

## **CHAPTER FIVE**

### **METHODOLOGY**

## **5.1 Introduction and Purpose**

In Chapter One, the primary purpose of this research was outlined as being to explore whether people living in the community with a chronic illness such as Parkinson's disease (Pd), and their partners, continued to maintain personally satisfactory occupational role performance (ORP). Chapters Two, Three and Four further explored the nature of chronic illness, with particular attention to Pd, partnership and caring, occupational therapy services, perceived control, and social and occupational role. To provide the fullest possible description of how such people fulfilled the occupational aspects of their roles in the presence of Pd, a naturalistic study was undertaken to meet the following research purpose:

- To describe the degree and manner in which people with a chronic illness, such as Pd, and their partners were able to continue to actively maintain the roles required to participate as members of their social environment,
- and to investigate if and how such people maintain an acceptable sense of perceived control in their every day occupational role performance.

## **5.2 Design**

In order to meet the research purpose, the research design utilised the naturalistic research paradigm to explore the nature and meaning of everyday community life for this group of people. Naturalistic inquiry employed qualitative research methodology in the environment of the people being studied in order to interact with them and learn from them (Lincoln & Guba, 1985).

### **5.2.1 Purpose and Characteristics of Naturalistic Inquiry**

Naturalistic Inquiry is based on two assumptions. First, that people cannot be separated or removed from the physical, social and cultural elements of the environment. Humans constantly seek to influence and are in turn influenced by it, and behaviour can be explained in terms of the person-environment interaction (Bell, Fisher, Baum, & Greene, 1990; Hasselkus, 1978; Lawton, Windley, & Byerts, 1982; Sommer, 1969; White, 1971). This assumption was explored in Chapter Four. Second, it is not possible to interpret behaviour simply by means of observation, because it is not possible to observe the personal meanings

and perspectives that guide a person's behaviour within a given environment. There is an internal interpretive element between people and their environment, which means that each person might behave differently in a given set of circumstances. Unique experiences and knowledge are brought to the situation (Fine, 1991; Frankl, 1963; Lincoln & Guba, 1985; Spradley, 1979). Research methodology that attempts to investigate the perceptions of people must find a means to access their internal beliefs and knowledge in order to develop an understanding of the world from their own viewpoint (Lincoln & Guba, 1985).

Characteristics that identify the particular design, implementation and data processing methods of naturalistic inquiry were proposed by Lincoln and Guba (1985) as follows: Naturalistic setting; human data collection instrument; utilisation of tacit knowledge; qualitative methodology; purposive sampling instead of random; inductive data analysis; emergent design; negotiated outcome; idiographic interpretation; tentative application (instead of generalisation); focus-determined boundaries; special criteria for trustworthiness.

### 5.2.2 Application of the Characteristics of Naturalistic Research Design to this Study

In this study, participants were interviewed in their own home settings. Interviews were tape-recorded and field notes kept. In addition, participants were asked to sort information revealed during the interview (Spradley, 1979). Characteristics of naturalistic research as outlined by Lincoln and Guba (1985) were applied to the design of the study in the following table (Table 5.1).

**Table 5.1 Application of characteristics of research to this study**

<b>Characteristic</b>	<b>Application to Study</b>
Natural setting	Data were collected in the participant's own home.
Human data collection instrument	Researcher was the primary collector of data. Two assistants trained by the researcher also collected data.
Utilisation of tacit knowledge	Researcher relied on personal experience in the clinical area.
Qualitative methods	Interview and field notes were used to collect data.
Purposive sampling	Participants were invited to participate either because they were members of a Parkinson's NSW support group, or because they had been nominated as a partner by another participant.
Inductive data analysis	Narrative data from interviews were analysed to identify themes that developed a picture about participants' ORP and sense of perceived control.

**Table 5.1 (continued)**

Emergent design	Ongoing analysis of data was used to change and clarify the nature of questions asked by the researcher.
Negotiated outcome	Participant involvement was negotiated through informed consent. In addition, findings were checked with participants during the course of each interview, and, in the second stage of data collection, summaries of interviews were written and checked with participants.
Idiographic interpretation	Information was requested and recorded on an individual basis and for how things were at the time of the interview.
Tentative application	Interpretation of the data resulted in a description of the occupational roles identified by participants, the meaning that participants ascribed to their ORP, barriers to performance and strategies employed to overcome barriers. From this information hypotheses were generated about the nature of perceived control in this group of people.
Focus-determined boundaries	The nature of self-perceived ORP in a selected group of people who had Pd or were the role partners of someone with Pd and who were living in the community only was studied. No other aspect of role was studied and no other group of people were involved.
Special criteria for assessment of trustworthiness	Participant generated data, participant checking of data (interview and sorting), verification of interpretation using two other investigators, and comparison of findings with current literature were used as criteria for establishing validity and reliability of data collected and interpreted.

### 5.2.3 Rationale for the Design

This study examined the *perceptions* of a particular group of people about their occupational roles and role performance in the presence of a chronic illness. A comparison of some of the axioms of naturalistic inquiry with the purpose of this study further demonstrated the appropriateness of the qualitative approach used.

First, the naturalistic paradigm states that realities are multiple, constructed and holistic (Lincoln & Guba, 1985). The aim of such inquiry is to seek information about the reality of the person or group being studied. This is in contrast to the positivist view that reality is single and fragmented. This study sought information from the participants about their own perceptions of their roles and role behaviour in the presence of Pd. A naturalistic approach lent itself to obtaining this type of information.

The second axiom states the knower and the known are interactive and inseparable (Lincoln & Guba, 1985). This study sought to gather information about knowledge as

perceptions of each person in the study, and how he or she developed and used that knowledge. An attempt to see knowledge as objective, separate and independent of the knower, as required by the positivist paradigm, would have been counterproductive to the purpose of the research.

Third, the naturalistic paradigm states that only time and context-bound working hypotheses are possible (Lincoln & Guba, 1985). When studying people's own perceptions of role performance, it is necessary to share their view of the world around them, including personal preferences or reactions to the environment that are based on attitudes, beliefs, group affiliations and background experiences. Such a view is unlikely to lend itself to the generalisation considered possible by the positivist paradigm. Instead, it lends itself to insights which are thought to assist in the development of hypotheses, which in turn may lead to an extension of theory and further research. Use of quantitative methodology for this current study would have required:

1. a known model of an internal frame of reference of role performance
2. that it was possible to pre-order findings

Although the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b) was used to guide the initial thinking in this study, its constructs required further development. One of the related intentions of the study was to develop and extend aspects of the model relating to ORP. For this reason it was not possible to pre-order findings.

The qualitative research process used in this study was not linear. Early findings informed later work in a cyclical fashion such that there was ongoing feedback into the research process, informing ongoing modifications to the methodology employed (Spradley, 1979). An area of interest was selected with the general goal of describing a phenomenon linked to a cultural group or subgroup. Data collection and data analysis proceeded simultaneously. Data were summarised, leading to the formulation of new questions, and written reports were viewed as part of an ongoing research process. Qualitative methods were intended to allow the discovery of possible relationships between variables that were not already known.

Where investigation relates to the perceived reality of people, qualitative methods have been reported to be an effective way to conduct research in that the researcher does not attempt to prove or disprove previously formed hypotheses in a situation where, despite best intentions, all variables that might affect the outcome cannot be known or controlled (Lincoln & Guba, 1985). While in the laboratory situation it might be possible to achieve a near approximation of this ideal, in the real world of human existence and cultural realities it is not possible to begin to attempt such control. In addition, if such control were possible, it would nullify the results because it would necessarily involve such a degree of interference with the natural setting that an unacceptable degree of change would be the result (Lincoln & Guba, 1985).

Many of the problems occupational therapists seek to investigate are suited to qualitative methodology and many researchers have discussed the appropriateness of its use within the discipline (Hasselkus, 1995; Kibele & Llorens, 1989; Kielhofner, 1982; Kielhofner & Mallinson, 1995; Krefting, 1989; Mattingly & Beer, 1993; Merrill, 1985; Robertson, 1988; Yerxa et al., 1990). Robertson, (1988), for example, wrote:

Considering that our field of expertise was to do with meaningful or purposeful activity in relation to the health of our patients or clients, it would seem that the qualitative approach should be an ideal one because phenomena such as meaning and purpose do not lend themselves readily to quantitative analysis. (p. 345)

Occupational role performance is a phenomenon that has not been greatly researched, as stated in Chapter Two. Of the studies that have been done, most had pre-ordained the roles to be investigated, and have sought indirect rather than direct information, about individual role performance. Although role assessment instruments have been developed for adults and elderly people, they are limited in the scope and type of information they can provide (see Chapter Two, section 2.3.6).

The present study utilised qualitative methodology to identify and probe in depth the participants' perceptions of their roles and role performance in order to develop hypotheses about:

- The nature of ORP as perceived by people with Pd and their partners.

- How participants went about planning and performing meaningful occupations.

In order to develop hypotheses, the naturalistic research design was employed to allow the researcher to study:

- Themes that might be identified from participant responses regarding their self-perceived ORP.
- Barriers to ORP that participants might identify.
- Strategies that participants might describe to overcome barriers to ORP.
- Whether it was possible to construct a conceptual model to describe how people with chronic illness (Pd) might work to maintain a sense of control.

A semi-structured interview was used. This type of interview involved questions of no fixed wording or order. Rather, the interview used questions that focused around the issues that were central to the research purpose. An interview schedule was used to aid interviewers to maintain this focus, as described by Minichiello, Aroni, Timewell and Alexander (1990) (see Appendices 5.1, 5.2, 5.3 and 5.4). It was expected that many of the participants would have disabilities. It was thought likely that some might have cognitive and/or communication difficulties and might tire quickly. A semi-structured design was considered more appropriate for this reason, in order to provide structure and ensure that the subject area was covered as fully as possible in the time available.

The study was designed to allow participants to name and frame their own roles. A sorting process was used in order to give further insight into the meaning of the role to the participant. Participants were asked to sort roles in order of their value and personal satisfaction. Participants named their own roles, and ordered them for value and satisfaction, in a way that enabled the researcher to gain an appreciation of what was important to each participant in terms of occupation at the time of the interview. Qualitative descriptive data were generated to form an understanding of the personal meaning of the role repertoire of each participant.

## 5.3 Participants

A convenience sample of twenty-five participants took part in the study. Fourteen participants had Pd and eleven were role partners. They met the inclusion and exclusion criteria as follows:

1. They either had Pd, or were the nominated partner of someone with Pd.
2. With one exception, they lived in the community in Sydney metropolitan area. This allowed convenience as the researcher visited each person's home.
3. They were members of Parkinson's NSW or the nominated partner of a member of Parkinson's NSW. Parkinson's NSW supported this study and provided contact information for its support groups.
4. They demonstrated willingness to participate in the study as evidenced by signed consent.

Exclusion criteria:

1. People who were unable to converse comfortably for an extended period, and in English. No funding was available for translators and such a process would have been inimical to the purpose of the study.
2. Did not have Pd or were not the nominated partner of someone with Pd.
3. Did not live in the community.

### 5.3.1 Recruitment Procedure

Ethical approval for this study was obtained from The University of Sydney Human Research Ethics Committee (HREC). The participant sample was recruited from five support groups of Parkinson's New South Wales Inc., which were affiliated to Parkinson's Australia. A letter outlining the study and requesting their support produced a positive response. They suggested that support group convenors should be contacted with a request to give a talk to the group and ask for study volunteers. Contact information for support groups was provided. Support group convenors were very positive and helpful when contacted and five support groups throughout the metropolitan area were visited. A talk outlining the need for and purpose of the study was given on each occasion and people with Pd were asked to

complete an 'expression of interest' form (see Appendix 5.5) and place it in a locked box, as required by the HREC. Those who completed the expression of interest form were contacted by telephone a week or two later. If they were still interested in participating, a time was arranged for interview, and they were sent a letter enclosing an information sheet and a consent form (see Appendix 5.6).

### Nomination of Partners

Participants with Pd were invited to nominate a partner who could also be interviewed. A partner could be a person they lived with, a close relative or a close friend. Partners were sent the information sheet for partners and a consent form (see Appendix 5.7) and asked if they would be willing to be interviewed in the same way.

All but one of the participants nominated their spouse. There were two stages to data collection (see 5.4). One participant with Pd was interviewed in both stages. She nominated her husband in the first stage and her close friend and neighbour in the second stage. Three participants with Pd declined to nominate a partner, and two nominated partners did not wish to participate. Three participants with Pd and one partner lived alone at the time of the study. Another had no partner, but lived with his two sons in the family home. One participant's husband (who had Pd) had recently died, and she volunteered herself to the study as a partner. The most common reason people gave for wanting to participate in the study was that they wanted to help in any way they could with research that might assist other people with Pd. There may have been an un-stated wish for social contact.

### **5.3.2 Description of Participants**

Each participant has been given a pseudonym in order to preserve confidentiality and to ease discussion. Please see Table 5.2 for pseudonym, details of partnership, age, functional performance and time since diagnosis for each participant, by phase of Pd development.