the adjustment process outlined in figure 2 is now described, followed by a discussion of how the factors summarised in figure 3 mediated this process. Quotes from participants will be presented as evidence for the interpretations made and to enable the reader to consider the plausibility of the account presented. Due to limitations of space, only a selection of representative quotes will be presented.

3.1 Description of the Theoretical Model of Participants' Experiences of Being Diagnosed with PD

3.1.1 Pre-diagnosis

This phase describes the time taken from first noticing the symptoms of PD to the point when a confirmed medical diagnosis was received. It comprised of four stages: noticing and discounting or rationalising; suspecting; deciding to seek medical help and searching for a medical diagnosis. At a general level these are consistent with the tasks of 'acknowledging symptoms' and 'seeking medical advice' identified previously by Habermann (1996). The current findings extend previous research, however, by considering the processes underlying these tasks.

Noticing And Discounting Or Rationalising

This initial stage was characterised by gradually increasing awareness on the part of the person with PD and others (e.g. family, friends) of "something being different". Initial 'symptoms' varied greatly but included changes in behaviour/skills (e.g. being able to get out of a chair, shave), mood (e.g. feeling tired, anxious or depressed) and/or physical sensation (e.g. poor balance, tremor, dizziness). The insidious onset of PD meant that early changes were often only recognised as being related to PD in retrospect after a diagnosis had been received. At the time 'symptoms' were either discounted or normalised by finding rational explanations such as overwork, weight increase, old age, depression or an existing health problem:

Mr B: But I must have had it for 2 years. Trouble getting out of bed and getting out of the chair was a lot longer than that wasn't it?

Mrs B: He put it down to weight increase.

Mr B: That's what I put it down to.

Mrs B: He thought it was 'I'll have to stop this eating; I'll have to do something about it'.

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2 The names of all participants, health professionals and any other relevant people have been changed to maintain confidentiality. 'R' is used to denote the researcher.
Suspecting

As 'symptoms' cumulated and had a greater impact on everyday life, people began to suspect that something more serious was wrong but were puzzled as to what this may be. Potential 'serious' causes were considered (e.g. ME, multiple sclerosis, dementia) but consideration of PD depended on whether individual symptoms (e.g. having a tremor) fitted with a person's understanding of PD. For many people 'suspecting' was associated with increased emotional distress characterised predominantly by feelings of anxiety but also feelings of depression arising from the belief that something was seriously wrong but, at the same time, not knowing what this was:

Mrs G: ...say that's why you were worried 'cause you know something's happening to you don't you?
Mr G: Yeah, but you're not sure what it is; you don't know what it is. Probably if I'd have known what it was I probably would not have been as depressed...

Deciding to Seek Medical Help

Deciding whether or not to seek medical help involved a process of 'weighing up the options' whereby the benefits of 'knowing' were balanced against anxiety about what may emerge. Seeking help was often delayed until it was no longer possible to ignore the emotional and/or physical impact of the 'symptoms' on everyday life. For many people the increased emotional stress was ultimately the catalyst for seeking help, usually after encouragement by the carer:

Mrs C: ...I thought I was getting very old very young sort of thing... and yet I was afraid to go to the doctor...
Mr C: Well she was getting on my ruddy nerves so I had to say to her... 'You've got to go and see the doctor, that's the end of it'. So I rang up.
Mrs C: And I knew in my heart that I had to go. I had to sort it out one way or the other, you know.

Seeking a medical diagnosis

For some people the conflict over 'knowing' versus 'not knowing' was subtly reflected in their help seeking behaviour. Instances were recalled of seeking help for minor complaints (being implicitly reassured when nothing serious was found) and actively hiding symptoms from the GP. These behaviours reflected difficulties in accepting the suspected reality of something serious being wrong.
Mr B: ...I went to the surgery to see my doctor for some reason or another and I struggled a little to get off the chair...

Mrs B: ...he said you're disguising things; you're hiding things from me...

R: Did you feel that you were trying to hide things Mr B?

Mr B: Well, em, I can say to you yes. I'd rather hide it and forget about it than go moping around and having to put up with it.

Consistent with previous research (e.g. Habermann, 1996), an early diagnosis, although commonly unwanted at the time, with hindsight, was recognised as being essential in legitimising ambiguous bodily changes and in enabling people to 'move on' and begin a process of adjustment. Four people (Mr F, Mr A, Mrs E and Mr H) experienced difficulties in obtaining a confirmed diagnosis and thus were left in a state of limbo as they did not have a framework within which to make sense of a puzzling experience:

Mr E: It was a traumatic few months that was. Because it was like as though you were in a wilderness, you couldn't get out. You couldn't get out of the wilderness. And then as soon as [Consultant] took over, that's the time you had a clear way didn't you?... He gave us, em, what do you me call it...

Mrs E: Diagnosis.

One person, Mr A, reported being unconcerned about receiving conflicting diagnoses due to his greater concern over other health problems at the time. For the others, however, the absence of a confirmed diagnosis had negative consequences for both physical and emotional well-being. Underlying the emotional impact was the invalidation felt by both the person with PD and their partners:

Mrs F: I think the worst part of it was, was he knew there was something wrong with him. He knew it just wasn't just depression but nobody could say to him this is what's wrong with you. And he wanted a name put to what was, you know, he knew there was something wrong. And at one time he said to the doctor, well look, there must be something wrong with me, and if it's not medical I think I'd better go and see a psychiatrist.

Without a diagnosis, appropriate medical treatment could not be prescribed resulting in a deterioration in the physical condition as the disease progressed. This deterioration was exacerbated by the increased emotional distress which, for Mrs E, became the focus of medical intervention:
Mr E: Now, [GP 1] said from the beginning she's got Parkinson's. Now then, [GP 2] was saying I don't think it is Parkinson's. So you know, one was like saying different to the other... we were in the middle so we didn't know where we were you see? But in the meantime, while they were arguing about this, she was getting no medication. So, in actual fact she was going worse... and he put her on tablets you see which weren't doing her any good.

Mrs E: I was like a zombie going round wasn't I?

Mr E: It was, em, a sedative. So she was walking round like a zombie, but the illness wasn't getting any better...

Mrs E: I was asking for help. I wasn't having no help, you know. Nobody was listening to me.

3.1.2 Receiving A Confirmed Diagnosis

The immediate impact of (finally) receiving a diagnosis of PD was characterised by a variety of emotional responses which were influenced substantively by what the person understood about PD. One person (Mr A) reported simply "absorbing" the diagnosis, but more common were feelings of relief (especially if the diagnostic quest had been problematic) and, most significantly, a feeling of intense emotional shock. Underlying this feeling of shock was the uncertainty associated with "not knowing" what PD was in both a clinical sense and, more importantly, in terms of survival and quality of life. Previous perceptions of having control in one's life and future were threatened:

Mrs G: ...it was just like an amazing shock because...

Mr G: But we didn't know what Parkinson's was at the time. It was nothing to us

Mrs G: You knew it was serious and it was something you didn't want to hear. It was like, oh, no let it just be this and then it will go or... but we knew it was serious and that it was something that was going to affect us forever.

For many people PD was "just a label" but one which generally had negative associations. Individual perceptions of PD (based on previous personal experiences of other people with PD) and assumptions about it's nature (e.g. that it's life threatening) influenced participants' emotional response to the diagnosis:

Mr H: When I was first told that I had Parkinson's? Oh you just feel yourself thinking about other people you know that's got it. Some people they... will be in their hands; hands going and you think, gosh, I don't want to be like that... it was like a death sentence really.
Perceptions of societal beliefs about PD, and illness in general, also had a significant influence on the emotional impact of the diagnosis. The word 'disease' carried particularly negative associations and reminded people of illnesses such as the plague and typhoid. The word disease was commonly associated with notions of an illness being contagious:

Mrs 1: ...Once one had told me you had it you don't forget because it was dreadful...
when they said Parkinson's Disease, I thought, oh, it makes you feel unclean that...

Mr 1: ...when they put disease on the end you know?

Mrs 1: ...It makes you feel dirty and unclean...

Mr 1: If they said Parkinson's complaint or something like that... Once they say disease, well your mind starts turning over and you think all sorts of things...

Mrs 1: I think it's a bad name for the thing... because years and years ago I do remember as a child, the woman that used to live next door to me mother, she used to shake terrible bad, from head to foot. And, em, she used to come into me mother's for drinks of tea and you see with [friends name] being like that they must have thought it was a disease as well because me dad wouldn't let her have a cup of tea unless it was out of her own cup.

3.13 Initial Adjustment

Armed with a label, people had to find ways of reducing the uncertainty of "not knowing", re-establish a feeling of control over life and cope with the emotional impact of the diagnosis. Ultimately sense had to be made of what PD meant for the self in the context of daily life. Analysis suggested that the process of initial adjustment consisted of three key 'tasks' which were aimed at reducing uncertainty and re-establishing a sense of personal control:

(1) information seeking
(2) resolving identity dilemmas
(3) coping with treatment demands and symptoms.

Each of these has been identified previously in the literature specific to PD (e.g. Habermann, 1996; Pinder, 1995) and the wider chronic illness literature (e.g. Charmaz, 1991) but the current analysis extends previous research by exploring how these tasks interact to shape the individual experience of adjustment. Central to understanding these interactions was understanding how PD was conceptualised by a person in relation to their daily life. Analysis suggested four patterns of conceptualisation which related to the extent to which the permanence of PD had been accepted:
The 'tasks' of adjustment will be presented before discussing how these interacted with conceptualisation. Although intrinsically linked, for ease of presentation each 'task' is considered separately.

Information Seeking

Key questions relating to the clinical aspects of PD were: is it life threatening?; if not life threatening is it curable or at least controllable?; how will it progress over time and what is the cause, in particular is it hereditary?. For each person the psychological benefits of seeking information to answer these questions were balanced against the fear of 'venturing into the unknown'. Individual responses to this decisional conflict were located along a continuum ranging from active seeking of information to active avoidance. Individuals moved in and out of different patterns of responding at different times in the adjustment process. Although located along a continuum, to help analysis four distinct patterns of responses to information seeking will be presented: (i) active seeking (ii) selective seeking (iii) active avoidance (iv) passive avoidance. This categorisation is broadly consistent with the patterns identified by Pinder (1995) but makes a further distinction between active and passive avoidance.

Active seeking of information

For these people the drive for information overpowered everything else including anxiety about what they may find. The fear of the unknown was outweighed by the current anxiety arising from the uncertainty of not knowing. Having information enabled people to correct previously erroneous beliefs (e.g. that PD is life threatening) and make sense of previously puzzling symptoms. It also provided the means whereby further support could be accessed. Several people reported difficulties in accessing information and had to rely on social contacts, the library or the (often limited) information given at diagnosis:
Mr C: ...We immediately made enquiries that day after we come back after the doctors innit?

Mrs C: ...yes, you know, trying to find out as much as I could about it. The knowledge of it...

R: How do you think the knowledge actually helped you? Having the information there, in what ways did it help you?

Mrs C: Well, you feel you know what you're coping with don't you. It's the unknown isn't it really... that makes you more frightened doesn't it?... And then getting people to help you as well. You know these meetings and things like that.

Although the need to know was paramount, anxiety about what may emerge was still evident. The need to regulate the acquisition of information to prevent it from becoming overwhelming was recognised:

Mrs G: Yeah, you want to know but you only want to know little bits at a time I think.

Mr G: It's sort of like a scary film on the television. You've got your hands over your eyes but you've got it open just a little bit, so you want to know a bit of like.

Selective seeking of information

People in this category were more cautious about seeking information. The desire for information fluctuated, reflecting the unresolved conflict of 'knowing' versus 'not knowing'. 'Middle ground' was found whereby some information was acquired but with an awareness of there still being some things unknown. Typically, the information 'selected' was the least threatening and usually related to the possibility of cures and advances in medical treatments:

Mr H: Sometimes you say to yourself, better not to know than know too much. Sometimes, as we say, it comes to a dead end. I don't know enough about it...
Sometimes they say that they've found something new or a gene or something like that. Lifts your moral up. Possibly they'll find something now and you keep on hoping and every time I look in different papers I look for the health columns and find if there's anything that they've found out about Parkinson's.

As Mr H confirmed during the validation interview:

Mr H: ...If I'm reading a magazine and read something I don't like then I stop reading and get on with something else.
Active Avoidance of Information

A small number of people, at times in the adjustment process, actively avoided seeking information. This occurred when the fear of what may emerge was greater than the distress caused by not knowing. Mr D's initial avoidance of information, for example, was based upon his (erroneous) belief that PD was life threatening. It is important to note that the strategy of avoidance is unhelpful in situations like this in that through avoiding information Mr D was unable to correct his erroneous belief:

Mr D: ...when the doctor told me I'd got it, I think that was the only time, I think the fear was me mother had it and she's dead...

Mrs D: ...because you didn't know any different. I think the more we found out about it, the more questions we asked about it, I think you felt more relaxed about it didn't you?

Mr D: Oh yes, definitely...

Mrs D: ...if you read about it and you get all you can information wise about it and you read it properly and understand it, it's not frightening at all.

Mr D: I think that's mainly because it's supposedly not life threatening... whether you'd have the same attitude of wanting to get all the information if you had something else and you were told that it was life threatening it may be different.

Passive Avoidance of Information

Passive avoidance of information was related less to fear about what may emerge but rather to the belief that any emerging knowledge would not be relevant or useful. This position was unique to Mr A in the current study:

Mr A: I don't know anything about it really... It's outside my experience and knowledge and I'm not very good with chemical terms or concept and, em, I'm not interested in it from a clinical point of view and not very much interested in it from the point of view of it's effect on me... I don't want it to remain a closed book just because I'm afraid of it. If I could absorb some interesting information well then I would read a little bit.
Resolving Identity Dilemmas

The diagnosis of PD posed fundamental threats to self-identity. PD had to be assimilated and accommodated into existing identity structures as people struggled with resolving the question of 'who am I now?'. Consistent with Breakwell's (1986) integrative model, PD threatened the continuity and distinctiveness of identity but this had to be considered in relation to both present and future identity. Diagnosis threatened identity as perceived by self (self-identity) as well as identity as perceived by others (social identity).

Threats to Continuity of Self-identity

For some people, simply knowing that they had PD threatened their self-identity:

Mrs C: ...But for weeks after [the diagnosis] I felt I was different. I didn't know anything about Parkinson but I knew I'd got it... For weeks I felt strange. I felt as if I was different. Until I'd got used to knowing that I'd got Parkinson's you know?

Consistent with previous research (e.g. Charmaz, 1995a), the most serious threat to the continuity of pre-illness identity was posed by changes in physical ability. Impaired physical ability required, to a lesser or greater degree, unavoidable lifestyle changes, but it was the meaning of these changes with respect to ability to continue in established social roles (e.g. as husband, wife, mother, friend, boss) that threatened self-identity and emotional well-being:

Mr H: ...we had a puncture some time ago, a few weeks ago. I tried to change the wheel, I couldn't do it. It really is a simple job really but everything like that you have to go on the phone for somebody to do the jobs for you. You feel [pause] I don't know, you feel...

Mrs H: frustration and inferior

Mr H: ...yeah.

R: When you feel inferior what sorts of feelings does it make you...

Mr H: It makes you a bit depressed I think. So many things and wife take the bin out. She goes out with the bin and I'm watching her.

R: Sounds like you find it really hard to watch your wife do things that you feel that you feel you should be doing?

Mr H: Quite; the things I should be doing.
The ability to continue in social roles depended on the nature and severity of the physical symptoms, characteristics of individual lifestyles and personal definitions of expectations within each social role. Thus, for example, a tremor in itself may not necessitate major changes in lifestyle for one person, but for another, this may mean an inability to drive and consequent loss of job. For another person, the inability to drive may not greatly affect ability to continue in social roles such as work.

Coping with threats to continuity of identity

Several coping strategies were employed to preserve aspects of self-identity. These included redefining the behavioural expectations within a given role to match the lessened physical capacity (e.g. allowing longer time to do the housework) and making 'identity trade offs' (Charmaz 1995a). This latter strategy involved giving up one aspect of identity in order to retain another aspect perceived to be of greater worth. This is illustrated by Mr G who, unable to continue in his existing job as an HGV driver, opted to accept a job of perceived lower personal value in the warehouse in order to maintain his identity as a member of the workforce:

Mr G: ...I told them [work] all about it straight up and I was thinking well they're going to get rid of me. No, they kept me on. They swapped a lad from the warehouse onto the road and I went into the warehouse...

R: How do you feel about having to make those changes?

Mr G: I was glad really because I still had a job but I would rather go on the road

Mrs G: Carl absolutely adored driving

Mr G: I loved it. I'd give my right hand to go back even now.

To compensate for 'lost' aspects of pre-illness identity, greater emphasis was often placed on existing roles and activities (e.g. as grandmother) and/or creating new roles which were less dependent on physical ability:

Mrs E: They [the grandchildren] keep me going you know? Don't they Thomas. Thomas says to me, come on we'll go to visit [daughter]. If he looks at me and if I'm a bit down, he says, come on we'll go for a run to [daughter's].

For several people, joining the Parkinson's Disease Society (PDS) provided the opportunity to develop new roles and identities:
Mr F: I think it, the matter as it is now, is keeping myself occupied within the thing. Since then of course I represent the [PDS] branch in a number of local charities as well... What I feel I'm doing now, I'm getting more out of it than what I'm putting in, in a sense. I mean it's all bouncing back on to me.

**Emotional changes experienced in relation to 'lost' aspects of identity**

'Giving up' valued social roles (either in part or in their entirety) was a difficult decision to make and was frequently associated with feelings low self-esteem and understandable feelings of sadness, anger and frustration:

Mrs E: And I want to do things and I can't you know?
R: How do you feel in yourself when you want to do things that you can't do?
Mrs E: Angry.
Daughter: Upset really. You cry don't you?
Mrs E: I cry. yeah, I get upset.
Mr E: Because before this happened to her she was involved in meetings, going to meetings and organising, you know, organisations, she was going to these things...
Mrs E: Youth club
Mr E: Youth clubs and all that and she put herself into it. but since everything's happened everything's stopped you know.

These feelings were similar to those characterising grief and, consistent with grief theory, generally lessened over time as PD was assimilated into self identity. Some people, however, described more fundamental emotional changes resulting from having made changes to self-identity structures. These were described as a loss of self-confidence and feelings of increased generalised anxiety (e.g. difficulties making decisions and general worrying, for example, over time keeping or the family):

Mrs G: ...Carl's changed a lot emotionally. Oh an awful lot...
Mr G: I don't feel as strong about my self
Mrs G: ...no as a person. He's not strong.
Mr G: Not as confident in making decisions sometimes. I dither and dother and things like that.
Mrs G: No, I'd say he's changed a lot emotionally...
Mr G: A lots gone physically but emotionally a lot's gone as well
Mrs G: ...Yeah, it's like it takes your strength from the inside, the person you are. I don't know, yeah, a lot of changes there definitely.
Mr G: Even though I'm on medication I still feel inside is not as good as I used to be.
The emotional experience of some people was more suggestive of clinical depression than grief. These feelings were less transient than feelings of grief and were characterised by feelings of worthlessness (e.g. feeling "rotten" about oneself or "inferior"), and extreme apathy, lack of motivation and loss of interest. Importantly, clinical depression, but not grief, restricted a person's ability to engage in activities which would promote adjustment to PD (e.g. developing new interests):

Mrs D: Early on you went into a deep depression... you just sat and sat and stared as though he didn't want anything else; nothing else outside mattered. It was just in that little world of his own.

Threats to Maintaining the Distinctiveness of Self-identity

The distinctiveness of self-identity was threatened by the possibility of acquiring an overriding [stigmatising] identity as a person with PD. Ironically, people became victims of their own [negative] social beliefs about PD (and illness) from which they had to distance themselves in order to maintain their individuality. The desire to be individual and not define oneself primarily as a person with PD was a reason why some people chose not to attend PDS meetings preferring instead to be with established friends whom they felt were more sensitive to their individuality:

Mrs E: I didn't want to go in that [PDS]. I'd go on the Wednesday morning, every other Wednesday, to the [name of home town] centre, you know. I like to communicate with the local people don't I Thomas?

Mr E: That's what she likes you see?

Mrs E: And we have a scone and a cup of tea and I know them all. Like they all talk don't they? Like I do.

Conversely, for other people, a perceived benefit of attending PDS meetings was the opportunity to be with people with whom they felt they could be themselves. By virtue of a shared diagnosis, other people with PD were believed to have implicit understanding of the threats to individuality posed by PD and were thus able to relate to the person beyond the label. For these people, PDS meetings were often perceived as more of a social occasion rather than being disease focused:

Mrs D: ...Because we were suggesting that she [a lady with PD] might like to come along. You know, when we have our social get togethers...

Mr D: ...because I mentioned to this lady that, em, we don't mention about one another's illnesses and how you're doing or whatever, unless there's a new drug comes out or there's been some sort of surgery you know.
Mrs D: You can if you want to but no one makes it a point of... If you wished to talk to someone, if you wish to discuss symptoms or anything to do with Parkinson's, you can do but not necessarily. You know, you talk about families, you talk about the grandchildren or children.

**Threats to Future Identity**

The progressive nature of PD meant that people were faced with living in conditions of continued uncertainty about the future. Especially in the early stages following diagnosis, fears about the future and the potential 'loss' of future plans were a primary concern. A future of disability and dependency was visualised which threatened any attempts made to preserve self-identity in the present. This supports arguments for the need to consider anxiety about the future, as well as depression, as a primary emotional feature of PD (Dakof & Mendelsohn, 1989). Fears about the future were most clearly reflected in participants' reports of anxiety about meeting other people with PD who were "worse off":

Mr B: What I don't want is to go there [group meeting] and everybody sitting round in a circle with, what shall I say, seriously ill? That would put me off straight away... Because I think to myself well I've got that stage to go through you know. Whereas if I'm at home here I wouldn't know anything about it.

R: You don't want to know what's coming up?

Mr B: I don't want to talk about what's coming up. I'll talk about what's gone and what it is at the present moment but em...

Mrs B: ...he doesn't want to see because he has got a bit of a fear of the unknown.

For most people, anxiety about seeing others "worse off" subsided over time. Strategies used to protect the self from negative images of the future included minimising contact with others with PD (especially in the early stages), and a variety of cognitive strategies which enabled people to see their own case as different. A common strategy for achieving this was capitalising on the clinical uncertainty of the disease course:

Mr G: Also, the times we've been to the meetings in [place name], they have Parkinson's meetings, I am not as bad as some of those people... It frightens me sometimes. Some of them are very, very poor off

Mrs G: Yeah but, it's like [consultant] told us, there's lots of different...

Mr G: aspects of it

Mrs G: ...kinds of Parkinson's. Like one person's symptoms are totally different from another's.
Once 'distanced' from the possibility that "I too may end up like that", many people used downward social comparisons on a physical dimension to increase self-esteem and well-being:

Mrs C: And if somebody's worse - I shouldn't say this - if somebody's worse than myself I feel good. But I'm, you know, not nasty, but I think well I'm not that bad.

Lateral and upward social comparisons were also made along dimensions of attitude and coping to further enhance esteem and well-being. Rather than seeking to create 'psychological distance', comparisons of this nature were aimed at identification and were particularly important with regards to increasing feelings of personal control along the lines of 'even if I do deteriorate physically, I can still control the impact of this by having a positive attitude':

R: Do you find it helpful talking to other people?
Mr A: I did yesterday for the first time.
R: What was helpful about that?
Mr A: Their experiences, how long they'd had it. Em, they were quite buoyant... I was interested in finding them so buoyant. They'd been over this ground such a long time and were relatively normal.

Threats to social identity

Social identity was threatened by the perceived stigma associated with PD and illness. This created fears of negative evaluation by others and a loss of status in society if others became aware of the diagnosis (either by explicit sharing of the diagnosis or by changes in physical appearance). Consequently there was a reluctance to share the diagnosis of PD with anyone apart from family and close friends, especially in the early stages when people were still 'coming to terms' with the diagnosis themselves:

Mrs F: ...because you wouldn't tell anybody outside that you had Parkinson's for quite a time...
R: Sounds almost like it was a secret before then...
Mr F: Yes, well that's how it is, I think, that's the thing, yes I do...
R: Why do you feel that people want to keep it a secret.
Mr F: I think this goes back to my mother. Because her fear of it, Parkinson's is, was, it's a no, no; which it was at those times. We're talking what about 20, 30 years ago.

Mrs F: Oh no, going longer than that.

Mr F: Longer than that. But it was, all she'd say was 'I haven't got Parkinson's; I haven't got Parkinson's' and that was it; denial. You know she just didn't want to know about it because it's a no word.

Mrs F: I suppose that it's just like it was with cancer. Nobody said like, you know, they'd got cancer... Nobody spoke about it.

Mr F: yeah, yeah

Several people also reported being reluctant to go out as they felt as though people were staring at them. Relatives observed, however, that at least some of this fear wasn't based in reality:

Mr C: She thinks sometimes that people are looking at her because, she thinks, because she's got Parkinson's they're looking at her. But they don't you see.

As PD was assimilated into self-identity, fears about going out and disclosing the diagnosis to others subsided. Disclosure was seen as positive in that it provided others with the opportunity to understand observed changes in behaviour and appearance:

Mr I: But she finds it better to talk about it rather then try and keep it undercover sort of thing.

Mrs I: Oh you know some people do that, you know, they keep it undercover and things like that... See, if I think I'm talking too much I say you'll have to excuse me I've got Parkinson's Disease and, em, I've got to talk when I want to... Good idea that. Just, em, you know crack on that you don't know what they're talking about and tell them first. See then the people don't bother you do they?... They're all different then you see? Sorry, really sorry, they're upset you see...

Coping With Symptoms And Treatment Demands

Medication and treatments

A central task following diagnosis was 'sorting out' medications and acquiring skills in other treatment domains such as speech and language and physiotherapy. Most people disliked taking medications due to the short-term side effects, the fear of
long-term side effects, fears that they were addictive and also because of having to take so many tablets. The effectiveness of medications in relieving symptoms, however, meant that 'sorting out medications' was a primary concern in the initial stages. The responsibility for taking medications was shared, to varying degrees, with the carer. Key skills to be acquired included, learning typical responses to medication, learning to sequence and time tablets to achieve optimum benefit, distinguishing side effects from symptoms and integrating treatment routines into daily life (e.g. remembering to take a supply of tablets when going out). The often high level of skill acquired is illustrated in the following quote by Mrs I:

**Mrs I:** Now I've had one at 2 o'clock so I'll have the next one 6 o'clock... I do usually try and take them at the same time every day, but if I forget I just take them and then measure out a bit more time afterwards. And when, you start tingling you see... it's telling me that it either wants one, or, you know, the effects are wearing off and to take another one. Because when I take the other one, it still rattles a bit for about quarter of an hour or so, 10 minutes, and then it settles down then and I can get on with a bit of work then can't I? But that's what you've got to do... When you're going out somewhere you make sure you go out so as you get the full 4 hours... I have them in the car don't I?... and then if you have something to eat, if you're going to stay out a bit later, then you buy something to eat and then you have extra hours.

Although clearly important from a medical perspective, the availability of effective drug treatments was also important psychologically. The beneficial effects of medications, and awareness of how treatments have improved over recent years, helped to generate feelings of control ('at least something can be done') and hope that further treatments and a cure will be found. Mr A's positive experience of being diagnosed was clearly related to him feeling that PD was controllable through medication in a way that his other health problems weren't:

**R:** You mentioned you thought that it actually had a positive effect being told that your husband had PD. Can you tell me a little bit more about that?

**Mrs A:** Well having this feeling that something was being done to help because as far as the osteoporosis was concerned I think that Mark felt rather negative...

**Mr A:** There's not treatment for it [osteoporosis]... There's a history of regulation now, of Parkinson's. I had one friend who died very rapidly after he retired of PD but obviously a lot of people live on for many years and I'm going to be one of those people. There's a lot more claret left to drink yet!
On the rare occasions when the medications were ineffective in bringing symptom relief, people were unable to derive the same positive feelings of control and the motivation to continue taking the tablets was reduced:

Mr H: I thought first they [the medications] were doing me worse...
Mrs H: Tried for a while without it didn't you?
Mr H: I wasn't much different was I?
Mrs H: No, he wasn't.
R: When did the tablets start to have a positive effect on you?
Mr H: I think recently, when he's made it up to one and a half...
R: How did you feel about taking tablets but them not seeming to work for you?
Mr H: Oh I felt dreadful; I'm taking these and they're not doing me any good at all. I expected that as soon as I took then I'd feel fine until the next one was due but it didn't work like that did it?

Coping with symptoms

Although generally successful in alleviating symptoms, medications were unable to eradicate symptoms completely and a variety of coping strategies were developed to minimise the impact of the remaining symptoms on everyday life. These included developing new skills (e.g. being able to shave with the left hand and speech and language techniques), pacing activities to accommodate reduced physical capacity and variations in functioning and using practical aids (e.g. a walking stick or wheelchair). The use of practical aids had psychological significance, however. Some people, for example, felt that using these drew attention to them being 'ill' or different and further coping aimed at reinterpreting changes in a positive way was required:

Mrs F: ...actually about the wheelchair business. He realises, well now he does, but at the time, 'I don't want to go into a wheelchair'. And Dr [consultant] just looked at him and he says I can always arrange to have your leg put in plaster if you like. And it was so typical of him and I thought well that's terrific because if you've got your leg in plaster, you'd sit in a wheelchair and you wouldn't worry about it but because you can't see what's wrong with you, you feel self conscious sitting in the chair. Which you don't now of course but you did.
Mr F: I know that I'm getting a better quality of life.
Mrs F: Exactly, yeah.
From a psychological perspective, social anxiety, particularly anxiety about going to crowded places, was commonly reported as a consequence of the physical symptoms of PD. Although feelings of social anxiety reduced over time, they were generally more persistent than the feelings of grief reported. Underlying the feelings of social anxiety was the fear of negative evaluation (what would others think if they saw me fall or shake?) and, in this way, was linked to the perceived threat to social identity. Consequently, especially in the early stages, people would commonly avoid social situations, particularly those involving strangers. Social anxiety therefore had a secondary impact on lifestyle over and above that imposed by the physical impairment per se:

Mr G: Meeting new people I get nervous. If I go into strange company I get more nervous. I'm more happy in the circle that knows I've got it. They know that if I start shaking that's what it is. I feel safer with people who know that I've got it. If I 'go out of it' I don't have to explain to people. I stay in now, it's easier.

Predictably, given the perceived social threat, visible symptoms (e.g. facial expression, slurred speech, shaking) posed particular difficulties with regards to social anxiety. Attempts to minimise the visibility of symptoms to others (e.g. by "flipping over" speech problems, trying to maintain a 'normal' posture) were common, especially in the initial stages of adjustment:

Mr B: ...I want to say something that I just can't start off... I know what I want to say but I just can't kick start it you know. I just can't get it going... it doesn't happen very often but if I'm talking to somebody you know? Can you describe what...

Mrs B: No not really because when it happens we can sort of flip over it can't we?
Mr B: Yeah, between the two of us we flip over it and nobody notices ...

Also problematic were unpredictable symptoms (e.g. freezing). The fear that something may happen (and the perceived lack of control in this) was significant in preventing people from being able to capitalise on 'good' days:

Mr A: ...This freezing, this where you can't move, is a hell of a deterrent from going out. A few weeks ago, for example, we went to lunch with the hospice and that was fine, and the very next day I went with one of my carers to the same place to have lunch and it took me about 20 minutes to get to her car. I just couldn't move. So I haven't been going out much lately.
R: I wonder what it is, when you do freeze when you're out, what it is that you're worried will happen when you freeze?

Mr A: Well it's a bit spectacular I suppose to other people watching. If they do watch. One tries not to make it too obvious but sometimes it is pretty obvious I think... I mean, it's a bit embarrassing for other people isn't it? Or it can be if it's too demonstrative! The fact that you can't move at all is something of a spectacle I'd have thought.

The interaction between emotional states and physical symptomatology also posed challenges. Vicious circles were sometimes created whereby increased emotion felt in relation to everyday events increased the likelihood of an 'absent' symptom occurring thus complicating a 'normal' emotional response. Conversely, the anxiety experienced in response to physical symptoms could cause an exacerbation in those symptoms thereby increasing the original anxiety and sometimes resulting in feelings of panic:

Mr H: when I used to get spasms, I'd have to lay down flat on the couch to try and relieve the shaking... I think the panic comes in then. It makes me worse.

Mrs H: I try and I reassure him sort of thing

R: What sorts of things do you panic...

Mr H: The shakes and fear I'm having a heart attack. I can't breathe properly. I get breathless and you're frightened of it getting worse, of the shaking getting worse...

Mrs H: ...that makes it worse, the tremor worse and everything.

The physical-emotional interaction did, however, create opportunities for increased control over 'unpredictable' symptoms through regulating emotion:

R: You mentioned early on when we were talking, initially you felt a little bit embarrassed when you first went out, when you were shaking, and then now you just say "I've got the shakes" and people ask questions or whatever. But you said that initially you felt embarrassed.

Mr D: Well I think because I'm not so, or not thinking about the shaking, you know. In new company, I probably at the beginning said 'Oh I hope I don't start shaking' so you'll get nervous, so you'll shake... I found that by saying straight away what I've got and, em, a laugh and a joke then I can remain quite calm.

Mrs D: It's out of the way then isn't it?
Conceptualisation of PD in daily life

The relative emphasis placed by each participant on each of the three tasks of adjustment varied. Some people, for example, focused primarily on coping with the treatment demands and symptoms rather than information seeking or resolving identity issues whereas others were more equal in their emphasis. The way individuals conceptualised PD within the context of everyday life was significant in understanding these differences. As described earlier, analysis suggested four patterns of conceptualisation which related to the extent to which the permanence of PD had been accepted: PD as irrelevant, an interruption, something to be integrated into current lifestyle and an intrusion. Each person's location within a pattern of conceptualisation was not stable, however, and participants moved in and out of different patterns at different times during the process of adjustment.

PD as Irrelevant to Daily Life

From this perspective PD was not conceptualised as having any relevance to everyday life beyond the physical experience. This was typically achieved through denial which, although a common initial response to the diagnosis, for a small number of people persisted for significant periods of time. Consistent with previous research (e.g. Parkes, 1997), denial could be understood as a way of coping with the current and anticipated emotional distress. It enabled firm separations to be made between the impaired body and self-identity thus preserving the pre-illness self. Consequently, less emphasis was placed on resolving identity dilemmas or seeking information and adjustment focused primarily on coping with treatment demands and symptoms:

R: Can you tell me about that 3 or 4 months time, what you said is denial time, and explain how it was for you?

Mr F: Em, well I just didn't want to know. I mean you hear about things, you know? I just didn't want to know about it. You know, I was going to have me treatment and that was it, I suppose.

Mrs F: Take the tablets and take no notice

Although the main focus of adjustment was on medication, it is significant that for the two people for whom treatments were initially ineffective, (Mr H and Mr F), the denial period was most prolonged. Paradoxically, it may be that the effectiveness of the medications in relieving symptoms implicitly reinforces the reality of PD making it more difficult to deny:
Mr F: I think what eventually did it, [ending the denial period]... I think I was, seeing I wasn't getting anywhere on the medication I was getting... I was then referred to [consultant] and from then I really haven't looked back.

In a similar way, obtaining information made the diagnosis of PD 'real' and often prompted movement to a different pattern of conceptualisation:

Mrs I: She went and had a look round, one of the nurses, and she found two pieces [of information] and she gave them to me you see. So that's when I woke up to the idea that I had it you know.

**PD as a temporary interruption to life**

When conceptualised as an interruption to life, resumption of 'normal' functioning was believed to be possible through medication and other symptom management techniques. Driven by this belief, initial adjustment focused primarily on developing skills in symptom management (e.g. managing medications, speech and language techniques). Immediate improvements in symptoms reinforced the belief of possible recovery and motivated increased efforts in controlling symptoms along the lines of 'if only I can manage things better then I will recover'. Predictably, a high level of personal control was evidenced by people conceptualising PD in this way. Information relating to advances in medical treatments and stories of people who have 'recovered' was selected to 'fit' with the conceptualisation of PD being something from which one would recover. Threats to identity were kept at bay by seeing any changes in lifestyle and social roles as 'temporary' and therefore not requiring any permanent changes to identity structures; past and future identities were put 'on hold' ready to return once 'better'.

To illustrate the above points, and also how this conceptualisation is vulnerable in view of PD being a progressive illness, Mr B is presented as a case example. Issues of medication and symptom management were very dominant in the interview with Mr and Mrs B who frequently recalled in great detail their development of skill in this area. The interview co-incident, however, with a time when, having experienced further deteriorations in symptoms despite feeling that he had achieved optimum control through symptom management techniques, Mr B's belief that he would 'recover' was threatened:
Mr B: I think that we're just about dead on target [with the medication]. It doesn't get too, too much and it doesn't get too little. So in other words it's the right mixture. I can't see as I can be made any better. If I've got it, I've got it and I don't see how I can be made any better than what I am now.

Mr B's avoidance of confronting identity dilemmas, was illustrated by his response to the researcher's use of the words PD:

Mrs B: ...you've got to the core of it. You've mentioned right out Parkinson's Disease...
Mr B: That's it isn't it?
Mrs B: ...and that's gone home like hitting a nail isn't it? It's better I think when you say PD. Nobody knows what it's about.
Mr B: Secret code
Mrs B: Well that's it isn't it.
R: So you feel that actually me actually saying the words Parkinson's Disease has made it come home.
Mr B: Yeah. Horrible. Sounds horrible doesn't it - Parkinson's Disease. To me it does.
R: What goes through you mind when you hear the words Parkinson's Disease? What images do you get?
Mr B: Oh. All sorts.

Mr B was tearful at times during the interview and at such times would often direct conversation back to issues of medication (possibly reflecting the desire to re-establish some feelings of control). Significant in his distress was having to accept that the changes he had already made in his life were permanent. Having previously believed these to be only temporary, he had been unable to grieve for the losses which he had experienced:

R: You said that the thing that's difficult is sometimes thinking about I won't be able to do that again
Mr B: That's right yeah. I was saying you put to one side things that you know perfectly well - this is what hurts - you know perfectly well that you won't be able to use them again. That hurts more than anything doesn't it?

Mr B's realisation that he was not going to get better (and in fact worse) threatened his previous feelings of personal control which he had derived from 'fine tuning' symptom management techniques. His consequent feelings of helplessness and hopelessness were evidenced in his frequent comments about there "being nothing I can do", the only possibility being to "forget about it" and "to hope for the best". He
frequently asked questions of the researcher about whether she had known any people who had been cured. This reflected his desire to continue conceptualising PD as just an interruption.

PD as something permanent to be integrated into life

From this position, people aimed to find a place for PD in their existing lifestyle:

Mr G: I try and keep myself as normal as possible. Not to try and make the Parkinson's dictate to me... like a normal life. I try not to let Parkinson's you know, to get on top of me, to beat me.

Mrs G: We just want it in the background don't we? We don't want it to be what we're about it. It plays very little part in our life now. We know it's there and we hate it but it's there and, yeah, but you've got to get on with everything else and it's not to be just what you're about at all is it?

Typically, an active search for information was embarked upon and the acquired information translated into meaning for everyday life. Active efforts were made to resolve the identity dilemmas created by the diagnosis. Whilst medication and symptom management were recognised as crucially important and led to beliefs that at least some control over disease progression was possible, expectations of what could be achieved by these were realistic. As with the 'sanguine and engaged' group identified by Dakof and Mendelsohn (1989), perceptions of control were not based solely on medications but also on having a positive attitude to coping with PD:

Mr F: Although I'm taking it, I know it's a progressive disease and I know that I'm not going to get any better but the point is I can slow it down and this is my attitude...

Mrs F: But I think it's being strong willed, you know, that's helped a lot with him.

Mr F: Positive attitude as a I still preach now myself, to the society, or anybody...

PD as an intrusion in daily life

A minority of people reported feeling overwhelmed by the presence of PD in their lives and became immersed in the tasks of adjustment. PD and illness became the primary focus in life:
Mr H: Even though I can't walk far we try to go out every day. You find yourself thinking of sickness and Parkinson's Disease all day so it helps to go out just to take your mind off it for a while.

Conceptualising PD as an intrusion was characterised by passivity and low feelings of personal control. There was a passive pre-occupation with symptoms (rather than active attempts to cope with them) and a heavy reliance on others (e.g. family, friends, health professionals). There was little evidence of independent attempts to develop new identities and threats to established identities were typically resolved by taking on a 'sick role'. The hope for a cure or improved medications was prominent as people believed that this offered the only possibility for improvement. Accordingly, information was often selected to reinforce the belief that a cure was possible. Relying on the hope for a cure prevented people from dealing with the current reality of PD being permanent and in this way was analogous to seeing PD as an interruption in life.

3.1.4 Transition to the Chronic Phase

This phase describes the transition from the 'crisis' to the 'chronic' phase of illness as identified by Rolland (1987). It did not occur at a discrete point in time but gradually, as the dilemmas of the initial adjustment were resolved. Analysis suggested that this transition was characterised by: (i) having found ways of living with continued uncertainty (ii) a reduction in emotional distress and (iii) having found meaning in the diagnosis.

Living with uncertainty

A central feature of PD is it's progressiveness and the limited amount of personal control possible in this. Finding ways of coping with this was key to being able to 'move on'. Coping strategies were highly variable and related to personal coping style, which was influenced by factors such as religious beliefs and previous coping history:

Mr A: I don't worry about things that I can't control... Yes, throughout my career I've always tried not to be, not to worry about things I couldn't control and so it is now. I don't worry about things that seem to be inevitable. In a big job, in a big organisation, there's plenty to worry about where you can control, or have a choice of controls, without worrying about those things that you can't influence anyway. I think that's how it is.
Consistent with previous research (Habermann, 1996), one strategy reported by all people interviewed was narrowing the attentional focus to the present day by taking a day at a time. The slow progression of PD was especially significant in people being able to accommodate and flow with the experience of illness. This is consistent with the suggestion that the rate of disease progression may be significant in adjustment (Brown and Jahanshahi, 1995):

Mrs G: ...But, if we just got working through it and the progression is just at a pace like that...
Mr G: minimal, minimal
Mrs G: ...then we're coping aren't we? Then we're going with it then. We're not thinking 'oh it's fine for now'. We know it's changing, we can see it ourselves, but because it's a gradual process it makes it, you get time to get used to it. Yeah? If you think ahead, you think well that's going to happen then you'd probably go bonkers the pair of us, but, em, it's gradual and you just take it a day at a time I think.

Although progression was slow, the cumulating deteriorations in symptoms ultimately required changes in medication. Additionally, there were also times of more marked deteriorations in symptoms. Such 'transition points' in the illness course were often associated with a re-surfacing of dilemmas and emotions which had previously been 'resolved' during the initial adjustment. This suggests a cyclical relationship between the chronic phase of illness and initial adjustment. In the following extract, for example, Mr G describes how increases in his medication challenged his feelings of control and required him to 're-resolve' dilemmas about his future identity before being able to 'move on' again:

Mr G: ...since the first day I was diagnosed, the tablets have gone up...
R: What sorts of thoughts does that make you have when you're tablets go up?
Mr G: Well I feel that it's failed me, that it's catching me up, you know. I don't, I don't want to be as bad as some that we see at that meeting. Some of the ladies, the lady who was very shaky.

Reduction in emotional distress

Consistent with the interpretation that some level of emotional distress is understandable and appropriate to being diagnosed with PD and reflects an underlying 'grieving' process, the transition to the chronic phase of illness was characterised by a reduction in this distress:
R: And so afterwards you felt - you used the words depressed - when you first found out. How long did that feeling last for?

Mr C: Like a grief you're talking about like?

Mrs C: Yes, for the first few weeks and then it blended back into, into... you accept it and then you just go back into routine, back again don't you? Nothing else happened. The tablets improved me in a few weeks. I was no worse, I was better and then I gradually came to accept.

The re-occurrence of feelings of grief at transition points in the illness course, however, lends support to the relevance of the concept of chronic sorrow to understanding the emotional experience of PD (Lindgren, 1996). People still experienced 'good' days and 'bad' days with regards to emotional distress but this was less severe and more short-lived:

Mrs F: I think there's times, times when you're a bit low and you think how much worse you can get; how we're going to cope.

Mr F: But I don't really think so much of that now.

Mrs F: I was just going to say, not as much as you used to.

Finding meaning in the diagnosis

A key feature of the transition to the chronic phase of illness was having found personal meaning in the diagnosis of PD through the resolution of identity dilemmas; that is, resolving the question of 'who am I now?'. This required the person to move away from the position of 'why me?' to accepting the reality of PD and finding a new way of living with this through the continuation and development of new and existing identities. Although the diagnosis of PD was unwanted, given that this had happened, it was important for people to feel that their own experience could be used to help others. Helping others included taking part in research projects (including the current one), promoting PD in the wider community (e.g. delivering leaflets to doctors surgeries, organising collection boxes) and supporting the PDS either financially or by being actively involved:

Mrs D: We don't make it the be all and end all of our lives. It's a thing that's happened. We're hopefully getting on with it. But, if we can be of any help to other people in any little way we try don't we?

Mr D: Yes... you know I've asked in the local shop would they have a collection box there.
3.2 Factors Mediating Participants' Individual Experience of PD

Although the model outlined in figure 2 can already account for individual differences (e.g., due to differences in the nature of social roles, differences in perceptions of societal beliefs etc.), analysis suggested five categories of factors to be particularly important in understanding individual experience: (i) age-related issues (ii) professional support (iii) family and social context (iv) past and current health status (v) the context of daily life. Together these provide the context within which adjustment can be understood.

3.2.1 Age-related Issues

Three broad categories of age-related factors were identified as significant in shaping the individual experience of PD: (i) differences in life circumstances (ii) the association between age and ill health (iii) the closer proximity to death with increasing age.

Differences in Life Circumstances

The generally more flexible lifestyle of older people, created by them being more likely to be retired and not having children living at home, enabled treatment demands and lifestyle changes associated with PD to be more easily accommodated:

Mr A: Life is a struggle in that there is so much more to do and everything takes so much longer which it does getting older anyway. But, em, to match that, however, you've got more time because you're retired. I mean I couldn't chair meetings at 8 o'clock in central London now even if I was down there a fortnight before. One knows that and it's a process of ageing.

Retirement status was particularly influential and was not always dependant on chronological age. One person (Mr H) had had to give up his job running his own garage business as a consequence of PD. Another person (Mr B), who also ran his own business, had had to significantly reduce his working hours. All other participants were retired at the time of diagnosis with the exception of Mr G who, as already seen, had been able to continue working, although in a different job. Consistent with previous research (e.g. Habermann, 1996), the potential, or actual, loss of work and associated roles (e.g. boss, provider) was a major source of threat to self-identity. Whereas people who had been retired for several years had already developed new roles and identities to compensate for the loss of work role, when retirement was enforced, as well as there being a sense of injustice, the development of new roles and identities was complicated
by the physical limitations of PD. The threat that the loss of work role posed to identity was particularly significant for both Mr H and Mr B for whom work had been a primary feature of their life:

Mrs H: He used to have a garage and cars and that has been his life; it was his life...

Mr H: I had a garage and a few people working for me. I rented the place out to one of the staff and then a few months ago now I sold it. I didn't like selling it... I thought I might go back, you know. In the garage I'm so busy and just never sit. Somebody wanted you all the time and different things and when you came home. When you stop working, nobody seems to want you then you know? Not nobody wants you then but you could see the difference. Everything stops. It's a jump from being active and doing nothing. When I read, I read for a while and the papers start to shake and I give in.

Being able to continue work was of prime importance in achieving continuity of self-identity and maintaining self-esteem:

Mr G: ...well they tell me why do you go to work? You can go on the sick. You can get as much money on the sick. I say going to work is part of my therapy

Mrs G: yeah, self-esteem really

Mr G: It's too easy to sit in a chair and watch the television all day long, day after day. I prefer to go to work because it's part of my therapy.

Continuing work was not without it's difficulties, however. For Mr G, the physical exhaustion of working sometimes impacted upon other aspects of his life and he reported having days when he "would love to retire" and find other ways of fulfilling his need to be productive. At these times, his motivation to continue work arose from financial needs.

The association between age, PD and ill health

Regardless of chronological age, the diagnosis of PD was generally experienced as a shock, but the implicit expectation of ill health with age ultimately provided chronologically older people with increased opportunities to develop strategies for coping, especially with the perceived injustice of having PD (why me?). A frequent coping strategy in this regard was using downward social comparisons ('at least I've got it when I'm older'):
Mrs D: I don't think you say that it doesn't matter that your older that you've got it. No one wants to be ill at any age but I think what you're saying is that you're glad it's come at this time of life as opposed to when you're younger... Because we've met quite a few of the young ones.

Mr D: yeah

Mrs D: It doesn't seem fair. But life isn't fair, is it, in a lot of ways but...

Mr D: And you get some where one poor lady goes and her husband has to give her an injection.

Mrs D: Immediately

Mr D: More or less immediately, yeah

Mrs D: Her whole body. You know that must be dreadful for her.

Mr D: She's years younger than me. If I've got to face that I'm glad it's going to be later rather than sooner.

Although older participants still felt the 'loss' of future plans, they were more likely to report feeling that they had "had a good life" and done the things they wanted:

Mr F: ...we did so much whilst we were young; I mean we travelled around Europe, the Middle East, Cyprus and the UK.

Mrs F: We did it all then.

Mr F: We did it all then, so really we don't want really to have a high life...

R: You think that you've got out life the things you wanted to get out.

Mrs F: Exactly

Mr F: This is it. We're quite content I think really to retire...

The similarities between the biological process of ageing and the physical symptomatology of PD also had implications for adjustment. The 'artificial' physical ageing created by PD was often discrepant with subjective feelings, and the challenge was to maintain a subjective feeling of being young despite having the physical 'appearance' of an older person:

Mr H: ...I don't feel, I don't know, I don't feel old. I think if I didn't have this I'd be very active. I'd walk fast and things I used to do in a hurry... I see people in their 80's walking down town here, gosh, aren't they lucky, you know? I'm not jealous or anything, why can't I? I feel like that.

This posed particular difficulties when chronological age was discrepant with societal perceptions of 'old age' especially as the PD clinic was located within older adult services:
Mrs G: The first time we came here [the clinic], like there was...
Mr G: A lot of older people
Mrs G: ...and like we sat here and everybody was looking as if to say 'Oh these 2 have probably come in the wrong place' or something.

Conversely, rather than try to reject an identity as an older person, some people chose to identify with it. The similarities between PD and ageing provided the opportunity for deteriorations in symptoms to be interpreted as being due to age rather than the progression of PD. In this way symptoms were perceived as more 'normal' and an identity as an old person was perceived as preferable to the more stigmatising identity of PD:

Mrs C: ...And then you see with age as well you're deteriorating anyway as you're getting older. Everything is going slower isn't it?... I do everything. I'm slower but then again I would be slower if I was old wouldn't I? It would come with that as well wouldn't it?
R: So it's what you'd be expecting anyway?
Mrs C: That's right; that's right... No, I really think to myself 'well it must be old age'. And I think well it comes to everybody that doesn't it? I don't feel quite as - a freak.

Closer proximity to death with age

The closer proximity to a 'natural' death when chronologically older provided a significant source of coping, particularly in relation to concerns about the future. Knowing that the disease would have less time to progress to a stage where medications were no longer effective, and where disability and dependency were realities, provided the basis for these coping strategies:

Mr A: As I said at the age of 75 I'm going to die of something in the next 10 or 15 years you know.

Mr D: I think, well, you know, I decided, well I've got it, I'm glad I've got it later than earlier seeing how it affected younger people. 'Cause you know if they were on drugs, then they'd have to stay on drugs a hell of a sight longer than me.
Mrs D: And they get stronger, don't they the drugs?
3.2.2 Professional Support

Perceptions of professional support were a critical influence on participants' experience of PD. Evidence for this came from comparing experiences of different sources of care (i.e. GP's, a specialist clinic and neurology consultant) both within and between individuals. Three key issues emerged from the analysis: (i) provision of a chronic versus acute model of care (ii) attention to the human significance of PD and (iii) accessing specialist PD services. Although inter-linked (e.g. a chronic model of care being more likely to attend to the human significance), each of these is considered separately.

Chronic versus acute models of care

This referred to the need to provide care which was sensitive to the long-term nature of PD and thus aimed to promote self-management of PD rather than providing a 'cure'. This was essential in bridging the gap between management of PD in a hospital setting and management in everyday life. A philosophy of joint working, which was sensitive to participants' psychological as well as medical needs, was a core feature of the care provided and has been identified as an important component of service models for people with chronic illnesses (e.g. Clark, Nothwehr, Gong et al., 1995). Involving people in their own treatment had important positive implications with regards to feelings of personal control and emotional well-being. People needed to believe, however, that services would also 'hold their side of the bargain' by being honest and providing a good standard of care. Having confidence in services was crucial to participants being able to develop confidence in their own abilities:

Mrs D: ...he [the consultant] tells you from the word go, there is no known cure. He tells you that straight away. There is no known cure. And there isn't for Parkinson's. Then he says but we can help. And then, in his words, we work together... and that's what it is; it's a joint effort... And then you think well his power, [consultant's] power, that he can do, you know between the two of you, he will do won't he?

Mr D: Yeah

Mrs D: If he can find any way that's going to be more beneficial to you he will find it and he will do it. And that also helps Robert then doesn't it?

Mr D: Oh yeah

Other important components of a chronic model of care were that it should be continuous (i.e. regular appointments provided with the same staff), accessible (i.e. being able to contact services between appointments) and multi-disciplinary. Regular
'check-up' appointments, during which medical and psychological status could be monitored and any necessary changes to treatment made, provided people with important feedback relating to the progression of PD. Having open access to services between appointments was of critical importance and had important psychological meaning. Knowing that "there's somebody there" provided a secure base for people to feel confident in managing PD on a day to day basis at home:

**Mr F:** You need to know that there's somebody there. This is the thing isn't it? Yeah. you need to know that somebody's there.

**Mrs F:** I mean, em, I should think that everybody who's under [consultant] knows that if they have a problem all's they've got to do is pick the phone up and talk to [nursing sister]. And their problems, if she can't sort it out, she'll refer...

**Mr F:** to somebody that can

**Mrs F:** ...And I think it's knowing that that's there, that, you know, as a safety net for you, I think it helps.

The psychological importance of having an accessible service was supported by comparing the experience of Mr H, who was receiving care from a different service to the other participants:

**Mrs H:** Able to have a Parkinson's nurse would be a useful thing... to have someone to, even if they didn't call regularly, just that there's somebody local sort of thing so they you could sort of phone up and ask. Like the district nurse had been coming for us now...

**Mr H:** She doesn't know a lot about PD...

**Mrs H:** ...no, but the feeling that there is something you can, when you badly need them, it's the feeling that there is... to know that there is backing and somebody to talk to... You feel you're all alone somehow.

**Attention to the human significance of PD**

Consistent with previous research (e.g. Pinder, 1995), It was important for people to feel that health care professionals were sensitive to the emotional experience of PD, especially at diagnosis, and viewed them as people rather than purely in terms of their disease. Feeling cared for in a personal way which respected individuality provided important messages with regards to self-identity, for example, 'you are still important and wanted (despite having PD)'; 'you are still individual'.
...I think it was a matter of, em, the whole attitude I got from here, that changed me as well.

R: Can you describe that attitude?

Mr F: Yeah, the attitude that...

Mrs F: They were very positive weren't they?

Mr F: Yeah and the things that he give me to do and everything else or whatever, em, to get the level that you are so they can probably give the correct diagnosis and see how you're getting on, I think. I don't know, I think it was just the general attitude; just the general attitude.

Mrs F: It was just the friendliness.

Mr F: Well the care...

Mrs F: Yes, and the care that they were showing. The indiv... you seemed as though you were getting individual attention. Obviously you weren't you know.

Mr F: Well we were, yes, essentially

Mrs F: Well you were yes but it seemed so personal as though they were concerned just about you.

Mr F: Where if you go to your GP or whatever it's getting you in for 10 minutes, 5 or 10 minutes and then you're out again as it were you know. So, you really didn't really have time to, well time to bother. Where you'd be here, you'd probably be here for 2 or 3 hours you know?... I think that's what changed. And I thought that all that would sort of give you a positive attitude. At least somebody else wants to know. Em.

Mrs F: Somebody realises you've got Parkinson's...

Mr F: yeah

Mrs F: You can talk about it

Feelings of being cared for and valued were related to the model of care provided (e.g. having time to listen and being accessible), but the individual personalities and [positive] attitudes of the professionals involved were also significant:

Mrs D: And I think his [the consultant] whole attitude, because to me, he's got, oh I don't know, if you can have a perfect attitude, he's got the right attitude because he gives you a feeling, if you like, of well being although you've got Parkinson's. Doesn't he? Every time we go you feel better once you've seen him...

Mr D: Oh yes

Mrs D: No matter what, you know, happens. Just chatting to him you feel...
Examples of individuality being neglected were rare but included occasions when other health problems were discounted (being attributed instead to PD), lack of privacy (e.g. when completing physiotherapy assessments) and, more notably for Mr and Mrs G, when age differences were ignored (largely as a consequence of services being located within the elderly sector):

Mrs G: There was the incident, I think I told you on the phone, where the lady from here phoned up, 'Oh does your husband need a wheelchair or can he walk?' I said do you actually know how old my husband is or anything about him?; 'what do you mean?', I said that he works full time; 'Oh I'm sorry I just presumed'. You know, this is like everybody's individual and that's how you want to be treated not like one of the mass...

Mr G: No, I don't want that

Mrs G: They assumed that he was 80 as well... But those are the things that are important to you. Those are the things that they keep your dignity don't they? They're the things that you're only herded with the rest of them; this is him; this is Carl and you know?

Accessing a specialist service

Whilst accessing a specialist service was considered important by most participants, what constituted a 'specialist' service was less easy to define. Perceptions of a service as 'specialist', were based not only on there being a medical consultant who specialised in PD, but also on participants' (positive) experiences of care. It is significant that only Mr H, who's experience of care had been less positive, did not spontaneously comment on the importance of being referred to a 'specialist'. Perceptions of a service as specialist were therefore embedded in personal experience:

Mrs D: Because the GP, after all, can't know about everything. He recognised it but he did need to see somebody like Dr [consultant]...

R: What is it about having somebody like Dr [consultant] that makes you feel happier about the treatment you're getting?

Mr D: He's a specialist isn't he?

Mrs D: Not so much a specialist but he is very, very keen and he's got time, you never feel rushed. He listens, and cares.

Mr D: Yes

Mrs D: He does care. He's a very giving man isn't he?

Mr D: Yes

Mrs D: And he sort of understands your mood and how you're feeling and he knows why.
Mr D: I think he felt a bit sorry to say I confirm the diagnosis.
Mrs D: Yes. He said, I don't like having to say but yes, it is true. But, we'll get on
with it. Didn't he?

3.2.3 Family and Social Context

Perceptions of family and social support were important in mediating
individual experience but it was impossible to make broad generalised conclusions as
to the benefit, or otherwise, of having 'social support' as has been done in previous
studies (e.g. Brod, Mendelsohn & Roberts, 1998). Making broad conclusions, ignores
the complex interactions between the individual with PD and the social and family
environment which shaped the individual experience of participants in the current
study.

Family Context

The family, in particular the spouse or partner, was the primary source of both
practical and emotional support. The universally perceived benefits of this support,
especially by those less physically able, was reflected in participants' descriptions of
their own experience but also in their perceived disadvantage of people "on their own".
Although important, family support created a number of dilemmas for the person with
PD (who had to adjust to needing support), the carer (who had to adjust to providing
this support) and in their relationship together.

Changes in family relationships

The physical and emotional changes on the part of the person with PD meant
that roles and relationships within the family, especially the marital relationship, had to
be renegotiated and reinterpreted. Established roles such as husband and wife had to be
redefined (to a greater or lesser extent) and new roles such as 'carer' and 'cared for'
assimilated into identity:

Mrs F: ...he's an old fashioned sort of man; he's got to be in control. So, I can be
stubborn but I can also be intentionally stupid and I give in and I give in to
him just so that he can feel that he is still in control. Because, you know, I
would say, em, 75% of him's still in control. I mean he deals with all the
financial side...
Mr F: I've always done that
Mrs F: ...he's always done it so he carries on doing it...
B: So it's something that you've always done and are able to maintain?
Mr F: Yeah, maintaining it, yeah

R: Are there any areas where you haven't been able to do that?

Mr F: Em, I've not been able to do a lot of the, as we say, decoration

Mrs F: Or general maintenance things; he can't do that.

Mr F: Margaret could do a lot of those things

Mrs F: But you won't accept it

Mr F: ...I've been used to doing it, that's your job as it were, that's part of your role in

the family... You rely a lot on the carer although I try not to.

Mrs F: And wouldn't like to admit that he does...

Mr F: Yeah

Mrs F: ...because he is such a stubborn...

Mr F: Stubborn, yeah, I'm a stubborn person, if you like...

A significant influence on couples' relationships was the extent to which the physical ability of one partner was discrepant with the other. Couples in which both partners were of a greater chronological age tended to be more matched in physical ability due to the natural 'slowing down' with age regardless of PD. Also, there was a greater likelihood of both partners suffering from ill health. When both husband and wife were of a lower chronological age, however, the discrepancy in physical ability was often more noticeable:

Mr G: Come the weekend I like to rest because some days at work it's hard work and at the end of the day I'm exhausted.

Mrs G: See, now this is the kind of thing that gets you into difficulty because come the weekend Carl wants to rest. Now come the weekend I want to go out because I've been in work all week. But we compromise. I only mean like go out shopping, or we go to [place name] for a walk or something, but not go out at night.

Issues of Dependency

The recognised need for some level of practical and emotional support created a number of dilemmas relating to dependency. Some participants reported feeling guilty at being a burden to their partner and retaining at least some level of independence was important for maintaining self-esteem. Consistent with Marr (1991), the desire to maintain independence motivated coping efforts and participants expressed worries about becoming dependant in the future:
Mrs I: ...If I wasn't able to look after myself, bathroom wise or any otherwise, they wouldn't want, you know, having me all the time; I wouldn't want to be with them [her children] all the time because I'd be hindering them doing what they want to do.

The type of help most welcomed involved allowing people to do things at their own pace even if it took longer. This frequently conflicted, however, with the partner's desire to 'care'. To minimise family stress either the person with PD or their partner would 'give in':

Mrs G: I used to find it very frustrating because he was so slow, I thought God, and I'm exactly the opposite. Oh, I do it myself, and I couldn't because I had to leave it. Em, he would struggle to pick things up and I said well I'll do it for you; 'no, I'll do it myself; if I stay here 10 hours I will do this myself'. But it's so frustrating isn't it? When you're with somebody, you'd think well I could do that in 2 minutes...
Mr G: I've got to do it for my own self to prove that I can still do it.

Having to rely on emotional and/or physical care also created (increased) anxiety for some participants about 'losing' their partner through death, illness, or breakdown of the relationship:

Mr E: Sometimes, she'll break down and cry with me and say I don't know what I'm going to do if anything happens to you. And I say to her look, it's useless thinking them things, you know, get 'em out of your mind like. Because one day, I says, it's going to happen to us. Just live for today, you know. And then she's all right then.
Mrs E: Yeah, I'm all right then.
Mr E: You know, once I've reassured her she's OK like. But often she comes, if anything happens to you and I don't know if I could live.
Mrs E: I wouldn't do. I wouldn't live on me own if anything happened to Thomas.

When a high level of emotional or physical care was required, or when carers themselves were in ill health, the need for relatives to have a break from, or support in, caring was recognised as important. This was often achieved through relying on family and friends but more formal services (e.g. caring agencies) were also used:
Mr A: If Anne is out, I tend to have a carer if she's out. Not if she's out for a couple of hours shopping but if she goes to London for a few days I stay here and a carer comes here... it's important to get her off sometimes because I should be greatly disadvantaged if anything happened there.

**Responding to emotional needs: the need for control in caring**

Carers were generally more comfortable providing support in which they were able to "do something". This met their own need to feel in control and reduced feelings of helplessness:

Mrs H: Well it's frustration really and not knowing what to do. You feel so helpless sometimes... It's the, em, standing and watching him sort of come to suffer... it's not like I can give him a tablet and think oh that's going to work in half an hour or quarter of an hour or whatever.

Emotional support was often offered in a 'practical' way, for example, motivating people to do things such as go out or engage in activities or symptom control techniques:

Mrs C: He's [her husband] a big help for me... because he likes going... because I'm inclined to be one of those people that would sit. I would give in, you know what I mean, I'd sit. I wouldn't bother going out but he makes me go so... and when I've gone I enjoy it and I say well I'm glad I went.

Mr C: ...If you're going to give into it well it's going to take over your life isn't it? It's going to ruin your life isn't it?

Whilst 'practical' emotional support was extremely important in minimising the secondary impact on life of emotional factors such as depression or anxiety, this was less helpful in facilitating 'grieving' for losses which had been experienced. Well-meaning attempts to alleviate emotional distress sometimes 'blocked' the expression of what is an understandable, and possibly necessary, emotional response to a stressful event:

Mrs E: Well Thomas is trying his best with me. If I start crying he starts fooling around or he'll say to me, you must try not to cry, you know, it's hard. Because now, I feel as if I want to cry now. But for no reason. You know? I said 'why me?'; why have I had this? You know, why has it picked on me? Don't I Thomas?
Mr E: Because there's nothing I can say. Like I've got this, em, this colostomy and I
live with it and I try and tell her the same, you've got to live with it. You can't
do anything about it.

In some cases, the comments of both the carer and person with PD suggested
that they believed emotional distress to be a sign of poor coping. In the interview with
Mr and Mrs B, for example, Mrs B's frequent assertions that "you've got to be willing"
or "it's the way you look at it" (especially when Mr B was upset during the interview),
although well-meaning, implicitly suggested that difficulties in "accepting it" (as
evidenced by emotional distress) were the result of poor coping. Mr B's desire to be
seen as coping well made it harder for him to share his emotional distress with Mrs B.
This reluctance also related to him not wanting to increase the burden of care on Mrs
B, and possibly risk losing her support:

Mr B: Actually what I heard about the disease and what I've found out about the
disease I'm very lucky. Very lucky aren't I?
Mrs B: Well you're willing. You've got to accept it and he has accepted haven't you?
Mr B: Yes. Oh aye. (Mr B becomes tearful)
Mrs B: It upset him but em... don't get emotional with it it's just one of those things.
As you just said you're a lucky lad. But em...
Mr B: This is when the trouble comes in when I have something like this. Starts it off
you see?
R: Do you find yourself getting tearful sometimes?
Mr B: Yeah but as I just said right know I think I'm very very lucky. If I've got the
disease what they say I've got, what has happened to me, I've been very lucky
but I've got help. I've got someone looking after me and seeing that I take my
tablets. Go back to the tablets Doris. [Sense that Mr B directing attention
away from his distress]

Several participants reported how acquiring information about the emotional
experience of PD had helped them to normalise the emotional experience of PD:

Mrs C: ...and then the depression comes - mind you it is part and parcel of
Parkinson's is depression isn't it?

Mrs F and Mrs D also reported how this information enabled them to respond
in more appropriate ways to their husbands' distress and also alleviated feelings of
guilt they reported having arisen from the belief that they had been responsible for this
in some way:
Mrs D: ...well I read everything I could about it. I even read a book about a man who's since died... and reading about him and it explained the frustration inside the person suffering with Parkinson's, which I think a lot of people you don't think about that it's frustrating for the person who's got Parkinson's, but I know that it is. Because through reading different things, you pick up; I mean we've been married for 44 years anyway, but I picked up different things as to how Robert had been, his attitude at times and you can relate, because you've read certain things you think, yes, well I can understand why.

Social Context

Non-family members were an important source of emotional and practical support for both the person with PD and their partners. This support helped to minimise the impact of both emotional and physical factors on daily life and enabled people to continue in established social roles as well as to develop new roles. Continuing to involve people in social activities and events provided important messages with regards to still being 'acceptable':

Mr G: Going out with the lads or going to the football and things like that. That helps
Mrs G: yeah, I think it makes you... you're still socially acceptable if you're part of something aren't you? It's like nothing changed. We're going out, you're coming, we accept you whatever this problem is. It makes no difference, you're still Carl, you're coming. You know, so that's what you need isn't it? You don't need somebody saying 'Oh God he's dead quiet' or 'he's dead miserable, you don't want to be taking him'... but no I think that having support is very, very important

Mr G: Oh definitely

3.2.4 Current and Past Health Status

The presence of previous and/or concurrent health problems shaped individual experience in a variety of ways depending on the nature of the other health problems, the extent of their impact on everyday life, the nature of expectations and coping strategies developed in relation to these other illnesses and the temporal relation of these to the diagnosis of PD. The differential impact of these variables on adjustment to PD is illustrated by comparing three cases, Mr B, Mr D and Mr A.

Mr B had suffered from bowel cancer 27 years ago resulting in him having a colostomy. His success in coping with the colostomy was significant in shaping both his, and Mrs B's, conceptualisation of PD as being something which was just an
interruption in life; 'I recovered from that so I will recover from this'. The ineffectiveness of this conceptualisation in relation to PD lay in the fact that PD is progressive rather than static as with the colostomy:

**Mr B:** It's [PD] not stopped me from doing anything.

**Mrs B:** No it's not stopped him at all

**Mr B:** I mean it's the same with all my other complaints I've got, it's never stopped me... I supposed I worked for 35, 40 years and never had a day off so I just carry on doing things now as I want to...

The importance of considering the temporal relation of other health problems to the diagnosis PD is illustrated by comparing Mr B's experience to that of Mr A. Whereas Mr B had experienced a long period of stability in coping with his colostomy, for Mr A, bowel cancer had been diagnosed only 3 years earlier. He had subsequently also been diagnosed with osteoporosis. Having already gone through an initial adjustment to 'being ill' (as a result of the cancer and osteoporosis), the diagnosis of PD was 'absorbed' into a general process of adjustment to ill health:

**Mr A:** It didn't seem to have any impact. I just absorbed it. I think, you know, by that time, I'd been through quite a bit and never been ill before as far as I can remember, hardly ever off work. If I was off work the occasional day then the news used to spread through the organisation like wild fire.

As commented further by Mrs A:

**Mrs A:** But I think the interesting thing yesterday was, talking to other people who had been very healthy before they were told that they had PD, you know to talk to them about their reactions which is so diff... I mean John was a sort of continuum of previous things that had been the matter with him. First of all the colostomy and then the osteoporosis and then the Parkinson's. So when there is a continuum, there isn't this sudden jolt of 'God, I've got a terminal illness'. It's just well, you know, well that's just one of those things... in as much as you've already adjusted to the fact that you're an invalid you see.

Comparing Mr A and Mr B's experience to that of Mr D provides further information relating to the importance of the temporal relation of co-morbid health problems. Mr D had suffered from TB arthritis since childhood and although this had remained stable for many years, around the time when PD was diagnosed, it had deteriorated. The combined effect of these health problems was perceived by Mrs D as significant in her husband's depression shortly after diagnosis:
R: ...what do you think was behind that period of feeling depressed?

Mrs D: To me it seemed as though you felt, you did feel so rotten about yourself, and I think he thought I've got enough to cope with because his leg, his hip, was getting worse and that's never going to get any better, nothing else can be done and I think it suddenly hit him, he'd been told he'd got Parkinson's as well. He'd retired, we'd planned to do things and I think he suddenly thought I'm not going to be able to do anything now. And he did give up didn't you?

Mr D: Yeah

People suffering from multiple health problems created a hierarchy of illnesses according to the perceived impact of each condition on everyday life. For Mr B, PD was at the top of this hierarchy whereas for both Mr A and Mr D, PD was of lesser concern than their other health conditions:

Mrs D: I think if you hadn't got the problem with your hip or your leg...

Mr D: it wouldn't bother me one iota.

Mrs D: Parkinson's itself, on it's own, at this stage, wouldn't bother him.

In the pre-diagnosis phase, the hierarchy of health problems explained why Mr A was not unduly concerned about receiving conflicting diagnoses; the symptoms which he suspected to be indicative of PD were of lesser concern than his other health problems at the time:

Mr A: I mean the osteoporosis, the incurable, that is not death but it's very, very unpleasant and very hard to live with, very hard to do things. Whereas the Parkinson seemed a longer term thing really. The finality of the thing was further ahead than the immediate pain and the crippling effect of osteoporosis. That's the best I can explain it.

In the initial adjustment phase, PD was only relevant to the extent that it interacted with these other, more troubling, health problems to produce a greater impact on lifestyle and coping with treatment demands:

Mr A: Really, with the coping with the colostomy, I am, I'm sure, at a grave disadvantage compared with most people you see, in that any trouble with the colostomy involves the osteoporosis and can involve the Parkinson's as well. I mean to be in that shower room in the middle of the night, or even the middle of the day because you can't get help from somebody, that is excruciating. The pain in the back brought on immediately by the tension and
the shaking as well, getting the pouch off and replacing it is pretty horrendous.

3.2.5 The Context of Daily Life

Coping with PD occurred in the context of daily life in which people experienced everyday stresses as well as more significant life events. These were both positive (e.g. children getting married) and negative (e.g. death of family members). The interaction of PD symptomatology and emotional states meant that symptoms often deteriorated during times of high emotional stress sometimes requiring increased medication:

Mr F: ...my brother in law died. He had a melanoma. He died and within a couple of months my medication had doubled.

Of longer-term significance, however, was having to adjust to the changes in the social environment following an event such as bereavement or children leaving home. This was clearly expressed by Mr and Mrs G who had suffered several significant bereavements around the time of diagnosis and subsequently:

Mr G: Because we've lost everybody around us... we've lost my parents, we've lost Karen's parents...

Mrs G: ...everybody around us who would have been the main support have gone, you know... it was just like a series of one thing after another. It was like... it was just like on this thing and you couldn't get off, it was horrendous.

Mr G: Once my mum died my father was in a house, a flat, by himself and I used to stay overnight. And I miss that now, even now, I miss the nights I used to stay with him overnight.

Mrs G: Well we used to think that worked out quite well because it used to be company for Carl's dad...

Mr G: A release for Karen's role

Mrs G: It was a break for Carl and it was a break for me...

3.3 Summary of Findings

This study has moved beyond existing descriptive accounts of people's experiences of PD (e.g. Habermann, 1996; Marr, 1991) to suggest a theoretical model which explains the processes which they use to seek, and psychologically adjust to, the diagnosis of this illness. This model was summarised diagrammatically in figure 2 (on page 26) and the factors shown to mediate this summarised in figure 3 (on page 27).
The findings are now summarised and discussed in relation to the original research questions.

(1) **What are the processes by which people decide to seek a diagnosis of PD?**

The pre-diagnosis phase comprised of 4 stages: noticing and discounting or rationalising; suspecting; deciding to seek medical help and searching for a medical diagnosis. These are summarised in table 2.

**Table 2: Summary of the stages comprising the pre-diagnosis phase of adjustment**

<table>
<thead>
<tr>
<th>Stages</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noticing and discounting or</td>
<td>Gradual awareness of &quot;something being different&quot;. Early changes were</td>
</tr>
<tr>
<td>rationalising</td>
<td>only recognised in retrospect. Once recognised, 'symptoms' were</td>
</tr>
<tr>
<td></td>
<td>discounted or rationalised as being due to non-serious causes.</td>
</tr>
<tr>
<td>Suspecting</td>
<td>The realisation that something more serious was involved.</td>
</tr>
<tr>
<td>Deciding to seek medical help</td>
<td>Weighing up the emotional costs and benefits of seeking medical help.</td>
</tr>
<tr>
<td>Searching for a medical diagnosis</td>
<td>The search for an 'official' diagnosis once the decision to seek medical help has been made. Difficulties in receiving a diagnosis potentially led to deteriorations in physical and emotional well-being.</td>
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</table>

The main theme of the pre-diagnosis phase was that of treatment delay, initially due to the 'symptoms' not being recognised as a sign of illness (i.e. discounting or rationalising) and, once recognised as a sign of potential illness (i.e. suspecting), due to anxiety about what may emerge if medical help was sought. The final reason for treatment delay was difficulties in obtaining a confirmed medical diagnosis once the 'search' had begun.
(2) **What are the processes which people use in their adjustment to PD?**

The process of initial adjustment to the diagnosis consisted of 3, interlinked, tasks: seeking information, resolving identity dilemmas and coping with symptoms and treatment demands. Each task was aimed at reducing uncertainty, re-establishing a feeling of control and alleviating the emotional response to the diagnosis. These tasks are summarised in table 3.

**Table 3: Summary of the tasks characterising the initial adjustment phase**

<table>
<thead>
<tr>
<th>Table 3: Summary of the tasks of initial adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information Seeking</strong></td>
</tr>
<tr>
<td>Weighing up the emotional costs and benefits of seeking information. Four patterns of responding to this dilemma were identified:</td>
</tr>
<tr>
<td>• active seeking</td>
</tr>
<tr>
<td>• selective seeking</td>
</tr>
<tr>
<td>• active avoidance</td>
</tr>
<tr>
<td>• passive avoidance</td>
</tr>
<tr>
<td><strong>Resolving Identity Dilemmas</strong></td>
</tr>
<tr>
<td>Finding meaning in the diagnosis of PD by resolving the question of ‘who am I now?’. Participants sought to maintain continuity and distinctiveness of self and social identity in the present and to find ways of coping with the likelihood of further adjustments being necessary in the future as the disease progresses.</td>
</tr>
<tr>
<td><strong>Coping with Symptoms and Treatment Demands</strong></td>
</tr>
<tr>
<td>Learning skills in medication management and other therapeutic techniques (e.g. speech and language therapy) and integrating these routine into daily life. Developing strategies for coping with physical symptoms that are unresponsive to medication and with the secondary psychological consequences of these (e.g. social anxiety).</td>
</tr>
</tbody>
</table>
The relative emphasis placed on each task of adjustment was determined by a person's conceptualisation of PD in daily life. Four patterns of conceptualisation were identified which reflected differences in the extent to which the reality and permanence of PD had been accepted. These are summarised in table 4.

Table 4: Summary of the different patterns of conceptualisation of PD in daily life.

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irrelevant</td>
<td>PD was conceptualised as having no psychological relevance to daily life. This was typically achieved through denial. Information was avoided and identity dilemmas ignored. The primary focus of adjustment was on coping with medications and treatment demands.</td>
</tr>
<tr>
<td>Interruption</td>
<td>PD was conceptualised as a temporary interruption to daily life and information was 'selected' to fit with the belief that recovery was possible. The primary focus of adjustment was on developing skills in medication and symptom management and high levels of personal control were evidenced. Threats to identity were not seen as permanent and were only therefore resolved in the short term.</td>
</tr>
<tr>
<td>Integration</td>
<td>PD was conceptualised as permanent and something to be integrated into current lifestyle. This group typically engaged in active information seeking and sought to resolve identity dilemmas through developing new and existing roles. Expectations of medications and symptom management techniques were realistic but contributed to people believing that at least some level of personal control was possible. This was enhanced further by believing that some control was also possible through having a positive attitude.</td>
</tr>
<tr>
<td>Intrusion</td>
<td>PD was accepted as permanent but became the primary focus of daily life. A passive approach to adjustment was evidenced which was characterised by a heavy reliance on others, over-reliance on the hope for a cure and low feelings of personal control.</td>
</tr>
</tbody>
</table>
Transition to the chronic phase of illness was a gradual process but was characterised by the person having found personal meaning in the diagnosis, ways to cope with living in conditions of uncertainty and a reduction in emotional distress. The relationship between the initial adjustment and chronic phase was cyclical rather than linear as the 'tasks' of initial adjustment were revisited at transition points during the chronic phase, for example, when there was a deterioration in symptoms.

What is the emotional experience of being diagnosed with PD and how does this interact with the processes in the pre-diagnosis and initial adjustment phases?

Emotional Experience of the Pre-diagnosis Phase

The pre-diagnosis phase was characterised by feelings of anxiety and depression which interacted with the processes of deciding to seek help in a variety of ways. In the initial stage of 'noticing and discounting or rationalising', emotional factors (e.g. tiredness, feelings of depression) were 'noticed' as being different to normal but were also used as rational explanations for the overall experience (e.g. "it's just depression"). The transition to 'suspecting' was characterised by the realisation that the symptoms were "not just depression". Believing that something more serious was wrong led to increasing levels of anxiety and depression which were critical in the process of deciding whether to seek help or not. Fear about what may be wrong was the primary reason why people often delayed seeking medical help. An important finding was the potential for emotional distress to be exacerbated if difficulties in receiving a medical diagnosis were experienced. This contributed to a deterioration in the physical symptoms of PD and emotional factors were sometimes used by health professionals as an explanation for the physical symptoms.

Emotional Experience of Receiving a Diagnosis of PD and Adjusting to this

Receiving a diagnosis of PD was typically a time of intense emotional shock, although feelings of relief were also expressed. Underlying this feeling of shock was "not knowing" what PD was. An important finding, however, was that although participants didn't know for certain what PD was, they held beliefs and assumptions about the illness based on their personal experience of people they have known with PD and their perception of societal beliefs about PD. These were often erroneous (e.g. it's life threatening or contagious) but substantively influenced a person's emotional response to the diagnosis as well as the processes by which they subsequently adjusted to this. The fear about what may emerge from seeking information, especially the fear that one's assumptions will be confirmed, was central to determining a person's
response to this dilemma. Perceptions of societal beliefs about PD also posed threats to social identity and threatened the distinctiveness of self-identity as participants feared that they would acquire an overriding stigmatising identity. The fear of negative evaluation was also a key process underlying the social anxiety and social avoidance frequently experienced in relation to 'visible' and unpredictable symptoms (e.g. shaking, freezing, speech problems).

The emotional experience of PD during the initial adjustment phase was characterised by a process of grieving for losses which had already occurred (e.g. loss of identity, loss of health) and anticipated 'losses' in the future. Grief was characterised by frustration and anger at "not being able to do what I used to" as well as feelings of sadness. Importantly, anticipatory grief was also accompanied by feelings of anxiety about the future related to 'not knowing' what further losses would be experienced. An important feature of grief is that it alleviates over time. Whilst the current findings were consistent with this, they also suggested the relevance of 'chronic sorrow' to PD as feelings of grief re-occurred (at a lesser intensity) at points during the illness course (e.g. at times of medication change). Another important feature of grief is that it is a normal response to any loss. Significantly, participants did not (initially) perceive it in this way and there were examples of some participants feeling uncomfortable with sharing their emotional distress. There was also an important distinction between the 'normal' feelings of grief and clinical depression. The latter was less transient in nature and characterised by feelings of low self worth and an intense lack of motivation and apathy which prevented participants from engaging in activities which would facilitate adjustment.
4.0 DISCUSSION

The current study is unique in its attempt to produce a theoretical model of the processes by which people come to receive, and subsequently adjust to, a diagnosis of PD. The theoretical model which emerged from the analysis was summarised diagrammatically in figure 2 (on page 26). This final chapter aims to consider the theoretical and clinical implications of this model and then to critically evaluate the research methodology.

4.1 Theoretical Implications

A critical feature of the theoretical model developed from the findings is that it is integrative. By this it is meant that, for the model to be comprehensively understood, integration of theories and concepts from research within several different areas of health and general psychology is required. The need for integration highlights the complexity of individual experience and is an important feature of the model. By drawing upon multiple theories, the model provides a broad, contextual framework within which to understand previous research which has been more narrowly focused. It also identifies areas which have been neglected in previous research (e.g. the experience of multiple health problems) but which require further exploration.

The following sections consider the specific areas of health and general psychology which have relevance to the current findings. Research within six broad areas needs to be considered: (1) health behaviour (2) stress and coping (3) loss and grieving (4) identity (5) lifespan (developmental) psychology and (6) systemic psychology. Although interlinked, for ease of presentation, these areas will be considered separately.

4.1.1 Models of Health Behaviour

Concepts from models of health behaviour have most direct relevance to understanding the pre-diagnosis phase. A key theme in this phase was the delay in receiving treatment, initially due to people not recognising the 'symptoms' as a sign of illness (e.g. 'noticing and discounting or rationalising') and then, once recognised as a sign of potential illness (i.e. 'suspecting') because the perceived emotional costs of seeking help outweighed the benefits. These findings are broadly consistent with the treatment delay model (Safer, Tharps, Jackson & Leventhal, 1979). This is summarised in figure 4a.
The treatment delay model identifies three phases of treatment delay: appraisal delay - the time taken to interpret a symptom as a sign of illness; illness delay - the time taken after recognising a sign of illness until deciding that medical care is necessary; and utilisation delay - the time after deciding to seek medical care until actually going to use that health service. Missing from this model, however, is any consideration of how treatment can be delayed due to difficulties in obtaining a confirmed diagnosis once health care services have been utilised. This is reflected in the 'searching for a medical diagnosis' stage in figure 2. A fourth phase, termed 'diagnosis delay' could therefore usefully be added to Safer et al's model. An appropriately amended version of this model is summarised in figure 4b.
Incorporating 'diagnosis delay' into models of health seeking behaviour is of critical importance as the current findings suggest that being 'stuck' in the search for a medical diagnosis can have potentially negative emotional, as well as physical, consequences. Whilst there may be genuine difficulties in diagnosing PD (due to the lack of agreed diagnostic criteria), the way in which health care professionals respond and communicate this to patients is likely to have an important influence on their emotional experience.

The process of weighing up the costs and benefits of utilising health care services is identified as a key process in the utilisation phase of the treatment delay model and is also a key process in the health belief model (Becker & Rosenstock, 1984). The current study also identified this an important process in 'deciding to seek medical help' and suggested the important role of emotional factors in this process. Significantly, emotional factors have not been emphasised in the above models and this has been cited as one reason why the health belief model has been unable to explain seemingly 'irrational' decisions such as failing to seek help even when the perceived risks of not doing so are high (e.g. Sarafino, 1990). One theory which does emphasise the role of emotional factors in decision making is conflict theory (e.g. Janis, 1984). According to conflict theory, emotional stress is experienced as a consequence of decisional conflict and is frequently a source of 'error' in decision making. When serious emotional risks are perceived whatever the course of action taken, conflict theory hypothesises that people will respond with "defensive avoidance". This involves trying to evade the conflict by procrastinating (i.e. delaying seeking help), using intrapsychic processes such as denial ('I'd rather pretend it's not happening') and by shifting the responsibility onto someone else (e.g. waiting for relatives to prompt action). All of these were observed in the current study which supports the relevance of conflict theory to understanding the processes by which people with PD decide to seek medical help.

4.1.2 Theories of Stress and Coping

Stress and coping frameworks provide a useful theoretical basis for exploring the experience of living with PD. Such frameworks emphasise the active role people take in adjusting to the diagnosis of PD and emphasise the resilience many people show. It can be argued, however, that previous studies in PD (e.g. Brod, Mendelsohn & Roberts, 1998; MacCarthy & Brown, 1989) have applied and interpreted stress and coping models in a causal and deterministic way which perhaps oversimplifies what the current study has shown to be a diverse, complex and dynamic process. The current findings strongly suggest the utility of Lazarus' (1993) theory of coping as
process and Lazarus himself has commented upon the tendency toward oversimplification in the application of this theory: "it troubles me that in spite of the popularity of our method of coping assessment, the consistent logic that lies behind it, and the substantial evidence that coping changes with the context and over time as the status of the problem changes, few studies on coping pay more than lip service to the basic idea" (Lazarus, 1993, p. 239).

Consistent with Lazarus' theory of coping as process, the current findings indicate that coping is a dynamic process which needs to be considered in relation to: (1) the changing illness course (2) the nature of specific demands and (3) individual coping style.

(1) Coping in relation to the changing illness course

The current findings provide supportive evidence for Rolland's temporal framework of chronic illness (e.g. Rolland, 1987) which suggests that coping changes over the different phases of the illness course as a consequence of them posing different adaptational demands or tasks. That this framework has been supported is of critical significance in that it has not previously been empirically validated. The findings also, however, highlight features of the framework which require clarification. One aspect concerns the nature of transitions between phases within the model. Whilst the pre-diagnosis and initial adjustment phases are clearly separated by the point at which a confirmed diagnosis is received, the transition between the initial adjustment and chronic phase is more blurred. Related to this, the current findings suggested a more cyclical relationship between the initial adjustment and chronic phase. Rolland himself hinted at this in his notion of their being "unfinished business" that can complicate or block movement between phases. This suggests that a person may have to return to the adaptational tasks characteristic of a previous phase to 'finish' the business. An example of this in the current study would be Mr B, who, having 'moved on' to the chronic phase without resolving identity dilemmas, had to 'revisit' the initial adjustment phase and begin to resolve these later in the illness course. Further research exploring transitions within and between phases is required.

(2) Coping in relation to the nature of the demand

This study attempted to be more systematic than previous studies (e.g. Marr, 1991) by considering coping in relation to specific demands. Consistent with previous research (e.g. Lazarus & Folkman, 1984), the findings suggested that an
important feature distinguishing different demands is the extent to which they are appraised as being within personal control. Some support is provided for the use of problem-focused coping strategies (e.g. learning to shave with a different hand or using a walking stick or wheelchair) in relation to 'controllable' demands and emotion-focused coping (e.g. believing that things could be worse) in response to 'uncontrollable' demands.

What is important, however, is not whether a demand can be objectively defined as controllable or uncontrollable but how the demand is appraised by the individual. Appraisals which are not appropriately matched to the properties of the demand may result in the use of inappropriate coping strategies and potentially create difficulties in the adjustment process. Appraisals (and indeed the demand themselves) do not necessarily fall neatly into categories of 'controllable' or 'uncontrollable' which are two ends of a continuum. Disease progression, for example, was variously appraised as controllable (when conceptualised as an interruption), uncontrollable (when conceptualised as an intrusion) or appraised as there being at least some opportunity for control (when conceptualised as integrative). 'Mixed' appraisals may therefore be responded to with a combination of problem-focused and emotion-focused strategies and, whilst there is considerable clinical utility in designing interventions to promote the development of coping strategies to 'fit' with demand characteristics, this may not always be straightforward. Furthermore, overly focusing on matching demand characteristics to specific coping strategies runs the risk of coping becoming decontextualised from the person. As noted by Lazarus, "we must try and put process measures of coping within the larger framework of a person's life and ways of relating to the world" (Lazarus, 1993, p. 243). Individual coping style is therefore an important consideration.

(3) Coping in relation to the individual

Lazarus (1993) asserts that process (state) and trait concepts are two sides of the same coin and that both are usually relevant. Trait concepts emphasise consistency across time and encounters and have an important influence on the appraisal process; a demand is likely to be appraised in such a way as to match the preferred coping style of a particular individual. Although it is difficult to assess trait concepts of coping in a cross-sectional study, the relevance of such concepts was suggested in the current study by examples of how the 'coping history' of a person influenced their appraisal of a demand and subsequent choice of coping strategy. An example of this would be how the experience of previous health problems influenced
coping with the demands of PD. Consistent with this, Rolland (1987) has emphasised the importance of assessing how previous experiences of illness may influence coping with subsequent health problems.

It can be concluded that studies considering coping as a variable in adjustment need to be more specific in their design (e.g. matching people according to phase of illness and specifying the nature of the demand) and more cautious in their interpretations. It may not be possible to identify universally 'good' or 'bad' coping strategies and using group data may obscure important individual differences arising from differences in coping style. Future studies also need to assess more clearly than was done in the current study the outcome of coping as well as the process.

4.1.3 Identity Theories

Resolving identity dilemmas was a key task characterising the initial adjustment phase in the current findings and could even be said to be pivotal to the other tasks of seeking information and coping with symptoms and treatment demands. Consistent with Pinder's (1995) findings, information was sought in such a way as to maintain a sense of self, and medication and symptom management techniques were important to the extent that they alleviated symptoms to enable people to continue in social roles which they otherwise may not have been able to. That chronic illness poses a threat to identity has been documented across a wide range of illnesses (e.g. Charmaz, 1995), but Breakwell's (1986) integrated model of threatened identity has received scant attention in this context. The current findings suggest that this model may have considerable utility in understanding the threat to identity posed by a chronic illness. The findings also suggest, however, that, at least for progressive illnesses such as PD, consideration of the threat to future, as well as present, identity is required. Anxiety about the future was central to most participants' experience, especially at diagnosis, and whilst attempts can be made to cope with actual threats to identity happening in the present, coping with the anticipated threats to future identity may be more difficult as the nature of these is unknown. This makes it difficult to re-establish a feeling of life being predictable as was perceived to be so prior to diagnosis.

A feature of Breakwell's (1986) model strongly supported by the current findings, but often neglected in health psychology research and models (Chamberlain, Stephens & Lyons, 1997), is the need to consider threats to identity within a social and historical context. Concepts such as stigma have not been widely
considered in relation to PD but would seem to be particularly important. Perceptions of societal beliefs about PD substantively influenced participants' emotional response to the diagnosis of PD, posed threats to their social identity and was a significant factor underlying the frequent reports of social anxiety and consequent social avoidance which were more persistent than the initial feelings of grief.

Scambler and Hopkins (1986) distinguish between 'enacted' and 'felt' stigma. 'Enacted stigma' refers to negative evaluations and their consequences (e.g. pity, disgust) and 'felt stigma' to feelings, such as loss of self-esteem, which are 'felt' even though there is no objective evidence of negative evaluations having been made. A pertinent question is therefore to what extent are people's perceptions of societal beliefs about PD, and their prediction that others will make negative evaluations on this basis, based in reality? This question is not easily answered by the current findings, although some evidence for 'felt stigma' was provided by relative's observations that participants' feelings of being stared at by others were not based in reality. Further, more detailed, exploration of the social context of PD is required.

With regards to the historical context of PD, the changing patterns of illness over recent decades may mean that older people are more likely to remember attitudes toward, and to have direct or indirect experience of, previously life-threatening infectious diseases (e.g. typhoid, diphtheria). Thus a person's age may influence their perception of societal beliefs about illness, particularly in relation to the word 'disease'. As the pattern of illness continues to change and chronic illnesses become more prevalent, societal attitudes and people's perceptions of these, may change and have a differing impact on adjustment.

4.1.4 Theories of Loss and Grieving

Consistent with Marr (1991), loss was a key theme in participants' experiences. Losses experienced as a result of PD included loss of an active social life, loss of job, loss of physical skill and loss of future plans, but central to all these was the loss of self-identity. This is consistent with Kelley's (1998) observation of people having a sense of "not being who I was" in relation to losses experienced as a result of illness. Feelings of grief (characterised by shock, denial, sadness, anger and frustration) were felt in response to the losses experienced and, in this way, the diagnosis of PD could be said to represent a psychosocial transition (Parkes, 1972). This study also supports previous research suggesting the relevance of the concept of chronic sorrow to progressive diseases such as PD (e.g. Lindgren, 1996). Although
of a lesser intensity than at diagnosis, feelings of grief re-occurred at times during the illness course, especially in response to transitions such as increases in medication.

The notion of grief and chronic sorrow being a 'normal' and expected response to a loss requires consideration in the light of suggestions from the current study that at least some participants' (and their relatives) did not conceptualise their emotional response to PD as 'normal'. Whereas losses such as bereavement are 'objective', many of the losses experienced in relation to PD are symbolic. In such circumstances, 'normal' feelings of grief may be less likely to be legitimised both by the person themselves and others. Furthermore, in a culture where emotional distress is often perceived as a sign of weakness, or poor coping, it is not surprising that some people may be reluctant to share their distress. This is important as, according to grief theory (e.g. Worden, 1991), blocking emotional expression can potentially lead to complications in the natural grieving process and lead to an exacerbation of emotional distress in either the short or long term. Consistent with this, Rolland (1994) has also described how either partner feeling that they have to 'hide' feelings such as anger and depression (which he says are natural in the context of illness and disability) can lead to communication difficulties in a couple's relationship. He emphasises the need for a couple to grieve together for the loss of a normal life. Complications in the grieving process may also arise if persistent difficulties are experienced in accepting the reality or permanence of PD (e.g. through continued denial or by seeing PD as an interruption).

Assessing whether the emotional distress experienced as a consequence of PD is 'normal' or indicative of complications in adjustment draws attention to the documented need to distinguish between grief and clinical depression, which is conceptualised as a less 'normal' response (e.g. Parkes, 1997). Distinguishing between these is clinically important because, as Parkes (1997) notes, clinical depression can complicate the experience of grief. This may have particular implications with regards to PD as the incidence of depression may be increased due to neurobiological factors. Although distinctions were made between grief and depression in the current study, detailed distinctions were difficult. Participants used words such as 'depression' to describe how they were feeling at a particular points in the adjustment process, but it could not be assumed that they were describing themselves as clinically depressed as may have been implied by a professional using this term. The word 'depression' was often used by participants to describe feelings of sadness (which may be indicative of grief rather than depression) and it was...

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3 The impact that this may have had on how participants' organised their accounts in the current research setting is considered in section 4.3.1
important to be sensitive to other aspects of their emotional experience which would suggest a more clinical level of depression (e.g. feelings of guilt and worthlessness, loss and interest and apathy and persistence of feelings over time). This remains an ambiguous area, however, and further research exploring the differences between grief and clinical depression in this context is required. Failure to be able accurately to distinguish between the two could lead to people being inappropriately labelled as 'depressed' or, alternatively, people who are clinically depressed not receiving appropriate support thus increasing the risk of complications developing in the grieving process.

4.1.5 Lifespan (developmental) Psychology

A critical finding of the current study was the influence of age-related factors on the individual experience of PD. This highlights the need for research to move beyond simply differentiating between people of different chronological ages to explore how lifespan issues interact with the process of adjustment. Two concepts central to existing theories of development (e.g. Baltes, Reese, Hayne & Lipsitt, 1980; Neugarten & Neugarten, 1986) are suggested by the current findings as having particular importance in understanding these interactions: the concepts of transitions and normativeness.

The Concept of Transitions

The concept of transition relates to a period of change or disequilibrium that may provide a bridge between one largely stable point in life and another relatively stable, but different, one. Consistent with previous research (e.g. Bury, 1982), in the current research the diagnosis of PD, for all people except Mr A, created a time of 'crisis' which required new meaning to be found. As such PD could be considered a 'transition' in the lifecycle and the emergent theory a description of the processes by which the 'bridge' between the pre-illness and post-illness phases of the lifecycle was built. Another implication of the current findings is that the experience of PD needs to be considered in the context of other 'transitions' which occur in the life cycle. These transitions can be due to internal causes (e.g. the diagnosis or deterioration of another illness) or external causes (e.g. a bereavement). Particular difficulties may be experienced if transitions occur together, for example, PD being diagnosed around the same time that a bereavement is experienced. Professional support is likely to be especially important at such times both psychologically (due to the increased emotional distress) and medically (due to possible deterioration in symptoms as a result of the increased distress).
The Concept of Normativeness

Many lifespan theories (e.g. Baltes et al. 1980; Neugarten & Neugarten, 1986) make the distinction between normative and non-normative events. The implication of this is that the individual experience of a transition may be affected by the timing of the event causing it. A key question then, is whether diagnosis of a chronic illness such as PD is a normative or non-normative event? The current findings suggest that to answer this question a distinction needs to be made between social and subjective normativeness. Both are crucially important but, although ageing research increasingly has emphasised subjectivity, most lifespan theories (e.g. Baltes et al., 1980) have tended to emphasise social normativeness.

Social normativeness refers to how expected an event is in relation to social norms. Chronological age is the objective marker against which events are judged as being expected or otherwise. The widely held societal belief that ill health, and PD in particular, is associated with 'old age', suggests that ill health is more likely to be perceived as 'normative' to later life. This suggestion receives some support from this study. Perceiving PD as more 'normal' in later life provided chronologically older people with greater scope to use emotion-focused coping especially in coping with the perceived injustice of being ill, for example, being able to say "at least I've got it when I'm older". It is important, however, that the social normativeness of PD to later life, does not detract away from the fact that, regardless of chronological age, PD is not 'normative' to subjective experience. Notions of subjective normativeness are crucially important in understanding the individual experience of PD, especially the intense shock at diagnosis. From a subjective perspective, the societal association between age and illness is potentially problematic in that it threatens the processes by which individuals have been able to reject an identity as an 'old' person. An interesting finding, however, was that some participants, rather than reject an identity as an 'old' person, actively sought to acquire this. The biological similarities between PD and 'normal' ageing may therefore be adaptive for some people in that they are able to capitalise on these and use it as a basis for emotion-focused coping (e.g. "this would happen with getting old anyway").

Subjective normativeness also has particular implications for understanding the experience of some, but not all, participants who were suffering from multiple health problems. That ill health was more normative to Mr A, due to his suffering from other health problems, explained why he did not experience the diagnosis of PD as a transition (i.e. a time of disequilibrium). Caution is required, however, in
making broad, generalised assumptions about the adaptiveness (or otherwise) of having multiple health problems as the current findings suggest the experience of past and current health problems interact in more complex ways to influence the process of adjustment for any individual.

4.1.6 Systemic Psychology

Although the focus of the study was on understanding the experience of the individual with PD, this person was only a focal point in an inter-related dynamic system of family, friends, work colleagues, health care professionals and society. This strongly suggests the need to incorporate systemic thinking into research on chronic illness, especially as health psychologists have been criticised for too frequently restricting their focus to the individual and ignoring the social context (Chamberlain, Stephens & Lyons, 1997). The interface between the person with PD and society has been discussed in previous sections, but the inter-relations between the individual, family and wider health care system requires brief consideration.

Interactions with the Family System

Even though previous research (e.g. Brod, Mendelsohn & Roberts, 1998) has suggested the important influence of interpersonal relationships on adjustment, there has been very little direct exploration of how one member of the family being diagnosed with PD may influence family relationships, or of how (changes in) family relationships may influence the emotional adjustment of individual family members. Rolland, writing within the wider literature (e.g. Rolland, 1987; Rolland, 1994), has emphasised the important interface between illness and the family and the current findings provide supportive evidence for his work which, again, is not empirically based. Areas of consistency include the need for couples' to acquire and develop new roles, particularly patient-caregiver roles, within the re-defined emotional and physical boundaries of their relationship. He notes feelings of burden and caregiver stress as potential difficulties associated with this. Rolland also describes how the 'age' of couples, (e.g. the chronological age each partner and the length of the relationship), may be significant in understanding how illness influences their relationship. Further, more detailed, research examining the interface of PD with the family system is required.
Interaction with the Health Care System

The current findings illustrate how interactions with health care professionals have a critical influence on a person's experience of PD and yet this has been neglected as a variable in many studies of psychological adjustment to PD (e.g., Brod, Mendelsohn & Roberts, 1998). It is increasingly becoming acknowledged that relationships with health care staff can be a major source of difficulty in the management of chronic illness (e.g., Petrie and Moss-Morris, 1997) and the generally positive reports of participants' experiences of health care in the current study contrasts with previous reports of negative experiences (e.g., Habermann, 1996). The present study complements previous research by providing information on specific factors which are significant (either by their presence or absence) in influencing patients' experiences of services. In particular, it extends previous research, which has focused on individual consultations (e.g., Weinman, 1997), by considering how the organisation of services (in terms of models of care) may influence patients overall experience of care. This is particularly important as most health care services are oriented toward acute episodes of care (e.g., Todd & Still, 1984) and, whilst the need to develop models more suited to the needs of people suffering from chronic illnesses has been identified (e.g., Thorne & Robinson, 1989), the current literature provides little guidance as to what would be important features of such a model. Important features suggested by the current findings are that a service should be based on a philosophy of joint working, multi-disciplinary, continuous, accessible and responsive to patients' psychological as well as medical needs. Attending to the human significance of PD was crucially important and although this was achieved, in part, by relatively easily defined factors (e.g. having time to listen), the attitudes of professionals involved were also extremely important. These, however, are much more difficult to quantify. The central importance of patient's perceptions of professional attitudes suggests that it is not so much the model of care but the way in which care is delivered that is crucial, especially in being able to develop effective working relationships with patients.

4.1.7 Relevance of the Model to Other Chronic Illnesses

Although the theoretical model in figure 2 was developed in relation to PD, it may also have utility in understanding people's experience of other chronic illnesses. This is supported by the consistency of the current findings with wider research within health psychology. Strauss and Corbin (1990) argue that a good grounded theory should be sufficiently general enough to be applicable to a multitude of diverse situations within the substantive area not just to a specific type of situation.
Thus, whilst specific illness characteristics may influence the individual experience of illness, the underlying processes which these characteristics impact upon may be consistent across illnesses. So, for example, whilst self-identity may be threatened in a varying ways (depending, for example, on whether an illness is visible or progressive), resolving identity dilemmas is still an important process underlying adjustment. The theoretical model developed in this study may have particular utility in exploring the experience of people who suffer from multiple health problems. The model is unique in it's explicit consideration of how a person's experience of multiple health problems (both in the present and past) may influence the adjustment process and provides an important basis for further research in this seemingly unexplored, but potentially important, area of health psychology.

4.2 Clinical Implications

The current findings have many implications for health care professionals working with people with PD. The following discussion will focus on the implications for reactive and preventative psychosocial interventions for people with PD and their families and the need to promote collaborative working relationships between families and health professionals. The potential role of the clinical psychologist in PD services will then be discussed.

4.2.1 Developing 'reactive' psychosocial interventions

'Reactive' interventions are directed at people experiencing difficulties in their psychological adjustment to the diagnosis of PD. Difficulties may be indicated by high, persistent, levels of psychological distress (e.g. clinical depression or social anxiety) which significantly restrict a person's ability to achieve optimum functioning within the constraints of their physical illness. The theoretical model which emerged from this study provides clinicians with a useful heuristic device for assessing why a person is experiencing difficulties in adjustment. Particularly important is assessing the processes by which a person is: (i) coping with treatment demands and symptoms, (ii) resolving identity dilemmas and (iii) grieving for the losses experienced. The mediating factors summarised in figure 3 may suggest reasons why difficulties in these processes have arisen. Thus, the clinician needs to assess the potential contribution of age related factors (e.g. retirement status), the family and social context (e.g. changes in family relationships), previous experiences of illness and current health status, the experience of other stressful life events (e.g. bereavements) and potential difficulties arising from in interactions with health care services. Assessing how a person conceptualises PD within their daily life may also
indicate how difficulties in adjustment have developed and suggest therapeutic aims. People who persistently deny their having PD, or conceptualise it as an interruption, will need help to accept the psychological reality or permanence of PD and to develop realistic expectations. Further support may be required to help a person adjust to the diagnosis of PD once accepted (e.g. through facilitating grieving for losses and resolving identity dilemmas). If PD is conceptualised as an intrusion, therapy may focus on helping a person to develop other interests in life and become less focused upon the illness and the hope for a cure.

Reactive interventions may take several different forms depending on the specific nature of the problem. Assessment may indicate individual, couple, family or group therapy using a variety of psychotherapeutic models. Cognitive-behavioural therapy, grief therapy, personal construct therapy and psychodynamic therapy can all be seen as appropriate depending on the nature of the difficulties. An important point to consider is that not all problems will necessarily require intervention from a clinical psychologist. Other professions (e.g. nursing) are becoming increasingly skilled in psychotherapeutic techniques and the number of PD specialist nurses is increasing.

4.2.2 Developing Preventative Interventions

Preventative interventions are aimed at minimising the likelihood of difficulties in adjustment developing. Working in this way enables health care staff to have a wider impact than just those few cases referred. Preventative interventions are well-established in many areas of health psychology (e.g. cardiac rehabilitation) and are usually group oriented, occur soon after diagnosis and are part of a wider multi-disciplinary programme. Ellgring, Seiler and Perleth et al., (1993) have described and evaluated a psychosocial preventative programme for people with PD and their spouses which involved both group seminars and individual counselling. Consistent with Ellgring and colleague's study, the current findings suggest that important 'psychological' components of a preventative programmes would include: (1) education about the psychosocial aspects of PD (2) providing opportunities for emotional expression and (3) promoting the development of coping skills.

(1) Education about psychosocial aspects of PD

The observation that people who suffer from PD and their families often do not perceive their feelings of emotional distress as a 'normal' response to the diagnosis of PD suggests that an important aim of a preventative programme would
be to normalise this. 'Normalising' the emotional response may involve providing the person with PD and their families with information about the psychosocial aspects of PD, including information about loss reactions, anxiety and also the possible contribution of neurobiological factors to emotional experience. This information may help people to make sense of their own experience and help them feel more able to express their feelings openly. This, in turn, may reduce the likelihood of complications in grieving developing.

(2) Providing opportunities for Emotional Expression

Providing the opportunity for people to share their feelings about the impact of the diagnosis with others (e.g. others with PD, health professionals, family members) may also be beneficial in normalising the emotional response to PD and facilitating 'grieving'. Having the opportunity to talk to non-family members may be particularly important if people are experiencing difficulties in their family relationships. Significantly, some participants in the current study indicated that they would have appreciated the opportunity to talk to someone from 'outside'. It is also significant that several participants reported to the researcher, either directly or via the nursing sister at the clinic, that they found taking part in the research beneficial. Frank (1995), who himself has suffered from chronic illness, argues that, in telling their stories, people who have suffered with serious illness are engaged in something deeper than reporting facts. They are remaking their world through articulating their experience, effectively reconfiguring themselves in the course of becoming storytellers of their encounters with illness. Thus, having the opportunity to share one's story may provide an opportunity for people to extract meaning from their experience and may facilitate the adjustment process.

(3) Promotion of Coping Skills

Interventions aimed at teaching people skills to help address the specific demands created by chronic illness are increasingly being documented in the literature relating to other chronic illnesses (e.g. Chesney & Folkman, 1994). These interventions aim to achieve a 'fit' between individual coping style and the nature of the demand by focusing on the appraisal process. Cognitive and behavioural techniques have particular utility here and formed the basis for Ellgring et al's (1993) intervention programme for people with PD. The main focus of this programme was on reducing social anxiety and, related to this, addressing the interaction between emotional state and physical symptomatology. The current findings would support
these as being particularly important areas for psychological intervention and suggest that an important process to be addressed is the fear of negative evaluation by others.

4.2.3 Promoting Collaborative Working Relationships

Consistent with previous research (e.g. Thorne, 1993), the current findings highlighted the need for health professionals to work collaboratively with people with PD and their families to promote self-management of illness in everyday life, away from the hospital setting. It is the responsibility of services to ensure that people have the appropriate medical and psychological support to be able to do this. The current findings highlighted a number of components important to developing professional collaboration with patients and their families. These included aspects of the model of care, such as accessibility and continuity and, importantly, the need for health professionals to be sensitive to the human significance of PD rather than seeing patients just in terms of their disease status. The positive experiences of the majority of participants in the current study illustrated the powerful effect feeling cared for (in a psychological sense) can have on a person's emotional adjustment to PD and on their confidence in managing PD on a day to day basis.

Developing collaborative relationships is a two-way process and it may also be important to educate patients about how to get the most out of their consultation. This could be another component of preventative interventions, examples of which have been described in the wider chronic illness literature (e.g. Greenfield, Caplan & Ware, 1985). Reported interventions generally involve delivering brief training packages to patients, prior to a consultation, which aim to increase patient's level of participation in the consultation to ensure that their own concerns are dealt with and that the information provided by the doctor is understood.

4.2.4 The Potential Roles of the Clinical Psychologist in PD Services

Although over recent years clinical psychologists have become increasingly involved in many areas of chronic illness (e.g. pain management and cardiac rehabilitation), they appear to have had only minimal involvement in PD services. This is surprising given the widely documented cognitive and emotional changes in PD and may partly be due to the dominance of the biomedical model of depression in PD. The previous discussion suggests that clinical psychologists could have a number of potentially valuable roles in PD services. These are summarised in figure 5.
Direct therapeutic work may involve working with complex cases and delivering psychological components of preventative interventions. Psychologists also have a potentially valuable role working 'indirectly' through other members of staff. It is the responsibility of all professionals to respond skillfully and sensitively to the emotional needs of people with PD and their families and to recognise when more specialised psychological help is required. Psychologists therefore have an important role in educating other health care staff and supporting them in their application of psychological techniques. 'Indirect' work may also involve psychologists becoming involved at an organisational level in developing and evaluating service policies and practices that will promote and enable monitoring of the psychological well-being of people with PD and their families. Finally, psychologists may be involved in research either at a service (e.g. service evaluation) or individual level (e.g. evaluating intervention programmes).

4.3 Critical Review of the Research Methodology

As with quantitative methodology, reliability and validity are important considerations in qualitative research. It has been coherently argued, however, that definitions of these concepts developed within a quantitative framework cannot be directly applied to the evaluation of qualitative research (e.g. Lyons, 1999). Within a qualitative framework, reliability and validity are concerned with "trustworthiness": reliability refers to the trustworthiness of the data and validity to the trustworthiness of the interpretations or conclusions (Stiles, 1993). Using these definitions, the following sections will consider issues of reliability and validity in relation to the current research and outline the steps taken to achieve these quality controls. Issues
of generalisability will then be considered before discussing further specific methodological limitations of the research.

4.3.1 Reliability and Validity

Although there are as yet no agreed criteria for assessing validity and reliability in qualitative research, guidelines for good practice have been provided (e.g. Smith, 1996; Stiles, 1993). A number of these practices were adopted in the current study:

(1) Presentation of Evidence

As qualitative research openly seeks to interpret data (Sherrard, 1997), it is important that enough raw data is presented to allow the reader to interrogate the interpretation being made (e.g. Smith, 1996). Accordingly, the researcher attempted to make her interpretations transparent by using direct quotes from participants in the results section.

(2) Member Validation

This involves taking the analysis back to the participants' to enable them to comment upon the interpretations. Member validation can occur at several points during the research process (e.g. after preliminary analysis or once a draft report has been written). Four people in the current study were asked to comment upon a draft of the final analysis and one person (Mr A) gave feedback on preliminary interpretations of his own initial interview. Potter (1996) also recommends checking understanding of participants' accounts within the interview as a check for validity. Accordingly, throughout the interview, basic counselling skills, such as reflecting, clarifying and summarising, were used to verify understanding.

Although recommended, several researchers have noted potential difficulties with using member validation as a technique for assessing validity (e.g. Henwood & Pidgeon, 1992). Difficulties include the possibility that, due to the power relations of the interview, participants may find it difficult to question the interpretations of the researcher. Although this requires consideration, several participants did voice disagreement with the researcher at times during the initial and validation interviews. Following Henwood and Pidgeon's advice (Henwood & Pidgeon, 1992), when this did occur, reasons for the differences in interpretation were explored in order to construct a joint reality. As noted by Smith (1996), member validation is not
necessarily an attempt to get at any 'truth' but to gain a fuller understanding of the situation.

(3) Triangulation

'Triangulation' means seeking information from multiple data sources, multiple methods of interpretation and multiple prior theories and assessing the convergence of these. The rationale is that convergence across several perspectives represents a stronger validity than does any one alone (Stiles, 1993). Multiple data sources were drawn upon by including relatives in the interview process thus enabling a fuller, richer story to be obtained. Convergence between relatives and participant reports provided good evidence for validity and points of disagreement provided a rich area for exploration. Exploring differences in carer and participant reports was particularly useful in advancing understanding of how relationship factors may influence the adjustment process. Although given the option to be interviewed alone, there were suggestions that some participants felt inhibited from sharing aspects of their 'story' by their partner being present. This was most clearly expressed by Mr G during the validation interview (which his wife couldn't attend) when he reported having felt reluctant to share some of his experience of PD (especially aspects relating to the marital relationship) due to his wife being present. A useful technique in future research would be to adopt the approach taken by Dakof & Mendelsohn (1989) who interviewed carers and patients individually as well as together.

(4) Coherence

Coherence refers to the apparent quality of the interpretation itself: "does it hang together?" (Stiles, 1993). Coherence can be assessed in a number of ways. Firstly, the method of constant comparison itself is a check for internal coherence by enabling the researcher to check for ambiguities and unexplained contradictions in the interpretations. Coherency can also be assessed by discussing the findings with other professionals who are knowledgeable about the research area and methodology. Throughout the research project the emerging analysis was discussed with the researcher's supervisor - a clinical psychologist working with older adults who had clinical experience of working with people with PD - and with an expert in grounded theory methodology whose own research interests were in the field of carer adjustment to Alzheimer's Disease. This provided a basis to discuss, critically evaluate and consolidate interpretations made. Additionally, the final analysis was also presented to the medical consultant and nursing sister from the specialist PD
Clinic from which the majority of participants were recruited. That the findings of a grounded theory study should be comprehensible to people working in the area under study has been identified as a core criteria for assessing quality (Strauss & Corbin, 1990).

Coherence also considers how the findings 'fit' with related research. The coherence of bodies of research is seen as providing evidence for the reliability and validity of findings, with each new project building upon insights from previous studies (Potter, 1996). As discussed in earlier sections of this chapter, the current findings confirm and build upon previous research in the field of PD and the wider field of health psychology as well as other areas of general psychology (e.g. lifespan psychology). The need to draw upon multiple theories to account for the findings is in itself a measure of validity and reliability in qualitative research. According to Glaser and Strauss (1967), good theory should be rich, complex, dense and integrated at diverse levels of generality.

(4) Reflexive Research Practices

A key difference between qualitative and quantitative research methods rests in beliefs about researcher subjectivity. Whilst quantitative research assumes an objective researcher and aims to limit wherever possible the effects of researcher bias, many qualitative researchers (e.g. Henwood & Pidgeon, 1992; Sherrard, 1997) argue that the personal is always present in research. From a qualitative perspective, the trustworthiness of the data and interpretations will be influenced by contextual factors such as characteristics of the researcher (e.g. age, gender, profession), the aims and objectives of the research and how these were presented to participants. The researcher is thus required to be reflexive about his or her own research practices. Keeping field notes was especially useful in this regard. Brief consideration will now be given to how the contextual factors outlined above may have challenged reliability and validity through participant and researcher bias.

Reflexivity requires the researcher to be explicit about the research questions and the research interests of the researcher (Stiles, 1993). This was done in the introduction and method sections and is important to establish a context for the presentation and interpretation of emerging data (Stiles, 1993). In terms of introducing the study to participants, care was taken to explain that the researcher was interested in hearing about their experiences of having PD. Thus, the themes that emerged were generated from participants' stories. Although the researcher did not have direct clinical input to the specialist PD clinic from which participants were
recruited, for reasons of rapport building it was felt to be important to identify herself with the clinic. Consequently, careful discussion of issues of confidentiality was required. Although participants were aware that names would be changed, given the small numbers involved, and that they were selected by the consultant and nursing sister, they may have been aware that they could possibly be identified. Whilst this may have inhibited participants from confiding certain aspects of their experience to the researcher, most people reported being unconcerned about confidentiality. Also, participants did give negative feedback on some aspects of the service received and it is significant that one couple (Mr and Mrs E) were careful to confirm confidentiality before sharing this.

The researcher's profession as a trainee clinical psychologist may have influenced interactions with participants and the development and pursuance of the research agenda. Whilst this background prepared the researcher to conduct interviews with sensitivity and empathy and helped with building rapport, it was important to be aware of how having an identity as a psychologist (especially in a medical setting) would be interpreted by participants. Radley (1999) has discussed how, in health psychology research, participants often use the interview as an opportunity to demonstrate "healthiness". Psychologists are often thought to represent the existence of a 'problem' and consequently there may have been an even greater desire for participants to present themselves as 'healthy'. It was therefore extremely important to look for contradictions in participants' accounts and attend to non-verbal communications which may have contradicted the 'words' being used. An example of this was during the interview with Mr B, where his distress during the interview contradicted his claims of having 'accepted' PD. Involving relatives was also important in this respect and on several occasions relatives contradicted claims from participants that they had not experienced any problems. As noted earlier, however, relatives may also want to demonstrate "healthiness", especially in their relationship with the participant (Silverman, 1993). There were some suggestions that the desire to demonstrate "healthiness" may have been greater for men than women. Significantly, it was often female carers who contradicted their husbands' claims that they hadn't experienced any emotional distress and when men did talk about any distress, it was often in the context of informing the researcher about how they had overcome this. These interpretations are also subject to possible researcher bias, however, due to the researcher's gender as a female which may also have influenced how able participants felt to share their emotional experience with her during the interview.
The researcher was significantly younger than all the participants and this required her to be aware of her own assumptions about age and ageing, both in relation to the way that the interviews were conducted and in the interpretations made. Attending to participants' own words was important. The younger age of the researcher may also have influenced aspects of the power relations within the interview. Commonly the researcher is seen as more powerful in terms of conducting the interview, having an academic expertise in the area of research, carrying out the analysis and writing the research findings (King, 1996). This may have created some tension with participants' feelings of being more experienced and 'expert' due to their greater age and personal experience of PD.

4.3.2 Generalisability

The generalisability of research findings is a main criterium for validity within experimental psychology. Following Henwood & Pidgeon's (1995) criteria, however, the aim of qualitative research is to generate information which is useful because it is contextualised rather than generalisable to the whole population. Strauss and Corbin (1990) have made clear that social phenomenon is not reproducible insofar as being able to match conditions exactly to those of the original study. It has therefore been suggested that, with regards to qualitative research, it is more appropriate to talk about transferability rather than generalisability (e.g. Henwood & Pidgeon, 1992). Most narrowly this term refers to applying the findings of a study in contexts similar to the context in which they were first derived. Consideration is thus required of how 'transferable' the emergent theoretical model is to people with PD in different circumstances to those in the current sample.

The majority of participants were recruited from a specialist PD clinic and all participants were receiving medical care from a consultant who specialised in PD. This therefore neglects a large population of people with PD who are managed by their GP. Another consideration with regards to the sample, is that all people recruited to the study were married or living with a friend. Thus, the study provides no direct information about the experience of single people with PD. Whilst the specificity of the sample necessitates caution in generalising the emergent theory beyond the context of the sample in the current study, this theory does provide plausible groundwork for continued research with under-researched populations such as single people and people managed by their GP. Due to the small sample size, possible selection bias by the medical consultant and nursing sister at the clinic (e.g. selecting people who they felt had positive experiences of the service) and time limitations meaning that 'saturation' of categories could not be achieved, caution is
also needed in generalising the theory to people who appear 'matched' to the current sample.

4.3.3 Specific Methodological Limitations of the Study

In addition to the limitations already discussed, two further methodological limitations require consideration. The first of these relates to the cross sectional design of the study. This means that information on how adjustment changed over time was based on retrospective recall and that the accounts given by participants were only reflective of their experience as remembered, or experienced, at the time of the interview. It was to minimise possible inaccuracies in recall that the initial selection criteria dictated that only people diagnosed within the last 18 months should be recruited. Although adherence to this was not possible, with hindsight, this may also have had advantages in that people diagnosed for longer periods of time were more able to reflect upon the overall process of adjustment. It is clear, however, that longitudinal designs which trace changes in the experience of PD over time would be highly appropriate to this area of research.

A second limitation of the study is the decision to interview a greater number of participants on a single occasion rather than interviewing a smaller number on multiple occasions. This decision was based on the desire to achieve breadth of coverage in a relatively unexplored area but, as qualitative methods are concerned more with the generation of rich, contextualised data rather than representativeness, it would have been equally valid to conduct multiple interviews with a smaller number of participants. This would have enabled deeper understanding of the emerging themes to be achieved and would also have had the advantage that the researcher may have been able to develop a more trusting relationship with the participants who may then have felt more comfortable sharing aspects of their experience which they may have been reluctant to share initially.
5.0 CONCLUSIONS

This study aimed to explore people's experiences of being diagnosed with PD and to suggest an inductive theory that could explain it. It is acknowledged that this study is interpretative and therefore any conclusions must remain provisional but the coherence of these findings with previous research does suggest that the emergent theoretical framework provides a plausible foundation to guide future psychosocial research in PD using a variety of methodologies. It may also provide a useful framework for researching the experience of people suffering from other chronic illnesses. The current literature on chronic illness is large and unwieldy, lacks a theoretical focus and is difficult to access by clinicians. It is hoped that integrating relevant research from several areas of health and general psychology into one model will make this research more accessible and useful to the clinician. This should promote better integration of theory with practice and ultimately lead to the psychosocial needs of people with PD and their families being more effectively met.
REFERENCES


**APPENDICES**

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APPENDIX 1

Letter of ethical approval from the school of psychology

Letter of ethical approval from the north Clwyd ethics committee
c.c. Bethany Lomas

July 7, 1998

Professor Bob Woods  
School of Psychology  
University of Wales  
Bangor  
Gwynedd LL57 2DG

Dear Professor Woods

**Understanding the psychological factors and processes underlying psychological adjustment to Parkinson's Disease**

Your research proposal (referred to above and on the attached sheet) has been reviewed by the School of Psychology Research Ethics Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines, **provided that** the consent form states that any complaints about the conduct of the research may be addressed to the Chief Executive of Clwydian Community Care as well as Professor Fergus Lowe at the School of Psychology, and also that the covering letter, information sheet and consent form are translated into Welsh **before** being submitted to Clwyd North research Ethics Committee.

If you wish to make any substantial modifications to the research project, please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if participants experience any unanticipated harm as a result of taking part in your research.

Good luck with your research.

Kath Chitty  
Coordinator -School of Psychology Research Ethics Committee
University of Wales, Bangor

School of Psychology

Ethics Committee
Proposal cover sheet

Chief investigator/Supervisor: PROFESSOR ROBERT COODS
Associate investigator/Student: BETHANY LOMAS

Brief project title: UNDERSTANDING THE PSYCHOLOGICAL FACTORS AND PROCESSES UNDERLYING PSYCHOLOGIC ADJUSTMENT TO PARKINSON'S DISEASE

Date of submission: 29/6/98

Form used to prepare submission:
- School ethics committee outline
- Gwynedd Health Authority
- Other (please give details) CLYROL NORTH

NB. All relevant paperwork (including consent forms and any translations) must be completed before submission to the School Ethics Committee.

Declaration of ethical compliance

This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research.

(Chief investigator/supervisor)
Signed:  
Date: 29/6/98

(Associate investigator/student)
Signed: BETHANY LOMAS
Date: 17/6/98

For School Use Only

Reviewer 1 M. STARTUP Approved MB (Initials) 6/1/98 (Date)
Reviewer 2 Proposal No. 99/233
Ms. Bethany Lomas,
Trainee Clinical Psychologist,
North Wales Clinical Psychology Course,
43 College Road,
Bangor,
LL57 2DG

Dear Ms. Lomas,

Re: 6.8.98 Understanding the psychological factors and processes underlying early adjustment to a diagnosis of Parkinson's Disease

At a recent meeting of the Research Ethics Committee held on Thursday, 5th November 1998 the amended documents relating to the above mentioned study, were received and approved by members present.

Yours sincerely,

[Signature]

Mr. U. M. Chouhan,
Secretary,
NWHA Research Ethics Committee (Central)
APPENDIX 2

Information sheet for participants
Dear Sir/Madam,

I am a Trainee Clinical Psychologist and am currently undertaking a piece of research looking at how people with Parkinson's Disease and their families cope when they are diagnosed with this disease.

I would be grateful if you would read the information sheet attached to this letter to see if you would be interesting in taking part in the study.

The study has been approved by the Glan Clwyd Hospital and University of Wales, Bangor ethics committees and is being supervised by Professor Robert Woods and Dr Jolyon Meara. Their addresses are given below:

Professor Robert Woods  
IMSCaR  
Wheldon Building  
University of Wales, Bangor  
Deiniol Road  
Bangor

Dr Jolyon Meara  
Academic Unit  
Health Care of the Elderly  
Glan Clwyd DGH  
Rhyl  
Denbighshire  
LL18 5UJ

Thank you for your time,

Yours sincerely,

Bethany Lomas
INFORMATION SHEET

HOW PEOPLE COPE WHEN THEY ARE TOLD THAT THEY HAVE PARKINSON'S DISEASE

To help us find out more about how people cope when they are told that they have Parkinson's Disease, I am asking people who have been diagnosed with Parkinson's Disease within the last 18 months if they would be willing to meet with me to talk about their experiences.

It is hoped that this information will help us to understand more about what having Parkinson's Disease means to people who suffer from this and their families.

What will the study involve?

If you choose to take part I will talk to you for about 1 hour about how you first came to realise that you had Parkinson's Disease, how you felt when you were told this, what things you found particularly difficult or helpful at that time and how you feel now. You could ask a family member or friend to be present when you are interviewed or, if you preferred, I could speak to you alone.

Depending on the information received from the first interview, I may ask you for a second interview. If you wish I will also contact you again at a later date to discuss some of the findings of the research.

The interviews will take place either at your home or Glan Clwyd Hospital depending on which you prefer.

Confidentiality

The information from each interview will remain confidential. Each interview will be audio taped but these tapes will be kept securely and destroyed when the research has been completed. The content of the interviews will only be discussed and/or written about after names have been changed. This will ensure that you cannot be identified.

What if I don't want to take part or if I change my mind?
If you choose not to take part in this study this will not affect your future medical care. If you do take part and then change your mind, you will be free to withdraw from the study at any time, including during the interview or afterwards. If you decide to withdraw you do not have to give any reason. Again, your decision to withdraw will not affect your future medical care.

**Do I want to know anything else?**

If you have any further questions, I would be pleased to discuss these with you either at our first meeting or before. You can contact me at the following address/phone number:

Beth Lomas  
North Wales Clinical Psychology Course  
43 College Road  
Bangor  
LL57 2DG

Tel: 01248 383719

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**What do I do if I want to take part?**

If you want to take part Dr Meara will let me know me and I will contact you by phone within about a week to discuss any further questions you may have about the study and/or to arrange a convenient time to meet.

If you decide at a later time that you would like to take part in the study, you can contact either myself at the address and phone number given above or Dr Meara or Sally Roberts at Glan Clwyd Hospital (Tel: 01745 534847 or 01745 534266).

---

**THANK-YOU FOR TAKING THE TIME TO READ THIS LEAFLET**
APPENDIX 3

Research consent form
Research Consent Form

Have you read the information sheet? YES / NO

Have you had the opportunity to ask questions and discuss this study? YES / NO

Have you received satisfactory answers to all of your questions? YES / NO

Have you received enough information about the study? YES / NO

Who have you spoken to? Dr/Mr/Mrs/Ms ________________

Do you understand that you are free to withdraw from the study:

- at any time

- without having to give a reason

- and without affecting your future medical care? YES / NO

Do you give permission for the interviews to be audio taped? YES / NO

Do you agree to take part in this study? YES / NO

Signed: ___________________________________________ Date: ______________

(NAME - in block letters) ________________________________________________

Signature of witness: __________________________ Date: ______________

If you have any complaints concerning the conduct of this research, please address these to:-
Professor C.F. Lowe, Head of School, School of Psychology, University of Wales, Bangor, Gwynedd, LL57 2DG.

Mr L.V. Wood, Chief Executive, Clwydian Community Care NHS Trust, Catherine Gladstone House, Hawarden Way, Mancot, Deeside, CH5 2EP.
APPENDIX 4

Areas covered in interview
AREAS COVERED IN INTERVIEWS

Pre-diagnosis

First signs that something was wrong
Explanations for 'symptoms' before diagnosis
Seeking medical help
Emotional experience

Diagnosis

When, who by, where?
Immediate reactions to the diagnosis, especially the emotional impact

Post-diagnosis

Changes occurring following diagnosis (lifestyle, family, emotional, social)
and changes in these over time
Emotional and coping responses to any changes; changes in these over time
Supports in adjustment
The future