

# **CHAPTER ONE**

## **INTRODUCTION**

## 1.0 Background to Study

The purpose of this study was to gain a better understanding of how people with a chronic illness such as Parkinson's disease (Pd) lived with their illness. In particular, it sought to provide an understanding of whether such people managed to maintain a sense of purpose and meaning in their lives. People with a chronic illness such as Pd can live and age in the community for many years, with the disease eroding levels of occupational performance related to personally valued roles. Little is known about whether they can control the impact the disease had upon their lives.

Occupational therapists view the loss of life roles that occurs with the onset of disability as a major problem (Pedretti, Smith, & Pendleton, 1996). However, the occupational role performance of people with Parkinson's disease and other chronic illnesses has not been well documented. There has been an assumption that in simply restoring function, occupational therapists were preparing clients for satisfying occupational performance in their valued roles. Occupational therapy functional outcome measures have mostly related to standardised activity of daily living (ADL) measures, rather than role performance (Hillman, 1999). However, many respondents in studies of people with Pd reported a lower level of life satisfaction and a higher level of depression than the general population (Gillen, 2000). Such studies have demonstrated that individual differences in adjustment to the disease appear to relate to the perceived impact of the illness. These differences were unrelated to the amount of physical dysfunction or the level of performance in self-maintenance tasks (Findley, 1999; Muldoon, Barger, Flory, & Manuck, 1998). This indicates the need for greater attention to investigating higher order functioning and sense of well-being in people with Parkinson's disease. Although partners of people with chronic illnesses such as Parkinson's disease are almost universally referred to as 'carers' in the literature, some studies have described partners who did not perceive themselves as carers (McPherson, 2004). There were positive and negative aspects to care (Wells & Kendig, 1997).

The social interactions of people with a chronic illness and their partners or carers have not been well documented. Little is known about the everyday performance of their roles in later life, with information based largely on anecdotal account (Brod, Mendelsohn, & Roberts, 1998). Questions that remain unanswered concern the nature of occupational role

performance for older people at the onset of a carer giver/care receiver relationship. Specifically, what happens to role performance following the advent of chronic illness? How does disability affect role performance in later life? What resources do older people use to facilitate role performance? What choices do older people make about their role performance?

## **1.2 Need for the Study**

This study represented the views of an increasingly important social group in the current ageing population. Parkinson's disease and other chronic illnesses are increasing in incidence as a consequence of the extended life span. The community partnership of care receiver/care giver is highly significant in maintaining older people with chronic illness in the community. The information gained from this investigation has direct application to the provision of effective community support and community services for this group.

The discipline of occupational therapy is based upon the philosophy of the human need to engage in purposeful daily occupation or *doing* (Meyer, 1977). This has led occupational therapists to deal with many issues that extend well beyond the scope of self maintenance and safety that is often viewed as paramount in a hospital or rehabilitation setting. Despite therapists' contribution to the development of interventions that facilitate the performance of daily tasks and routines (Law, Baum, & Dunn, 2001; Neistadt & Crepeau, 1998; Pedretti, 1996), the literature indicates that occupational therapists have not always been effective in targeting the areas of occupational performance that are meaningful to clients in the context of their daily lives (Campbell, 1994; Hawking, 1996). Professional knowledge of how clients actually perceive their daily performance appears minimal (Hillman & Chapparo, 2002f).

Occupational therapists have a pivotal part to play in scaffolding the support to enable people with Parkinson's disease and their partners to maintain a positive sense of control and well-being in regard to valued occupational role performance in their own community. People with chronic illnesses such as Parkinson's disease are prevalent in the caseload of occupational therapists working in the community with elderly people, and are commonly seen by therapists working in other areas such as acute care, adult rehabilitation and aged care services. Within these service delivery contexts, occupational therapists have a

mandate to develop and implement therapy programs aimed at promoting maximum levels of independence in life skills and optimal quality of life (Chapparo, 1997). There is an obligation to do this in the most efficient and cost effective way possible (Rogers & Holm, 1994). In the area of community services, as in other areas, the concerns of occupational therapists are not simply with the satisfactory restoration of lost function, but with occupational performance in everyday life that is specific and meaningful to each person.

Parkinson's disease is a chronic illness. As the disease progresses, people face increasing levels of disability. Yet perusal of support group magazines and websites indicates that people with Parkinson's disease are often active in their community for many years. Partners have to deal with the disease as it impacts upon their own lives. How do such people cope with maintaining a personally meaningful life? Information about the everyday lives of people living with chronic illnesses such as Parkinson's disease is sparse. This study has helped to fill a gap in knowledge about daily life from the perspective of people with Pd and their partners. It has provided information about personal coping strategies and personal control in the presence of Parkinson's disease which may be useful in to clinical practice, and inform further theory development and research in this important area.

### **1.3 Purpose of Study**

The overall purpose of this study was to:

1. Describe the manner in which people with a chronic illness such as Parkinson's disease and their partners continued to actively maintain the roles required to participate as members of their social environment.
2. Investigate if and how such people maintained an acceptable sense of perceived control in their everyday occupational role performance.

The particular focus of chronic illness was chosen because it represented:

- one of the largest areas of practice in occupational therapy,
- a social group of increasing importance with the current ageing of populations in Australia,

- a group of people that represents the trend towards an increasing rate of morbidity in later life,
- a community partnership (care receiver / care giver) of increasing importance with the current ageing population and rate of morbidity,
- a specific disease (Pd) that is increasing in incidence,
- an area of intervention for older adults with a chronic illness or disability that is familiar to the researcher.

Central to the overall purpose were the following five research objectives. To describe the:

1. Perceptions of the nature of occupational role performance of the twenty-five participants by investigating such dimensions as:
  - the experience of occupational role performance as perceived by the participants.
  - The perceived value and satisfaction of occupational role performance.
2. Barriers to occupational role performance experienced by the participants by investigating such dimensions as:
  - the nature of barriers to occupational role performance as perceived by participants,
  - whether barriers are related to the symptomatology that accompanies Parkinson's disease or factors consequent upon that symptomatology,
  - the extent to which Parkinson's disease results in barriers to social and psychological well-being.
3. Strategies or coping plans developed by participants to maintain a perception of control over their occupational role performance by investigating such dimensions as:
  - the nature of problem solving or planning undertaken by participants,
  - the resources utilised in dealing with perceived barriers to control,
  - participants' perceptions of what constitutes satisfactory outcome in relation to control of occupational role performance.
4. Changes in the occupational role performance of people with a chronic illness (Parkinson's disease) and their partners by investigating such dimensions as:

- the differences in occupational role performance of participants at different stages of the disease,
- the differences in the barriers described by participants at different stages of the disease,
- the differences in perceived success of coping plans at different stages of the disease,
- the differences in participant's perceptions of personal control at different stages of the disease.

## **1.4 Definition of Terms**

These definitions provided the conceptual focus at the outset of the study.

### Role

Role theorists define role in diverse ways. A simple definition is that “Role refers to the expected and actual behaviours associated with a position” (Hardy & Hardy, 1988b, p. 165). Within the discipline of occupational therapy, roles are defined as “a set of behaviours that have some socially agreed upon functions and for which there is an accepted code of norms (Christiansen & Baum, 1991, p. 857). In this study, the occupational aspects of role will be considered. Occupational therapy theory holds that role has three closely interacting components: social role, cultural role and occupational role (Moorhead, 1969; Vause-Earland, 1991).

### Occupational Performance Role

Occupational performance roles have been defined as “roles that are composed of patterns of occupational performance that are determined by a person's requirements of daily routines of self-maintenance, productivity, leisure and rest within specific sensory, physical, cultural and social contexts” (Chapparo & Ranka, 1997a, p. 5). The term occupational role performance refers to the behavioural aspects of the role. Occupational performance role can be seen as part of a hierarchy of occupational performance.

### Occupational Role Performance

A formal definition of occupational role performance was not found. However, perusal of occupational therapy literature has led to the following conceptual definition. Occupational role performance refers to behaviour that is motivated by the roles held and results in interaction with environments or contexts specific to each role. Such behaviour is purposeful, strongly linked to role partners and intended to answer social and personal needs perceived by the role holder and/or role partners. There are social rules that guide occupational role performance (Chapparo & Ranka, 1997b; Christiansen & Baum, 1991; Kielhofner, 1995). The outcome of occupational role performance affords high levels of satisfaction and hence well-being when personal needs are met. In this study, occupational role performance was considered largely from the perspective of the performer. The term is indicated by the acronym 'ORP'.

### Perceived Control

Perceived control is defined as the degree to which people believe their behaviour will influence outcomes in their lives (Bertrand & Lachman, 2003). In this study, perceived control was used to describe the degree to which participants felt able to control their personal context and performance at any given moment in relation to personally meaningful ORP.

### Context

The social, cultural, sensory and physical environment that surrounded the person during ORP was termed his or her context (Chapparo & Ranka, 1997a). In this study, the context considered is that which is role specific.

### Chronic Illness

Chronic illness has been defined in a number of ways. The following definition focused upon the experience of the person with the illness:

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 (Ironsides et al., 2003, p. 172).

In this study, the chronic illness being studied was Parkinson's disease. Parkinson's disease is represented by the acronym 'Pd'.

### Partner

The term partner refers to role partner. Role partners are those who have related positions and who interact with the role occupant in the performance of a given role (Biddle, 1979). In this study, someone was considered a partner if they were nominated as such by a participant with Pd. Participants with Pd were asked to nominate someone who was a "significant activity partner", or someone whose life was significantly entwined with theirs.

### Carer

A carer is someone who is perceived to care for someone else and is ascribed the role of carer by those around them. Social expectations are that a carer has primary responsibility for the provision of care (Lubkin & Larsen, 2002). In this study, a carer was someone who provided assistance to someone with Pd and who identified themselves specifically as a carer in addition to being a role partner.

## **1.5 Design of Study**

In this study, participants with Pd and their partners were interviewed in depth about their most significant roles, what they *did* in these roles, the *knowledge* or strategies they employed to deal with everyday barriers to *doing*, and the *personal meaning* such roles had. Investigating the nature of ORP and perceived control in people with a chronic illness was primarily a descriptive task requiring:

1. the identification and analysis of relevant variables from the literature, and,
2. an appropriately chosen group of people with Pd and their partners.

A naturalistic qualitative form of enquiry was selected to achieve this (Guba, 1981). Research methods employed tape-recorded semi-structured interviewing of selected

participants in their own homes with coincidental field observations. Constructs from the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997a) were used to develop areas of enquiry in the semi-structured interview. Role performance has been described as a product of people and their environment (Chapparo & Ranka, 1997a; Larsson & Bränholm, 1996). The model chosen offered one view of the person–environment relationship in terms of role. Occupational performance roles were seen as the central organising construct of the model. This model applied the construct of role to everyday performance in a way that allowed for the consideration not only of specific role performance, but also the antecedent and subsequent physical, cognitive and emotional processes relevant to that performance (Chapparo & Ranka, 1997a). Such a view compelled a style of enquiry that yielded descriptions of behaviour that might be observable to others, and of the thinking and feeling aspects of role performance.

Inductive qualitative analysis using the constant comparative method (Portney & Watkins, 1993), was employed to identify and describe elements of the nature of ORP, perceived losses of control, and strategies developed for restoration of personal control. These descriptions were based on the analysis of data from those who participated in the study. Analysis of earlier interviews informed later interviews, suggesting additional questions to ask and areas to explore.

## **1.6 Summary of Findings**

Personally meaningful activity and the need to contribute to community life were of great importance to the participants. The significance of the disease was seen principally within the context of its impact upon ORP. Participants dealt with the barriers Pd presented to them in an active and intensely personal manner, and worked towards maintaining personal control.

Four major themes were identified, with each theme leading on to the next:

1. The impact of the primary disease process upon *doing* in everyday roles.
2. Secondary personal limitations to occupational role performance.
3. Secondary social limitations to occupational role performance.

#### 4. Occupational role performance limitations in valued roles.

Consideration of the findings, together with information from the literature about role, ORP, perceived control in chronic illness and, more specifically, Pd led to the proposal of a dynamic model to describe the process of seeking to maintain personal control of significant ORP. This conceptual model described elements of personal control and was named the Cycle of Control Model. It was intended as one interpretation of how participants with Pd and their partners perceived barriers to ORP and developed strategies to cope with these barriers.

### **1.7 Relevance of Findings**

The results of this study may encourage occupational therapists and other health and social care service providers to consider people with chronic illness as (1) active and knowledgeable participants in health care, (2) people with histories and experiences that can be tapped in order to achieve goodness of fit in the provision of health services. A greater understanding of personal goals, coping styles and social fit could enable health professionals to work more effectively as partners in care, utilising strongly focused interventions, and avoiding a wastage of resources.

Implications for therapy across all disciplines were that generalised advice may be less useful to clients with chronic illness than a discussion that relates more specifically to their own roles and coping style. The results indicated that people organised and actively controlled their lives in idiosyncratic and personal ways. The proposed Cycle of Control Model may be useful as the basis to development of an assessment tool to enable therapists to pin-point where and why clients are having difficulties in establishing a role specific sense of personal control. Further research to investigate the extent the findings can be generalised may lead to new ways of interacting with clients that acknowledge them as partners in care rather than as recipients. Please see Table 1.1 for an outline of the phases of research and organization of the thesis.

**Table 1.1 Phases of research in the study and organisation of the thesis**

<p><b>PHASE ONE</b> (Reported in Chapters Two, Three and Four)</p>
<p>A <b>literature review</b> of research on the concept of role in the social sciences and occupational therapy, chronic illness, Pd, the effectiveness of occupational therapy services, partnership, caring, and perceived control.</p> <p><b>Outcome:</b></p> <ol style="list-style-type: none"> <li>1) A description of role and occupational role content and process that have been previously identified through research.</li> <li>2) Identification of variables that have the potential to impact upon people with chronic illness, people with Pd, and people who are their partners, together with the services offered by health professionals.</li> <li>3) A description of perceived control content and process that has been previously identified through research.</li> </ol>
<p><b>PHASE TWO</b> (reported in Chapters Five and Six)</p>
<p>A <b>naturalistic study</b> that explored the content of occupational performance roles and the nature of losses and restorations of perceived control in the context of ORP in a group of people with Pd and their partners.</p> <p><b>Outcome:</b></p> <ol style="list-style-type: none"> <li>1) A description of the nature and content of occupational roles and role performance as identified and related by a group of people with Pd and their partners.</li> <li>2) Descriptions of specific losses and restorations of perceived control in the context of ORP as related by a group of people with Pd and their partners.</li> </ol>
<p><b>PHASE THREE</b> (reported in Chapters Seven and Eight)</p>
<p>Consideration of the findings from this study as they relate to the existing literature, implications for clinical practice and recommendations for further research.</p> <p><b>Outcome:</b></p> <ol style="list-style-type: none"> <li>1) The formulation of a preliminary conceptual model of a cycle of control in ORP</li> <li>2) Description of constructs and their possible relationships.</li> </ol>