

CONCLUSIONS
AND
RECOMMENDATIONS

8.1 Introduction

The purpose of this final chapter is to provide a concise overview of the research study as a whole, in order to determine what has been learned and what significance the findings have for the occupational therapy profession and other health professionals. The chapter provides a brief overview of the purposes, methodology and outcomes of the research. This is followed by a discussion of the limitations of the study and of its theoretical, methodological, empirical and practical significance. The study has generated some hypotheses and implications for future research and practice and recommendations are made about these. Once the study has been reviewed, and the findings placed in context, its conclusions are stated.

8.2 Overview of the Study

The study was prompted by an interest in how older people cope with occupational role performance required for living in the community in the presence of chronic illness. What is their quality of life like? Do they take steps to maintain their sense of occupational 'fit' in the face of losses engendered by the disease, and if so, how do they do this? A concern regarding the effectiveness of occupational therapy interventions for people living in the community formed the basis for the need for this study. Occupational therapists are commonly expected to enable clients to maintain personally meaningful occupational role performance (ORP) in the presence of chronic illness. However, there is little reliable information about the occupational performance roles of older people living with chronic illness. In particular, little is known about people with Parkinson's disease and their partners, who may live in the community for many years following diagnosis. Although perceived control is strongly linked to a sense of well-being in the literature, it has not been considered in relation to the ORP of people with a chronic illness.

Occupational role performance is a construct that remains ill-defined. Descriptions of occupational roles are based largely on assumption, rather than empirical data, making effective therapy designed to address problems at this level of performance difficult. In particular, there is little consideration given to how people perceive their ORP and whether they are able to maintain a sense of control in personally valued roles. In the light of these considerations, the research purposes of this study were:

Research Purpose One

To 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.

Research Purpose Two

To investigate how such people maintained an acceptable sense of perceived control in their everyday occupational role performance.

The research purposes, as stated in Chapter One, were addressed by means of a substantial review of the literature and a naturalistic study. The literature reviewed related to social, anthropological and psychosocial role theory, and the application of role theory in occupational therapy; chronic illness, Parkinson's disease and occupational therapy services; partnership and caring; and perceived control. Variables that might affect perceptions of occupational role performance of participants in this study were identified. Very little information was located about the self-perceived ORP of people with Parkinson's disease or other chronic illnesses and their partners. Although some literature was identified regarding coping behaviours in the presence of Parkinson's disease, it gave the external, generalised view, rather than providing insights into how people might work to maintain or regain a sense of personal control over their own occupational performance.

This literature review was followed by a naturalistic study that explored perceptions of the ORP of fourteen people with Parkinson's disease and eleven partners who were living in the community. The participants were interviewed once using a modified version of the Occupational Performance Role Assessment (OPRA) (Hillman, 1999) (see Appendix 5.1), that was designed to examine the *doing*, *being* and *knowing* elements of self-perceived ORP (see Appendices 5.8, 5.9 and 5.10). Data were recorded in the form of field notes, digital photographs, and tape recordings. Inductive qualitative analysis of this data revealed the following findings.

Participants were able to identify and discuss their roles and ORP. They had no difficulty indicating which roles were most important to them. They demonstrated that they

were still participating, to a greater or lesser extent, as members of their community. Four major themes emerged from the data. The order of these themes was significant as they had a cumulative effect. The first related to the impact of disease processes on ORP *doing*. The second theme related to the secondary personal limitations to ORP produced by these changes. The third theme related to the social impact to ORP participants experienced as a result of the losses of themes one and two, and to the attitudes they perceived others had towards them. Their sense of self and social fit changed. These three themes combined to produce the final theme, which was the negative impact upon the individual's ability to participate as a member of his or her community. Partners were affected indirectly by these themes in relation to the degree of support they gave.

It became evident from the data that the secondary psychological and social impacts of the disease were more significant than the physical symptoms themselves. Sense of self and social fit were highly significant factors in participants' perceptions of the impact of Parkinson's disease.

Parkinson's disease was viewed as delivering a series of personal *barriers* to desired ORP. These barriers were often complex, because they were the product of the both the symptoms and the individual responses to it. Participants made efforts to regain or maintain the course, or trajectory of their life roles, developing and employing *strategies* to overcome perceived problems. Sometimes they were successful, sometimes they were partially successful and sometimes they failed. Personal barriers had the largest impact when they impacted role performance in what were perceived as major roles because they impacted upon perceptions of sense of self and social fit.

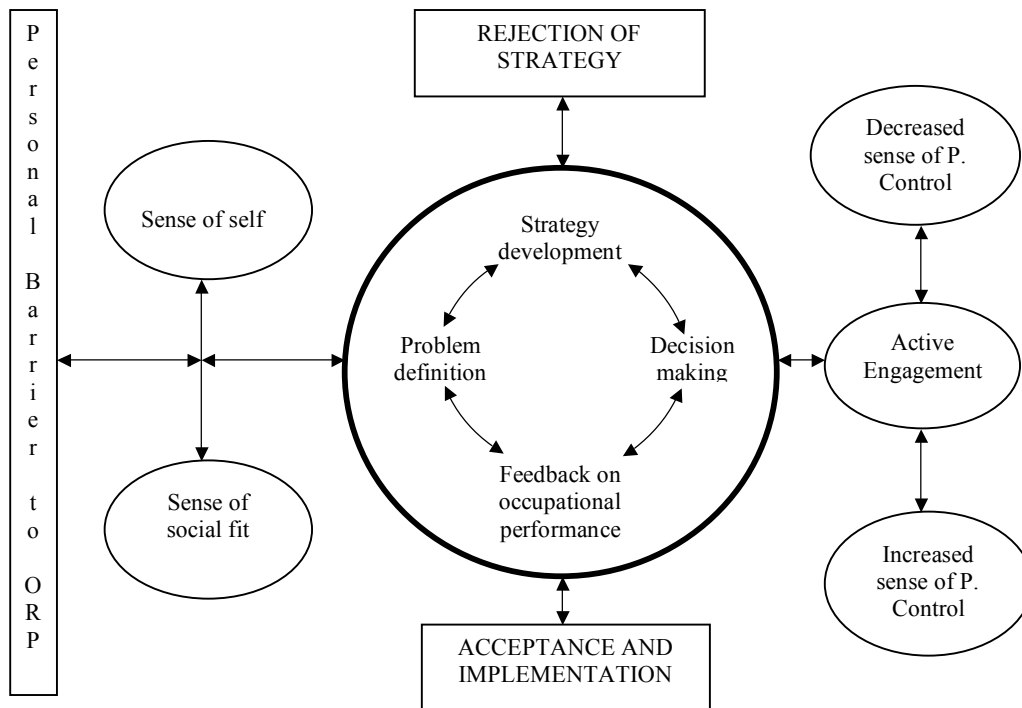
Although there was a general trend over the course of the disease towards a greater number of personal barriers that could not be overcome, there was no direct link between the stage of the disease process and its impact upon the individual. The impact was mediated significantly from one individual to another. The manifestation of a particular symptom could have a major impact upon one participant and only minor effects upon another. Personal barriers were not always clear cut. One barrier might have a very specific impact, but more often the barrier impacted upon an individual in a variety of ways and at a variety

of levels. Similarly, strategies developed by participants could be specific, but often had multiple outcomes at a variety of levels.

Participants attempted to maintain primary control of their lives. They were not passive recipients of impacts. They all tried to deal with what was happening to them and they were highly individualistic in the way they did this. The strategies they employed to soften the impact of the disease varied widely. The type of control achieved by participants varied according to the stage of the disease process. Participants with Parkinson's disease appeared able to achieve primary control, modifying their environment, more frequently in the early to middle stages of the disease. Those in the middle to late stages more often appeared to achieve forms of secondary control, modifying themselves. Participants in the late stage often appeared to feel they had little control over their ORP.

Generally speaking, the partners of those with Parkinson's disease were unconcerned with control issues in the early stage of the disease, supported and worked together with their partner to mitigate problems in the middle stage, and exerted considerable control over their partner in the late stage. At the same time, partners of those in the late stage felt they had little control over their own lives, with the role of carer leading to role loss in other life areas. The findings contributed to the development of a dynamic model that represents one possible interpretation of the data to explain how participants worked to maintain a sense of personal control over their occupational role performance in their everyday lives. This model suggested that a personal barrier was perceived by participants in terms of its impact upon sense of self, social fit and valued ORP. It described a coping process that involved the use of a personal blueprint, consisting of knowledge about themselves and their past transactions with various external contexts, which could be represented as a set of rules or procedures. This personal blueprint assisted in defining the problem in personally relevant terms, prompting the use of strategies that fitted their personal needs, trying out these strategies, and either accepting or rejecting them. An important part of this model was the idea that outcomes may be personally acceptable even when they result in loss of some personally meaningful ORP (see Figure 8.1).

Figure 8.1 The Cycle of Control Model



8.3 Limitations of Study

Limitations of the study related to the characteristics of the participants, to the data gathered, to the data gathering techniques and to the data analysis techniques. There were attempts made, in conducting the research, to compensate for the effects of the limitations.

8.3.1 Limitations Associated with the Characteristics of the Sample

The small number of participants chosen for the study was partly determined by the large amount of data produced by the forty-four interviews, and partly by a sense of repetition emerging from the data analysis of the participants interviewed. It is recognised that the findings relate only to the twenty-five participants studied and that other participants may have reported a different set of self-perceptions in relation to ORP.

The participants were a non-representative group of all people with Parkinson's disease and their partners in Australia, having volunteered as a result of talks given to five Parkinson's support groups within the Sydney metropolitan area. Given that this was a

descriptive study of an area in which little information was previously available, it was considered difficult and inappropriate to set relevant criteria for selection to ensure participants were representative of all people with Pd.

The participants represented a particular sub-group of people with Parkinson's disease, in that they were all people who chose to attend a support group. The literature showed that only 5% of people on Parkinson's specific medication in NSW are members of Parkinson's NSW Inc., although the Association believes quite a number attend their support groups who are not members (Irwin, 2005). It is possible that those who attend support groups are likely, as a group, to be more socially orientated and more interested in being proactive in managing their disease than those who choose not to attend. In relation to perceived control, this would indicate that the participants in this study were perhaps more motivated to maintain a positive sense of personal control than the much larger general population of people with Parkinson's disease and their partners. It might also mean that these participants were more accepting of their Pd, and that possibly those who were attempting to maintain perceived control by mechanisms of denial would not attend such groups. As volunteers, they represented a group who were prepared to talk about their experiences in a way that others might not.

There was a gender bias within the sample, with an overall bias towards women with Pd (eleven women to three men), and a consequent gender bias with partners. Although participants were asked to select a partner who could be their spouse, a family member or a friend, the majority selected their spouse. This meant that the majority of partners were male (four women to seven men). In view of the literature on gender and caring, this gender bias would have had a definite effect. It is likely that people of differing genders would also view their ORP differently. No gender based conclusions have been drawn in this study, but it is possible that the findings largely reflected the experiences of women who have Pd and men who are partners.

No attempt was made to limit participants to people from a particular social stratum or income level, although subjective perceptions from visiting their homes and from the way they described their lives indicated that participants were homogeneous in this regard, with

one or two exceptions. In view of the literature on the relationship between health and income levels this may have had an impact upon the findings.

8.3.2 Limitation in Data Gathered

This study was about the personal perceptions of ORP and consequent community participation of this group. This means that the data gathered was intrinsically limited by the interview method of data gathering. It is not possible to gain complete access to another person's mind. Research at best can only gather external data and make inferences about the nature of participant thinking about their ORP. Efforts were made to verify information, by getting each participant to nominate his or her own roles, to confirm these and to sort and rate them in various ways. This data was subsequently compared with the transcript. A brief summary of each interview was written and participants were asked to read it and confirm or correct it prior to the next interview as one way to redress this limitation.

In the first stage of data collection, the data gathered was limited by being a 'snapshot' study, gathering information about the self-perceived ORP of the participants at the time of the interview only. In the second stage of data collection participants were interviewed three times over a period of months. This approach confirmed that ORP in various roles did change over time, emphasising the dynamic nature of ORP. Findings generated by this study would need to be considered with this in mind.

8.3.3 Limitations of the Data Analysis Techniques

It is recognised that in all qualitative research the perceptions of the researcher will affect the interpretation of the data to some extent. Theoretical, practical and life experiences of the researcher in this study have been stated, and another researcher with different theoretical and professional experience may have interpreted the data in different ways. In an attempt to reduce possible researcher bias, a number of transcripts and related data were reviewed by an independent academic researcher using the same analysis techniques as the first researcher. Comparisons were made between thematic characterisations of the data which indicated general agreement between the two analyses. More importantly, checks on interpretations were made with participants at the time of the interview regarding role

identification, naming, sorting and rating of roles, and for second stage participants, by means of a written summary of each interview.

8.4 Significance of Study

In fulfilling both of the research purposes, this study has made a contribution to occupational therapy theory and to research methodology, and has important implications for occupational therapy practice in the area of valued ORP and its relationship to perceived control.

8.4.1 Theoretical Contribution

This study was unique in gathering information on a number of different levels about individuals' views of their lives using the construct of role. While role is generally described in terms of externally observable behaviour and the expectations role partners, this study assumed it was possible to consider both this external view and the internal view and expectations of the person occupying the role, as two parts of the same phenomenon. As such, this study has merged divergent theoretical views of role. The study challenged the sociological view that data about role be gathered via objectively observable behaviour. Occupational therapy research on ORP has tended to reflect the assumptions of the social sciences and has largely investigated people's abilities to comply with the demands or expectations of those around them, with less consideration given to the perceptions of the role performer about the very individual choices he or she might make. A basic assumption of this study was that the self-report or *perceptions* of the participants can provide trustworthy data.

Using the perspective of the holder of the role, the study provided valuable information about what participants perceived they *did* in a given role, what participants perceived they *knew* about themselves and their context in any given role, and how participants experienced *being* as personally important ORP.

The study provided detailed descriptions of personal barriers to ORP identified by participants and the strategies they employed to cope with them. While some of this information is available elsewhere in the literature, most is reported in generalities. There is

little specific information that provides insights into the highly personal perspective of people's own ORP and their interactions with occupational role partners within the context of their everyday lives. This study has developed the concept that sense of self and sense of social fit as they relate to valued ORP are of major importance to a satisfactory sense of personal control.

The study has suggested the existence of a personal *blueprint* or set of plans that participants referred to when selecting a coping strategy for generating occupational performance that would fit with their personal set of circumstances. This concept is an innovation that does not appear to have been suggested elsewhere.

The study has proposed a dynamic model, termed the cycle of control. The model extends theoretical views about how people cope with disability, by suggesting a way in which participants actively responded to the perception of a barrier to ORP in order to develop a coping strategy that they believed might work for them.

The Occupational Performance Model (Australia) was used to inform this study in its early stages and is one international practice model that is continuing to be refined. The study has further developed the concept of occupational performance role as conceptualised by the authors of the model (Chapparo and Ranka 1997; Hillman, 1999).

8.4.2 Methodological Contribution

The findings in this study confirmed previous findings (Hillman, 1999; Hillman & Chapparo, 1995a) that role is a real construct that is used by people in their everyday lives to enable them to think about, plan and perform their occupations. The findings free future researchers and therapists from the necessity to impose an external structure upon data gathering about role performance. The findings showed, for example, that it is not necessary to use standard occupational role assessments that may impose an interpretive interface between the role performer and the interviewer by providing a list of pre-determined roles with pre-determined definitions (Oakley, 1981; Oakley, Kielhofner, Barris, & Reichler, 1986). Toal-Sullivan & Henderson (2004) for example, have already commented that the OPRA (Hillman & Chapparo, 1995a) as used in this study, with its free choice of roles, was likely to be a more useful approach to role assessment than forced choice assessments.

This study has further developed a number of innovative methods of eliciting information about participants' perceptions of their ORP. The role sorting task proved to be a valuable tool in accessing the meaning participants attached to their ORP. The idea of a 'snapshot' view or a slice in time assisted in simplifying the interview and enabling interviewer and participants to remain focused on the task. The concrete task of role sorting enabled participants to prioritise data in a manner that they could control and understand, affording them the possibility to change their mind and consider their responses visually. This method gave the interview greater form and clarity, enabling data analysis to proceed more smoothly.

The majority of studies researching Parkinson's disease use the Hoehn and Yahr scale (1967). Participants were allocated to disease stages according to their self-report of functional performance in personal care, mobility and communication. Their self reported symptoms corresponded with the detailed descriptions of functional performance given by Jahanshahi and MacCarthy (1998). This supports the method used in this study to allocate people to each phase in future studies, using the system described in Appendix 5.2.

8.4.3 Empirical Contribution

The results of this study provided a detailed description of a number of constructs relating to the personal perceptions of ORP. It described the nature of ORP, provided insight into its meaning and suggested possible reasoning processes that contribute to the maintenance of a sense of personal control in a specific group of people.

A possible dynamic model was developed to describe the process undertaken by participants to cope with the loss of control they experienced when encountering barriers to ORP. This model provided hypotheses that could form the basis for hypotheses to generate further research into the constructs of the model and their relationships. Many of the constructs in the model have been described previously, but had not previously been integrated within the context of occupational role performance. The findings of this research extend the body of empirical data that reflects occupational performance at the role level.

8.4.4 Practical Contribution

The findings of this study provided an extended knowledge base about the complex nature of reasoning and meaning behind observable ORP, which can be used by occupational therapy practitioners. As discussed in Chapter Two there is a lack of a reliable knowledge base with accompanying techniques for dealing with the role level of occupational performance. This study provided descriptive information and theory development that can assist clinicians to gain further insight and develop appropriate techniques in this area of function.

The findings confirmed the use of the construct of role as an organiser of personal meaning by every one of the participants. This has important implications for practitioners seeking to support or bring about change at the role level in their clients. It means that occupational therapists can talk confidently and directly to their clients about their occupational role performance to gain an understanding of what is of particular significance and meaning to each of them. It reinforces the need for practitioners to clarify the highly personal knowledge base, or blueprint, from which each client is operating. It removes the need to use a standardised assessment by explicating elements of a role interview that could be applied to any client group.

The majority of participants sorted roles into those they considered to be primarily occupational in nature versus those that were primarily social in nature, confirming the existence of occupational performance roles for those in this study. This finding is significant in view of the controversy within the profession about the use of the construct of occupational role performance. The findings reinforce that each participant's role repertoire and priority is unique, with each role interacting with the others in a hierarchical and complex manner. Contrary to the picture of chronic disease that is painted in health literature, many participants were able to achieve role continuity despite the progression of their Pd. This reinforces the need for occupational therapists to assist in maintaining that continuity when required.

The cycle of control model, if validated by further research, could provide a useful practice model of role performance. The model could be used to assess why clients are having difficulty coping with a personal barrier to ORP. The model could be used to assist

occupational therapists and other health professionals in constructing a therapy plan that is personally relevant to each individual's ORP.

8.5 Recommendations for Future Research and Practice

It is possible, as a result of this study, to make some recommendations about areas where future research would be valuable to clarify and further develop the concept of occupational performance roles.

8.5.1 Theoretical Recommendations

The dynamic model developed in this study has not been validated in any way. Further research to determine the validity of each of the constructs and to investigate further the relationships between the constructs would provide a useful model for further theory development and testing in this area. This study has demonstrated the need for ongoing theory development in the study of human occupation and occupational therapy. It has modelled a way to critique theories from outside the profession, such as those from sociological and anthropological disciplines, and through research, reformat elements of them to create contemporary notions of occupation.

8.5.2 Methodological Recommendations

The hypotheses generated from the data gathered from the participants in this study require validation by studies of other groups of men and of women, both with and without disability using similar methodology. One or more constructs in the model could be investigated to determine their validity and relationship to each other. In this way, each of the constructs could be tested, with the findings contributing to the development of a verifiable model for practice that could be used across a diverse range of areas of occupational therapy practice.

8.5.3 Practice Recommendations

The results of this study are complex, but it is possible nevertheless to draw useful conclusions that can be applied in health policy and practice. The findings demonstrate

clearly the paramount importance of working with individuals within the context of their own world. Occupational therapy and other health services can be inflexible, offering too much or too little. By allowing service users to be the experts about their own lives, information about *how* health services might fit a person's personal and environmental context becomes available. The cycle of control model that is suggested here, with further research, could become the basis of a clinical tool that would enable service providers to 'tune in' to the health and occupational performance needs of people within the community and to tailor the way services are offered. This has the capacity to inform development of community health initiatives and health policy, including allocation of resources that can target relevant needs of a rapidly aging population, and the predicted rise in incidence of chronic illness.

For occupational therapists, forced choice role assessments and role assessments that assume the 'therapist as expert' should be avoided in clinical practice. Instead, the philosophy of the 'individual as expert' should be practiced. In real terms, this means that clients be invited to '*tell me about your most important roles*'. This type of questioning can lead to a focused discussion of the person's needs and priorities at that time, and how health services can best respond.

8.6 Conclusions

This study has focused upon the ORP and related sense of perceived control of a number of participants with Pd and their partners. In this, it has departed from other studies on ORP that have taken a more external view. It has demonstrated how the participants in this study used role as an organising construct for everyday life. It has provided a detailed description of personal barriers to ORP experienced by people who have Parkinson's disease and their partners, and identified a wide range of personal strategies that they developed to cope with these barriers. Data analysis, supported by the literature, suggested that perceived control was a central factor in participants' maintenance of a sense of well-being. Finally, it has suggested a dynamic model that might represent the way participants worked to restore a sense of personal control in their everyday lives.

This study has provided insight into the complexity of factors involved in the process of choice and decision-making in relation to ORP. It has provided descriptive data not only about ORP, but about the internal processes that are part of that performance. In particular it has provided further insight into the relevance and meaning that specific roles have for their performers and confirmed the wealth of insight and understanding that is available if role is used as a construct in both research and practice.

Finally, this study has extended the concept of occupational performance roles by demonstrating that it is a construct that is used by people that may be clients of occupational therapy. The findings and methods used in the study have demonstrated that accessing perceptions of ORP provides valuable information about the unique reasoning used by each person to meaningfully organise their occupations.