

## **CHAPTER FOUR**

### **PERCEIVED CONTROL**

## 4.1 Introduction

The previous chapter discussed the impact of chronic illness, specifically Parkinson's disease, upon occupational role performance. This chapter contains a review of the literature about perceived control as it relates to ageing and chronic illness. It considers the significance of perceived control, the nature of a sense of personal control, and reviews some of the theories relating to perceived control as they relate to ageing people. A more specific view of the strategies employed by people to cope with Pd, and thus maintain a positive sense of perceived control, ends this chapter. The chapter contributes to the fulfilment of the research objectives related to perceived control which include identification of:

- The differences in participant's perceptions of control at different stages of the disease.
- Strategies or coping plans developed to maintain a perception of control over occupational role performance.

## 4.2 The Significance of Perceived Control

A review of the literature revealed perceived control to be highly significant in relation to well-being. The nervous system of human beings reacts, not to stimulation, but to change in stimulation (Vernon, 1963). Studies demonstrate that the removal of environmental stimulation results in disordered thoughts and behaviour. Humans need something to work against to balance them, a challenge (Vernon, 1963). The literature shows that human interaction with the environment is a purposeful challenge. In order to *do* something, people need to interact with their environment. Furthermore, in order to achieve their goals they need to *control* that interaction. To this end, people use a wide range of abilities and skills to respond to and manipulate a range of environments in subtle and sophisticated ways. Although people with a high level of skill in one or two areas but not in others, might control the environments to which they are suited in a highly effective manner, they have greater difficulty in environments that do not match their skills. Those with few skills might only be able to respond in basic and relatively ineffective ways. In relation to a sense of well-being, it is the *perception* of environmental control that appears to be important.

This *perception* has an impact not only on well-being but also upon survival. Langer and Rodin (1976) conducted a simple, but classic experiment. They identified choice as an important factor in facilitating a sense of perceived control. They postulated that if increased perceived control had beneficial effects, then physical and mental alertness, activity, general level of satisfaction and sociability should all be affected. Langer and Rodin (1976) tested whether feelings of control over particular elements of a situation affected more broadly based attitudes and behaviour. They assigned people living in a nursing home to one of two groups. The responsibility-induced group were invited to choose a pot plant and told it was theirs to do with as they liked. The comparison group were handed a pot plant and told that, although it was theirs, the nursing staff would look after it for them.

Residents were assessed one week prior and three weeks after this talk. They were asked how happy and active they felt. The nurses rated how happy, alert, dependent, sociable, and active the residents were and how they spent their time. Langer and Rodin (1976) found there were reliable differences between the two groups, with 48% of the responsibility-induced group reporting they felt happier, while only 25% of the comparison group did. The nurses' responses showed that 93% of the first group demonstrated overall improvement, while 71% of the comparison group had become more debilitated. Eighteen months later, 30% of the comparison group had died, while half that number had died in the responsibility induced group. The responsibility-induced group had made significant further gains in happiness, general activity and alertness over the course of the time they had the plant. Rodin (as cited in Peterson, 2004) later commented that against a background of virtually no choice, the seemingly trivial choice of taking charge of a pot plant represented quite dramatic choice. Rodin and Langer concluded that offering choice boosted a person's sense of perceived control and hence well-being (Rodin & Langer, 1977).

A number of other studies have shown that a perceived failure of control in a personally significant context can lead to a phenomenon that is described as *learned helplessness* (Baltes & Baltes, 1986; Decker & Schulz, 1985; Kuhl, 1986). It is possible that a significant proportion of the second group in Langer and Rodin's experiment (1976) demonstrated this phenomenon. Such a person appears to lose all confidence in being able to effect environmental change or meet personal needs (Peterson, 1993). Some of the negative effects of learned helplessness are boredom, reduced activity, passivity and depression

(Peterson, 1993). For participants with Pd in this study, it is likely that those who feel able to practice some level of autonomy and choice will feel happier and be more active than participants who perceive their occupational role performance has been absorbed or assumed by their partners. Table 4.1 summarises the overall significance of perceived control.

**Table 4.1 The significance of perceived control**

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| <ul style="list-style-type: none"><li>• Humans function in terms of their environmental interaction</li><li>• Sense of well-being subjective rather than objective</li><li>• Control of environmental interaction central to well-being</li><li>• Loss of perceptions of control can shorten life</li></ul> |
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### **4.3 Environmental Interaction and Perceived Control**

Maslow (1968) theorised that humans work towards an ultimate goal of self actualisation by fulfilling their needs. A simplified version of Maslow’s hierarchy proposes four levels of need from lowest to highest: physiologic/health needs, emotional/personal needs, participation and extra-personal needs, and life satisfaction and esteem needs (Mandich, 2005). Maslow’s view was based upon the person’s perception of self and environment, and therefore his hierarchy related to what was perceived as personally meaningful at any given moment.

There have been a number of constructs that have been related to a sense of control. White (1959; 1971), for example, suggested there was an inherent satisfaction in influencing the environment successfully that comes from what he called a ‘feeling of efficacy’. He theorised that this in turn gives humans a feeling of self esteem, and that high or low self esteem is related to their sense of confidence, based on experience, that they are environmentally competent.

Bandura (1997) further developed the concept and termed it *self efficacy*. He defined efficacy as “... a generative capability in which cognitive, social, emotional and behavioural skills [are] organised and effectively orchestrated to serve innumerable purposes” (Bandura, 1997, p. 37). He defined *perceived* self efficacy as “... what [*you believe*] you can do with

what you have under a variety of circumstances” (Bandura, 1997, p. 37). A large body of research has been developed around the construct of self efficacy.

A related concept developed by Burger and Cooper (1979) was the idea of *desire for control* (DC). They defined this as a stable personality trait reflecting the extent to which people were motivated to control the events in their lives. Central to the concept is that those people with a high desire for control prefer to make their own decisions and take action to avoid potential losses of control. Persons low in desire for control might avoid responsibility and prefer others to make decisions for them. Burger (1985) proposed that people who have a high desire for control display many behaviours of high achievement, and related this to a sequence of four task related steps:

1. *Aspiration Level.*

- Persons high in desire for control (DC) have high aspirations for their performances, while those with low desire for control had low aspirations.
- High DC people select aspiration levels that realistically reflected their potentials. If a task was considered a challenge to personal control, then success at the task demonstrated an ability to control such situations, and gave a sense of more general mastery. Failure to conquer the task could be considered as a threat to perceived control. Those with high DC were highly motivated to succeed in any task they undertook, and to seek out challenging tasks. However, unrealistically high aspirations could result in unwanted failure, so those high in DC learned to set realistic aspirations.

2. *Response to a Challenge*

Those with high DC responded to a challenge by trying harder, while those with low DC did not put in more effort. The motivation to avoid failure was strong for those with high DC.

3. *Persistence*

In the same way as for the other steps, those with high DC persisted longer with their efforts, than those with low DC who sought help or gave up sooner.

#### 4. *Attributions for Success and Failure*

Those with high DC attributed both success and failure in ways that increased motivation for subsequent tasks. High achievement was associated with giving oneself credit for successes and attributing failure to lack of effort or bad luck.

Burger pointed out that people who were high in desire for control should not be considered as superior to those that were low in desire for control. At each step of his model, he saw that high DC could become a liability. For example, a high level of *aspiration* might lead to engagement in impossible tasks. Similarly, those with high DC might take on too many tasks, limiting their ability to do any of them well. Those who *responded to challenges* in a task with increased effort might also *persist* beyond a point where it was reasonable to give up, wasting time and effort. Such people responded to failure by feelings of helplessness, leading to reluctance to try again in similar circumstances. Burger and Arkin (1980) showed that those with high DC, in experimental circumstances, showed a greater helpless response (*learned helplessness*) and were more likely to show signs of depression following a learned helplessness experimental manipulation than those with lower DC. Finally, Burger (1985) argued that *attributing success to oneself* might lead to higher levels of motivation on later tasks, but could also give such a person a false impression of his or her own abilities, leading to subsequent mistakes and failures. Burger and Cooper (1979) found that those high in DC were more susceptible to the illusion of control than those with low DC.

The work of Burger and Cooper (1979) and of Burger (1985) developed the idea of a range of perceptions of personal control and described the impact different levels of perception might have upon the person. Their work did not appear to consider what was personally important to each person. In relation to this study, these findings demonstrate that there are likely to be complex factors determining the sense of control felt by participants, and indicates the importance of considering personality and 'style of doing' in relation to perceptions of control. Further research is needed to investigate how a desire for control affects perceptions of control and actions to regain control in chronic illness.

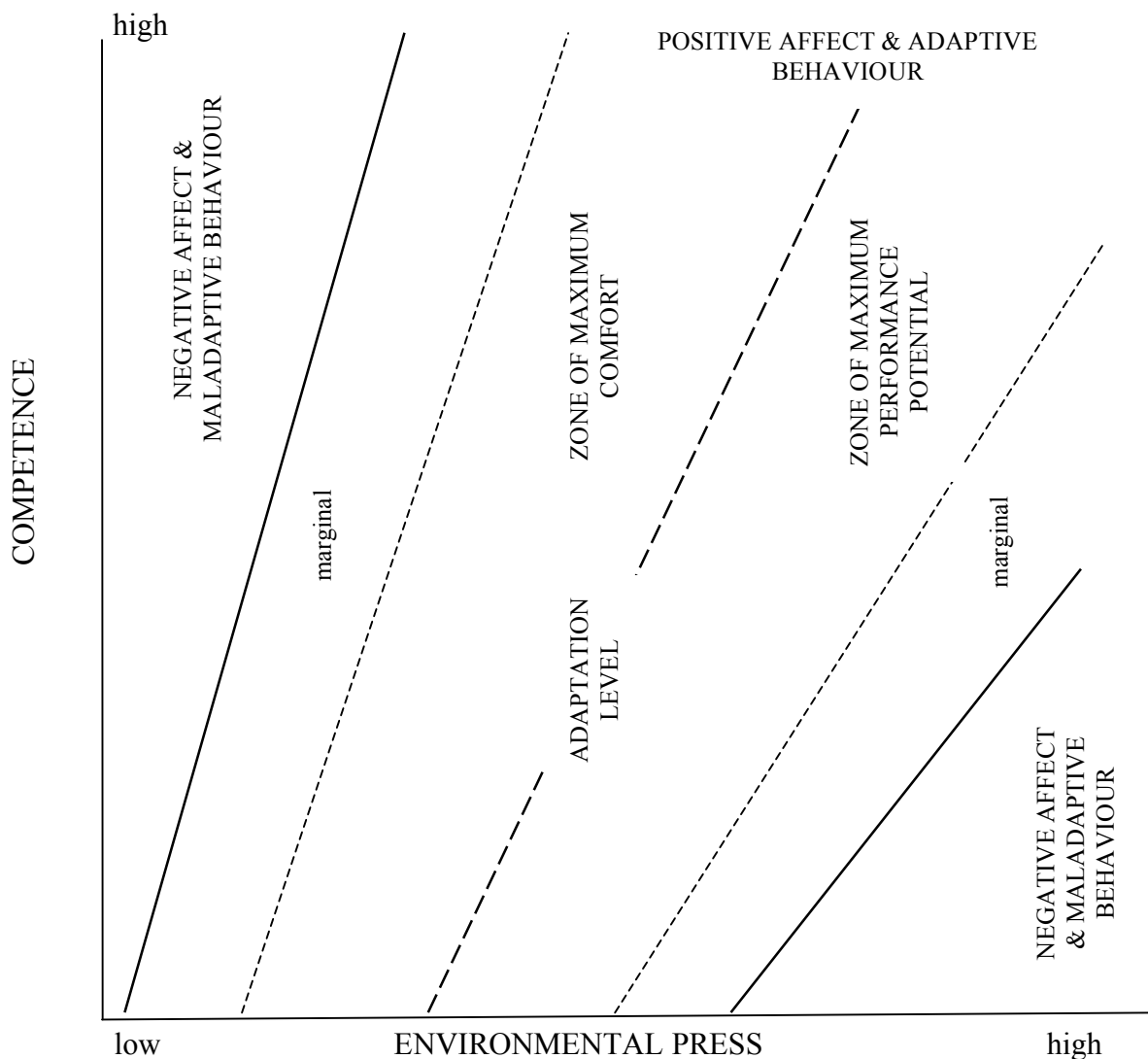
Lawton (1982) provided further insight into the processes determining whether environmental interactions were deemed successful or unsuccessful by the person and

proposed an ecological model of ageing. This model utilised the concepts of environmental competence and environmental press. Lawton and others viewed competence as a characteristic of the person, while environmental press represented a demand, with some motivating quality, that is placed upon the person by the environment (Murray, 1938). Environmental press might be objective, or construed by the person, but it is a demand that is relevant and specific to a need of the person (Murray, 1938). To take a simple example, many railway stations in Sydney have daunting flights of steps (an objective environmental press) to the railway platform. If a person with Pd wishes to catch a train, then negotiating these steps becomes a demand construed by the person (a subjective environmental press). It must be met in order to achieve the desired goal of catching a train. If the person is still fully mobile, (s)he is *competent* to meet this demand. If the person has problems with mobility, then the environmental demand might be too great, leading to an inability to carry out the activity that required catching a train. Thus Lawton (1982) talked about the *Person Environment Transaction*, and described the outcome of such transactions in terms of occupational behaviour.

Lawton and Nahemow (1973) developed the Press-Competence Model (see Figure 4.1). A continuum of competence formed one axis of this model, while a continuum of environmental press formed the other. The model has the advantage of linking behaviour to environmental press and competence. Behaviour in the model is considered as adaptive through to maladaptive in relation to both competence and environmental press, with a corresponding affective response. Where competence is low and environmental press is high, then behaviour is adaptive and the affective response is negative. This is represented at its greatest in the model at the upper left hand corner and the lower right hand corner. In the upper left hand corner, people encounter circumstances where the environment offers little or no challenge to a highly competent person. At the bottom right hand corner, is the opposite, an impossibly high demand without the competencies to deal with it. In the middle of the model, sits the adaptation level. This was defined by Lawton (1982) as representing "... a state of balance between the level of external stimulation and the sensitivity of the person's sensory, perceptual and cognitive state" (p. 45). A person at the adaptation level tends to adapt to any given level of stimulation in such a way that awareness of the stimulation recedes (Lawton, 1982). An example is the way the touch of clothes on the skin vanishes once dressed. A change of intensity brings it back to awareness (Lawton, 1982). Each person

has a different point at which they reached the adaptation level for a given environmental stimulus because all humans have differing competencies (Lawton, 1982). Lawton suggested that to the left of this line, lay the zone of maximum comfort, where people feel relaxed and a bit under stimulated. The person may feel bored, but not excessively so. To the right is the zone of maximum performance potential. In this zone the environment provides sufficient stimulation to make people want to respond to it. In this zone people perceive competence to a level where they feel challenged and are able to meet the personal and environmental demands, experiencing interest and pleasure (Lawton, 1982).

**Figure 4.1. Press-competence model.** From Lawton, M. P. (1982). Competence, environmental press, and the adaptation of older people. In M. P. Lawton, P. G. Windley & T. O. Byerts (Eds.), *Aging and the environment: Theoretical approaches* (pp. 33-59). New York: Springer, p. 44.



The Press-Competence Model (Lawton & Nahemow, 1973) provides some insight into how a sense of control might be perceived differently by different people with differing needs and competencies functioning in differing environments. Taking mobility as an example, perhaps participants with Pd in this study may find the familiar environment of home offers challenges that they can mostly meet, putting them in the adaptation zone or the zone of maximal performance potential in the Press-Competence model. The community environment may offer such high levels of demand in relation to their competence that they may be in the zone of negative affect and maladaptive behaviour in the model.

The environmental docility hypothesis proposed by Lawton (1970) relates to this model, and may explain why people with Pd have been described as living the life of a much older person (Oxtoby, 1982; Singer, 1973). This hypothesis stated that people with low levels of environmental competence have to rely on the environment to support them much more than people with high levels of competence. It follows that people with Pd might only fit within environments that support that disability (Hasselkus, 1993). For example, someone using a walking frame can only match with an environment with steps and doorways of sufficient width to allow passage, whereas those without a disability can match a wider range of environments. It is yet to be demonstrated whether people with Pd move from zone to zone in the Press-Competence model, and whether they take their partners with them. Table 4.2 provides a summary of this section.

**Table 4.2 Summary of some of the relevant features of environmental theory**

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| <ul style="list-style-type: none"><li>• Priorities for environmental interaction set according to need</li><li>• Environmental competence related to ability to match specific environments</li><li>• Competency varies according to variation in environmental demand</li><li>• Variation in ability to respond to specific environmental demands</li><li>• Varying perceptions of control</li><li>• Variation in levels of desire for control reflected in achievement-related performance</li><li>• A sense of self efficacy closely related to perceived control</li><li>• A generally low level of competency leads to environmental docility</li></ul> |
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#### **4.4 The Experience and Management of Perceived Control**

A sense of personal control has been defined as the degree to which people believe their behaviour influences outcomes in their lives (Bertrand & Lachman, 2003). Although many researchers have assumed this sense of control to be global, there is evidence that people experience varying degrees of control in different domains of their lives (Brandtstädter & Rothermund, 1994; Kuhl, 1986; Lachman, 1991).

Lang and Heckhausen (2001) believed that perceived control should not be considered globally, but rather, in relation to specific domains of life, and that it is possible to feel high levels of control in some areas and low levels in others. Brandtstädter and Rothermund (1994) found in their study that, in the transition to later adulthood, the degree to which a sense of control in a particular domain (such as health) affects the person's general sense of control is directly related to the value or importance the person ascribes to the specified domain. They also found that when a person is able to downscale the importance of a domain in which they experience a lowered sense of control, it has a positive impact upon their general sense of control.

A sense of personal control has been linked to role. In a large longitudinal study, Krause and Shaw (2000b) examined the impact of two different types of personal control on mortality in later life: control over specific roles, and control over life as a whole. They took a national sample of 1,103 adults aged 65 and older, and completed repeated measures of role-specific personal control, global feelings of personal control, health behavior, obesity, physical health status, and demographic variables over six years. They found that feelings of control over the person's single most important role significantly reduced the odds of dying. There was no such correlation with other roles, nor with a sense of control over life as a whole. Their study showed that maintaining a sense of control over the role perceived as personally most important may enable a person to live longer. This finding has major implications for the way in which health professionals, and in particular, occupational therapists, assess and plan therapy for people with Pd and their partners.

Lawton's Press-Competence Model suggests that the higher the level of disability experienced by the person, in relation to their needs and environments, the lower or more negative would be their perception of control. It is easy to see how this could lead to a steady

decline in a sense of well-being with the progression of a disease such as Pd, and possibly to an earlier death, as shown by Langer and Rodin (1976) and Krause and Shaw (2000b). The literature reviewed showed that the severity of the disease did not correlate with perceptions of quality of life (Findley, 1999). The work of Rothbaum, Weisz and Snyder (1982) and Heckhausen and Schulz (1995) not only explains this apparent contradiction but supports the emphasis on studying participant's most important roles in this study.

#### 4.4.1 Primary and Secondary Control

So far, perceived control has only been considered as a single process. Rothbaum, Weisz and Snyder (1982) in hypothesising perceived control as a two-process model, considered 'inward' behaviours such as passivity, withdrawal, and submissiveness as signs of relinquished control. They argued that such behaviours, instead of representing a sense of uncontrollability, represented another type of perceived control that had been overlooked and redefined perceived control to include the second type, naming them: *primary control* and *secondary control*. The model stated that when employing strategies of primary control, people bring the environment in line with their wishes. In Lawton's (1982) terms they are environmentally competent. By contrast, when using strategies of secondary control, people bring *themselves* in line with environmental forces.

Rothbaum, Weisz and Snyder (1982) went on to define four types of secondary control:

1. Attributions to severely limited ability can enhance *predictive control* and protect against disappointment. Passive and withdrawn behaviours reflect the attempt to inhibit unfulfillable expectations.
2. Attributions to chance can reflect *illusory control*, since people often construe chance as a personal characteristic akin to an ability ('luck').
3. Attributions to powerful others permit *vicarious control* when the person identifies with these others. Submission to a powerful leader, a group, or a deity sometimes enables the person to join in their power.
4. All of the preceding attributions may foster *interpretive control*, in which the person seeks to understand and derive meaning from otherwise uncontrollable events in order to accept them (Rothbaum et al., 1982, p. 5).

They concluded that when perceived control is recognised in both primary and secondary forms, a range of inward behaviour can be viewed as efforts to sustain control rather than to

give it up. Similarly, Heckhausen and Schulz (1995) examined control related life transitions and argued that the principal difference between primary and secondary control relates to the target of action. In primary control, that target is the *outside* world or external environment. In secondary control, the target is the self and changes occur *within* the person.

Heckhausen and Schulz (1995) further argued that secondary control acts as a compensatory mechanism for failures in primary control by acting as a buffer to their negative effects. In this way it protects emotional well-being and self-esteem. It also preserves the motivational resources of the person so that they can maintain and enhance primary control in future environmental interactions. Heckhausen and Schulz (1995) say “... in this way, secondary control serves as the pathway from loss of control back to primary control” (p. 286).

The second way in which secondary control facilitated primary control was by managing the choices that needed to be made about which goals should be pursued (Heckhausen & Schulz, 1995). Secondary control addressed three different aspects of action regulation: “1) Expectancy of goal attainment, 2) Value of goal attainment, 3) Causal attribution of action outcome” (Heckhausen & Schulz, 1995, p. 287). These in turn related to three types of secondary control strategies:

1. Expectation biases such as optimism, defensive pessimism, adjustment of aspiration level and strategic selection of social reference group.
2. Shifts in goal values such as the ‘sour grapes’ effect, disengagement, and changes in goal hierarchy and;
3. Biased attributions of outcomes such as egotistic attributions of success and failure” (Heckhausen & Schulz, 1995, p. 287).

The work of Rothbaum, Weisz and Snyder (1982) and of Heckhausen and Schulz (1995) moved thinking away from the concept of learned helplessness to a consideration that even when passivity and submissiveness are the observable behaviours, a sense of control could exist. Similarly, where the observable behaviour appears to be actively focused on regaining control, the person might, in fact, be experiencing low levels of perceived control. If this is so, then it follows that externally observable behaviour does not necessarily indicate the level of perceived control a person observed is experiencing. Table 4.3 summarises this section.

**Table 4.3 Summary of concepts in theory of perceived control relevant to this study**

- Loss of environmental competence not linked to lost perception of control
- Perceived control varies from one role to another
- Losing control of most important role linked to dying sooner than if control is maintained
- Two types of perceived control, primary and secondary
- Primary control has primacy over secondary control
- Primary control brought about change in the environment by range of observable behaviours
- Secondary control brought about change in the person by a range of inward behaviours
- Secondary control managed choice about action in terms of expectancy, value and cause of outcome
- Secondary control could compensate for losses in primary control
- Externally observable behaviour might not represent the level of perceived control being experienced

## **4.5 Perceived Control in Later Life**

### **4.5.1 The Ageing Process**

Peterson (2004) reports two types of ageing. Primary ageing represents a process that occurs without obvious influence from disease or abuse processes. Secondary ageing relates to decline for pathological reasons. Contrary to stereotyping, primary ageing in general terms does not represent an overall loss of function until well into late adulthood. Maximal performance (such as running to catch a bus, or working out a particularly complex and difficult problem) declines markedly with age, to a point where it tends to become limiting in those over 65. Habitual (as in routine) performance in most areas does not decline to the point of limitation until after the age of 85 (Charness, 1985).

#### Attitudes To The Ageing Process

Primary ageing carries with it stereotypes that are held by the general population, including those who are ageing. These stereotypes are usually negative and represent people's fears about growing old (Bytheway, 1995). There is an assumption by many younger people of almost universal physical and intellectual calamity associated with getting

old (Rodin & Langer, 1980). The literature shows that reality is different. The rates of dementia for those over 65 years of age is around 6%, with a range from 1.4% for those under 70 to 24% for those over 85 (Australian Institute of Health and Welfare, 2002). For physical disability, around 10% of those under 74 experience core activity restriction (self-care, mobility and communication) while for those over 85 the figure rises to 70% (Australian Institute of Health and Welfare, 2002).

Such levels of disability represent objective loss of control and consequent dependence in those affected in these age groups. However, attitudes to ageing can in themselves cause a loss of control (Garstka, Schmitt, Branscombe, & Hummert, 2004; Rodin & Langer, 1980). A direct negative link has been found between perceived age discrimination and well-being among older adults (Garstka et al., 2004). For example, Rodin and Langer (1980) showed that an observed behaviour commonly associated with negative aspects of ageing (such as forgetfulness) would typically be ascribed by the observer to an infirmity associated with old age (such as dementia), where the person performing the behaviour is represented as old. In fact, older observers do this to a greater degree than younger observers. They argued that such attitudes could lead to excessive care being shown to people so ascribed, fostering loss of remaining skills and consequent loss of control and dependence (Baltes, 1988; Rodin & Langer, 1980). Indeed, Baltes (1988) observed a cycle of dependent behaviour followed by dependence-supportive behaviour, followed by more dependent behaviour, in nursing home residents and staff over time. She concluded that over-helping produces dependence and proposed three types of dependence:

- True physical or mental incompetence.
- Selective optimisation (person chooses to be dependent in one area in order to have energy and time to be independent in others).
- Social stereotyping and underestimation of competence.

#### **4.5.2 Decline of Primary Control in Late Adulthood**

Primary control declines in late adulthood (Mirowsky, 1995; Wolinsky & Stump, 1996). Wolinsky studied 1,051 adults with serious health problems. He found that the relationship between age and the sense of control was “negative, strong and linear” (p. S219). Heckhausen and Schulz (1995) developed a life-span model that described an

inverted U-shaped curve for the primary control trajectory. In other words, potentials were low in early life, high in adulthood, then declined again in late adulthood (see also Schulz, Heckhausen, & Locher, 1991). This decline might be associated with the ageist attitudes described above. These negative changes in primary control were usually attributed to declines in functional ability with advancing age. Interestingly, level of education was identified by Mirowsky (1995) and Wolinsky (1996) as a significant factor in this decline, with lower levels of education correlating with a more negative sense of primary control.

### Decline in Primary Control and the Continuation of a Positive Outlook

Although a decline in primary control has been associated in adults with negative symptoms such as depression, people in late adulthood appear able to maintain emotional stability despite lower levels of primary control (Lang & Heckhausen, 2001). Heckhausen and Schulz (1995) found that people were able to maintain stability of perceptions of primary control well into late adulthood, despite ageing changes which were often associated with loss of function and health problems. While Lachman, Ziff and Spiro (1994) found that higher levels of social support act as a buffer, counteracting the effects of a lower sense of primary control, Lang and Heckhausen (2001) found that experiencing negative social support was a potent predictor of a lower level of perceived control and negative affect. Heckhausen and Schulz (1995) argued that, in the face of lower primary control, people in late adulthood effectively used secondary control strategies well into old age.

### Decline in Primary Control and Secondary Control Strategies

Heckhausen and Schulz (1995) identified secondary control strategies that they found older people typically used:

- Flexible goal adjustment
- Regulating emotion rather than action (distancing, acceptance of responsibility, and positive reappraisal)
- Emphasis of 'brain over brawn' in defining quality of life
- Religious coping
- Downward adjustment of ideal self
- Positive view of the past (possibly compensating for a less promising future)
- Comparison with others to own benefit ('there were others much worse off')
- Viewing a serious personal problem as being even more serious for others of their age (Heckhausen & Schulz, 1995, p. 297).

They commented that stereotypes of ageing might even be helpful to people seeking support for the last two strategies.

When both primary and secondary control strategies fail, the person becomes distressed and, over time, demoralised and depressed. Sudden and substantial losses such as those following a stroke are particularly devastating because the person lacks the resources to meet the immediate threats to primary control. However, over time, crises can be overcome and control can be re-established and elaborated (Heckhausen & Schulz, 1995).

### Choosing Not to Exert Control

In order to control, the person has to feel there is a choice. Judith Rodin (1986) argued that this meant there were times when a person might want the opportunity not to control and to allow others to make decisions instead. She argued that some people find high levels of choice or control have negative consequences, leading to stress, worry and self-blame.

## **4.6 Perceived Control and Chronic Illness**

This section deals with issues of perceived control as they relate to chronic illness, and in particular, Pd. Miller (2000) identified a perceived lack of control to be a prevalent theme that pervaded all aspects of the literature on chronic illness. Although the literature contains reports of coping strategies to deal with the impact of chronic illness upon perceived control, there is very little about what people with chronic illness actually do in this regard on an everyday basis. The literature has focused more upon loss, and an absence of doing, reinforced by the negative sickness role concept.

### **4.6.1 Coping With Stress and Loss of Perceived Control**

One source that provided a useful view of the process of coping with Pd was Jahanshahi and MacCarthy (1998). They describe three factors they considered crucial to considerations of stress and coping in relation to Pd. They were *antecedents to stress*, *mediating factors* and *outcomes*.

### Antecedents to Stress

Antecedents were made up of environmental conditions and personal characteristics. Jahanshahi and MacCarthy (1998) reported that a sense of well-being is linked to a good match between the quantity and quality of *social support* available and the needs of the person. Purchasing supportive services and equipment, modifying physical environments such as the home, ensuring ongoing relevant therapy, and indulging in the odd luxury are all factors that might make a significant difference to the ability of the person to cope with stress and achieve an ongoing sense of well-being (Jahanshahi & MacCarthy, 1998; Minichiello, Alexander, & Jones, 1992; Pedretti, 1996).

*Personal characteristics* were described by Jahanshahi and MacCarthy (1998) as motives and beliefs about the self and the world. They identified self esteem as a strong determinant of how well a person will cope with stress and loss of perceived control. Motives shapes emotional and practical responses to stress. Beliefs regarding the degree to which events are personally controlled affect the person's approach to coping. In the presence of illness, beliefs about how much symptoms are objectively controllable and how much they are personally controllable are likely to have an important impact on the choices people make about the coping strategies they choose (Jahanshahi & MacCarthy, 1998).

### Mediating Factors

Mediating factors were identified by Jahanshahi and MacCarthy (1998) as personal appraisal and coping strategies. *Personal appraisal* is about the person's perceptions of the stress they experience. What one person perceives as stressful might be viewed as an interesting challenge by another. Both people might perceive a given situation as stressful, but each might find different aspects of the experience problematic. (Jahanshahi & MacCarthy, 1998). *Coping* is used to describe the efforts employed to deal with perceived loss of control (Jahanshahi & MacCarthy, 1998). It includes all the practical efforts made and the intellectual and emotional responses used to come to terms with and reduce the emotional impact of the stressor (Jahanshahi & MacCarthy, 1998).

Jahanshahi and MacCarthy (1998) identified two major methods of coping. *Problem-focused* coping relates to people trying to actively change some aspect of their environment

or of events. These strategies are more likely to relate to re-establishing primary control. For example, people with Pd might seek more information about a type of therapy they had heard was helpful. *Emotion-focused* coping refers to efforts to control the emotions people experience as a result of stressful changes. Emotion-focused coping was described by Jahanshahi and MacCarthy (1998) as an active process that involves restructuring personal goals and values in line with the limitations imposed by the stressful situation.

Pd stimulates most people to become active problem solvers (problem-focused coping). They consider the situation they are in, what they wish to achieve and what they know, in order to work out how best to continue to achieve their goals in the presence of increasing levels of disability. A range of problem-focused or primary control coping strategies are described in the literature. For example, people change their routine in order to make best use of times in the day when their energy levels are highest and their medication is working well, and to rest at the times when they are at a lower ebb. They might change the method they use to do something. Perhaps they use equipment where before they did not. They could work with a physiotherapist and an occupational therapist to overcome movement control problems (Brown, 1998).

In terms of role repertoire, Hillman (1999) found, for a group of older men with a disability (stroke), that they chose to change role priorities to accommodate lower levels of activity, and even chose to minimise involvement in one role in order to maximise the opportunity to continue at the level they expected and desired in another. Within specific roles, they chose to reduce their levels of activity, change what they did and/or increase the time they allocated to the role in order to accommodate ORP changes (Hillman, 1999).

Few reports of emotion-focused or secondary control coping are recorded in the literature. A person with Pd may try to shift their expectations, values and perceptions of outcome as described by Heckhausen and Schulz (1995). They may join a Parkinson's support group, develop a new interest, or change role priorities to focus more on their relationships with others.

Coping strategies can be *adaptive* or *maladaptive*. Jahanshahi and MacCarthy (1998) defined adaptive strategies as '... any coping strategy that improves people's adjustment to

their new situation and enhances their sense of well-being ...' Maladaptive strategies were defined as '... coping strategies that interfere with acceptance and adjustment ...' Some strategies such as misusing alcohol and unnecessary risk-taking behaviour rarely fulfilled the function of being adaptive (Jahanshahi & MacCarthy, 1998). Other strategies often viewed as maladaptive, such as denial and emotional distancing, might not be so (Jahanshahi & MacCarthy, 1998). People who cope by systematically using a limited range of specific problem-focused and emotion-focused strategies relevant to the type of stressor were found more likely to be successful in reducing stress than those who grabbed randomly at a large number of strategies. Jahanshahi and MacCarthy (1998) believed that effective and realistic coping incorporates emotion-focused as well as problem-focused approaches.

### Outcomes

The third set of factors important to considerations of stress and coping identified by Jahanshahi and MacCarthy (1998) were termed outcomes. Outcomes that are considered satisfactory involve improved adjustment to the stressor(s) and physical and psychological well-being. Deterioration in adjustment to the stressful situation, and declines in physical health and mental health are considered poor outcomes (Jahanshahi & MacCarthy, 1998). In the presence of a chronic illness such as Pd, poor emotional well-being is often thought to have a negative effect upon physical well-being and the progress of the disease. There is evidence that the longer-term effects of stress are more closely related to a person's expectations and aspirations than to external circumstances. Coping behaviours that are focus upon meeting or changing personal agendas are therefore more likely to be successful (Jahanshahi & MacCarthy, 1998).

Miller (2000) saw people with chronic illness as having the *ability* to cope with their illness. She identified power resources available to them that include:

- Physical strength and reserve
- Psychological stamina and social support
- Positive self-concept (self esteem)
- Energy
- Knowledge
- Motivation

- Belief system (Hope)

She detailed how nurses could help people who were chronically ill develop and use these power resources in order to better cope with their situation, and achieve a more positive sense of personal control.

It should be noted that chronic illness is not a wholly negative experience. Once psychological adjustments are made, some people have been shown to enjoy dealing with the challenges offered on a daily basis by their illness (Jahanshahi & MacCarthy, 1998). Aldwin (1991), for example, found that for some people, coping with health problems is actually a positive experience (leading to a sense of mastery) which has a positive effect upon their sense of self efficacy and well-being. Such people did not necessarily see their health problems as controllable, but felt that they were manageable. Table 4.4 summarises this section.

**Table 4.4 The impact of chronic illness upon perceived control**

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| <ul style="list-style-type: none"> <li>• Chronic illness reduces range of environments with which person can match</li> <li>• Sense of reduced control causes stress</li> <li>• Responses to stress are complex and personal</li> <li>• Relevant environmental conditions and personal characteristics influence degree of stress experienced</li> <li>• Personal appraisal and coping strategies mediate how a person perceives stressor</li> <li>• Coping may be problem-focused or emotion-focused</li> <li>• Problem-focused coping relates to primary control strategies</li> <li>• Emotion-focused coping relates to secondary control strategies</li> <li>• Active problem solving an important part of coping</li> <li>• Coping strategies may be adaptive or maladaptive</li> <li>• Experience of chronic illness can be positive if people enjoy meeting the challenges it presents</li> </ul> |
|--|

## **4.7 Caring and Perceived Control**

The literature reviewed so far has emphasised the need to consider issues of stress, coping and perceived control on an individual basis. This applies to the partners or carers of people with Pd as well as those who have the illness. Health professionals have a tendency to

apply their own attitudes to these issues, rather than consider what perceptions might be held by the people that they work with. The issue of *burden* is one example of this.

The sense of burden described by many researchers suggests that many carers experience low levels of perceived control. There is an implication of some compulsion about assuming the role of carer – ‘someone has to do it’. There has been an assumption of loss of control and hence choice when taking on the role of carer (Chow, 2001; Riemsma et al., 1999). The social expectation of carers is that they will place their care receiver first in all things and give up whatever is necessary in their own lives in order to meet the needs of the people they are caring for. Despite this, as reported in the previous Chapter, research has found hardly any relationship between the perceived workload and a sense of burden in carers (Braithwaite, 1990; Chow, 2001; Rees, O'Boyle, & MacDonagh, 2001).

In the context of this thesis the word ‘burden’ has been replaced by the more neutral word ‘impact’. While the concept of burden is useful, the word is highly negative in tone. There are advantages to the carer in providing support for others. Krause, Herzog and Baker (1992) were able to demonstrate, in a longitudinal study of 1,174 people over 60 years of age, that those who provided informal support to others reported higher levels of personal control than those who did not. They suggested that for older adults, maintaining a sense of reciprocity was important. The same study was used to show that providing social support for others bolstered self esteem and self worth (Krause & Shaw, 2000a). There was, however, a socio-economic difference. Krause and Shaw (2000a) demonstrated that people in lower socio-economic and lower educated groups felt more coerced about providing care and less able to do so. They consequently expressed a lower sense of personal control than those with more education and in a higher socio-economic group (Krause et al., 1992; Krause & Shaw, 2000a).

## **Summary**

This final chapter in the review of the literature addressed the issue of perceived control. It discussed and described the concept of a sense of control, outlined some of the theory relating to perceived control, including the concepts of primary and secondary control, considered how the ageing process might affect perceived control and looked more

particularly at the impact of Pd upon perceived control. It was clear from this review that a consideration of the person as a person should be paramount when considering issues of perceived control.

### **Overview of Literature Review**

Chapters Two, Three and Four have reviewed the literature relevant to the purpose of this study, which is to:

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

To this end, the literature has been reviewed from the perspectives of role, chronic illness and perceived control. This section will relate the conclusions of the literature review to the stated research objectives. The overview is summarised as a series of tables of findings, each relating to a different research objective (see tables 4.5, 4.6, 4.7 and 4.8).

**Table 4.5 Findings of the literature review in relation to research Objective One: To describe perceptions of the nature of ORP.**

<b>Research Objective</b>	<b>Relevant Findings from Literature Review</b>
The Nature of ORP	<ul style="list-style-type: none"> <li>• Role concepts are a valid means of considering the everyday occupational performance of the people in this study.</li> <li>• Role language (while imprecise) is in common usage, allowing the researcher to enquire directly about ORP.</li> <li>• Roles are performed within a context or range of contexts that may define or limit the role.</li> <li>• Little is known about everyday ORP in later life.</li> </ul>
The experience of ORP	<ul style="list-style-type: none"> <li>• The internal/personal aspects of role are acknowledged but not well understood.</li> <li>• Role behaviour is idiosyncratic and subject to choice.</li> <li>• Conflict between expectations provides opportunities for choice.</li> </ul>
The perceived value and satisfaction of ORP	<ul style="list-style-type: none"> <li>• People assign varying priorities to roles in their role repertoire.</li> <li>• Expectations (internal and external) associated with specific roles provide a guide to ORP.</li> </ul>

**Table 4.6 Findings of the literature review in relation to research objective two: To describe barriers to ORP experienced by people with chronic illness (Pd).**

Research Objective	Relevant Findings of Literature Review
Perceptions the nature of barriers to the ORP of people with chronic illness (Pd)	<ul style="list-style-type: none"> <li>• The experience of being chronically ill is poorly documented in the professional literature.</li> <li>• The sick role as described in role theory can lead to poor understanding and unrealistic expectations when applied to chronic illness.</li> <li>• Chronic illness presents a complex picture, interacting with other health-related changes and with primary ageing changes.</li> <li>• Carers experience the same losses as their partner with Pd.</li> <li>• Primary control declines with increased age and has been linked to declines in physical ability and low levels of education.</li> </ul>
The relationship between barriers and the symptoms that accompany chronic illness (Pd) or to factors consequent upon that.	<ul style="list-style-type: none"> <li>• Neither chronic illness nor ageing are well understood, leading to the possibility of a difficult social context for participants.</li> <li>• People with chronic illness emphasise well-being. Health professionals emphasise symptom control. This leads to a likely dissonance between the two groups.</li> </ul>
The impact of losses upon the social and psychological well-being of people with chronic illness (Pd).	<ul style="list-style-type: none"> <li>• For those with Pd, mental health losses have a greater negative impact upon the partner or carer than physical losses.</li> <li>• Carers express distress about having to witness their partner's struggle.</li> <li>• Poor communication causes problems with relationships.</li> </ul>

**Table 4.7 Findings of literature review in relation to research objective three: To describe strategies or coping plans to maintain a perception of control over their ORP.**

Research Objective	Relevant Findings of Literature Review
The nature of problem solving or planning undertaken by people with chronic illness.	<ul style="list-style-type: none"> <li>• Carers maintain their own ORP as far as possible.</li> <li>• Carers consider the illness as secondary to the relationship.</li> <li>• In the presence of chronic illness, a combination of problem-focused coping and emotion-focused coping is important.</li> </ul>
The resources utilised to deal with perceived barriers to control.	<ul style="list-style-type: none"> <li>• Sense of control is modulated by secondary control mechanisms in ways that soften the impact of loss of primary control.</li> </ul>
Perceptions of what constitutes satisfactory outcome in relation to control of ORP.	<ul style="list-style-type: none"> <li>• The motivation or desire for control varies from one individual to another.</li> <li>• A loss of perceived control in an older person's most important role is linked to early death.</li> <li>• There appears to be no link between the amount of care carers are required to provide and the degree of negativity they experience in relation to the role of carer.</li> <li>• People with chronic illness do not consider objective change as an end in itself. Their concern is its impact upon personally meaningful ORP.</li> </ul>

**Table 4.8 Findings of the literature review in relation to research objective four: To describe the changes in the ORP of people with a chronic illness (Pd) and their partners.**

<b>Research Objective</b>	<b>Relevant Findings from Literature Review</b>
The differences in ORP at different stages of Pd.	<ul style="list-style-type: none"> <li>• Symptoms are largely controlled by medication in early phase, become more prominent in middle phase and are overwhelming in late phase of Pd.</li> <li>• For the person with Pd, psychosocial impact is likely to be greater in the early and late phase.</li> <li>• Impact upon ORP is not clear, but a gradual withdrawal is indicated.</li> <li>• Carers provided health related care and social care.</li> <li>• Some partners do not identify themselves as carers, and see caring as an extension of the role of partner.</li> <li>• There is a lack of information about caring over the course of Pd.</li> <li>• Partners have to readjust their relationship as chronic illness progresses.</li> </ul>
The differences in perceived barriers at different stages of the disease.	<ul style="list-style-type: none"> <li>• Social isolation appears to gradually increase as the disease progresses for both partners.</li> </ul>
The differences in perceived success of coping plans at different stages of the disease.	<ul style="list-style-type: none"> <li>• Coping behaviour is more successful in the early and middle stages of Pd than in the late stage.</li> </ul>
The differences in perceptions of personal control at different stages of the disease.	<ul style="list-style-type: none"> <li>• There is little correlation between the early, middle and late phases and findings on quality of life measures.</li> </ul>