

CHAPTER THREE

CHRONIC ILLNESS, PARKINSON'S DISEASE AND OCCUPATIONAL ROLE PERFORMANCE

3.1 Introduction

The last chapter dealt with the concept of role as it organises behaviour. The concept was examined from the perspective of role theory and its application within the discipline of occupational therapy. This chapter considers the possible impacts of a chronic illness such as Parkinson's diseases upon the occupational role performance of people with the disease and their significant role partners. In doing so, it contributes to fulfilment of research objectives two, three and four, which were to describe the:

2. Barriers to ORP experienced by the participants;
3. Strategies or coping plans developed by participants to regain a perception of perceived control; and
4. Changes in the occupational role performance of people with a chronic illness (Parkinson's disease) and their partners.

3.2 The Role of Being Chronically Ill

In Australia, 84% of those aged 65 and over have a long-term health condition of some kind (Australian Bureau of Statistics, 2002). The chances of being profoundly or severely restricted by one's health or disability remain relatively low (around 9%) until the about age of 70. After this it increases rapidly until by the age of 85 onwards almost 65% of this population have a profound or severe restriction (Australian Bureau of Statistics, 2002). Living with a chronic disease is a complex, often life changing experience. The impact of the disease processes on the everyday life of the person and those around him or her are not fully understood (Braithwaite, 1990; Lubkin & Larsen, 2002; Strandmark, 2004).

3.2.1 Definition

There are a number of definitions of chronic illness, none of which succeed in embracing the complexity of the experience. Curtin and Lubkin said it "is the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability" (Curtin & Lubkin, 1995, p.8). This definition appears to

imply that dependency is a central part of being chronically ill. It ignores those in the earlier stages of many chronic conditions, where dependency may not yet be part of the picture.

Strandmark (2004) broke the concept of *ill health* down into three sub-constructs, sickness, illness and disease. She defined sickness as an all-embracing term that covers the external view of health, including social role, status and one's negotiated position in the world or 'fit'. Sickness was the social role of being ill. Illness was defined as a subjective experience on the part of the person, involving negative changes in ways of being and in social functioning. She argued that disease was often associated with illness but not causal to it. It was possible to experience illness in the absence of detectable disease, and to have a disease without experiencing illness.

Ironside et al. (2003) asked their participants to provide their own definition of 'being chronically ill'. From this they developed the following definition:

Chronic illness ... is a disease or injury that has lasted more than 6 months and has caused a person to significantly alter his or her day-to-day activities. Alterations in daily activities may be due to factors such as decreased endurance, mobility, or cognitive functioning resulting in a limitation of the person's ability to continue his or her usual lifestyle (Ironside et al., 2003, p. 172).

This definition is fundamentally different to the others in that it reflects the perceptions of those experiencing the phenomenon rather than those observing it.

3.2.2 The Sickness Role

Parsons (1951) introduced the concept of the *sick* role to partner the physician's role. He portrayed the sick role as having four expectations:

1. Exemption from normal social role responsibilities, relative to the nature and severity of the illness.
2. The sick person cannot be expected to recover through an effort of will. This also is an exemption from normal responsibilities.
3. The state of being ill is undesirable, and carries the obligation of wanting to 'get well'.
4. There is an obligation to seek technically competent help, such as a physician, and to cooperate with him in the process of trying to get well (Parsons, 1951, pp. 436-437).

People who are recognised by others to be in the sick role have the right not to carry out their normal responsibilities and the right to be cared for. At the same time, they are obliged to seek qualified help and to comply with what health professionals instruct them to do. Those who attempt to continue with their normal lives risk having their illness claims discounted (Jones & Jones, 1998).

Parsons (1951) saw the relationship between the physician and the person in the sick role as somewhat akin to that of parent and child. He stated that the sick role is a 'contingent' one – negatively achieved through a failure to keep well. Anyone, regardless of their social status in other respects, could enter this role. Parsons saw the role as temporary.

3.2.3 Being Chronically Ill

Parson's views were supported by subsequent research based upon those who were acutely ill (Steward & Sullivan, 1982), but only where there was a clear agreement that the person was ill. Segall (1976) pointed out that society does not always have a clear agreement about who should enter the sick role, indicating that people with chronic illness have no clear role. Similarly, Lubkin and Larsen (2002) commented that while Parson's view might be applicable to acute illness, it had little relevance to those experiencing chronic illness. The role of being chronically ill is not temporary. They described Parson's observations as an 'outsider' view of illness and an attempt to objectify something which is subjectively experienced in relation to an individual inner meaning.

3.2.4 Impact Of Chronic Illness

Research that described the impact of chronic illness was largely related to specific chronic conditions. In older adults, there were found to be a number of co-existing conditions leading to a more complex picture of impairment. It was generally observed that the perceived impact of a chronic illness will differ from one person to another due to personality traits, support systems and other unique factors (Braithwaite, 1990; Miller, 2000).

Several studies showed that socially, being old and chronically ill is a double misfortune, as both are considered highly undesirable by those in other age groups and by older people themselves (Ellefsen, 2002; Ironside et al., 2003; Lubkin & Larsen, 2002; Strandmark, 2004). Chronically ill people are viewed primarily as people who are *ill* and who have *debility*, leading to *dependence*. Older people are perceived primarily in negative terms. Being old is considered similar to being dependent, even when the person is physically and mentally fit (Blaikie, 1999; Bytheway, 1995; Lubkin & Larsen, 2002).

There are socio-cultural differences in relation to attitudes towards sickness (Lubkin & Larsen, 2002). Lubkin and Larson saw Parson's model as having best fit with middle-class behaviours in response to illness, pointing out that people on a low income are often unable to give up role responsibilities as they need to work in order to survive. This led to denial of illness, if symptoms permitted this, and a failure to seek help. There might be other specific motivations for denying illness in present day society.

The work of Ironside et al. (2003) demonstrated further that an objective approach to classifying the experience of chronic illness was too narrow. They interviewed people with chronic illness and subsequently worked with them as equal partners in the analysis of their interview transcripts and in the development of three major themes. The first was that a focus upon symptoms and functional performance did not adequately account for how chronic illness was experienced and must be supplemented by narrative accounts to appreciate the significance of the illness in relation to personal meaning. Participants did not discuss such things as a move from wheelchair to crutches as major milestones, but rather as incidental to other events that were far more personally significant.

The second theme was that discussions of meaning in the context of living with chronic illness was as important for clients and clinicians as the treatment of symptoms. Treatment of symptoms, while considered important, was only part of what the participants needed from health professionals. Participants needed to discuss their daily experiences, such as 'hitting a brick wall' of exhaustion unexpectedly, or dealing with feelings of extreme embarrassment about an episode of incontinence (Ironside et al., 2003).

The third theme was that the 'space' between 'acutely ill' and 'being well' was poorly documented, yet this was where most persons with chronic illness placed themselves. Participants were still going about their daily lives and striving to do as much as they could, while having to face the reality that they could not control their lives in the ways that they would like. Participants talked of learning to accept what could not be changed, without giving up (Ironsides et al., 2003). It is this poorly documented space that is the focus of the present study.

3.2.5 Occupational Therapy and Chronic Illness

Occupational therapists who work with people with chronic illness largely work with care rather than cure (MacWhannell & Blair, 1998). This orientation provides an appropriate philosophy and culture for working with those living in the community and experiencing chronic illness. They have a key role in enabling community care, and work with carers such as family members and partners (Ravetz, 1998).

When subscribing to a holistic approach, occupational therapists consider biomedical issues, cognitive issues, and psychosocial issues related to chronic illnesses (Ravetz, 1998). They consider the whole picture of the person living in his or her own environment. They believe each person they work with to be an individual and unique. This belief has led to the development of the concept of 'client-centred practice' whereby the client seeks advice from the therapist but retains control in the interaction (McCull, Gerein, & Valentine, 1997). This basic principle is, in effect, a re-statement of an idea that was central to the discipline of occupational therapy from its outset. Adolph Meyer, widely credited as the founder of occupational therapy, suggested that the provision of occupation that matched individual interests could stimulate the person to interact purposefully with his or her environment (Meyer, 1977). This approach facilitated the ability of the occupational therapist to support a person with chronic illness living in the community.

The need to restate the principle of dealing with the person as an individual came about because occupational therapy had become much more closely allied to the medical profession since its early days, leading to the dilution of some of the original principles and the development of a more 'scientific' approach during the 1950s, '60s and '70s (Shannon, 1977). This has been demonstrated again by another current movement, evidence-based

practice. Evidence-based practice supports the view that therapeutic interventions are acceptable only when they are supported by research literature. Although qualitative methodology has been included in the notions of 'acceptability', in practice, emphasis is given to statistically based methodologies (Popay, 1998). Although statistical evidence provides important generalised knowledge that enables occupational therapists to be more aware of the issues a specific client may be facing, it does not always help therapists to respect the principle that a client's knowledge and experiences are central to therapy. Rather, it may encourage the tendency to view clients as an illness rather than as a person with an illness.

Contemporary literature is beginning to lament the lack of appropriate evidence on which to base health policy for people who have chronic illness and disability. The current evidence debate demonstrates the rise of reductionist science across health and disability services including ageing. For example, Australia's National Health and Medical Research Council (2000) outlined three dimensions to evidence: strength (level of study; bias minimisation; statistical precision), size of effect and relevance. Assumptions that underlie this view of evidence subscribe to the notion that health can be measured the same way for all people; that ill health and disability can be reduced to small units of measurement that reflect a larger problem; and that what professionals choose to, and are able to measure is relevant to people who experience chronic illness and disability (Sibthorpe & Dixon, 2001). The impact on occupational therapy is clear. It calls for, and favours randomised controlled trials, even when occupational therapists know that for something as complex and complicated as human occupation, they are difficult to conduct and often unhelpful in terms of the information they produce (Chapparo & Ranka, 2005). Although the increased interest in qualitative research within the profession in recent years has helped to redress the balance between the objective and subjective aspects of working with people as individuals, little research has been done to investigate the experiences of those in receipt of occupational therapy (as opposed to the outcomes of therapy). Unfortunately, what has been done demonstrates that occupational therapists do not always put the principle of respecting individualism into practice. Professor Stephen Hawking, a physicist with amyotrophic lateral sclerosis, has led a legendary life in which he has achieved far more than his peers, despite living for most of his adult life with a chronic illness and a severe level of disability. He wrote: 'I have not received much help from people calling themselves occupational

therapists' (Hawking, 1996, p. 27). He went on to say that what he did not receive was support to help him play a full part in society. The cartoonist Callaghan (1989), living with the results of a spinal cord injury, was similarly unimpressed with his occupational therapists.

Rebeiro (2000) interviewed two clients of mental health services in Canada. Their perceptions were that the occupational therapists they encountered were prescriptive and paternalistic in their approach, failing to offer meaningful choices in relation to therapy, or an accepting, supportive environment with opportunities for personally meaningful occupation. Both of her participants felt that the volunteer work and the job that each had acquired in the community offered far more in terms of personal recognition and a sense of place than all the occupational therapy interventions they experienced. They felt their knowledge and experiences of themselves and their lives were ignored or devalued. Other studies have shown or suggest similar results (Campbell, 1994; Hillman, 1999; Jongbloed & Morgan, 1990; Neistadt, 1995).

3.2.6 Barriers to Client-Centred Occupational Therapy Services

Despite a general agreement in the profession that occupational therapists should all be moving to a more client-centred approach (Christiansen & Baum, 1997a; Law, Baum, & Dunn, 2001), they often remain firmly situated within the medical model when offering therapy to people with chronic illness. This has given rise to problems of lack of continuity of therapy, ideological dissonances for occupational therapists working in this area, and consequent values conflicts, leading to a sense of isolation for the therapist (Hasselkus, 1997).

For older people in Australia, occupational therapy contacts and interventions are mostly made in one of three ways:

- 1) Initiated within a hospital setting, after admission for an acute episode. Depending upon the length of stay, an occupational therapist may see the person once or several times and facilitate discharge home by liaising with family members, providing education about the disease process, and environmental modification.

- 2) When clients visit a specialist clinic where there is a medical team which specialises in their particular disease.
- 3) When clients are referred to or seek out a community-based occupational therapist.

In all cases, contact is usually brief and focused upon a list of specific problems. It is unusual for a plan for regular checks to be in place and it is the therapist who determines when contact should be ended. Therapists are obliged to account for their time in order to be paid, and have to justify to medically orientated managers what they are doing with clients.

Most occupational therapists working with people with chronic illness are working within the rehabilitation model. This model carries the central expectation that the client will improve, there will be a restoration of function, and a consequent return to previous lifestyle. Therapists working as part of a medical team (such as in a hospital setting) are expected by the rest of the team to focus on specific functional outcomes in order to restore independence. This ideology does not fit when working with people with chronic illness (Hasselkus, 1997). Such people are more likely to have a disease process that is on a plateau or deteriorating. This has led to value conflicts for therapists. Hasselkus (1997) interviewed 148 therapists working in this area, and found they expressed frustration at not being able to deal with what had personal meaning for their clients.

3.3 Parkinson's Disease

Parkinson's disease is a chronic and progressive disorder that affects a significant number of Australians in late adulthood either directly or indirectly. It is a disorder of the extrapyramidal system characterised by loss of dopaminergic neurones in the basal ganglia. This results in the development of abnormal movement patterns. Unlike catastrophic disease processes such as stroke, people with Pd remain community members for many years.

The incidence of Pd is around 1% of the older population (Murphy & Tickle-Degen, 2001; Pentland, 1999). The precise incidence of Pd in Australia is not known, but recent surveys indicate there are approximately 100,000 diagnosed people (37,000 of whom are living in NSW) and possibly another 40,000 who have not yet been diagnosed (Irwin, 2004).

Research into Pd has been largely medical. The majority of studies typically focus upon achieving an understanding of the clinical development and progression of the disease and its response to pharmacological and surgical interventions. As a result, a good deal is known about these aspects of the disease process.

3.3.1 Clinical Progression

Statistical studies of the progression of clinical symptoms show that although there is a general course that can be defined, there is no strict time frame for clinical progression. In 1967, Hoehn and Yahr developed a scale which has been the benchmark description of the clinical progression of the disease ever since. It arose from the results of a longitudinal study, which collected data over a 15 year period. They followed people diagnosed with Pd who attended a specific clinic. Hoehn and Yahr (1967) observed a progression from unilateral involvement with little functional impairment through to wheelchair confinement and severe impairment. The scale they developed focused upon loss of motor control and hence mobility. Hoehn and Yahr identified five stages in disease progression:

- “Stage I: Unilateral involvement only, usually with minimal or no functional impairment.
- Stage II: Bilateral or midline involvement, without impairment of balance.
- Stage III: First sign of impaired righting reflexes. This is evident by unsteadiness as the patient turns or is demonstrated when he is pushed from standing equilibrium with the feet together and eyes closed. Functionally, the patient is somewhat restricted in his activities but may have some work potential depending upon the type of employment. Patients are physically capable of leading independent lives, and their disability is mild to moderate.
- Stage IV: Fully developed, severely disabling disease; the patient is still able to walk and stand unassisted but is markedly incapacitated.
- Stage V: Confinement to bed or wheelchair unless aided” (Hoehn & Yahr, 1967, p. 433).

Hoehn and Yahr were careful to point out that the stages were a general guide and that there will always be exceptions. They identified the impairment of the righting reflex (Stage III) as the point at which the disease became disabling. They found that, after five years, 25% of the people they studied had balance difficulties, had progressed further still or had died. From five to ten years, the proportion increased to around 63% and by 10 to 14 years that percentage became 80%. They identified a significant minority group of people

(34%) who, after ten years, still did not have impairment of righting reactions. These people often did not acquire balance problems until twenty years or more after the initial diagnosis, and they were termed atypical. Although Hoehn and Yahr (1967) pointed out that their scale was only of moderate use in assessing the functional capacity of people with Pd, nevertheless, the majority of medical research studies related to Pd have used the scale as part of the methodology (Peto, Jenkinson, & Fitzpatrick, 2001). Hoehn and Yahr's scale describes what are referred to as the primary symptoms of Pd. Brod, Mendelsohn and Roberts (1998) described tremor, rigidity and bradykinesia as a triad of primary symptoms. Pentland (1999) described key diagnostic features as hypokinesia, rigidity, tremor and impaired postural reflexes.

In addition to these primary symptoms, a wide range of secondary symptoms have been described. These include cramps, problems with salivation and swallowing, difficulties in speaking and expression, decline in libido, balance problems, pain, nausea, reduced appetite and weight loss, insomnia and bladder and bowel problems (Brod et al., 1998; Gillen, 2000; Jones et al., 1999; Pentland, 1999).

A number of authors referred to the possible slowing of cognitive processes (e.g. Pentland, 1999). The presence of confusion and the incidence of dementia as secondary symptoms of Pd has remained controversial (Pentland, 1999). Some health professionals and texts report confusion and/or dementia as a secondary symptom. Mendelsohn, Dakoff and Roberts (1995) found higher levels of reported confusion, forgetfulness and absent-mindedness in people with Pd than in a typical matched community sample. Hooks (1996) reported that 30% of people with Pd in the USA have dementia. On the other hand, a study by Jones et al. (1999) of the needs of 521 people with Pd in the UK found, when compared with a typical matched community sample, there was no difference in the incidence of confusion or dementia.

Jahanshahi and MacCarthy (1998) identified four phases to the clinical progression of Pd, adapted from a more general description of chronic illness, that included primary and secondary symptoms:

1. Pre-diagnosis and immediate post-diagnosis phase. Symptoms develop gradually and become clinically manifest over time.

2. Early phase. The period when the signs and symptoms are so mild that no treatment is yet required, or when changes are well controlled with treatment. Impairment and disability are either non-existent or mild.
3. Middle phase. Usually the longest. As the disease progresses, impairment and disability will become greater. Treatment will still effectively control the symptoms, but they will show variations in severity during the day, with wearing-off effects and on-off changes. Medication-related dyskinesias including dystonia may cause additional problems.
4. Late phase. By now the disease is producing severe symptoms. Medical treatment produces little relief, and the medication-related fluctuations and side-effects lead to marked disability (Jahanshahi & MacCarthy, 1998, p. 100).

3.3.2 Impact upon Occupational Performance (Doing)

Although descriptions of symptomatology and physical disability were helpful to this study, a more functional understanding of the impact of Pd upon the daily life of people was necessary to appreciate its impact upon quality of life (Peto et al., 2001). Many authors have described disease progression in terms of functional performance, with an initial period, of variable duration, corresponding to phases (1) and (2) of Jahanshahi and MacCarthy's (1998) clinical progression. During this period, the literature reports that medication is able to effectively control early symptoms (Hooks, 1996). People experience only mild functional problems and remain largely independent. Nevertheless, fine motor control, evident particularly in hand function, may be affected at this stage, limiting the ability to write and carry out other fine motor tasks (Gillen, 2000). Jones et al. (1999), in a study of 521 people with Pd using the Barthel ADL Index, found that ten years after diagnosis 60% of the participants were fully independent, despite experiencing a wide range of symptoms. They also found that 50% of symptoms in this early stage were not reported to health professionals.

As the disease progresses, people move into Jahanshahi and MacCarthy's (1998) middle phase. They experience symptoms more severely than before, and the impact on functional performance is more serious. Jones et al. (1999) found that around 30% of their participants had moved to mild or moderate levels of disability within the first ten years following diagnosis, while 8% of them still remained in this stage 24 years after diagnosis. Falls become more common. Motor function may be affected in an on/off manner, such that it is possible to be moving freely one minute and unpredictably freeze up the next (Pentland, 1999). In relation to mobility, turns, starts, stops, changes in direction and backing up are all

reported problems (Hooks, 1996). Cognition may be affected and speech might be slowed or lose volume (Pentland, 1999). Reading becomes more difficult because the eyes no longer coordinate effectively (Hooks, 1996). People usually experience reduced energy (Gillen, 2000), making previous levels of occupational performance harder to maintain. Hooks (1996) described a 'moving therapeutic window' within which the person with Pd learns to function. The time of day in relation to medication is usually an important part of this functional window. To complicate the picture further, medication is often increased as the disease progresses in order to minimise symptoms, which in turn leads to previously unexperienced side-effects.

A third and final stage, corresponding to Jahanshahi and MacCarthy's (1998) late phase, involves severe and increasing levels of disability that are no longer controlled by medication. People in this stage become fully dependent upon their carers for most daily activities. It is worth noting that, because Pd occurs late in life, people often die from other causes before reaching this final stage of the disease process (Jahanshahi & Marsden, 1998). Only 10% of the people in the study by Jones et al. (1999) had severe or very severe levels of disability. Brod, Mendelsohn and Roberts (1998) found their sample of 101 did not have a good representation of people in advanced stages of Pd.

3.3.3 The Impact of Parkinson's Disease upon Everyday Activity

There was little in the literature that was not anecdotal descriptions of the impact of Pd upon social interaction. Singer (1973) compared people with Pd with available population norms and found that people with Pd were less likely to engage in household tasks, or have a close circle of friends. They were more likely to spend time in solitary occupations such as watching television, reading, or listening to music. Seventy-five percent of those under 65 reported spending some part of their day napping or doing nothing. These figures were supported by Oxtoby (1982) and correspond to 80 year-olds in the general population.

3.3.4 Psychological Impact

Brod, Mendelsohn and Roberts (1998) report a dearth of research about the psychosocial responses of people with Pd, apart from depression and dementia. Research that is available indicates that the impact of Pd upon mental health and social interactions can be quite profound. Depression linked to Pd is common and has been well documented

(Gillen, 2000; Jones et al., 1999; Pentland, 1999). Other commonly reported psychological symptoms included anxiety, lowered self esteem, and feelings of foreboding (Brod et al., 1998; Jahanshahi & MacCarthy, 1998). Jones et al. (1999) found that over one third of the people in their study were anxious, and depression affected almost one third. These responses were not linked to any particular phase, but were found throughout the disease process.

Jahanshahi and MacCarthy (1998) outlined psychological responses to their four phases in the progression of the disease:

1. *Pre-diagnosis and immediate post-diagnosis phase.* This first phase is often marked by feelings of uncertainty and shock. Typically, people search for ways to understand their emerging disability. Diagnosis may be associated with confusion, anger, apprehension, resistance and denial, or acceptance and relief that the symptoms have been finally given a label that does not involve an immediate death sentence and is not of psychological origin.
2. *Early phase.* A major psychological transition is required at this point. There is a need to modify self-image and perceptions of social status to accommodate the knowledge that they are no longer perfectly healthy and never will be again. Feelings of loss are very common. Financial and occupational planning for the future is needed.
3. *Middle phase.* The style of coping identified in this phase is 'sanguine and engaged'. There are active efforts to cope with altered circumstances and an enjoyment of the challenge of managing the practical and emotional consequences of the disease. Some social and occupational roles may be voluntarily relinquished and others developed. If the disease progresses fast then people may feel they have been engaged in an unsuccessful struggle. Depression may ensue with sudden or severe worsening of symptoms.
4. *Late phase.* Depression is much more common. Feelings of helplessness may develop as the disease appears to take over and physical dependence increases. Dependency entails the further loss of roles and loss of privacy and dignity. There are high demands on mutual trust between the person with Pd and his or her carer. Coping efforts at this stage tend to focus more on emotional responses (Jahanshahi and MacCarthy, 1998 pp 103-104).

Studies have shown that the severity of the disease process does not correlate with a person's perceptions of quality of life (Findley, 1999; Muldoon, Barger, Flory, & Manuck, 1998). People with mild clinical involvement may express high levels of distress, while those with severe involvement might express satisfaction with their lives. Jones et al. (1999) compared the statements of people with Pd with objective measures of anxiety and depression. They found that a significant proportion of people who stated at interview that

they were usually happy, rarely worry and/or rarely get depressed, were clinically anxious or clinically depressed.

It appeared there was a link between depression and the degree to which the disease was impacting upon the person's everyday social, work and leisure roles (Brod et al., 1998; Brown, 1998). Brod, Mendelsohn and Roberts (1998) stated that the social effect of Pd is a specific instance of premature ageing with an increased dependence upon others. They interviewed 101 people with Pd, using a number of instruments to assess psychosocial and mental status as well as other aspects of the disease process. They found no correlation between the severity of the disease or its duration and the person's mental status. They concluded "the patient's concerns and problems are a product of the interaction between the disease and the personal, developmental, and social contexts in which it unfolds" (Brod et al., 1998, p. P221).

3.4 Interventions for Parkinson's Disease

3.4.1 Medication and Surgery

Medication is the central platform of intervention to relieve the primary symptoms of Pd. Medication is designed to replace dopamine or to prevent its breakdown. Medication is usually highly effective in the early to middle stages of the disease process, but as time goes on, it gradually loses effectiveness, and wears off more quickly. A higher dose is required, producing a greater number of side effects. Interactions with medication needed for other medical conditions can be a problem (Pentland, 1999). Surgical intervention may bring about a dramatic improvement, but carries the usual risks associated with neurosurgery and may worsen symptoms.

3.4.2 Rehabilitation

Rehabilitation, as an adjunct to drugs to manage symptoms is considered by many authors to be of paramount importance. Pentland (1999) stated the skills of many professions can be invaluable in helping the person to cope with the disease. He said "such expertise should not be reserved for people with advanced disease but be available from early in the course of the illness" (Pentland, 1999, p. 10).

Occupational Therapy Rehabilitation Services

Rehabilitation literature relating to occupational therapy for people with Pd has a strong focus upon understanding motor problems and developing interventions designed to lessen or overcome the triad of primary symptoms (tremor, impaired postural reflexes and rigidity) as they impact upon motor performance, activities of daily living and safety (Gillen, 2000; Hooks, 1996; Newman, 1995). While some texts mention the need to deal with lifestyle issues, there is not much specific information about how this can be achieved. Hooks (1996) listed seven goals for occupational therapy in relation to Pd. They are to:

1. Develop a routine for performing the acts of self-care within the limitations of functional mobility.
2. Educate and direct the performance of independent living skills through movement facilitation, therapeutic techniques, and sensory stimulation
3. Establish a repertoire of adaptive techniques and behaviours to stimulate movement.
4. Establish an adaptive environment that accommodates immobility and maximises sensory stimuli.
5. Educate the person, care partner, and family about Pd and the process of habilitation.
6. Develop a relationship with a support group.
7. Provide guidelines for habits that facilitate movement and good posture, such as stretching, relaxation, and cognitive and physical activity (Hooks, 1996, p. 849).

These goals provide a comprehensive basis for addressing functional problems arising from the primary triad of symptoms, but do not facilitate consideration of functional difficulties arising from secondary symptoms, and do not address occupational performance at the role level in areas other than self maintenance.

Gillen's (2000) discussion of occupational therapy interventions addressed motor problems as they relate to mobility, activities of daily living and safety. However, discussion of intervention at the role level was limited to the role of self maintainer, as it is defined by occupational therapists and other health professionals (ADL and IADL). There was consideration of the carer role, but only in relation to carer assistance with ADL tasks.

Gillen (2000) and Newman (1995) used the word *patient* when referring to people with Pd, indicating perhaps an unconscious view of people with Pd as being in the *sick role*, and implying an intervention outcome of 'getting better'. Gillen (2000) referred to

occupational role performance, saying the purpose of occupational therapy intervention is to promote wellness by "...assuring that the patient is functioning at his/her maximum potential in terms of the occupational roles that he/she fills" (Gillen, 2000, p.65). In common with many occupational therapists, he limited occupational roles to the areas of work, self maintenance and leisure, as delineated in the Model of Human Occupation (Kielhofner, 1995), excluding consideration of occupational performance in social and cultural roles. Overall, there has been acknowledgement by some sources of the need for occupational therapists to address psychosocial issues (e.g. Newman, Echevarria and Digman, 1995), but the emphasis has remained firmly on symptom management.

Effectiveness of Therapy as Defined by Health Professionals

Research into the effectiveness of therapy for Pd has demonstrated a tendency to exclude the opinion of consumers of the services from consideration (Chesson, Cockhead, & Romney-Alexander, 1999). Findley (1999) identified discrepancies between the perceptions of clinicians and their clients about the person's state of health and how well people were coping with the disease.

The occupational therapy literature has focused upon achieving change in skills and abilities and in activity and task performance, rather than in achieving satisfactory occupational role performance. Murphy and Tickle-Degnen (2001), for example, conducted a literature review of studies with experimental or quasi-experimental design. Their meta-analysis, to establish if occupational therapy was effective in addressing the functional problems posed by Pd, found sixteen studies that met their inclusion criteria. They were able to put these studies into three categories in terms of the purpose of the research. Ten evaluated the effect of a specific treatment strategy on outcomes. Four examined the effect of a more generalised rehabilitation program on outcomes. Two focused on motor control and motor learning. Only one study measured the effect of occupational therapy-related interventions on outcomes at the role level. Fifteen studies measured outcomes at the abilities and skills level. Ten of these showed positive outcomes, while four reported no change and one reported a negative effect. Thirteen studies measured outcomes at the activities and task level. Nine showed a positive effect. Three studies showed no effect and one study had a negative effect. Murphy and Tickle-Degnen (2001) reported limitations to some of these studies that may have led to an underestimation of treatment effects.

Satisfactory Therapy Outcomes as Defined by the Consumers of Rehabilitation

There is little literature that describes what people with Pd consider desirable outcomes of therapy, although there are some recent studies seeking the perceptions of people with Pd. These studies interviewed people with Pd to find out such things as their perceptions of quality of life (Chesson et al., 1999; Findley, 1999), sources of support (Yarrow, 1999), needs (Jones et al., 1999) and experiences (Brod et al., 1998). These studies create a picture of what people with Pd might want health professionals to provide support for, and what they would consider good outcomes of therapy. Good control of symptoms by whatever method was found to be a high priority (Brod et al., 1998; Chesson et al., 1999). Beyond that, most studies discussed quality of life.

Quality of life was elusive, as it was dependent upon the judgement of the person and could therefore mean many things to many people. Findley (1999, p. 404) defined it as a 'perceived state of well-being that is influenced by physical, mental, functional, social and emotional factors'. Chesson, Cockhead and Romney-Alexander (1999) asked for definitions of quality of life from their participants. Being able to do what they did before was identified as an important part of quality of life by a number of respondents (Chesson et al., 1999).

Community access was identified as a significant issue in a number of these studies (Chesson et al., 1999; Jones et al., 1999; Yarrow, 1999). A perception of being in control of the disease process, and being able to successfully avoid negative thoughts were identified by Brod, Mendelsohn and Roberts (1998) as important psychosocial factors linked to a lower perception of disease severity.

There was a clear difference in emphasis of what constitutes desirable therapy outcomes between health professionals, including occupational therapists, and people with Pd in the studies reviewed. While symptom control was of primary importance, those with Pd saw this in the context of a broad and personalised conception of quality of life such as '...being able to do what I did before' or 'the joy of living' (Chesson et al., 1999). Health professionals, including occupational therapists, often perceive symptom control as an end in itself, and there was no literature that emphasised the importance of the person's life context.

Provision of Therapy

Surveys of people with Pd showed that only a small proportion (15-20%) ever saw an occupational therapist. The percentages were as low or lower for other allied health professionals such as speech therapists and physiotherapists (Chesson et al., 1999; Pentland, 1999; Yarrow, 1999). Chesson, Cockhead and Romney-Alexander (1999) pointed out that the majority of referrals to allied health professionals were made by medical practitioners (either general practitioners or specialists). Jones et al. (1999) found that most disease management was done by general practitioners, with negligible input from other health professionals. Chesson, et al. (1999) suggested that many British medical practitioners may not be aware of the ways in which occupational therapists and other health professionals could support the daily living of this group of people. Those who had contact with allied health professionals did not always report satisfactory outcomes. Some of the literature documenting health management and rehabilitation outcomes as perceived by people with Pd indicates there is disappointment and dissatisfaction with health professionals and the services offered. Occupational therapy services are included in this dissatisfaction.

Poor communication with health professionals was identified as a major problem in a number of studies. Jones et al. (1999) reported 50% of the 521 people they studied were dissatisfied with the way they were told of their diagnosis and with ongoing communication about their disease. They commented that the situation did not improve over the decade that data were collected. Chesson, et al. (1999) interviewed thirty people with Pd in the UK. They found that while 60% felt that their therapist (occupational therapist, physiotherapist or speech therapist) understood their problems, 17% did not. The remainder were not sure or did not express an opinion. Problems identified included a lack of continuity with therapy and therapists. Fifty-seven percent felt they benefited from therapy, with the value of the social interaction being given a high priority, while 23% felt they did not benefit. None of the participants in the Chesson, et al. (1999) study mentioned quality of life issues when discussing the benefits of therapy. Another study found incongruities between clinicians' and patients' perceptions of their state of health and how they were coping with the disease (Findley, 1999). Both these studies suggested from their findings that factors affecting quality of life may include the attitude of clinicians, the manner in which the diagnosis was delivered, the infrastructure of the support offered, the nature and quality of communication

between people with Pd and their health-care teams, and the nature and control of access to information.

In terms of quality of life, there is a poor match between the therapy outcomes that health professionals consider important, and the outcomes that people with Pd expect or wish for. It is likely that people with Pd perceive that health professionals are not willing to provide meaningful support and that they are expected to deal with the wider implications of the impact of Pd upon their daily lives by themselves.

3.5 The Role of Partner or Spouse

As discussed in Chapter Two, role partners are an indivisible part of occupational role performance.

3.5.1 Role Behaviour

Although each marriage or partnership is an intensely personal relationship and therefore unique, a developmental pattern emerges from the literature (Peterson, 2004). A typical marriage course for people of the age of participants in this study is as follows. The first twenty to thirty years were spent bringing up children. The marriage is most likely to follow a traditional pattern, where the husband is the breadwinner and the wife stays at home, working to maintain the household and care for the family (Peterson, 2004). Once the children leave home, the couple are left together for the first time since the early days of their marriage (Sarantakos, 1996). The wife's workload reduces a little at this point (Bittman, 1992), and she may choose to take up new roles, such as leisure or voluntary work, and she may assist her children by caring for the grandchildren. Following the retirement of the husband, the couple do more together (Bittman, 2000). This pattern continues until death, unless interrupted by chronic illness or disability.

How partners feel about each other changes over the development of the relationship. A number of authors have identified a common pattern of a u-shaped curve to marital happiness (Peterson, 2004; Sarantakos, 1996; Weishaus & Field, 1988). Disenchantment and dissatisfaction with marriage begins shortly after the partnership commences. There is a continued decline through child rearing years, followed by an upturn once the children leave

home. The levels can be restored to those of early marriage in later life (Peterson, 2004). While there can be slight differences, this trend is much the same for both men and women (Glenn, 1998).

The reasons for the disenchantment are not entirely clear, but the pattern is well established (Peterson, 2004). If couples remain married long enough, re-enchantment occurs in later middle-age, after the children have left home or after the couple's 25th wedding anniversary (Peterson, 2004). Post retirement, couples report very high levels of satisfaction with their partner (Weishaus & Field, 1988). There is greater equality now that the husband is retired, and greater reliance upon each other for support and companionship (Sarantakos, 1996). It seems that with more time to spend together, the relationship is able to develop and couples get to know each other better, leading to a renewed appreciation of each other. Greater value is attributed to the relationship (Peterson, 2004; Weishaus & Field, 1988). If the participants in this study followed this marital pattern, then for most the advent of Parkinson's disease would have coincided with high levels of satisfaction within their marriage.

3.5.2 Thinking About the Relationship

Retirement has been referred to as the 'role-less role' (Burgess, 1960). Social expectations are that couples in retirement will put their feet up and enjoy a well-earned rest. There is an implication that older people should keep out of younger people's way. These social expectations provide little guidance to how older people should construct their lives, allowing them to develop a more idiosyncratic lifestyle.

If either partner develops a chronic illness, it changes the developmental path of their partnership. Often, one partner requires the assistance of the other to remain living the community. This is thought to change the attitude of both partners to each other. Care giving has been found to lead to imbalance and a loss of the equality that had been gained upon retirement (McPherson, 2004; Sarantakos, 1996).

Partners may or may not identify themselves as carers (McPherson, 2004). Some see caring as part of their role as partner, while others see it as a separate role. The reasons for this are complex and not well understood, but McPherson (2004) suggested that it may

reflect (a) the nature and extent of caring tasks the partner has to perform and/or (b) the quality of the relationship that exists between them. Where a sense of reciprocity and sharing exists, the partners are less likely to refer to themselves as carers.

3.6 Caring

The purpose of this section is to link the concept of role as reported in Chapter Two with the experience of caring for someone with Pd.

3.6.1 What is a Care Giver?

The Australian Census has provided information about people who have identified themselves as care givers in the community. In Australia, 13% of people living in the community have identified themselves as carers, and one in five of these were primary care givers (Australian Bureau of Statistics, 2000). For those who were 65 years of age or older, 75% were caring for their partner. While overall, women were most likely to identify themselves as care givers, for those over 65, it was men who were more likely to identify themselves for the census in this way, reflecting the gender differences in life expectancy. Women were most likely to be care givers between the ages of 55 and 64 years (26%), and most likely to be a widow after 74 years of age. Men were most likely to be a care giver over the age of 74 (24%) (Australian Bureau of Statistics, 2000).

People who are perceived to care for their partners are ascribed the role of *carer* by those around them. They are recognised by the wider community and formal support systems as carers. Social expectations are that a carer has primary responsibility for the provision of care (Lubkin & Larsen, 2002). Braithwaite (1990) defined carers as “people who assume the major responsibility for providing or organising services on a regular basis to someone who was incapable of providing for her or himself” (p. 36). In addition, Braithwaite specified that the major responsibility of a carer is considered by others to be in the areas of household tasks, personal care and/or supervisory care.

3.6.2 What do Care Givers ‘Do’?

The literature reviewed did not provide a great deal of information about what people with a chronic illness did on an everyday basis. In contrast, there were plenty of descriptions of what carers did. Care givers spend a great deal of their time in caring. Riemsma et al. (1999) studied 40 Dutch men and 40 women with rheumatoid arthritis and their carers. They found that 60% of the carers in their study assisted the care receiver seven days a week, with an average of 33 hours per week being allocated to assistance. Lubkin & Larsen (2002) identified two types of care: health-related care and social care. Health-related care consisted of specialised treatment carried out by health professionals and daily treatments done by the carer following the instruction of health professionals (for instance, medication management). Social care included functional assistance (providing assistance with instrumental activities of daily living) and emotional support. Emotional support included enhancing such feelings as self esteem, hope, contentment and dignity in the care recipient (Lubkin & Larsen, 2002).

Social Care

There is a perception within the general community that caring is a *burden* to be shouldered by the carer. Jahanshahi and MacCarthy (1998) defined the term burden as the impact of a chronic disorder upon a specific person and significant role partners as perceived by health professionals.

Two types of burden were described: *objective burden* and *subjective burden*. Objective burden refers to the difficulties and limitations that are observable by others. Someone with Pd might have obvious difficulty negotiating the steps and turns involved in walking through a shopping centre for example. They might need someone with them to provide assistance and support, placing an objective burden on that person. Potential objective burdens include economic hardship, the physical and social consequences of providing physical care, a loss of autonomy and dwindling social networks (Jahanshahi & MacCarthy, 1998).

Braithwaite (1990) used the Macquarie Dictionary definition of burden as “that which is borne with difficulty” (Delbridge, Bernard, Blair, Ramson, & Butler, 1981) when

interviewing 144 unpaid care givers recruited through two community care programs in Australia. Sixty-two of these were caring for a spouse, 73 for a parent or parent-in-law and nine for a relative or friend. Each person was interviewed in a semi-structured, flexible manner about their care giving experiences.

Braithwaite's (1990) findings can be related to Lubkin's (2002) social care in that she identified household tasks and personal care as the most obvious and observable type of care. She identified shopping, meal preparation, cleaning, laundry, ironing, house repairs, gardening, finances and transport as household activities where care was provided. An overwhelming majority of care givers provided support in these areas, with shopping, heavy cleaning, minor house repairs, gardening and transport assistance being provided by 100% of the carers (Braithwaite, 1990). Fewer care givers reported providing personal care. Care receivers were mostly autonomous in decision making, with the exception of food preparation, where the person making the meal decided what it should be. Women care givers were more involved in decision making than care givers who were men. Further, 58% of care receivers were left alone for short periods during the day and could summon help if needed, while 74% were rarely separated from their carer at night. Supervision to prevent falls, assistance with mobility, calming distress and as a response to emotional blackmail by the care receiver were common reasons given by carers.

Social Support

Braithwaite (1990) used three measures in her care giver interviews to assess the amount of social support the carer offered. She measured the degree to which the care giver was the care receiver's confidante. Being a confidante was defined as being someone the person leant on, who they were close to, who they shared their happiness with, who they shared their most private feelings with, and who comforted them with a hug. She found that 20% of care givers identified themselves as their care receiver's only confidante. Being the confidante of a care receiver was not linked to being that person's spouse, or with the care receiver being a woman. However, female care recipients had a larger social network than their male counterparts.

Braithwaite (1990) assessed whether the care giver worked to maintain the care receiver's social network. This was done by asking how often the carer arranged outings.

She found that 37% of carers arranged outings suggested by the care receiver, but that outings were more likely to happen when the care giver took the initiative. Spouses were more likely to support outings suggested by the care receiver. Increasing age was related to fewer outings, but this seemed to stem from less interest on the part of the care receiver.

Acquiring the Role of Carer

The expectations of carers in taking on the role were found by Braithwaite (1990) to be accurate. She found that over half the carers had quite extensive knowledge about the care receiver's condition before commencing care, but that older carers were less knowledgeable than younger ones. Older carers were more likely to have taken the role on gradually rather than suddenly. Less than half reported that the person they cared for deteriorated in unexpected ways. The remainder expected the changes.

3.6.3 The Experience of Caring

Negative Aspects of Caring

The literature associates the role of carer with negative outcomes. There is a strong focus on the 'stress-coping' model (Wells & Kendig, 1997). The term 'burden' is used to describe their experiences (Braithwaite, 1990; Östman & Hansson, 2001; Rees, O'Boyle, & MacDonagh, 2001; Riemsma et al., 1999). Subjective burden refers to the degree of distress subjectively experienced by people with a chronic illness and those around them (Jahanshahi & MacCarthy, 1998). Subjective burdens include the degree to which the person finds the objective burden distressing, and the overall impact of coping over a long period of time with a chronic disease. The degree to which objective and subjective burdens coincide varies widely (Jahanshahi & MacCarthy, 1998). The levels of subjective burden are determined by the personal goals and expectations of the people concerned. Subjective burden increases or diminishes the impact of an objective burden (Jahanshahi & MacCarthy, 1998). Personal perception is the medium through which judgements are made regarding the nature of any given burden. Where subjective burdens are high, there is a greater chance the person will experience high levels of anxiety, distress and possibly depression than where subjective burden is low (Jahanshahi & MacCarthy, 1998).

Investigations of carers' perceptions of subjective burden have not found any link between the objective burden or work load and the care-giver's sense of burden (Braithwaite, 1990; Chow, 2001; Riemsma et al., 1999). Common issues that have been identified as facing carers are:

- Fear of the future;
- Depression and/or anxiety;
- Deterioration in partner relationship and/or sex life – decreased interest and enjoyment;
- Concern about suffering of patient;
- Implications of care giving role on own health (particularly the elderly);
- Fatigue/sleep deprivation;
- Social disruption – either through looking after spouse or unwillingness to attend social functions;
- Financial difficulties – patient and/or partner unable to continue working. Expense of private care and adaptations to home (Rees et al., 2001, p. 564).

Chesson (2003) found that the majority of carers had weak links with other family members, who were often geographically distant. As the demands upon carers increased, the level of support offered by family and friends decreased, and social services were offered too late. She described a spiral of social isolation that accompanied the assumption of the role of carer.

Rees, O'Boyle and McDonagh (2001) reviewed the literature on quality of life for carers of people with a chronic illness. They concluded that three characteristics influenced the quality of life perceptions of carers. They were the characteristics of the care giver, the characteristics of the care receiver and the characteristics of the care situation.

The characteristics of the care giver:

- Partners bore a larger proportion of burden than non-partners.
- Care giving seemed to have a greater negative impact upon female partners.
- Those who lived alone with their spouse experience isolation.
- If partners have unmet needs of their own it seems to heighten the sense of burden (Rees et al., 2001, pp. 564-565).

The characteristics of the care receiver:

- The mental health of the care receiver is more directly related to negative outcomes for the care giver than physical health.

- Behavioural disturbances on the part of the care receiver were more likely to have a negative effect on the care giver than cognitive impairment.
- Characteristics of the care situation:
- Where the care receiver is confined to the house the impact on the care giver is likely to be more negative than when the care receiver is able to participate in the community.
- Where the care receiver requires assistance with personal care it is likely to have a greater negative impact on the care giver than when assistance is given for household tasks only.
- When care is provided over a long period of time the care giver/care receiver relationship becomes increasingly important to the care giver's well being (Rees et al., 2001, pp. 564-565).

Other studies supported these findings (Braithwaite, 1990; Chow, 2001; Riemsma et al., 1999; Wells & Kendig, 1996), with long-term outcomes for carers including anxiety, depression and ill health (Lee, Strauss, Wittman, Jackson, & Carstens, 2001; Wells & Kendig, 1996; Wells & Kendig, 1997).

Carers dealing with behavioural problems and cognitive changes, such as those accompanying dementia, experienced the highest levels of stress (Lubkin & Larsen, 2002; Wells & Kendig, 1997). They were likely to report higher levels of mental and physical illness than carers of those without dementia (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Braithwaite (1990) identified what she termed the "crisis of decline" in care givers who observed signs of cognitive impairment and emotional disturbance in the person they were caring for. The response to physical deterioration was much less marked and Braithwaite concluded that the 'loss of a person' was much harder to endure than physical deterioration.

Positive Aspects of Caring

Despite the focus upon 'burden' and 'coping' in the literature, there was evidence of positive aspects to the experience of caring. For couples over 65 in Australia, where care givers were asked to report the effect giving care had upon their relationship, approximately 55% reported no change, 30% said it had brought them closer together and only around 15% said the relationship had become strained (Australian Bureau of Statistics, 2000).

Wells and Kendig (1997) questioned whether care giving was universally stressful. They pointed out that most studies used samples of people who had identified themselves as

carers seeking help from service providers. As such they were likely to be among those with the greatest negative experiences of caring. Second, there was an emphasis in the literature on care givers who cared for people with dementia, which is considered the most stressful caring task. Finally, Wells and Kendig (1997) observed that most studies cued the carer to focus upon the most negative aspects of their experiences.

Wells and Kendig (1997) studied married people who were 65 and over. They compared care giver groups with non-caregiver groups and found that 22% of current and former care givers reported themselves to be in excellent health as compared with 12% of non-care givers. Conversely, 45% of caregivers reported being under so much stress that their health was likely to suffer, versus 25% of non-care givers. They concluded that it was too simplistic to stereotype carers as the hidden victims of their spouses' illness. They suggested that care giving is a complex challenge that can provide a sense of competence and satisfaction that counterbalances the losses experienced. It is clear that more research is needed to further uncover the meaning of care-giving in the context of long term partnerships such as those of participants in this study.

3.6.4 Impact on Partner Role

If there are undoubtedly many negative aspects to being a carer, why is it that so many partners choose to be carers? Chesson (2003) identified the marital relationship as the central factor in sustaining the carer. Spouses showed greater commitment to the role than other carers (Braithwaite, 1990; Gilleard, Gilleard, Gledhill, & Whittick, 1984). Braithwaite found that those being cared for by their spouse required higher levels of reported care than those being cared for by others, indicating the willingness of the spouse to persist with caring for their partner at home beyond the level of care offered by non-spousal carers.

When caring for a spouse, it appears the role of carer is reinforced by the role of partner, forming a partner/carer complex role. The commitment shown by carers who are spouses reflects the long-term commitment each partner has made to the other over many years of marriage. The closeness of the relationship must surely have a major impact. A sense of reciprocity was identified as significant by Krause, Herzog and Baker (1992) who suggested that informal care giving allowed the care giver to experience a sense of balance.

One hypothesis that stems from the literature reviewed is that spouses might experience greater satisfaction from caring and have higher levels of personal control than other carers, counterbalancing Braithwaite's (1990) 'crisis of decline'. Furthermore, as the person with a chronic illness's condition worsens, it seems likely there is a sense of loss of control on the part of the partner/carer as their support is no longer viable.

3.7 Caring and Parkinson's Disease

Studies describing the nature of caring for someone with Pd are recent in origin. The findings reflect those for more general studies on chronic illness. Studies tend to focus on negative caregiver outcomes such as declining health status and caregiver burden (Berry & Hardman, 1998; Speer, 1993; Waite, 2000). Few describe the process of caring over the course of the disease. Fewer still consider caring in the context of being a partner. Typically, studies of couples experiencing Pd do not refer to the 'partner' but only to the 'carer' of the person with Pd, even when care is not being given. The person with Pd is referred to as the 'patient' in the majority of these studies. There appears to be a lack of consideration of the fact that there had been a prior, much more deeply established role as spouse before caring became an issue in the partnership. This infers an assumption that the marital relationship has virtually disappeared with the advent of Pd. This contradicts the finding of Chesson (2003) that the marital relationship is central in sustaining the carer of a partner with a chronic disease.

3.7.1 The Experience of Caring for People with Parkinson's Disease

Two major studies were found that discussed the experience of caring for people with Pd. In an American study, Carter et al. (1998) used a cross-sectional design to examine caregiver role strain, caregiver tasks and caregiver health by stage of the disease, using the Hoehn and Yahr scale (1967). They summarised the scale to early, middle and late stage disease. They used a questionnaire to study 380 participants who were spouses of people with Pd. In a British study, Davies, Cousins, Turnbull, Playfer and Bromley (1999) conducted a longitudinal study of 83 couples in which one partner had Pd. Each person was interviewed twice, with the second interview being approximately 14 months after the first. Couples were at different stages in the disease process when recruited to the study, allowing a longitudinal view across the progression of the disease. They used their findings to

describe the experience of caring by stage of the disease, using four stages similar to the phases identified by Jahanshahi and MacCarthy (1998) earlier. The findings of the two studies are summarised together as follows:

Early Parkinson's Disease (Onset and Diagnosis)

In the onset and diagnosis phase, symptoms, because of their insidious onset, were often dismissed as 'getting old' or attributed to other causes. There was commonly a period of wondering or worry lasting several years, while symptoms increased. It was often the partner of the person with the symptoms who eventually pushed for a medical consultation. This consultation did not always result in an accurate diagnosis and partners worried that the person might have had a stroke or a psychological breakdown. The uncertainty prior to diagnosis was stressful to partners. When the diagnosis was made, some partners were relieved, while others were distressed. In relation to knowing, most couples had little knowledge of Pd prior to diagnosis. Partners with little knowledge tended to try to carry on as normal. Denial was common and such partners did not express concern. Others, who knew more about the disease expressed feelings of concern and fear about the future (Davies et al., 1999). Carter et al. (1998) found that caregiver strain was low in the early stages of the disease.

Mild Parkinson's Disease (Early Phase)

Time demands from partners in terms of care were generally low (Carter et al., 1998), but varied quite widely from one partner to the next (Davies et al., 1999). Partners who had a job were able to keep working (Davies et al., 1999). Davies et al. examined why there was such a range of time given to care. The variation did not relate to level of functional performance, but rather to the pattern the couple had already established in their marriage. At this stage, there was a choice about how much assistance to give (Davies et al., 1999). Partners felt they did little for the person with Pd, seeing the assistance they did give as an extension of what they did as a matter of course as a partner. Some felt the situation was better because their partner was now on medication (Davies et al., 1999). Carter et al. (1998) found that spouses showed little to no role strain in this stage. Davies et al. (1999) found that 48% of spouses felt at this stage that the situation was 'not at all hopeful'. Changes in knowledge about the disease were not reported in either study.

Moderate Parkinson's Disease (Middle Phase)

The number of caring activities that partners did increased markedly from the mild stage. Davies et al. (1999) found that the carers in their study recorded a mean of 21 hours of caring per week. Carter et al. (1998) measured the number of care-giving activities performed and found it doubled from the mild phase. Davies et al. (1999) again found that the amount that spouses did for their partners varied greatly and that the variation did not correspond to the level of disability being experienced by their partner. By this stage most spouses were providing some assistance with getting out of bed, bathing and dressing (Davies et al., 1999). Some couples had started to modify their home to make things easier (Davies et al., 1999). Once the first dose of medication had been metabolised the partner needed less help through the day. Some partners were prone to falls and these spouses felt the need to be very vigilant. Carter et al. reported significant negative lifestyle changes for the spouse starting at this stage. Role strain increased significantly (Carter et al., 1998). By the end of this stage Carter et al. reported increased tension and frustration as a result of communication problems. Worry, strain from direct care, role conflict and global strain all increased. Davies et al. reported that hopefulness increased slightly. One in seven felt angry about the Pd. Changes in knowledge of Pd were not reported.

Advanced Parkinson's Disease (Late Phase)

The mean number of care-giving activities carried out by the spouse trebled from mild to advanced Pd in Carter et al.'s study. They found that spouses reported they received very little help from others, other than more formal care such as home help, day care, and care aides. Davies et al. reported that caring for someone with advanced Pd was often a 24 hour job. The mean of hours of caring per week at this stage was 54. Hallucinations and dementia were common among this group (Davies et al., 1999). By this stage, role strain had increased significantly, with the added factors of financial uncertainty, a lack of resources, feelings of being manipulated and unmet expectations. The average care-giver in Carter et al.'s study was reporting a 'moderate' amount of lifestyle change. Care giver health did not change across the three stages in their study. In particular, depression did not increase significantly, although it did increase slightly. In earlier stages, predictability or a sense of

control had not been an issue, but by this stage ratings of predictability had declined significantly, leading to a much lower sense of perceived control (Carter et al., 1998).

3.7.2 Parkinson's Disease and the Partner/Carer Complex

Caring is an interpersonal process. Its success depends upon the beliefs and qualities of both the care recipient and the carer (Hall, 1990). This is the case for those who care for people with Pd. As the disease progresses, the relationship between the care recipient and carer is reported to change over time, requiring renegotiation and the establishment of different equilibriums (Davies et al., 1999).

Habermann (2000) investigated the experience of being a partner of someone with Pd and identified some of the coping strategies that such people develop. Very few other studies have considered coping strategies. She avoided the use of the term 'carer' and designed her study to allow her participants to talk about what they considered most important. She chose to interview people in middle age and interviewed eight spouses in depth using a semi-structured interview. Two of her participants were providing care to a partner who was in Hoehn and Yahr's (1967) stage one, one was at stage two and five were at stage three. None were in the later stages of the disease.

She identified the primary challenge of the spouse as having to witness their partner's struggle to manage the illness. Participants recounted their distress at having to observe their partner's frustration and unhappiness. Participants experienced the same losses as their partner: loss of employment, difficulty in pursuing interests and hobbies, and problems in continuing with many of the activities they used to do together. This meant they had to renegotiate how they spent time together, including a reduction in social activities and changes in sexual relationships.

Habermann (2000) found that changes were not universally negative with five of the eight participants reporting their partner's illness had a positive influence upon them, leading to their further development in various ways. Three common strategies leading to positive outcomes identified by Habermann's (2000) participants were to maintain their own life, look upon the challenges they faced as a couple as secondary to the relationship and encourage their partner to remain active and involved. Spouses reported doing anything they

could to be supportive, and described this as being ‘what one does for one’s partner’, rather than seeing the role as the management of the illness.

Participants saw what they were experiencing as being secondary to the experiences of their partner, who had to live with the disease. They often expressed respect and admiration for how their partner was coping. Spouses felt that they would be able to face the challenges of the future together as long as their partner was able to continue doing things that were personally satisfying and meaningful. Overall, her participants appeared to experience a satisfactory level of perceived control.

Habermann (2000) concluded : “Rather than experiencing their relationship as a care giver-care receiver dyad, they experienced their partners’ illness in the context of their past and ongoing relationship” (p. 1414). She observed that this suggested that their partners’ illness did not require the acquisition of a new role (carer) as spouses saw what they were doing as an extension of their current role as marital partner.

It should be remembered that none of Habermann’s (2000) participants were in the later stages of Pd where symptoms increase markedly and medication loses its efficacy. The people in her study were in middle age rather than later life and were less likely to be experiencing other health problems. The work of Davies et al. (1999) and Carter et al. (1998) showed that there is a marked decline in the spouses’ sense of perceived control in this final stage of the disease.

Perceptions of the marital relationship were identified in Davies et al. (1999)’s study. They found the positive changes reported by Habermann (2000), but also found that where there was a personality change, spouses found the quality of the marital relationship declined. For these people, lack of communication was a major problem. Carter et al. (1998) found that the positive qualities of the marital relationship declined significantly during the course of the disease.

Summary

This chapter has reviewed the literature regarding the impact of chronic illness, and of Pd upon the everyday lives of people with the illness and their partners. It has identified that the sick role, as described in classic role theory, does not fit with being chronically ill, perhaps leading some health professionals to view chronic illness inappropriately as a result. It has discussed how the rehabilitation model can foster this unhelpful attitude, leading occupational therapists using this model to become frustrated when working with people who are chronically ill.

This exploration of the literature on chronic illness, Pd, partnership and caring has identified a recurring theme: Having a perception of satisfactory levels of control in relation to what is personally meaningful is central to the well-being of people with chronic illness and their partners (e.g. Braithwaite, 1990; Brod et al., 1998; Davies et al., 1999; Habermann, 2000; Ironside et al., 2003; Jahanshahi & MacCarthy, 1998; Krause et al., 1992). The next chapter will examine the concept of perceived control in more detail.