

# **CHAPTER SEVEN**

## **DISCUSSION**

## 7.1 Introduction

This study has provided a description of the barriers to occupational performance for a group of fourteen people with Parkinson's disease and eleven of their partners. The study has provided accounts of how participants experienced consequent losses in their sense of personal control through the impact of Parkinson's disease. It has demonstrated that the disease's impact extended from problems with basic task performance, to psychological problems, social problems, difficulties with community access and the loss of valued occupational role performance. Participants were shown to be active in their attempts to restore control of their occupational being, and the study has provided a detailed description of the strategies they employed to achieve this.

An important finding of this study was that barriers to occupational performance were not viewed objectively by participants. Participants interpreted what was happening as it pertained to their own personal circumstances. In particular, participants' perceptions of themselves and their sense of social fit strongly influenced how barriers were perceived and defined. Consequently, a significant part of their strategy development involved the consideration of these two constructs.

A significant finding of this study was that all the participants coped with Parkinson's disease almost entirely through using their own personal resources. They relied upon their past life experience and the knowledge they had gained, put this together with how they perceived specific problems and worked out strategies to meet each challenge. They preferred not rely on others to solve problems for them, but sought to take direct control themselves. Participants with Pd and their partners largely worked together as a team in dealing with the barriers to occupational performance that Pd presented, until the severity of the disease made this untenable. Health professionals were peripheral to this process.

In this chapter, the findings of the study are discussed in the context of literature on role; chronic illness and Pd; occupational therapy theory and practice in relation to chronic illness and Pd; and the concept of perceived control. The discussion is structured around the overall research purpose of this study which was:

To describe the manner in which people with a chronic illness such as Pd, and their partners, continued to actively maintain the roles required to participate as members of their social environment.

The first section of this chapter focuses on a discussion of the four major themes that were identified as they relate to the self perceived ORP and role development for this group in the context of the progression of the disease.

The second overall purpose of the study which was stated in Chapter One is:

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

The second section of this chapter describes a possible way of integrating the findings in the form of a dynamic model that describes a cycle of personal control. Each of the constructs of the model are defined, and there are descriptions of how they may interact. Several examples of how the model might work are given, along with examples of how the model might be applied in practice and research. This model represents one interpretation of the process participants went through in trying to actively mitigate the impacts of Pd and restore a sense of personal control.

## **7.2 Occupational Role and Active Engagement in the Social Environment**

All participants in this study made it clear that they wished to remain active members of their social environment. The disease acted against this. This study interviewed participants who were in all three phases of Pd (Jahanshahi & MacCarthy, 1998). This made it possible to take a cross-sectional view of occupational role performance across all phases of the disease process. The findings suggested a picture of participants with Pd and their partners moving along a life trajectory. In this picture, Pd delivered a series of deflections or barriers, each with the potential to knock them off the course they might otherwise have followed in life. The idea of a trajectory through time is similar to the concept of a person

moving through time as described in the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b).

Participants made efforts to regain their former trajectory, developing and employing *personal strategies* to overcome perceived problems and regain control. Sometimes they were successful, sometimes they were partially successful and sometimes they failed. Over time, the gap widened between the person's trajectory as it might have been without Pd, and how it was with Pd. Deflections tended to be mostly in a negative direction, away from what the participant wished for themselves and towards change that they perceived as loss. In other words, loss was interpreted as a move away from the life trajectory the participant would have preferred.

Barriers were often complex, because they were the product of the symptom and the individual. Each participant in this study perceived and reacted uniquely to each symptom. The same objective barrier was shown to be perceived as major by one participant and minor by another. For this reason, the word *personal* was used to describe barriers. Attention to this comparison could be useful in occupational therapy practice when discussing priorities and goals with clients.

Personal barriers were not always clear cut. They could be major or minor. One symptom might have a very specific impact, but more often the symptom impacted upon each person in a variety of ways and at a variety of levels. Personal barriers cross-cut each other, intertwined and interacted to produce complex effects. Similarly, personal strategies developed by participants to deal with personal barriers could be specific, but more often had multiple effects at a variety of levels and interwove with each other to create complex outcomes.

Analysis of the data suggested four major themes:

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

These themes are discussed together as they relate to the nature of ORP, and how participants actively participated as members of their social environment in the presence of Pd.

### **7.2.1 Did Role Exist as a Construct for Participants?**

There was a controversy identified in the literature about whether role was an appropriate construct to use in the discipline of occupational science and the practice of occupational therapy. A number of important practice models incorporated role (for example, Kielhofner, 1995). At the same time its use had been criticised as a contravention of the profession's philosophy of a holistic approach (Jackson, 1998a, 1998b). Classic role theory, which based role upon the notion of normative behaviour attached to a position, works against the principle of holism, and a belief in client-focused practice. Such arguments have been largely theoretical. A significant gap in the literature is the investigation of whether the concept of role is routinely used by people who do not have a special awareness of it.

A central finding of this study was that participants were comfortable about discussing their current daily lives in relation to their roles. They were not coached about the meaning of role, and the interview was structured as far as possible to allow them to discuss issues in their own way, using their own language. Participants were not confused by interview questions requesting them to talk about 'their roles'. They understood the question and, while not listing and defining their roles, they spoke freely about how they perceived their lives in role terms at the time of the interview. The interviewer worked with them to arrive at a list of roles they believed they held. The findings showed that they considered these roles very much from a personal perspective, while acknowledging the expectations others had of them because of their role positions. The roles they identified as most important to them tended to be the ones they spent most time discussing during their interview(s), indicating that these did indeed represent a significant part of what was important to them about their everyday lives.

The findings confirmed the existence of role as a real construct, used by the participants in this study in their everyday lives to help them think about, plan and perform

their occupations. This reinforces the need to research the phenomenon of role as it relates to occupational performance. The use of the construct of role in the structure of the interview helped participants to identify what was most important to them at the time, and to discuss it in their own way. At the same time, discussion of occupational performance at the role level helped the researcher to discover areas of occupational performance that were of personal significance to them. 'Talking roles' gave structure to their accounts of their lives, making the information more accessible to others. It was not necessary to impose further external structure upon data gathering about role performance via a structured assessment. This has important implications for role assessments used by researchers and clinicians. The findings of this study suggest that it is not necessary, for instance, to use standard occupational role assessments which may provide an interpretive interface between the role performer and the interviewer in order to translate their responses into role relevant language. Indeed, assessments such as The Role Checklist (Oakley, 1981; Oakley, Kielhofner, Barris, & Reichler, 1986) and the Occupational History Interview (Kielhofner & Henry, 1988b; Kielhofner et al., 1998) which provided a list of predetermined roles with pre-determined definitions and responses may provide a barrier to occupational therapists' ability to discover information that is relevant and meaningful. Allowing clients free choice in naming their roles recognises them as the expert informants about their own lives, enabling them to organise role information in a way that is personally logical. Researchers and therapists alike can use such information as the basis for further communication and planning, allowing both parties to be more truly active and focused as research or therapy partners.

### **7.2.2 Consideration of Role Repertoire**

This study considered the interaction of roles within a *role repertoire* for each participant. Findings about the participants' self-perceived role repertoires either described the *structure* in terms of the nature of the roles and their organisation, or described the *style of performance* in terms of attitudes and behaviour. Little research has been reported that examines whole role sets or role repertoire (Adelmann, 1994; Cheng & Rogers, 1989), making these findings of particular interest. Biddle (1979) stated that people do not usually study the entire role performance of people, but instead choose a particular context for role performance. Often, occupational therapists study the performance of activities without including the *context* in which the activity is performed. A consideration of role repertoire is

an important extension of activity context, and could be conceptualised as an occupational context.

Participants discriminated between what was a role and what was not, thus defining their role repertoire. They established and organised their behaviour around roles that varied in terms of personal significance. Major roles were clearly defined. Minor roles were more indefinite. There appeared to be a kind of ‘funnelling’ from major roles through minor roles, to routines and tasks, according to the *importance* of the occupation and its *size*. This kind of gradation has not been described before by people doing everyday tasks. Occupational therapy literature generally implies some kind of conceptual division or variation of level between occupational roles and activities, routines or tasks (e.g. (Kielhofner, 1995; Pedretti, 1996)).

### **7.2.3 How do the Findings of this Study Relate to Role Theory?**

Participants demonstrated an understanding of the concept of role that was consistent with aspects of role theory as described in Chapter Two, supporting the finding that they were indeed discussing roles. They talked in terms of *actions* or goal directed behaviour. They demonstrated an awareness of the *prescriptions* related to each of their roles. They spoke of their own *evaluations* of their role performance. They *described* role performance. Finally, they showed an awareness of *expectations*, both positive and negative. Participants talked of both *overt* and *covert* behaviour related to roles. They demonstrated an awareness of the various *positions* their roles afforded them. They talked of role partners, who acknowledged the position they held, and who shared a common *identity* with them.

In relation to symbolic interaction, the findings demonstrated that participants had a holistic view of their world. They perceived themselves as unique and having a reciprocal relationship with their social environment. They appeared to learn from their social environment and to use past experience and their knowledge of the past and future to determine appropriate action. Role partners worked together adjusting attitudes and actions towards a shared perspective.

Studying participants' *perceptions* of their own role performance is not a usual part of enunciated structuralist role theory. This discussion focuses upon participants' own

perceptions of their role performance, not only in terms of *doing* as advocated by role theorists such as Biddle (1979), but in terms of *knowing* and *being*. An occupational therapist's interest in the concept of role goes beyond observation to the conceptual meaning that the person ascribes to the role. It is not possible to observe *knowing* and *being*, yet these are central to determining the nature of occupational performance. A previous finding by Hillman and Chapparo (1995a), that it was not possible for an interviewer to accurately predict the major purpose an individual will ascribe to a specific role, demonstrated that it is not possible to make reliable inferences about a person's reasons for occupational role performance. Gaining insight into how people think about their roles is as important as gaining insight into what has real meaning to each person, for occupational therapists to use the construct of role effectively in clinical practice and research.

This study did not support the central tenets of role-related social ageing theories of disengagement (Cumming & Henry, 1961), activity (Havighurst & Albrecht, 1953), personality continuity theory (Atchley, 1989) or socio-emotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999) as described in Chapter Two, section 2.2.8. However, it is possible to see how one or other of these theories might have been applied to aspects of individual participants in relation to their role participation. A clearer pattern might have emerged if the people being investigated did not have a chronic illness which interfered with ORP.

#### **7.2.4 The Occupational Aspects of Role Performance: Doing, Knowing and Being**

Participants' discussions revealed *doing*, *knowing* and *being* aspects of ORP as described in the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b). They demonstrated the process of *doing* by describing the performance of routines and tasks that they related to specific roles.

They demonstrated *knowing* by describing planning and problem-solving processes linked to their ORP. They discussed their ORP in terms of quality and expectation. They knew about their roles in a developmental way, comparing past, present and future performance. They knew about the external context of their role performance (the physical, sensory, social and cultural environments they found themselves in). They knew about the

internal context of their role performance (their own role-related abilities and skills, including any perceived shortcomings).

They demonstrated *being* by identifying varying values for each of their roles, by identifying meanings related to specific roles, by expressing a degree of satisfaction or dissatisfaction in relation to their own ORP, and by expressing a sense of *position* or *fit* within their external context. These findings support a previous study by Hillman (1999; 2002f), (Chapparo & Ranka, 1997a) and social role theory<sup>1</sup>.

### **7.2.5 Specific Occupational Role Performance: The Role of Being Chronically Ill**

All the participants with Pd in this study were forced to assume the role of someone who was chronically ill, but this role was not well understood. There has been a tendency to view it in the same way as being 'sick' (Lubkin & Larsen, 2002). The sick role has been described in social structural theory terms by Parsons (1951; Hardy & Conway, 1988b). His description was supported by subsequent work with those who were acutely ill (Steward & Sullivan, 1982), but was questioned in relation to chronic illness (Lubkin & Larsen, 2002). As the concept of role current among occupational therapists relates to social structural role theory (Kielhofner, 1995; Reilly, 1969), it is worthwhile considering how the findings of this study fit with the sick role as described by Parsons (1951). Parsons identified four expectations of behaviour in the sick role.

- The first was that the individual would be exempt from normal social responsibilities in proportion to the severity of symptoms. Participants with Pd in this study did not seek exemption from every social 'responsibility', but did on occasion seek exemption from specific requirements. Family and friends did not always understand the need for such exemptions. Having a chronic illness presented a more complex situation than being acutely ill in that the participant often appeared able. Early phase participants and some in middle phase were able to go out into the community without apparent difficulty. This caused misunderstandings with friends and family members. It even led to confusion

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<sup>1</sup> For a more detailed account of how these findings fit with social role theory, see Hillman (1999).

among partners, who found the fluctuating nature of symptoms difficult to understand. Some partners were confused about the level of care they needed to offer from moment to moment. This finding indicates that education of family members and friends about Pd as it is being personally experienced by their role partner at different phases in the disease process should be an important aspect of clinical care. They need to be prepared to expect a range of behaviours and to learn about a range of strategies that they can use to meet these behaviours.

- Parsons' (1951) second expectation stated that the sick person could be expected to recover through an effort of will. This exempted him or her from regular responsibilities. Participants with Pd in this study frequently spoke in terms of making an effort of will, not to recover, but to live with the disease. They tried to achieve a positive feeling of control of the impact it was having upon their lives. A number of participants experienced the expectation from family and friends that they would behave as a 'well' person in ways that were, in fact, beyond them. These findings support the suggestion by Steward (1982) and Segall (1976) that while Parsons' role description might fit those who are acutely ill, it is insufficient to describe the complexity of the chronic illness role. The findings might better fit with Jones' (1998) observation that attempts to continue a normal life in the presence of chronic illness could lead others to discount the illness. This finding cautions occupational therapists to be aware of the essential difference between being acutely ill and chronically ill in terms of ORP and the expectations of self and others. It is important to consider whether partner, family and friends understand the seriousness of the illness in conjunction with the determination of the person who is ill to lead as normal a life as possible.
- Parsons' third expectation of behaviour in the sick role was that the state of being ill was undesirable and carried the obligation of wanting to 'get well'.
- This went together with his fourth expectation, that there was an obligation to seek technically competent help (i.e. from a health professional) and to cooperate with this person in trying to get well. Findings in this study showed that while all participants with Pd wanted to get well, and did seek advice, health professionals

were not, of course, able to offer a cure. In terms of disease management, participants did not always find the health professional trustworthy and reliable. Participants and their partners had concerns about health professionals' proficiency in relation to medication management, being understanding of their needs, and in how Pd interacted with other symptomatology and medication. The majority of participants spoke of managing their own illness to a greater or lesser extent, often ignoring the recommendations of health professionals in favour of what they believed suited their personal needs. This finding is not well understood in the literature, often being labelled as 'non-compliant behaviour'. On the one hand, it is possible that participants were applying personal knowledge that was not accessible to the health professional, choosing to make more refined judgements about the personal relevance of the advice or care being offered. On the other hand, health professionals might have failed to communicate the information that supported their reasoning. Close attention to communication issues is indicated. Occupational therapists could spend time finding out more about the personal knowledge being employed by clients to make health-related decisions. They could then consider how best to present the information behind their reasoning in terms that make it as personally relevant as possible.

The differences between the expectations of those with a chronic illness and those with an acute illness (Parsons, 1951) emphasise the particular importance for health professionals of ensuring they are working with clients from their perspectives, rather than providing standard advice and symptom management. The use of the rehabilitation model, with its expectation of restoration of function and resumption of a previous lifestyle, is inappropriate for people with a long-term, chronic illness such as Pd (Hasselkus, 1997). There is a danger that clients receiving occupational therapy under this model do not feel supported in pursuing what to them may be a personally meaningful life (Campbell, 1994; Hawking, 1996; Hillman, 1999; Jongbloed & Morgan, 1990; Rebeiro, 2000).

#### **7.2.6 Specific Occupational Performance: Role of a Person with Parkinson's Disease**

The role of being someone with Pd was particularly significant in this study. This role was discussed across the three phases of Pd, and from the perspectives of the *doing*, *knowing* and *being* aspects of occupational role performance. The progression of symptoms

from early to late phase of Pd were described in the findings. For instance, the issue of mobility moved from being of minor concern for the majority of those in the early phase to being a major issue of safety for the majority of participants in the late phase. Participants with Pd defined problems with ‘doing’ that went beyond the primary symptoms most commonly described (Hoehn & Yahr, 1967), and included secondary symptoms such as ‘feeling bad’, pain and cognitive problems. While all the symptoms most commonly discussed by participants in this study are described in the literature (e.g. Pentland (1999)), the findings have extended this knowledge by obtaining insights into how participants with Pd and their partners perceived the impact of specific symptoms upon themselves and upon their partners.

A number of participants were confused about which of the ‘doing’ difficulties could be linked to Pd, which to other medical problems, and which to ‘just old age’. Partners indicated awareness of the primary symptoms being experienced by their partners, but appeared less aware of the impact of some of the secondary symptoms such as ‘feeling bad’, nausea and sleep disturbance. Partners also identified health issues of their own. Particularly, partners of participants in late phase expressed how tired they were because of their full-time carer role.

Participants in the study responded in individual and idiosyncratic ways to the impact of their disease. The findings gave a detailed description of the typical intrapersonal and interpersonal responses of participants with Pd and their partners to the impact of the disease. While a trend between phases was identified, there was no clear correspondence between psychosocial responses and the degree of disability they experienced. This finding supports the work of Brod, Mendelsohn and Roberts (1998).

The findings of this study suggested that loss of ORP in valued roles entailed lost opportunities for active engagement in valued ORP and hence a loss of opportunity for self expression. On top of this, the negative outcomes participants experienced as a result of ineffective engagement in valued roles led to loss of sense of self. Participants in this study described how they had to choose between adjusting their ideas of who they were, or trying to deny changes. As the disease advanced, denial was not an option, and in consequence, a gradual erosion of participants’ sense of personal control occurred. All the partners of those

in the late phase of Pd felt their partner had difficulty accepting loss and put themselves at risk by doing more than they were able to. This meant that partners were put in the position of trying to control their partner's active occupational engagement for safety reasons. This was viewed by participants with Pd as negative feedback about their occupational performance, and further reduced their sense of personal control.

The findings show that Pd is a complex experience. Some definitions of chronic illness related it to symptoms (Cluff, 1981) and included a requirement of dependence (Curtin & Lubkin, 1995), yet in this study it was clear that participants experienced losses in ORP in the early phase of Pd that did not relate to dependence. Instead, participants in this early phase appeared more concerned about the differences they felt in how they perceived themselves and how they fitted into their social context, both in the present and in the future. Indeed, Jones et al (1999) found that 50% of symptoms in the early phase were not reported to health professionals. As the disease progressed, some dependence began to appear, but even in the middle phase, both types of participants were not considering the issue of dependence as much as they were other limitations. It was only in the late phase of Pd that participants identified dependence as a major problem.

These findings support the work of Ironside et al (2003). In their study, participants were asked to be co-researchers. Their definition of chronic illness placed the emphasis on an interruption to the individual's ability to continue with his or her usual lifestyle. In the present study, participants' identification of personal barriers centred around just this issue. This meant that the impact of Pd was felt not in terms of basic function, but in terms of interruptions to accustomed ORP. Further, these interruptions were most commonly identified in relation to priority roles. This finding indicates that occupational therapists could become more effective in their interventions by giving greater weight to occupational role performance, rather than single tasks such as mobility. The limitation to personally meaningful community participation could be the issue of greatest significance to the person with the illness. The findings facilitate a better understanding of how a disability may have a large impact at the psychological and social level. In consequence, health professionals could be better placed to communicate with clients in personally relevant ways and to work in partnership to develop interventions that are likely to achieve desired outcomes.

### 7.2.7 Specific Occupational Role Performance: The Partner/Carer Complex Role

Participants who were partners increasingly perceived the need to provide their partner with Pd with care and assistance as their symptoms progressed over time. This led to the process of *role transition*. The role of partner became modified, as the symptoms got worse, to include caring aspects. By the late stages of the disease, partners were identifying a separate role as a carer. The development of this role is discussed here from the *doing, being* and *knowing* aspects over time.

Participants identified care occupations that were similar to those Braithwaite (1990) found in her Australian study. There was a preponderance of household management occupations, with a lesser emphasis upon personal care, supporting the work of Riemsma (1999). In addition, partners in this study followed the pattern identified by Braithwaite (1990) in that the majority of those whose partners were in middle to late phase reported working to maintain their partner's social networks and community participation. However, it was clear that by late phase, partners had accompanied their spouses into the spiral of social isolation described by Chesson (2003), with the level of social support from family and friends declining as level of care required increased. From the findings this study, this decline in social support appeared to occur in part because partners made the judgement that the job was too much for anyone else to do, even for a short time.

The overwhelming majority of partners interviewed for this study were spouses. The well documented u-shaped curve of marriage (Peterson, 2004) meant that most participants in this study were likely to have had the opportunity to re-establish a close relationship in later life, before Pd began to have a real impact. This renewed satisfaction with their partnership (Weishaus & Field, 1988) appeared to be based, at least in part, upon a greater sense of equality or balance now that both partners had retired from their respective roles of paid work, and managing the family (Sarantakos, 1996).

The impact of Pd, as shown in the findings of this study, had an important negative effect upon this recently developed or reaffirmed sense of equality and balance. In the early phase, it was possible for partners of those with Pd to ignore the problem and continue with life as before. This supports the findings of Davies, Cousins, Turnbull, Playfer and Bromley (1999) who reported that in the early phase there was a choice about how much assistance to

give. In addition, this study showed that some participants in the early phase of Pd worked hard to shield their partners from the impact, even though they were finding their symptoms personally disturbing.

By middle phase, partners talked of the need to understand their partner's symptoms, of how they helped out in various ways with daily tasks, and how they acted as an advocate for their partner with others who did not understand. As in early phase, there were variations in the amount of assistance partners provided that were not related to the degree of disability being experienced by their spouse. This supports the findings of Davies, Cousins, Turnbull, Playfer and Bromley (1999). Some partners had given up leisure or other roles in order to spend more time with their spouse, but referred to this as part of getting older anyway. One of the middle phase partners reported feeling anxious and stressed. Carter et al (1998) found that by the end of this stage partners were reporting increased levels of tension and frustration.

By late phase, partners' attitudes had changed. They were now providing full-time care to their partner. They had given up practically all social contact that required them to leave their partner. Community access was drastically reduced in keeping with this, and partners' role repertoires were essentially reduced to the single role of partner. They reported feeling very stressed by the need to care for their spouse 24 hours a day. This finding supports Davies et al (1999). Carter et al (1998) reported a much lower sense of predictability in this late phase than in the other two phases, leading to a reduced sense of personal control. Some participants reported a marked decline in the marital relationship in the late phase of the disease, and made comments that indicated their partner had changed as a person. Communication problems were reported in all of the late phase couples. These findings support Davies et al (1999) and Carter et al (1998). It would seem that communication between partners should be considered a priority issue by health professionals for those in the late phase of Pd.

When partners who were spouses were asked to name their roles, all identified the role of husband or wife in their top three most important roles. None of those whose spouses were in the early phase of Pd identified the role of carer. In the middle phase, two partners identified the role of carer as part of their role as spouse. Partners of those in the late phase

all identified separate roles as spouse and carer and put carer as their most important role. This finding supports the work of McPherson (2004), who suggested that when a sense of reciprocity is present, a partner may be less likely to refer to him or herself as a carer.

The use of the concept of role, beyond the role of carer, was not common in the Pd literature, and little information about other roles and role repertoires in the presence of chronic illness was found. The findings of this study show that major role transitions took place for participants who were partners during the course of the disease that almost equalled those experienced by their spouses.

The need to provide increasing levels of care as the disease progressed eroded the sense of balance and equality identified as a major reason that marital relationships improve so much in later life (Sarantakos, 1996). The role of carer carried with it a great deal of power. In the late phase, partners felt compelled to take control of the behaviour of their spouse with Pd in many different ways in order to ensure they were safe, getting enough to eat, getting their medication, not getting too tired, and so on. They were aware they were taking over, but felt at a loss as to how else to deal with the situation. For both partners in this study the sense of balance in their marriage appeared to be largely gone by late phase Pd.

Rees, O'Boyle and MacDonagh (2001) reviewed the literature on quality of life and found that three characteristics influenced carers' perceptions: the characteristics of the care giver, the characteristics of the care receiver, and the characteristics of the care situation. In this study, in relation to the characteristics of the care giver, all partners were living with just their spouse. This promoted social isolation (Rees et al., 2001). The partners of those in late phase Pd in this study all identified unmet needs of their own, which Rees, O'Boyle and MacDonagh (2001) found could be linked to a higher perception of burden for the carer.

In relation to the characteristics of the care receiver, the mental health of the care receiver was more important than their physical health in provoking negative outcomes for the care giver (Rees et al., 2001). In this study, participants with Pd in the late phase tended to be depressed and anxious, and their partners reflected this too. Rees, O'Boyle and MacDonagh (2001) found mental health issues appeared to concern carers more than the physical problems their partners were experiencing. They also stated that behavioural

disturbances on the part of the care receiver were more likely to distress their carer than cognitive disturbances. In this study, a number of partners described their partner's cognitive problems without expressing personal distress, while others described behavioural issues that distressed them greatly.

In relation to the characteristics of the care situation, in this study, carers in late phase had partners who were largely, although not entirely, confined to the house; they needed assistance with personal care, and they had needed gradually increasing levels of care for very many years. All three of these factors are identified by Rees, O'Boyle and MacDonagh (2001) as being linked to negative outcomes for the carer. This may assist in explaining more specifically why carers in this study found caring harder as their partner moved into late phase Pd, further supporting Braithwaite's (1990) claim that the 'loss of a person' was much harder to deal with than physical deterioration.

The positive aspects of caring identified in the literature were also evident in the findings of this study. Wells and Kendig (1997) argued that most research with carers had been done with those seeking support, and especially those caring for people with dementia. While participants with Pd in this study sought support through attending a support group, their partners were not necessarily doing so. Wells and Kendig (1997) argued that care-giving was a complex challenge and that care-givers should not be stereotyped as the hidden victims of their spouse's illness. In this study, three out of eight spouses denied they had the role of carer. Those who claimed the role identified ways in which they felt anxious and stressed, but they also spoke of a sense of mastery in the role. They reported taking pleasure in looking after their partner, making life more pleasant for him or her, and fulfilling their own expectations of themselves as a spouse. Fulfilling personal expectations as a spouse was identified by Chesson (2003) as the central factor sustaining carers.

Braithwaite (1990) found that spouses will persist with care when the levels required are well beyond those tolerated by non-spousal carers. She felt this reflected their long-term commitment. Another factor suggested by Krause, Herzog and Baker (1992) was that informal care giving was seen by the carer as an act of reciprocity. Some partners in this study certainly talked of how their spouses had supported them in the past, or commented that they knew their spouse would be doing the same for them if things were the other way

around. Habermann (2000) found that partners experienced their spouse's illness in the context of their past and ongoing relationship.

When the findings are reviewed from the perspective of the person with Pd and their partner working together as a team, both members of the couple related working hard to maintain the relationship despite the pressures of the illness. The cross-sectional approach of the study allowed data to be viewed across the three phases of Pd, and a pattern of teamwork was identified over the course of the illness. In the early phase, couples were able to maintain the relationship much as it had been. Participants with Pd worked to minimise the impact of the disease upon their partners and partners offered assistance as they chose and in accordance with the way they were accustomed to interact. In the second phase, participants with Pd needed more support, and both partners worked together, tailoring their occupational *doing* to fit their partner and provide support in order to achieve the joint outcome of continuing the relationship and their life together. In the late phase the needs of the partner with Pd were so great that teamwork was no longer possible. The findings describe a number of instances of role conflict as a consequence. Partners started to see themselves primarily as carers, and for some, teamwork came to an end. The teamwork of couples in the presence of chronic illness has not been described in this way before, and approaches to therapy that recognise the couple as a team rather than someone with a disability and their carer have not been developed.

This study showed that partners expressed disappointment and distrust of their partner's health care providers. There appeared to be communication difficulties, and it is possible, given the strong team approach described in the findings, that partners or carers did not feel that their contribution was recognised. Chesson (2002) found that carers felt largely unsupported by health professionals. A consideration by occupational therapists of the couple functioning as a single unit could lead to a more effective inclusion of the person's spouse in all aspects of discussion and intervention planning.

### **7.3 Perceived Control**

All the participants in this study demonstrated a desire for control of their choice, pattern and engagement in occupations. The second section of this chapter considers how

participants maintained a sense of perceived control in their daily lives. It discusses the findings in relation to the literature relating to perceived control and proposes a possible model of personal control that has arisen from the data.

Participants described a range of behaviours and attitudes that were designed to regain a sense of control. This fitted with Jahanshahi and MacCarthy's (1998) definition of coping as all the practical efforts and emotional and intellectual responses used to come to terms with and reduce the emotional impact of a stressor. Some of the responses were problem focused and some were emotion focused. In this way participants provided evidence of practicing both primary (problem focused) and secondary (emotion focused) control in their daily lives.

Primary control, as described by Rothbaum, Weisz, and Snyder (1982), was evident. The findings showed that some participants appeared to have a high desire for control (Burger & Cooper, 1979) while others appeared to have a low desire. Participants' desire for control appeared to vary from role to role according to how important it was to them, or how appropriate they felt it was to want to take control. In the role of person with Pd, participants appeared to express varying levels of desire for control. Participants discussed a wide range of strategies that could be seen as seeking to achieve primary control.

Participants described a number of behaviours and attitudes that fitted with Heckhausen and Schulz's (1995) list of secondary control strategies typically used by older people. As a group, they were flexible in their goals, they worked to regulate their emotions, and they used their cognitive skills to compensate for the losses in their ability to move. They adjusted their picture of their ideal self downwards so that they expected less of themselves, they maintained a positive view of the past, and they compared themselves with others to their own benefit. In addition, a number of strategies not discussed by them were identified and described, extending knowledge in this area (see Chapter Six, section 6.6.2). Participants would describe both primary and secondary control strategies, utilising both to deal with different specific barriers to ORP as they considered appropriate.

The findings relating to primary and secondary control support the work of Heckhausen and Schulz (1995). The detailed knowledge of the strategies employed by the

participants in this study as they relate to primary and secondary control provides important information for occupational therapists and other health professionals about the ways in which people with Pd and their partners may be managing their own occupational performance.

### **7.3.1 Choice**

Participants appeared to value having a sense of choice, because a sense of choice provided opportunities for experiencing personal control. Using an environment which offered low levels of choice, Rodin and Langer (1977) demonstrated that being able to make even a small choice boosted an individual's sense of perceived control and hence well-being. From the accounts of ORP with Pd given in this study, participants in the middle to late phases of Pd spent a great deal of their time in environments offering low choice (predominantly the home environment). Perhaps this was a secondary control strategy – by reducing the level of choice, making a choice became more significant, giving a greater sense of perceived control. Choice within the home environment might feel more controllable and more personally significant. Perhaps this was one reason that the majority of participants with Pd in middle phase appeared sanguine about their lives. Despite experiencing loss, for which they grieved, they retained the ability to make choices that felt significant. This finding supports the work on environmental docility by Lawton (1970). He hypothesised that people with low levels of environmental competence were forced to rely on the environment to support them to a greater extent than people with high levels of environmental competence. The home environment offered participants a greater level of support than the community, while still providing opportunities for choice.

For participants in the late phase, these opportunities for choice were almost gone, and most choices were made by their partners. Participants with Pd had become much more dependent upon their partners and their partners had taken over the management of almost every aspect of their lives in consequence. This imbalance of choice may explain the sense of mastery in the role of carer that was expressed by some partners in late phase.

A specific example where choice was clearly exercised by most participants was in their dealings with health professionals. The findings showed they felt no obligation to follow the advice of health professionals if it did not fit with what they believed they needed.

Perhaps by making this powerful choice to go against socially sanctioned advice they felt an improved sense of control and empowerment in their difficult roles of person with a chronic illness or partner of someone with a chronic illness.

### **7.3.2 Occupational Role Performance Knowledge**

Participants in this study identified specific, role related knowledge as an important tool in maintaining a sense of personal control. They demonstrated personal ORP knowledge in a way that integrated present knowledge with past experience. Participants displayed knowledge about their current ORP in four different ways.

- They demonstrated knowledge about how they performed. Findings showed such knowledge was formed either through the experience of performing in the role, or through extrapolating knowledge of performances in other roles to give assumed knowledge of performance. This finding supports the literature on learning theory (Neistadt, 1998).
- They demonstrated knowledge about the outcomes of the strategies they implemented. Where strategies were successful, it led to the development of knowledge about useful strategies for overcoming personal barriers. Where strategies had not helped, it led to a greater conviction that the barrier in question could not be overcome by the participant. Feedback from occupational performance provided opportunities for participants to learn about both their current level of ability and strategies that might or might not be successful in dealing with specific personal barriers. This finding supports Learning Theory and occupational therapy literature on cognitive aspects of performance (Crepeau, 1998; Neistadt, 1998; Wheatley, 1996).
- They demonstrated knowledge about relevant role-related beliefs. These beliefs were sometimes about how participants expected themselves to behave in carrying out their roles and sometimes about how they believed people in general should behave in a particular role. Role-related beliefs appeared to be of two types. The first type appeared closely related to sense of self and sense of social

fit. The second appeared to relate to role learning as described within Mead's (1972) approach of symbolic interaction.

- The last type of knowledge was knowledge about the environmental context. Participants had detailed knowledge of the social and cultural context (including the expectations of role partners) and the physical and sensory environment relevant to their role performance. They put these together to inform their perception of environmental demand (Lawton, 1982) as well as of resources that were present in the environment that might support occupational role performance. This information was used as a reference in planning role behaviour and provided information about perceived barriers to role performance. This finding is consistent with The Press-Competence Model developed by Lawton and Nahemow (1982).

For each of these types of knowledge, past experience (sometimes going back many years) was integrated with knowledge currently gained from ORP. The four types of knowledge were constantly being added to and modified as further experience informed them. The finding that participants used past experience as an important source of knowledge about role performance is supported by the work of Kendig, Davison and Walker-Birckhead (1993) and by Mead's work on symbolic interaction (1972).

It is suggested that participants used the four types of knowledge to create an *internal picture of the environment* that had personal relevance. Participants perceived the environment around them in terms of relevance to their sense of themselves, their sense of social fit, their beliefs and values and the relevant tasks of desired role performance. The idea of an internal picture of the environment is consistent with basic concepts of role theory, being part of the role description classification of Biddle and Thomas (1966b).

The findings in relation to the personal nature of ORP related knowledge support the work of Levine (1987), who suggested that people direct their attention, in any interaction with the environment, to those factors that have significance to them because of their cultural background and the ways of *being* that they have learned from their parents and peers.

The findings in relation to ORP knowledge demonstrate how clients could be operating from a knowledge base that leads to reasoning that is different to that of the occupational therapist or other health professional. This different reasoning could produce priorities and performance plans that differ from those envisaged by an occupational therapist, even when goals for therapy have been agreed. It is important for the therapist to have some understanding of the knowledge base of each client and how this informs their reasoning. Such knowledge would enable a more focused and meaningful interaction between therapist and client, leading to greater efficiency and effectiveness in the therapeutic relationship.

### **7.3.3 Perceived Outcomes of Occupational Role Performance**

Participants indicated that they thought about their roles and spent time reviewing role performance in an attempt to overcome barriers to ORP. They demonstrated that they used the four types of knowledge described in the previous section in order to interpret or make sense of the feedback they perceived about their ORP. This knowledge allowed them to *evaluate* or judge whether the outcome from that performance was satisfactory or not. Perceived current occupational role performance was evaluated by comparing it with past performance, and by comparing role performance outcomes with desired outcomes. The judgements made as a result of this process formed the basis of a dynamic knowledge about perceived ORP outcomes. This information then informed planning about future role performance. The collection and application of knowledge about role performance was dynamic and cyclical in nature, with earlier performance informing later performance in a manner similar to that described by Mead's (1972) work on symbolic interaction.

The findings indicated that participants compared perceived performance outcomes to the goals they had in mind to determine whether outcomes were satisfactory. A number of participants were continuing in valued roles, but their performance had changed. Participants appeared to apply different standards for acceptable role performance to the different roles in their repertoire depending upon the importance of each role. It is suggested that participants used the outcomes of role performance *evaluation* in order to predict future role performance. Evaluation was an important means of informing the person about their performance and it provided them with a sense of how in control of a specific role they were.

There is a need for further research into the nature of occupational performance role reasoning and planning carried out by the role performer. These internal processes are not currently well understood. Better understanding of this whole area would greatly enhance the ability of occupational therapy clinicians to assess, predict and intervene in areas of occupational role performance difficulty with their clients.

#### **7.3.4 Sense of Self**

It appeared in this study that losses or gains were perceived in relation to whether a sense of self as an occupational being was being maintained, developed in a positive way, or developed in a negative way. Experiencing a satisfactory sense of personal control appeared to relate to whether the individual's sense of self had been preserved. The unpredictability of symptoms seemed to make it difficult for participants to experience mastery in some roles, while still feeling in control of others. Some expressed a reduced sense of self efficacy in important roles and consequent depression, anxiety and stress. They tended to criticise themselves and experienced loss of motivation. Partners empathised with how they must be feeling, as in the findings of Habermann (2000). This finding that a sense of self-efficacy could vary supports the work of Bandura (1997). He described belief in self-efficacy as varying in several dimensions. First, it could vary in level. It could relate to a simple task demand, all the way through to a highly demanding and very taxing area of performance. Efficacy beliefs could vary in generality. People might judge themselves efficacious across a wide range of activities or only in relation to a specific area of functioning. It could vary in terms of strength. Weak beliefs were easily negated by negative experiences, while strong beliefs persisted despite setbacks (Bandura, 1997).

There was very little literature that dealt with the intrapersonal responses of individuals to having Pd (Brod et al., 1998). Some information was available about the typical responses experienced by people with Pd (e.g. Jahanshahi & MacCarthy (1998)). This was largely supported by the findings of this study. Much less information was available in the scientific literature about how individuals with Pd and their partners coped with these psychological responses (Chesson, Cockhead, & Romney-Alexander, 1999). This study has demonstrated that participants had a clear sense of who they were. They were able to describe the sort of person they were as well as the sort of person they were not. They were able to provide reasons for the way they were that were linked to past experiences, and

they showed an awareness of who they were at the time of the interview, and how Pd had impacted upon or shaped their sense of self. They talked about expressing themselves through active engagement, for example, what made them happy or sad, and showed that this was a primary means of making judgements about who they were at any given moment. An occupational therapist or other health professional who is sensitive to the importance of sense of self is likely to be able to work effectively with clients to develop interventions that are both acceptable and successful in their outcomes.

### **7.3.5 Sense of Social Fit**

Participants showed they had a clear sense of their social context and how they fitted or did not fit with it. Sense of social fit was judged through the nature of relationships. ORP was the vehicle for providing opportunities for negotiation and feedback about how the participant related to those who were important to them - usually their partner, family or friends. The judgements participants made about their sense of social fit appeared to relate not only to what they thought others expected of them, but also to how they believed they ought to meet other people's expectations. In this way, the model of ORP developed by Hillman and Chapparo (1995a) from the work of (Heard, 1977) appeared to be supported by this study. This model featured the expectations of others as an important determinant of occupational choice, but showed it being balanced by expectations of self. This fits with Burns (1991), who put forward the idea of a balance between the nomothetic and idiographic aspects of role. Conflict could occur between these two expectations, as shown in Heard's (1977) model of occupational role acquisition. It was suggested that such conflict would be at its height during the acquisition of new roles, and when roles were in transition. These findings also support role theory (Biddle, 1979).

As participants had knowledge and beliefs for maintaining their sense of self, so they had knowledge and beliefs for maintaining a sense of social fit. They showed awareness of social norms, which are a form of belief, but they also had their own beliefs. These related to the things they would do to accommodate the needs of others, and the things that they found helped them to fit in.

### 7.3.6 Active Engagement, Sense of Self and Sense of Social Fit

The findings of this study suggest that active engagement in personally meaningful occupational roles were used by participants to develop and maintain a sense of self, because it informed the interactive and functioning self. Further, active engagement, by permitting experience of self, allowed further learning, and therefore development, of self in significant roles. This finding was supported by the alternative finding that where participants were not able to *do* in valued roles they expressed loss of a sense of purpose and even a sense of a worthwhile future. The finding supports the work of Mead, who held that inner experience was determined during and as a result of involvement in social processes (Hardy & Conway, 1988b), and that it was not possible to consider a self outside of social experience (Mead, 1972). Because of this it is suggested that meaningful and active engagement enabled participants to gauge the status of their sense of self and hence experience greater or lesser amounts of personal control.

Occupational performance in roles and occupations that linked participants in a personal way to their social contexts allowed for active engagement that not only permitted expression of self but also expression of social fit. Within these roles, the nature of relationships was identified as an important barometer of sense of social fit. Judgements about relationships appeared to relate to the degree to which participants perceived they were meeting the expectations of others. This finding was supported by symbolic interactionism (Mead, 1972), which saw the reality of socially coordinated behaviour as the outcome of a process of mutual interpretation and adjustment.

Participants made their own judgements about how they wanted to fit with the expectations of others and how they felt able to differ. Burns (1991) emphasised the degree of choice individuals had in relation to the expectations they perceived within the roles they held. This led some participants into conflict with others in some roles. Partners experienced conflict between what they expected of themselves in the roles of partner and/or carer and what other people expected of them as a partner or of the two of them as a couple. Mead (1972) described expectation in terms of knowledge about how a role should be performed, leading to beliefs that may be accepted by both partners, or be solely in the mind of the role performer, explaining differences in expectation.

It is proposed that personal judgement about whether sense of self and social fit have been maintained or eroded is what makes each individual's responses to a given set of external circumstances unique. In so far as sense of self is closely linked to social, cultural and occupational roles and ORP, this supports the literature. Brod, Mendelsohn & Roberts (1998) and Brown (1998) both found a link between depression and the degree to which the disease impacted upon social, work and leisure roles. Participant's responses did not appear to relate strongly to the level of disability being experienced, a finding supported by Muldoon (1998) and Findley (1999). Perhaps the reason was that it is only when sense of self and sense of social fit were threatened that people reacted negatively.

Perceived losses were not, for the most part, accepted. Participants were aware of their own resources and made positive statements about themselves that identified what they were good at. They developed strategies to deal with problems with doing that were personally acceptable, thus restoring a sense of personal control. They appeared to draw upon a store of strategies and beliefs that arose from their past experiences. This supports the work of Mead, who held that past experience was used to determine appropriate action (Joas, 1985).

Literature on coping strategies specific to Pd was hard to find, as the focus tended to be upon external support such as support networks, carers and health professionals, rather than upon how people with Pd helped themselves. Participants with Pd commonly identified medication, exercise, timing task performance to fit fluctuating symptoms, avoidance, and conscious control of movement. These were all mentioned in the literature (e.g. Brown (1998)). One factor not identified was the degree to which participants with Pd and their partners managed Pd medication. Both partners had no compunction about experimenting with dosage, timing and frequency of medication without first consulting their prescribing doctor. A sentiment commonly expressed was that they were more in touch with their own or their partner's needs in regards to medication than their doctor.

The findings of this study showed that the impact of the disease processes were most keenly felt by participants in relation to their sense of self, their sense of social fit and their ORP. All four themes identified were interdependent, such that the occupational performance or *doing* resulting from Pd symptoms impacted upon sense of self, which in

turn impacted upon sense of social fit which again impacted upon ORP. It appeared that being able to maintain a sense of self and sense of social fit enabled participants to maintain a sense of purpose that led them to interact with their environmental contexts in ways that gave them satisfaction, through valued ORP. This turn further reinforced sense of self and sense of social fit, giving a sense of personal control in relation to a specific personal barrier.

## **7.4 A Cycle Of Control of Occupational Performance**

A review of the findings of this study in the context of the relevant literature suggested the possibility of a dynamic model that could represent how participants worked to restore a sense of personal control in their lives. This model is presented here in the following sections. A brief overview describes how the model might work, followed by a detailed presentation in which the constructs are defined and their interactions described. This is followed by some examples illustrating how the model could be applied to the data.

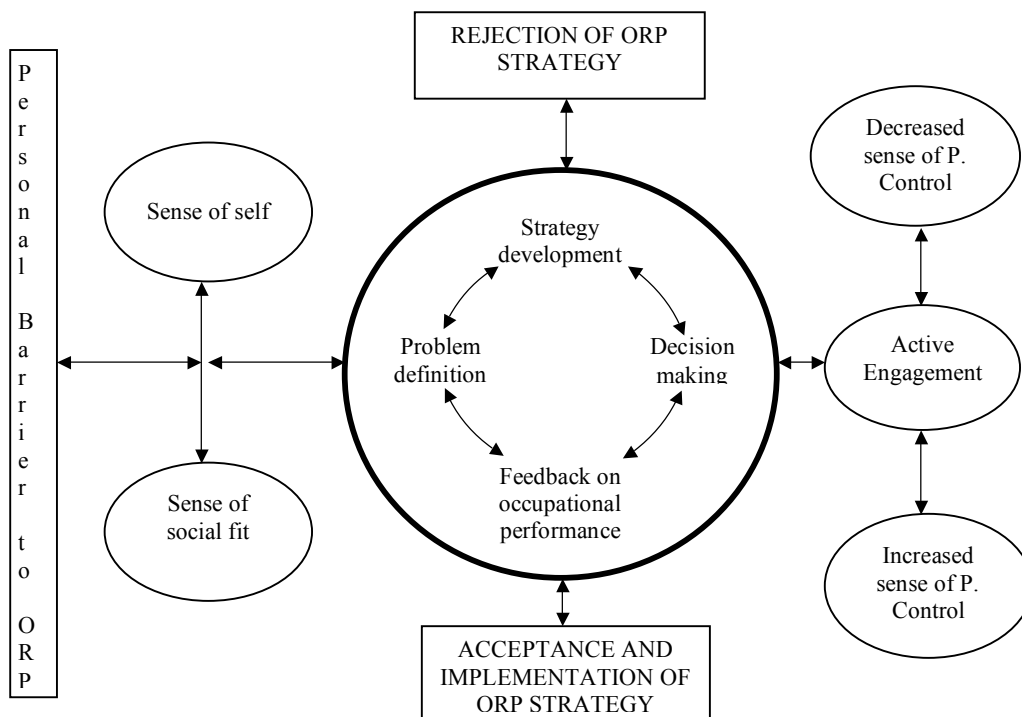
### **7.4.1 An Overall Explanation of an Emerging of the Cycle of Control Model of Occupational Role Performance**

Sense of self and sense of social fit appeared integral in participants' identification of personal barriers to ORP. Ways to maintain these two constructs appeared central to the strategies they developed to restore a sense of personal control. In considering the findings, it seemed that participant's choices about how to deal with their personal barriers were largely directed by their own life experience, which formed a *personal blueprint*. This blueprint was a store of personal knowledge about themselves, about their context, and about strategies that had been successful in the past. They used this to guide their decisions. They appeared to prefer to select from this store first when searching for a strategy. Only when such strategies were rejected did they seem to consider new strategies. This personal blueprint appeared to guide their choices far more than the advice they might receive from health professionals.

A possible model of a cycle of personal control was suggested by the findings (see Figure 7.1). In this model, when a barrier to ORP was perceived, participants (both those with Pd and their partners) used their personal blueprint to guide them through a process of planning for action. The *problem* was *defined* in personal terms. It was considered in relation to the person's knowledge of their personality, significant roles, interactions with others, and

the context of the problem. Once the problem was defined in this way, *strategies* were *recalled, considered* and possibly *modified* to fit the problem, using the personal blueprint as the main reference point. A *decision* was made, and the chosen strategy was applied to the perceived problem. This entailed *active engagement* with the environment in the context of the barrier. A period of experimentation could ensue to ‘fine tune’ the strategy. The information gained through this active engagement provided the individual with an increased sense of personal control if it was successful and a decreased sense of personal control if it was not. Where a strategy was deemed successful it was likely to be adopted by the individual. Where a strategy did not work, it was rejected, and the individual went through the cycle again in order to review the problem in the light of the information gained and select/develop a new strategy.

**Figure 7.1 Model representing a possible cycle of control practiced by participants to maintain or regain perceived control of specific ORP.**



## 7.4.2 Definition of Constructs and Description of Links

A Cycle of Control of Occupational Role Performance was informed by three major constructs.

- 1) The personal blueprint
- 2) Contextual knowledge
- 3) The personal barrier

### *The personal blueprint*

Blueprint is defined as ‘a plan of action, or something already done that can be used as a guide to doing something in the future’ (The Microsoft Word Dictionary) or a ‘formula’ (Bernard, 1984). The term *Personal Blueprint* is used in this study to describe the knowledge people have about themselves and how they interact with a range of environments. It is suggested that they employ their personal blueprint to assist them in solving problems related to their own ORP. It consists of the reference points, beliefs and plans of action that participants appeared to use to help them plan how to overcome personal barriers in order to maintain or restore personal control in their everyday lives. As such, it may be defined as:

A background reference or guide used by participants to assist them in the tasks of defining problems, developing strategies, engaging actively with the environment, interpreting feedback and making decisions.

It can be seen as a collection of formulae for doing, to be applied in appropriate circumstances. These formulae were not fixed and could change and develop as new information was acquired and attitudes changed – as in “I used to do ...” “Now I do ...” It provided essential background information for occupational performance. It is suggested that a sense of positive personal control arose from occupational performance that fitted or develops the person’s personal blueprint. Negative perceptions of control arose from occupational performance that did not fit.

As the purpose of the blueprint was to aid in the restoration of personal control, the major *reference points* were the person’s knowledge or sense of self and knowledge or sense of social fit. Personal *beliefs* guided expectation. *Plans of action* were past strategies that

restored a sense of personal control. The concept of a personal blueprint extends Mead's suggestion that unpredictable conditions produced reflexive thought in which past experiences and general knowledge were drawn upon in order to decide how to proceed (Joas, 1985). The proposition that people use a personal blueprint in their everyday transactions, while not conceptually new, is an important reminder to occupational therapists that the people they work with have their own personal set of tools for dealing with their own personal problems. Accessing these tools may prove to be a fruitful guide to planning effective intervention.

### ***Contextual knowledge***

Participants gathered knowledge from the physical, sensory, social and cultural environments pertinent to the specific personal barrier being considered. Contextual knowledge is widely accepted in the literature (e.g. Mead (1972) and Chapparo and Ranka (1997b)). Therapists who are aware of the status of a client's contextual knowledge are in a better position to facilitate change.

### ***The personal barrier***

Personal barriers can be defined as any factor or issue related to the impact of Pd that was perceived by the individual to obstruct or weaken his or her ability to meet ORP goals. In this way personal barriers were role specific. One specific impairment may lead to the perception of a range of personal barriers. For example, it was postulated that a personal barrier could be interpreted in terms of how it limited opportunities for self expression. In this scenario, where active engagement that permitted self expression was limited, there was a threat to sense of self. A personal barrier, then, could be interpreted in terms of sense of self in two ways. It could directly obstruct actual occupational performance in ways that threaten sense of self, leaving the individual with three choices: to maintain sense of self in the face of direct evidence that it has changed; change sense of self; or strive to find a way to maintain sense of self while altering occupational performance. It could limit opportunities for ORP, with the same result. Further research to test out these ideas could lead to therapy techniques that allowed occupational therapists to pin-point which occupational performance limitations had the greatest consequence in terms of threats to the individual's sense of self.

### 7.4.3 Description of the Model

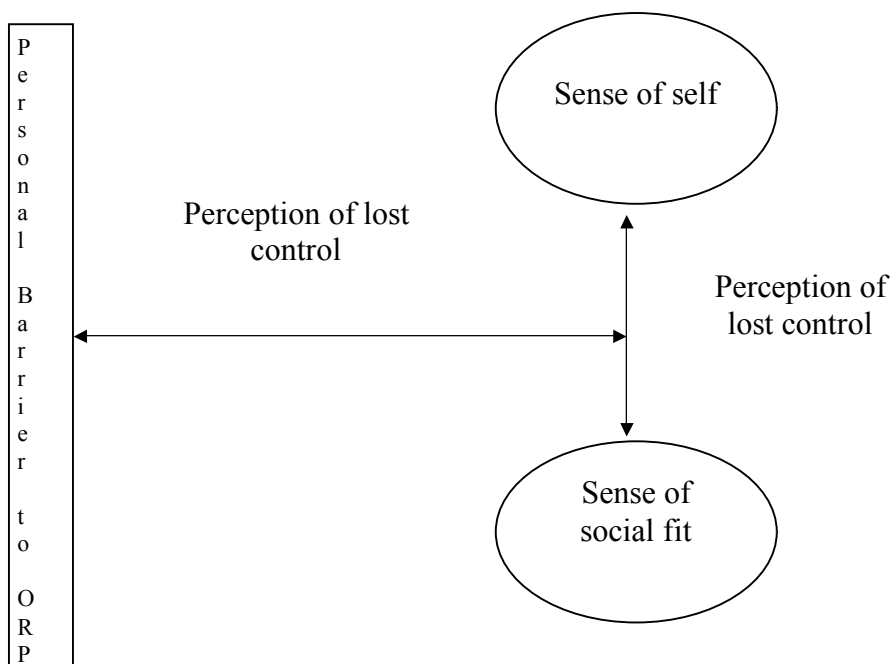
The model is made up of four parts:

- 1) The impact of a personal barrier upon occupational role performance
- 2) The planning cycle to regain control of occupational role performance
- 3) Testing strategies to regain control of occupational role performance
- 4) The outcome of decision making in relation to occupational role performance

#### *The Impact of a Personal Barrier Upon Occupational Role Performance*

The purpose of a cycle of control was to suggest how participants reason when dealing with the personal barriers imposed by Pd. It was proposed that when a participant encountered an event or factor in their everyday life, they might conceptualise it as a barrier if they perceived it had negative impacts upon their sense of self and sense of social fit. For this to occur, there must be feedback from the event to the person's sense of self and social

**Figure 7.2 The impact section of a cycle of control of occupational role performance**



fit. Each of these are intricately related, so each informs the other. Some of the personal barriers described in the findings were seen to have an impact in both of these areas. This could act in turn to magnify the person's perception of the barrier. In this way, information may move backwards and forwards between the three constructs as perceptions are formed. The left- hand section of the cycle of control is therefore about the perception of lost control. Sensing the impact section of a personal barrier through disruption to sense of self and sense of social fit prompted the planning cycle.

### ***The Planning Cycle to Regain Control of Occupational Role Performance***

A perception of negative impact motivated the person to employ their personal blueprint and their contextual knowledge to guide them through a cycle which described the process of solving the problem and arriving at a satisfactory solution. Participants used the information they had about their perceptions of the nature of a particular personal barrier, and put it together with their blueprint and contextual knowledge to define problems, develop strategies, consider feedback and make a decision. It was proposed that the personal blueprint and contextual knowledge were used at every stage of the cycle, to provide context and motivation to reasoning. The central section of a cycle of control was thus about informed *planning* (see figure 7.3). This central section of the cycle of control model had four stages:

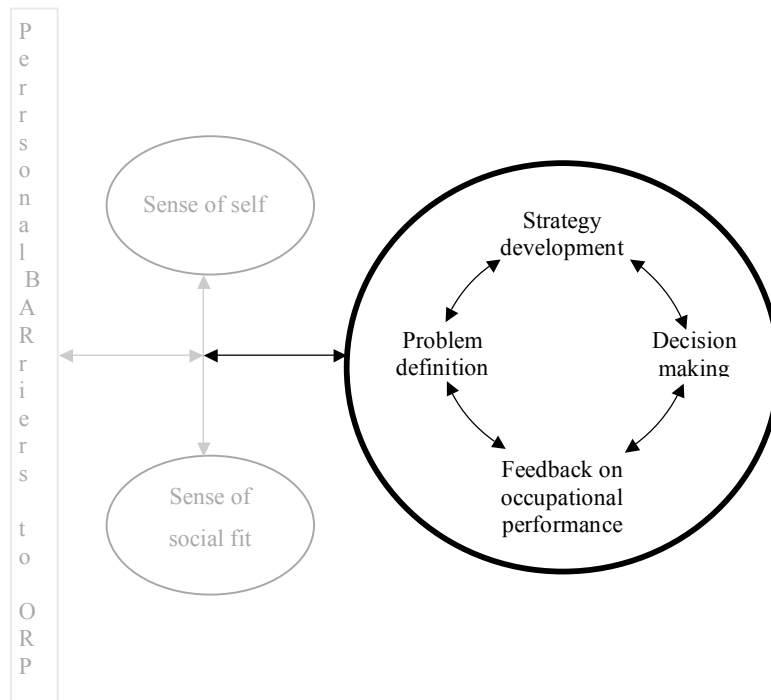
1. Problem Definition
2. Strategy development
3. Decision making
4. Feedback on occupational performance

#### **Problem Definition**

Once a barrier was identified, it was defined further, using the feedback from perceptions of sense of self and sense of social fit, along with relevant contextual knowledge. Using the personal blueprint, comparisons were made to find other, similar past experiences and associated beliefs which may help to further define the problem. Personal barriers were further defined within and/or across these broad headings with the aim of gaining enough understanding to create strategies for the removal or modification of the barrier so that

acceptable ORP was possible. In order to fully define the barrier, the person would refer back to sense of self and sense of social fit in the process of definition.

**Figure 7.3 The planning cycle section of a cycle of control of occupational role performance**



### Strategy Development

These were developed as they related to the defined problems. Three important points related to strategy development were:

- The development of strategies was strongly influenced by the person's blueprint. That is, the person drew on the reference points, beliefs and plans perceived as relevant to their definition of a specific personal barrier.
- The more specific the problem definition, the more specific the strategy developed to deal with it.
- Strategies generally needed to be tried out to see if they would work before a final decision to implement the strategy was made.

In the process of strategy development, any relevant beliefs recalled as part of the person's blueprint are considered first. What had worked in the past was given priority in dealing with a new problem. Strategies formed a behavioural intention and were developed in the context of perceptions of:

- Available resources: perceived abilities and social supports
- Specific goals or consequences – overt and covert
- Expectations of self
- Expectations of others

In the process of strategy development, the person would continue to refer back to problem definition.

### Decision Making

Once a strategy had been developed, the person moved on to make a choice about whether to accept or reject the strategy. If the strategy was rejected, the participant moved back to the strategy development phase and might go back to problem definition to reconsider the nature of the barrier. Decision making or choice was an important part of the findings. If the decision was to accept the strategy, then the person was likely to trial the idea. This entailed moving out of the planning cycle and into the third, right hand section of the model.

### ***Testing Strategies to Regain Control of Occupational Role Performance***

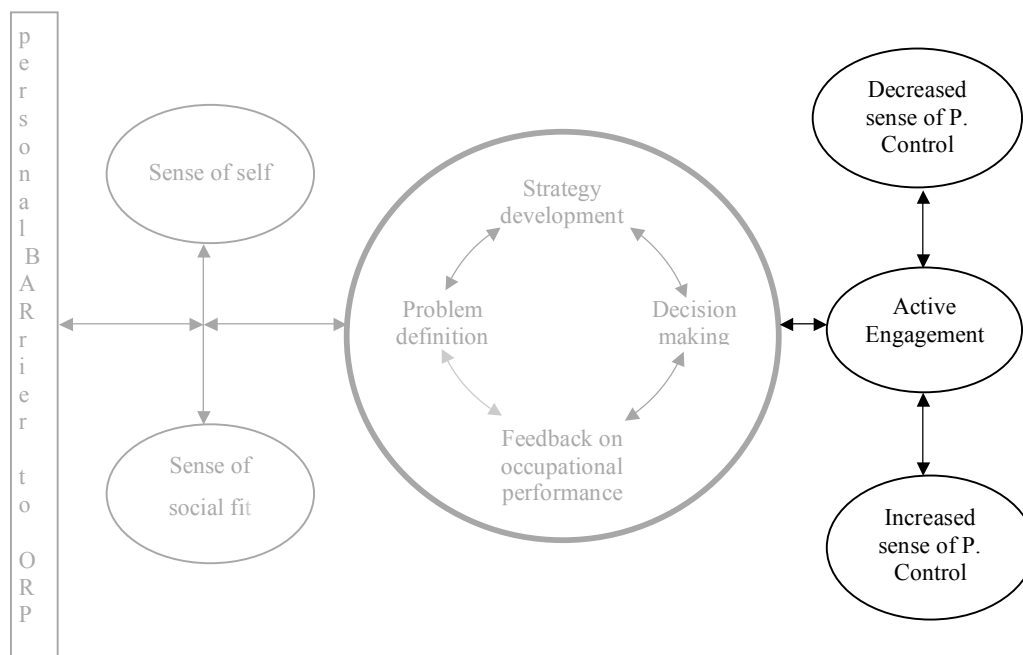
This section of the model related to the process of testing or experimentation in the context in which the barrier occurred (see figure 7.4). The testing section of the model had three parts:

- 1) Active engagement
- 2) A sense of perceived control
- 3) Feedback to the planning cycle

### Active engagement

This described a period of experimentation. Developed strategies were tried out in the context of the barrier that was being addressed. By actively engaging with the problem in the relevant context, environmental feedback could be obtained about how effective the strategy has been. Active engagement was an important part of the findings.

**Figure 7.4 The testing section**



### A sense of perceived control

It was proposed that the experience of actively engaging with the personal barrier being addressed using the chosen strategy, in the appropriate context, provided the participant with a learning experience. This experience was perceived by the participant in relation to any changes it produced in sense of self and/or sense of social fit. The experience might be interpreted positively if the strategy worked and negatively if it did not. If the experience was positive, then it would convey an increased sense of personal control, while if it was negative then the person would experience a decreased sense of personal control. Perceived control was an important part of the findings.

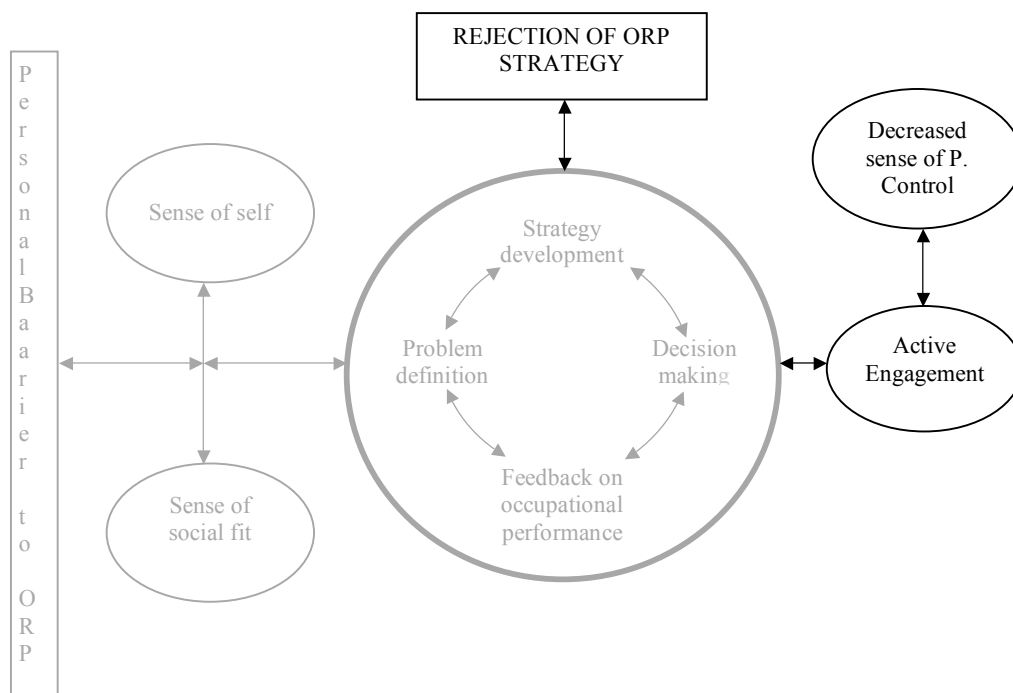
## Feedback

Information about Active Engagement in the form of an increased or decreased sense of personal control was taken back into the planning cycle where it was further considered in the context of the defined problem and the developed strategies. Feedback in the form of ORP outcomes was an important part of the findings.

### ***The Outcome of Decision Making in Relation to Occupational Role Performance***

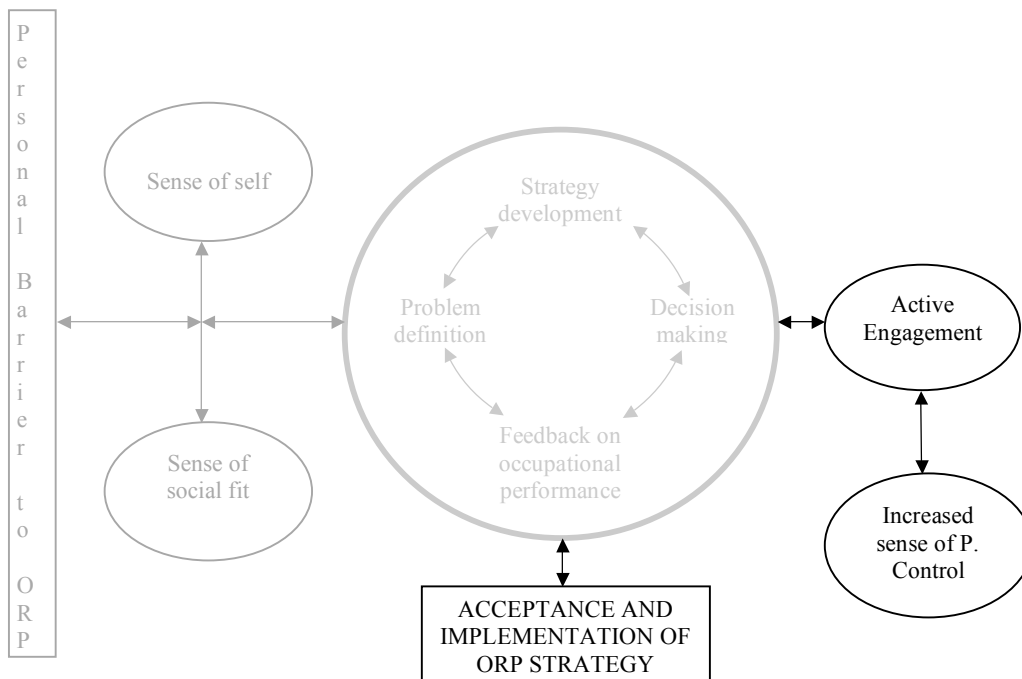
As a result of the processing of feedback from active engagement, a decision was made about whether to reject or accept the strategy. Rejection means the information gained through reasoning was used to more closely define the problem and hence develop a more effective strategy, thus going around the planning cycle again. It is proposed that participants who were unable to develop a strategy that was acceptable to them in terms of sense of self and social fit were likely to go round a cycle of control each time they encountered or thought about a particular personal barrier (see figure 7.5).

**Figure 7.5 The outcome section, showing rejection**



It is proposed that a strategy was accepted if it fitted with sense of self and social fit. Acceptance of a strategy meant the person moved out of a cycle of control. Once a strategy had been accepted, it was suggested that the person would make a determined effort to make it work. The strategy may need to be refined over time, necessitating a return to a cycle, but the overall principle was upheld. In other words, the person *commits* to the strategy. He or she acknowledged ownership and took responsibility for it. In this way, perceived control was restored. The decision was made by the person, rather than by some outside agency. It should be noted that a decision to avoid the situation or accept the loss were also strategies (see figure 7.6).

**Figure 7.6 The outcome section, showing acceptance**

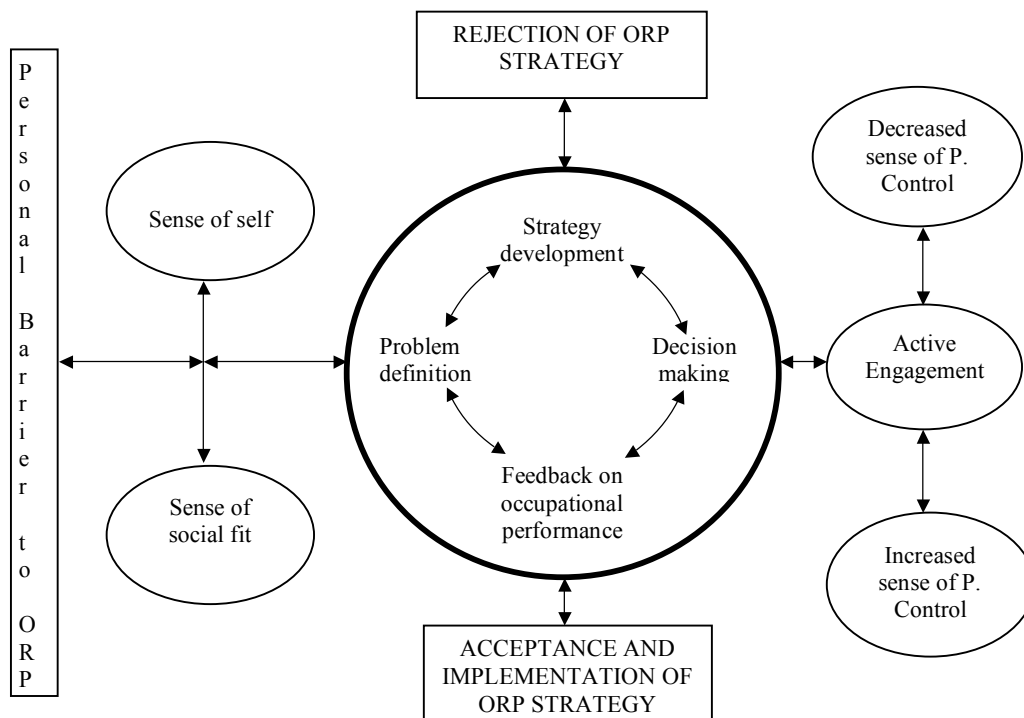


Outcome had an impact upon the person's personal blueprint. This impact could be seen as follows:

- Confirmation of self – maintenance of blueprint
- Maintenance of social fit – maintenance of blueprint
- Extension of self – a positive change in blueprint
- Increased social fit – a positive change in blueprint

Loss of function, of ORP, of sense of self and/or social fit could all produce a change in the blueprint that could be positive or negative depending upon whether it was accepted or not. Figure 7.7 the cycle of control model as a whole.

**Figure 7.7 A cycle of control showing all three sections of the model**



***Interruptions To A Cycle Of Perceived Control***

It was proposed that blocks could occur at almost every stage of the cycle, and could lead to an inability to resolve the problem. These blocks could be due to poor cognitive function leading to problems such as poor attention, difficulty marshalling and considering all the relevant information or a tendency to perseverate. Several participants felt their cognitive function had declined. Blocks could be due to insufficient information about the perceived barrier, or about possible strategies to deal with it. This latter was mentioned by a number of participants in relation to Pd. Blocks could occur because conflicting information made problem definition difficult. Blocks could occur in relation to making a decision to

accept the strategy or choose between two or more possible strategies. Participants might not get the opportunity to test out their proposed strategies through active engagement. This could be due to over-protective partners or a low level of function in relation to the barrier. Finally, a strategy might be developed, only for the external circumstances or context to change, making the strategy invalid and necessitating further consideration through a cycle of control.

#### **7.4.4 Examples to Illustrate a Cycle of Control**

##### ***Example One. Travel: Peter's Experiences***

This example shows how a narrative can be interpreted in relation to the four major themes of this study and a cycle of control. Travel, whether by car, public transport or on foot, was a necessary pre-requisite to community access. A cycle of control is discussed in relation to this mundane but necessary task. Peter, a participant in the early phase of Pd provided the narrative for this example, in which he was able to achieve primary control of an important personal barrier.

##### **Theme One: The Impact of the Primary Disease Process upon 'Doing' in Everyday Roles**

Level one participants were able to continue travelling as before for some time after their diagnosis. However, sooner or later, the impact of the primary disease process of Pd limited their ability to continue doing this, providing a *personal barrier* to travel. Peter ceased all his medications on the advice of a naturopath he consulted who claimed to have cured himself of Pd.

##### **Barrier**

The Pd symptoms he experienced included quite severe rigidity and tremor in his dominant right leg and arm. This limited his ability to perform the types of fine movements required of his right upper and lower limbs when driving. He also experienced shoulder pain as a consequence of poor right arm swing, making driving painful as well. He found that all this precluded him from driving his manual car as before.

### Peter's blueprint

At the time of interview, Peter *believed* he was the sort of person who loved taking risks and meeting challenges. He said, "Oh yes, I love taking a risk". He enjoyed finding solutions to difficult problems. He also did not believe in pretending a problem does not exist, saying: "... I'm not an ostrich". He believed that being purposefully active was the way to maintain self-esteem. He said, "The less you do the poorer you feel about yourself".

Peter could be seen to have a set of general *beliefs* about how he dealt with barriers or problems. His perception of himself, which formed part of his blueprint, was that he enjoyed taking risks, meeting a challenge and problem solving. He believed in meeting difficulties head-on and he believed that purposeful *doing* was important to feeling good about himself.

### Problem definition

Peter lived in a country town and needed to drive, not only around town, but also longer distances for his work and also for consultations relating to his health. He perceived a serious loss of personal control as a result of his lost driving ability.

### Strategies – 'developing a coping plan'

In accordance with his blueprint, Peter saw his loss of driving ability as a challenge and developed a strategy to restore it. He used his knowledge of the different types of controls in commercially available cars, and supplemented it with further information gathering, to develop a coping plan. At no point did he consider consulting a health professional or the Road Traffic Authority about his problem.

### Active engagement

Peter experimented with different types of car controls that were commercially available.

### Feedback

He found that he could control a car with automatic and cruise control. He also felt a left sided accelerator would help. This feedback on his occupational performance enabled him to make a decision.

### Decision

He referred back to his problem definition and to his 'blueprint' to check he had an acceptable 'fit'.

### Acceptance of strategy

He sold his manual car and bought one with automatic and cruise control and had a left foot control accelerator fitted. This represented a major commitment to his strategy.

### Owning outcomes – 'restoring control'

He found he could drive effectively in his new car, being able to use the hand controls to set the automatic function with his left hand, control the accelerator with his left foot over short distances, and use the cruise control over longer distances. Peter was happy to accept this as the solution to his problem, and experienced a restoration of perceived control in relation to his driving.

## Theme Two: Secondary Personal Limitations to Occupational Role Performance

### Barrier

Not being able to drive was a significant personal *barrier* and not acceptable to Peter. It represented a major loss of self-efficacy to Peter and a major interruption to his normal ORP in all his roles, because all had a strong community element.

### Blueprint

Part of his 'blueprint' was that as a single man he had to fend for himself. He said, "I've got to look after myself or nobody's going to look after me. I've got to look after myself or be in a nursing home. ... It's not as if you can bludge on a partner". He also had three children all in need of financial support: the youngest was still at school; the middle one was studying at university; and the eldest had a young child and a broken marriage. As a father, he believed that he should be supporting them. Peter had a strong work ethic, as well as a perceived need to work to survive, so in addition to being independent in his everyday living, he needed to be able to get to the wide range of locations that were his work sites. His sense of self was strongly linked to his work role. he said:

*“... it’s always better when you’re making a good quid at it cause you feel so much better about it, but I used to enjoy doing the jobs that were challenging ... I used to do the jobs nobody else would price because they were scared of it”.*

It was vital to him to remain in control of driving because not driving had so many negative implications for his future. All this provided strong personal motivation to ‘develop a coping plan’ and ‘put the plan into action’.

#### Strategy and implementation

The strategy he chose and implemented is described above.

#### Owning outcomes

The strategy worked because it enabled Peter to drive wherever he needed to go (including the 294 kilometres to Sydney). It removed the serious limitation to his community access and thence to the loss of personally meaningful ORP he had been experiencing. This in turn gave him greater opportunities for self expression, lifting his mood by reinforcing his sense of self, restoring his autonomy and therefore restoring his positive perception of control.

### Theme 3: Secondary Social Limitations to Occupational Role Performance

#### Barrier

Peter had some negative experiences in relation to the attitudes of others to his driving problem. His found his family did not agree with him about the satisfactory outcome he felt he had achieved. His sister, an occupational therapist, strongly recommended he should see the RTA to tell them he had Pd and take a test. He was very cross about this. He said:

*“I got poor advice. ... that’s been a trauma ... I don’t know whether I had to do it or not, but I did it and they took my truck licence off me ... and my bike licence ... and [I’m] locked into a system where I do a driving test every 12 months”.*

Peter seemed to feel victimised, but had no strategy to avoid it and accepted it as a necessary evil. He said:

*“... but it’s just – you know. It doesn’t worry me. It’s not an issue, but apparently if you’ve got Parkinson’s disease you’re supposed to notify the RTA of the disease or something. Anyway, it’s bad advice from [name of sister’s OT practice].”*

Peter was also irritated by the attitude of his father. He said, "... my father's got to realise that I'm driving better than him. ... He let me drive to give me a lecture on how poor I was driving". These two issues did not cause Peter to change the strategy he had developed in order to control a car.

#### Theme Four: Occupational Role Performance Limitations in Valued Roles

Peter's ORP in the role of health manager resulted in, amongst other things, his difficulty with driving. He attempted to achieve a cure for Pd by following a naturopath's advice. Going off all medication proved disastrous for his occupational performance generally. Despite this, Peter's difficulty in driving and the success he then experienced in solving the problem gave him an increased sense of personal control in relation to the role of Health Manager. Part of this sense of control could have been linked to another issue relating to his sense of social fit. He talked of how he wished his symptoms were concealable – that his tremor and rigidity made him immediately look different to others and gave him a label he did not want. Being able to drive in a 'normal' way was one thing he felt he could do to show others he was not so different, and that he did still 'fit' socially.

There was a further revolution through a cycle of control when Peter decided to abandon the advice of the naturopath and resume his medication. He found his general level of function improved so much that he no longer needed the left accelerator pedal. He now drove his car in the usual way, using a right accelerator pedal, automatic controls and cruise control.

#### ***Example Two. Communication: Enid***

This example shows how a cycle of control might result in what was perceived by role partners as a negative outcome. The narrative was provided by Enid, who was in the late phase of Pd.

#### *Personal blueprint*

Enid *knew* that she enjoyed other people's company and that she and her husband had a close circle of friends of long standing. She *believed* she liked her relationships to be

smooth and harmonious. She said, “... *I like everything to be nice and easy and everybody talks to everybody*”.

#### Personal barrier

Enid had serious cognitive dysfunction, and poor oral control when eating. She *knew* that she and her husband had always greatly enjoyed the regular dinners they had with their closest friends. Now she found these dinners were an ordeal.

#### Problem definition

She *defined* this *problem* in the following two ways. She saw that she had cognitive difficulties affecting her ability to converse, and she dribbled when eating. She said, “... *dribble and drool. That does embarrass me*”. These things gave her a *negative sense of self*. Enid experienced a reduction in her sense of *personal control* that threatened her sense of *social fit*. She said: “... *they just kept getting on and ... I felt out of it. ... not that they were nasty or anything ... You feel like you've lost something ... You're not being wanted*”.

#### Strategy development

The *strategy* she identified was to refuse to attend these dinners.

#### Active engagement

She tried this out and found it restored her sense of personal control by removing the *negative feedback* that was affecting her *sense of self* and *sense of social fit*.

#### Acceptance and implementation

She *accepted* and *implemented* this strategy, to the dismay of her husband and friends. For her husband in particular it meant the loss of an important source of social interaction and support. Despite their protestations, she held firm to her decision. Although this meant that she saw little of her friends, she found this preferable to struggling to converse and fit in with a group of people over dinner.

Enid's cognitive problems hampered her ability to develop strategies that might have allowed her to continue to enjoy the support of her friends. By understanding the issues in this way, an occupational therapist might, for example, have suggested to Enid that she try to initiate when she sees her friends, that she avoid eating meals with them and that she see

them individually rather than as a group. With Enid's agreement, the therapist could talk to her friends and to her husband or provide written information to help them understand how things were for Enid.

### ***Example Three. Cognition: Una Lewis***

Una Lewis was the partner of Frank, who had middle phase Pd and high blood pressure.

#### *Personal blueprint*

Una was accustomed to Frank being an intelligent and competent partner. She had always *believed* that she was less intelligent and less competent than him. She said:

*"I'm just ordinary ... never had to do anything brainy very much. Even when I went to work I never did anything that - making trousers and things like that. Hard work but nothing that you had to use your brains for".*

#### *Problem definition*

Una felt that Frank was losing his intellectual ability. She talked about this loss of cognitive function as a problem that was defined in relation to their partnership – a barrier to the continuance of their life together and hence her sense of *social fit*. To illustrate the problem she told a story. They were driving to a friend's place for a social function. In order to explain how things were now, Una started off by saying how things used to be. She said, "... *he's always been able to do everything himself without me telling him, you know*". Then she identified the problem: "*Well, just now he needs to be told*". She moved on to explain further, using their journey to the function to do it: "*I said: 'you've got to go to the left'. [Frank said:] 'I can't go to the left there'.*" He got lost, she had to tell him what to do, and he would not listen to her direction. She said, "*Anyway, I don't know how long it was, we went back to the people*". She was embarrassed they were so late: "*Oh! I'd have liked to have gone home*".

This was a new experience – Frank had always been so reliable. She said, "*So things like that would never happen before*".

### Strategy development

Una *believed* she should take over and be the decision maker in their partnership.

### Problem definition

She felt inadequate, and her *sense of self* was threatened. She said “*Am I strong enough to cope with both of us?*” Una’s *personal blueprint* meant that she did not *believe* that she was good at solving problems or being the strong one in the partnership. Her sense of perceived control in her role as a wife was linked to letting her husband take charge. She defined the problem of her husband’s declining cognitive function as a loss in the way that they functioned as a couple. The strategy she identified to deal with this was to make good the loss by substituting her own cognitive abilities for his. However, she did not feel able to do this. This was to her possibly the most important reason it was a problem. She developed a *strategy*, but rejected it, reverberating from *problem definition* to *strategy development* without achieving a satisfactory outcome.

An occupational therapist or other health professional, having this understanding of Una’s concerns, could perhaps work with her with sensitivity for their relationship. Together, they could put some strategies in to place that would enable her to develop her skills and implement them in ways that would increase her confidence in her ability to deal with financial matters and make important decisions. They could work out ways that would help her to support her husband’s role participation while she assumed a more active role herself, without completely changing how they functioned as a teamed couple.

These three examples show how this model of a cycle of control allowed greater insight into complex problems. It showed how a person might move fairly smoothly around the model as in Peter’s case, and arrive at an outcome that directly altered the personal barrier in a favourable way. It demonstrated how someone with fewer personal resources, such as Enid might arrive at an outcome which was acceptable to her (although not to her husband), but had the potential to lead to further erosion of personal wellbeing. The last example showed how someone could get ‘stuck’ within a cycle, without achieving strategic resolution.

#### **7.4.5 Theory Development and Application of the Model**

The constructs and their relationships to each other as described in the suggested cycle of control model could be applied to the real life situations described by the participants in this study, as demonstrated in the previous section. A number of constructs in the model have been described elsewhere.

Conceptually, the model extends the theory on environmental interaction in relation to occupational *context*. It suggests an inner context for strategy development that includes sense of self, sense of social fit and personal blueprint. The model offers a possible picture of the way in which information from the environment is interpreted by the person in terms of their inner context, and used in the negotiation between the person's internal and external contexts. The model suggests a dynamic process which can move backwards and forwards within and between the relevant internal and external contexts in the course of developing an acceptable strategy to deal with a perceived barrier to occupational role performance. There is an increasing awareness of context as an important part of occupational therapy in theory and practice (Whiteford & Wright-St. Clair, 2004).

In this way, the model supports the notion put forward by symbolic interactionism that role performance is interactive. Mead saw the environment as the means for social learning and development, and that there was a reciprocal relationship between mind and society (Hardy & Conway, 1988b). Through the two constructs of sense of self and sense of social fit, the model provides one view of the avenues by which such social learning and development might take place. Mead studied subjective experiences to understand the relationship between mind and society and suggested that external experiences produced reflexive thought that contributed to internal experiences. The model supports this perspective, with its attention to perceptions of barriers to occupational role performance, problem definition and the planning and the testing of strategies via active engagement. Mead believed people used their past experience and a general knowledge about the past and future to inform their decisions. The construct of the personal blueprint within the model supports this view.

The model supports the constructs of expectation and choice that are central to the role theory as put forward by Burns (1991), Landis (1995) and others. The construct of sense

of social fit demonstrates awareness of external expectations, while the construct of sense of self demonstrates awareness of internal expectations. The personal blueprint relates to knowledge of both. Fulfilling perceived expectations and maintaining a sense of choice contribute strongly to the purposefulness of occupational role performance (Black, 1976; Heard, 1977).

The model supports the view of occupation performance role put forward by the OPM (Aust.) (Chapparo & Ranka, 1997b) as having both internal and external perspectives. Importantly, it supports the ‘doing’, ‘knowing’ and ‘being’ elements of occupational performance role as described in the OPM (Aust.). The ‘doing’ element is reflected principally in the active engagement construct. ‘Knowing’ is reflected in all the constructs, but to a lesser extent in active engagement and sense of perceived control. ‘Being’ is reflected mainly in the constructs of sense of self, sense of social fit and sense of perceived control. Because the nature of the model is to look at specific experiences of lowered control within the internal and external context of the person’s life, it is able to accommodate the picture of complex interaction between a range of roles that are held at the same time, and a range of environments for one specific role, that is presented by the OPM(Aust.).

By addressing specific instances of lowered control the model supports the application of the view that perceptions of control can vary from one role to another (Bertrand & Lachman, 2003; Krause & Shaw, 2000b). Bandura’s definition of self efficacy as “what [you believe] you can do with what you have under a variety of circumstances (Bandura, 1997, p.37) is important in relation to the process of problem definition and strategy development. In the model, these are informed by sense of self and by the personal blueprint. It is possible that a belief of lowered self efficacy, in a particular context of occupational role performance, may lead to relinquishment of the specific role-related occupation without the participant completing a cycle of the model.

The planning cycle has many similarities with other problem solving processes developed and used in occupational therapy practice. For example, a problem solving framework termed IDEAL (Bransford & Stein, 1984) identifies the steps in problem solving as:

*Identify the problem*  
*Define the problem precisely*  
*Explore possible strategies*  
*Act*  
*Look at the effects*

There are obvious parallels here between the latter four constructs of IDEAL and the planning cycle or central section of a cycle of control. The difference is that the present model enables consideration of the problem solver as an individual, adding a subjective element to the objective process.

The Cycle of Control model as presented here develops theory in this area in the following ways:

- 1) The cycle must be considered in the context of three major constructs: the personal blueprint, contextual knowledge, and the personal barrier.
- 2) The cycle proposes that personal barriers are perceived in relation to impact upon sense of self, sense of social fit and consequent ORP.
- 3) The cycle is strongly linked to personal meaning
- 4) The cycle is linked to the concept of perceived control
- 5) In terms of outcomes from the cycle
  - a. The outcome is considered in relation to the individual's ORP.
  - b. the emphasis is upon achieving a sense of personal control as represented by acceptance by the individual, rather than upon solving the problem.

#### **7.4.6 Possible Application Of The Model In Clinical Practice**

Elements of the cycle of control model have important implications for health policy. Chronic illness is a major feature of later life, and the care receiver/care giver partnership is becoming increasingly important in relation to this. With the growth in population numbers of those in old age, there is a growing need to ensure that this group are able to continue at home together maintaining a satisfactory quality of life for as long as possible. The model provides opportunities to gain greater insight into how people with Parkinson's disease and possibly others with chronic illness manage their own health in the context of their own

lives. It has a number of important implications for client-focused practice that relate to assessment, intervention, and evaluation of outcome.

### ***Communication***

The cycle of control has the potential to have profound impact upon communication in occupational therapy practice in both style and content. For those in old age effective communication is particularly important (Hobson, 1999). This model could provide a structure for communication that ensures the therapist and client are talking together rather than at cross-purposes. It promotes their ability to understand each other, because it provides the therapist with a structure for obtaining the expert information held by the client regarding their priorities and their context.

The content of such communication changes in consequence of the different style. Clients are now invited to provide information about themselves in the *context* of their significant occupational roles, role performance and role partners at the time of the interview. The therapist is then able to couch further communication in terms that directly relate to the client, making the conversation, the further assessments that may be required, the intervention and the evaluation coherent and unified for both of them as participants in a process.

### ***Assessment***

The model cycle of control model placed emphasis upon occupational role performance viewed from the inner perspective of the performer. The model proposed that a barrier was perceived by participants in a subjective fashion, through the twin filters of a sense of self and a sense of social fit. This would indicate that assessments that investigated these two constructs could provide an extremely useful basis for the planning and evaluation of occupational therapy interventions.

Elements of the interview protocols used in this study are directly applicable to clinical practice. A guiding principle for future work in this area should be that an assessment facilitates the person being interviewed to be the expert on his or her own life. This means interviewees need to be able to tell their own story in their own way. Table 7.1

provides principles that would be useful in applying this rule. In the context of specific roles that have been identified, the questions in table 7.2 are suggestions or examples of questions that could be asked, using the model as a guide. As an initial interview, this approach would allow the therapist to gain information about the person from their perspective from the outset. It could be fitted in to other things that might be going on at the time, and could be carried out in greater or lesser depth as appropriate. It should feel like a conversation. It could allow the therapist to establish rapport, and enable her or him to gain a perspective about what was most important to this person at the time of the interview. The information gained could be used to tailor subsequent assessment so as to more specifically address the person's immediate and long term needs.

**Table 7.1 Interview principles to facilitate perspective of client as expert**

- The focus is upon how the person sees their life at the time of the interview.
- Open ended questions are important.
- The interview should commence with a global question, to allow the person to choose what to talk about first. Examples could be: "Tell me a bit about your roles" or "Could you tell me about your life at the moment?"
- As the participant talks, the interviewer could use the technique of funnelling questions (see Chapter Five) to find out more about specific areas.
- The purpose of the interview for the interviewer should be to gain perspective on what the person's life is like, how the person feels about themselves and how they see themselves fitting in to their social context.

**Table 7.2 Examples of occupational performance role-related questions that address the constructs of the model**

- Personal barriers: "So what stops you doing that?" "Tell me more about ..."
- Sense of self : "How did that make you feel?" "Tell me about what is important to you." "How did that fit with the sort of person you are?" "What makes you feel good about this?"
- Sense of social fit: "How do you feel when other people ...?" "What do you enjoy about the relationship?"

**Table 7.2 (continued)**

- Problem definition: “What do you think makes this such a problem?” “Is this a problem every time ...?”
- Strategy development: “What have you tried to do to overcome this?” “Have you got any ideas about how to deal with this?”
- Decision making: “what made you decide to...”
- Active engagement: “Did you try that out?” “What did you do?”
- Personal control: “So how did it work out?” “How did that make you feel?”
- Feedback on occupational performance: “So how well did you think that worked?”
- Rejection or acceptance of strategy: “So did you do that?” “Why did you decide not to do that?” “what made you decide that was the right thing?”

The cycle of control model suggested that sense of self and sense of social fit were used as a filter in considering the barriers the person faces. It means the therapist needs to consider these factors using information from the person rather than relying upon empathy. Further assessment development is needed to effectively obtain this type of information.

Where clients are having difficulty achieving satisfactory outcomes in coping with a perceived barrier, the model could be employed to identify with more accuracy and specificity where the process is breaking down. Blocks could occur at every point in the model. Using this structure, it may be possible to develop assessments that enable the therapist to accurately identify why a client is having difficulty achieving a particular outcome. It may be possible to set up a quantitative instrument to do this.

### ***Intervention***

Interventions that focus on bringing about change in sense of self and social fit could mean that the perception of the barrier changes. This may empower the person to move through a cycle of control in a different, more personally effective way.

Intervention that addresses specific blocks that may be occurring in the way someone progresses through the model would enable them to move on to dealing with their personal

barrier in their own way, rather than implementing a strategy that might be developed by someone else.

Discussion of the data obtained in this study shows that the cycle of control model represents an oversimplification of a complex phenomenon. Further development of the model in research and in clinical practice will lead to greater refinement and accuracy in its conception and application.

### ***Evaluation***

If the model has been used as a basis for assessment and intervention, then evaluations can be set in relation to the kind of information not usually amenable to accurate evaluation. The model allows for focused goals to be written by the client and therapist together that address the problems being experienced by the client *in context*. Standardised assessments may be selected as appropriate to evaluate progress in relation to specific parts of the model.

## **Summary**

In this chapter the findings of this study have been discussed in the context of stated purpose of the study, and the relevant literature. Significant aspects of the four major themes identified indicate the need to broaden the present major emphasis upon the overt impact of symptoms of Parkinson's disease to a consideration of the indirect impact the disease has upon sense of self, sense of social fit and occupational role performance for those with Parkinson's disease and their partners. A model was proposed that could conceptually facilitate this process, both in research and in clinical practice. Important points discussed in this chapter are listed here:

- Participants were comfortable discussing their roles without prior coaching as to the meaning of the word. They represented their roles as they perceived them.
- Participants were active in their attempts to restore control of their occupational being.

- The findings about teamwork indicate a need to consider approaches to therapy that genuinely recognise people with disabilities and their partners as a team rather than as people with disabilities and their carers. Health professionals were peripheral to this process.
- Participants coped with Pd largely through using their own resources, reinforcing the need for therapists to ascertain what these resources are and work with them.
- ‘Talking roles’ enabled the participant to discuss significant occupational performance in ways which were personally logical and helped make it accessible in context to the interviewer.
- Standardized role assessments are not necessary or even desirable, as they impose the assumptions of the interviewer and do not reflect the diversity of role perceptions found in this study.
- Participants’ perceptions of barriers to ORP were not objective and were strongly influenced by sense of self and sense of social fit. Strategy development addressed these two constructs in consequence.
- The cross-sectional approach of this study revealed a picture of participants with Pd and their partners moving along a life trajectory that had been deflected in a mostly negative direction by Pd. Each deflection was interpreted by participants as a barrier to their realisation of themselves as occupational beings. Barriers could be complex and could cut across several layers of the participant’s occupational performance.
- There appeared to be a gradation from major roles, which were clearly defined by participants, through minor roles to routines and tasks. This picture of a continuum of organization for occupational performance from role to task has not been described before.
- The findings supported the concepts of primary and secondary control and the primacy of primary control. Participants appeared to practice a combination of primary and secondary control in relation to significant ORP, but indicated primary control was the most desirable.
- The cycle of control model is directly applicable to participant narrative and has the potential to provide a useful practice model for working with the client in context.

The study is summarised in the following chapter, and the limitations, scope and significance of the findings are discussed.