

Living Situation

All but one of the participants lived in the metropolitan area of Sydney. The exception lived in a country town in NSW. Living conditions for all participants, as observed by the interviewer, were modest but comfortable. Four participants with Pd lived alone, two of them in self-contained flats. One partner lived alone, since her husband had died five months before she was interviewed. The other participants all lived with their spouses. Two couples lived in retirement villages, while the others all lived in houses with gardens that they owned.

Length of Time Since Diagnosis with Parkinson's Disease

Most participants with Pd had been diagnosed for some years. The average interval between being diagnosed with Pd and participating in the study was around six years, with a range from one year to approximately fifteen years.

Functional Performance

The three post-diagnosis phases described by Jahanshahi and MacCarthy (1998) were used to describe the level of function of participants. Each participant was asked briefly about their level of mobility, communication and personal care and rated by the researcher (according to his or her responses) as independent or having mild, moderate or severe difficulties with occupational performance. Mild equated to independent performance, moderate to an ability to perform with the assistance of equipment or minimal assistance of another person, while severe meant the participant was dependent upon others for occupational performance (see Appendix 5.8 for further definition). These three ratings were then combined to determine whether participants were in the early, middle or late phases of Pd. Those with at least one rating that was moderate were considered to be in the middle phase of the disease, while those with at least one rating that was severe, or two ratings that were moderate were considered to be in the late phase.

This process meant that in this study, five participants with Pd were identified as being in the early phase, five were in the middle phase and four were in the late phase. Three participants were rated as being functionally independent in all three areas, while only one

participant was rated as having severe difficulties in all three areas. Placing people in these categories proved to be rather arbitrary (as expected) and some participants appeared on a cusp between phases. There was a rough correspondence between decline in function and the number of years since diagnosis, but there were notable exceptions to this, with two participants in the late phase being diagnosed more recently than a participant in the early phase.

Participants' Social and Cultural Context

This study was designed to investigate participants' social interactions via the construct of occupational role. Their social and cultural background gave context to their stories. The average age of participants with Pd was 70, with a range from 46 to 87 years. Partners had an average age of 73, with a range from 53 to 84. All were Australian born. Consequently all participants shared a life-long experience of Australian culture. An Australian study of the perceptions and actions of older people in relation to health and independence in everyday life found that a person's present health behaviour was influenced by his or her past life experience (Kendig, Davison, & Walker-Birckhead, 1993). The study found that people who were old today reflected strongly the social circumstances of their childhoods, with history-normative influences at their greatest in adolescence and early adulthood (Danish cited in Hayslip & Panek, 1993; Kendig et al., 1993).

Seven of the participants in this study were old enough to remember the Depression. Twenty-one were five years or older during the Second World War, while four were 'baby boomers'. Thus participants spanned three cohorts in relation to significant cultural experiences.

Priority Roles

Participants were asked to nominate their life roles and to indicate their order of priority. Table 5.3 lists the top three roles identified and ranked by each participant.

Table 5.5 The most important three roles identified and ranked by each participant.

Participants with Pd are in alphabetical order, with their partners next to them. Participants for whom no partner was interviewed are listed at the end.

Pseudonym	Role One	Role Two	Role Three
Helen Adams - Pd Phillip Adams - Ptnr	Grandmother Carer	Mother Husband	Friend Home Maintainer
Michelle Coffey - Pd Ken Coffey - Ptnr	Wife Husband & Carer	Mother Member, Pd Support Group	Grandmother Home maker
Yvonne Freeman -Ptnr	Mother & Grandmother	Meals on Wheels Volunteer	Friend & Sister to Michelle Coffey
Adele Dewar -Pd Steve Dewar - Ptnr	Wife Husband	Friend Housekeeper	Housekeeper Socialiser
Wendy Egan - Pd Tom Egan - Ptnr	Wife Husband	Mother Father	Grandmother Church-goer
Caroline Harper - Pd Imogen Yates - Ptnr	Wife Wife	Mother Mother	Friend Work
Enid Irwin -Pd Rex Irwin - Ptnr	Wife Carer	Mother Husband	Friend Friend
Frank Lewis – Pd Una Lewis – Ptnr	Husband Wife	Family Member Bowler	Friend Home Maintainer
Jenny Morgan – Pd Arthur Morgan – Ptnr	Wife Carer	Mother Husband	Grandmother Home Maintainer
Gwen White – Pd Vince White – Ptnr	Wife Carer	Mother Friend	Home-maker Home Maintainer
Dorothy Barker – Pd	Wife	Mother	Grandmother
Lynne Grant – Pd	Spiritual Person	Family Member	Congregation Member
Bruce Jones - Pd	Health Manager	Rester/Relaxer	Poet Lyricist
Nancy Peters –Pd	Shopper	Receiver, Community Assistance	Cook
Olive Roberts – Ptnr (husband deceased)	Mother	Grandmother	Home Maintainer
Peter Vaughan - Pd	Father	Health Manager	Businessman

Participant Stories

A short introduction to eight of the participants follows (Table 5.4). They were chosen to represent the three phases of the disease as determined in this study.

Table 5.6 Participant stories

Person with Pd	Partner
<p><u>Wendy Egan (Early Phase)</u></p> <p>Wendy had had two bad falls which had given her a fear of falling. She tried to avoid having to walk far. She found getting dressed was time-consuming and difficult. She drove a car and had an active community life, but she had lost some of her confidence. She had done a lot of voluntary work in the past but did not feel able to continue. She identified wife as her most important role.</p>	<p><u>Tom Egan (Early Phase partner)</u></p> <p>Tom was 73 and still worked a full week with his five sons in the family electrical business. He did not feel the need to retire while he and Wendy both still had their health. He played golf regularly and did not believe Pd interfered much with their lives. He identified husband as his most important role.</p>
<p><u>Michelle Coffey (Middle Phase)</u></p> <p>Michelle Coffey had been married 54 years, with two daughters and a number of grandchildren. She identified wife as her most important role. She spent most of her time at home. She had a fear of falling which made her unwilling to go into the community. Michelle enjoyed playing the piano. At home she rested during the day and did the housework. She enjoyed doing large jigsaw puzzles, crossword puzzles, reading and watching sport on television with her husband.</p>	<p><u>Ken Coffey (Middle Phase Partner)</u></p> <p>Ken had been retired for almost ten years. He identified the role complex of Husband/Carer and gave it top priority. He had a constant concern for his wife Michelle and lived flexibly to suit her needs. He accompanied her whenever she went out into the community. Ken was able to get away sometimes to pursue his own interests – principally snooker and fishing. He had to give up golf. He felt he did a good job of being Michelle’s carer, and he did not see any reason why the role should change.</p>

Table 5.6 (continued)

<u>Enid Irwin (late phase)</u>	<u>Rex Irwin (Late Phase Partner)</u>
Enid lived with Rex in the house that he built for them many years ago. Enid used to be a very fit and active sportsperson. She found it difficult to get things done because she tired easily, and had problems lifting her right arm. She needed help with self care and with getting out into the community. She got stuck with her thinking, making talking difficult. Enid placed her role as a wife as her top priority.	Rex was waiting for a hip replacement. He identified the complex role of Carer/Home Maintainer/Husband as his top priority. His whole time was taken up with looking after Enid. He was unable to leave her as she became distressed by his absence. He worried about her safety as her cognitive condition deteriorated. He felt that the time might come when he could no longer deal with the situation effectively.

5.4 Data Collection Methods

A total of 44 interviews were conducted for this study, and around 540,000 words were recorded and transcribed. Data collection was carried out in two stages. Stage one was intended as an overview to gain information that could be explored in greater depth in stage two. Stage two utilised the knowledge gained in stage one and was designed to explore the *doing, knowing and being* aspects of occupational role performance (ORP) in greater depth, in order to identify relevant detail about possible barriers and strategies to ORP maintenance and development in the presence of Pd.

5.4.1 Stage One

In stage one, participants with Pd and their nominated partners were interviewed once using the Occupational Performance Role Assessment (OPRA) (Hillman, 1999; Hillman & Chapparo, 1995a, 2002f) (see Appendix 5.1). This assessment was designed by the author for a previous study investigating the ORP of men following stroke. It departed from other role assessments in that its intention was to facilitate participants to identify and describe how they perceived their own roles, rather than rely upon the interviewer to translate what they said into role terms. A recent study by Toal-Sullivan and Henderson (2004) developed the Client Orientated Role Evaluation (CORE) that used forced choice from a preset list.

They encountered some problems with this and commented in their discussion that the free choice used by the OPRA would probably be a more effective approach.

The OPRA was piloted prior to its use in the study of the occupational role performance of men who had experienced stroke (Hillman, 1999; Hillman & Chapparo, 1995a). It was piloted again prior to its use in this study. Because role is a concept with a large body of theory attached to it, there was some concern as to whether participants, without expert knowledge, would understand what the term meant. The findings of the previous study using the OPRA and the pilot for this study showed that, while participants did not always answer role questions in ways that named and framed their roles, they answered in ways that showed they understood what was being asked.

Women with Pd were targeted in the first stage of this study. A number of studies found that there were differences in occupational performance in later life between men and women. Women were chosen because they have traditionally been described as the caring gender, with the carer role generating more description from the female perspective. For those that nominated their husbands as partners, it was an opportunity to describe the process from the perspective of males.

A small grant for the first stage of data collection was received from the Health and Ageing Research Program, an initiative of the Faculty of Health Sciences at The University of Sydney. Fourteen people were interviewed once. Eight were women with Pd, and six were their nominated partners. Two partners, when invited, declined to participate. The interviews were around one and a half hours in duration, and transcripts averaged just over 9,000 words in length, ranging from around 6,700 words to 20,000 words.

5.4.2 Stage Two

Stage two of data collection was based upon the findings of stage one. In stage two both men and women with Pd were interviewed, to further explore the experience of Pd for both genders. Participants with Pd and their nominated partners were interviewed in greater depth, using an expanded interview protocol. Please see Appendices 5.2 (Doing), 5.3 (Being) and 5.4 (Knowing). These interview protocols were piloted prior to their use.

Structure of Stage Two Data Collection

In this second stage of the study, twelve people were interviewed (seven with Pd and five who were partners). There were four women and three men with Pd and four women and one man who were partners. Three participants with Pd were single and did not wish to nominate a partner, and one partner's husband, who had Pd, had died about five months prior to the interviews. The number of interviews varied. Five people with Pd and three partners were interviewed three times each. One person with Pd was interviewed twice only, with the second interview being designed to cover all remaining areas of inquiry. One partner was interviewed once only, as she indicated she did not wish to continue. The length of interview varied, and ended when the participant became tired or saturation of information occurred. The length of interviews ranged from one to three hours, with the average duration being two hours. An average of almost 15,000 words per interview were recorded and transcribed.

5.4.3 Stage One Interview Protocol

Participants were interviewed using the Occupational Performance Role Assessment (OPRA) (Hillman, 1999; Hillman & Chapparo, 1995a). The OPRA is briefly described here. Please see Appendix 5.1 for greater detail. The interview protocol had six parts:

- Part 1: Explanation of purpose of interview and obtaining of consent.
- Part 2: Recording demographic information.
- Part 3: Gathering information about role performance.
- Part 4: Participant confirmation of roles.
- Part 5: Sorting roles under occupational performance area and socio-cultural meta-role headings.
- Part 6: Participant rating of roles.
- Part 7: Nomination of a partner to participate in the study

Part One: Explanation of the Interview

The interview commenced with an explanation of its purpose. In order to involve the participant in collaborative research, it was necessary to ensure that he or she was fully informed (Minichiello et al., 1990). Although prior descriptions of the purpose of the

research had been given to participants, a further explanation was given at the outset, to focus attention. This was done in two ways. A verbal explanation was given by the researcher and a copy of the information sheet already posted by the interviewer was handed out again (see Appendices 5.6 and 5.7). Time was allowed for the participant to read the written material. The opportunity was given for questions to be asked. If the participant appeared satisfied with the explanation, he or she was asked to sign the consent form (see Appendices 5.6 and 5.7).

Part Two: Recording Demographic Information

Following the signing of the consent form the participant was asked for date of birth, ethnicity, living situation and the year of diagnosis with Pd. The participant was then asked to describe her or his level of performance in mobility, communication and personal self-care. The interviewer used this to allocate them to early, middle or late phase Pd. See Appendix 5.8 for the protocol for such allocations.

Part Three: Gathering Information About Role Performance

Part three formed the major part of the interview. The technique of ethnographic semantics (Spradley, 1979) was used to discover the way participants categorised their own immediate roles, role performance and role needs. This involved asking questions of four orders: descriptive, structural, associative and contrast. The form of these questions changed with the understanding of the participant. There was a strong emphasis on open-ended questions in this part of the interview to allow the comments of the participants to be spontaneous and self-generated. The whole process commenced with a 'grand tour' question such as: "Can you tell me how you see your roles at present?" The purpose of this question was to allow participants to choose what area of their lives they wished to discuss first. Participants answered in ways that showed they understood the question. For example:

"Some of the roles? Well, I guess ... I retired early from teaching. I do quite a bit of work for the local Parkinson's support group. I organise the guest speakers, excursions and newsletter that goes out. ... I've started writing this poetry,.... I usually read out a verse to the local support group at the start of each meeting and

Parkinson's New South Wales is actually publishing a volume of the poetry in a month or two."

Quite often participants would talk at some length about what appeared to be most important to them at the time of the interview in response to this global question. Prompts, both verbal (for example, "go on" or "yes...") and non-verbal (for example, nodding, looking expectant), were used to encourage participants to continue. Follow-up questions were only asked as needed. With some participants fewer questions were asked because the person spoke fluently and comprehensively about their occupational role performance. Other participants were not so eloquent and more questions were employed.

Most of the questions following the grand tour question were descriptive in nature. Descriptive questions yielded information about what the daily roles and role related routines and tasks actually were for the participants. For example, "Tell me about what happens at the senior citizen's club". "So how do you go about writing poetry?" "What do you do down in the workshop?" These types of questions usually yielded information about an area of the participant's life. Routines and tasks were discussed and later consolidated to form role patterns. Sometimes the participant responded with a role statement. For example: "But you know, as far as I'm concerned my role is here" (with his wife as a carer).

As roles were identified, questions designed to establish the nature of ORP, including personal value and satisfaction with performance were asked. Examples of descriptive questions at this stage were: "How important is being a grandmother to you?" "How does flying make you feel?" "What are some of the things you like about the Senior Citizen's Club?"

As the interview progressed, more structural questions were used to further develop the information given in response to the descriptive questions. Structural questions gave information about how the participant structured and organised roles and role knowledge. An example of a structural question was: "Why do you play the piano at the Senior Citizen's Club?" "Tell me a bit more about what you do as a father." "So where do all these things about health fit in to your life?"

Associative questions were asked to allow the researcher to build up a picture of the relationships between the different topics and role areas discussed. An example of an associative question was: *"So how does the role of carer relate to the role of husband?"* *"How does this connect up to the other things that you do?"* *"Is that a distinct part of your life, or is it part of something bigger?"* Contrast questions were asked more frequently towards the end of this section. Contrast questions helped to access information about meaning, personal beliefs and values. They were used to help participants identify what they would like to do that they were not able to do and to further describe their perceptions of the frequency value and satisfaction of role performance. Frequency was discussed in terms of how often participants did things in that role. Value was considered as relative to the importance ascribed to it. Participants were asked to consider satisfaction in terms of how they felt about their own performance in the role. An example of a contrast question was: *"Could you explain what the difference is between visiting your friends and having them visit you?"* *"Is going fishing becoming less important or more important for you now?"* They could be hypothetical such as: *"If you could spend your day doing anything you wanted, what would you do?"* *"What do you like or don't like about being a cook?"* Contrast questions of this type were used to assist participants to focus on immediate role performance rather than role performance prior to the advent of Pd. (See Appendices 5.1, 5.2, 5.3 and 5.4 for further examples of questions that were used).

As participants talked about their role performance and responded to the questions asked, the researcher formulated ideas about what roles they might have. Attempts were made to confirm these ideas, to ensure that roles were current rather than past roles, and that they were not merely activities that in fact could be related to another role. This was done by asking follow-up questions and probes such as: *"So would you say that is still a role you have, even though your husband ...?"* *"Is that still the case?"* *"So do you see that as a separate role?"* *"That sounds as though it fits with this. Is that right?"* *"So how do you see being a father and being a grandfather. Are they separate, or do they go together?"*

Part Four: Participant Confirmation of Roles.

In Part Four of the Occupational Performance Role Assessment (see Appendix 5.1) the researcher presented the participant with a list of the roles they had discussed, as she had interpreted them. Participants were asked whether they considered each one to be a role, and

whether they agreed with the name given to it. Quite often this led to more discussion about the roles and for some roles a process of teasing out meaning was required to determine whether something was a separate role or simply another part of the same role. This discussion was continued until a list of named roles was generated.

Part Five: Sorting Roles Under Occupational Performance and Socio-cultural Meta-role Headings.

Structural questions in the form of role sorting enabled the researcher to determine how participants organised these role patterns into major role categories. Role titles were then written by the researcher on “post-it” notes. These were handed to participants one by one and they were invited to sort them by placing each one under the heading that best described the reason the role was performed. A role sorting board was employed to help participants decide which role heading best described particular patterns of activity. The board was made of cardboard with a whiteboard surface and measured 610 mm x 440 mm. It carried simple definitions of each of the major role headings in large bold print for easy reading. The researcher provided clarification if needed. The meta-role definitions were as follows:

Productivity:	Work, giving a service, doing something that can be used by others
Self Maintenance:	What you need to do to survive, and get on with the rest of your life
Leisure:	Fun, enjoyment
Social Cultural:	Relationships, being with others
Other:	(no definition given)

These definitions were composed by the researcher, based upon occupational therapy literature (Chapparo, 1993; Christiansen & Baum, 1991; Hopkins & Smith, 1993; Kielhofner, 1985; Pedretti, 1990), and previous investigation of role performance in elderly people where individual and unique roles could be sorted and categorised by the people who held the role within the larger meta-role structure outlined above (Hillman, 1999; Hillman & Chapparo, 1995a).

The role sorting exercise sometimes led to deeper discussion about the nature of the role, providing further information about the motivation to perform it. Participants often commented there was more than one reason they performed the role. If they asked for further clarification they were requested to sort the role according to the main reason they performed that role.

Part Six: Participant Rating of Roles.

Participants were then asked to rate, as a single unit, each meta-role area according to frequency of meta-role performance, value of the meta-role and satisfaction with meta-role performance. They were shown a five point scale represented on a large piece of card measuring 360 mm x 240 mm and asked to rate by pointing. Each scale had polar descriptions, with one as the lowest rating and five as the highest.

This process did not often give rise to further discussion, and generally did not seem as meaningful to participants as the earlier parts of the interview. This might indicate that participants felt saturation had already been achieved, or that this exercise had little relevance for them. While some participants indicated by body language that they found the process tiring, others seemed happy to do it.

Part Seven: Nomination of a Partner

Participants with Pd were asked to nominate a partner to participate in the study. It was made clear that this partner could be anyone who was close enough to them to know what life was like for them on a daily basis, and actively engaged in role performance with them on a regular basis.

At the conclusion of the interview the information that had been obtained was summarised for participants by the researcher in terms of roles and how they had rated themselves. Any further comments or corrections were noted. If participants wished to discuss anything further the interview continued. Participants were thanked, given the researcher's contact details and invited to ring or write if they had any further queries.

In summary, the interview yielded a range of data that described aspects of self perceived roles. Information gathered related specifically to the participants' own perceptions of their current ORP in the areas of productivity, self maintenance and leisure, as well as their socio-cultural role performance. Perceived frequency of performance, perceived role value and degree of satisfaction with role performance were discussed and evaluated for each of these areas.

5.4.4 Stage Two Data Collection

The data from stage one were analysed on an ongoing basis and this information was used to develop a second stage of data collection. Where stage one had been designed to give an overview, stage two was designed to provide more in-depth information.

Stage Two Recruitment

Participants for this second stage were recruited following further talks with a number of Parkinson's NSW support groups. A handout was provided, outlining the findings of stage one (see handout Appendix 5.9). Recruitment otherwise followed the same pattern as for stage one. Participants were sent a different information sheet to accommodate the request for three interviews instead of one (see Appendix 5.10).

Stage Two Interview Protocols

Protocols for three interviews were developed using the findings from Stage One data. In addition, these three interviews made use of earlier findings (Hillman, 1999) (See Chapter Two) and used the concepts of *Doing*, *Knowing* and *Being* linked to occupational role performance in the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b). The protocols incorporated and extended the elements of the Occupational Performance Role Assessment (Hillman, 1999; Hillman & Chapparo, 1995a). (Appendices 5.2, 5.3 and 5.4) . The goals of the interviews were as follows:

Interview one: (doing as it relates to occupational role performance).

- Gather demographic data,

- Establish the phase of participant's Pd,
- Identify and define roles in role repertoire, develop role map,
- Identify 'doing' with partner and 'doing' alone,
- Frequency of performance in specific roles,
- Time allocation and time use,
- Barriers and facilitators of role performance,
- Role development, role transitions, and role continuity.

Examples of 'doing' questions were:

- "What sort of things do you do at home?"
- "What is involved for you in taking your sister-in-law shopping?"
- "How often do you go to the Probis Club meetings?"
- "Do you do that on your own?"

Interview two: (*being* as it relates to occupational role performance).

- Clarify and confirm major points from interview one (*doing*),
- Establish role priorities,
- Establish the principle reasons roles were performed, investigate motivation, attitude,
- Value,
- Expectations,
- Satisfaction with performance and any sense of loss.

Examples of 'being' questions were:

- "Is being mother more, or less important to you, than being a grandmother?"
- "How important is being able to drive to you?"
- "Is there anything you do not like about going to the Parkinson's support group?"

Interview three: (*knowing* as it relates to occupational role performance).

- Clarify and confirm the major points from interview two (*Being*),
- Investigate knowledge of ORP held by each participant

- Thinking and decision making strategies used by the participant in problem solving, role evaluation and planning future ORP,
- Principal elements of thinking and planning that were perceived to contribute to successful ORP.

Examples of ‘knowing’ questions were:

- “I’d like to know more about how your own abilities affect the way you help Steve with his singing”
- “Tell me a bit more about why you don’t like to go out to dinner?”
- “So how did you work that out?”

A digital camera was used to record role sorting. This promoted accuracy in recording important data, and reliability, as the photographs became part of each participant’s data set. Each interview was analysed prior to the next. This analysis guided the interviewer in planning the next interview. A one to two page summary was written (see Appendix 5.11 for examples). Participants were asked at the beginning of interviews two and three to read the summary and comment upon it. Their comments were noted and changes to the data made accordingly. These summaries were unexpectedly popular, with participants reporting they had shown them to their friends and family. They seemed to feel they provided a kind of biography, and perhaps a validation of themselves to others.

5.4.5 Location

Nearly all the interviews in both stages were carried out in the participant’s home, with the exception of two people in stage two who had the first interview in an interview room on the university campus and the remaining two interviews at home. All interviews were carried out in a part of the house of the participant’s choosing, with no-one else present in the room, although in the most cases there was someone else present in another part of the house.

Interviews carried out at home allowed the researcher to gain a sense of context for each participant through experiencing their personal living environment and the objects within it that had special personal significance.

5.4.6 Interview Context

In both stages of data collection, the interviewer took care to ensure that the participant felt at ease. Before each interview, she rang to check how participants were feeling, and if they were having a bad day the interview was rescheduled. This happened twice. The interviewer took care to maximise each participant's sense of personal control. For instance, participants were encouraged to choose a place for the interview, either in the community, or within their home or garden, where they would feel most comfortable.

Participants often offered the researcher tea, coffee or a glass of water. Acceptance of this offer assisted the participants (and the interviewer) to relax, and facilitated conversation. Some participants used such an offer as a means of providing a break in the interview. Breaks were more easily achieved at home where the person could get up and move about, perhaps showing the researcher family photographs or other mementos. Breaks also allowed medication to be taken as needed.

Permission was obtained to tape the interview and a tape recorder and microphone were placed in full view on a convenient surface nearby. For some participants with Pd it was necessary to use a lapel microphone, as their voices were faint. Often participants started talking about their lives even before the explanation of the interview, information sheet and consent form had been dealt with. When this happened, the researcher asked permission to turn on the tape recorder and listened carefully to what participants said. She then waited for a natural break to return to the interview structure. Often the information in this initial part of the interview related to what was of most concern to the participant at the time of the interview.

Using the principles of ethnographic interviewing (Spradley, 1979), efforts were made to achieve rapport using the researcher's knowledge from past experience of working with people of this age and disability. During the interview, the researcher used appropriate tones of voice and body postures to signal interest, and listened to the way each participant used language in order to match it as naturally as possible. The researcher used body language to encourage conversation, sitting facing the person, leaning forwards much of the time. Verbal prompts such as '*mm*', '*so ...?*', '*yes*', and silence were used to encourage further information about particular points (Minichiello et al., 1990).

5.5 Reliability and Validity of Data Collection and Interpretation

In the past, attempts have been made to use quantitative terminology to judge the validity and reliability of qualitative research methodologies. However, terms such as reliability and validity are not considered appropriate to the way in which qualitative research is conducted .

Acceptable criteria for assessing the worth of qualitative research are still evolving (Hasselkus, 1995; Sandelowski, 1986). Several authors note the epistemological influence when considering the worth and quality of a research study (Fossey, Barvey, McDermott, & Davison, 2002; Lincoln & Guba, 1985; Miles & Huberman, 1984; Tesch, 1990; Whittemore, Chase, & Mandle, 2001) Guba (1981) developed a model for judging the rigour of a naturalistic enquiry which he referred to as *trustworthiness*. This model has been discussed and accepted by a number of researchers (Gliner, 1994; Mays & Pope, 2000; Sandelowski, 1986; Tesch, 1990; Tobin & Begley, 2004), and has been used by qualitative researchers in recent years in the health sciences and education (Dreissen, Van der Vleuten, Schuwirth, Van Tartwijk, & Vermunt, 2005; Treadwell, 2001; Webb et al., 2003). Guba identified four factors that provide a useful framework for naturalistic enquiry: *truth value*, *applicability*, *consistency* and *neutrality*.

Consistent with the naturalistic paradigm used in this study, Guba's (1981) model was employed to evaluate the rigour of data collection and interpretation. This section of the chapter outlines each of the factors in Guba's model and demonstrates how they were applied to this study.

5.5.1 Truth Value

The concept of internal validity is based on the idea that there is only one possible reality. Naturalistic inquiry rejects this view and incorporates the assumption that people have multiple constructed realities. There is no benchmark to aim for, but rather, the need to represent these multiple constructions as accurately as possible. The question asked, in terms of rigour in truth value, is whether the reconstructions (research findings and interpretations) are credible to the constructors of the original multiple realities (Lincoln & Guba, 1985). To

test for credibility, the researcher is required to test the findings against the groups from which the data were drawn, or persons who are familiar with the phenomenon being studied.

In this study, the following checking measures were used to determine trustworthiness of the data collected.

Triangulation

Triangulation refers to the combining of several methods of data collection within the same study. Triangulation can highlight different aspects of the same phenomena and can increase the validity of findings by considering them from different perspectives (Mays & Pope, 2000; Minichiello et al., 1990; Tobin & Begley, 2004). Three methods were used to collect data: interview, participant sorting of information and rating scales. Comparisons were made of the data collected by each method. Generally, agreement was found between the transcript data and role sorting and role rating.

The transcripts were examined for statements relating to specific named roles and analysed for information that might relate them to one of the meta-role headings. It was harder to find agreement for this role sorting, as participants responded in complex ways, indicating more than one reason for performing the role.

The transcripts were examined for statements about role priority and role value and strong correlations were found in every case between the role given top priority and statements made about it in the transcript. The correlations tended to decline in relation to the level of priority given to each role, with the roles given lowest priority also being the ones spoken about least in the transcript. Similar correlations were found for role frequency and role satisfaction.

Member Checks

These consist of an informal review of the researcher's findings and interpretations by the person who provided the data in the first place (Lincoln & Guba, 1985; Mays & Pope, 2000). In this study participants were asked to:

1. Check the list of roles the researcher had determined from the second part of the interview. This was a valuable tool that often led to further discussion and clarification of the roles.
2. In Stage Two of data collection they were asked to check the brief summaries written between interviews. These summaries stimulated further discussion and expansion of information.

Prolonged Engagement

Although prolonged engagement is considered important by Lincoln (1985), it does not guarantee support for an hypothesis, while short engagement does not exclude such support (Gliner, 1994). A short engagement is considered acceptable when the researcher is familiar with the culture, setting and tacit nature of the participants (Bernard, 1988; Patton, 1980; Spradley, 1979).

The researcher has worked with and studied older people with chronic disability for many years. She has previous experience in conducting this type of interview and piloted the interview formats prior to commencement of data collection. The interview format, although styled on ethnographic principles outlined by Spradley (1979), was used within a naturalistic research paradigm, and was focused, semi-structured and time limited. Participants in stage two were interviewed three times, over a period of several months allowing for the development and verification of ideas over time. The total process of data collection took place over a period of two years, allowing for the evolution of ideas and modification of data collection methods during the course of the study. Stage one of data collection and preliminary analysis was completed before the commencement of Stage two, allowing for further development of the Stage two methodology that reflected the earlier findings.

Negative Case Analysis

Negative cases are instances that contradict the hypotheses being developed during analysis of the data. Negative cases provide the instrument to test hypotheses, or interpretations. They are studied in the light of the interpretation to find out if it fits the case. If it does not, then the interpretation is reworked or the phenomenon being studied is

redefined to exclude the case (Bühler-Niederberger as cited in Flick, 2002). The cases that did not fit with the interpretations formed as a result of this study were examined, and attempts were made to try to ascertain why they differed. Gliner (1994, p. 85) believes that, "If the naturalistic paradigm implies the existence of more than one reality, or that reality is constructed (Lincoln & Guba, 1985), then one would expect differences that might not be resolved". Positive and negative cases were identified and are discussed as they related to themes reported in the findings.

Credibility of the researcher

Gliner (1994) maintained this should be a minor consideration. In this study, the researcher was an experienced clinician, who had worked for many years with people who were elderly and who had a chronic illness or disability of some kind. She had previously completed research under the supervision of an experienced qualitative researcher with a special knowledge of occupations and occupational role performance and an associate supervisor was also an experienced qualitative researcher with a special interest in ageing, chronic illness and carers.

5.5.2 Applicability

One of the features of qualitative research is the absence of control of independent variables prior to commencing the study. The concept of generalisation, as discussed above, is therefore rejected by the naturalistic inquirer. Indeed, as Lincoln and Guba (1985) pointed out, even in quantitative research, the likelihood of controlling all variables that are not to be manipulated is remote, and therefore the danger of generalisation is that it could lead to misunderstandings and distortions of the real world. Lincoln and Guba (1985) proposed a concept more appropriate to qualitative research, that of transferability. The emphasis is on hypotheses that might be generated as a result of this interaction which might then be used to drive further research in the area. Because qualitative research involves a particular person interacting with a particular researcher it is argued that direct transferability to other people or groups is inappropriate unless the investigator knows a great deal about both groups and is able to make direct comparisons based on detailed definition.

Lincoln and Guba (1985) saw transferability as essentially the responsibility of the subsequent researcher who sought to apply the findings of the original study elsewhere. They stated that it was therefore the responsibility of the original researcher to provide as much contextual detail (dense description) as possible to facilitate this process. This means that an accurate description must be provided of units of analysis, concepts generated, population characteristics and setting. It is important that the researcher allows others to understand the methods of research, theories and definitions (Goetz & LeCompte, 1984). In this study, care was taken to provide as much detail as possible to allow understanding of the research process used to permit the possibility of replication.

5.5.3 Consistency

Unlike quantitative research, where the research instruments are required to measure phenomena in precisely the same way each time to achieve reliability, in qualitative research, the researcher and the participants are the research instruments. It is accepted that they vary and consistency is defined in terms of dependability (Guba, 1981). Variation should be traceable to various sources.

In this study, each interview transcript was analysed for statements that confirmed or denied information obtained through that person's role sorting and role rating, regarding nature of roles, frequency, value of roles, and satisfaction with performance of roles. This process allowed the researcher to determine the consistency of the data and to track where variability in the data occurred. In addition, a second investigative researcher experienced in qualitative analysis reviewed one third of the transcripts and associated data collected by the first researcher. Comparisons were made between the findings of the first researcher and the findings of the second (Minichiello et al., 1990).

5.5.4 Neutrality

Neutrality refers to freedom from bias in research procedures and results (Sandelowski, 1986). It denotes the degree to which the findings are a function solely of the participants and conditions of research and not of other biases, motivations and perspectives (Guba, 1981). Lincoln and Guba (1985) shifted the emphasis of neutrality in qualitative research from the researcher to the data, so that the neutrality of the data was considered.

They suggested that confirmability be the criterion of neutrality. This is achieved when truth value and applicability are established. As discussed above, attempts were made to establish truth value and applicability for this study. In addition, questions relative to the style of questioning used in interviews and interpretation of the data were proposed. This process assured a certain freedom from bias in interpretation of the data that came from the natural biases, motivations and perspectives of the researcher herself. This resulted in an ongoing modification and refinement of the interview technique.

Treatment of Researcher Effects

Because people are indivisible from their environments, in any form of research, the researcher affects the behaviour or environment under study. Measures were taken in this study to minimise these effects and use them as sources of data (Miles & Huberman, 1984). In this study, researcher effects took two possible forms:

1. Changes in participants' behaviour as a result of researcher presence.

Participants could have presented themselves to the researcher in ways that misrepresented who they really were and what they were really like. In this study, both partners were interviewed. Each reflected upon issues that meant they talked about their partner. This data confirmed that the way participants' partners represented themselves during the interview corresponded with the way they were perceived by their partner. In the second stage of the study the reactions of the participants to the researcher were minimised through prolonged engagement with each participant in their natural settings. The researcher interviewed each participant three times over a period of months, getting to know them well and developing a sense of trust. Their behaviour towards the researcher was not observed to change over this time.

2. Changes in the researcher as a result of the data collection procedures.

As research proceeded, the researcher might lose sensitivity to the full range of events occurring in the setting (Miles & Huberman, 1984). These effects were minimised in two ways. First, the researcher sought informal feedback about her data collection techniques and interpretations from two academics (an occupational therapist, and a sociologist). They were experienced researchers and 'non-natives'. That is, they were not in any way involved with

the participants, their families or any other part of their social system. Second, the findings of the study were reviewed in a number of ways. Transcripts were analysed to identify themes which were then canvassed via supervisory discussion and formal and informal presentations within academic forums. This helped to alert the researcher to aspects of the interpretation of data that might have been unduly biased or narrow. Informal presentations were made within the School of Occupation and Leisure Sciences. There were discussions with a number of visiting faculty with experience in this area of research. During the course of the study, the researcher sought feedback in the public forum via nine conference presentations (Hillman & Chapparo, 2001b, 2002c, 2002d, 2002e), three poster presentations (Hillman & Chapparo, 1995b, 2001a, 2001c, 2003), three seminar presentations (Hillman, 2001a, 2003a; Hillman, Chapparo, & Chesson, 2005), and eight invited talks to Parkinson's NSW support groups (Hillman, 2001b, 2001c, 2001d, 2001e, 2003b, 2003c, 2003d, 2003e) and to a Rotary Club (Hillman, 2003f). Publications, including an article in the Parkinson's NSW newsletter (Hillman & Chapparo, 2002b) and a journal article (Hillman & Chapparo, 2002f) relating to the previous study also provided some helpful feedback. This process of discussion and feedback, along with supervisory discussion, allowed the researcher to subject the phases of the study to ongoing review and reorientation to the original purpose and research questions. Such feedback created new perspectives, that in turn contributed to the richness and volume of data. Strategies used to establish trustworthiness of data are summarised in Table 5.5.

Table 5.5 Summary of strategies used in this study to establish trustworthiness using Guba's Model (1981)

Criteria	Strategies used
Truth value	Triangulation, member checking, prolonged engagement, peer examination of data, negative case analyses.
Applicability (transferability)	Dense description enabling replication and comparison.
Consistency	Dense description of research methods, triangulation, peer examination, code-recode procedure used.
Neutrality	Triangulation, member checking, peer examination of data, questioning style of interviews and interpretation of data.

5.6 Data Analysis Methods

Data analysis in this study sought to discover how people with Pd and their partners actively participated in their occupational performance roles as members of their social environment, and to find out if they felt able to maintain an acceptable sense of personal control in relation to their most valued roles. Analysis of Stage one and Stage two data followed similar lines, and data from both stages were analysed in the same way.

Analysis was interpretational rather than structural in nature (Tesch, 1990). That is, it was intended to provide descriptive information and to establish possible links and connections that would illuminate meaning and lead to a description of patterns and themes and to theory development. Certain concepts used to structure the analysis were determined by the researcher before the commencement of research. Some were determined in the course of the interview, and others were generated by the researcher as a result of systematic description of the data. The analysis was characterised by the following ten principles of data analysis as summarised by Tesch (1990, pp. 95-96):

1. **Analysis is not the last phase in the research process; it is concurrent with data collection or cyclic.**

Data analysis was conducted at the same time as data collection and began as soon as the first set of data was collected. They informed each other (Miles & Huberman, 1984).

2. **The analysis process is systematic and comprehensive, but not rigid.**

The analysis proceeded in a systematic way using a coding system developed by the researcher. The analysis ended when the process 'exhausted' the data.

3. **Attending to data includes a reflective activity that results in a set of analytical notes that guide the process.**

A dossier was kept on each participant as the data collection process continued.

These were used to record process and as an aid to concept development (Miles & Huberman, 1984). They were attached to the raw data sets and are available for outside verification.

4. **Data are 'segmented', i.e., divided into relevant and meaningful 'units' yet the connection to the whole is maintained.**

After reading the whole data set, first level coding was carried out to divide the data into meaningful smaller units that were found recurring both within and across data sets. These units were then used in the process of concept development.

5. **The data segments are categorised according to an organising system that is predominantly derived from the data themselves.**

Certain topical categories relating to the conceptual framework and research questions were developed prior to the commencement of analysis. Pattern coding was used to identify themes relating to these concepts and to identify new themes that ran through the data. These themes were developed by an inductive process from the data.

6. **The main intellectual tool is comparison.**

In this study, the analysis took the form of identifying recurring patterns and themes by the process of comparison.

7. **Categories for sorting segments are tentative and preliminary in the beginning; they remain flexible.**

Categories were initially tentative and remained flexible, going through a process of evolution as the data informed them in order to accommodate later data.

8. **Manipulating qualitative data during analysis is an eclectic activity; there is no one 'right' way.**

The researcher developed the process of analysis for this study.

9. **The procedures are neither 'scientific' nor 'mechanistic'.**

While utilising methodological knowledge and a logical system, there were no strict rules set and adhered to rigidly for data analysis. Speculation and the making of inferences were an important part of the process (LeCompte, Preissle, & Tesch, 1993).

10. **The result of the analysis is some type of higher-level synthesis.**

The product of analysis as outlined in later chapters could be described as a composite summary of factors involved in self-perceived ORP that focused upon perceived control. From this summary, a model was proposed to describe the way in which participants sought to regain control when a barrier to ORP was encountered. Its purpose was to develop new concepts or theoretical categories that could be tested in subsequent research.

5.6.1 Procedures

Data analysis procedures involved conversion of data to 'write-ups', coding, weighting the data and finally model development.

Conversion Of Data to "Write-Ups"

All raw data obtained (taped recordings of interviews and field notes) were converted to 'write-ups' (Miles & Huberman, 1984, p. 50). Field notes were recorded at the time of interview on the Occupational Performance Role Assessment (OPRA) form or written up separately (see Appendix 5.12). This information was later transferred to the participant's evolving dossier. Tapes were converted to written transcripts. After each transcription was complete, it was edited by the researcher for accuracy (see appendix 5.13).

Multiple copies of the transcribed data were made and the majority of participant data sets were double coded (Miles & Huberman, 1984) to determine the internal consistency of the researcher's interpretation of the text.

5.6.2 Coding Process

Following preliminary or first level coding of the data, there was subsequent pattern coding and finally the data was thematically coded.

First-Level Coding

This was done on each manuscript once transcription, editing and checking were complete. The level of detail of coding was multi-sentence 'chunks' with occasional sentence or phrase coding (Miles & Huberman, 1984). Passages of script were coded using descriptive terms according to the thematic interpretation made by the researcher. Coding was written in the left-hand margin of the script, with possible themes and other notes written in the right-hand margin (see Appendix 5.14 for an example). Generally, scripts were examined and coded in the following way:

1. The script was coded down the left hand side for information relating to mobility, communication and personal care (part two of interview).

2. Information relating to the roles that had been identified and agreed to by the participant was then coded down the left hand side with the name of the role.
3. The script was coded down the left hand side for information relating to any additional roles that were apparent to the researcher as likely roles when reading the script.
4. The script was then further examined and coded down the left hand side for statements of frequency, value and satisfaction relating to performance of each of the roles identified.
5. Any additional comments were written in the margin next to the section of script to which they related.

This first-level coding was then analysed as follows. The first-level coding was reduced and summarised by this means.

1. The overall impression of the researcher when reading the script was noted and compared to the notes written at the time of interview.
2. Mobility, communication and personal care ratings were compared with supporting or contradictory evidence in the script, using the definitions in the Appendix of the OPRA manual (see Appendix 5.2) as a benchmark.
3. The marked sections of the script were examined to find supporting or contrary evidence for the rating given for frequency, value and satisfaction with performance at end of the interview by the participant.
4. Ratings for frequency, value and satisfaction were examined using the OPRA Appendix definitions as the benchmark (see Appendix 5.2). This was done at the end, after the transcript has been analysed to avoid bias.

In addition, notes were kept on how the interview had gone and the efficacy of different forms or types of questions. Suggestions were made on the basis of this about changes that could improve the quality of data or further develop promising areas in future interviews.

Feedback on the methodology was received during this process of data collection and data analysis by the presentation of four conference papers and two posters presenting the

methodology as part of the findings of the previous study (Hillman & Chapparo, 2001a, 2001b, 2001c, 2002c, 2002d, 2002e).

Pattern Coding

Pattern coding proceeded in three steps.

Step One

Following this preliminary coding, the data were reviewed and emergent themes were identified. An electronic file on each participant was developed and updated regularly as analysis proceeded (see Appendix 5.16). Notes were kept of themes as they became evident to the researcher (Miles & Huberman, 1984). Topics and themes that occurred and re-occurred were then identified and assigned preliminary codes that subsequently became the initial content label. A number of themes were identified at this stage:

1. Role statements: information about the statements made by participants when asked about their roles.
2. Role sorting: information relating to the nature of role sorting.
3. Role rating: information relating to perceptions of role performance (frequency, value and satisfaction).
4. Barriers to ORP.
5. Strategies to overcome barriers to ORP.

Step Two

The transcript was further coded according to the roles, barriers and strategies that had been identified and sorted by the participant. These sections were then cut and pasted under the relevant theme headings, so that all the sections of the transcript relating to a specific role were placed together under the relevant meta-role heading. A brief summary or description of the participant's performance in each role was written. Statements considered significant by the researcher were highlighted and given tentative thematic labels (see Appendix 5.15).

Step Three

Interpretive: An extensive description of role performance was written for participants, to aid in achieving greater insight into the nature of role performance over their whole role repertoire, and in an attempt to access the meaning behind what had been said in the interviews and identify themes of meaning (see Appendix 5.16).

Thematic Coding

The data so organised was reviewed to further identify themes of meaning for each participant. These were summarised in point form and subsequently compared with the themes identified for each of the other participants to identify common themes or patterns that might be recurring across the participants' data. As a list of themes was further developed, a process of constant referral back to the raw data occurred to ensure that there was sufficient direct input to justify the theme (see Appendix 5.17).

5.6.3 Weighting the Data

The source codes described above were used to determine the strength of the evidence of a particular theme that was developed. Each theme identified by the data analysis was required by the researcher to contain data from direct input. Direct input included data that were obtained directly from the participants. Information was weighted according to how frequently the different participants chose to talk about it, and whether the information related to major or minor roles. Indirect input, particularly researcher interpretations of events, reports of informal conversations and data from secondary sources were used to substantiate themes found from direct data. Themes with insufficient weight or that were not directly relevant to the purpose of the study were discarded at this stage. Themes were examined in relation to each other, to identify **levels** of theme. Some themes became subsumed in other themes. Others became sub-themes of larger themes.

As data analysis from the first stage of data collection reached this stage, an invited seminar presentation for Parkinson's NSW (Hillman, 2003a), four talks to Parkinson's NSW support groups (Hillman, 2003b, 2003c, 2003d, 2003e), an invited talk to a Rotary Club (Hillman, 2003f), conference poster presentations (Hillman & Chapparo, 2002a, 2003) and

an article in the Parkinson's NSW Inc. Newsletter (Hillman & Chapparo, 2002b) afforded opportunities for feedback about interpretations made.

5.6.4 Model Development

As a result of this analysis, relationships between the major identified themes began to emerge. There appeared to be four major themes, each with a number of sub-themes. A process of checking and re-checking to establish the validity of these themes took place, along with referral back to the literature for further validation. A reasoning process to establish a relationship between these themes was thought through and evidence was sought from the data and from the relevant literature for potential relationships (see Appendix 5.18). Theoretical concepts drawn on to develop the model, from both inside and outside the discipline of occupational therapy, included occupational performance, theories of perceived control, environmental theory, role theory, personal meaning and systems theory.

In this way the constructs of an emerging model and their possible relationships were developed. This model is still in the preliminary stage and represents an hypothesised notion of the process participants went through in order to regain a sense of personal control in relation to their ORP. It requires further research to establish its validity.

The process of data analysis and the findings were further formalised at this stage by the presentation of four more conference papers (Hillman, 2004, 2005b; Hillman & Chapparo, 2004; Hillman et al., 2005). A written paper (Hillman, 2005a) was published in the refereed proceedings of the Emerging Researchers in Ageing Conference. The specific purpose of this conference was to showcase research work at the national level to policy-makers and academics in the field of ageing. The methods used for analysis and their findings were formally validated.

Summary

This chapter has described the nature and purpose of naturalistic enquiry and related it to the methodology employed in this study. A rationale for the research design was presented. The participants were then described, along with the procedure used to recruit them. Data collection methods were outlined in detail. The reliability and validity of the

method of data collection and interpretation was discussed. Finally, the data analysis methods and procedures were described. The findings of this study, as generated by the methods described in this chapter, are described in the next chapter.