

CHAPTER ONE

BACKGROUND AND PURPOSE OF THE STUDY

1.0 INTRODUCTION

This naturalistic study investigated the occupational role performance of thirteen older men who had a stroke, went through rehabilitation, and returned home to resume their everyday lives. The study participants were interviewed in their own homes and descriptive information about their perceptions of their own role performance at the time of the interview was recorded and analysed.

Stroke is the third largest cause of death in developed countries, and the single largest cause of long term disability (NSW Health Department, 1997). Stroke mortality in Australia is declining by around 4.5% per year for both men and women (Donovan, 1995), following a world-wide trend. However, an aging population and the continued high incidence of stroke mean that there is an increasing number of people surviving stroke to live into old age with a significant level of disability (NSW Health Department, 1997; Rowland, 1991). These people experience a degree of handicap and consequent role loss. Australia has a history of high rates of referral to rehabilitation for stroke as compared to some other developed countries (Shah & Bain, 1989).

Occupational therapists see the loss of life roles that occurs following stroke as a major problem (Pedretti, Smith, & Pendleton, 1996). However, the occupational role performance of people who have had a stroke is not well documented. There is an assumption that in restoring function, occupational therapists are preparing clients for the satisfying occupational performance of their roles when they return to the community. However, occupational therapy functional outcome measures for stroke rehabilitation mostly relate to standardised activity of daily living (ADL) measures (Shah, Cooper, & Maas, 1992), rather than role performance. Rehabilitation outcome, when measured in these ADL terms, has been shown to demonstrate a marked improvement from admission to discharge (Shah, Vanclay, & Cooper, 1991) and for some time thereafter (Niemi, Laaksonen, Kotila, & Waltimo, 1988; Schmidt, Smirnov, & Ryabova, 1988; Silliman, Wagner, & Fletcher, 1987; Thorngren, Westling, & Norrving, 1990). Nevertheless, the literature shows that long-term rehabilitation

outcome, when measured in terms of restoration to a lifestyle perceived as meaningful by the person who has had the stroke, is not so satisfactory (Månsson, Fredriksson, & Bränholm, 1995; Niemi et al., 1988; Viitanen, Fugl-Meyer, Bernspång, & Fugl-Meyer, 1988).

Respondents show a lower level of life satisfaction and a higher level of depression than the general population. These differences are unrelated to physical dysfunction or level of performance in self-maintenance tasks (Aström, Asplund, & Aström, 1992; Niemi et al., 1988; Viitanen et al., 1988), indicating the need for greater attention in rehabilitation to higher order functioning and well-being.

Little is known about the everyday performance of roles in later life. Questions that remain unanswered concern the nature of occupational role performance for older people. What happens to role performance following stroke? How does disability affect role performance? What resources do older people use to facilitate role performance? What are the choices that older people make about their role performance?

1.1 PROFESSIONAL SIGNIFICANCE OF THE STUDY - PERCEIVED NEED

Occupational therapists have a pivotal part to play in the successful rehabilitation of people to the point where they are able to resume and continue to develop their everyday occupations and roles in their own community. Stroke is the most prevalent diagnosis for therapists working with adults who have physical disabilities (Trombly, 1989). Occupational therapy programs for adults who have had a stroke occur in acute hospitals and rehabilitation centres, or in community based services. Within this context, occupational therapists have a mandate to develop and implement therapy programs aimed at promoting maximum levels of independence in life skills and optimal quality of life (Chapparo, 1997). There is an obligation to do this in the most efficient and cost effective way possible (Rogers & Holm, 1994). In the area of stroke rehabilitation, as in other areas, occupational therapists' concerns are with the satisfactory restoration, not just of lost function, but of occupational performance in everyday life that is specific and meaningful to each of their clients.

Occupational therapists have developed an effective array of techniques for working with people who have had a stroke. Many of these techniques are aimed at restoring lost motor, sensory and cognitive abilities. For example, a study carried out by Brodie, Holm and Tomlin (1994) used World Health Organisation definitions of impairment, disability and

handicap (World Health Organization, 1980) to study occupational therapy rehabilitation services for stroke. They showed that most occupational therapy interventions in their study were impairment oriented, working mainly at the performance component level to restore ability.

This finding mirrors an assumption held by many therapists that the acquisition of ability is the major hurdle to the restoration of function that is purposeful, specific and meaningful to each person in his or her everyday life. Less attention is given to developing skills in relation to specific task performance. Even less attention is given to developing organised meaningful activity in the context of the person's own lifestyle and environment. This is despite acknowledged difficulties in achieving generalisation (the spontaneous ability to transfer what is learned in one situation to a different situation) (Neistadt & Crepeau, 1998). People may be able to perform tasks well in therapy, but do not always utilise the skills learned in therapy outside the occupational therapy department (Guiffreda, 1998; Wheatley, 1996).

Why is it that therapists focus so much on impairment and so little upon working to enable the person to develop or return to meaningful role performance? One proposition is that occupational therapists do not have enough applied knowledge about role and the elements of role. Occupational therapists working within the stroke rehabilitation system in this country have a conflict between the expectations placed upon them by their own profession, reflecting their personal professional identity, and the expectations placed upon them by their more medically orientated team colleagues and hospital administrators. Resolving this conflict has often led therapists to focus upon the more medically acceptable aspects of the therapy they offer clients with stroke. This means dealing with impairment as the first priority of therapy. Such therapists may neglect the disability level, which focuses on task performance (with the exception of activities of daily living). The handicap level, with its focus on role performance, is overlooked, leading to difficulties for people who have had a stroke in effectively reintegrating into their own lifestyle and environment.

1.1.1 Stroke Rehabilitation and Occupational Role

This study is based on the proposition that the concept of occupational role is a useful means of integrating the effectiveness of occupational therapy at the performance component level with the much needed development of more effective interventions at the role level for

people who have had a stroke (Chapparo & Ranka, 1997b). Occupational role is a concept that was first put forward by Mary Reilly (1969) as part of her theory of occupational behaviour. The term 'occupational role' has been used by the profession since that time. The concept was borrowed from the social sciences, without significant modification.

1.1.2 Role Theory

The concept of role is part of everyday thinking within Western societies. It is used both informally and formally. Informally, the word 'role' is widely found in literature and in the media (Horin, 1995; Margo, 1995; Smith, 1995). The concept of role is used to guide behaviour at all levels of society, from the individual, through social institutions, to society as a whole. Judgements are made by others about the quality of a person's role performance, and people feel able to judge their own performance in their roles. What criteria are applied in order to make these judgements? They are not universal. Do people use the same or different criteria when judging the performance of others, than they apply to their own performance in the same role? Formally, the concept of role is used to produce documents outlining exactly what is expected in a particular role. Job descriptions are one example of this. The concept of role is used theoretically by sociologists, politicians and administrators to research, understand and explain the workings of society.

The word role has been widely used in relation to health and well-being, with the World Health Organisation referring to role in its definition of handicap (World Health Organization, 1980). Occupational therapists started using the concept in both theory development and clinical practice in the late nineteen-sixties and early seventies (Black, 1976; Matsutsuyu, 1971; Reilly, 1969).

However, the idea of role is of such generality that the term is imprecise in its meaning. It has consequently proved difficult to define (Biddle & Thomas, 1966b). The Macquarie Dictionary defines it as: *"proper or customary function"* (Delbridge, 1981, p. 1496). The Dictionary of Sociology defines roles as *"bundles of socially defined attributes and expectations associated with social positions"* (Abercrombie, Hill, & Turner, 1984, p. 209).

Roles are generally seen as belonging to single entities, whether they be people, organisations or whole societies. However, roles cannot be conceived or enacted without the

existence of role partners. Roles are seen as a way to determine the person's place or fit within the social structure that surrounds him or her. People both take and are ascribed by others particular and different positions in society in consequence of their different roles.

While there is general agreement about these broad concepts, there are differing views about how roles actually work. There are several schools of theory, principally: structuralist, sociometric and symbolic interactionist (Biddle & Thomas, 1966b; Hardy & Conway, 1988). None of these theories has been demonstrated to fully describe how role-taking and making and role interactions occur. In particular, little is understood about how people use the concept in relation to their perception of self, and when thinking and planning their behaviour. What personal and contextual elements are involved in making role-related decisions? It is not even known if every person uses the concept, or whether it is familiar only to certain members of society.

1.1.3 The Concept Of Occupational Role

Occupational therapists have had a philosophical commitment to an holistic approach to the science of occupation, from the earliest days of the profession. A review of current occupational therapy texts shows that every aspect of a person's life is considered to be of potential interest to occupational therapists in terms of formulating interventions that will facilitate a satisfactory return to desired occupations (Christiansen & Baum, 1997b; Neistadt & Crepeau, 1998; Pedretti, 1996b; Zemke & Clark, 1996). The problem that faces occupational therapy practitioners as a result, is how to organise their clinical reasoning to focus upon the essential issues relevant to the problems each of their clients is facing. Despite the fact that role is often neglected in stroke rehabilitation, occupational role and occupational role performance are concepts that for many years have been found useful in dealing with this difficulty (Bränholm & Fugl-Meyer, 1992; Hallett, Zasler, Maurer, & Cash, 1994; Heard, 1977; Kielhofner, Harlan, Bauer, & Maurer, 1986; Matsutsuyu, 1971; Oakley, Kielhofner, Barris, & Reichler, 1986; Pedretti, 1996a; Reilly, 1969).

Occupational role performance has a direct influence on lifestyle and health issues (Barris, Kielhofner, & Watts, 1988b; Bränholm & Fugl-Meyer, 1992; Elliott & Barris, 1987; Heard, 1977; Jackoway, Rogers, & Snow, 1987). Occupational therapists see the concept of role as having social, cultural and occupational aspects (Moorhead, 1969; Vause-Earland, 1991). Occupational roles have been viewed as patterns of self maintenance, work, leisure

and rest occupations that are done on a daily basis (Chapparo & Ranka, 1997b, p. 6).

Occupational role performance refers to the manner in which these occupations are carried out.

Controversy about the use of this concept has arisen in both occupational therapy and other disciplines (Jackson, 1998a; 1998b). Nevertheless, there is an ongoing interest amongst occupational therapists in the concept of role as a mechanism for gaining access to the meaning behind the everyday occupations of their clients. Role information can give a sense of how each client *fits* with those around him or her and what is important and meaningful to each person. Information about the occupational aspects of role allows the therapist insight into what elements of occupational performance in everyday life are essential and what elements are valued in a client's return to or further development of desired or needed occupations. Discovering ways of identifying the meaning clients attach to their everyday life, and what motivates the manner of their interaction with their social, cultural, sensory and physical environment is increasingly considered to be central to the further development of theory and practice in occupational therapy (Helfrich, Kielhofner, & Mattingly, 1994; Mallinson, Kielhofner, & Mattingly, 1996; Matsutsuyu, 1969; Sharrott, 1983; West, 1984).

Despite the continued interest in the concept of occupational role, not all occupational therapy models utilise the construct of occupational role. Examples of models that do include this construct are: the Model of Human Occupation (Kielhofner, 1995); the Model of Person-Environment Occupational Performance (Christiansen & Baum, 1997c); and the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b). All are practice models, indicating the recognised need for the concept of role in occupational therapy practice.

The Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b) will now be discussed in more detail. Its primary focus is *"the lifelong person-environment relationship and its activation through occupation"* (Chapparo & Ranka, 1997b, p. 3). The model utilises the concept of occupational performance role as a central organising construct. When applying the model, occupational performance roles are the beginning and end point of clinical reasoning. The construct allows the therapist access to a perception of 'fit' for his or her clients. That is, investigation of the construct of occupational performance role provides information about where the person sees him or herself fitting within his or her own social, cultural and physical environment. It can provide information about where significant others

see that person fitting from their own perspective. Insufficient emphasis upon the concept of environmental fit at the role level can lead to therapeutic activity that lacks direction and may provide outcomes that are unsatisfactory to occupational therapy clients and/or those around them, in ways that were described earlier (p. 2-3). This idea of environmental fit provides the focus that is lacking if the holistic view of occupation is not closely defined. The nature of occupational performance roles has not, as yet, been a focal point of research, despite the increasing use of the construct in occupational therapy practice (Baker, 1997; Hillman & Chapparo, 1995a; Hummell, Barnett, & Doyle, 1997; Innes, 1997; Weigl, 1997; Wilkinson & Chapparo, 1997). Although role is a useful construct within the model, the concept of role meaning has not been fully explicated, nor has the way in which people use the construct been described.

Little is known about the occupational performance roles of older people, or about their own perceptions of their roles, or the way elderly people who have had a stroke organise their daily occupations when they finish rehabilitation. Although role assessment instruments have been developed for adults and for the elderly (Jackoway et al., 1987; Kielhofner & Henry, 1988a; 1988b; Oakley, 1981), they have limitations in the scope and type of information they provide. Roles are often pre-defined, with an assumption that there is general agreement about the nature of the role and how it should be performed. This assumption denies the interactive and dynamic nature of roles, and the degree of choice available to individual role performers, as described by most role theorists (Baldwin, 1986; Banton, 1965; Biddle & Thomas, 1966b; Burns, 1991; Hardy & Conway, 1988; Landis, 1995). It is this uni-dimensional view that leads to dissatisfaction with the construct. For example, a great deal of the research done on occupational role in the elderly has used The Role Checklist as its instrument (Dickerson & Oakley, 1995; Hallett et al., 1994; Larsson & Bränholm, 1996). This checklist consists of ten named roles and a space for 'other'. It is a pen and paper exercise, with very little scope for research participants to name and frame their own roles. They are asked to fit into a pre-determined series of 'boxes'. This approach does not fit with the philosophical view of the profession that occupational therapists are holistic, working with individual clients in their own environment as far as possible, without imposing their own assumptions or values, or trying to make the client fit some pre-determined 'norm' (Chapparo & Ranka, 1997b; Christiansen & Baum, 1997c; Jackson, 1998a; Law, Baptiste, & Mills, 1995).

It is clear that not enough is known about occupational roles and occupational role performance - particularly from the perspective of the performer. Similarly, little is known about the self-perceived roles and role performance of people who are elderly and have a disability. This study is intended to develop a greater understanding of role performance in later life for people experiencing disability. It is designed to gather descriptive information about the everyday role performance of men who are living with residual disability following a stroke. It is hoped that this descriptive information will lead to the development of some hypotheses about the role performance of this group of men which may in turn inform further research into occupational performance roles in later life.

1.2 PURPOSE OF THE STUDY

The overall purpose of this study is:

- 1) To describe the self perceived occupational performance roles of men over 65 who have had a stroke, in order to gain insight into the meaning, motivation for, and organisation of their occupational roles.**
- 2) To explore the possibility that role is a concept that is understood and utilised by these men in the planning and performance of meaningful occupations.**

The particular focus of stroke has been chosen because:

- i) it represents one of the largest areas of practice in occupational therapy and
- ii) it represents a social group of increasing importance with the current aging of developed populations and
- iii) it represents a disability group of increasing importance with the increasing rate of morbidity following stroke and,
- iv) intervention for older adults with disabilities resulting from stroke is an area that is familiar to the researcher

Central to the overall purpose are the following research objectives:

To describe the nature of occupational role performance as perceived by the thirteen participants by studying such dimensions as:

- Whether the participants can discuss their occupations in role terms.
- The nature of occupational role performance among the participants.
- Whether they are able to ascribe meanings to their roles that are either primarily occupational or primarily socio-cultural.
- Participant perceptions of their own role performance.
- Themes that might be identified from participant responses regarding their self-perceived occupational role performance.

To describe the use of role as a concept by the participants in planning and performing meaningful occupations by considering:

- Whether it is possible to construct a conceptual model of self-perceived occupational role performance that could inform knowledge and understanding of occupation, and further develop occupational performance role constructs within current theoretical models of human occupation such as the Occupational Performance Model (Australia).

1.3 DESIGN AND OVERVIEW OF THE STUDY

Investigation of the nature of self-perceived occupational role performance is primarily a descriptive task, requiring:

- 1) the identification and analysis of relevant variables from the literature; and
- 2) an appropriately chosen group of elderly men who have had a stroke.

A qualitative form of enquiry was selected to achieve this.

Research methods employed tape-recorded semi-structured interviewing of selected participants in their own homes with coincidental field observations. Constructs from the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b) were used to develop areas of inquiry in the semi-structured interview. Role performance has been described as a product of people and their environment (Chapparo & Ranka, 1997a; Larsson

& Bränholm, 1996). The model chosen offers one view of the person - environment relationship in terms of role. Occupational performance roles are seen as the central organising construct of the model. This model applies the construct of role to everyday performance in a way that allows for the consideration not only of specific role performance, but also the antecedent and subsequent physical, mental and emotional processes relevant to that performance (Chapparo & Ranka, 1997a). Such a view compelled a style of inquiry that yielded descriptions of behaviour that might be observable to others, and thinking and feeling aspects of role performance.

The first part of the study involved inductive qualitative analysis, whereby elements of the self-perceived nature of occupational role performance were described based on the analysis of data from those who participated in the study as well as the literature about role and occupational role performance. Analysis of earlier interviews informed later interviews, suggesting additional questions to ask and areas to explore. The subsequent task of identifying elements that form the structure of a preliminary model of occupational role performance required further analysis of the descriptive data.

The following table (Table 1.0) describes the phases of the research process, its outcomes and how these will be reported. It provides an outline for the organisation of this thesis.

PHASE ONE (Reported in Chapter 2)
A literature review of research on stroke outcome, the effectiveness of occupational therapy interventions for stroke, and the concept of role in the social sciences and in occupational therapy in particular. Outcome: 1) Identification of variables that have the potential to impact upon the perceived occupational role performance of elderly men who have had a stroke. 2) A description of role and occupational role content and process that have been previously identified through research.
PHASE TWO (Reported in Chapters 3 and 4)
A naturalistic study that explored the content of self perceived occupational performance roles in a group of elderly men who were experiencing ongoing disability as a result of stroke. Outcome: A snapshot description of the nature and content of occupational roles and role performance as identified and described by a group of elderly men with ongoing disability following stroke.
PHASE THREE (Reported in Chapter 4)
Further analysis of data from the phase two study, with the purpose of developing a preliminary conceptual model of occupational role performance for this group of men. Outcome: 1) Description of constructs and their possible relationships. 2) The formulation of a preliminary conceptual model of occupational role performance for this group of men.
PHASE FOUR (Reported in Chapters 5 and 6)
Discussion of the descriptive data and preliminary model of occupational role performance in relation to the existing literature; implications for clinical practice and recommendations for further research.

Table 1.0 Phases of research in the study and organisation of the thesis

CHAPTER TWO

REVIEW OF THE LITERATURE

2.0 INTRODUCTION

As outlined in Chapter One, the purpose of this study was to describe the self perceived occupational performance roles of men over 65 who have had a stroke and are living at home. The study aimed at gaining an insight into how they organise and carry out the meaningful performance of their roles and whether they use the idea of role in the planning of their everyday lives.

Occupational performance roles have been variously defined. They have been described as those roles that together form the bulk of daily function and routines (Kielhofner, 1995; Kielhofner & Burke, 1985; Llorens, 1991). They have been linked to social role and role theory, although there is a lack of clarity in occupational therapy literature about the nature of occupational performance roles and how they relate to social roles or social role theory. The most common view is that roles have social, cultural and occupational aspects (Barris, Oakley, & Kielhofner, 1988c; Christiansen & Baum, 1997c; Jackoway et al., 1987; Moorhead, 1969; Vause-Earland, 1991). Occupational performance roles have been defined as a specific subset of the broader construct of role and involve patterns of self maintenance, work, leisure and rest activities that are done on a daily basis (Chapparo & Ranka, 1997a; Llorens, 1989; Llorens, 1991). The term occupational role performance has been used to describe the way these activities are organised and carried out (Chapparo & Ranka, 1997a; Christiansen & Baum, 1997c; Kielhofner, 1995). It is proposed that occupational role performance has a direct relationship to lifestyle and health issues (Barris et al., 1988b; Christiansen & Baum, 1997c; Elliott & Barris, 1987). Within occupational therapy literature, there is an increasing emphasis upon the need to preserve, maintain and develop valued roles (Barris et al., 1988b; Bränholm & Fugl-Meyer, 1992; Chapparo & Ranka, 1997b; Christiansen, 1991; Christiansen & Baum, 1997c; Hallett et al., 1994; Heard, 1977; Henry & Coster, 1997; Jackoway et al., 1987; Kielhofner, 1995; Matsutsuyu, 1971; Moorhead, 1969; Oakley et al., 1986; Vause-Earland, 1991; Versluys, 1980; Weigl, 1997). Despite this, occupational roles remain ill-defined, with relatively little information about the nature of occupational role performance, or the ways in which occupational aspects of roles

are conceptualised by those who hold them. Occupational therapists see the loss of life roles that occurs following stroke as a major problem (Forsberg-Wärleby & Möller, 1996; Greveson, Gray, French, & James, 1991; Jongbloed, Stanton, & Fousek, 1993; Morgan & Jongbloed, 1990; Pedretti et al., 1996). However, little is known about the occupational roles of the elderly, and almost nothing is known about the way elderly people who have had a stroke organise their daily activities following discharge from rehabilitation programs.

This chapter begins by giving an account of the development of occupational therapy and the influence the medical profession has exerted, in order to give further insight into why occupational therapists continue to be interested in role and occupational role performance. This is followed by an overview of aspects of role theory that are relevant to occupational performance. Use of the concept of role in occupational therapy theory and practice is examined, with a discussion of some concepts that relate to occupational role performance from the perspective of the performer. Theories relevant to occupational role performance in later life are explored. Finally, background information is given about stroke, disability and occupational therapy stroke rehabilitation, followed by a discussion of some of the difficulties related to occupational therapy stroke rehabilitation outcomes as they relate to occupational role performance.

2.1 MEDICINE, OCCUPATION AND ROLE

The ancient Chinese, Greek, Roman, Egyptian and Persian civilisations all recognised occupation as an important factor in the recovery of acceptable levels of health (Hopkins, 1988). The discipline of occupational therapy came into existence in the early years of this century, and the concept of occupation has always been a central tenet. *Occupation* has been defined as: "*chunks of culturally and personally meaningful activity in which humans engage that can be named in the lexicon of the culture*" (Clark et al., 1991, p. 301).

The paradigm of occupational therapy grew out of the 19th century school of thought called "*moral treatment*".

... the history of moral treatment in America is not only synonymous with, but is the history of occupational therapy before it acquired its 20th century name of 'occupational therapy'. This assertion is based on the conception that occupational therapy is based first and foremost upon respect for human individuality and on a

*fundamental perception of the individual's need to engage in creative activity **in relation to his fellow man** [emphasis added]. (Bockoven, 1971, p. 223)*

Originally, the intention of this movement was the promotion and maintenance of health for those without access to the 'normal' human occupations, often because they were incarcerated in an institutional setting (Wilcock, 1990). The American psychiatrist Adolph Meyer, working at the end of the nineteenth century and into the twentieth, took these ideas and expressed them in terms which are credited with providing a strong contribution to the philosophy upon which the profession is based (Hopkins, 1988; Shannon, 1977; Wilcock, 1990). He stated:

Our conception of man is that of an organism that maintains and balances itself in the world of reality and actuality by being in active life and active use... in harmony with its own nature and the nature about it. It is the use that we make of ourselves that gives the ultimate stamp to our every organ. This philosophy ... appeals to me because it expresses ... the simple and yet most valuable experiences of real life.
(Meyer, 1977, p.56)

These statements reflect two themes - *purposeful activity*, and *personal meaning*. From the beginnings of the profession, occupational therapists have been interested in purposeful activity as the means whereby people with functional difficulties can take an active part in creating an everyday life or environment which is culturally 'normal' to them and relates to their own style of environmental interaction. In order to achieve this, the environment should enable people to 'make use' of themselves in ways that have personal meaning. Meaning was related to activity involving interaction with other people. These themes represent early manifestations of the concept of occupational role.

The development of occupational therapy has always been closely allied to that of medicine. In the early days, the association was viewed as beneficial (Reilly, 1962). However, the rise of reductionism as a scientific approach changed the relationship between the two professions (Kielhofner & Burke, 1977; Shannon, 1977). Reductionism became successful for the medical profession, facilitating research that led to the great age of 'cure', when enormous progress was made in eliminating disease (Jaffe, 1986). Medicine placed great faith in research that reduced phenomena to their measurable parts, finding this a suitable method for overcoming biological problems. Reductionism has only been partially

successful for contemporary occupational therapy (Jaffe, 1986; Kielhofner & Burke, 1977; Reilly, 1969; Shannon, 1977). Rather than biological deficits, occupational therapists most often see people who are experiencing functional deficits that affect their daily life (Christiansen & Baum, 1997b; Neistadt & Crepeau, 1998; Pedretti, 1996b; Trombly, 1995). In this context, there is a greater need for the synthesis of daily occupations into a meaningful whole than is present where "cure" is possible. The concept of occupational performance role can facilitate insight into the effect of disability upon meaningful environmental interactions at the highest level, and perhaps provide an understanding of how people use role to achieve meaningful occupation.

Through a reductionistic focus, occupational therapy has developed an expansion of technologies to deal with specific impairments and disabilities. However, occupational therapists found themselves pressured strongly by the medical profession, with whom they still work closely, to abandon the more holistic aspects of their thinking (Kielhofner & Burke, 1977; Reilly, 1969; Shannon, 1977). As medicine moved away from a view of the person in their environment, it took occupational therapy with it (Shannon, 1977), and the profession gave up the earlier view of role that had been developing.

Shannon (1977) described a philosophical shift in social thinking at this time from a view of society governed by ethical concern for a *good society*, and a *quality of life*, to one where society is driven by a need for self preservation. He described occupational therapy's response to these changes:

Occupational therapy abandoned its more substantive concern for health in adopting the rationality of the medical model with its focus on pathology. Its systematic approach to wholesome, healthy living as seen in the processing of competency behaviours was replaced with the narrow perspective of the medical model based on the homeostatic principle of symptom reduction. Its epistemological base shifted from the social sciences to the functional requirements of the physical sciences and a focus on the minute and measurable. This attachment to the medical model, an attachment that was less than visionary, signalled the beginning of the derailment process (for the profession). (p. 231)

Shannon maintained that the medical model was committed to self-preservation and to the prolongation of life, while ignoring the conditions that make life worth living. Adherence to

the medical model meant a move away from the more holistic approach that had been espoused in earlier years, and entailed a reduction in the motivation of the profession to concern itself with what was meaningful to individual clients, focussing instead upon developing techniques for symptom reduction. There was little consideration of role-related issues.

More recently, there has been a growing disillusionment on the part of the general public with medicine's ability to cure all ills. The AIDS epidemic, for example, demonstrated that medicine could not always produce the desired result (Jaffe, 1986). At the same time, the concept of institutional care changed dramatically. The advent of economic rationalism placed unprecedented pressure upon health services, leading to an ever increasing pressure on bed occupancy (Griffin, 1993). With swifter medical remediation and the well established principle that people recuperate faster at home, there has been a dramatic shortening of the average time from admission to discharge (Griffin, 1993). A large percentage of occupational therapists are still employed in acute and rehabilitation hospital settings - almost 40% of Australian Association of Occupational Therapy members (Australian Association of Occupational Therapists, 1995). These changes have placed enormous pressure on these therapists to consider self care aspects as paramount, to ensure that their clients will be able to cope safely at home on discharge (Griffin, 1993; Hanschu & McFadden, 1981).

This pressure has been yielded to, to the point where acute care and even rehabilitation therapists may feel justified in addressing only the self care aspect of their clients' lives. A study of occupational therapists' work patterns in acute hospital settings in New South Wales showed that they tended to follow an assess/discharge plan cycle, mainly working as a coordinator of services. The focus was found to be upon self maintenance, and therapists heavily relied upon being able to refer clients on to community or rehabilitation services (Griffin, 1993). Almost thirty years ago, Reilly (1971) commented with some acerbity: *"Occupational therapists could stand accused by history of reducing the richness of their humanistic mandates to an ADL self-care list"* (p. 224). Her comments are still relevant. Many occupational therapists find hospital work frustrating for this reason. Conversely, there is now greater pressure placed upon occupational therapy services based in the community to provide ongoing support and rehabilitation for those people discharged before they have had the opportunity of benefiting from such in-patient services (Griffin, 1993). It is possible that use of the construct of occupational role in assessing and planning intervention in acute care and rehabilitation might redress this situation, enabling therapists to work in a more focused

and effective manner, by giving them a more efficient means of gaining access to what is most important and significant for each of their clients, enabling them to ensure that the most important outcomes are brought about in the least amount of time.

The introduction of Diagnostic Related Groups (DRGs), Casemix and other measures of accountability in the USA and Australia has meant that, as a profession, occupational therapy has to be able to clearly define and categorise every service provided in order for therapists to receive funding (Neistadt & Crepeau, 1998). Therapists are encouraged by the system within which they work to value measurable, standardised techniques. Because of the profession's clinical focus, the assessment tools currently in use are particularly designed to measure the demonstration and performance of specific abilities, skills and tasks (Neistadt & Crepeau, 1998; Trombly, 1995; Turner, Foster, & Johnson, 1992). The results of these tests are used to demonstrate the effectiveness of therapy to third parties such as hospital administrators, who see simple discharge as a satisfactory outcome, and do not consider the successful re-integration of the whole person back to his or her life roles in the appropriate environmental context as a priority (Feinglass & Salmon, 1990).

There have been strong movements, however, to develop beyond this skills-based approach within the profession. A great deal of work has been done in developing and researching the philosophical underpinning of the profession, and in educating others through changes in undergraduate and postgraduate courses. There has been a re-emphasis on such basic precepts as achieving a balance between self care, productivity and leisure, acknowledging the importance of the client's life roles and effective interaction with the environment, and a reaffirmation of the central concept of achieving health through occupation (Chapparo & Ranka, 1997d; Neistadt & Crepeau, 1998; Wilcock, 1998; Zemke & Clark, 1996). There is a resolve to develop a mature and disciplined base for the profession. Part of this resolve has included a renewed commitment to research in order to substantiate or disprove the key concepts that make up occupational therapy's philosophical base (Dunn, 1985; Ottenbacher, 1987; West, 1989; Yerxa, 1987). The profession's efforts to develop theoretical ideas that are carefully developed and researched have led to a number of themes, models and movements that have emerged in recent years (Chapparo & Ranka, 1997b; Christiansen & Baum, 1997c; Kielhofner & Burke, 1985; Law et al., 1996; Reilly, 1969; Zemke & Clark, 1996).

With these changes in the profession, the need to see people as individuals has been more widely recognised (Christiansen & Baum, 1997b; Law et al., 1994). Working in this way means focussing on each client as an unique person. Assessments using this approach are tailored to enable the definition of what each client sees as his or her greatest difficulties, needs and strengths so that interventions can be truly appropriate. Therapists use this approach in order to attempt a marriage between the reductionist approach and the need to be able to see clients as people, living within their own particular physical, sensory, social and cultural environment.

The profession's renewed commitment to this holistic view has been accompanied by a research trend towards a focus upon meaningful occupation (Zemke & Clark, 1996). Narrative research methodology has been used to gain greater insight into how people find meaning in their lives (Frank, 1996; Helfrich & Kielhofner, 1994; Larson & Fanchiang, 1996; Mattingly & Beer, 1993). Less research has been done on how people conceptualise and organise that meaning (Cheng & Rogers, 1989). The construct of role as a conceptual tool used to organise meaningful occupation has not been well researched within the profession (Hillman & Chapparo, 1995a). Nevertheless, as discussed earlier, the restoration of clients to satisfactory occupational role performance is being increasingly considered an important part of clinical practice (Chapparo & Ranka, 1997b; Christiansen & Baum, 1997c; Kielhofner, 1995). The next section will outline aspects of role theory that are particularly relevant to occupational performance.

2.2 ROLE THEORY

The following discussion of role theory will draw extensively upon the work of Biddle & Thomas, 1966b and Biddle, 1979. These authors are frequently cited by other researchers working in this area, and they provide a helpful overview of the history and development of role theory (particularly structural role theory).

As discussed in Chapter One, the word 'role' is widely used in professional and popular literature and in the media. It appears that people have an opinion about their own role performance and the role performance of others. The word is found in relation to health and well-being, with the World Health Organisation using the term role as part of its definition

of handicap (World Health Organization, 1980). Biddle has commented on its importance for anyone interested in human behaviour:

Role theory is but a young science at present - rich in promise and insight, but yet short in integration and basic research. We ignore its problems at our peril. But role theory offers us the potential for studying human beings as sentient, rational beings - and for gaining control of our precarious social existence. (Biddle, 1979, p. 19)

A review of the literature reveals that there are many concepts and theories linked to the idea of role. It is important to note that within this broad spectrum there is a sectioning of ideas based upon role's application within sociology, social psychology and anthropology. There are conflicts between the different views of role, and in occupational therapy it is purported by some that role theory is not a helpful basis for research (Jackson, 1998a; 1998b). The idea of role is viewed by others as enabling clear thinking about a number of issues related to how people organise their lives; how they see themselves, and how others see them (Hillman & Chapparo, 1995a). This section contains a discussion of the history and development of role theory and describes a number of the major constructs relevant to this study.

2.2.1 The Concept Of Role

Biddle (1979) defines role theory as: "... a science concerned with the study of behaviours that are characteristic of persons within contexts and with various processes that presumably produce, explain, or are affected by those behaviours" (p. 4). The term role was first used by early writers in the area of role theory in the 1920s, although it did not become common usage until the 1930s (Biddle & Thomas, 1966a). The term is derived from using a theatrical analogy whereby a role is played by an actor. Using this analogy, there is a difference between actors in the way that they interpret their part. However, each actor is strongly influenced in his or her performance by external factors such as the script and the shape of the stage and there are therefore similarities to be found between the performance of different actors playing the same part. When this analogy is taken into real life, according to this view, people are seen as occupying positions in society. These positions are defined by social norms, demands and rules which can be summed up as *expectations*. They are determined by the performances of others occupying complementary societal positions, by yet still others who observe and react to the performance and lastly by the person's particular capabilities and personality. Role associates the person with sets of people who share a

common *identity*. A position is something that is acknowledged by others, often the person's role *partners*. Role partners are those who have related positions and who interact with the person in the performance of a given role. The term implies an internal (as seen by the person) and an external (as seen by the person's role partners and other onlookers) aspect to role performance. Some roles confer well-defined social positions recognised by everyone, such as paid worker roles, gender roles and family roles. Other roles are not so well defined and therefore do not carry such a clear definition of social position and thence identity (Biddle, 1979). People do not hold just one position, and may be referred to as holding a *position set* (Biddle, 1979). For example, they may have positions as a retired person, a family member, and a hobbyist.

However, as Biddle and Thomas (1966a) acknowledge, just as actors invest personal meaning into their part in order to play it convincingly, there are differences between people as to the motivation of role performance. This leads to the concept of individual differences in the way that specific roles are enacted, even though the rules for a given role may be the same; and to the proposition that there is an inner perspective to role as well as the observable external behaviour.

2.2.2 History And Development Of Role Theory

The concept of role has been developed by a number of different thinkers and researchers chiefly from the anthropological, social, and psychological sciences, to explain how society is organised in terms of the people within it, and how people interact and function within a social system in terms of their social position or fit. Two major strands of role theory are discussed - structural role theory and symbolic interactionism. Sociometric role theory is discussed briefly.

2.2.2.1 Structural Role Theory

Initial theories about society in the 1800s proposed that it be considered as a system with interrelated parts. After the French Revolution, attempts were made to understand the workings of society as a whole. These attempts often used biologic systems as an analogy. Comte (1798 -1857) studied society as a entity (as cited in Biddle & Thomas, 1966a). He believed that empirical knowledge had to be obtained in order to understand and create a better society. He identified similarities between biologic organisms and society, including

the idea that social systems have needs and functions which contribute to their survival. He is considered the father of positivism - a philosophical system that deals only in positive facts and observable phenomena (Hardy & Conway, 1988). Durkheim followed Comte in making biological comparisons. He saw society functioning at different levels, each with its own set of needs. He introduced the idea of *normalcy* and *pathology* within society. Anthropologists took Durkheim's ideas and applied them to the supposedly simple societies they were studying (Hardy & Conway, 1988). Linton, for example, contributed to structural anthropology by proposing that societies are composed of patterned relationships which are centred on the reciprocity of *rights* and *obligations*. He saw the polar relationships which engage in these reciprocal interactions as a *status*, and the dynamic aspect of status as role. He defined role in the following way:

A status, as distinct from the individual who may occupy it, is simply a collection of rights and duties. When [an individual] puts the rights and duties into effect, he is performing a role. Status and role serve to reduce the ideal patterns for social life to individual terms. They become models for organising the attitudes and behaviour of the individual so that these will be congruous with those of the other individuals participating in the expression of the pattern. (as cited in Banton, 1965, p. 25-26).

Linton originated the idea of the role repertoire when he said that a person has:

... a series of roles in which he participates and at the same time a role general, which represents the sum total of these roles and determines what he does for his society and what he can expect from it. (as cited in Biddle & Thomas, 1966a, p. 7).

Linton (as cited in Banton, 1965) saw status and role as inseparable concepts. Banton (1965) reports that Linton later changed his emphasis to view role as an *ideal pattern of conduct* which actual behaviour rarely fulfils. He saw a distinction between the concept of role that may be in a person's mind and the actual role behaviour that might be performed by that person. Newcombe (as cited in Banton, 1965), saw every member of society as occupying a *position*, using this word rather than *status*. Each position had a function in the life of the group and consisted of rules concerning behaviour towards others. Importantly, he observed that agreement about the content of a role can vary.

Linton (as cited in Banton, 1965) proposed the idea that some roles were *ascribed* and some were *achieved*. Ascribed roles were such roles as gender, age and kinship roles.

Ascribed roles were not chosen. They resulted from events beyond the control of the individual. Achieved roles were such things as paid occupation and marriage roles. Achieved roles involved *choice*.

Parsons (as cited in Hardy & Conway, 1988), a subsequent theoretician of the structuralist school, espoused a particular view which became known as functionalism. He was greatly influenced by Comte's view that societies have needs and functions which contribute to their survival. Parsons was a sociologist whose thinking dominated American sociology for many years (Fennell, Phillipson, & Evers, 1988; Hardy & Conway, 1988). He saw integration or social cooperation as a central *need* of society and existing social arrangements as a reflection of how society could best meet its needs. The maintenance of social order through reciprocal role relationships was central to his thinking. His work had a strong ideological component which eventually led to its rejection in the 1960s when it became evident that he did not advocate deliberate social change, seeing the inequalities that existed as necessary to social order and societal well-being (Fennell, Phillipson, & Evers, 1988; Hardy & Conway, 1988). Despite this rejection, his ideas of using role as a means of maintaining the status quo still persist in an implied way in some writing about role theory (Christiansen & Baum, 1997c; Kielhofner, 1995), and are used to criticise role theory by others (Connell, 1987; Jackson, 1998a; 1998b).

S.F. Nadel (1957) stated "*The role concept is not an invention of anthropologists or sociologists but is employed by the very people they study... it is the existence of names describing classes of people which makes us think of roles*" (as cited in Banton, 1965). He was interested in the *verbal labels* people used and saw that roles can be imposed upon all members of society.

Banton (1965) saw the concept of role as an intellectual tool. He developed Linton's idea of rights and obligations, describing role as an organiser, and an elicitor of cooperation. He described structural role theory as the legal view of social relations. A right is a socially sanctioned claim upon society, and clusters of rights and obligations constitute roles. Every social relationship consisted of a pair of roles (role reciprocity). Some roles were clearly defined by society - for instance, being a king, or a priest. These were deemed *formal* roles. Role allocation was done according to set criteria - heredity for kings, training and a testing of religious beliefs for priests. With these roles, others are able to observe role performance and identify when the 'player' is in the role and when he or she are not. In other more *informal*

roles people are freer to choose what they consider to be appropriate behaviour for that role. Role allocation may be on ability or other criteria appropriate to the role and observers are not so able to identify when the role is being performed. People may or may not choose to take up roles for which they are qualified. Banton (1965) saw status related to role as differing in different communities. In a small community everyone was more likely to be familiar with the actual performance of others in their various roles and ascribe status or importance on that basis, whereas in larger communities actual role performance was less likely to be known and status was ascribed on the basis of the role itself rather than the performance.

2.2.2.2 Symbolic Interactionism

The body of knowledge that has become known as symbolic interactionism originated with the social psychologist and philosopher George Herbert Mead (Baldwin, 1986; Biddle & Thomas, 1966b; Hardy & Conway, 1988). His approach to research was naturalistic in nature, although his experimental experience gave great rigour and thoroughness to his work and to his theories (Joas, 1985; Kang, 1976). Unfortunately, Mead's own writing was lost for many years, as he published only in German journals (his country of origin), despite working in America (Baldwin, 1986; Hardy & Conway, 1988). The publication originally used to disseminate the theory of symbolic interactionism and upon which subsequent research was based is "Mind, Self and Society", published in 1934. This book is not actually by Mead, although attributed to him. It is a collection of his students' lecture notes for a particular course in social psychology that he taught over a number of years. These notes were edited by C.W. Morris to produce this book. Although now rediscovered, Mead's own writing is reported as difficult to master both in the original and in translation (Baldwin, 1986; Hardy & Conway, 1988; Joas, 1985). For this reason, the following discussion of Mead's work will be based upon secondary sources.

Mead became committed to the scientific method as the highest form of thinking when studying with Wundt. Wundt's simultaneous studies of neurological and psychological phenomena led Mead to reject the philosophy of dualism - a separation of mind and body. He believed that the study of complex human systems should be done in the context of their entirety, not by studying parts in isolation (Hardy & Conway, 1988). This is the basic assumption of holism - a concept that was to be attacked by many philosophers and scientists in the sixties and seventies (Hollis, 1986). Holism is part of occupational therapy's philosophical base, as discussed earlier.

Mead (as cited in Hardy & Conway, 1988) stated that humans used their minds to manipulate their environment. In a mutually reciprocal relationship, Mead saw the mind and the self as developing through social forces. He understood the social act to be an objective, observable entity composed of social, psychological, and biological elements which could be identified and analysed. This analysis was always conducted in the context of the complete social act. Mead proposed that attainment of immediate goals was too simplistic a way of viewing role performance. He theorised that the performance of social roles that are coordinated with the roles of others allows the development of moral excellence, self-realisation, and self-actualisation (Baldwin, 1986). He saw social interaction as a process whereby people achieved a consensus on the nature of a situation and then cooperated to achieve a goal or outcome. Only as agreement developed was it possible to coordinate activities to obtain a shared goal. He saw what he termed *reality* in socially coordinated behaviour as the outcome of a process of mutual interpretation and adjustment. Communication was central to this process (Hardy & Conway, 1988).

Symbolic interactionists are concerned with explaining social actions in terms of the meanings that people give to them (Haralambos, van Krieken, Smith, & Holborn, 1996). Mead (as cited in Haralambos et al., 1996) saw human beings as interacting in terms of symbols, chiefly language. Symbols are not just representational, they impose meaning on people, events and things, excluding other possible meanings. Symbols are created by people and provide the means whereby they can interact in a meaningful way with their natural and social environment (Haralambos et al., 1996). In order for people to interact, there needs to be an understanding of the meaning and intention of others. Symbols assist with this. Furthermore, for effective interaction, people must do what Mead termed *role-taking*. Role-taking as defined by Heiss (1981), involves "*the ability to take the role of the other - that is, the ability to put oneself in the place of another and to see things as he or she sees them*" (p. 25). The person anticipates the response of the other to his or her behaviour. Development of the self, the experience of self-awareness, and role-taking all occur and develop in social interaction (Heiss, 1981). Mead saw this purposeful activity with persons cooperating to achieve goals as *social action*. The basic unit of *social action* is the *social act*. As people adjust their action to the actual situation to establish a shared perspective, reality and meaning emerge. Changes in thinking, emotion and various biological states occur. Through this process socially coordinated, goal-directed activity results (Hardy & Conway, 1988).

Mead (as cited in Hardy & Conway, 1988) proposed that a reciprocal relationship existed between *mind* and *society*. He studied *subjective experiences* (without the use of introspection as a means of data collection). He postulated that inner experience is determined during and as a result of involvement in social processes. He felt that to have knowledge of a person's external social experiences is to have partial knowledge of his or her internal experiences. Uncertainty and unpredictable conditions produce reflexive thought, in which past experiences are drawn on and general knowledge of the past and future is used to determine how best to proceed. Mead saw that this provided valued opportunities for successful change and progress (Joas, 1985).

Central to Mead's theories (as cited in Heiss, 1981) was the idea that socialisation for roles or role learning is a continuous and cumulative process that relates to and corresponds with the passing of developmental stages throughout the life span. Socialisation for roles begins in infancy and early childhood, first with the acquisition of language and then the development of role-taking ability, followed by the development of self, interpersonal competence, motivation and moral values. New roles continue to be assumed throughout life (Heiss, 1981).

2.2.2.3 Sociometric role theory

Joseph Moreno was a clinician who developed his theoretical ideas about role as a result of clinical experiences. He pioneered the use of role-play in psycho-drama and socio-drama and was the inspiration for a number of specialisations now known as sociometry (Biddle & Thomas, 1966b). Moreno was interested in Mead's work, and as a clinician, he was interested in changing the behaviour of his clients. He conceived role as a dynamic thing. *"Role-playing may be considered as an experimental procedure, a method of learning to perform roles more adequately"* (as cited in Biddle & Thomas, 1966a). He used this idea in conjunction with Mead's concept of role-taking. *"In contrast with role-playing, role-taking is an attitude already frozen in the behaviour of the person. Role-playing is an act, a spontaneous playing; role-taking is a finished product, a role conserve"* (as cited in Biddle & Thomas, 1966a). Moreno envisaged the genesis of roles as going through two states - role-perception and role enactment (Biddle & Thomas, 1966b). Moreno hypothesised that role-playing was prior to the emergence of self. *"Roles do not emerge from the self, but the self emerges from roles"* (Moreno, 1977, p. II).

2.2.2.4 Basic Concepts of Role Behaviour

A thorough attempt to classify role concepts related to behaviour was presented by Thomas and Biddle (1966). It is important to note that while Thomas and Biddle acknowledged the importance of symbolic interaction and sociometry, their focus was mainly structural. They found that the basic concepts for behaviour used by most role analysts could be classified as *action*, *prescription*, *evaluation*, *description*, and *sanction*. For each of these they said behaviour could be described as either *overt* or *covert*. This classification relates to description rather than function.

Action

Action is behaviour that has been learned previously, is goal directed, and apparently voluntary. Action behaviour may be *overt* as seen in role *performance*, or *covert* as a *motive* to achieve, or an intention (Thomas & Biddle, 1966).

Prescription

Social behaviour is affected by prescriptions. These are stated in terms such as *demands*, *expectations*, *standards*, *norms* and *rules*. Many social situations are dominated by *overt demand*, such as the demands parents place on their children for particular behaviour. For adults, many of the more important prescriptions that govern behaviour are *covert*. They are learned and, when internalised, they govern behaviour without further need for the pressure of external demands. Examples of such prescriptions are customs and etiquette, the requirements of religious beliefs, and the laws of society. These may be seen as *norms* (Thomas & Biddle, 1966).

Evaluation

Behaviour is deemed to be evaluative when it relates primarily to approval or disapproval. The terms *preference*, *value*, *affect* and *esteem* are commonly used in relation to evaluative behaviour, as well as *reward*, *punishment* and *sanction*. Thomas and Biddle (1966) assign to *covert* behaviour involving evaluation the term *value*, and for *overt* behaviour that is evaluative, *assessment*. Evaluations are pervasive. The friend who frowns, the audience member who claps or boos, the teacher who grades a student's work are all expressing overt *assessments* of the performance of others. Overt and covert evaluations are often influential in governing behaviour (Thomas & Biddle, 1966).

Description

Behaviour without evaluative or affective accompaniments is designated as descriptive. Descriptions are ubiquitous in human activity. *Overt statements* about the nature of a given situation are regularly sought and given when someone enters a new situation. *Covert conceptions* are cognitive pictures of the person's environment including the anticipated reactions of others. Role theorists often attach a time dimension to description using such terms as *role perceptions* or *memories* to refer to the past; *role conceptions* or *cognitions* and *subjective role* are not bounded by time; and *anticipations* or *expectancies* are terms used to refer to conceptions of future events (Thomas & Biddle, 1966).

Sanction

Behaviour is considered a sanction when it is engaged in with the intention of achieving change in some other behaviour. The direction of the desired change is generally toward increased conformity with prevailing prescriptions, although this is not always the case. Terms such as *punishment*, *reward*, *incentive* and *motivation* may be used in this context. Sanctions may be *covert* or *overt*. They may be seen as *positive* or *negative*. Positive sanctions involve reinforcing desired behaviour, while negative sanctions imply punishment for failing to produce desired behaviour (Thomas & Biddle, 1966).

By way of summary, Biddle (1979) lists five propositions about which he feels there is general agreement among role theorists:

1. *Role theorists assert that 'some' behaviours are patterned and are characteristic of persons within contexts (to form roles).*
2. *Roles are often associated with sets of persons who share a common identity (i.e., who constitute social positions).*
3. *Persons are often aware of roles, and to some extent roles are governed by the fact of their awareness (i.e., by expectations).*
4. *Roles persist, in part, because of their consequences (functions) and because they are often embedded within larger social systems.*
5. *Persons must be taught roles (i.e., must be socialised) and may find either joy or sorrow in the performances thereof. (p. 8)*

2.2.2.5 Criticism of Role Theory

Role theory has been the subject of a range of criticisms over the years. Some of these are discussed in this section. Various authors have attempted to classify roles (Banton, 1965; Biddle, 1979; Biddle & Thomas, 1966b). However, Banton identifies a major problem with role classification. It requires the assumption that the role definition is agreed to by all parties to the role performance. Clearly, this is not the case, or each person's role performance would be identical to every other person's performance of the same named role (Banton, 1965).

There is criticism levelled at role theorists such as Talcott Parsons who saw role as a means of maintaining the existing structure of society, precluding change and limiting choice. Although this narrow view of role has been refuted, it is still referred to by those seeking to discount role theory (Fennell et al., 1988; Hardy & Conway, 1988; Jackson, 1998a).

The vocabulary or language of role theory is open to criticism. Biddle and Thomas (1966b) point out two basic difficulties. First, there is a lack of denotative clarity. They note that terms have popular as well as technical meanings and that the two are not always identical. Furthermore, they say, terms frequently relate to multiple concepts and even technical meanings are not always exact. Second, there is a problem with the incompleteness of the language, as new phenomena are identified but are not effectively named because of the first difficulty.

There are problems with the dramatic role analogy. Goffman (1959), points out that there is a danger in applying such an analogy to real life.

The stage presents things that are make-believe: presumably life presents things that are real and sometimes not well rehearsed. More important, perhaps, on the stage one player presents himself in the guise of a character to characters projected by other players; the audience constitutes a third party to the interaction - one that is essential and yet, if the stage performance were real, one that would not be there. In real life, the three parties are compressed into two; the part one individual plays is tailored to the parts played by the others present, and yet these others also constitute the audience. (as cited in Biddle & Thomas, 1966b).

Because role theory relies heavily on metaphors it is open to criticism. Nash (as cited in Biddle & Thomas, 1966b) has five such criticisms: 1) irrelevance to scientific theory; 2)

lack of parsimony (parsimony in this case meaning that no more causes or forces should be assumed than are necessary to account for the facts); 3) unbelievableability; 4) imprecision of comparison; and 5) conducibility to error. Banton (1965) agrees that all of these criticisms may be levelled against the metaphors of the role vocabulary, especially the last point, this being the most general and telling. He holds that if a metaphorical conceptual scheme is used, it may provide a distorted view of human behaviour. This is one of the criticisms that has been made of symbolic interactionism. These difficulties have not been resolved over the years, and have led to a number of theorists moving away from role theory. However, the concept of role is so universally acknowledged, and is such a part of everyday thinking that contemporary theorists still find it to be a useful tool for analytical thinking about human behaviour (Burns, 1991; Heiss, 1981; Landis, 1995).

2.2.2.6 Role Theory and Choice

The writing of Burns (1991), a social psychologist provides a useful functional view of how the concept of role is applied today. He demonstrates that role theory provides opportunities for individualism and choice, despite the arguments of some critics. Burns states: *"The importance of role theory is that it directs our attention, in the first instance, to the properties of situations, rather than to the properties of individuals"* (p.212). However, both Burns (1991) and Landis (1995) strongly emphasise the degree of choice for the person that is present, with Burns commenting that some writers *incorrectly* state that human behaviour is determined almost entirely by the expectations of others. Burns (1991) and Landis (1995) both see a large degree of latitude allowed to many roles, particularly in the nature of role performance. Landis (1995) clarifies the distinction that should be made between *status* and *role*, stating that *status* relates more to the position occupied, whilst *role* refers to the individual's behaviour when in that position. He demonstrates that people often behave outside the norms or expectations that others associate with the position. Burns (1991) points out that the expectations of others are often about prohibition rather than prescription, giving as his example the role of husband. How a man should behave in this role is not closely defined, but wife battering is strongly prohibited. In well defined roles such as work roles, the term 'failure' is used when a health worker behaves unethically, rather than 'achievement' when he or she meets expected standards. Often, there is a continuum of prescription for role behaviour, whereby there are 'must' expectations, 'should' expectations and 'could' expectations. Failure to meet a must expectation will produce severe censure. Failure to meet a 'should' may produce social exclusion, while disregard for a 'could' may lead

to a loss of popularity or approval (Burns, 1991). There can be incompatibility among the different expectations of someone occupying a *role position*. For instance, as discussed earlier, occupational therapists may experience conflict between the standards and values of their medical colleagues who expect them to use a medical or 'cure' approach to therapy, and the standards and values of academics and leaders within the profession who expect the therapist to work holistically. It is possible for someone to experience *role conflict* between two or more role positions. The shift worker may be a wife and mother, with unsociable work hours interrupting her performance in the other two roles. Conflict can occur within a given role, if the definition of role performance is ambiguous, and the person is unsure what is expected of him or her. Burns (1991) discusses how every role is part of an interconnecting web of roles. People who have roles within this web have their own expectations of how an person within another role in the web should be performing that role. There may be conflict between people about these expectations. A person with a role in the middle of an organisational hierarchy may often have this dilemma, with different people in related roles having differing expectations of how he or she should perform in the role.

Conflicting role expectations are seen by Burns (1991) as opportunities for choice, with people basing their decision upon a perception of the expectations of others, put together with a perception of their *own needs*. He identifies the significant factors in making these choices to be related to *audience groups* and *reference groups*. Audience groups are made up of those people who are perceived by the person as observing and evaluating his or her performance in a given role. They have expectations of the person. Reference groups are made up of those people who hold similar roles to the role in question. Members of a reference group hold values and standards that the person aspires to and believes in. Each role performer attaches a *degree of significance* to each of the sources of expectation placed upon him or her, and makes judgements about which ones must be complied with and which ones can be ignored with relative impunity. Role performers make choices based upon the degree of significance they attach to each expectation placed upon them. Burns states there is a judgement made about the *legitimacy* of different expectations. He concludes that despite the pervasive influence of other people's expectations, the role performer retains substantial opportunities for choice in the nature of his or her role performance, and that each person's behaviour in a given role will be qualitatively very different from another's behaviour in the same role.

Burns (1991) goes on to say that, as in all social systems, role has two dimensions: *nomothetic* and *ideographic*. It is the interaction of these two that leads to observed behaviour or role performance. The nomothetic dimension is concerned with the demands placed upon the person. People may assume roles as a result of the expectations of the normative rights and duties associated with the particular social position held. The ideographic dimension is concerned with what will satisfy a person's needs within a context of environmental living. If one of these is stressed much more than the other, then there may be a failure of articulation between the two, leading to possible dysfunction for the person. Burns sees any behaviour, whether observable or not, as a function of both the ideographic and the nomothetic dimensions. The proportions of role and personality factors will vary according to how closely the role is prescribed. Burns envisages a *continuum* of roles from those that are closely prescribed, such as soldier, with a high nomothetic dimension, to those for which there is very little prescription, such as artist, with a high ideographic dimension.

Burns' idea of a role continuum avoids the criticisms attached to attempts to classify roles. By describing an audience group and a reference group he goes some way to meeting the criticisms of Goffman (1959). His use of role language is sufficiently general to give a flexibility to conceptualisation while still being disciplined enough to provide clarity about the type of phenomenon referred to. He avoids the structuralists' urge to reduce role to a number of closely defined, invariable and therefore measurable constructs. Most importantly, both Burns (1991) and Landis (1995) embrace the dynamic nature of role through the emphasis they give to the idea of individual choice in role performance.

Burns' work supports the view that roles are assumed or discarded by choice (internal) or need (external press) that is stated by Chapparo and Ranka (1997). The idea of choice may be expanded further, by suggesting that a given role can be given a different occupational meaning by different people. For example, the role of cook may be self maintenance to one person, productivity to another, and leisure to a third (Chapparo & Ranka, 1994). Chapparo and Ranka further suggest that the same person may view such a role in different ways in different circumstances. For example, preparing Sunday breakfast may be seen as a family activity, while cooking the regular evening meal may be seen as work (Chapparo & Ranka, 1994). This view reinforces the conceptualisation of occupational roles as being individualistic in the nature of their conception and performance, despite their socially interactive nature. It emphasises the need to see them as bound by a context that is more complex than just the people with whom the performer is interacting.

2.2.2.7 The Developmental Nature of Role

Finally, it is important to consider the developmental nature of role. Roles are lost, gained and changed throughout the lifespan in a process of transition (Barris et al., 1988b; Biddle, 1979; Forsberg-Wärleby & Möller, 1996; Heiss, 1981). These changes may occur in response to life events such as starting work or losing a friend or partner. They may occur as a result of changes within the person which may relate to moving through the normal developmental stages of the lifespan, or to the advent of disease or disability. Dealing with change requires a process of adaptation (Fine, 1991; Forsberg-Wärleby & Möller, 1996). Where the change is imposed rather than chosen, such as with a stroke, adaptation is accompanied by stress. Schlossberg (as cited in Forsberg-Wärleby & Möller, 1996) states that a transition has occurred "*... if an event results in a change in assumptions about oneself and the world and thus requires a corresponding change in one's behaviour and relationship*". Schlossberg proposed the Model for Analysing Human Adaptation to Transition in which adaptation is seen as a dynamic process thought to be dependent upon the person's perceived and/or actual balance of resources and deficits. The model suggests three sets of factors that influence transition:

- 1) *The characteristics of the particular transition: role change (gain or loss), affect (positive or negative), source (internal or external), timing (most adults have built-in 'social clocks' by which they judge whether they are 'on-time', or 'off-time' regarding life events), onset (gradual or sudden), duration (permanent, temporary or uncertain) and degree of stress.*
- 2) *The characteristics of the pre- and post-transition environment: eg. social support and physical setting.*
- 3) *The characteristics of the individual: including psychosocial competence, sex-role identification, age and life-stage, state of health, race/ethnicity/cultural, socio-economic status, value orientation and previous experiences with a transition of a similar nature (as cited in Forsberg-Wärleby & Möller, 1996, p. 117)*

It can be seen from this model that role transitions elicit a complex response and require considerable resources both within and outside the person. The ability to perceive and utilise these resources effectively is required in order to make successful transitions. Role transitions

or changes occur over a period of time which may be prolonged (Forsberg-Wärleby & Möller, 1996; Heiss, 1981).

Further models for role acquisition and role performance will be discussed in the next section, which outlines how the *occupational* aspects of role have been developed and used since the introduction of the concept of role into the occupational therapy profession.

2.3 THE CONCEPT OF ROLE AND OCCUPATIONAL THERAPY

The term *occupation* is central to the everyday language of occupational therapists. However, what is meant by occupation within the profession is still not clearly defined. Indeed a whole new academic discipline, Occupational Science, associated with, but separate to occupational therapy, has emerged in the last decade. It is dedicated to investigating the nature of occupation in order to explore and develop it beyond the broad concept that the term 'occupation' relates to all purposeful human activity (Wilcock, 1998; Zemke & Clark, 1996).

Occupation has been conceptually ordered or organised in a number of ways by occupational therapists, who need to structure their thinking in order to carry out research and practice. The idea of a hierarchy of performance is commonly used in clinical practice, where there is a need to grade occupations in terms of complexity in order to achieve therapeutic change (Neistadt, 1998a). Traditionally, *activity* has been the term used by occupational therapists to denote purposeful action, with the implication that it describes a particular hierarchical level in the complexity of occupational performance (Christiansen & Baum, 1991; Mosey, 1981). However, the term activity has become so broad and flexible in its use, that it is no longer able to denote any hierarchical level of complexity within a structure of purposeful occupation or to direct or influence the focus of occupational therapy intervention (Chapparo & Ranka, 1997a; Christiansen & Baum, 1991; Nelson, 1988).

Occupational therapists use the term occupation interchangeably with activity. The use of the term occupation was challenged because of this ambiguity by Nelson (1988). He pointed out that occupational therapists and others use the term to describe both structure and performance (or *doing*). For example, occupation is used to describe someone's paid employment and how people pass the time. Nelson saw this as a serious limitation to the further development of the profession. He proposed a separation of terms to clarify the meaning of occupation. He suggested the term *occupational form* to refer to the structure of

occupation and *occupational performance* to refer to the human actions that take place in response to occupational form. He defined occupational form and occupational performance as follows:

An occupational form is an objective set of circumstances, independent of and external to a person. The individual's occupational performance (the doing) can be understood only in terms of the environmental context in which the performance takes place (that is, only in terms of the occupational form). (p.633)

A number of conceptual models have been developed to facilitate the further development of both theory and practice within the profession. The majority of these models use the terms occupation and occupational performance. The Model of Human Occupation (Kielhofner, 1995), the Person-Environment-Occupational Performance Model (Christiansen & Baum, 1997c) and the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b) all incorporate the construct of occupational role. In this way, aspects of role theory have been taken by the occupational therapy profession and somewhat extended. In each of these models, occupational role is seen as encompassing task, routine, activity or actions (a variety of terms and hierarchies are used to describe the nature of occupation by the different models). In every case roles are seen as conceptual organisers, serving to give significance and meaning to specific occupational performance.

The evolution of the construct of occupational role and its use within the profession of occupational therapy will now be outlined in greater detail, and some of the concepts important to current thinking about occupational role will be discussed.

2.3.1 The Emergence of Occupational Role as a Concept in Occupational Therapy

2.3.1.1 Occupational Behaviour

Occupational behaviour was an approach or paradigm proposed in the late sixties by Reilly (1969). She believed the profession needed to turn to the behavioural sciences (defined as psychology, sociology and anthropology) to broaden and deepen understanding of issues relevant to therapy. She felt strongly that occupational therapy needed to develop a greater distance from the medical model. The theory of occupational behaviour was developed by

adapting the concepts of role and choice to fit with the philosophies of occupational therapy (Reilly, 1969). In occupational behaviour, Reilly took the view that role could be used by occupational therapists to assist people to meet the expectations and responsibilities placed upon them by society, so that they could take their place in that society. She stressed the importance of examining the life roles of the population relative to *community adaptation*, in order to identify the various skills that support occupational roles, and create an environment where the relevant behaviour could be evoked and practiced (Laukaran, 1977). She described the paradigm of occupational behaviour as arising from an *achievement* frame of reference. This achievement was seen in terms of the "... *patient's ability to carry on the daily activities required by his social roles*" (p. 302). She appeared to see the concept of role as a tool for evaluating what Burns (1991) describes as the 'must' expectations, and perhaps the 'should' expectations, placed upon people in their daily lives. She identified the *play* and *work* continuum as being the area of interest to occupational behaviour. Reilly described role theory as having divided roles into three sub-systems: masculine and feminine identification, group membership, and occupational behaviour. She used the term *occupational role* in stating that it was the last system that was of interest to occupational therapists (Reilly, 1969). The strength of the occupational behaviour paradigm was seen by Reilly as giving therapists the ability to see clients in the context of their own social history or developmental experience. She envisaged each phase of life as having its own identifiable major life role, naming them as pre-school child, student, worker, housewife, and retiree. She referred to the concepts of *occupational choice* and *occupational satisfaction*. Reilly saw the concept of occupational role as a means of moving away from the focus on disease and disability she perceived in the profession and towards the more holistic original principles of the profession (Reilly, 1969).

The occupational behaviour paradigm suggested that everyone had just one major occupational role at any given time (Reilly, 1969). Role was used to examine the person's place in the generally accepted social environment rather than to examine the person's interaction with his or her own particular social environment (Reilly, 1969). In doing this, the implication was that an occupational role could be given a definition acceptable to all, and that people should be assisted to either maintain or return to their 'place', as so defined, by performing to the satisfaction of those around them. This approach may be adequate for the structured and well prescribed roles of paid worker and student, where the emphasis is upon the obligations that go with the role as related to the expectations of others. It is not

satisfactory for the less prescribed roles that Reilly names of pre-school child, housewife and, in particular, retiree.

An assessment using the occupational behaviour paradigm was developed by Moorhead (1969) and termed the Occupational History. The Occupational History relied on self-report, although Moorhead did not exclude the possibility of interviewing relevant or significant others. She gave emphasis to the person's involvement in the role saying:

The overriding commonality between these roles [of home-maker, volunteer and student] is their meaning and importance to individuals as vehicles for social involvement. People identify each other by the occupational roles they perform and these roles become incorporated into personal self-identification systems. (p. 330)

Matsutsuyu (1971) wrote about occupational behaviour and occupational role. Both Matsutsuyu and Moorhead (1969) emphasised the developmental nature of role performance, describing how earlier experiences contributed to current performance, informing *occupational choice*. Matsutsuyu saw occupational choice as really consisting of many choices and of the elimination of choices leading, as changes occur in the person and the environment, to a decision. She identified *exploration, mastery, decision-making, achievement* and *competence* as recurring themes of occupational role performance as the term applied to productivity.

A model was proposed by Black (1976) which, while using the occupational behaviour paradigm, broadened the concept of occupational role. She used systems theory to explain the process of role performance as follows: The social expectations that are formed by society and by the individual could be seen as input that would influence the choice of behaviour alternatives and have an impact on the preferred performance output of the person. Black saw feedback from role performance altering the system by influencing future role performance (see figs 2.1 and 2.2). She discussed how skills learned in the performance of one role may be practiced, generalised and transferred to other roles. She used the idea of habituation, stressing that this does not imply rote-like performance, but the development of flexible routines. She saw that within each role, a person would build many habits that would form a hierarchy of behavioural options. The building of role *competence* involved the

In-Put

Out-Put

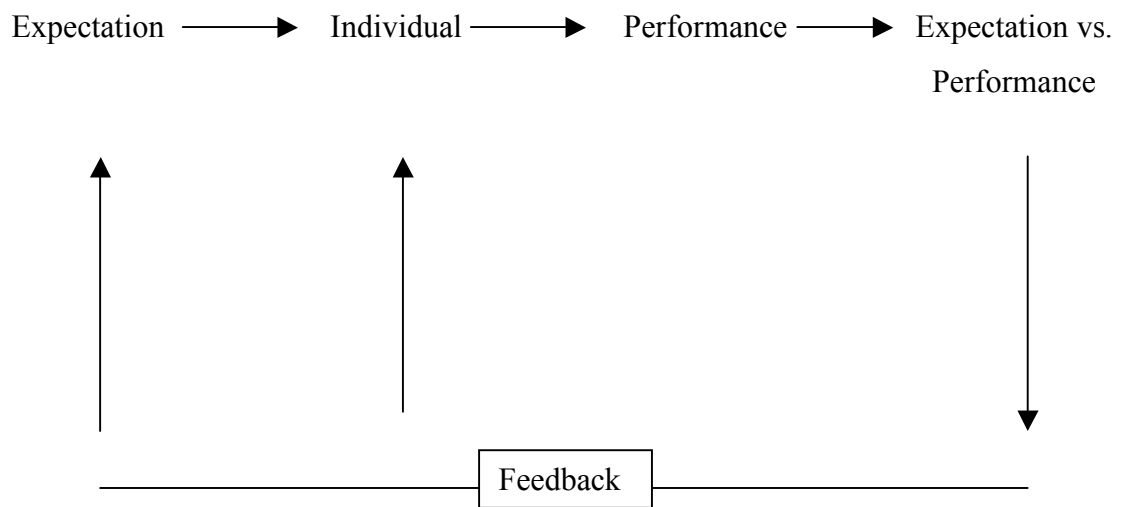


Figure 2.1 Black's Role Theory Model: Fig. 1 Boundary of Role. Reproduced from Black (1976, p. 226).

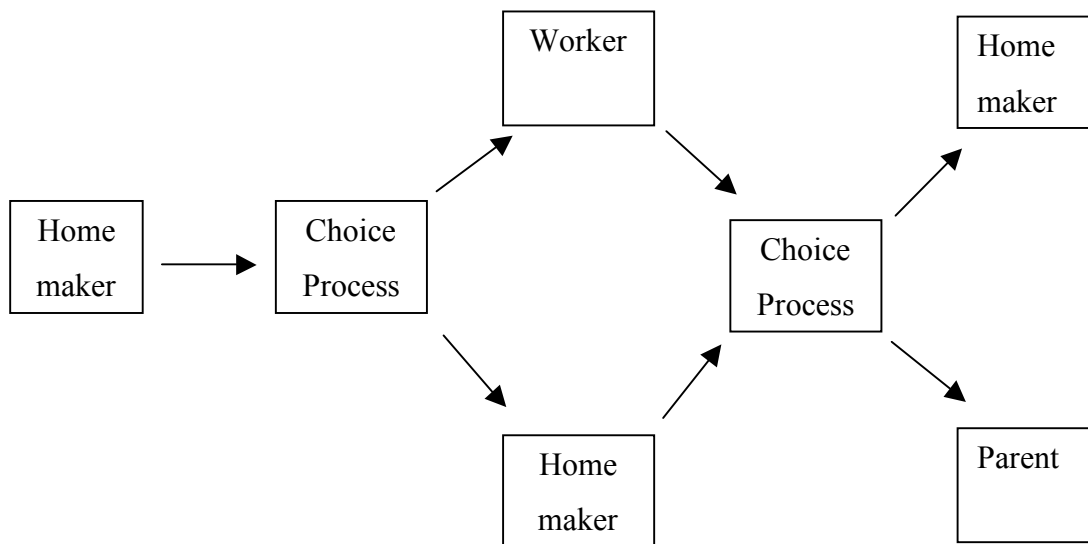


Figure 2.2 Black's Role Theory Model: Fig. 3 - Occupational Career. Reproduced from Black (1976, p. 226)

building and effective selection of these habits. She described the occupational therapist's task as being to design a program that would promote the formation of skills, appropriate to the relevant occupational role, that could be practiced and exercised in order to become habits. Black described role as "*... a position in society that contains a set of expected responsibilities and privileges*" (p. 226).

Most importantly, Black (1976) considered the implications of a set of interacting roles or role repertoire. She introduced the idea of the occupational career. She broadened the usual paid employment use of the word *career*, stating it could be used to study movement within a single role and movement from one role to another. Black viewed each person's occupational career as unique and as spanning his or her lifetime, with each role forming an evolutionary step, providing the skills and habits needed for future roles. She described failure in a given role as being attributable to earlier failure to develop the skills and habits needed for satisfactory role performance. She considered occupational choice pivotal to the course of the occupational career saying that assigned roles were still influenced by personal attributes and personal decisions.

Black's (1976) view of role allowed a much broader and more flexible approach for conceptualisation, and, along with Moorhead (1969), she gave much more importance to the view of the person interacting within his or her own environment and making choices about role performance. Reilly (1969), Moorehead (1969), Matsutsuyu (1971) and Black (1976) all gave emphasis the importance of achieving a balance between work, rest and sleep, but did not define what that balance might be.

2.3.1.2 Heard's Model of Role Acquisition

The next year, Heard (1977) published a model of role acquisition (see fig 2.3). This model was still within the occupational behaviour framework, and had some similarities to the ideas put forward by Black (1976) the previous year. Heard classified occupational role as follows:

1. *Habits and skills are components of role, so their presence is necessary for role fulfilment.* (Heard, 1977, p. 244)

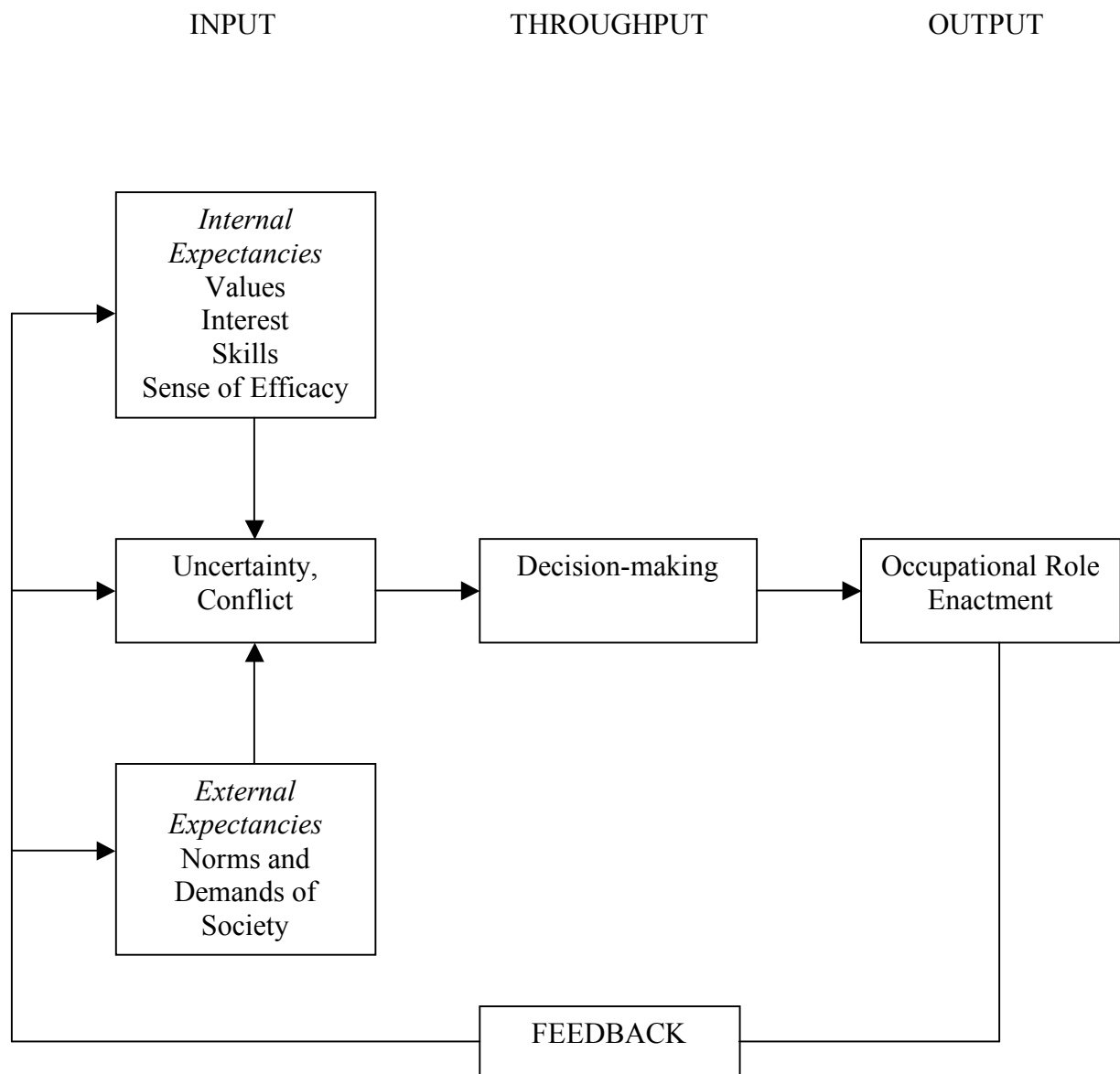


Figure 2.3 Model of occupational role acquisition. Reproduced from Heard (1977, p. 245)

Heard (1977) defined skills as conscious manipulations of the environment, and habits as mastered skills that, with repetition become automatic routines. This mastery enabled attention to be reserved for novel demands for skills. As new roles were developed so were the skills required for them. These skills became integrated into the habit structure as the new role became more established in the person's repertoire.

2. *Role is the organising component for competence in daily life.* (Heard, 1977, p.244-245)

The ability to perform certain service tasks associated with a particular role means competence in the performance of that role.

3. *The ease of occupational role acquisition is dependent upon the adaptive nature of the individual.* (Heard, 1977, p. 245)

Heard (1977) commented "*the skilled role player is more flexible than the less skilled in adjusting to sudden, unforeseen changes in external role demands*" (p. 245). She instanced people who have a chronic disability as a group who, due to their impaired capacities were less flexible in their behaviour strategies than those without disability.

Like Black (1976), Heard (1977) used systems theory as the basis for her model. Heard described input as including both *internal* and *external expectancies*, with possible conflict existing between the two. Internal expectancies were based upon the *values, interests, skills* and *sense of efficacy* of the person. She defined *values* as the goals and commitment for acquiring a particular role, and saw them as responsible for differences in interpretation of role demands. *Interests* determined the commitment to internalise external role demands and indicated the choices that might be made for a particular course of action. *Skills* determined the role that may be fulfilled, because they were necessary to role performance. Those able to use their skills to effect change experienced a sense of having power to control their destiny - they experienced a sense of *efficacy*. Heard stated that this sense of efficacy influenced the person's willingness to try out new roles. Those who felt incompetent were less likely to assume new roles. External expectancies were *implicit* or *explicit*. Heard stated that they served to prescribe role behaviour. Implicit expectations were the rules society or culture impose upon people and were determined by age, sex and position. Within their own cultural setting, people were permitted wide freedoms in some ways but required to rigidly conform

in others. The final input that Heard described were *transactions*. When the norms and demands of a role differed from the expectancies of the person, a bargaining series began to lessen the differences. Heard saw conflict and uncertainty in meeting given role demands as the usual state when role acquisition was occurring.

Throughput in Heard's (1977) model was described as decision-making behaviour that served as the transforming process in role acquisition. Decision-making helped to organise behaviours and sort and select the eventual role behaviour. There was a need to have good quality information about the external expectations so that they could be effectively weighed up with the internal expectations to achieve a compromise that would provide the best advantage to the person.

Output was described as the actual role behaviour implemented from the selected alternatives. There was a trial period which was subject to feedback and revision, allowing the person to 'try on' the role and determine how much its obligations would enhance or conflict with other roles. Heard saw role acquisition occurring in the context of the person's role repertoire. For those with fewer appropriate skills, this 'try on' period was seen by Heard as critical to the future performance of the role, as conflicts frequently occurred.

Feedback occurred from both internal and external sources in Heard's model, with the obligations and norms within the role serving as the standards for feedback. If the behaviour was not acceptable, then further transactions could occur for a more suitable output, or the person might decide not to take up the role. Another reason for failing to take up a role according to Heard, could be the excessive conflict it created with the demands of other roles that the person might have.

This model provided a valuable basis for considering occupational role *performance* in that it provided the opportunity to see occupational role as a dynamic system that changes over time, and to identify its facilitating and modifying factors.

Occupational Role as Productivity Role

The use of the definition of occupational role as relating to productivity roles was continued, with studies being done relating to paid productivity or career development (Webster, 1980). These studies continued with the structuralist and developmental view of

role, however, they reflected a move away from the earlier work of Moorhead (1969), Matsutsuyu (1971) and Black (1976), because they considered role in terms of the external view of the person's place in society, as judged by others. This shift in emphasis away from considering the balance of internal and external perceptions of role, to a greater focus on the external view represented a response to external pressure to become more reductionist that resulted from social changes as observed by Shannon (1977) and discussed earlier.

2.3.1.3 The Model of Human Occupation

A comprehensive occupational therapy theory entitled the Model of Human Occupation was proposed by Kielhofner and Burke (1980). The Model of Human Occupation draws heavily on the constructs of occupational behaviour, and was intended to more closely link Reilly's occupational behaviour model to clinical practice. It includes a consideration of roles as part of one of three subsystems - the habituation subsystem - rather than as the overarching construct as seen in occupational behaviour. The prefix *occupational* was dropped and the range of roles considered legitimate for occupational therapists to consider was broadened. Kielhofner and Burke (1980) saw roles as images held by people about the various *positions* they occupy in the different social groups of which they are a member, and the *obligations* that go along with those positions. They saw roles and habits as together managing occupational behaviour by serving to organise, regulate and maintain behaviour to help the person meet socially approved standards and enable adaptation to the environment (Kielhofner, 1983). This model uses the concept of *internalised roles*. These are roles that have been accepted by people as being part of their self-identity and self-perception. Each person's skills, values, interests, and views of self as a causal agent are seen as determining which roles are chosen and the role expectations that are negotiated between the person and society. In this model, there is a recognition of the person's influence on role performance, but the emphasis is more on how role can serve to mould and form social interactions. The model excluded some *doing* from the realm of occupational behaviour - for example sex was excluded, although included by many other writers and researchers (Freda, 1998; Neistadt, 1993).

2.3.1.4 The Development of Standardised Occupational Role Assessments

By the early 1980's occupational role and the concept of role were becoming key constructs in occupational therapy, and further assessments were devised to assist therapists

in clinical practice. The Role Checklist (Oakley, 1981) was developed using the Model of Human Occupation as its conceptual base. This was an assessment tool developed for psychiatric clients, and was designed to identify role occupancy across time. It listed ten roles: organisational participant, hobbyist/amateur, friend, family member, care giver, home maintainer, student, religious participant, worker, volunteer, and a category for respondents to enter an 'other' role. This assessment reflected a move away from considering only productivity roles as occupational roles, following on from the broadening of the concept of roles of interest to occupational therapists signalled by Black (1976). It represented an attempt to find common categories for the roles that people might identify. Respondents were asked to tick role occupation for each of the listed roles in the past, present and future. Each role was defined and criteria for incumbency were given. These criteria included a frequency of performance of at least once a week, to ensure performance was active or occupational. 'Occupational' was defined by Oakley (1981) as meaning observable. Barris (1988c) described the checklist as assessing roles that have an occupational component. The concept of occupational role changed from one of productivity to the broader concept of *occupation*. Roles were now seen to have an *occupational* element, which was the performance part of the role.

Oakley (1981) made it clear in her discussion paper that she saw role as externally defined and sanctioned, defining role as: "*... a socially identified, comprehensive repertoire of behaviour associated with occupying a particular position in society.... Roles function to organise behaviour, thereby permitting individuals not only to meet environmental demands, but also to pursue goals and interests*" (p. 1). She described roles as defining the person's social worth.

Oakley, Kielhofner, Barris and Reichler (1986) subsequently achieved content validity and test-retest reliability for the Role Checklist, using occupational therapy students and community volunteers as their subjects, 95% of whom had a college education or above (Vause-Earland, 1991). Oakley added a second part to the checklist, which measured the degree to which people valued each role they had identified in part one of the assessment. They were asked to indicate whether they considered the role 'not at all valuable', 'somewhat valuable', or 'very valuable' (Barris et al., 1988c; Oakley et al., 1986). This enabled the Role Checklist to obtain some grasp of the meaning or significance of the role to the person in a way that was lacking in the original assessment. The information the Role Checklist provides is of a rudimentary nature, giving only yes/no answers about role incumbency and a three

point rating of role value, with no information about the nature of role performance. It is difficult to gain an idea of the *degree of participation* of a person in a given role. Because the roles are pre-determined and pre-defined, the Role Checklist is of limited use for assessing role performance on an individual basis, as role theorists agree that no two people performing the same role will look the same. However, because it has test-retest reliability, it has been the predominant research tool for investigating occupational role (Bränholm & Fugl-Meyer, 1992; Dickerson & Oakley, 1995; Elliott & Barris, 1987; Hallett et al., 1994; Larsson & Bränholm, 1996; Vause-Earland, 1991).

Other role assessments were developed that maintained the emphasis upon the need for the person to meet the external expectations of society (Good-Ellis, Fine, Spencer & DiVitis 1987; Kielhofner & Henry, 1988). They did not provide information about people's own perceptions of their roles and role performance because they assumed that the therapist would be best placed to interpret the information obtained and make professional judgements about the person's specific role needs. For example, The Occupational Performance History Interview (Kielhofner et al., 1986; Kielhofner & Henry, 1988a; Kielhofner & Henry, 1988b) placed an emphasis on the concept of role function/dysfunction or role competence as judged by the therapist administering the test. Roles were pre-named or categorised and there was an underlying assumption that a role of a given name would always be performed in a similar fashion, or at least carry the same societal obligations for each person being assessed. There was no apparent consideration of cultural differences for example. The more recent version of this assessment, the OPHI-11 continues this bias towards the need to meet external expectations (Kielhofner et al., 1998).

Assessments like the Role Checklist (Oakley, 1981; Oakley et al., 1986), and the Occupational Performance History (Kielhofner et al., 1986; Kielhofner & Henry, 1988a; Kielhofner & Henry, 1988b; Kielhofner et al., 1998) attempt to reduce what can be a very complex and subtle interaction to something that can be counted, with the underlying assumption that all people can be compared to some externally determined norm for role behaviour. Role or role areas are named, with the assumption that the range covered in the assessment is comprehensive and represents all major roles for each person likely to be tested; yet they are not based on descriptive research using people comparable to the client group. As Banton (1965) pointed out (see section 2.2.2.5), it is highly questionable that everyone would agree to a single definition of a named role. Likely role performance or what 'norms' could be expected is not established. When external value judgements are made by

the therapist about the person's performance in that role or role area, and the concept of 'good' or 'bad' role behaviour is implied, people are at risk of being labelled and categorised inappropriately by these assessments. While these types of measures have value for studying populations, they miss the opportunity to gain real insight into what it is like to *be* the person being assessed.

2.3.1.5 The Role Change Assessment

The Role Change Assessment represented an attempt to redress some of the problems of categorisation and inadequate language (Jackoway et al., 1987). The Role Change Assessment was designed to look at the total role involvement of older adults. The researchers wished to be able to measure role change in terms of the addition or loss of roles, and in terms of increases and decreases in the time allotted to the performance of specific roles. They used the Model of Human Occupation as their theoretical framework, and stated that the measure was to be a data gathering tool rather than a test of responses to specific questions about role. They developed six role categories: social and family roles, vocational roles, self-care roles, health care roles, organisational roles and leisure roles. They developed a list of 48 roles, with definitions, from the literature, and sought to establish content validity by submitting them to four experts in the fields of gerontology and health care. Five additional roles were added following trialing of the instrument, when 25 subjects were asked to add any roles they held that were not mentioned. Each of these roles was assigned to one of the six categories by the researchers. They used a semi-structured interview, to allow flexibility and to enable the interviewer to reword questions or ask additional ones. They asked first about present role performance, and then repeated the interview to find out about past performance (defined as one year ago) in order to identify any role changes that might have occurred. They rated responses in terms of role gain and role loss, and in terms of increases and decreases in role activity, measured by the amount of time spent in the role. They used this information to provide an overall summary of role performance in terms of stability and change. The interviewee was asked to attach a value to each role of positive, negative or neutral. They recommended that for clinical purposes, narrative summaries should accompany the ratings. This assessment avoided some of the value judgements of other assessments by looking principally at role change in terms of role gains, role losses and time spent. It acknowledged the wide range of roles held by people, although the attempt to try and name them all was difficult, as evidenced by the additions made when the instrument was trialed.

2.3.1.6 Occupation and Role

As the difficulties with conceptualising and assessing role performance became evident, some theorists began looking for a more effective way to investigate the meaning that occupation had for client groups and the general population. As a result, the meaning of *occupation* was broadened to include everything purposeful that people *do* (Chapparo & Ranka, 1994; Hopkins & Smith, 1993; Pedretti, 1996b; Wilcock, 1998). In occupational science, the concept of culture was applied to the term occupation. (Clark et al., 1991; Yerxa et al., 1990). Chapparo and Ranka (1997a) refer to an *occupational being* : "*An occupational being is that aspect of a human being that ideates and actualises engagement in occupational roles. This occupational being is expressed through occupational performance and ultimately defined by peoples' occupational roles*" (p. 2).

Clinicians looking for outcome assessments related to handicap still felt the need for something quantifiable in order to demonstrate effectiveness of therapy. However, naturalistic methodologies became more acceptable for research, and there was no longer such a pressing need to attempt to develop standardised instruments for that purpose. Narrative research was considered more satisfactory than standardised assessment because it provided the richness of detail and the context that had been lacking (Helfrich & Kielhofner, 1994).

2.3.1.7 Domains of Life

Some researchers who have investigated peoples' views of their lives as a whole, have tried to avoid role theory as a conceptual basis for their work and referred to *domains of life* instead. Domains have been used in researching life satisfaction (Allen, 1990; Bränholm & Fugl-Meyer, 1992; Campbell, 1976; Fugl-Meyer, Bränholm, & Fugl-Meyer, 1991; Morgan, 1990; Niemi et al., 1988; Viitanen et al., 1988) and in researching self-efficacy (McAvay, Seeman, & Rodin, 1996). The domains used appear to be externally and arbitrarily defined by the researchers prior to the study, rather than being ascertained as part of the study. No rationale for using domains rather than roles is given by these researchers. It appears that in terms of producing a standardised list of life areas that can be studied, domain has just the same problems of definition as role, with different domains being defined for each of the above studies.

2.3.1.8 Occupational Science and the Concept of Role

In 1998, Jackson (1998a; 1998b) published two articles questioning the place of role theory in occupational science. She pointed out that occupational science was rooted in the occupational behaviour frame of reference, with role as its central concept. She identified role as an imported theory, and suggested that perhaps the time had come to review its effectiveness. She pointed to sociologists, who appeared unsure whether to retain it as a viable theory, rework it to relieve some of the identified problems or disregard it completely. She suggested that perhaps occupational science needed to review the use of role in the same way.

Jackson presented role theory in its most external and prescriptive form, using formal, closely prescribed roles such as doctor/patient as examples, and implied that the exercising of choice in occupational role performance was likely to be considered abnormal by role theorists. She based her criticisms of role theory in the field of women's studies, where it had been identified as a vehicle for control and reduction of choice. Jackson based much of her argument against the use of role on Connell's work on gender roles (Connell, 1987). Gender roles are biologically ascribed, and, because of their significance in human reproduction, carry a high level of biological, social and cultural prescription. They are not representative of the wide range of roles encountered in most people's role repertoires (Burns, 1991).

Much of Jackson's (1998a) criticism of the effects of using role theory appeared to be based upon Talcott Parsons' view of role as a means of preserving desirable differences of place in the existing social structure and of preventing social change. This is no longer a view that is commonly held (Fennell et al., 1988; Hardy & Conway, 1988), but it seems to have persisted within the profession of occupational therapy. Jackson (1998b) identified five criticisms of role theory:

1. *Role theory reifies social ideologies into concrete entities which have become universal standards of behaviour.*
2. *Role theory promotes social conformity with less emphasis on providing a critical analysis of existing social ideologies and policies.*

3. *The socialisation process, as presented by some role theorists, fails to portray a complete picture of the means by which children or others become integrated into society.*
4. *Role theory's depiction of human agency does not fully account for the subjective experience of humans or their creative and resistive adaptations.*
5. *Role theory promotes a segmented description of occupation, ignoring its enfolded nature.*

If Jackson's (1998b) five criticisms of role theory are accepted, then there is clearly a high degree of cultural bias engendered by such a system. Cultural issues are not generally discussed in role theory, perhaps reflecting the times in which the theories were formulated, when there was a greater cultural homogeneity among the developed nations than exists today, with less general understanding and tolerance of cultural differences. Jackson discussed how those who differ from the norm in their gender roles are considered deviates and labelled maladaptive. If the concept of culture is brought into the equation, then it can be seen, using this example, that homosexuals and lesbians, while labelled as deviates by mainstream American culture, have created their *own* cultures of acceptable behaviour. While moving within the special environment they have created for themselves, they do not encounter the same sanctions for their behaviour that they may encounter when moving into the wider cultural environment - for instance in pursuance of their paid employment roles.

Jackson's (1996; 1998a) criticisms reflected the external or judgemental view of role promoted by assessments such as the Role Checklist (Oakley, 1981; Oakley et al., 1986) and the Occupational History Interview (Kielhofner et al., 1986; Kielhofner et al., 1998). She ignored the work of earlier occupational therapists such as Moorhead (1969) and Black (1976), who gave greater weight to the person's own perspective or perceptions of role performance. Jackson failed to note the wide range and sophistication of choice available to role performers as discussed by various role theorists, social psychologists and sociologists such as Banton (1965), Burns (1991), Landis (1995), Mead (1934), and Moreno (1977).

Occupational therapists need to deal effectively with the realities their clients are experiencing in a non-judgemental manner, and Jackson's criticisms (1996; 1998a) are valid in this regard. However, perhaps it is the misuse or misunderstanding of role theory that has

led to the perception of role theory as judgemental and restrictive. The purpose of this study is to use the concept of role to gain access to peoples' perceptions of their own reality in order to achieve an understanding of how they organise and deal with that reality, rather than using role theory to pass judgement and identify abnormal or deviant behaviour.

To this end, a preliminary model of occupational role performance was proposed as a part of the conceptual preparation for this study, (see fig. 2.4). This model is an extension of Heard's model of role acquisition (Heard, 1977). It shows that the reasons for role performance are individually determined and depend upon the person's own perceptions of what is expected of them by others, what they expect of themselves and what resources are available to them for achieving performance. Based on this model, it is clear that there is a need to investigate peoples' own perceptions of their performance at the role level, rather than make decisions based on indirect information given.

2.3.1.9 Discussion of section 2.3.1

It appears from the literature that in embracing the concepts of role theory there have been misunderstandings from the beginning about its focus and complexity. If the acquisition and use of role theory by occupational therapists is viewed in the context of the profession's history and development, it is easy to see why this has occurred. Role theory was introduced as a way to counteract the effects of reductionism upon the thinking and development of the profession. However, in its application it has succumbed to the pressures it was intended to counteract. The need to be able to simplify and reduce role assessments in order to present data that was statistically reproducible and comparable to a norm has led to a distortion of role theory concepts. In particular it has led to the general assumption that it was possible for therapists to make judgements about a person's role competence without fully understanding the context within which that person performed his or her roles. If occupational therapists have the aim of returning their clients to an independent and productive life, then the emphasis on role obligations and sanctions is understandable. However, if occupational therapists, in addition, see their role as working to restore their clients to a lifestyle that is *satisfactory* to them, then they must consider role rights as well as role obligations, and place emphasis upon context, occupational choice and the inherent creativity of the person. To fully

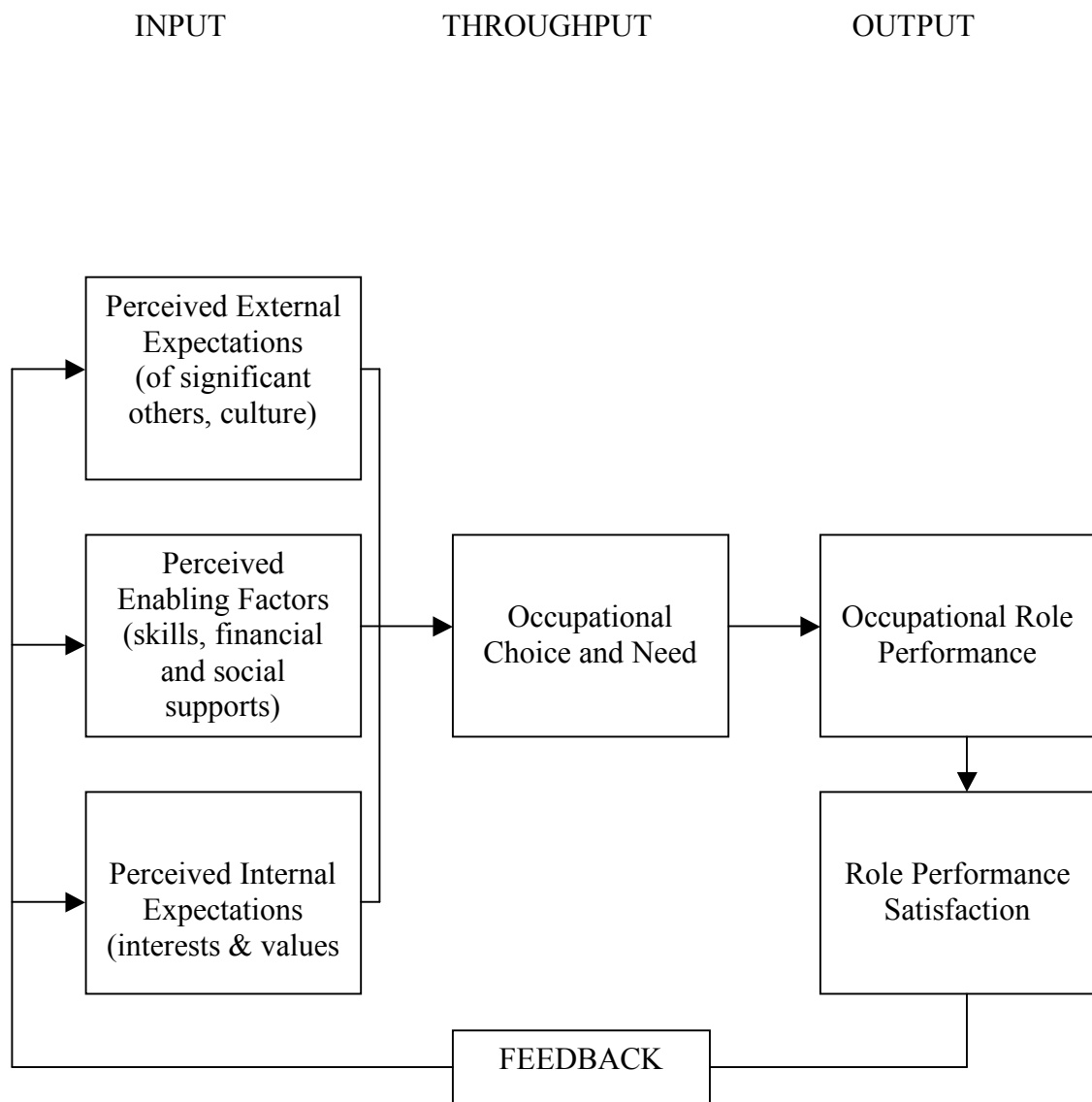


Figure 2.4 Model of occupational role performance (adapted from Heard). Reproduced from Hillman and Chapparo (1995a)

understand role context, cultural issues must be taken into account. Any consideration of the concept of role should therefore include social, occupational and cultural aspects.

If occupational therapists take into consideration the context of their clients' role performance they are less likely to impose values that may be inappropriate. In particular, they are less likely to impose their own values. If the whole person-environment interaction is considered, then it is easier to understand what the 'norm' is for each client, instead of imposing an external and uninformed view. The problem with role theory has perhaps more to do with the way that it has been utilised by the profession - as means of passing judgements of competence based upon externally sanctioned criteria - than with role theory itself.

There is still a need for an explanatory model or system to provide structure in order to effectively organise occupational therapy thinking and communication at this level, and there is an increasing emphasis in the literature on the need to consider role related matters in occupational therapy interventions (Ottenbacher, 1998; Chapparo & Ranka, 1997; Christiansen & Baum, 1997).

2.3.2 Occupational Therapy Models That Include the Construct of Role

There are three contemporary models of practice that include the construct of role or occupational performance role. The way in which role is conceptualised within each of these models will now be discussed.

2.3.2.1 The Model of Human Occupation

The Model of Human Occupation (Kielhofner, 1995) has three subsystems; the Volition Subsystem, the Habituation Subsystem, and the Mind-Brain-Body Performance Subsystem. The construct of role appears as one of the two constructs of the Habituation Subsystem, and is termed Internalised Role. Internalised Roles are described as providing avenues for function by giving purpose and identity to behaviours. They are seen as placing expectations upon people and providing structure and regularity to life. Roles are described as the means of maintaining social structure and function. The degree of role prescription present in a person's roles is seen as depending upon the type of social structure that prevails

for their specific social group (Kielhofner, 1995, pp. 72-74). In this model, the therapist is the expert.

2.3.2.2 The Model of Person-Environment Occupational Performance

The Model of Person-Environment Occupational Performance (Christiansen & Baum, 1997c) describes role as the top level of a performance hierarchy that moves from actions to tasks to occupations to roles. Patterns of occupations that meet the needs for self-maintenance, recreation, rest, creativity and productivity are said to characterise social roles. Occupational performance deficits are seen to have meaning mainly in terms of the person's role responsibilities. Smooth social functioning is described as requiring effective role performance from every member of the group. Christiansen and Baum describe the concept of *satisfaction with role performance* saying that internal appraisal of role performance occurs as well as external appraisal. The model considers *occupational choice* but appears to relate this to choice of role rather than choice of role behaviour, giving the example of the decision adolescents must make about their paid work role. This model is client-centred in its approach.

Both of these models adopt the traditional role theory view of role, with no real consideration of self-perceived or internal aspects of role performance.

2.3.2.3 The Occupational Performance Model (Australia)

The third practice model to utilise the construct of role is The Occupational Performance Model (Australia) (Chapparo & Ranka, 1997b). Like the Model of Person-Environment Occupational Performance (Christiansen & Baum, 1997c), it expands the concept of occupational performance. While the term is now used extensively, Chapparo and Ranka's model provides an extended view of what the term means as related to everyday human performance.

Constructs

There are eight constructs to the model and all of them are considered capable of interaction with most if not all other constructs. The constructs are: *occupational performance*, *occupational performance roles*, *occupational performance areas*, *components*

of occupational performance, core elements of occupational performance, environment, space and time.

Assumptions

Assumptions in the model are stated, and are derived from the core philosophical tenets of the profession (Chapparo & Ranka, 1997a). The assumptions about human occupations state:

Engagement in occupation involves an interaction between people and their environment. Health is not the absence of disease, rather, it is competence and satisfaction in the performance of occupational roles, routines and tasks. Humans are active in the process of creating their occupational being or identity. This active participation can be intrinsically driven by choice or need, or externally imposed by environmental factors. An occupational being is that aspect of a human being that ideates and actualises engagement in occupational roles. This occupational being is expressed through occupational performance and ultimately defined by peoples' occupational roles. (p. 2)

Application

A therapist using this model for the purposes of clinical reasoning commences with a consideration of the client's occupational performance roles (see fig 2.5). These then guide the therapist to work down through the levels of the model to deal with any difficulties that have been identified in the performance of each role, before integrating the abilities and skills that have been developed back into the relevant tasks and routines that make up each occupational performance role, completing the therapeutic interaction with a consideration of outcome in terms of occupational role performance that is satisfactory to the client (Baker, 1997; Chapparo & Ranka, 1997a; Innes, 1997).

Occupational Performance Role

Occupational Performance Role is therefore the central organising construct of this model (Chapparo & Ranka, 1997b). The view of role in this model is much broader than that seen within the occupational behaviour framework. The central proposition in this model is that all goal-oriented behaviour is *occupational* in nature. Occupations are characterised by

Figure 2.5 Occupational Performance Model (Australia) reproduced from Chapparo and Ranka (1997)

purposeful changes in behaviour that can be *physical, cognitive or psychosocial*.

Performance, as defined in this model, extends the usual notions from that of motor action only to include antecedent and subsequent physical, mental and emotional processes relevant to the task performed. *Occupational performance* is defined as:

The ability to perceive, desire, recall, plan and carry out roles, routines, tasks and subtasks for the purpose of self-maintenance, productivity, leisure and rest in response to demands of the internal and/or external environment. (Chapparo & Ranka, 1997a, p. 4)

Definition of Role

The definition of role in this model is taken from Christiansen and Baum: "... *a set of behaviours that have some socially agreed upon functions and for which there is an accepted code of norms*" (Christiansen & Baum, 1991, p. 857). The concept of role is seen as complex, and composed of many different components and behaviours. Roles are described as being vehicles for social involvement and productive participation, and possibly as the nucleus of social interaction. Competence and satisfaction with role performance arises in the Occupational Performance Model (Australia) from internal as well as external perceptions of performance. Chapparo and Ranka (1997a) say: "*Role behaviour is viewed as the way people express their place in society, both in terms of their unique and valued contribution and their ability to conform to the code of personal acceptability within a particular socio-cultural environment*" (p. 4). In the conceptualisation of role in this model, there is a move away from the single social environment that tends to be envisaged in role theory to the possibility of several different environments occurring in the course of a day for a given person. Chapparo and Ranka consider the cultural nature of these environments. The concepts of 'choice' and 'need' are seen to drive people to engage in occupational roles. These reflect the fact that a role can be chosen by a person or be taken up due to social press. Cultural differences are seen in relation to the balance (or even the possibility) of choice and of social press.

Doing, Knowing and Being

Occupational performance roles are viewed as patterns of occupational performance that are determined by a person's needs in the daily routines of self-maintenance, productivity, leisure

and rest within specific sensory, physical, cultural and social contexts (Chapparo & Ranka, 1997a). Occupational performance roles are conceptualised as having three dimensions:

Knowing:

... an intuitive or concrete understanding of desired or expected occupational performance roles. This knowing results in the person having ideas about organised patterns of occupational performance that are expected or accepted by the physical-sensory-socio-cultural environment. (p. 5)

The Process of Doing:

... usually entails the physical action of people within their environment. (p. 5)

Being:

... a fulfilment or satisfaction component of occupational performance roles ... [which may be] ... linked to personal meaning which contributes to valuing of one's occupational role. (p. 5)

The Varying Nature of Occupational Performance Role

People may participate fully or partially in the performance of occupational performance roles. For those who participate partially, such participation may consist mainly of the 'knowing' dimension, with others providing the 'doing' dimension (this may be the case for someone who requires considerable physical assistance for example). Others may contribute to the 'knowing' and 'doing' but not experience satisfaction or 'being'. Still others such as someone with severe cognitive as well as physical disabilities, may experience the 'being' but not be able to contribute much to the 'doing' or 'knowing' aspects of the role (Chapparo & Ranka, 1997a, p.5).

Occupational performance roles are dependent upon changing personal-performance components such as age, ability and physical-sensory-socio-cultural circumstance. Most people assume a number of roles at once. People balance configurations of roles that change with time. The decision about which roles are discarded and which are assumed form

transitions in occupational role behaviour that are constantly made throughout the lifespan in response to the demands of the internal and external environment (Chapparo & Ranka, 1997a).

Because occupational performance roles are part of an interactive system, they are seen, in this model, as being able to influence and be influenced by other parts of the system (Chapparo & Ranka, 1997a). In many cultures, the worker role determines the balance of self-maintenance, productivity, leisure and rest areas of occupational performance. These in turn, determine the component requirements necessary for performing in the productivity area. Alternatively, where circumstances permit the choice of an occupational performance role, then the choice may be based on particular component strengths such as the problem solving abilities of a mathematician.

Definition of Occupational Performance Role

Chapparo and Ranka (1997a) define Occupational Performance Roles as follows:

Occupational Performance Roles are patterns of occupational behaviour composed of configurations of self-maintenance, productivity, leisure and rest occupations.

Occupational Performance Roles are determined by individual person-environment-performance relationships. They are established through need and/or choice and are modified with age, ability, experience, circumstance and time. (p. 6)

This view of role allows the therapist to consider people's own perspective of their roles as well as the views of those around them. It provides the flexibility needed to be able to consider roles on a continuum from highly prescribed to very little prescription. It permits the consideration of social and cultural contexts, and does not require the imposition of the views and judgements of the therapist upon the client. At the same time it provides sufficient structure to permit the therapist to apply a system of clinical reasoning that is not confined to specific disability groups. It enables the therapist to communicate effectively with the client, with other therapists and with the rest of the medical team. However, although the Occupational Performance Model (Australia) places the concept of role in a central position in relation to the other constructs of occupational performance, the elements and relationships that make up occupational performance roles are not developed. Questions that remain include: how do constructs in the model link to occupational role? Do people utilise the

construct of occupational role in planning and thinking about occupational performance?
What resources do people use to support their occupational role performance? Are there any discernible patterns that can be related to people's role repertoires?

The Occupational Performance Model (Australia) provides the conceptual framework which is used in this study to investigate the occupational role performance of a number of men over 65 who have had a stroke, been through rehabilitation, and are now living at home.

The next section will consider in more detail some theoretical areas of relevance to the internal or personal aspects of occupational role performance.

2.4 CONCEPTS OF RELEVANCE TO INTERNAL ASPECTS OF OCCUPATIONAL PERFORMANCE ROLES

This study is designed to gather information about the participants' own perceptions of their occupational role performance. Some of the theoretical issues and research findings related to individual or self-perceived factors of relevance to occupational role performance are discussed in this section. The factors: are environmental interaction, meaning, choice, self-efficacy and satisfaction.

2.4.1 Environmental Interaction

When considering human function, the first and foremost factor to understand is the nature of human interaction with the environment. The external environment presents complex social, cultural, sensory and physical stimuli that must be dealt with. Failure to respond effectively can lead to serious consequences for continued well being.

Dunning (1972) was one of the first occupational therapy writers to put human activity in context by attempting to describe the environment in terms of the human activities that take place within it. She saw practitioners attending to some aspects of the environment that were obviously impinging upon the occupational performance of their clients, while ignoring others that were of relevance. She stressed the importance of being able to see the person in the context of his or her own environment and proposed a way of defining it that would facilitate this process. She suggested using concepts from the then newly emerging field of environmental psychology to classify the environment in terms of *space, people, and*

task. She felt this would facilitate the evaluation of the person's daily performance "*within the context of his or her roles, the task expectancies of role partners who share the particular environment, the physical characteristics of space and the availability of objects and materials*" (p. 296). She further proposed that objects and space could be classified in terms of *presence, availability, desirability and feasibility*. Availability was seen in terms of social restrictions that might be placed upon objects and space. Feasibility related to personal constraints such as skill level, dysfunction, and age.

This last factor of feasibility can be related to The Press - Competence Model (Lawton, 1982; Lawton & Nahemow, 1973). This model was developed using the concept of *environmental press* (Murray, 1938). Murray described the occurrence of stimuli in the environment that possessed a motivating quality to a given person by activating need. In this way he identified factors in the environment capable of placing a *demand* upon a particular person within that environment. He termed this demand environmental press. Lawton and Nahemow (1973) developed the concept further, using the work of others to examine how environmental press interacted with the person's level of *competence*. Personal competence was seen as the person's ability to meet the demand, or environmental press placed upon him or her. First, they stated that environmental press could never be stable as the environment changed all the time. A person's response to environmental press must be variable over time. Second, they proposed a level they termed the adaptation level, at which the environmental press, or demand, was in a state of balance with the person's sensory, perceptual and cognitive competence. They postulated that when personal competence and environmental press were in balance, the person was at what they termed the *adaptation level*. At this level, awareness of the relevant environmental stimuli receded. They saw adaptiveness of behaviour as "*the extent to which it meets society's expectations and/or the individual's standards or requirements for goal fulfilment*" (Lawton, 1982 p. 44). They further postulated that when personal competence was slightly higher than environmental press, the person experienced maximum comfort. In this state, the person was passive and may be a little bored. Alternatively, when environmental press was slightly stronger than personal competence, Lawton and Nahemow (1973) proposed, then the person was able to perform at his or her maximum. They saw this state as being associated with activity, mild restlessness, goal directed behaviour and achievement. Where environmental press was too weak or too strong, this produced mal-adaptation, as the person was unable to respond effectively.

The work of Lawton and Nahemow (1973) has implications for occupational therapists who need to understand the person's ability to develop *control* of the environment by being able to respond effectively to the stimuli it presents. It should be added that a demand can only exist when it is perceived as such by the person, or has *meaning*. This concept of *environmental control* has important implications for purposeful or meaningful occupational performance.

Environmental control was seen as essential by Kiernat (1987). She said: "*The need to control one's personal environment has long been described as an intrinsic necessity of life itself*". This need for control motivates the person to continue to learn from experience and apply that learning to new situations. The process of adaptation, leading to the achievement of control, produces satisfaction. Adaptation is the process of learning, with sensory input as its raw material. King (1978) saw the environment as demanding of the person a positive role involving action of some kind. It could not be imposed, but must be actively created. This creation is based upon the person's own specific past experiences. Kiernat discussed a classification of control developed by Averell (as cited in Kiernat, 1987). Averell divided control into three types: *behavioural*, *cognitive* and *decisional*. Behavioural control allowed some control over the environment and involved actions. Cognitive control involved interpreting or evaluating an event. Decisional control involved the opportunity to choose from among a number of options.

In this way it can be seen that environmental responses are individual and complex. They may be reactive or proactive. They are the product of the person's prior learning, and are undertaken in order to exert environmental control. Because of the complexity of the environment, these responses need to be highly organised and related to specific areas of activity and purpose. Occupational performance role is one way such areas of activity and purpose can be conceptualised that is useful to practicing therapists and researchers.

If these concepts are accepted, it follows that it is in a person's interest to avoid environmental demands that are perceived to be too great. In terms of occupational role performance, this may lead to the rejection of roles that might otherwise be assumed, because they are perceived by the person to be beyond his or her current abilities and skills. Conversely, someone may reject possible roles because they are seen as representing an area of environmental demand that is too slight and does not have personal meaning. Finally,

someone may seek out role performance in areas that have personal meaning and that are perceived to be challenging but manageable.

2.4.2 Meaning

Meaning is strongly tied to interests and motivation and is a significant factor in making occupational performance choices. Frankl, (1963) discussed the importance of meaning to people in the extreme conditions of concentration camps in the Second World War. He saw that it was not necessarily those with the greatest physical strength who survived, but those who had a reason to live. These people were able to retreat within themselves and continue to make choices, no matter how small, within that extremely deprived environment. These choices were often not visible to others by an overt action, but they dictated the way in which the person dealt with his or her environment and were linked by an underlying meaning that gave the will to live. A person who perceives that he or she can make choices that are meaningful is healthier and happier than those who feel a lack of control over their environment (Frankl, 1963; Williamson, 1995; Yerxa, 1967). This is illustrated by the work of Gregory (1983). He provided people with a list of 23 activities and asked them whether they did them, how often they did them, whether they enjoyed them, whether they felt competent doing them and how autonomous they felt when doing them. He used scales to enable people to rate each of these parameters. He found a significant correlation between life satisfaction and meaningful activity as interpreted using these scales. He wrote:

Much of the research that relates activity with life satisfaction in retirees fails to account for the value an individual places on activity. It is the meaning of the activity that is of primary importance in effecting satisfaction and helping individuals adapt to their environments. (p. 550)

Research that involved sorting activities according to meaning has revealed the highly personal nature of that meaning. Marino-Schorn (1986) asked people to nominate activities that they did and to sort them under work or leisure. She found that different people sorted the same activity under different headings. Yerxa and Locker (1990) compared people with and without spinal cord injury. The two groups were matched in other respects, with the exception that only one third of the people in the group with a spinal cord injury were employed, while all but one of the group without a disability had a job. They asked them to sort their

occupations into the categories of work, rest, sleep, play, self-maintenance or other using an Activity Configuration Log. From the data reported, respondents from both groups sorted possible activities under more than one heading. Some activities were sorted under all possible headings by different respondents. Yerxa and Locker (1990) found that rest, sleep and play had more consistency in sorting, while work, self-maintenance and other showed greater differences. They took their work one step further, by asking occupational therapists to carry out the same classification from the same raw data. They found that occupational therapists agreed with each other more strongly than they did with the respondents in categorising activities. This finding demonstrated that occupational therapists may have a different perspective to their clients about the reason behind the performance of different activities. Yerxa and Locker (1990) went on to question the way that occupational therapists had been viewing the meaning behind activity performance:

The fact that the same occupation was classified into four different categories supports the need for a phenomenological perspective on the meaning or purpose attributed to activities. It refutes analysis of activities according to their inherent qualities and suggests instead that the occupational therapist needs to understand the patient's goals for engagement in occupations. It also raises a question about whether occupation can be understood from a behaviouristic approach, that is, by only observing what people do. This study emphasises the significance of the subject's experience as important information in an activity analysis. (Yerxa & Locker, 1990 p. 324)

They concluded *"the individual patient may be the most valid source of information regarding the classification of activities and interpretation of their meaning"* (Yerxa & Locker, 1990 p. 324).

2.4.3 Choice

The perception of occupational choice, leading as it does to a feeling of control, has a large impact upon well-being (Langer & Rodin, 1976; Williamson, 1995; Yerxa, 1967). The three types of control described by Averell (as cited in Kiernat, 1987) (behavioural, cognitive and decisional) and discussed in section 2.4.1, could all be seen as making up the components of occupational choice. In order to choose, it is necessary for the person to cognitively assess and interpret the information being received, envisage the options that are available in terms

of possible responses that are interesting, good or meaningful, choose one of these options, and act upon that decision. It should be noted that no action can still be seen as making a choice. In order to choose between a number of options, the person must rely upon information from within him or herself as well as the information that is received from the environment. One very important area of knowledge is that of *perceived level of skill* in relation to the task that is being contemplated (Gage & Polatajko, 1994; Heard, 1977). Another is knowledge of the level of correlation between the task and the interests of the person (Matsutsuyu, 1969).

Interests, like skills are unique to the person. Like skills, they must be tried out or practiced to be developed. Rogers (1988) said *"interests that have not been tried out have a quality of vagueness, since there has been no opportunity to test one's aptitude for the action involved in the interest"* (p. 96) Subsequent choices are generated from the accumulation of experience about what is interesting and what is not. Matsutsuyu (1969) characterised interests as follows:

- interests are family influenced
- interests evoke affective response
- interests are choice states
- interests can be manifested in effective action
- interests can sustain action
- interests reflect self-perception.

Meaningful choices may involve an element of risk. The Press-Competence Model (Lawton & Namehow, 1973) proposes that people perform at their best when the environmental demand is slightly higher than their level of competence (see section 2.4.1). For most people in Western society the huge amount of choice that may be perceived as available in everyday life can provide a sense of uncertainty (Beier, 1983). However, Beier pointed out that there are areas in life where people seek out uncertainty. This can be termed risk taking - seeking out a challenge. Cheron (1982) found that perceived risk in leisure activities fell along two dimensions - that of functional risk and that of psychosocial risk. He defined functional risk as *"both the potential inability to perform an activity well and the danger of physical injury"*(p. 153). He defined psychosocial risk as relating to *"failure to meet personal or social standards, as well as feelings of frustration derived from an unsatisfactory experience and the associated waste of valuable leisure time"* (p. 153).

Choice in occupational performance relates to what has meaning and interest for the chooser. Choice carries an element of risk and can be seen as closely related to a sense of control.

2.4.4 Perceived Self-efficacy

Perceived self-efficacy refers to the idea that people who *perceive* themselves as being competent are more likely to view their overall well-being as favourable and are more likely to continue working on tasks despite early set-backs than those who see themselves as incompetent (Bandura, 1997). Perceived self-efficacy is a concept developed in the field of social cognitive theory by Bandura (1977; 1986), and defined by him as follows: "*Perceived self-efficacy is a judgement of one's ability to organise and execute given types of performances*" (Bandura, 1997). People who perceive that they repeatedly fail can develop a negative view of their personal competence and may experience feelings of helplessness. Helplessness is frequently accompanied by depression, a pessimistic outlook toward the future and considerable anxiety (Christiansen & Baum, 1997c).

2.4.5 Satisfaction

A great deal of work has been done on investigating the level of well-being and satisfaction experienced by a given group of people - either the general population, or those with a disability. Satisfaction with *performance* is not often considered as a contributor in these measurements, although more recently there has been a realisation that satisfaction with the various domains of life (identified differently by different investigators) is an important contributor to global satisfaction (Bränholm & Fugl-Meyer, 1992; Niemi et al., 1988; Viitanen et al., 1988; Viney, 1981). Where performance is considered, it is measured more often at the activity level than at the role level. As a result, the author had difficulty accessing literature on the subject of satisfaction with occupational role performance.

Many researchers have assumed that external factors such as standard of living and financial security will determine the quality of life experienced by people (Markides & Martin, 1979). This approach was refuted by Kirchman (1986) who pointed out that since the Second World War Americans have become more and more affluent. This improvement in material well-being should have been accompanied by an improvement in quality of life for

the population as a whole. However, this has not been found to be the case. Now it is realised that financial security alone does not bring happiness and contentment (Elliott & Barris, 1987).

Current findings about life satisfaction in later life were summed up by Ogilvie (1987a). He said they suggest that on the average, a person in late adulthood who is in good health, who is not economically deprived, who participates in social activities with friends and family members, who is married, and who is not institutionalised will rate him or herself as more satisfied than will someone who is ill, poor, widowed, and in a nursing home. However, he points out that where there is an average there is variation from that average, and the picture is likely to be more complex than such findings imply. Ogilvie tried to avoid the effects of statistical reduction to a mean in studying life satisfaction. He used sophisticated methodology that involved obtaining participants' own perceptions of their range of *identities* and the establishment of a hierarchy of identities based upon the self identified self-structure of each of his participants. In this way, he was able to distinguish higher order identities from lower order ones, such that higher order identities gave greater opportunities for the expression of multiple aspects of the self than lower order ones. Using this approach, he found that the more time people spent in higher order identities, the more satisfied they were. Identity is a term related to role (Biddle, 1979; Heiss, 1981), and it may be that this finding is relevant to satisfaction with occupational role performance.

The final section of this literature review will focus upon the effects of stroke and occupational therapy rehabilitation upon the occupational role performance of men in later life. In order to gain a better understanding of normative role performance, the next section will consider what is known about the social roles of those in later life who do not have a disability.

2.5 SOCIAL ROLES IN LATER LIFE

There has been some controversy over the years in gerontology literature about the nature of role performance in old age. Old age has been and still is often seen as a major social problem. Thinking about role performance in old age has been strongly influenced by three theories: disengagement theory, activity theory and continuity theory. The first two theories of aging - disengagement theory (Cumming & Henry, 1961) and activity theory (Havighurst & Albrecht, 1953) directly oppose each other. Disengagement theory has the

older person gradually withdrawing from society in a way that is mutually beneficial to the person and to society as a whole. The person was permitted to give up commitments that he or she may now find arduous, while society benefited from such roles being taken up by younger, more active people. The disengaged person spent more and more time on the end of life task of reviewing and reworking their past life. Activity theory stated the opposite - the more active older people can remain, and the more they are able to maintain their life roles, the more satisfied they will be with their lives.

These two theories fit with the traditional psychology viewpoint on research. Many psychologists believe the way to study the human mind is by measuring observable behaviour. A number of studies into quality of life in old age have been based on the idea that an investigation into the activity levels of older people will provide information about the nature of their quality of life or life satisfaction. Markides and Martin (1979) subscribed to the activity theory and argued that health, income and education were important predictors of life satisfaction in that they all facilitated a higher level of activity. A positive link between activity level and life satisfaction was established by Palmore (1970a), supporting activity theory. However, he found that people maintained their activity level into old age rather than changing it, leading some years later to the statement of yet a third theory of activity as related to life satisfaction - the continuity theory (Kelly, 1982; Atchley, 1989). This theory stated that people, in the absence of disability or handicap, maintain the activity level in old age that they had earlier in their lives, even though the nature of those activities might change.

Currently, none of these conflicting theories finds unanimous support (Adelmann, 1994; Morgan, 1982). Inherent in activity theory is the assumption that occupying multiple roles is associated with higher levels of well-being. At the same time, it has been postulated that there is a significant degree of role loss concomitant with advancing age, and that this is accompanied by a loss of life satisfaction. It has been argued that events such as retirement, widowhood, and children leaving home all lead to *role transition*, defined by George (1980) as situations in which both the status and accompanying role are changed or lost. Role theorists saw loss of work as producing demoralisation and reduced self-esteem, particularly as there were no substitutes with the same cultural value (Fennell et al., 1988). Blau (1981) stated that there were no positively valued roles that older adults were expected to assume. Burgess (1960) put forward the idea of the roleless role, with old people cut off from their work and family. However, Bell (1976) stated that such views are anecdotal in nature and not

borne out by research. Albrecht (1951) found the majority of people over 65 in her study were still highly active and carried responsibility concentrated mainly in the home and in family relationships.

There exist two conflicting theories about occupying multiple roles (Adelmann, 1994). The role strain hypothesis put forward by Goode and Merton (as cited in Adelmann, 1994), suggested that occupying many roles may have negative psychological consequences, either because the demands of different roles are incompatible or because of the cumulative effect of role obligations. This contrasts with the role enhancement hypothesis put forward separately by Gove, Marks and Sieber (as cited in Adelmann, 1994) which proposes that multiple roles promote well-being via complementary resources shared across role domains, or through the buffering effects of one role on stresses experienced in another. Erikson (as cited in Adelman, 1994) argued that while reworking the past (seen as a late life task by disengagement theory) is essential, optimal adjustment requires continued active engagement in roles such as paid work, creative leisure pursuits, volunteering, grand-parenting, education and household work.

It can be argued that there is no viable theory of roles through the life span - especially in relation to later life (Rosow, 1976). Rosow saw a problem with equating role with status, leading to a focus on roles that afford clear status, such as the work and family roles so characteristic of early and middle adulthood. These 'institutional' roles have explicit, normative, consensual expectations within their reference groups. He argued that in later life people more commonly held what he termed 'tenuous' roles. These roles were *"vague, limited, variable or unpatterned with negligible consensus or normative elements"* (Rosow, 1976 p. 462).

The literature on role and well-being was reviewed by Adelman (1994). She reports that nearly all the research on multiple roles and psychological well-being excludes older adults, being mostly focused on young adults. Such research tends to limit the number of roles studied to just three: employee, parent and spouse. Some work has been done on other individual roles, such as volunteer, home-maker, student and grandparent, but roles are rarely examined in the context of the other roles the person occupies (Adelmann, 1994). She also pointed to the lack of consideration of ethnic and cultural differences in considering role performance within a selected group of people. A study conducted by Adelman, that included up to eight roles that older adults may occupy, was claimed by her to be unique. A correlation

between a high level of role incumbency and psychological well-being, as measured by life satisfaction, depression and self-efficacy, was found in this study (Adelmann, 1994). This supported activity theory rather than disengagement theory, and reflected the findings of work done with younger age groups.

With so little known about the day to day social roles of older people, it is hoped the current study will provide much needed descriptive information upon which further research can be based.

The final section of this review of the literature will deal with the impact of stroke, outcomes from stroke rehabilitation, and the effect of stroke upon occupational role performance.

2.6 STROKE

Stroke is a major cause of long-term disability (NSW Health Department, 1997), but stroke mortality in Australia is declining (Donovan, 1995). The reasons for this are not well understood, as insufficient research has been done in this area (Donovan, 1995), but it appears there is a shift to a less severe form of stroke (Wise & Graham-Clarke, 1994). This is attributed at least in part to a reduction in risk factors for the population as a whole (Donovan, 1995). However, the incidence of stroke remains high. It is estimated that approximately 37,000 people experience a stroke each year in Australia. About half of these are over 75 (Wise & Graham-Clarke, 1994). It appears there is a statistical difference in the incidence of stroke between men and women. A Western Australian study found the age-adjusted rates to be 132 per 100,000 males and 77 per 100,000 females (Anderson et al., 1993). This gender difference is thought to be related to a higher incidence of smoking and other lifestyle related risk factors for stroke among men than among women in the older age groups most susceptible to stroke. Aging of the population and the continued high incidence of stroke mean that there are an increasing number of people surviving stroke to live in old age with a significant level of disability (NSW Health Department, 1997; Rowland, 1991). Good health care and rehabilitation for this group are therefore of great importance to ensure that they are able to return to a lifestyle that they find meaningful and worthwhile, and in order to limit the ongoing health and social services that this growing sector of the population might otherwise require.

2.6.1 Stroke Outcomes

Before discussing the long term effects of stroke, the view of role in relation to disability given in the classification of impairments, disability and handicap provided by the World Health Organisation (WHO) (1980) will be outlined. The WHO classification is as follows:

Impairment:

Any loss or abnormality of psychological, physiological, or anatomical structure or function.

Disability:

Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap:

A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual. (pp. 47, 143, 183).

The WHO makes a clear distinction between a specific impairment and the functional implications of that impairment to the person, acknowledging that the same impairment can have a widely ranging impact upon functional performance from person to person, both at the task or activity level (*disability*) and in terms of role performance (*handicap*).

Although current figures are difficult to access, Australia has a history of a high rate of referral to rehabilitation for stroke as compared to other countries. 43% of stroke survivors in Brisbane in 1984 were referred for rehabilitation (Shah et al., 1991). In 1992, The Review of the Role of Primary Health Care in Health Promotion in Australia (as cited in Wise & Graham-Clarke, 1994), recommended a primary health care model that identified a number of criteria they considered important for good health care in Australia. They were:

- building self-reliance at a personal and community level;
- supporting community participation in health care programs and health development;

- inter-sectoral collaboration in working towards environments which are supportive of health and in which healthy choices are the easier choices;
- integration of health services to facilitate continuity of care and efficiency in resource use;
- special attention to high risk and vulnerable groups, as a precondition for equity in health outcomes and health care access; and
- appropriate technology.

These criteria were identified as important for the development of programs and services for those with cardiovascular problems, including stroke, by the authors of the review (Wise & Graham-Clarke, 1994).

In this country and overseas, the type of data that is readily available regarding stroke outcomes heavily emphasises the physical abilities and self maintenance task performance of stroke survivors. For instance, in Australia, a study using the Barthel Index (a self maintenance independence measure), found that there was a significant improvement in functional independence from admission to a rehabilitation program to discharge from it (Shah et al., 1991). Overseas, a study that mainly addressed mobility found that for clients who enter a stroke rehabilitation program, approximately 80% will achieve independence in walking, and 65 - 70% will be independent in activities of daily living. 70% - 80% will have a mild deficit or no functional deficit. 20% will have a moderate degree of disability and less than 10% will have a severe degree of disability (Brandstater, 1991). In Russia, those registered as having had a stroke in one district of Moscow were studied. The researchers found an increasing mortality rate as time went on from the first stroke. For those who survived, 68.2% were fully independent in activities of daily living after one year, while 81% of those surviving seven years were fully independent. It is not clear from this study how many (if any) of these people received any rehabilitation services (Schmidt et al., 1988). In Sweden, 90% of people discharged from rehabilitation in one study were still living in their own home after one year. Of those still living at home, 99% could walk independently indoors, 92-95% could climb a staircase, and 90% could manage their daily hygiene (Thorngren et al., 1990). In Australia, Stroke Australia Task Force (as cited in NSW Health Department, 1997) reports that of those who survive stroke:

- about half remain dependent on others for at least some activities such as showering, toileting and dressing one year after the stroke;

- almost three-quarters have difficulty with physically demanding activities such as shopping and housework;
- about one-third have some degree of cognitive impairment;
- about one-fifth have some degree of speech impairment;
- around one-fifth have major emotional or adjustment problems with a high proportion experiencing anxiety or depression;
- although around four-fifths have some level of independent mobility, for many it is not functional and they have difficulty walking outside, climbing steps, doing housework or using public transport.

It is not clear how much functional recovery following stroke can be attributed to the rehabilitation process and how much is the result of natural recovery, following reduction in cerebral oedema and other neurological processes not currently well understood. Restoration of function is influenced by a number of factors besides rehabilitation. A number of studies have demonstrated that those who are older, more severely ill, less educated, poor and socially isolated will not have as good a functional outcome as those who are younger, less ill, wealthy and with good social support (Greveson et al., 1991; Kendig et al., 1996; Morgan & Jongbloed, 1990; Rogers & Holm, 1994; Shah et al., 1991). In addition, there is little information about the level of disability and handicap that accompanies impairment, despite the fact that such data is of great importance in program planning. Questions exist about how impairments resulting from stroke actually affect people in the performance of their personal life roles. How effectively are people who have been through a rehabilitation program able to return to the level of meaningful occupation that they experienced prior to the stroke? Qualities such as self reliance and issues such as the presence or absence of effective support for making meaningful and/or healthy choices are not often the subject of program evaluation or research (Jongbloed, 1994; Kendig, 1998). In one study that did investigate role change following severe traumatic brain injury, 71% of role changes were found to be losses (Hallett et al., 1994). These losses were in major organising roles such as work, leisure and friendship roles. The overwhelming majority of respondents identified these roles as very valuable to them (Hallett et al., 1994). Studies of people's roles, social and leisure activities and life satisfaction following stroke show significant losses (Aström et al., 1992; Drummond, 1990; Jongbloed, 1994; Labi, Phillips, & Gresham, 1980; Månsson et al., 1995; Niemi et al., 1988; Viitanen et al., 1988).

The Stroke Australia Task Force (as cited in Wise & Graham-Clarke, 1994) have identified that rehabilitation resources are inadequate at inpatient, outpatient and community levels. They found that rehabilitation services failed to give sufficient attention to the social and emotional sequelae of stroke, and failed to provide an active learning experience, with over 50% of time in rehabilitation spent by clients doing nothing. A Federal Government report (Wise & Graham-Clarke, 1994) identified that new research is needed to develop guidelines and outcome measures, enabling research to be carried out to determine best practice in this area. The report particularly identified a need to develop a greater understanding of cultural, social and economic determinants of health and illness to promote cardiovascular health in Australia.

2.6.2 Stroke Rehabilitation And Occupational Therapy

In occupational therapy practice, and in the sciences that support occupational therapy theory, there has been an explosion in technology and knowledge. Within this context, occupational therapists have an ongoing need to develop and implement therapy programs aimed at promoting maximum levels of independence in life skills and life roles, and optimal quality of life. Occupational therapists must review the way they practice in the area of stroke rehabilitation in order to effectively meet these demands.

2.6.2.1 Occupational Therapy, Impairment and Disability

Stroke is the most prevalent diagnosis encountered by occupational therapists working with adults who have physical disabilities (Trombly, 1989). Occupational therapists have a pivotal part to play in the successful rehabilitation of people back into their own community following stroke. Occupational therapists' concerns are with the satisfactory restoration, not just of lost function, but of occupational performance in everyday life that is specific to and meaningful for each person with whom they work (Neistadt & Crepeau, 1998; Pedretti, 1996b; Trombly, 1995).

In the following discussion, distinction will be made between the terms *skill* and *ability*. It is possible to provide a relatively small list of abilities, which can be seen to underlie all of human task performance (Fleischman and Quaintance as cited in Christiansen & Baum, 1997b). Abilities can be defined as general traits which are products of genetic make-up and learning. *Skill*, on the other hand, relates to specific task performance, being an

expression of level of proficiency in that task (Fleischman and Quaintance as cited in Christiansen & Baum, 1997b). From this, it can be seen that therapists who are working on developing *ability* in their clients are operating mainly at the *impairment* level of the WHO classification. Therapists who are working on developing *skills* in their clients are working mainly at the *disability* level of the WHO classification. Rehabilitation, to be effective, must address all three levels of impairment, disability and handicap (Ottenbacher, 1998).

2.6.2.2 The Rehabilitation Model and Role

The Rehabilitation Model is the model of practice most commonly applied to stroke rehabilitation by occupational therapists and other members of the rehabilitation team. It has a close affiliation to the medical model (Pedretti, 1996b), and places emphasis upon the problem rather than on people in the context of their own environment. Problems are seen in terms of impairment and disability. Occupational therapists working in teams where this model prevails frequently focus their rehabilitation on redressing impairment - that is, on developing skills to deal with loss of motor control, sensory and cognitive abilities (Brodie et al., 1994). Occupational therapists have developed an array of techniques that assist them to work at the performance component (or impairment) level in restoring biomechanical, sensory-motor, cognitive and inter and intra-personal function (Mathiowetz, 1993). They make a priority of skill redevelopment in activity and task performance in such self maintenance areas as dressing, toileting, and preparing a simple meal. Such routines or activities are collectively termed activities of daily living (ADL) (Dean & Unsworth, 1997; Jongbloed, 1994; Pedretti et al., 1996; Wilcock, 1998). Far less attention is generally paid to reducing the level of handicap that clients may be experiencing, or will experience upon discharge home (Mathiowetz, 1993; Radomski, 1995). Satisfactory outcomes using the Rehabilitation Model entail meeting goals set by the therapist. Rehabilitation outcome measures routinely used by occupational therapists, such as the Functional Independence Measure (FIM) or the Barthel, reflect a bias towards the performance area of self maintenance as they are developed to measure performance in activities of daily living (ADL) (Ottenbacher, 1998). Occupational therapy texts reflect this focus on self-maintenance (Neistadt & Crepeau, 1998; Pedretti, 1996b; Trombly, 1995; Turner et al., 1992). As the generally stated outcome for occupational therapy is meaningful and effective occupational performance in the context of the person's everyday life (Neistadt & Crepeau, 1998; Pedretti, 1996b; Trombly, 1995; Turner et al., 1992), this may seem a surprising priority for therapy. Self-maintenance is not a major focus for meaning in most people's lives.

Studies have shown that the focus upon remediation of specific problems at the ability and skill level only, leads to a lack of congruence between the goals of the therapist and those of the client. Campbell (1994) wrote from the consumers' perspective about the differences in priorities between consumers of rehabilitation and health care workers. She argued the case for Independent Living as a fundamental human right. The Independent Living movement identified the environment which surrounds the person with a disability as being problematic, rather than the person. Modification of the environment to fit the person is the focus of action under the Independent Living Model. This is in contrast to the Rehabilitation Model, with its emphasis on the person with the problem. Occupational therapists acknowledge the Independent Living movement and utilise the model particularly when working on community re-integration. However, Campbell felt that what Independent Living meant is often misunderstood by health care workers who apply it to self maintenance only. She felt that within health care services, independence in self care was seen to be the ultimate goal, even though it meant that the role of self-carer dominated, taking up the bulk of the person's available time, leaving no time for other, more highly valued roles. The option of arranging for someone to assist with personal care was not considered by therapists. The consensus arrived at by people with a disability themselves was described by Campbell as follows "*... our independence was about having control over our daily activities and choosing our life styles: that independence was a state of mind, rather than a physical ability*" (p. 89). Accounts by other recipients of occupational therapy rehabilitation services support this view (Callahan, 1989; Hawking, 1996).

There is an assumption by many therapists, particularly those using the Rehabilitation Model, that the restoration of ability and the acquisition of skills are the major hurdles to function. It is assumed that by improving abilities, developing or restoring skills, and practicing the integration of such skills into routine set tasks such as showering, dressing, and making a cup of tea, performance in the context of the person's daily life will follow (Brodie et al., 1994; Mathiowetz, 1993). It has been further assumed that such routine task performance will lead, by a process of generalisation (the spontaneous ability to transfer what is learned in one situation to a different situation), to performance of less routine tasks and the integration of such tasks into meaningful role performance (Brodie et al., 1994). Less time is spent on task performance in the person's own environment, and even less on meaningful occupation in the context of the person's own role repertoire. A study of how therapists used the amount of time they spent in rehabilitation found that therapists spent most time on

redressing impairment (56%). Therapy directed at the level of disability accounted for 28% of their time. The rest of the time was spent mostly on assessment, with a small amount of time spent on dealing with adaptive equipment (Brodie et al., 1994). This is despite the fact that there are well documented difficulties in translating skill acquisition into effective performance of meaningful occupations in the context of the person's everyday life (Mathiowetz, 1993; Neistadt & Crepeau, 1998). People can often perform tasks well in therapy, but do not utilise the skills learned outside the occupational therapy department (Guiffrida, 1998; Wheatley, 1996).

There is even some question as to whether skills learned are translated effectively, into the specific basic ADL tasks that are practiced (Mathiowetz, 1993). Filiatrault, Arsenault, Dutil, and Bourbonnais (1991) measured the upper extremity function and ADL performance of people who were recovering from a stroke, using standardised tests. They expected to find a correlation between the two, but found there was none. They concluded other factors must be involved. Another study found that there was a significant decline in bathing and dressing skills of stroke clients who had been through rehabilitation once they were discharged home, indicating that the skills learned in rehabilitation were not carried through into community life (Strub & Levine, 1987).

When role-related outcomes from stroke rehabilitation are examined, it is evident that rehabilitation fails to restore function at this level. A study of the psychosocial outcomes of stroke rehabilitation found that despite having gained independence in self-care and mobility, a significant proportion (50%) of the people in the study experienced social disability. They failed to return to pre-stroke social activities, and did so in a manner that was unrelated to their functional abilities (Labi et al., 1980). Other research looked specifically at the occupational roles of those who had experienced a stroke (Jongbloed & Morgan, 1990; 1991). The researchers found that thirty percent of their subjects had to alter certain roles or activities. Some were primarily attributable to the severity of the stroke and resulting physical impairment, but they found more frequently that reasons were far less obvious and more complex. They concluded that the severity of the disability was not the most significant factor in the adjustment process. Instead, they identified the most important factor as the interaction of the subject with his or her total environment. They felt that the attitudes and behaviours of the person's family and friends were a vital part of that environment and exerted a strong influence on how the person viewed his or her disability and on how roles and activities were maintained or altered (1994; Jongbloed & Morgan, 1990; 1991; Morgan & Jongbloed, 1990).

Their findings are supported by the work of Aström, Asplund and Aström (1992), Drummond (1990), and Viitanen, Fugl-Meyer, Bernspång and Fugl-Meyer (1988), who all found that life satisfaction and leisure activity following stroke was adversely affected by loss of social support and interaction.

Goals based on the client's own concerns are often not addressed in therapy (Nelson & Payton, 1991). A study interviewing adolescents with cerebral palsy found that occupational therapists working under the Rehabilitation Model did not always set realistic treatment goals for community living or goals that were appropriate to their clients' developmental stage (Kibele, 1989). The consequence of this sort of therapy is that rehabilitation has little meaning for the person, leaving him or her unmotivated and possibly uncooperative. Another study (Chiou & Burnett, 1985) has given further insight into why this might be happening. The degree of importance ascribed to ADL tasks by therapists and by their clients was examined. Therapists were paired with their own clients. It was found that, when individual therapist ratings were compared with the ratings of his or her own clients, there was only one therapist/client pair that showed significant agreement. Twenty-eight pairs did not agree. However, when the ratings of the client group as a whole were compared with the ratings of the therapist group, there was agreement that was statistically significant. In other words, the therapists had a good idea of the overall values of their client group, but not of the values of their individual clients. More recently, a study designed to identify what has meaning to stroke recoverers pointed to individual life experiences as being significant. It was found that this in turn affected how well people were able to return to an active and meaningful life following stroke (Knutas & Borell, 1995).

There are a number of measures that can be used in health care to examine how a person feels about his or her quality of life. These measures involve such things as anxiety levels, perceptions of external control versus internal control and affect. There is a problem with many of these scales in that they present the person with a number of preconceived or set situations and ask them to comment, when in reality different people experience a wide range of situations that cannot all be anticipated by the person devising the test (Viney, 1981). This problem of the examiner setting the agenda by providing lists or set options for response is common even among researchers who believe they are investigating how things are perceived by the person. Viney comments *"there is little understanding among health professionals of the experiences of patients with chronic illness and disability outside the*

hospital setting" (p. 45). This lack of understanding is illustrated by the work of Osberg, McGinnis, DeJong and Seward (1987) who say

Rehabilitation patients are encouraged to discount pre-disability functional levels and to work patiently to enhance their ability to perform everyday activities of daily living. Although this emphasis may serve to reduce the importance of activity as a determinant of life satisfaction, it may increase the importance of the Barthel, which measures changes in the ability to perform these activities of daily living. (p. 229)

The message they describe as being given to rehabilitatees is that all roles (which equate with their identities as people) held prior to the onset of their chronic condition must now be abandoned with the exception of the self maintainer role. All efforts should now be focused on performing satisfactorily in this role alone. In the light of these findings, it is possible that the Rehabilitation Model may limit the ability of clinical practitioners who use it to deliver a satisfactory outcome in terms of a return to community living that has significance and meaning for each person undergoing rehabilitation. The model works well when used to restore lost biomechanical, sensory-motor and cognitive function. However, using only this model, there is insufficient consideration of which specific abilities and skills are needed by each different person undergoing rehabilitation in order to restore meaningful role performance. Therapists using current standard methods of assessment do not have access to this type of information. The information they obtain does not provide cues to what skills are particularly needed by each individual client. It does not inform about the specific nature of each skill or to what level it is required. Neither does it give insight into what steps are needed to ensure that those skills will be translated by people undergoing rehabilitation into the performance of occupations that have meaning to them in the context of their own particular physical, sensory, social and cultural environment.

There is currently a growing awareness of the need to intervene and be accountable for outcomes that are of meaning to the person undergoing rehabilitation. Treatment planning should be organised around each client's definition of the good life (Rogers, 1983). Therapists need to consider quality of life issues and look beyond activities of daily living in planning rehabilitation (Radomski, 1995). Outcome evaluations should address all levels of function, from performance component, through task performance to occupational role performance (Ottenbacher, 1998).

2.7 OVERVIEW OF CHAPTER TWO

This chapter reviewed literature relevant to the purpose of this study, which is to describe the nature of the self-perceived occupational role performance of men in later life who have had a stroke and are living at home.

The philosophical dualism between holism and reductionism within the profession has been strongly influenced over the years by the reductionist approach of the medical profession. This has had the effect of devaluing the philosophy of holism and biasing the level of focus for therapy away from the role level, where holism is the strongest relevant philosophy, and towards the performance component level where reductionism has the greater influence.

In this chapter some of the relevant principles of role theory and the use of role within occupational therapy have been described. It was demonstrated that within the discipline of occupational therapy, where role has been considered, there has been a tendency to limit the concept of role to the structuralist view. This has led therapists to attempt to equip clients to meet some externally sanctioned idea (often determined by the therapist) of how they should perform in their various roles. In addition, it would appear, from the occupational therapy role assessments that have been developed, that there has been a tendency to use the reductionist approach, resulting in an over-simplification of role theory. This in turn has led to an implied expectation that role performance will look the same from performer to performer for specific, named roles.

Occupational therapy models that use the construct of occupational role were outlined, and The Occupational Performance Model (Australia) was described in more detail. This practice model attempts to integrate the concept of role into an overall structure that facilitates the therapist being able to achieve the transition between the philosophy of reductionism (used mostly at the performance component level) and the philosophy of holism (used mostly at the role level). It also describes the use of occupational performance roles in ways that permit consideration of both the external and internal aspects of role performance, although the construct requires further development.

In order to provide further background for the study, some concepts of particular relevance to the internal or self-perceived aspects of occupational role performance were described, such as environmental theory (including environmental control), personal

meaning, choice and satisfaction. Relevant theories and research into social roles in older adults were discussed.

In the final section the literature on stroke outcomes was examined. It was shown that outcomes reflected poor social re-integration and significant losses in terms of roles and role performance. The Australian Federal Government has made recommendations for further research into the cultural and social determinants of cardiovascular health in Australia. In terms of the outcomes of occupational therapy services in this area, there appears to be a discrepancy between the therapist and the client about whether a satisfactory outcome has been achieved. Taking the 1980 WHO definitions of impairment, disability and handicap, occupational therapists, due to the reductionist outlook prevalent in stroke rehabilitation, often focus upon redressing impairment, rather than upon minimising handicap. Stroke rehabilitation clients are much more concerned with the minimisation of handicap, which involves the minimisation or removal of limitations in occupational role performance. Studies of stroke outcomes consistently report serious levels of social disability and handicap that are unrelated to functional ability. There have recently been strong recommendations from within the profession to redress this failing and to move through all levels of performance in rehabilitation.

The move away from holism and towards reductionism has had unfortunate consequences for the discipline of occupational therapy. Neither the concept of role nor its relation to disability are well understood within the discipline. This study provides valuable information about self-perceived occupational role performance in the presence of disability for a particular group of older men. The next chapter will describe the methodology employed to gather this information.

CHAPTER THREE

METHODS

3.0 INTRODUCTION AND PURPOSE

In Chapter One, the primary purpose of this research was outlined as being both to describe the self perceived occupational performance roles of the men in the study in order to gain insight into what is significant to them in their everyday lives, and to explore the possibility that role is a construct that is used by these men in the planning and performance of meaningful occupations. Chapter Two further explored the relevance of role to the practice of occupational therapy in stroke rehabilitation, discussed role theory and identified various factors that may relate to the role performance of older people and those who have had a stroke. To provide the fullest possible description of self-perceived occupational role performance and to identify elements of a possible conceptual model of the nature of self-perceived occupational role performance, the following naturalistic study was undertaken to fulfil the following research objectives:

- 1) To describe the self perceived occupational performance roles of men over 65 who have had a stroke, in order to gain insight into the meaning, motivation for, and organisation of their occupational roles.
- 2) To explore the possibility that role is a construct that is understood and utilised by these men in the planning and performance of meaningful occupations.

3.1 DESIGN

The research design utilised the naturalistic research paradigm to explore the nature and meaning of occupational role performance for men over 65 who have had a stroke and are living at home. Naturalistic inquiry employs qualitative research methodology in the environment of the people being studied in order to interact with them and learn from them (Lincoln & Guba, 1985).

3.1.1 Purpose And Characteristics Of Naturalistic Inquiry

Naturalistic enquiry is based on two assumptions. First, that human beings 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). 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 which 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 may behave differently in a given set of circumstances because unique experiences and knowledge will be brought to the situation (Fine, 1991; Frankl, 1963; Lincoln & Guba, 1985; Spradley, 1979). This means that the research methodology employed must find means to access the internal beliefs and knowledge of the people in the study 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 have been 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.

3.1.2 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 and asked rating questions (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 3.1)

Characteristic	Application to Study

Natural setting	Data was collected in the participant's own home.
Human data collection instrument	Researcher was the primary collector of 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 selected according to their medical history, age, living conditions and employment status.
Inductive data analysis	Narrative data from interviews was analysed to identify themes that developed a picture about participant role performance.
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.
Idiographic interpretation	Information was requested and recorded on an individual basis and for how things were at the time of the interview only.
Tentative application	Interpretation of the data resulted in a description of the occupational roles identified by participants and the meaning that participants ascribed to their occupational role performance. From this information hypotheses were generated about the nature of role performance in this group of men.
Focus-determined boundaries	The nature of self-perceived occupational role performance in a selected group of men over 65 who had had a stroke and were living at home only was studied. No other aspect of role was studied and no other group of men were involved.
Special criteria for assessment of trustworthiness	Participant checking of data, participant generated data (sorting and rating), verification of interpretation using a second investigator, and comparison of findings with current literature were used as criteria for establishing validity and reliability of data collected and interpreted.

Table 3.1 Characteristics of naturalistic research as they relate to the study

3.2 RATIONALE FOR THE DESIGN

This study examined the *perceptions* of a particular group of men about their occupational roles and role performance. A comparison of some of the axioms of naturalistic enquiry with the purpose of this study further demonstrates the appropriateness of the qualitative approach used.

First, the naturalist paradigm states that realities are multiple, constructed and holistic (Lincoln & Guba, 1985). The aim of such enquiry 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 fragmentable. The present research sought information from the participants about their own perceptions of their roles and role behaviour. A naturalistic approach lends 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 the perceived knowledge of each person in the study, and how he developed and used that knowledge. An attempt to see knowledge as separate and independent of the knower, as required by the positivist paradigm, would have been counterproductive.

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 individual 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 may assist in the development of hypotheses which can in turn be tested further in other research. Use of quantitative methodology for this current study required

- i) a known model of an internal frame of reference of role performance
- ii) that it is 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 parameters require further development.

One of the purposes of the study was to develop and extend the aspects of the model relating to occupational role performance. 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 was summarised, leading to the formulation of new questions, and written reports were viewed as part of an ongoing research process. Qualitative methods are intended to allow the discovery of possible relationships between variables that are not already known.

Where investigation relates to the perceived reality of people, qualitative methods are 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 may affect the outcome cannot be known or controlled (Lincoln & Guba, 1985). In the laboratory situation it may be possible to achieve a near approximation of this ideal, but 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. Writers 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) writes:

Considering that our field of expertise is 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, many have 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 have limitations in the scope and type of information they provide. Some assessments, like The Occupational Performance History Interview (Kielhofner & Henry, 1988a) rely heavily upon the interpretation by the investigator of information obtained by structured interview to determine role performance. The majority of studies provided people with a list of assumed roles and asked for an indication of participation and value. Satisfaction with performance was not always considered (Barris, Dickie, & Baron, 1988a; Bränholm & Fugl-Meyer, 1992; Cheng & Rogers, 1989; Cohen-Mansfield, 1989; Dickerson & Oakley, 1995; Elliott & Barris, 1987; Good-Ellis, Fine, Spencer, & DiVittis, 1987; Hallett et al., 1994; Jackoway et al., 1987). Little opportunity was given in these studies for the respondents to identify their own roles. Only one study could be found that appeared to allow the participants to identify and name their own roles (Jongbloed et al., 1993).

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:

- 1) The nature of occupational role performance as perceived by the performer (men over 65 who have had a stroke).
- 2) The use of role as a construct by the participants in planning and performing meaningful occupations.

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

- 1) Whether the participants can discuss their occupations in role terms.
- 2) The nature of occupational role performance among the participants.

- 3) Whether they are able to ascribe meanings to their roles that are either primarily occupational or primarily socio-cultural.
- 4) Participant perceptions of their own role performance.
- 5) Themes that might be identified from participant responses regarding their self-perceived occupational role performance.
- 6) Whether it is possible to construct a conceptual model of self-perceived occupational role performance that could inform knowledge and understanding of occupation, and to further develop the occupational performance role construct within The Occupational Performance Model (Australia).

A semi-structured or focused interview was used. This type of interview involves 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 the interviewer to maintain this focus, as described by Minichiello, Aroni, Timewell and Alexander (1990) (see appendix A). The reason for adopting this style of interview was that most of the men in this study had disabilities. It was considered likely that some of them would have cognitive and/or communication difficulties and that they might tire quickly. A one-off, focused interview approach was considered more appropriate for these men, 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. This sorting provided information about which roles the participant perceived were performed primarily for socio-cultural reasons and which roles were perceived as being performed mainly for occupational reasons. In addition, the roles that were perceived as occupational in nature were sorted further into productivity, self maintenance and leisure. Participants were then asked to provide a rating for each occupational role performance area or meta-role and a rating for their socio-cultural roles. They were asked to rate for frequency of performance, value of the role area and satisfaction with performance in all the roles in that role area or meta-role. In this way, participants named their own roles, gave the main reason

for the performance of each, and rated them for frequency, value and satisfaction, in a way that enabled the researcher to gain an appreciation of what was important to this person in terms of occupation at the time of the interview. Both quantitative and qualitative descriptive data were generated to form an understanding of the meaning of roles.

3.3 PARTICIPANTS

A convenience sample of thirteen participants took part in the study. They met the inclusion criteria as follows:

- i) They were all male. A number of studies have shown that there are differences in occupational performance for this age group between men and women (Bränholm & Fugl-Meyer, 1992; Lipka & Brinthaup, 1992; Palmore, 1970b; Penning & Strain, 1994; Söderback, Ekholm, & Caneman, 1991; Wan & Odell, 1983). Men were chosen because they have a higher incidence of stroke (Anderson et al., 1993; Wise & Graham-Clarke, 1994) and are identified as having fewer resources such as social supports (Horin, 1991; Kendig et al., 1996) to deal with the effects of disability upon role performance.
- ii) Over 65 years of age. Little investigation of this age group has been done from a role performance perspective.
- iii) Have had a stroke requiring admission to hospital and some rehabilitation. The rehabilitation requirement was intended to select those more likely to have some ongoing deficits, of a biomechanical, sensory-motor or cognitive nature.
- iv) Discharged home three to six months prior to interview. The intention here was to allow participants some time to settle into life at home following rehabilitation so that they were able to talk with experience about their current role performance.
- v) Not engaged in paid work. This was intended to eliminate people whose time was largely organised for them by a formal work role.

- vi) Live in the Sydney metropolitan area. This allowed convenience as the researcher visited each person's home.
- vii) Willingness to participate in the study as evidenced by signed or, if willingness expressed but signature not possible, taped verbal consent.

3.3.1 Description Of Participants

3.3.1.1 Participants' Social and Cultural Context

Although this study was designed to describe the self-perceived occupational role performance of participants, consideration of their environment - particularly their cultural and social environment is included to give context to their stories. The youngest participant was 67 and the oldest was 84. Ten were Australian born, while the other three had migrated from Ireland, England and Malta. The three migrants had lived in Australia for most of their adult life. Consequently all participants shared a long-term experience of Australian culture and spanned one generation only; that is to say, the oldest participant was barely old enough to be the father of the youngest participant, and the group represented a reasonably close cohort. An Australian study of the perceptions and actions of older people in relation to health and independence in everyday life found that an important influence on a person's present health behaviour was his or her past life experience (Kendig, Davison, & Walker-Birckhead, 1993). The study found that people who are old today reflect strongly the social circumstances of their childhoods and the effects of the Depression and the Second World War during late adolescence and early adulthood (Kendig et al., 1993). All of the participants, in their youth, would have experienced these two major social events (the youngest participant in this study was born in 1929). History-normative influences are at their greatest in adolescence and early adulthood (Danish cited in Hayslip & Paneck, 1993). As a generality, those who were children or young adults during the Great Depression demonstrate great frugality and a strong sense of independence, having grown up in times of economic hardship, with little institutionalised social support (Hayslip & Paneck, 1993). Hudson (cited in Hayslip & Paneck, 1993) described the historical values of this group as nationalistic, work-oriented, conservative and naive with an optimistic and realistic mood. Although each of the participants had had very different specific life experiences, the general cultural milieu in which they had lived their lives up to the point of the interview would have been shared, in at least some particulars, by the majority of the group.

Analysis of transcripts showed that some of the participants demonstrated great self-reliance and stoicism in dealing with their stroke, and there was an almost universal modesty in talking about themselves. Many spoke of working hard all their lives up to their retirement. A determination to be optimistic was evident, with comments such as "*It could have been worse*", and "*I'll get right!*". Participants were generally reluctant to talk directly about their feelings, preferring to stick to factual descriptions in their responses.

Twelve had experienced life-long marriages, with ten men still married. All of these spoke of how much they valued their partners and how much support they received from them. Of the others, one person lived in a complex situation with his relations-in-law, one lived with a single daughter, and one with a daughter and her family.

All members of the group lived in detached houses with surrounding garden. Living conditions for most participants, as observed by the researcher, were modest but comfortable. Each of the participants had retired prior to his stroke, although for some it had been only partial retirement. More recently, they had all had a stroke, and subsequently experienced disability, being a patient, and going through rehabilitation.

Before describing them further, it should be explained that each participant was given a fictitious name in order to preserve confidentiality and to ease discussion.

3.3.1.2 Participant Reports of Level of Performance in Selected Tasks

Each participant was asked briefly about his level of mobility, communication and personal care and rated by the researcher according to his responses (see Table 3.2). The majority of the participants required at least some assistance in managing personal care and mobility tasks. All participants were able to maintain a social conversation. There were difficulties evident with articulation, memory, attention and concentration span in some of those interviewed. Although therapists who had recruited participants were not asked to give any specific information about them, they did indicate that Mr. Hicks, Mr. Ianna, and Mr. Cousins had cognitive difficulties. These cognitive difficulties were evident during the interview and included such things as short term memory problems, difficulty with attention, concentration and visual perception (arising from hemianopia).

Name	Mobility	Communication	Personal Care
Mr. Flynn	1	1	1
Mr. King	1	1	2
Mr. White	2	1	1
Mr. Cousins	1	2	2
Mr. Driver	2	1	2
Mr. Edwards	3	1	2
Mr. Jacks	2	1	3
Mr. Hicks	3	1	3
Mr. Armstrong	3	1	3
Mr. Gardener	3	1	3
Mr. Leach	3	1	3
Mr. Baldwin	2	2	3
Mr. Ianna	3	2	3

Table 3.2 Level of ability in mobility, communication and personal care of each participant (rated by researcher based on self-report of participant). Level 1 = Performs independently. Level 2 = Able to perform with assistance of equipment or minimal assistance of another person. Level 3 = Dependent upon others for performance.

3.3.1.3 Participant Stories

A short introduction to six of the participants follows. They were chosen at random.

Mr. Armstrong:

When the researcher arrived at the house, the door was answered after a long time by Mrs. Armstrong, who was using a walking frame and an extended oxygen line. She explained that Mr. Armstrong was asleep, but was expecting the researcher, so she would go and wake him. After a little while, she showed the researcher to the family room at the back of the house, where the interview took place. There were several shelves of sporting trophies lining one wall of the room.

Mr. Armstrong lived with his wife who had a disability. Up until his stroke, he had been her carer. Now they cared for each other, with the assistance of Home and Community Care and their family. He expressed a strong commitment to his wife and saw both of them as a team who worked together to achieve what needed to be done.

Mr. Armstrong reported difficulty sleeping, and napped during the day. He and his wife were largely confined to the house, although he attended the hospital for therapy once a week. He received assistance to shower and dress from Home and Community Care and had to be ready for this at 6.30 am. on a daily basis. He experienced difficulty getting himself and his walking frame into the cramped toilet, despite modifications that had been carried out. He spent a large part of each day either doing his remedial exercises or helping his wife with self-maintenance tasks such as meal preparation and washing up. He did not express high levels of frustration, and reported that his day passed quickly because he had so much to do. He appeared most concerned about how little he could now help his wife.

Mr. Armstrong had always been very good at sport - particularly golf and recreational fishing. He no longer played golf or went fishing. He had a number of friends, mostly through his sporting activities and he kept in touch with them mainly by telephone, although some visited him as well. He indicated that he believed in the power of physiotherapy to restore his mobility and carried out his home program with care and determination.

His stroke formed a central theme of the interview, influencing changes in all his other roles. It meant he was no longer able to play golf or assist his wife in the way that he did before. His relationship with his son had been one of a shared interest in sport. Now he and his wife had to rely on their son and daughter-in-law to provide food and do the shopping.

Mr. Baldwin:

Mr. Baldwin lived with his wife at home at the time of the interview. The interview was carried out in the front room of their small suburban house. His stroke had left him labile and depressed. He was unable to read, had some difficulty swallowing and said he found it difficult to communicate what he wanted to say, which he found particularly upsetting. He had hemiplegia but was able to walk short distances with a stick. He spent the majority of his time sitting in a wheelchair and listening to talking books or the radio, street watching and catnapping. Prior to the stroke, he had enjoyed making leather goods, but had given this up because of the loss of function in his left hand. He was distressed at being so dependent upon his wife and appeared fearful of the effect that this might have upon their relationship. He attended outpatient therapy but did not believe that it was effective. He perceived that certain of the staff (particularly the physiotherapists) inflicted pain upon him for no good reason. However, he did enjoy the day out, particularly the opportunity for social contact. He was strongly family orientated and expressed pride that his hard work - twenty-five years without a holiday - had enabled his six children to all receive a tertiary education.

Mr. Hicks:

Mr. Hicks lived with his wife in a comfortable suburban house surrounded by a neat and thriving garden. The enclosed back patio, where part of the interview took place, was full of plants and flowers.

The first interview was cancelled on the arrival of the researcher by Mrs. Hicks because the community nurse had not yet been to give him his shower. She said he was not having a good day. On this first visit, Mrs. Hicks spoke to the researcher for at least half an hour in the front garden about her husband. She reported that he was depressed and angry, and had experienced a series of setbacks with his health, which had not been helpful. On the second visit, he was still in bed following an after-lunch nap. His wife again spoke to the

researcher at length both before and after the interview took place. She appeared stressed and anxious.

The first half of the interview took place in the bedroom, with Mr. Hicks lying in bed. At the commencement of the interview, Mrs. Hicks answered the researcher's questions on her husband's behalf. Despite the researcher's request to interview Mr. Hicks on his own, she remained for a large part of the interview, letting him talk, but interjecting every now and again. Half way through the interview, she suggested a move to the patio. Mr. Hicks got out of bed and transferred into his wheelchair, with the assistance of the researcher. The interview was concluded on the back patio.

Mr. Hicks talked at length. He was quite tearful at times, sometimes becoming upset as he reminisced about past roles as a soldier in the Second World War and as a farmer and livestock buyer. He had spent his working life in Goulburn, but had retired and moved to Sydney several years previously. Until his stroke, he continued to drive from Sydney to Goulburn regularly, to buy and sell stock. His stroke had put an end to this routine although he continued to watch stock prices and advise others when to buy and sell. He and his wife still ran a small business together, buying, making up and supplying high quality lambskin products such as rugs to one or two retail outlets. He still utilised his knowledge and contacts to buy skins and assisted his wife with some of the make-up work.

Mr. Edwards:

Mr. Edwards was a retired stockbroker. He lived with his wife in a pleasant house in an affluent suburb. His stroke had left him unable to walk or use his left hand. At the interview, he spoke cheerfully and at length, with energy and gusto.

The interview was held in the large kitchen of the house, seated at a table strewn with newspapers. His wife was present for part of the interview, working in the background. She did not take an active part in the interview except when appealed to by her husband. He spent quite some time each day keeping up with the news and using his computer to write letters of protest or complaint regarding selected issues that he championed. Much of the interview was taken up with his expositions of these.

Mr. Edwards attended a Day Care Centre one or two days a week. He said he did this mainly to give his wife a break, and to support the centre. He reported it as a rather frustrating experience. He was concerned that his disability and consequent dependency made things difficult for his wife.

Mr. White:

Mr. White lived with his daughter and grand daughter. He was alone in the house during the day as his daughter worked and his grand-daughter was at school. He reported he walked with a stick, but at home, he tended to use the furniture for support. Mr. White attended two different Day Centres two days a week. He did not find the experience valuable and went because he felt that was what was expected of him by his family. The rest of the time he stayed at home in the company of his dog and cat.

Mr. White did not appear to emphasise any particular aspect of his life. He spoke of his various ailments and the importance of taking care of himself, but gave the impression he was trying not to be too much of a nuisance to anyone else, apparently content with his life.

Mr. Ianna:

Mr. Ianna had migrated to Australia from Malta with his wife as a young adult. He worked as a fitter and welder and took pride in his work. An injury resulting from an accident in a car park led to his early retirement. Prior to his stroke, he spent much of his time in the workshop he had set up in a shed in the garden. He enjoyed fishing and took pleasure in cooking for his family. He was a musician, being a guitarist and the conductor of a brass band.

His stroke had resulted in major changes for both himself and his family. This was difficult for his wife. At the interview, almost as much time was spent talking to Mrs. Ianna afterwards as was spent with Mr. Ianna himself.

For Mr. Ianna, his newly acquired disabilities became the focus of his life. He was surrounded by family and friends who had restructured their time in order to look after him. His wife was assisted in her care of him by their daughter, who lived nearby. She had given up her job in order to help her mother from 10.00 to 3.00 each day in caring for her father.

She had a small child of her own. A good friend of Mr. Ianna's came each day at lunchtime to assist him into bed for his afternoon nap. In addition, he helped by taking him to the toilet and showering him occasionally.

During the interview, Mr. Ianna was voluble about his health problems. He was not hopeful of recovery through rehabilitation, but said he "*prayed for a miracle*".

3.3.2 Recruitment Procedure

The participant sample was recruited from the caseloads of occupational therapists working at a number of major teaching hospitals and rehabilitation units in the Sydney metropolitan area. Ethical approval was obtained from the University of Sydney and six hospital ethics committees. Ethics committee requirements did not permit the researcher to actively engage in the selection process or in inviting potential participants to take part. The principle researcher visited the relevant hospitals in the Sydney metropolitan area to inform therapists of the study and its aims and asked for volunteers. Occupational therapists who agreed to assist were sent written information about the study. Therapists selected potential participants from their own caseload or by obtaining nominations from other therapists, according to the criteria set down by the researcher. These people were then contacted by the therapist who nominated them. The researcher provided therapists with material to distribute to potential participants. This material varied slightly as a result of a range of modifications required by different ethics committees. Sometimes the information sheet and the consent form were combined. It consisted of a letter containing information about the study and inviting participation (see appendix B). If people indicated they were interested in participating, permission was obtained by the therapist to forward their contact details to the researcher. Where people were still attending an occupational therapy outpatient program another therapist in the department who had not worked with them made the contact in the same way.

Because selection of participants was done by people not directly involved in the study, some of the criteria were not met in those selected. This meant rejecting some participants before the therapists contacted them to invite them to participate. Originally, participants were required to have had just one stroke. However, this proved difficult to achieve, in part because it was not always easy for the therapist to ascertain whether there had been a previous stroke. This criterion was relaxed.

3.4 DATA COLLECTION METHODS

Participants were contacted by the researcher and an appointment was made. Interviews were held in the participant's own home, in an area chosen by him. The researcher was often offered a cup of tea or a drink and some cake or biscuits during the course of her visit. These offers were accepted where appropriate and were helpful in creating a relaxed atmosphere for the participant.

In most cases there was no third party present. The length of interview varied from 45 minutes to 2 1/2 hours and ended when the participant became tired or saturation of information occurred. Permission was obtained to tape the interview and a tape machine and microphone were placed in full view but in a non-intrusive way on a convenient surface nearby. Participants commented more than once that they had forgotten they were being taped. Efforts were made to achieve rapport using the researcher's knowledge from past experience of working with people of this age and with this disability. During the interview, the researcher was well-mannered and courteous, 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 interview process had six parts (see Appendix A):

- 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.

3.4.1 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 is necessary to ensure that he or she is 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 given to him by the therapist was handed to him again by the researcher (see appendix B). Time was allowed for him to read the written material. Sometimes the participant asked the researcher to read it to him. The opportunity was given for questions to be asked. If the participant appeared satisfied with the explanation, he was asked to sign the consent form (see appendix B). An example of the explanation taken from a transcript is given as follows:

Researcher:

What I am looking at is what people are doing once they have had a stroke and are living back at home again.... I am particularly interested in the roles that you have in life, so that is what I will be focussing on. If there is any problem at any stage with the interview, or if you want to stop, just say so, and we will stop. The contents of this interview are confidential.... The information that you give me will be compiled along with other people I am talking to.... And I will be writing papers for publication and ... a Master's thesis.

3.4.2 Part Two: Recording Demographic Information

Following the signing of the consent form the participant was asked his date of birth and ethnicity. He was asked who he lived with or if he lived alone. He was then asked to describe his level of performance in mobility, communication and personal self-care. The researcher used the following definitions and three point scale to rate the response.

Mobility:

Level 1 independent in community mobility. The person is able to move about his local community without assistance. This may include walking, driving a car and/or using public transport (including taxis).

- Level 2 able to move about the community with assistance. The person is able to move about his local community but requires the assistance of others. This assistance may be in the form of lifts in someone else's car, assistance in negotiating architectural barriers in the community and/or assistance in managing mobility aids.
- Level 3 the person is housebound. He is unable to move about his local community without the full assistance of others.

Communication:

- Level 1 independent in communication.
- Level 2 able to communicate with difficulty.
- Level 3 unable to speak, dependent on non-verbal communication.

Personal Care:

- Level 1 independent in all aspects of showering, dressing, feeding and toileting.
- Level 2 independent in showering, dressing, feeding and toileting with minimal assistance from others. This may take the form of minimal assistance with transfers, verbal prompting or preparation and/or placement of equipment.
- Level 3 dependent upon others for one or all activities of showering, dressing, feeding and toileting.

3.4.3 Part Three: Gathering Information About Role Performance

This section 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 now?"* The purpose of this question was to find out what meaning the participant ascribed to the general term of role. Most of the questions following this grand tour question were descriptive in nature.

Descriptive questions yielded information about what the daily roles, functions and activities actually were for the participants. These types of questions usually yielded a list of tasks and activities that were later consolidated to form role patterns. Sometimes the participant responded with a role statement. As roles were identified, questions designed to establish the nature of role performance, including frequency, value and the participant's satisfaction with his own performance were then asked. Examples of descriptive questions were: *"So how do you spend your time?"*, *"What sort of things do you do with your grandchildren?"* and *"What do you do around the house?"*

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 his roles and role knowledge. Examples of structural questions were: *"How often do you see them?"*, *"Does anyone help you do that?"* and *"Is that role of being a father important to you?"*

Associative questions were asked to allow the researcher to build up a picture of the relationships between the different topics and role areas discussed. Examples of associative questions were: *"So does that relate to another role you have?"*, and *"What about your son? Does he do that too?"*

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. Examples of contrast questions were: *"if you could spend your day doing anything you wanted, what would you do?"*, and *"what is it that stops you doing this?"*. Contrast questions of this type were used to assist participants to focus on immediate role performance needs rather than role performance prior to their stroke. Contrast questions led ultimately to participants being able to **rate their role performance**.

3.4.4 Part Four: Participant Confirmation Of Roles.

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 have been related to another role. This was done by asking follow-up questions and probes:

So would you say that is still a role you have, even though your wife ...

Would you say that you had a role as a stroke rehabilitatee? Or somebody trying to restore his function?

It sounds as though that's not just something that you do on Sundays - is that right?

You take it with you every day?

Would you say you had separate roles as a father and as a grandfather?

At the end of the information gathering stage, the researcher presented the participant with a list of the roles they had discussed, as she perceived them. The participants were asked whether they considered each one to be a role, and whether they were happy with the name given to it. Quite often this led to more discussion about the roles themselves 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.

3.4.5 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. At the end of Part Four the researcher privately sorted the agreed list of roles under the meta-role headings of productivity, self maintenance, leisure and socio-cultural roles. Participants were then asked to do the same thing. Role titles were 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 these major role

headings in large bold print for easy reading. The researcher provided clarification if needed. The 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 get by and get on with the rest of your life.
Leisure:	fun, enjoyment.
Social Cultural:	relationships, being with others, beliefs and values.
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).

This role sorting exercise sometimes led to deeper discussion about the nature of the role, providing further information about the motivation to perform. Participants often commented there was more than one reason they performed in the role. However, only one participant did not sort his roles. The others all sorted roles under the occupational performance meta-role headings as well as the socio-cultural meta-role heading.

3.4.6 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 1 as the lowest rating and 5 as the highest (see Figure 3.1). Four participants did not rate their roles. This was the last item in the interview, so perhaps they were tired. However, these participants were reported to have cognitive difficulties by the referring therapist, so the task may have required more effort than role sorting or may have

FREQUENCY

I do things in this role:

1	2	3	4	5
Never				Very often

VALUE

I consider this role to be:

1	2	3	4	5
Not at all valuable				Highly valuable

SATISFACTION

I feel satisfied with my own performance in this role:

1	2	3	4	5
Almost never				All the time

Figure 3.1 Scales used for part six - participant rating.

been beyond their abilities. This process did not often give rise to much further discussion, and generally did not seem as meaningful to participants as the earlier parts of the interview. Perhaps this is an indication that participants felt saturation had already been achieved, or that this exercise had little relevance for them. They may have been tired or bored by the process. Some participants did indicate by body language that they found the process tedious. Others seemed happy to do it.

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. If they wished to discuss anything further the interview continued. The researcher then thanked the participant, made sure he had her contact telephone number and understood that he could ring if he had any further queries about the interview, and left.

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 role performance 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.

3.5 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 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). 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 writers (Gliner, 1994; Sandelowski, 1986). He identified four factors that provide a useful framework for naturalistic enquiry: *truth value*, *applicability*, *consistency* and *neutrality*.

Gliner (1994), following a review of the literature, including Guba's (1981) model, developed a set of criteria for evaluating qualitative research articles for the level of credibility or truth value - terms which are seen as parallel to internal validity (Gliner, 1994; Lincoln & Guba, 1985; Sandelowski, 1986). He identifies triangulation, negative case analysis and testing rival hypotheses as being of highest priority, with member checks and peer debriefing to be used if possible. Alternatively, he suggests that researcher credibility and prolonged engagement "*should not be given much weight*" (p.86). Hasselkus (1995), feels these attempts to parallel quantitative terminology are not necessarily helpful as they continue the perception that quantitative criteria must somehow be considered when evaluating qualitative research. She cites Lincoln (1986) to support this view.

For the purpose of this study, Guba's (1981) model has been employed for evaluating the rigour of data collected and interpreted. This section of the chapter outlines each of the factors in Guba's model and demonstrates how they have been applied to this study.

3.5.1 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 was 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:

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. Twelve of the thirteen participants sorted their roles and nine rated them.

The transcripts of the nine participants who rated their roles were analysed for role frequency, value and satisfaction statements. These statements were then subjectively compared with each of the twelve ratings given by each participant, using definitions given for part six in the appendix of the Occupational Performance Role Assessment (see Appendix A.2) as a guide. Agreement was recorded only where there was evidence of a match. A conservative approach was taken. An estimated 80% overall agreement was established in this way, with a range from 66% to 92% agreement. Mr. Jacks, who had the lowest agreement at 66%, was interrupted repeatedly by other occupants of the house during the rating process. It would seem that overall, the ratings could be usefully examined as a numerical representation of how the participants saw their roles at the time of the interview.

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

Member checks:

These consisted 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). In this study participants were asked to 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.

Prolonged engagement:

This is considered important by Lincoln (1985), however, Gliner (1994) considers that prolonged engagement does not guarantee support for a hypothesis, while short engagement does not exclude it. Although, in this study, there was not prolonged engagement with each participant, 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. Earlier data was used to inform the evolution of the data collection methods. In particular, the final six interviews, conducted in the second half of 1996 reflected a change in emphasis during data collection from mostly descriptive and structural questions to an increased number of contrast questions. This proved to be more successful in tapping the personal views of the participants.

Negative case analysis:

The cases that did not fit with the conclusions or hypotheses formed as a result of this study were examined, and attempts were made to try to ascertain why they differ. Gliner (1994, p. 85) believes that philosophically, *"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"*. Such negative cases were identified and will be discussed in Chapter Four.

Testing of rival hypotheses:

Patton (1997) suggests that researchers should search for other possible explanations to describe findings and that failure to find these adds support for the developing hypotheses. Efforts were made at the data analysis stage in this study to investigate alternate explanations of the findings by returning to the data to search for evidence to support them, and the perspectives of the second reviewer were sought about possible alternative explanations.

Credibility of the researcher:

Gliner (1994) maintains this should be a minor consideration - as it is for quantitative research. In this study, the researcher is an experienced clinician, who has worked for many years with people who are elderly (mostly Australian male war veterans) and with people who have had a stroke. She was supervised by an experienced researcher.

3.5.2 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) point 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 can lead to misunderstandings and distortions of the real world. Lincoln and Guba (1985) propose a concept more appropriate to qualitative research - that of transferability. The emphasis is on hypotheses that may be generated as a result of this interaction which may 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 see transferability as essentially the responsibility of the subsequent researcher who seeks to apply the findings of the original study elsewhere. They state that it is 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 has been taken to provide as much detail as possible to allow understanding of the research process used to permit the possibility of replication.

3.5.3 Consistency

Unlike quantitative research, where the research instruments are required to measure phenomenon 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 will 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 confirm or deny 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, another researcher reviewed a number of 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).

3.5.4 Neutrality

Neutrality refers to freedom from bias in research procedures and results (Sandelowski, 1986). It refers to 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 have been 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 constant modification and refinement of the interview technique (see appendix A1).

Treatment of Researcher Effects

Because people are indivisible from their environments, in any form of research, the researcher will affect 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 three possible forms:

i) *Changes in participants' behaviour as a result of researcher presence.* All participants have to determine what information they will offer and what information they will keep to themselves. In this case, because of ethical requirements, participants were originally approached by their therapist, so there may have been an ongoing perception that the researcher was part of the hospital system. If the participant was still undergoing outpatient treatment or believed he would need the hospital's services in the future, this could have influenced the information he was prepared to vouchsafe. In order to counteract this effect, as well as to provide identification, the researcher wore a name badge with the University of Sydney crest on it and handed the participant her card on arrival. In addition, the information sheet given to the participant at the outset was written on University of Sydney headed paper. It was stressed that all information given would be treated confidentially, and if the opportunity arose, the researcher stressed that she was not part of the participant's hospital system.

Signing the consent form was a problem for some participants, who showed some reluctance. They read the form very carefully and asked questions about why they were being asked to sign something before agreeing to sign. In one instance, the wife of the participant suddenly appeared at his side when he was signing the consent form - apparently to check he was not signing anything that could be detrimental to either of them.

ii) *Changes in the researcher as a result of the data collection procedures.* As research proceeds, the researcher may 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 three academics - an occupational therapist, an anthropologist and an educator. They were all 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 study was reviewed in a number of ways. Transcripts were analysed to identify themes which were then discussed via supervisory discussion and formal and informal presentation. This helped to alert the researcher to aspects of the interpretation of data that may 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. The researcher sought feedback in the public forum via five conference presentations (Hillman, 1993; Hillman & Chapparo, 1995b; Hillman & Chapparo, 1997a; Hillman & Chapparo, 1997b; Hillman & Chapparo, 1998); a poster presentation (Hillman & Chapparo, 1995c); and a journal article (Hillman & Chapparo, 1995a) which was subsequently reproduced in a monograph (Hillman & Chapparo, 1997c). 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 3.3.

3.6 DATA ANALYSIS METHODS

Data analysis in this study sought to discover the nature of occupational role performance in men over 65 who had had a stroke and were now living at home in the community. 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 the possibility of

CRITERIA	STRATEGIES USED
Truth value	- Triangulation - Member checking - Prolonged engagement (with the data) - Peer examination of data - Negative case analyses - Testing of rival hypotheses
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

Table 3.3 Summary of strategies used to establish trustworthiness using Guba's Model (1981)

further theory development. Certain concepts used to structure the analysis were determined by the researcher before the commencement of research. Others were determined in the course of the interview, while 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).

- i) **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) (see appendix D).

- ii) **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 (see section 3.6.2 and appendix D). The analysis ended when the process 'exhausted' the data.

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

Memos were kept as the data collection process continued (see appendices A1 and D3 for examples). 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.

- iv) **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 (see Appendix D).

- v) **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 (see appendix D).

vi) **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 (see appendix D).

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

Categories were flexible, going through a process of evolution as the data informed them in order to accommodate later data (see appendix D).

viii) **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 (see section 3.6.2 and appendix D).

ix) **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).

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

The product of analysis as outlined in later chapters can be described as a composite summary of factors involved in self-perceived occupational role performance for men over sixty-five living at home who have had a stroke. Its purpose was to develop new concepts or theoretical categories that could be tested in subsequent research.

3.6.1 Procedures

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

3.6.1.1 Conversion Of Data To "Write-Ups"

All obtained raw data (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 (see appendix A3). This information was later transferred to the Preliminary Transcript Analysis Form (see appendix D2). Tapes were converted to written transcripts (see appendix C for examples). After each transcription was complete, it was edited by the researcher for accuracy.

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

3.6.2 Coding Process

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

3.6.2.1 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' rather than word or sentence 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 D1 for example). Specifically, 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 right 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 right hand margin next to the section of script to which they related.

This first-level coding was then analysed using a standardised form (see appendix D2) 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 by the researcher at the time of interview.
- 2) Mobility, communication and personal care ratings are compared with supporting or contradictory evidence in the script, using the definitions in the appendix of the OPRA manual (see appendix A2) as a benchmark.
- 3) Roles identified by the researcher in the first level coding were compared with those confirmed or identified by the participant.
- 4) Role sorting done by the researcher was compared with role sorting done by the participant.
- 5) 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.
- 6) Ratings for frequency, value and satisfaction were examined using the OPRA appendix definitions as the benchmark (see appendix A2). 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 (see Appendix A1). Feedback on the methodology and early analysis was sought at this stage by the presentation of the first conference paper (Hillman, 1993).

3.6.2.2 Pattern Coding

Stage One

Following this preliminary coding, the data from the first seven interviews conducted by the researcher were reviewed and emergent themes were identified. Notes were kept of themes as they became evident to the researcher (Miles & Huberman, 1984) (see appendix D3 and D4). Topics and themes that occurred and re-occurred were then identified and assigned preliminary codes that subsequently became the initial content label. The following themes were identified at this stage:

- 1) Role statements: information about the statements made by participants when asked about their roles.
- 2) Commonly occurring roles: information about roles that were most commonly held by participants.
- 3) Role sorting: information relating to the nature of role sorting and to discrepancies between the sorting of the researcher and the participant.
- 4) Role rating: information about the ratings made by different participants and how those ratings compared with statements made earlier in the interview.

The process of data analysis was formalised at this stage by the presentation of the second conference paper (Hillman & Chapparo, 1995b) and the publication of a journal article (Hillman & Chapparo, 1995a).

Stage Two

The transcript was further coded according to the roles that had been identified and sorted by the participant. These sections were then cut and pasted under the relevant occupational performance meta-role and socio-cultural role headings, so that all the sections of the transcript relating to a specific role were placed together under the relevant meta-role heading. All the roles the participant had sorted under a particular performance area were listed, and 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 D3, stage 2).

Stage Three

Interpretive: An extensive description of role performance was written for a number of the 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 D3, stage 3).

3.6.2.3 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 may be recurring across the participants' data (see appendix D4). 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.

3.6.3 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 was obtained directly from the participants. Information was weighted according to how frequently the different participants chose to talk about it. Indirect input, particularly researcher interpretations of events, reports of informal conversations and data from secondary sources was 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.

3.6.4 Model Development

As a result of this analysis, relationships between the major identified themes began to emerge. There appeared to be three 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. Theoretical concepts drawn on to develop the model, from both inside and outside the discipline of occupational therapy, include occupational performance, 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 how the construct of occupational role performance is perceived and utilised by the participants in this study. It requires further research to establish its validity. The process of data analysis was further formalised at this stage by the presentation of three more conference papers (Hillman & Chapparo, 1997a; Hillman & Chapparo, 1997b; Hillman & Chapparo, 1998).

3.7 OVERVIEW OF CHAPTER THREE

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 Chapter Three are described in the next chapter.

CHAPTER FOUR

FINDINGS

4.0 INTRODUCTION

This chapter presents the information that was obtained in accordance with the purpose of the study outlined in Chapter One, and using the methodology outlined in Chapter Three. The purpose of the study was to describe the nature of occupational role performance in this group of men, and to explore the possibility that they understand and use role as a construct in the planning and performing of meaningful occupations. As described in Chapter Three, participants were asked to discuss their roles in terms of the here and now. Because roles are dynamic in nature, it was hoped in this way to get a slice in time - a section of the person's life as he saw it at the time of the interview. This approach has lent itself to viewing data in a spatial manner. This can be done both at the role repertoire level, and at the individual role level. From a temporal perspective, comparisons were not actively sought by the researcher between participants' present and past role performance. Nevertheless, most participants volunteered information about their self-perceived past role performance and made such comparisons. When discussing role performance in the here and now, at the time of the interview, information was provided about the temporal organisation of the person's occupational performance role repertoire.

On analysing the data, three major themes emerged, which had both spatial and temporal aspects. They were:

- 1) Active Engagement
- 2) Personal Meaning
- 3) Perceived Control

Each of these major themes has a number of sub-themes. Further consideration of the themes that were identified led to the emergence of a preliminary structural model that represents the extended development of the personal aspects of occupational performance roles that were identified.

Research findings in this chapter are outlined as follows. Participant perceptions of the concept of role and a list of the roles that were identified, is followed by a presentation of each of the major themes with their sub-themes. The development and form of the model is discussed, and finally there is a summary of the findings.

As previously stated, it should be noted that in order to identify and discuss participants more easily, and to respect confidentiality, each has been allocated a fictitious name. For the purposes of clarity, and ease of reading, participant quotes are given in italics.

4.1 PARTICIPANT PERCEPTIONS OF ROLE

The main part of the interview began with a grand tour question - typically: "Can you tell me a bit about the roles you have right now?" Although only one participant responded with a role statement, participants replied in a manner that indicated an understanding of the level of the question. It was possible, through discussion, to establish clearly with participants what the definitions of their roles were. For example, Mr. King disagreed when the researcher suggested he had a role as a time passer, saying that he always had a reason for everything he did. He decided that the activities that had been identified and grouped together (for example, sitting in the sun and watching television), were his Leisure role. Mr. Cousins became quite angry when the researcher suggested to him that watering a tree in the garden, which he did regularly, could perhaps be seen as part of a role he might have as a gardener, saying "*I think that's bull!*" He saw his watering as an activity unconnected to any particular role, saying "*I just water the tree*".

Participants talked of their roles in the context of their lives. They chose to respond to the grand tour question by discussing the thing that most concerned them or that was their main life focus at the time of the interview. Mr. Gardener's response was:

My main idea is to get out of the wheelchair and able to walk. That's the main thing I want to do. That's why I will do whatever therapy they've got for me to do ... And as I say, what's taught me today - they can tell you what you've got to do. They can't make you do it. You've got to do it yourself.

For the rest of the interview, Mr. Gardener returned often to this theme. Overcoming the after-effects of his stroke formed a major part of his life and his aspirations at the time of the interview.

Mr. Hicks response was:

*Oh, just looking after the family the best I can, you know. ... I worked right up to this stage. Mainly on salaries and commissions and that. **I am a livestock buyer.** Mainly sheep and cattle.*

He chose to mention two roles that were central to his life - the role of family man and his paid work role, in which, although retired, he was still active. His stroke had left him with severe disabilities and he spent a great deal of his time in the overt and covert performance of his role as a Livestock Buyer. He reminisced extensively throughout the interview about this role.

4.1.1 Participants' Perception Of Occupational Role Performance

Participants talked of their roles predominantly in ways that could be interpreted in terms of **occupational performance**. They responded often to the grand tour question by talking about **patterns of occupational behaviour**. For example, Mr. Flynn did not have much disability following his stroke. Nevertheless, he spent most of his time resting or pottering around the house. He responded to a request to name his most important role as follows:

Yeah, important ... my, my. (laughs) I can't, you know. An important role? What roles are they? Can you help me? Cos I don't have any important ... See ... I'm a useless being. ... See, most of the time is what you see me now ... Sittin' down, to be honest. I've never been ... a bloke who's, you might say, energetic. ... No skills. You know, like, I was in the foundry. A moulder in the foundry, but apart from that ... apart from that ... by God there's nothin' glorious about me. You know?

Because he did not see his **person-environment-performance** relationships as being very active or requiring the employment of any specific skills, he was unable to identify that he had any **important** roles. He was equating role directed activity and skill with importance.

The nearest he could come to answering the researcher's question was to refer to his old paid worker role. The concept of **occupation** was a significant part of Mr. Flynn's concept of role.

Mr. King was someone who had gone through life doing things for other people. He was finding his dependency on others particularly difficult. In response to the grand tour question he said:

Very limited. I try to help when my wife washes up, I try to wipe up and I can't hold anything in this left hand because I've got no strength in it ... I find life at the present moment very frustrating.

For his role of Husband, he demonstrated an **acceptance of a code of norms** in terms of helping his wife with the washing up. One of his **chosen patterns of occupational behaviour** was to help his wife. He felt a strong **need** to do more and help his wife in his **chosen** role as a partner, but felt he was no longer **competent** in this role because he was unable to **express his place** by making a **contribution** and demonstrating his ability to **conform**. In this instance, he was discussing his performance in the **self-maintenance** aspects of his role as a Husband. At other times he talked of other roles that were important to him that were predominantly **productive** in nature. He saw himself as providing a service to others in these roles. He was, for example, an active member of a Surf Lifesaving Club. His **person-environment-performance** relationships were not satisfactory to him because of his disability. His **Occupational Performance Roles** had changed due to the **circumstance** of his stroke and his resultant loss of **ability** (Chapparo & Ranka, 1997a).

4.1.2 Roles Identified

A wide range of roles was identified at the time of the interview. Sometimes these were named by the participant. More often, the names were suggested by the researcher, based on what the participant had told her. In every case, the named role was discussed and confirmation was sought that the participant did indeed see it as a role. Participants identified an average of seven roles each, with the smallest number identified being five and the largest ten.

A total of 42 named areas of activity were discussed and confirmed as roles by the participants. These roles refer to areas of activity ranging from the very specific (for example

Newspaper Reader) to the very broad (for example General Leisure) (see table 4.1). The role of Father was most commonly named (ten times), followed by the role of Husband (nine times), Friend (eight times) and Grandfather (six times).

4.2 THEMES ARISING FROM THE DATA

Three levels of theme emerged from the data analysis procedures described in Chapter Three. In the early stages of data analysis, three themes emerged. These were named Active Engagement, Personal Meaning and Perceived Control. As data analysis proceeded further, these themes became unmanageably large. A number of sub-themes and then strands within the sub-themes were developed. Each major theme has three or four sub-themes, and many of the sub-themes have several strands. The major themes will be presented in turn, along with their sub-themes and strands.

4.2.1 Active Engagement

The first of the major themes is Active Engagement. As themes were identified, a number of them could be seen to relate to aspects of participants' active occupational role performance or engagement with the environment. Each participant had a certain style about the way he performed in his roles. The theme of Active Engagement relates primarily to how participants described their role performance in terms of the *doing* aspects of each role, although caught up in that are aspects of *knowing* - about themselves and their environment and *being* - about motivation, how their performance affects them and how it makes them feel.

A number of sub-themes relating to participants' perceptions of their Active Engagement emerged from analysis of the data. The main sub-themes identified in relation to the major theme of Active Engagement are:

- 4.2.1.1 Occupational performance role repertoire
- 4.2.1.2 Temporal perceptions of occupational role performance
- 4.2.1.3 Occupational performance role transitions and role continuity.

Animal Lover	Bird Watcher	Bowler
Brother	Business Partner	Campaigner
Christian	Club Member	Consultant
Correspondent	Day Care Attender	Dog Owner
Expert Adviser	Family Member	Father
Friend	Gardener	General Leisure
Grandfather	Great Grandfather	Home Maintainer
Husband	Mate	Meal Preparer
Model Railway Buff	Neighbour	Newspaper Reader
Personal Carer	Person With a Disability	Pet Owner
Remedial Exerciser	Self Maintainer	Shareholder
Sports Follower	Stamp Collector	Street Watcher
Stroke Manager	Stroke Recoverer	Stroke Survivor
Talking Books, Radio Listener	Time Passer	TV Watcher

Table 4.1 List of named roles identified by participants arranged in alphabetical order

4.2.1.1 Occupational Performance Role Repertoire

Each participant had a range of roles that were discussed at the interview. Using probing questions, the researcher made sure that all the roles identified were being actively performed by the participant at the time of the interview. While not all roles were necessarily identified in the interview, it was assumed that those that were had relevance to the person at that time. It was clear from the data that participants organised their roles, and that their role repertoire had a certain structure, in terms of priorities and time allocated to role performance. When the role repertoires of individual participants were viewed as a whole, the following strands were identified.

Role Hierarchy

It became clear from early interviews that participants viewed their occupational performance roles as forming a hierarchy. This was further demonstrated when participants in later interviews were asked to sort their roles from first to last in order of priority.

Example: Mr. Driver

Mr. Driver belonged to a number of clubs and went to a club at least once a month. He was not enthusiastic about this role, and placed it last in order of priority.

I'm not ... not much of a club man really.

Q: "So, you go for special events do you?"

Not if I can get out of it. (laughs)

His main reason for going seemed to be because of his roles as a Husband and a Father. He went because his wife and daughter wanted to go - even though he would have preferred not to.

*No, I went for my birthday the other day, that is all. My daughter came down. She said "Come on we'll take you to the club". **I didn't want to go but I went.***

Q: "Did you enjoy it?"

Not really. No. I can't see any sense in it.

Mr. Driver identified his role as a Husband as being his most important role. He described his wife as his "*best mate*". However, from what he told the interviewer, it seemed that he felt the role had changed and that he was no longer able to support his wife in the ways that he had done before his stroke. Instead, like so many of the participants interviewed for this study, he was now more dependent upon his wife. He needed her help to shower and dress and to drive the car.

Well, I can't manage without her ... No, I couldn't manage without her. ...

Example - Mr. Leach

Ascribing a high level of importance to a role did not mean that participants were always very active in that role. Mr. Leach identified the role of Stroke Manager as his top priority. He attended outpatients twice a week, and considered his rehabilitation important. However, he was not a very active participant.

Q: "Do you do much at home, to supplement Outpatients?"

Not much. ... They give me exercises but, I don't get round to doing them, somehow.

Q: "What's the main reason you go [to Outpatients]?"

Oh, exercises. To get better.

Another form of hierarchy was discerned. Some participants described roles that had the potential to encompass broad areas of activity. Other participants identified or confirmed very specific areas of activity as roles. For instance, Mr. King confirmed Leisure as one of his roles. In this role, he described doing things to pass the time. He sat in the sun and watched television. Mr. Flynn confirmed Newspaper Reader as one of his roles. He described this role as reading the newspaper every day and taking an interest in current affairs. Some participants specified separate roles for Father, Grandfather and Great grandfather. Others had at least two of these titles, but expressed satisfaction with the role name of Family Member.

The last hierarchy that was identified related to the degree of clarity with which roles were defined. Participants identified some roles clearly and spoke with confidence about what they did in that role. Other roles were identified with less certainty, and at times there appeared to be considerable overlap between roles. For instance, Mr. Edwards identified the roles of Campaigner and Letter Writer. The letters he wrote were mostly about the matters he took up in his role as a Campaigner. It was not clear, from what he said, quite where one role stopped and the other started. However, when discussing his role as a Father, Mr. Edwards was able to delineate the role clearly in terms of what he did and did not do. Roles that carried overt social prescriptions such as Father generally seemed easier for participants to define than roles with little external prescription.

Occupational Performance Role Focus

Some participants had one or perhaps two roles that were of particular importance to them at the time of the interview. This role or roles took up most of their time and energy, as they sought to exert as much control as possible in this or these areas of their lives. For some it was their role as a person with a newly acquired disability following their stroke. For others, it was a role that they now considered lost, for instance, Mr. Hicks and his lost roles as a Livestock Buyer and Farmer.

Example - Mr. King:

Generally, it was clear from his responses that Mr. King had a very strong community service orientation. His stroke had severely interfered with this and the loss of this ability to do things for others caused him a great deal of distress. The occupational performance meta-role area of focus for Mr King was Productivity. He sorted four of his nine roles under this heading. He gave two of them (Husband and Father) first and second priority when asked to prioritise his roles. Prior to his stroke, he had just retired from his own plumbing business, employing other plumbers. Despite being the boss, he had kept himself on call on weekends right up until retirement, and had planned to continue working in a smaller way:

Yes, I had retired. ... Yeah, we'd got out of the business. But I'd only just had a couple of months of retirement and then I had the stroke. ... You see we had a business at Seven Hills and I had nine people working for us. And we downsized that. And I was just going to ... just continue on, on my own, doing little bits and pieces you know. But that's all gone now.

He had been in the habit of doing all his neighbour's and friend's plumbing without charge, lending a helping hand where needed.

*No. Well, ... not patting myself on the shoulder or the back or anything, but ... **I used to look after a lot of houses around here for friends**, you know. If they had problems with their building or plumbing or anything like that, I could fix it for them. I find that now that I can't do it. ... they're all saying well ... 'we all know how bloody expensive plumbers are now that we've to get one and pay one'. Where I used to do it all for free for them. **And I find that frustrating, that I can't get out and help these people**. As I said to (Mrs. King) when I first had the stroke: 'God, who is going to fix all these things up if I'm incapacitated?' You know. Her reply was 'don't worry about it, it's not your worry'. But ... **I used to get a great joy out of that. Being able to go down and help people**.*

He had been a very active life saver in the past, and still organised something once a year for his surf club. It seemed that he felt the loss of independence he was experiencing as result of his disabilities particularly as a loss of being able to do things for others.

The participants who could be defined as having a role focus were Mr. Armstrong, Mr. Cousins, Mr. Gardener, Mr. Edwards, Mr. Hicks, Mr. Ianna and Mr. King. For the other participants, (Mr. Baldwin, Mr. Driver, Mr. Flynn, Mr. Jacks, Mr. Leach and Mr. White), the role focus was not strong. Their role repertoire appeared more diffuse, with no obvious commitment to Active Engagement in any specific role or meta-role area.

Purposeful Occupational Role Performance

Those participants who were strongly role focused appeared to be very purposeful in their role performance. Those who were unfocused appeared happy to just let things roll along.

Example - Mr. Gardener:

Of those who rated their roles, Mr. Gardener was the only participant who indicated he was maximally satisfied in all areas with his role performance. His stroke had left him with a dense hemiplegia, a mild dysarthria, and some difficulty swallowing. The imposed role of managing these disabilities had changed his life. He said:

Because when you [have a stroke], well, you are in it. It's a nightmare, and ... you can't get out. It's like ... going through a tunnel and you can see the light at the end of it and you're clawing and clamouring to get to it, but you can't.

Mr. Gardener took active steps to deal with the unwanted position in which he found himself. He read about his condition:

I read up on these things ... I like to know how they start in the first place. Strokes and things like that. What I've read is all right about them. Just the things I thought were important. I realise how that works and what happens.

He thought and planned what he was going to do to deal with the situation and was very organised in his role performance. He found role sharing was of great assistance in managing this role. His wife helped him with his home therapy program:

The wife gives me therapy twice a day. I get it three times a week over at the day care centres. What I learn there, I've been able to tell the wife. We try to carry that out as further therapy. Because I look at this way - what you learn on Wednesdays, if you don't get any more done till the following Wednesday, you go backwards. ... So you've got to have it continuous. ... That's what we do. ... I go in on Wednesday and have full therapy, for walking. I walk with an aid but can't walk without, because I can't stand alone. Then I come home and tell the wife what's been doing. Then we put the actual therapy into practice. ... We spend two hours a day doing it. First thing of a morning, (then in the) afternoon, say about two o'clock. Then just before going to bed at night. Takes about an hour and a half to get into bed, by the time I start off. ... Have a cup of tea or coffee or something. Get dressed ... ready to go to bed. Get on the bed from the chair and then we start therapy. It runs then for about an hour ... by the time we do all we want to - got to do. And then ... you feel all right. Sometimes you feel good. Other times, it's an effort to do the work ... what you want to get done. It's very difficult doing it that way. And of course, this week, the therapist at the Day Care Centre wants to see the wife to give us more instructions on what to do. Well, if you carry that out together it's not so bad.

Mr. Gardener dealt with his role as someone with a disability in the same way as he had been accustomed to dealing with all his roles. He worked hard at doing what he

considered, after careful thought and planning, would produce the outcome he wished from his Active Engagement. This active approach to role performance, along with the tactic of role sharing, was successful for Mr. Gardener, despite the difficulties he was experiencing.

Active Engagement versus Passive Engagement

It appeared that two of the participants (Mr. White and Mr. Leach) could be characterised as being much more passively engaged in their roles than the rest of the participants. They used passive language about their role performance, and appeared somewhat detached from the world around them. They both seemed happy to let events unfold around them without seeking to take a particularly active part, relying on their role partners to largely determine the nature of their role performance.

Example - Mr. White:

Mr. White had a number of roles, but did not show a great deal of interest in any of them. The only time he became animated during the interview was when talking about his dog and his cat. His somewhat passive attitude was perhaps summed up by what he said when discussing giving up his driving licence:

*Well, I decided that I wasn't quite with it when I am out on the road so to speak. That's it. **Let somebody else dodge me instead of me dodging them.** And I gave up my licence.*

Mr. White's response to the grand tour role question was:

Well, I'm just looking forward to the time when it folds up, and ... somebody else has got to look after that problem then. ... It doesn't worry me. I've got a limited time I know, and I just keep on going.

Q: "It sounds like you are just ticking over now?"

Oh, I'm ticking over, yes. ... It doesn't worry me in the slightest.

Q: "So, you're not unhappy about things ...?"

Oh no!

He explained that he knew that his health was precarious, and had adopted a philosophical attitude as a result.

... and I'm lucky to be here. Oh well, day in day out. ... Oh well! That's me!

His attitude may explain his passive approach to occupational role performance.

Alternatively, it may be that he had actively chosen to wait out his time until his death. His occupational role performance may have been more active than it appeared.

Role Repertoire Performance Style

Participants' reporting of their role performance repertoire revealed variations in style. Three styles of performance were identified as a result of further examination of the data. These were *planned and active*, *unplanned and active*, and *passive*.

Planned and Active. As discussed earlier in this section, some participants demonstrated *role focus*, talking about one role in particular with emphasis and enthusiasm throughout the interview. There were variations in the role *level* for this focus. Sometimes it was on a whole occupational performance meta-role area and all its roles, and sometimes it was on just one or two roles. Those who had a role focus behaved or attempted to behave purposefully in carrying out that role. They talked at interview about matters related to setting goals for achievement, planning carefully for future performance, and evaluating role performance outcomes. The *occupational* aspect of the focused roles was most important to these participants, whether overt or covert. Their performance in relation to these roles was *planned* and *active*.

Unplanned and Active. There was a distinction observed between role priority and *role focus*. Some participants sorted their roles in order of priority, but did not appear to have one role or role area that was particularly absorbing to them. They appeared to spread their time and their thoughts fairly equally among a number of roles. The occupational aspect of their roles appeared important to them and they remained *actively engaged*. These participants tended to be *unplanned* and *active* about their role performance, taking things as they came, but participating actively in whatever role they were in at the time.

Passive. There were several participants who seemed to have a much more passive attitude to life and their place in it. They did not demonstrate the enthusiasm and drive found in participants who were role focused, and there was not the same evidence that they thought a great deal about how to achieve in the performance of specific roles. These participants did not describe active participation in their roles, and may even have become 'stuck' in the development of their roles. They tended to speak quite a lot during the interview about the relationships they had with others. They may have been more focused upon the *social* and/or *cultural* aspects of their roles, to compensate for losses in occupational role performance.

4.2.1.2 Temporal Perception of Occupational Role Performance

From what the participants reported about the nature and frequency of their performance in specific occupational performance roles, it became clear that they used the concept of role to organise their time. To a greater or lesser extent, it appeared that all of the participants had had their time use seriously altered by the results of their stroke. Nearly all reported a wish to spend their time more actively doing more in their roles of choice, rather than spending time in enforced idleness. Both Mr. Driver and Mr. Hicks wanted to return to farming, for example. Those with a severe disability had, by necessity, to spend longer than usual periods of time in their Self Maintainer role, dealing with personal care and, for some, home maintenance aspects of occupational performance. A number of participants took the remedial aspect of their role as a Person With a Disability very seriously, and spent a significant amount of time actively engaged in this role, either attending physiotherapy and occupational therapy or doing the home exercises prescribed for them. Time was set aside each day by Mr. Armstrong and Mr. Gardener specifically for this. Others appeared to spend their time more evenly across their role repertoire.

A number of participants reported that they did not feel time passing slowly.

Mr. Armstrong:

And the day is gone. Goes so quickly because we've got so much to do.

Mr. Flynn:

Well, I dunno where the time goes!

Mr. Driver reported that he never felt that time was heavy on his hands.

It seems to go pretty quick, remarkably. You know, you would think it'd be boring, but it's not boring.

When asked what he did, he said:

Just normal things, you know. Just ... sit around living. That's all there is.

It seemed that he spent his time moving in and out of most of the roles in his repertoire with no particular temporal emphasis, apart from keeping appointments to help his son with his horses.

Others complained of boredom.

Mr. Baldwin:

That's the worst thing ... the monotony. It drives you mad.

He related this to his disability, implying he would fill his time more effectively if he were able:

I've always been a worker. Not happy unless I'm working. ... Not being able to do anything makes me mad.

Mr. Ianna said:

I would like to find another way to work on my lathe. Because that was the very first, best thing I know to pass the time. And that's what I need at the moment - passing the time.

He spoke of spending much of his time in bed, trying to sleep and not being able to.

Mr. White was asked why he attended Day Centres two days a week. He said, in part:

Because there is nothing else to do.

Even some who actively planned their time, found the need to do things to pass the time. Mr. Gardener said he watched television from about 5.00 p.m. to 7.00 p.m. each day.

Well, it's generally a way of passing the time.

Participants self-perceived time use did not appear to be the same as their role or meta-role focus. Some participants with a role focus sometimes experienced boredom, while some participants without a role focus did not. Even when participants spent a good deal of their time in highly valued roles, they did not always feel satisfied with their performance. Mr. King spent much of his time in the two Productivity roles he valued most - Husband and Father. However, he expressed dissatisfaction with his ability to perform in these roles in the way that he wished to and used to do.

4.2.1.3 Occupational Performance Role Transitions and Continuity

The experience of having a stroke, followed by a degree of disability consequent upon it, meant that nearly all participants in the study experienced some role loss. At the time of the interview, many were undergoing a transition to at least one new role via the sometimes lengthy process of role acquisition. In most cases, it was the stroke that had driven these changes to the participant's role repertoire. The changes were often not brought about through choice, but through the needs of the person and his level of ability as perceived by himself and those around him. Most participants were able to continue with at least one major role much as before, by modifying their performance to achieve the same outcome.

Occupational Performance Role Transitions

Where the new role was being imposed upon the participant by changed external circumstances (their newly acquired disability and the resultant change in the expectations of others) there were feelings of frustration and reduced self esteem. However, the degree to which this occurred varied considerably.

Example - Mr. Armstrong:

Mr. Armstrong was undergoing a transition from the role of Sportsman to the role of a Person With a Disability. The aspect of this role that related to his lost role of active sportsman was that of being a remedial exerciser. This transition was eased by his ability to apply his past experience as a sportsman to the new role.

At the time of the interview, Mr. Armstrong had a strong focus to his life. In the past, possibly his most important role, the one most closely fitting his **self concept**, had been as a **sportsman**. He still saw himself as having this role. In the past, he had achieved a high level of skill in several sports, notably fishing, golfing and clay pigeon shooting. At the time of the interview, following the onset of disability, he was no longer an active sportsman. The high achieving performance aspect of this role had been lost, and a process of **transition** was taking place.

Mr. Armstrong now identified strongly with the physiotherapy exercises employed as part of his rehabilitation program. He was able to use the knowledge and skills he had learned as a sportsman and apply them to his exercise program. He returned to this role many times in the course of the interview and this appeared to be a major focus in his life at the time of the interview. This role was named Remedial Exerciser, and he sorted it under **Self-Maintenance**. He rated the **Self-Maintenance** meta-role at five for value and four for satisfaction.

... And, I haven't settled down to reading yet because purely my number one priority is to keep up the exercise program which is pretty extensive.

... as far as I can teach anyone, is to work on their exercise program. And to do that takes up

Q: "A lot of time. But, you feel it is worthwhile do you? Spending that time?"

Yes. Definitely. There's no medicine or anything for stroke. It's physiotherapy. And physiotherapy is just doing the exercises you are told to do. (demonstrates some of the exercises)

Q: "Yes. And you have to do them all so many times, do you?"

Yes. (demonstrates some more)

Q. And can you see progression? Are you pleased with the results from it?

Yes. Definitely.

Again:

Actually that's the number one thing. (demonstrates one of his exercises) ... That is, number one priority and it's ... the only priority.

Q: "Yes. That's a really a major role for you isn't it?"

Yes.

For Mr. Armstrong, it seemed remedial exercise assisted him in coming to terms with his new role of a Person With a Disability by giving him something that he knew about and felt he could perform well.

For other participants, the new role of dealing with a stroke had no familiar characteristics.

Example - Mr. Hicks:

Mr. Hicks had been a livestock buyer and farmer until his retirement. He had spent most of his adult life giving priority to his productivity role and his family roles. Mr. Hicks was still dealing with the loss of his major productivity roles, and his energies were still bound up with thinking about them. He appeared to have little time left to attend to his new, imposed role as someone dealing with the consequences of a stroke, despite the fact that he now had quite severe disabilities. He sorted the role under the socio-cultural meta-role heading, but did not rate it. He attended the outpatient appointments arranged for him and did his exercises at home largely at the prompting of his wife. He had experienced several falls since being discharged home. According to his wife, at least some of these had occurred because he did not seek or did not wait for needed assistance. In his own mind, he still wanted to see himself as a fit and active man.

Mr. Hicks appeared to perform in his major new role as someone with a disability at the prompting of those around him - his wife and his therapists. He seemed to have not yet internalised the role for himself, although he did discuss how he felt the therapy he was receiving assisted him. For him, the process of role transition had been one of devastating loss. The role that Mr. Hicks was acquiring did not appear to have any of the familiar features for him that made the transition easier for Mr. Armstrong.

Occupational Performance Role Continuity

Occupational performance role continuity in this study refers to roles that have remained essentially unchanged by the major event of the stroke in terms of the participant's self perceived role performance outcomes. This does not mean, however, that such roles are frozen in time, as all roles continue to change and evolve. Occupational performance role continuity of at least one role was achieved by the majority of participants.

For some, this was achieved by a continuation of the same type of role performance that had occurred before the stroke. For others, occupational performance role continuity was achieved by role sharing in a way that had not occurred before the stroke. In this second case, the role was shared with some other person in order to achieve continuity of perceived role performance outcome.

Example - Mr. Edwards:

Mr. Edwards appeared to have achieved continuity in his role as a Father without significant changes to his mode of performance. He sorted the role under Productivity, and rated it at five for frequency, three for value and four for satisfaction. He and his wife had eight children and thirteen grandchildren. He saw his wife as being the one who had brought up their children; helping them with their school work and dealing with their everyday problems. He was proud of his children's achievements and ascribed them to his wife's efforts:

Yeah, they've all done well. Most of them graduated with honours from the university ... at least half of them. ... Later on in life, people say to me you're terribly lucky. Your kids are all doing well at school. They're all doing this that and the other thing. You're very lucky. I says, no luck. It was all my wife's work.

Mr. Edwards denied doing very much in this role.

Q: "So as a father ... what do you do now?"

Oh, I don't have much of a role now. I ... think.

However, he spoke at length about different problems his children were experiencing and what he had been able to do to help them without appearing to interfere.

Overall, he successfully continued with what he saw as the essential part of his role as a Father - providing a service to his children. This service consisted of being able to help them financially - an extension of his past paid productivity role as a stockbroker. Since his stroke, Mr. Edwards spent a great deal of his time reading the newspapers (particularly the financial sections) and working at his computer. Although he was experiencing quite severe disability, he retained the knowledge and experience necessary for the continued performance of this aspect of his role as a Father, and the ability to put that knowledge and experience into action via his computer. He was still able to achieve the same role outcome as before the stroke. For instance, he was able to use his knowledge and experience to help one son who is a lawyer:

Another bloke has a problem in the partnership where a bloke is going to leave and so I write the letter ... to him. Now that took about six days I suppose. A lot of thought went into it. And it's got to look casual. ... A senior partner has a read and asks if he can have a ... private copy of it. Yeah, I let him have a copy. And a couple of others want copies, because it really tells the story as it is, and what it means if you have a partnership break up.

He spent a lot of time ensuring that all his children prospered and felt strongly that this must be done tactfully. He displayed concern and love for them all.

... the youngest [grandchild] of the lot comes from the parents who have the least, and what are you going to do to be able to do to fix them up without it distressing the others? Ah, it gives you something to think about. But they're eight children and they've got eight different requirements.

He was keen that his children should enjoy some of the fruits of his success. For example, although he was no longer an active club member himself, he was pleased to be able to use his position as a member of The Australia Club (considered prestigious in business and professional circles) to speed up the waiting time for those of his sons who wished to join. Referring to when he was young, he said:

We had no money for a lot of the things that I do [now] and ... I make sure my children can have that.

Mr. Edwards appeared to feel he had retained the ability to carry out his role as a Father in the same way and achieve the same desired outcomes as before the stroke.

Example - Mr. Gardener:

Mr. Gardener had always shared everything with his wife. He described his role as a Husband as follows:

It's still there. ... But, carried out in a different way now. We do everything together, we consult each other in what we are going to do. Always have in life, and I think that's about the biggest part of your life - married life. Work together and do what you want to do and don't do something that the other one's not aware of. As much as you would like to. You just got to confide in each other to do what you're going to do and ... it has got to be ironed out, and thrashed out what you're going to do.

This belief in sharing had been of particular assistance to him in ensuring continuity of valued roles. Prior to his stroke, Mr. Gardener had been a keen hydroponic gardener. He sorted this role under Productivity and rated it at five for frequency, value and satisfaction. He utilised his own knowledge and experience and applied that to the physical work required to produce the satisfying and successful outcome of garden produce for the table. Since the stroke, he and his wife had achieved successful continuation of the role by sharing. He contributed his knowledge and experience, and she contributed the physical labour, done under his instruction. He was able to achieve continuity by sharing the role with his wife.

*I've got troughs of what they call hydroponic gardening, and I've got them all going down there. Haven't been down to 'em yet, **but the wife can look after them for me.** ... I've strawberries and ... all salad foods. ... Lettuce, tomatoes, carrots, parsnips,*

*and shallots. They're all growing down there - just starting to come up now. **So I can just look at 'em.***

He did have hopes that he would be able to resume solo performance in this role again in the future:

*To give you some hope that you will be able to get down ... and get both hands moving. ... That'll come yet. When I'm down the back there. ... It's all ready to be transplanted when they are ready. ... **And I'll keep 'em going then.** Then we've got our own lettuce. ... Whenever we want.*

He found role sharing produced the role performance outcome he wanted and anticipated in a way that he continued to find satisfying. He was asked:

Q. The way that you carry that role out now, - do you get some satisfaction out of that?

Oh yes, knowing that it is going to be still done. I've got it in my computer, which is the brain box. ... And what's got to be done is there and can be done. ... Somebody carries it out with the instructions, and that's done satisfactorily so I don't worry about it now.

Mr. Gardener, like Mr. Edwards was able to achieve the same desired outcome for this role as before the stroke. However, he had had to change the mode of his performance and now successfully shared the role with his wife.

Example: Mr. Armstrong

Mr. Armstrong was able to receive support by achieving continuity with aspects of his role as a Sportsman. Although he was no longer an active sports performer, he reported that he received visits from many of the people with whom he used to play golf or fish. People sought him out to ask his advice, and he was happy to respond. He remarked that he had been in many clubs where he had served terms as President and Secretary. It would seem that this area of his occupational role performance may represent the continuation of a volunteering aspect to the role.

*Oh, endless members of the golf club have come to see me since I was in St George, and they ring up to see how I am going. I'd been going a long time and always been regarded as a good fisherman, and **those that wanted help, got it**. Some that I met up there visited me in hospital. ... And they came back to Sydney and came and visited me **because I helped them** and they wanted me to get fit. Only because I'd been going there for a long, long time. That's why.*

Mr. Armstrong continued to follow sport on television, much as he had always done. By taking the role of Sportsman to include advising and following sport, it can be seen that Mr. Armstrong was experiencing a level of **role continuity**. While hoping to return to being an active sportsman, he seemed to have taken on the physical aspects of his rehabilitation program as an acceptable substitute and one in which he was able express himself. Mr. Armstrong seemed to be comfortable with the status of this important role at the time of the interview. He confirmed a role as Sports Follower, sorted it under Leisure, and rated it five for frequency, five for value and four for satisfaction.

For each of these participants, role continuity in certain roles was achieved. For Mr. Edwards the role was unchanged. Mr. Gardener utilised the strategy of role sharing to continue with his role, while Mr. Armstrong received ongoing ascribed status and personal satisfaction by continuing with those aspects of the role he was still able to perform.

4.2.2 Personal Meaning

The second major theme is Personal Meaning. This theme illustrates how the need for participants to experience a sense of congruence or **fit** with themselves and within their own social and cultural environment influences the choices they make. These choices determined the goals they set for themselves and lead to a internal picture of ideal role performance. Achievement of an approximation to this ideal role performance leads to self-expression and the experience of satisfaction. The nature of the Personal Meaning theme, then, is mainly related to *being*. *Being* is experienced in relation to *doing* (occupational role performance) and *knowing* - about the nature of their occupational role performance and how well it fits their own choices and needs and their socio-cultural environment.

The individual Personal Meaning behind the performance of all the roles in each participant's role repertoire was demonstrated by considering the results of the sorting the

researcher did at the end of Part Four of the interview, after all the roles had been discussed and confirmed by the participant (see Table 4.2). When attempting to pre-determine the meaning behind each role that had been identified (as described in Chapter Three), the researcher made errors in every interview, with an error rate averaging 47%. Error rates for specific interviews covered a wide range from 12.5% to 70% error. The reason for the high rate of researcher error became clearer when the way participants sorted their roles was examined. Several commonly occurring roles were sorted across a number of meta-role headings. For instance, the role of Father was sorted under every heading, as were roles that related to disability, such as Person With a Disability and Stroke Recoverer. Other roles that are usually associated with the occupational performance areas of Productivity, Self-Maintenance and Leisure were spread across a number of meta-role headings. Roles that related to Productivity such as Consultant, Business Partner and Expert Adviser were sorted across three meta-role headings. Roles that related to Self-Maintenance, such as Self Maintainer, Home maintainer and Personal Carer were sorted across four meta-role headings. Roles relating to passive or active leisure, such as Sports Watcher, TV watcher and Time Passer were sorted across three meta-role headings.

Participants were asked to comment on the way they had sorted particular roles. Most were able to give clear reasons for their decision. For example, Mr. King sorted his role as a Husband under the Productivity heading. He was asked:

Q: "You see being a husband as providing a service to your wife, do you?"

And to my children, yes.

Q: "So you are a resource to them?"

Well, yes, I think so, yes. They rely on me, and I enjoy the fact that they do rely on me. I enjoy the fact that I can do something to help them.

Productivity	Self-Maintenance	Leisure	Socio-cultural
Father (3)	Father (1)	Father (1)	Father (5)
Health Maintainer (1)	Stroke Survivor (2) Stroke Recoverer (1) Stroke Manager (1) Remedial Exerciser (1) Person with Disability (1) Day Care Attender (2)	Person with Disability (1)	Stroke Recoverer (1) Day Care Attender (1)
Expert adviser (1) Shareholder (1) Horseman (1) Scholar (1)	Consultant (1)	-	Business Partner (1)
Home Maintainer (1)	Self Maintainer (1) Meal Preparer (1) Personal Carer (3)	Gardener (1)	Home maintainer (2)

Table 4.2 Examples of idiosyncratic sorting of named roles under occupational performance and socio-cultural meta-role headings, with the number of sortings next to each role. Roles that appear similar in nature have been grouped together horizontally.

Another participant, Mr. Jacks, sorted the previously identified roles of Friend and Time Passer under Leisure. He was asked first about his role as a friend:

Q: "Friend?"

Fun and enjoyment. That's to be with others.

Q: "Time Passer?"

Fun, enjoy ... There (points to Leisure column on the board).

Mr. Driver said, when asked to sort the role of Husband:

I s'pose that'd have to go in with that (points to board).

Q: "Under Self-Maintenance?"

Well, I can't manage without her.

If specific roles are followed across participants, the widely ranging perceptions of the same role are evident. Taking the role of Father as an example, participant comments were as follows. Mr. White sorted Father under Self-Maintenance saying that his children were always asking after him, and that they were important to his welfare. He felt that he was important for their welfare as well. Mr. Edwards, who had been a stockbroker, placed the role under Productivity and discussed how he tried to provide unobtrusive financial services to all his children. Mr. Flynn said 'Well, I enjoy them' and sorted the role of Father under Leisure.

When the role sorting done by all the participants is represented together, there is clustering under meta-role headings that follows a pattern that is closer to what most therapists would expect. For instance, the majority of family member roles were sorted under the Socio-cultural meta-role heading, although individual roles were sorted under every heading. Similarly, the majority of roles for Leisure were sorted under Leisure and the majority of roles for Person With a Disability, were sorted under Self-Maintenance. For the

thirteen participants in this study as a whole, role sorting followed a more expected pattern than it did for individual participants.

In presenting the findings in this section, the impact of an acquired disability is clearly evident. Much of this section relates to how participants responded to this major life change. A number of sub-themes were identified which related to what had personal meaning to the individual participant. The main sub-themes that have been identified in relation to the construct of **Personal Meaning** are:

- 4.2.2.1 Fit - Self-identity and perceived expectations
- 4.2.2.2 Choice and ideal role performance.
- 4.2.2.3 Self-expression and satisfaction
- 4.2.2.4 Self perceived occupational role performance viewed over time

4.2.2.1 Fit - Self-identity and Perceived Expectations

One sub-theme that became apparent upon analysis of the data was related to social fit. Participants often implied or indicated that they had a perception of where they were placed in their social network, and what others expected of them. For instance, Mr. Flynn in discussing his role as a Father said:

Now whether I'm an inspiration to them or not, now, I don't know that.

It would seem he felt his children expected leadership of him, or that people in general would expect it, although it may have been that that is what he hoped would be the outcome of his performance in that role. He sorted this role under Leisure, rating it five for frequency and value, but only three for satisfaction.

Some indicated concern that their position had changed in ways that they did not like, in that they were no longer able to fulfil the expectations they had of themselves or that they felt others had of them. Mr. King deeply regretted no longer being able to fulfil his expectations of himself and the expectations he perceived others had of him to perform in his service roles.

Three strands were identified that related to this sub-theme. They are self-identity, beliefs and values and perceived expectations of others.

Self-identity

It seemed that self-perceived expectations were built upon the concept of self-identity. Participants demonstrated a concept of self-identity in various ways. Sometimes participants made clear role statements, claiming a role in a statement that said "*this is who I am*". Some of these statements related to roles that had been much larger in the past than they were now:

Mr. Ianna:

I am a tradesman too. I am a fitter and welder by trade.

Mr. Hicks:

I am a livestock buyer.

Mr. Armstrong:

I am a sportsman.

Roles that participants made such direct claims to appeared to be ones that they felt had status within their community.

Mr. Hicks confided to me:

I didn't want to say it in front of M. (his wife), but I'd like to get back to B. (his old property, now sold) and build a nice home on the property, and ... In the future, you know?

Mr. Hick's sense of self-identity appeared not include his role as a Person With a Disability. This new role had little personal meaning in terms of self-identity, despite the huge impact it had upon his occupational role performance. Consequently, he preferred to

spend his time reflecting on roles with greater personal meaning. He appeared to carry out the role of someone with a disability solely in terms of what was expected of him by others.

Beliefs and Values

Linked to self-identity was another strand that related to the participant's beliefs and values. They appeared to strongly influence the expectations he had of his own role performance and consequently the standard of performance he set himself.

Mr. Edwards, for example, demonstrated how his beliefs determined his role performance as a Father:

... but my wife does most of that. My wife's the brains. Wives are so much more important than men in this - really they are.

He felt that the university education that she received had enabled her to pass on the right values and skills for the children to do well academically. Because of his belief that the mother's role was paramount, he preferred to act in the role of Father discreetly, behind the scenes.

Mr. Armstrong believed in his abilities as a Sportsman. He knew he had been capable of performing as well or better than his peers in this area. His prowess as a Sportsman was highly valuable to him. He was able to utilise this valued belief and apply it to his rehabilitation program. His past experience gave him the belief that hard work and practice would improve his physical performance. He believed that he could improve his performance now in the same way by following his exercise program. He clearly saw it as the road to recovery.

Mr. Gardener believed that sharing everything with his wife was an important way to achieve what they both wanted out of life. This had been a successful strategy in the past, and consequently he valued it highly. He continued with this strategy now in relation to his rehabilitation program and in relation to other roles that had been affected by the stroke.

Perceived Expectations of Others

Participants appeared to have a clear idea of the expectations of others, which informed their sense of social fit. When asked why he attended Day Centres two days a week, Mr. White said:

They've sent me there because they expect me to carry on with the exercises they hand out.

I've only got ... my children ... W's one. She's the eldest. ... And they keep on ringing up to see how I am so, I've got to keep up to the health business.

Q: "Yes. So you are doing it because they expect you to?"

Yes.

Mr. White remained uninvolved in his role performance, doing what was expected of him by others, but happy to let life pass him by. His roles perhaps had less intrinsic personal meaning to him than some other more role focused participants.

Example - Mr. Leach:

Mr. Leach had severe disabilities following his stroke. He spent most of his time sitting in the lounge in his special chair. He spent his time talking to his wife or to other family members who came to visit, watching television, or sleeping. He attended as an outpatient for rehabilitation, but felt no need to carry on the program at home in the way that Mr. Armstrong and Mr. Gardener did. Like Mr. White, he seemed willing to let the world carry on about him. Unlike Mr. White, Mr. Leach was living with his wife. When the interview was over, she came outside to see the researcher off and said:

He's the same husband he has always been to me. I missed him very much when he was in hospital and it is lovely to have him home. He is a wonderful partner and a great friend and companion. He was wonderful before he had the stroke, and he's wonderful now.

Perhaps Mr. Leach enjoyed such unconditional acceptance from his wife, that he felt no pressure to perform in his role as a Person With a Disability. Perhaps, like Mr. White, his roles had less intrinsic personal meaning to him than some of the other participants. Perhaps

of greater personal significance to him were the expectations placed upon him by his wife. Because there was an absence of external expectation from the person who was most significant to him, and he placed no expectations upon himself beyond what he was already doing, there was congruence between occupational role performance expectations and actual performance. His perception of his social fit may have been satisfactory to him meaning that he felt no need to modify his behaviour to improve that fit.

4.2.2.2 Choice and Ideal Role Performance

Each of the participants in the study had an important need to deal, on a daily basis, with the effects of his stroke. Yet the way in which each one worked to meet this need was different. Some, like Mr. Armstrong, Mr. Gardener and Mr. King saw active rehabilitation as the way to successfully meet the needs imposed upon them by their disability. Others, like Mr. Baldwin, Mr. Flynn, and Mr. Ianna looked to their partners and others around them for support. They were not particularly interested in rehabilitation. Still others, such as Mr. Edwards, chose to make the best of what they had left, maximising opportunities for satisfactory role performance in valued role areas. All were given similar opportunities for rehabilitation, but only some **chose** to actively pursue this option.

Many participants appeared to have a picture in their minds of what an ideal performance in a given role would look like. They seemed to use this as a yardstick for their present level of performance in that role.

Mr. Ianna had had an important role as a musician in the past. He had this to say:

I have to have my eyes fixed because since the stroke my eyes have started going a bit you know. When I start to read - I used to read fluently before - I was quite a good reader. But now! Especially music. I read music you know. I play guitar, and I also conduct sometimes. I find it very difficult to follow the music now because when I come to the centre of the page, I lose the other half. I lose it completely ... This has given me a lot of disturbance you know. A lot of depression. When I see what I lost ... You know I studied quite a while to get where I am and I've done my best, and then all of a sudden like this I have lost everything.

His musical training had given him a picture of how he should perform as a competent musician, and his past performance knowledge provided information about how the role should **ideally** be performed.

Mr. Driver still spent a good deal of time working with horses. However, when asked what he did with the horses he responded:

Ah, nothing ...

He was unable to match his physical performance to the picture he had in his mind of how it should be done.

This picture of role performance – possible only if the person was able to perform exactly as he chose - has been termed **Ideal Role Performance**.

Others had **ideal roles** – roles, such as traveller and farm worker, that they felt unable to assume at present, but which they hoped to develop in the future. There seemed to be a picture in their minds of how that role would look.

Mr. King was asked:

Q: "If you could do anything at all that you wanted, what would it be?"

Travel. We've planned a few trips together ..., but, you know, when the finances get better one day, there's things we'd like to do.

Mr. Hicks wanted to return to his old farm and build a nice home. Mr. Driver was asked what he would like to be doing if he had not had a stroke. He replied that he would like to be on his son's farm in Taree, doing general farm work such as fence mending and stock work.

4.2.2.3 Self-expression and Satisfaction

Participants who were able to achieve self-expression through performing in valued roles as they chose, appeared to derive considerable satisfaction from this. Conversely, those

whose performance did not match their ideal role performance (or what they would have chosen to do), did not experience satisfaction.

Example: Mr. King:

Mr. King had stated that his Leisure role largely consisted of sitting in the garden in the sun. He rated this role as low for satisfaction. He explained it as follows:

Well, I feel as though I could do better ... I find that ... I'm wasting time there.

Q: "So would you feel more satisfied with your Leisure role if you were doing better in your Productivity roles?"

Yes.

Q: "So those two are linked together?"

Yep.

Q: "One's dependent on the other? You don't feel able to enjoy sitting in the sun without ..."

When I sit there, I feel as though - I'll put it crudely, as most others would: I feel as though I'm bludging on myself.

His beliefs and values in relation to leisure affected the level of satisfaction he felt when carrying out that role. His leisure had not been earned.

Example: Mr. Gardener:

Mr. Gardener, on the other hand, was satisfied with his performance as a Person With a Disability. When asked to rate his level of satisfaction in this role, Mr. Gardener said:

All the time. I am satisfied with what I am trying to do ...

In so far as this role affected his performance in nearly all his other roles, his satisfaction appeared to be high overall.

Oh yes, I'm contented. Everything moving along the way I want.

He was asked:

Q: "Do you do find time lies heavy on your hands?"

Oh, it does if I can't do anything. I try to do everything that I want to do.

Mr. Gardener's stroke meant he could no longer drive. This had meant changes for both himself and his wife in their Self Maintainer role. Because his wife did not drive, they were both now dependent upon their daughter for shopping and any other assistance that required transport. He said:

Oh yes, I have done everything I could for my daughter, and she's doing everything for me now.

His own satisfaction with his past performance as a Father enabled him to feel comfortable about accepting his daughter's help now.

Example - Mr. Edwards:

Mr. Edwards, in his role as a Campaigner, was able to achieve self-expression in the way he chose to go about performing in this role (composing letters and making telephone calls) and in seeing outcomes that he found amusing and that gave him satisfaction.

Mr. Edwards had been a successful stockbroker before he retired, and he lived in affluent circumstances. It was clear from the interview that he had had a position of some influence in the business world and felt he understood how things were done both in business and politically. Now, following his stroke, Mr. Edwards kept up with the news. Whenever he identified something that was of concern to him, he wrote a letter to whomever he considered to be the appropriate person. This letter writing had consequently become a sport in its own right. Some of the issues he had an interest in when interviewed were: lack of wheelchair access to a French exhibition; judges who think the answer to everything is to be able to sue; parents who are required to pay insurance premiums in order for their child to play football; small businesses being strangled by having to make redundancy payments; people who lost money investing in Rothschilds because they were not told everything they should have been;

being told his water was going to be cut off despite the bill having been paid; the Prime Minister trying to change the Constitution; a faulty refrigerator; and several matters where he felt the 'little person' was being ground down by the system. He felt that life was more difficult now than it had been when he was young.

From my generation to this there's been a massive change in the standards of all sorts ... particularly honesty. I mean things that were regarded as extremely dishonest in my day, are regarded as quite normal today. They look at it a different way. ... but for real life there's ruddy enormous complications.

He found the computer a great boon. Because of his right hemiplegia, he could not write letters without it, and it helped him to keep organised.

So you ... write your letters to the politicians and probably the greatest single event ... is the computer, that you type your letters and keep a memory, and do all those sort of things.

The role occupied a significant amount of his time and his thoughts. It was something he was able to pursue despite having some severe disabilities, and it satisfied his need to feel he was able to make a difference in the world, as well as giving him pleasure in the chase.

There's always sort of things to think about and write, consider and write to them and chase 'em up.

He displayed a great sense of humour in the way he went about his campaigns. When discussing who he had written to regarding wheelchair access to the French Exhibition he said:

... And then the President of France at his palace.

His wife, who had been half listening at this point, while busying herself in the kitchen, responded:

Oh! Oh really darling.

It gives him something to do, love!

His wife laughed.

He described the campaign about the faulty refrigerator:

Well, look at the fridge for example. You know, you hear people screaming about the fridge. What do they do? Ring up a girl and, poor girl's trying to do several things, and child's sick at home and .. You know? She's got her problems and the girl on the phone's coping all the flack. Well, you go through your normal repairman - then you write the letters. ... You never complain to the girl on the phone ... she has no choice. So, all right, I've a fridge that's not working well. So I make my calls, and I write my letters and ... thing isn't fixed properly. It ticks on for months on and off, so you just keep sending the letters just letting them know that it is still not right and then eventually, I bring it to a head a bit. But I think what brought it to a head was ... the anniversary. I used to send a birthday cake ... with a candle on it ... to go on the top - you know, today I am one - making the first anniversary of my request for you to fix the door. ... Anyway, ... it got fixed up. They had four blokes along with their own cake!

He summed it up by saying:

I feel sorry for those who can't look after themselves. And if they can't look after themselves, God gave me a brain, and I will do my best to fix myself (laughs) and them with it. And them with it.

The researcher tried to move the interview to another topic as this role had been discussed at considerable length by this stage in the interview. He said:

Yes. But that's important. ... Because that's keeping my mind busy.

Clearly, Mr. Edwards met his own expectations in this role because he performed in a manner entirely of his own choosing in a role that utilised his special knowledge and skills, enabling him to achieve performance at a level very close to his ideal role performance. He was able to achieve a high level of self-expression and satisfaction.

4.2.2.4 Self-perceived Occupational Role Performance Viewed Over Time

These sub-themes of self-identity versus the expectations of others, choice and ideal role performance and the consequent levels of self-expression and perceived satisfaction experienced by individual participants are illustrated further by considering information participants gave regarding occupational role performance over time. Participants reviewed their past role performance and made comparisons with the present. They had a vision of the future as well.

Example - Mr. Driver:

Mr. Driver had owned and raced pacers all his life, having started to work with horses when he was twelve. He had amassed a great deal of knowledge and experience in this area. In the past it was clear that working with horses had been a major role which had great personal meaning for him. For instance, there were a large number of framed photographs hanging on the living room walls of all the winners he had owned and trained, taken as they crossed the finish line. When I asked him what he did now with the horses he replied:

Ah, nothing. I don't do anything. I just talk, you know. Make suggestions and get told to mind me own business.

He immediately went on to describe what he was currently doing in this role. Because of disability following his stroke, he was no longer able to handle horses himself as before. However, it became clear that he still did a great deal. He went to trotting trials once a week, and went to race meetings on a regular basis. Most of all, he worked with his son, who had now taken over his two horses.

On Sunday I went out. We went to the trials Sunday morning, and then I went out to help him shoe the horse - show him how to do it, you know, because he'd never done 'em. Well, he sort of did 'em but I used to do all that. Shoeing and that. I had to show him how to do it because I couldn't do it.

He was asked:

Q: "So did you feel good about doing it that way?"

Oh yeah, yeah. Well, he was happy.

Q: "And he wouldn't have been able to do it otherwise?"

*Oh yeah, he still would have done it. I just explained things to do, you know. **Yes, like it's pretty hard to put on old experience isn't it?***

From what he said, it was now what his son wanted that mattered. He was continuing to work with the horses because his son needed his knowledge and advice. Mr. Driver recognised that he did still have one thing to offer and that was experience.

He was asked:

Q. What's the main reason that you continue to be interested in the horses do you think?

*Well, mainly for him. Yeah. Mainly for him. **I could do without 'em now.** ... While he is interested in them, I got to be interested too.*

Mr. Driver did not see the role of Horseman as continuing to have personal meaning. In his own mind, he had given it up. He now saw working with horses as part of his role as a Father. He only continued to work with horses because he perceived that that was what his son expected or wanted of him.

Occupational Role Performance Centred in the Past

Where valued roles have been lost, reminiscence may offer a way of continuing to actively engage in roles that have personal meaning.

As already discussed, Mr. Hicks was still dealing with the loss of the greatly valued past roles of Farmer, Livestock Buyer and, to a lesser extent, Soldier. He spent a great deal of

his interview talking about these roles and it was clear that they had great personal meaning to him. He told several long stories in the course of the interview about being a Farmer and Livestock Buyer in Goulburn, and discussed his war experiences. He did not appear to have any current roles of similar value or significance. It was hard to get him to talk about the present, in which his occupational role performance of valued roles was limited by severe disability. By reminiscing about past valued roles, Mr. Hicks was able to relive occupational role performance that had great personal meaning to him.

Other participants, such as Mr. Ianna, Mr. Driver, and Mr. King, spent time during the interview reminiscing about past role performance, even though they had not been invited to talk about the past and were asked more than once to focus on the present.

Comparison of Past and Present

Knowledge of the outcomes of past role performance appeared to be an important factor in determining what currently had personal meaning to the individual. Past performance that gave outcomes that were significant in terms of personal meaning ensured that the continuity of that role was valued. If the person felt unable to continue in a role in a way that had meaning for him, due to his newly acquired disability, then a number of responses were discernible from the transcripts. Some, such as Mr. Hicks, spent a lot of time reminiscing and grieving for roles they perceived to be lost. Some, such as Mr. Leach and Mr. White, appeared to focus on the roles that were left to them. Some, such as Mr. King, Mr. Armstrong and Mr. Gardener actively sought rehabilitation as a means of restoring lost occupational role performance.

Occupational Role Performance Centred in the Present

Some participants were able to find personal meaning in their current role performance. As discussed earlier, Mr. Armstrong was able to apply his past experience in the role of Sportsman to his newly acquired role as a Person With a Disability. He was able to find personal meaning in the rehabilitation exercises he had been given because of his past experience that practice and hard work produces results in terms of physical performance. He valued his rehabilitation program and saw it as the means of restoring his physical abilities. Similarly, Mr. Gardener (4.2.1.1) found current relevance or personal meaning in his role as a

Person With a Disability, as well as in several of his other roles. He spent very little time reminiscing during the interview and spoke mostly about the present.

Some participants did not appear to see rehabilitation as a satisfactory means of dealing with the imposed role of a Person With a Disability. They sought other ways to manage this role.

Example - Mr. Ianna:

Mr. Ianna responded to the initial grand tour role question in terms of illness and disability.

Well, the roles ... I'll give you the trouble I got now. The worst handicap part of my life now is: go to the toilet and sleeping. ... Otherwise, my wife looks after me very well. ... And I've got a friend of mine. He's like a qualified nurse. He is so good. He handles me very well. He transfers me from the bed to the wheelchair. From the wheelchair to the toilet chair.

He spoke constantly as someone who had experienced loss.

... and that's why I feel so depressed sometimes. Because there are so many things that I can't do ... any more.

He appeared to see himself as unable to perform in any occupational role until all his previous abilities were restored to him. For instance, he identified past occupational performance roles as a cook, a skilled handyman, a fisherman, a dog owner and as the conductor of a brass band. He did not perceive himself as having any current occupational performance in these roles. He drew on his knowledge of his past occupational role performance in these four roles and made judgements about what he was able to do now by comparison. These judgements were based upon what had personal meaning to him. He had rejected his current performance and did not attempt to pursue Active Engagement, other than thinking and talking about getting back to them when he had recovered. He even complained that the dog would no longer come near him.

In fact, he had conducted his band as recently as the previous week. This had been organised by the members of the band and his wife. He did not mention this to the interviewer, and seemed to have forgotten when his wife reminded him. He said:

I wish I could stand on my feet. If I could stand on my feet without holding onto anything, I would start cooking again and I would start conducting again.

Mr. Ianna had lost his sense of fit, because he had lost roles that gave him his sense of identity. He felt unable to perform in these roles and had no ability to match his ideal role performance.

Despite this, he was passive about seeking recovery through rehabilitation. He did not appear to see any value in the therapy he was receiving as an outpatient, but appeared rather to allow the physiotherapist to work on his body. He was asked:

Q: "What do you think about the therapy that you are doing? Do you think it helps?"

I don't think so, to tell you the truth. All I know is that sometimes it hurts, to no avail.

Personal Meaning in the present for him appeared rooted in his socio-cultural roles - his relationships with his family and friends. Active Engagement was evident in these roles, and was strongly tied to his dependence upon those around him.

Future Occupational Role Performance

Most participants commented about what the future might hold for them. Those who were purposefully engaged in present role performance in the role of Person With a Disability were seeking to improve their future role performance in all the significant roles that had been affected by their reduced level of ability. The need to hope for a better future was evident. Mr. Ianna described seeking information about what the future held for him from various health professionals:

And I also asked ... J. ... She looks after me in the pool - I said 'Oh my gosh', I said, 'Do you think I will be walking in the future?' She said 'Yes, but very slow. It takes a

long time'. So it wasn't very encouraging ... but at least, a long time I don't mind. But never - I can't take it.

He had more hope of a recovery stemming from his religious faith:

But I do a lot of praying. I'm a Catholic. And I do a lot of praying that I hope that I might get a miracle one day.

He was clear about what he would like to be able to do in the future, identifying the three roles he perceived he had lost that still had personal meaning to him:

There's three things I'd like. I'd like to go back to cooking, working in my workshop in the garage and fishing.

Mr. Driver seemed to find his doctor's comments rather ironic. He was discussing a shed that he had been in the middle of building in his back yard when his stroke intervened:

See what happens. I might get better.

Q: "So you would like to get back to it?"

Oh yeah! Oh I'll get better! I'll get right.

Q: "So do you think much about it? Do you think much about what you would be doing if you could get into the shed and do it?"

*No, no not really, I don't pine on it. The doctor said you might get right and you might not. That's the advice he gave me. **He said you've a lot to look forward to.** (laughs) But I will, I'll get right. Once I get rid of this pain - down here.*

Mr. King, although he had less disability than most of the other participants interviewed, found his present occupational role performance untenable at times. He described how he had contemplated suicide. His roles as a Husband and a Father pulled him through, giving him something that enabled him to look forwards into the future with greater equanimity. He was asked:

Q: "What about the other side of dealing with this? Like at home - the frustration that you've been talking about. How do you deal with that?"

*Very difficult. I know there was a couple of times. **This may sound rather extreme, but I have seriously considered suicide.** I haven't told anybody. But I have seriously considered it. But then I think of this and this (points to stickers with 'husband' and 'father' on them). ... And put it out of my mind. I get that cranky with myself. I think to myself what do I have to look forward to. (his voice breaks)*

Q: "So you do get very down."

Yes, very. Especially when I had this set-back the other day (he had had a seizure). I think to myself, you know, 'here I go again'.

Q: "But this is what keeps you going?" (points to stickers)

Yep.

Q: "Being a husband and a father?"

And a father, yeah. And a home life and everything, you know.

4.2.3 Perceived Control

The third and final major theme is Perceived Control. Perceived Control deals with the knowledge and perceptions participants had about their own occupational role performance, and the judgements they made about their ability to control role performance outcomes. It looks more particularly at how participants were able to monitor their performance and make decisions about how closely their occupational role performance approximated their ideal role performance.

Three themes were identified in relation to Perceived Control:

- 4.2.3.1 Occupational Role Performance Knowledge
- 4.2.3.2 Perceived outcomes
- 4.2.3.3 Perceived self-efficacy

4.2.3.1 Occupational Role Performance Knowledge

Knowledge about occupational role performance appeared to be of four different types. Participants had knowledge about the nature and quality of their own performance; problem-solving outcomes; the social and physical environment in which they were performing; and role rules - either the rules they imposed upon themselves, or the rules imposed by the expectations of others.

Knowledge of Current Role Performance

Participants discussed their perceptions of their own current abilities in the context of their occupational role performance.

Example - Mr. Cousins:

Mr. Cousins had no apparent physical deficits following his stroke. However, he had severe memory problems. This meant that he found it hard to hold a consistent conversation with others, as he found it difficult to retrieve the necessary information to discuss anything. For example, he was asked:

Q: "Do you have any brothers and sisters?"

He replied:

Now you're getting awkward. I don't know ... can't remember them.

This disability appeared to have severe consequences for him in terms of his socio-cultural roles. This was the focus of his conversation. He spoke of having been an active member of the local Bowling Club:

Q: "Do you have friends down there?"

Oh yes. Son-in-law goes there. That's how I come to join. ... Now he goes and leaves me here. (laughs) That's the snag. You've got no one to look after you sort of ... to take you. They don't have to take you - just let you go along. ... That's what I find. They just drop you now because you can't ... rattle like they can.

Mr. Cousins was acutely aware of the losses in role performance his disability caused him - particularly in valued social role performance.

Mr. Gardener spoke about his ability to drive:

Then my own estimate of driving ... I might be able to drive ... I've got an automatic car ... but when you get in, there's other things come into being in your mind. And this hand, it won't hold on to anything. Only got one hand, so you can't steer properly. There's one thing straight away. Then, changing the gears ... in a manual car you couldn't change gears because the left foot wouldn't allow you. ... The same thing with automatic. Your left hand can't put it into gear. ... So it's more danger to yourself than anybody else, so that's the attitude you got to take and be aware of it. ... You can't be held responsible in any way, and if you were to go down the road in a car and lost control and caused an accident, killing somebody, then that'd be the end of everything for you then. So you just don't put yourself into any ... handicapped position to do those things.

Knowledge of Problem solving Outcomes

Participants described ways in which they had attempted to solve the performance problems they were encountering and what the results had been.

As mentioned previously, Mr. King had an important role as a home maintainer. He was greatly concerned about keeping the garden neat and tidy:

But, I find I can't do it. Now I've got to ring up and rely on my son. ... People say to me ... get your lawns mowed. Well, when you've got no income ... I've got to rely on my son coming over ... by the time he finishes his own lawns and then comes here, he's ... You know - OK Dad, I'll do it tomorrow. ... Sometimes tomorrow never comes.

... And then it becomes a big deal by the time he does get here and he spends a lot more time here than he should. ... It's getting harder and harder, because he's very tangled up with his job. I used to like to do it myself. I had it the way I wanted to do it. ... And I've tried to do it now and I've had to ... get a different mower because I can't ... The Victa - I've got to pull the rope back, and as soon as I do that I fall over. Whereas... I've got a four stroke now, I can pull it straight up ... but I ... still find it difficult, putting the catcher on and off because you've got to lift it up with this hand and try and get the catcher in. These are the things that I find very frustrating.

Mr. King had really tried to continue with this role himself and **knew** that it was not possible for him to mow the lawn. He had tried out the options for getting someone else to assist him and knew that this was not practical either.

Environmental Knowledge and an Internal Picture of the Environment

The above two examples show that participants had a detailed knowledge of factors in the physical environment that limited their ability to perform. Mr. King even bought a new mower in an attempt to modify this environment to enable better role performance on his part. Participants' knowledge about their environment in relation to role performance could be described in terms of things that facilitated role performance and things that constrained it. Participants showed a similar awareness of the social and cultural environments that surrounded them.

Mr. Gardener shared his role as a Person With a Disability with his wife. In particular, she helped him with his rehabilitation. Mr. Gardener was clear about how much assistance she was to him. A number of other participants identified their wives as providing tremendous assistance to them.

Example - Mr. White:

Mr. White said a number of things which implied that, for his role as a Health Maintainer, he saw others as having control of his rehabilitation. He no longer perceived himself as being in charge of this part of his life.

*I was in Lottie Stewart Hospital and **they made me** use a stick.*

While Mr. White did not appear to object to this external control, he perceived it had its drawbacks. He saw the expectations of others resulting in outcomes that he did not find satisfactory, and that could perhaps be constraining. He attended Day Care twice a week, and felt that most of the time it was not worthwhile. He said:

***I got shovelled into that.** ... actually, to me, it's a waste of time.*

***They've sent me there** because **they expect me to carry on** with the exercises they hand out. ... I go there ... and do the therapy with them ... And the rest of the time is wasted.*

He felt the therapy was worthwhile, but that he did not always even get that:

Lucky if you got the therapy! ... You've got your therapist there and she's wandering around all the time. And, to me she's pretty important. ... Oh, I'm not complaining.

Q: "You said you go just because you'd accepted that that's what people want you to do. Is that right?"

*They've sent me there because **they expect me** to carry on with the exercises they hand out.*

He was asked if there were any reasons other than his health that he attended Day Care:

Because there's nothing else to do.

Q: "So, it's a way of passing the time?"

Yes.

Time was perhaps another environmental constraint, perceived by some of the participants as one that had to be dealt with somehow.

Example - Mr. Cousins

Mr. Cousins found the expectations of others were a major constraint on his Leisure occupational role performance. He was very keen to continue as a member of the local

bowling club, but believed that he was no longer wanted there because he was seen as a nuisance.

*Yes. He's a bowler next door. ... opposite - he's another bowler. Two opposite - his wife or his mother - she's another bowler. ... What I'd like to do is ... Chap's cars ... they're going to somewhere to play Bowls - to give me a lift ... **Well, they don't want hangers on around the place.** But that's what I'd like to do.*

This environmental knowledge, perceived in the context of the participant's own ability to perform, formed a mental or **internal picture of the environment**.

Role Rules

Several participants made statements about how they felt they or others should behave. These statements were in the form of general rules or guidelines for behaviour. While these rules were not necessarily specific to particular roles, they had an obvious impact upon role performance. They appeared to relate to what had personal meaning for the individual.

A number of participants expressed general rules or principles about the manner in which they should relate to those around them, and perform in their various roles. For Mr. Ianna, a benchmark to his interactions with others was whether he was able to keep them smiling.

I try to make you laugh and everybody laugh anyway. I don't like to see anyone unhappy around me.

Mr. Edwards believed that he should keep using his brains to think through problems and arrive at a solution. To him, it was an important way of demonstrating to himself that he was still in control. In relation to his role as campaigner he said:

By the time you write your letters and all that - it keeps you going you know? But you've got to keep your mind going on to these sort of things. If you don't you are not going to go anywhere.

Again:

There's always a way around these things. If you use your brains you'll think out a way of doing it.

He said, in relation to his stroke:

But the key, I reckon, to the whole thing is: if you have your mind, and in your mind you are not going to let the bloody thing beat you, you can eventually beat it.

He was identifying himself as a fighter who used his brains as his weapons. By characterising himself in this way, it gave him a rule or premise about how he expected himself to behave and how others could expect to see him behave - particularly in roles where he was dealing with adversity.

Mr. Gardener believed hard work was the way to achieve, so this was a rule that he used. In relation to his role as a Person With a Disability he said:

I work very hard. ... The real thing is to try.

He stated another rule in relation to his role as a family man:

I do everything to suit myself and my family in the home here. Then we just hope that everything's right.

Mr. Driver believed in being realistic. He said:

You've got to know your limits.

Some participants voiced rules that were about how they believed people in general should behave. Mr. Flynn was of a philosophical turn of mind:

Yeah but, as I tell the boys and the girls (his grown-up children), it doesn't matter what you are or who you are or how tall you are ... How small you are - you're only as good as you are. ... Because, at the last day ... Like, I just tell them treat every day

as the last day - because one of them will be. One of them will be. And be as nice as you can to everybody and treat everybody OK.

I asked him if he was satisfied with his role as a Father:

I suppose I'd never be satisfied. One is never satisfied in this life. ... Satisfaction and happiness is only ... everybody will have sorrows and unhappiness ... And disappointments in this life ... and that's why we try to live as good as we can, so that at the succumb of this life, there'll be greater things to come.

Mr. Flynn may well have learned this philosophy from his strong Catholic faith.

4.2.3.2 Perceived Outcomes of Occupational Role Performance

Participants demonstrated they made ongoing close assessment of the consequences or outcomes of their role performance, by using their knowledge of their current role performance and of the relevant environments in which they were performed. These assessments informed them of how much control they had over their role performance and were used to try to predict future occupational role performance outcomes.

Perceived Outcomes

Participants talked about the nature of consequences from their changed role performance. Mr. King said:

This is one thing that is frustrating. ... We're selling the house because I can't look after it any more. ... My wife can look after the inside but then I can't look after the outside. ... Mowing the lawns and things like that - vacuuming the pool. ... You know, [we]... used to get quite a few compliments about ... the way the place looked.

He knew that his reduced performance in this role had led to the loss of their home.

All participants who were married talked of the assistance they now needed from their wives. Mr. Ianna seemed to believe that he could not perform at all in any of his valued roles. Many other examples have already been given in earlier sections.

Outcome Predictions

In relation to the imposed occupational performance role of Person With a Disability, participants monitored their present performance and tried to predict future outcomes in terms of regaining control and achieving a closer approximation to their ideal role performance. Many expressed a fear of how continued disability might affect their occupational role performance even more adversely than at present. The role of Husband was of particular concern in this regard.

Example - Mr. Baldwin:

Mr. Baldwin was depressed and labile at the time of the interview, and he had severe disabilities as a result of his stroke. He was experiencing a loss of control and increased dependence in relation to this very important role as a Husband. He expressed concern about his dependence upon his wife. When asked to rate the role he said:

My wife is highly valuable to me. (sobs) I'd be dead now but ... (sobs) I keep telling her why didn't she leave me on the floor where she found me (sobs).

He hated depending upon her for personal things. He was talking about the Day Centre he attends:

Soon as I get to the door, this one, she rushes up with a cup of tea. That's fatal to me. It just goes straight through me and then I've got to get out to that toilet pretty quick. (long pause) That's another thing I've had trouble with all the time. At night. Worrying me wife all the time. (pause) That upsets me.

He was asked how he felt about his occupational role performance as a Husband:

(Sobs... long pause) I got the best wife any bloke could ever have.

Q: "And you're a good partner too?"

I hope I am. You'd have to ask her that. About two weeks ago she said she was going to divorce me. She said she was going to clear out. One day I was sitting there out the back. I was snoozing off and I woke up - she was knitting in her chair next to me - and I woke up and she wasn't there! My goodness, I thought, she's bloody well gone!

(laughs) So I went up the street there looking for her - thinking that she must have left - cleared out and left me. 'Don't you ever do that again' I says. Don't you, I says, cause ... you'll have ... to try to get away from me. ... No matter where you go I'll follow I says, though it's up to you whether I follow you or not.

His performance as a Husband had changed from that of partner to that of a dependent person. He was fearful that if this change continued, his wife would leave him. He seemed to feel powerless to do anything about it except hope that it would not happen.

Example - Mr. King

Mr. King felt his loss of independence was putting a strain on the relationship he had with his wife - not only because his wife needed to assist him more but because he felt he was now a more difficult person to be around.

I think you lose your independence, to a degree, you know. Like, my wife's very easy to get along with and she does everything to possibly help me. But ... I find sometimes I'm being ... a bit demanding

His motivation for working hard in rehabilitation was to restore the occupational aspects of his role of Husband to their former status.

Yes, I want to get back to the role that I had before as a full time husband ...

He believed that a restoration of function would enable him to regain control in that it would lead to a restoration of the more satisfactory occupational role performance he perceived he had prior to his stroke.

Example: Mr. Driver

Mr. Driver clearly enjoyed the relationship he had with his wife, but found that it had changed with his stroke. It appeared that prior to the stroke he perceived his role as a Husband was as equal partner in the marriage with his wife. Now, since the stroke, he saw a shift in the balance between them. He needed her to help him in many ways, including being there when he showered and dressed in case he had a fall. He may have felt that his role as a Husband was being subsumed at times by that of a Person With a Disability, because he now had to share with her the performance of Self-Maintenance tasks that he once would have

done by himself. He had had to hand over driving the car to his wife, and cars were important to him. There were a number of them awaiting his attentions in the back yard of the house.

From the transcript, Mr. Driver appeared to indicate that he would once have sorted the role of Husband under Leisure, but now had difficulty coming to a decision about the main reason behind the role. He felt unable to perform as a Husband as his wife might wish:

I can't put it under there any more. (Points to board) I don't know where you put that. (pause) See, I can't do nothing to suit anyone else.

He decided that the Self-Maintenance heading best described the way he saw the role now, linked perhaps to an underlying fear that his wife might become dissatisfied with his role performance:

*I s'pose that'd have to go in with that (points to Self-Maintenance). Wouldn't it? ...
Well, I can't manage without her. I shouldn't say that in front of her, or she'll ...*

He spoke of a significant change in his performance in terms of their sexual relationship:

*Yeah, I think she reckons I am in her road all the time! ... No, I couldn't manage without her. **Though, I'm not her husband - that way, you know?** We're just ...
We're good mates, that's all. Because I'm ... no good any more. (taps the table) Not that way. (taps the table again).*

Like Mr. Baldwin and Mr. King, Mr. Driver felt that the stroke had changed his performance in his role as a Husband for the worse. Like Mr. Baldwin, he felt unable to restore it to the way it was before the stroke, leading to a perception of a reduced sense of control and a fear that there might be a deterioration in the relationship in the future.

4.2.3.3 Perceived Self-efficacy

It appears that participants considered the types of knowledge discussed above, and put that knowledge together with what had personal meaning for them as people to form an opinion or judgement about how effective they were able to be in a given role.

Several participants talked of the frustration of not being able to perform in a way that met their own expectations. As discussed earlier, Mr. Driver had been a farrier and had many skills in handling horses. Despite the fact that he was still spending a significant amount of time with horses, he was now doing it to pass on the skills and knowledge he had acquired to his son. He no longer saw himself as being an effective horse handler, and appeared to doubt his effectiveness in educating his son.

Example: Mr. Ianna

Mr. Ianna had been a fitter and welder. When he retired at the early age of fifty-nine (because of an old injury from a motor vehicle accident) he fitted out his own workshop and spent a lot of his time doing repairs and inventing and making machines. He spoke of a marked change in his occupational role performance since his stroke and of how that affected him:

I get into the workshop on the wheelchair, but I still can't do anything. ... Well, when I get there, all I do is cry. I look at the things that I made and the things I could do, and I cry like a baby.

Mr. Edwards spoke of being difficult to live with. For him, the role of being a Father was sometimes a struggle for him, and the stroke had produced a change in his occupational role performance. Since the stroke, he had lost his relationship with one daughter:

One daughter ... I'd rather not talk to her. I'd rather just forget her. ... And this is partly due to the pure fact that ... we're too alike. As my wife says, she's doing exactly what you do. It's only happened since the stroke. ... It was all right until then.

He explained the change:

... This (the stroke) makes ... your temperature soar and you're not as ... (sighs) ... You become more difficult to handle, and you shouldn't be.

Mr. Cousins saw a contrast between his own perceptions of his performance and the perceptions of those around him:

*I go down to the Bowls Club. What do I do down there? I just sit and watch. I used to play, but now I'm too old to play or some damn thing or other. **I'm still the same as I was before.***

The researcher commented:

"You still look fit."

Yes, I am fit - fit for what?

Mr. Cousins memory loss made it extremely difficult for him to be effective in achieving the outcomes he desired in the role area that was a focus to him, despite the fact that physically he could well have been "*the same as he was before*". He saw himself as having a low level of self-efficacy.

Example - Mr. King

Mr. King was asked what he would most like to do if he could do anything. He responded:

*Travel. We've planned a few trips together, but, you know, when the finances get better one day, there's things we'd like to do. But **the way I am at the present moment I'm afraid to do those things now.** Plus the fact that we **haven't got the finances at the present moment.***

A picture of ideal role performance (as a traveller) was stated, but immediately followed by a list of personal (internal) and environmental (external) constraints that he perceived prevented that role performance, leading to a perception of reduced self-efficacy.

Mr. King felt that he was a burden to his wife and hated it. He needed his wife to help him to dry himself after a shower and to get dressed. He needed her help to drive him if he wanted to go somewhere. He minded very much not being able to drive himself. He needed to be driven because of his disability, and because he had a recent history of seizures.

There are things that I want to do. I've got to make my wife take me now. Or ask her to take me there to do them. ... Before I had the stroke, I'd think of something, and I'd

just jump in my truck, and away I'd go, and I'd do it. Now I can't. I've got to ask my wife to drive me there. Sometimes I feel as though I'm such a burden on her.

An outcome that Mr. King perceived was a feeling of terrible frustration and impotence because he was unable to perform in his roles in the way that he chose.

You feel sometimes you can become violent with people around you, because you become so frustrated and so annoyed with yourself. Like [his wife] has often said to me "don't smash something because we can't afford to replace it", you know? Sometimes I'll try to do something and it won't work so I'll throw it. And then you think "you silly bugger what did you do that for?" ... And one thing I find is that ... when things go wrong, you have a tendency to take it out on your mate. And this is something you shouldn't do. Because without your mate you've got nothing.

He was not in control of his own role performance. When asked what, given that he had the stroke, he would like to be able to change, he said:

I'd like to be more physical. To be able to ... Like, [my wife] and I walk around the oval opposite there every night. We walk down the road and go right around there, but I find that I get terrible back pains because I must be walking incorrectly. I'd say to not be so reliant on other people and to being able to do things physically without having to ask people to help me. Because I've been a very independent person all my life. And I find it hard to ask people to do things for me.

Mr. King found the current outcomes he was experiencing in his performance roles most unsatisfactory. However, like Mr. Armstrong and Mr. Gardener he perceived he was able to do something about it. He had a very clear idea of what he wanted to change about his own abilities following the stroke. His solution was to pursue active rehabilitation. He was attempting to recover control of his life.

4.3 A PRELIMINARY MODEL OF OCCUPATIONAL ROLE PERFORMANCE

Further consideration of the three main themes that arose out of the research data led to the formulation of a preliminary model, with the three themes as the major constructs of

the model. Each major construct has a number of sub-constructs derived from the sub-themes of the three major themes. The constructs, their sub-constructs and the possible relationships between them are described in this section, based upon the findings that have been discussed.

4.3.1 Features Of The Three Major Constructs

4.3.1.1 The Features of Active Engagement

Each participant has a occupational performance role repertoire that is unique. Participants perceive their role repertoire as an interactive whole and can distinguish between roles that are predominantly occupational and roles that are predominantly socio-cultural. Roles are defined by participants at differing levels. The level is determined by the person's perception of a specific, well developed group of activities with a common purpose he calls a role. It can be difficult to delineate roles that have few overt prescriptions and there may be overlap between roles in performance. Occupational performance role is used as an organising construct in relation to time, priority and performance style. Role transition and role continuity require a perception of, and ability to use resources in the form of other people, social services and relevant personal knowledge and skills.

Active engagement describes the nature of occupational performance roles. There is an emphasis on *doing* in this construct. This *doing* may be overt or covert. The individual role performances described require *knowing* about self and environment in the context of role expectations. The uniqueness of each participant's role repertoire and the presence of individualistic role behaviour that is related to the value placed on each role demonstrates *being*.

4.3.1.2 The Features of Personal Meaning

Personal Meaning appears to determine the nature of Active Engagement, and choices about role performance are made on the basis of what has significance to the person. The quality of active engagement is judged, via the medium of perceived occupational role performance outcomes, in terms of personal meaning.

Meaning is ascribed to roles in an occupational and dynamic fashion. Self-identity is strongly bound to roles which are shared with role partners who share the same definitions and value for the role. Roles that offer a sense of self-identity may also offer a sense of social

fit. Roles performed solely because of the expectations of others hold little value or personal meaning. Role performers hold a picture of what ideal role performance should look like in their minds and use it to evaluate their performance in terms of meaning. The closer their performance approximates their ideal role performance, the more rewarding is the experience and the more the role is valued. Occupational performance role choices are influenced by estimations of reward, cultural beliefs and values, interest and perceived risk. Occupational role performance satisfaction is related to meeting the expectations of self and of others in a way that permits the expression of self-identity, and to the expectation of reward. The construct of Personal Meaning describes the meaning behind occupational role performance. There is an emphasis on *being* in this construct. However, this *being* is strongly related to the nature of *doing* (Active Engagement), and to *knowing* about self and *knowing* about others (Perceived Control).

4.3.1.3 The Features of Perceived Control

Knowledge about occupational role performance is acquired and maintained in a dynamic manner. Such knowledge is made up of the nature and quality of occupational role performance, the environmental context of that performance and the expectations of self and of role partners about specific occupational role performance. These expectations can be used to judge the quality of occupational role performance.

Knowledge about past performance, expectations, and beliefs and values go together to form a picture of Ideal Role Performance that can be used as a comparison with actual perceived role performance. This enables judgements to be made about the outcomes of occupational role performance in order to determine whether they are satisfactory or unsatisfactory. Based on this knowledge and these judgements, attempts are made to predict future occupational role performance outcomes. The results of these judgements contribute to a sense of perceived self-efficacy, which in turn influences motivation regarding future occupational role performance. The emphasis is on *knowing* in this construct. However, a sense of perceived self-efficacy is strongly related to *being*. Perceived Control informs the choices about occupational role performance that are made and strongly influences *doing*.

4.3.2 Features Of The Ten Sub-Constructs Of The Three Major Constructs

4.3.2.1 Features of the Sub-constructs of Active Engagement

Occupational Performance Role Repertoire

The occupational performance role repertoire is characterised by three types of hierarchy.

- 1) Level of priority.
- 2) Level of breadth of related activity.
- 3) Level of definition.

When the role repertoire is viewed as a whole, the pattern of occupational performance varies in terms of the style of occupational performance. A person's performance style may be planned and active, unplanned and active, or passive. It is possible that observed passivity may also be planned or unplanned.

Temporal Aspects of Occupational Role Performance

If occupational role performance is planned and active, time becomes an important means of organising performance. For those with disability, time must be spent dealing with the impact of that disability upon role performance. If roles have been lost, time may be spent in enforced idleness.

Occupational Performance Role Transitions and Role Continuity

Both role acquisitions and role continuity are facilitated by previously acquired knowledge and skills. Role partners and other perceived environmental supports may be utilised. Effective use of prior knowledge and skills facilitates smooth role transitions and the continuity of roles in which occupational role performance has to change due to disability. Conversely, an absence of, or inability to utilise prior knowledge and skills greatly reduces the ability to acquire new roles or continue roles of significance.

4.3.2.2 Features of the Sub-constructs for Personal Meaning

Fit - Self-identity and Perceived Expectations

A sense of *self-identity* informs occupational role performance via *expectations* of self, which are closely tied to personal beliefs and values. Self-identity is more strongly bound to some roles than to others. Some roles are low in value and not part of self-identity. However, they are performed because of the acknowledged *expectations* of others and therefore relate to a sense of social fit. Conversely, roles that are highly identified with are likely to be those shared with a role partner whose expectations of the role match the role performer's. Performing in such roles enhances a sense of social *fit*. Roles that carry social status are part of self-identity, and performance in these will enhance a sense of social fit.

Choice and Ideal Role Performance

Choice is exercised in the way that roles are performed, meaning that the nature of occupational role performance in any given role will be unique to that person. Choices about the nature of role performance are influenced by estimations of reward, interest and/or motivation and a sense of social and cultural fit. These factors, together with knowledge about the role, form an idea or picture in the mind of what *ideal role performance* would look like. This picture guides the nature of occupational role performance, with the person striving to meet the ideal. A large discrepancy between perceived actual role performance and ideal role performance leads to a sense of frustration and dissatisfaction. Conversely, if a close match is perceived, then a high level of satisfaction is experienced.

Self-expression and Satisfaction

When *Ideal Role Performance* conforms with the perceived outcomes from Active Engagement, there is a sense of self-expression and satisfaction. Satisfaction with occupational role performance appears to relate more to meeting the expectations of self and others and the possibility of future reward than to a sense of pleasure or enjoyment. The opportunity for self-expression is reinforcing to self-identity, while a sense of satisfaction provides motivation for continued occupational role performance. Role performance in roles assumed largely because of the expectations of others carry fewer opportunities for self-expression than role performance in roles perceived to be part of the person's self-identity.

Self Perceived Occupational Role Performance Viewed Over Time

The present meaning of a given role is based upon past experiences. Such experiences influence the choices made about present role demands. Information about likely future occupational role performance influences present choices.

4.3.2.3 Features of the Sub-constructs of Perceived Control

Occupational Role Performance Knowledge

Occupational role performance knowledge takes four forms:

- 1) Knowledge about present occupational role performance in terms of relevant abilities and skills and performance outcomes. This knowledge is acquired through *doing*.
- 2) Knowledge of occupational role performance strategies perceived to be successful or unsuccessful.
- 3) Knowledge about role rules. These are used to guide judgements made about performance. These rules may be self-imposed, or relate to perceptions about general standards of performance.
- 4) Knowledge about the physical, social, cultural and sensory environment that is relevant to the performance of a given role - the environmental context. In particular, a perception of factors that facilitate and inhibit performance is important.

This knowledge forms an *internal picture of the environment*.

Perceived Outcomes of Occupational Role Performance

Occupational role performance is evaluated in three ways:

- 1) Perceived performance is compared with past role performance.
- 2) Perceived performance is compared with *ideal role performance*

- 3) Perceived performance outcomes are compared with desired outcomes.

The judgements made as a result of this process form the basis of a dynamic knowledge about perceived occupational role performance outcomes. This information is used to predict future role performance outcomes. These predictions can then be used to plan more effective strategies for current role performance in order to achieve long-term rewards.

Perceived Self-efficacy

As a result of an assessment of perceived outcomes of role performance, as compared to desired outcomes that are linked to Personal Meaning, a sense of self-efficacy is developed in relation to the performance of each role in the role repertoire. This sense of self-efficacy will vary from role to role. Where self-efficacy is low in relation to valued roles this lowers self esteem and reduces the sense of self-identity. A high sense of self-efficacy in valued roles leads to feelings of wellbeing.

4.3.3 Relationship Of Constructs

Active Engagement is determined by what has Personal Meaning to the person at that moment, providing the motivation to act. Active Engagement is determined by Perceived Control, in terms of a perception of what action is possible. There may be a motivation to act, but a judgement that the action is not feasible, with no Active Engagement taking place. There may be a judgement that action is possible, but no motivation to act because there is little relationship to what has Personal Meaning. Active Engagement informs Perceived Control, such that reduced Active Engagement leads to reduced knowledge about personal abilities and skills, reduced confidence and a lessened likelihood of Active Engagement, even in the presence of Personal Meaning.

The preliminary structural Model of Occupational Role Performance is represented in figure 4.1. All of the elements in this model were identified in each participant's transcript. The application of the model is demonstrated by an excerpt from one of the transcripts.



Fig. 4.1 Preliminary Structural Model of Occupational Role Performance

4.3.3.1 An Example of the Application of the Model

Mr. Flynn identified a role as a home maintainer. His **self-identity** (Personal Meaning) was of someone who had always hated mess:

I was proud. I was house proud. ... Now, even, you know. Just as long as I can remember. Everything had to be in order. Everything had to be the way it should be.

He perceived that tidiness was something that was expected and appreciated by others (Perceived Control):

Give that bugger [himself] a sweeping up job.

Before his stroke, he was the one who did the washing up, tidying, dusting and vacuuming around the house and the sweeping and mowing in the garden. On his return home following his stroke, he was keen to continue with this role of home maintenance, displaying a **sense of purpose** (Personal Meaning). He perceived, however, that his wife expected him to stop performing in this role and to spend his time sitting around resting (Perceived Control):

For instance, now I do the - there's only two of us anyway - but I do the little bit of washing up after all the meals. ... Now I always done that, and when I came home, I said to Mammy [his wife] "Now" I said ... She said "oh ... I guess" ... she tried to argue back. I said "look here Mammy, I'm home now", I said "and I'm not going to be defeated. I'm not going to play on this" ... you know. I'm not going to. ... I'm going to carry on just ... and do the little things. I don't do much. I say "I'll carry on and do the little things I've always done". ... You see? You know? And so that's about the size of it.

He had identified himself as a home maintainer, referred to his past **experience** and **knowledge**, and employed a **role rule** "I'm not going to be defeated" in order to successfully overcome his wife's opposition to his resumption of this role.

Well, the biggest job ... my biggest job would be the vacuuming of the house (Active Engagement). ... And that's about ... it's not that bloody big an area is it, like really? But at the same time ... there's times now, you know, even able bodied people - there

are things that are a bit big for them. That's ... that's nature, shall we say. That's nature.

He felt in **control** of his performance in this role (Perceived Control) and further, **perceived a satisfactory outcome** (Personal Meaning) in that he felt that his performance could reasonably be compared with that of other able-bodied people. His **perceived self-efficacy** for this role was high (Perceived Control).

When asked if he was satisfied with his performance (Personal Meaning) he responded:

Well, there ain't no complaints from anybody else, so ...

He explained the significance of this role in terms of past **life experience** and the **beliefs and values** he had acquired:

Well, it [home maintenance] is important enough. I hate to see untidiness like. ... Always did. Even [inaudible] when I was a child. See, ... our life - it's completely different to those days. Every child in the family - there were six of us. And every one of us had got a job to do. ... You started off cleaning. Cleaning the shoes. Polishing the shoes. Then you advanced on... and then you might get ... every week, all the cutlery had to be polished. ... You'd polish that. It was a great crack years ago. Everything was ... linoleum or oilcloth. That would have to be polished. ... And, you went through all these - which made you very handy in a way - All these jobs. Everyone had a job to do in the family, you know? There's no family life today like this.

This was a role that had **personal meaning** to Mr. Flynn beyond the stated end of having things look clean and tidy.

4.4 SUMMARY OF FINDINGS

This summary of findings is presented in relation to the purposes of this study as described in Chapter One, namely,

- 1) To describe the self perceived occupational performance roles of men over 65 who have had a stroke, in order to gain insight into the meaning, motivation for, and organisation of their occupational roles.
- 2) To explore the possibility that role is a construct that is understood and utilised by these men in the planning and performance of meaningful occupations.

4.4.1 Summary of findings that relate to the first stated purpose of the study - to describe the self-perceived occupational performance roles of the participants.

4.4.1.1 Participant Perceptions And Use Of The Concept Of Role

A central finding of this study was that the participants were comfortable about discussing their current daily life in terms of role performance. They were clear about what was a role and what was not, and discussed role in the context of their own lives.

- Participants discussed their roles in terms that could be interpreted from an occupational performance role perspective, and were able to distinguish between the occupational performance aspect of their roles and the socio-cultural aspect. They spoke about their roles in terms of *doing*, *knowing* and *being*.
- Participants saw role as developmental in nature, discussing present performance in the context of past and possible future performance.

Analysis of the data gave rise to the three major themes of Active Engagement, Personal Meaning and Perceived Control. These major themes each had a number of sub-themes. The Active Engagement theme relates mainly to actual occupational role performance and is strongly related to *doing*, although there are elements of *being* and *knowing* present. The Personal Meaning theme relates mainly to the meaning behind occupational role performance and is strongly related to *being* although there are elements of *doing* and *knowing*. The Perceived Control theme relates to the nature of the knowledge that

participants had about their occupational role performance and therefore relates strongly to *knowing*, while having elements of *doing* and *being*.

4.4.2 Active Engagement

- Participants used role as an organising construct. They demonstrated this by discussing their behaviour in role terms, by describing different behaviours and identifying them as part of the same role, by sorting their roles under occupational performance meta-role headings, according to their own perception of the nature of the role at the time of the interview, by allocating differing priorities to different roles according to the value they placed on the role, and by dividing up their time according to the roles in their role repertoire.

Role Repertoire

- Each participant had a role repertoire that was distinctively different.
- Role repertoires were characterised by three role hierarchies. First, each role was ascribed a particular level of importance or value relative to the others. Second, areas of performance named as roles varied in breadth from very specific roles such as Newspaper Reader, up to whole meta-role areas such as Leisure. Third, there was a hierarchy in terms of level of role definition, with some roles being clearly defined and others that had poor definition and demonstrated overlap with other roles - particularly if the role had few *overt prescriptions*.
- Some participants were focused on one or two roles and behaved purposefully in relation to them. The role of focus could be a meta-role or a specific role within a meta-role. Their occupational role performance could be overt (observable by others) or covert (thinking about the role). Other participants had no particular role focus but remained orientated to the occupational aspects of their roles. Still other participants were not role focused and appeared not to be orientated to the occupational aspects of their role. These people appeared more orientated to the socio-cultural aspects of their roles.
- There were differences of style in terms of Active Engagement. Some participants were planned and active. Others were unplanned and active. Still others were passive.

Temporal Aspects of Occupational Role Performance

- Participants who were role focused used time to organise their role performance. Most found the impact of their stroke increased the amount of time they spent in Self-Maintenance, in rehabilitation and in enforced idleness, and reduced the time they could spend in roles of high priority. Nearly all spoke of the need to find things to do to pass the time.

Occupational Performance Role Transitions and Role Continuity

- All participants were going through a period of role transition forced upon them by their stroke. They all appeared to be at different stages of adaptation. Most were still preoccupied with the changes and were experiencing a sense of loss. Some were able to utilise resources such as the assistance of other people, health services, personal knowledge and personal skills in this adaptation process. Others seem to lack the resources or the motivation to even begin the process.
- Some participants found ways to achieve satisfactory role continuity in valued roles by using the same resources as for role transition. Others did not seem to find anything less than full restoration to the way they used to perform the role satisfactory, and preferred to reminisce rather than modify their ideal role performance in any way.

4.4.3 Personal Meaning

- Participants sorted their roles under occupational and socio-cultural meta-role headings in an idiosyncratic manner and were able to give reasons for their placements. The researcher was unable to predict the sorting, despite having spoken to the participants about their roles beforehand. The sorting appeared to be occupational and dynamic in nature, indicating the possibility that role sorting would change over time as the occupational nature of the role changed and developed.

Fit - Self-identity and Perceived Expectations

- Participants demonstrated their self-identity was strongly bound to some of their roles. The roles most highly identified with appeared to be those that were shared

with role partners who valued them highly and shared their definition of the role. Partner and Family Member were commonly acknowledged to be highly valued roles. Performing in such roles enhanced their sense of social fit.

- Participants demonstrated a sense of how they fit into their own community. Roles that were perceived to carry status were sometimes claimed even though there was no longer any recognised performance in that role. Past work roles are an example of this.
- Participants had some roles with which they did not identify, that were performed solely because of the expectations of others. These roles were performed from a sense of obligation and were part of their sense of social fit, but not part of their sense of self-identity.
- Occupational role performance was influenced by the individual participant's personal set of beliefs and values and the consequent expectations he placed upon himself.

Choice and Ideal Role Performance

- Participants exercised choice in the way that they performed in individual roles. Occupational role performance choices were influenced by estimations of rewarding outcomes, and personal interests.
- Participants had a picture of *ideal role performance* in their minds which was influenced by past life experience and beliefs and values. They used this when evaluating their own occupational role performance. Where the discrepancy between ideal role performance and actual role performance was great, participants experienced high levels of frustration and depression.

Self-expression and Satisfaction

- The closer a participant's performance approximated his *ideal role performance*, in terms of perceived role performance outcomes, the greater the satisfaction he experienced, and the more he was likely to value the role.
- Satisfaction with role performance did not necessarily equate with pleasure, happiness or improved quality of life. Satisfaction was more likely to be related to meeting the expectations of self and others and to the possibility of future reward.

Self-perceived Occupational Role Performance Viewed Over Time

- Present meaning in a given role was built upon past life experience. Past life experience influenced how participants chose to respond to present external demands, as illustrated by the imposed role of Person With a Disability.
- All participants attempted to predict what the future held for them and linked this to what was meaningful to them in terms of occupational role performance. Participants expressed the need to hope for recovery.
- Reminiscence provided an opportunity for continuing a role with the same meaning as before beyond the time when physical performance or *doing* was possible. Meaningful *being* could be deeply significant to the person.

4.4.4 Perceived Control

Occupational Role Performance Knowledge

- Participants had a detailed knowledge of their perception of their own abilities and disabilities and how these affected occupational role performance.
- They used role rules to guide their perceptions of their own performance. These could be personal, self-imposed rules or rules related to how they believed people in general should behave.
- Participants displayed a detailed knowledge of how they perceived factors in the physical and social environment limited or facilitated their ability to perform. This knowledge formed an *internal picture of the environment*.
- Participants actively pursued strategies to overcome environmental barriers to occupational role performance and consequently had self-perceived knowledge about what worked for them and what did not.

Perceived Outcomes of Occupational Role Performance

- Participants evaluated their occupational role performance and formed judgements based upon desired outcomes, comparison with their *ideal role performance*, and comparison with past role performance. These judgements formed the basis of a dynamic knowledge about the outcomes of their own occupational role performance.

- Participants tried to predict future occupational role performance based upon their knowledge of their current performance and the environmental resources available to them. Many expressed the fear that continued poor performance would lead to further deterioration of their roles. They spoke of the need to hope for improvement in order to be able to keep going.
- Some participants used their own occupational role performance predictions as the basis for planning strategies to regain control of valued roles.

Perceived Self-efficacy

- Participants experienced a level of perceived self-efficacy as a result of the knowledge they had developed in relation to the occupational performance outcomes of their roles.
- Perceived self-efficacy was particularly important in relation to valued roles, and had a direct effect upon self esteem and self-identity. A low level of perceived self-efficacy could lead to depression, while a perception of high self-efficacy could lead to a sense of well-being.

These findings demonstrate that the first stated purpose of the study has been fulfilled.

4.4.2 Summary of findings that relate to the second stated purpose of the study - to explore the possibility that role is a construct that is used by the participants in the planning and performance of meaningful occupations.

A structural model was developed (see fig. 4.2) that demonstrated how the participants in this study used role as a construct to organise meaningful occupation. The elements of this model were described and were found in every participant's transcript. A transcript excerpt was used to illustrate how the model can be applied.

These findings demonstrate that the second stated purpose of this study has been fulfilled.

The findings of the study described in this chapter will be discussed, in relation to the relevant literature identified in Chapter Two, in the next chapter.



Fig. 4.2 Preliminary Structural Model of Occupational Role Performance

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 INTRODUCTION

This chapter contains a discussion of the findings outlined in Chapter Four in the context of literature on role, and occupational therapy theory and services in relation to stroke rehabilitation, as outlined in Chapter Two. The discussion within this chapter is structured around the overall Research Purpose. There are two sections to this chapter. The first part of the overall purpose of the study as stated in Chapter One is **To describe the self perceived occupational performance roles of men over 65 who have had a stroke, in order to gain insight into the meaning, motivation for, and organisation of their occupational roles.** The first section of the chapter focuses on a discussion of findings concerning the way participants spoke about their roles, the kind of roles participants identified, the nature of their role performance, the way roles were organised, and the meaning that participants ascribed to their roles. The second section contains a discussion of the findings related to the second overall purpose of the study which was stated in Chapter One which was, **to explore the possibility that role is a construct that is understood and utilised by these men in the planning and performance of meaningful occupations.** The discussion in this section focuses on a preliminary conceptual model of occupational role performance developed from the findings and on its potential in terms of future research.

5.1 DISCUSSION OF FINDINGS RELATING TO PARTICIPANT UNDERSTANDING OF THE CONCEPT OF ROLE

5.1.1 Participant Perceptions Of Role

A central finding of this study was that the participants were comfortable about discussing their current daily life in terms of role performance. Participants were able to discuss their occupational performance at the role level, identify roles that they had and discriminate between what was a role and what was not. Participants' discussion of their role performance revealed *doing*, *knowing* and *being* aspects, as described in The Occupational Performance Model (Australia) (Chapparo & Ranka, 1997a) and in Chapter Two. They

demonstrated the process of *doing* by describing the performance of routines and tasks that they related to specific roles. They demonstrated *knowing* by describing planning and problem-solving processes linked their role performance. They discussed their own role performance in terms of quality and expectation. They knew about their roles in a developmental way, by comparing past, present and future performance. They knew about the external context of their role performance (the physical, sensory, social and cultural environment relevant to performance of specific roles). They demonstrated *being* by identifying varying values for each of their roles, by identifying meanings related to specific roles, by expressing a degree of satisfaction or dissatisfaction about their role performance, and by expressing a sense of *position* or *fit* within their physical, sensory, social and cultural environment. Participants were able to decide whether a given role was predominantly socio-cultural or predominantly occupational in nature, further demonstrating the meaning of the role to them.

These findings confirm the existence of role as a real construct that is used by the participants in this study in their everyday lives to help them think about, plan and perform their occupations. This reinforces the need to research the phenomenon of occupational performance role. It frees the researcher and therapist from the necessity of imposing external structure upon data gathering about role performance. The findings of this study suggest that it is not necessary, for instance, to use occupational role assessments which provide an interpretive interface between the role performer and the interviewer in order to translate their responses into role relevant language. Examples of such an interface are found in The Role Checklist (Oakley, 1981; Oakley et al., 1986) which provides a list of predetermined roles with pre-determined definitions, and the Occupational History Interview (Kielhofner & Henry, 1988b) which relies upon the therapist to interpret interview data in terms of role.

5.1.2 A Discussion Of The Findings Of This Study As Related To Role Theory

Participants demonstrated an understanding of the concept of role that was consistent with aspects of role theory as described in Chapter Two (section 2.2), supporting the finding that they were indeed discussing roles. They talked in terms of *actions* - goal directed behaviour. They demonstrated an awareness of the *prescriptions* related to each of their roles. They spoke of their own *evaluations* of their role performance. They *described* role performance. Finally, they showed an awareness of *sanctions* - both positive and negative. In

all of these, participants talked of both *overt* and *covert* behaviour. Participants demonstrated an awareness of the various *positions* their roles afforded them. They talked of role partners, who acknowledged the position they held, and who shared a common *identity* with them.

Studying participants' *perceptions* of their own role performance is not a usual part of enunciated structuralist role theory. As described in Chapter Three, and in keeping with the purpose of this study, the method used to find out about participants' self perceived occupational role performance was to interview them and ask them to discuss their role performance with the researcher. Biddle (1979) specifically states that while understanding meaning is most important to understanding behaviour, when investigating role theory, the only behaviour that it is acceptable to study is that which is observable. He rejects attempts to study *covert* behaviour as he feels role theory should be an empirically based science. He says:

In short, the real world of behaviours is a complex environment that is only partially mapped by the conceptions of subjects. And if we are to study behaviours (and we must) the concepts we use for this purpose must be clearly separated from those used to express the conceptions held about behaviours by participants and others. (Biddle, 1979, p. 54)

Symbolic interactionists, on the other hand, are interested in studying covert behaviour, and indeed believe, as part of their basic premise, that it is important to know how a person *perceives* their world (Heiss, 1981).

Biddle's view is not relevant to this study. While his approach is important in order to gain insight into and to further develop the concept of *social* roles, where it is hoped that generalisations and therefore predictions can be made that can then be applied to whole groups of people, the purpose of this present study is rather different. This study, which is being conducted within the discipline of occupational therapy, is not about extending social role theory, but about investigating people's perceptions of their roles. This discussion will focus upon participants' own perceptions of their role performance, not only in terms of *doing* as advocated by Biddle, but in terms of *knowing* and *being*. An occupational therapist's interest in the concept of role goes beyond observation to the conceptual meaning that the person ascribes to the role. It is not possible to observe *knowing* and *being*, yet these are central to determining the nature of occupational performance. The findings in section 4.2.2

of Chapter Four regarding the idiosyncratic placement of roles demonstrates that it is not possible to make reliable inferences about a person's reasons for occupational role performance. Gaining insight into how people think about their roles is as important as gaining insight into what has real meaning to each person, if occupational therapists are to use the construct of role effectively in clinical practice and research.

5.2 DISCUSSION OF FINDINGS RELATED TO THE IDENTIFICATION AND DEVELOPMENT OF THEMES ABOUT THE NATURE OF OCCUPATIONAL ROLE PERFORMANCE

5.2.1 Active Engagement

The major theme of active engagement encompasses what Biddle (1979) would term *role behaviour*. However, the construct extends the idea of role behaviour beyond what is externally observable behaviour - *doing* - to actively thinking and experiencing the role - *knowing* and *being* as described by Chapparo and Ranka (1997a). Findings relating to Active Engagement will be discussed in this section.

5.2.1.1 Role As Organiser

Participants in this study demonstrated that they used role as a conceptual tool for organising their behaviour. Participants organised themselves conceptually in terms of the reasoning behind role performance or *meaning*. They were able to sort roles under occupational and socio-cultural meta-role headings without difficulty, indicating they had a clear idea of the major purpose of the role in their lives. Three participants who had difficulty with this sorting were reported by their referring therapist as having some cognitive disability as a result of their stroke, indicating difficulty with sorting as a task. These participants demonstrated they had no difficulty with role understanding however, as they were able to discuss their lives in role terms in a fashion similar to other participants. This supports the idea that role is a basic organising construct used by everyone. Participants saw their roles as part of an *interacting whole*. For example, many of the participants spoke of the way in which their disability had adversely affected their ability to *perform* as before in a number of different roles. This in turn had the cumulative effect of adding to their perceptions or feelings of dependency and led to changes in their self-perceived identity and social position.

This self-perceived view of roles as part of an interacting whole is not one that is emphasised by role theorists. Participants - in particular those who were role focused - organised their roles in terms of *time*, choosing to spend more time in valued roles and less time in other roles.

This view of role as organiser finds early support from Banton (1965). He saw role as an intellectual tool that has an important function as an organiser, stating that people use the concept of role as a cognitive tool to organise their activities and their time.

5.2.1.1 Role Repertoire

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

Features of Role Structure

Roles Named:

Each participant in the study had a distinctive role repertoire. As reported in Chapter Four (section 4.1.2), a total of 42 different roles were named by all the participants, with participants identifying around seven to eight roles each (see table 4.1 for the full list of role names). When these named roles were compared with the extended list of 48 roles with descriptions generated by Jackoway, Rogers and Snow, (1987), (discussed in Chapter Two, section 2.3.1.5) there were only 20 roles that appeared to correlate in meaning. Conversely, there were a group of roles identified in this study relating to providing specialist advice to others, such as Unpaid Consultant, and Business Partner, that were not identified in Jackoway, Rogers and Snow's list. Similar results are evident when the roles identified in this study were compared with the ten roles identified in the Role Checklist (Oakley, 1981) (see section 2.3.1.4). None of the participants in this study identified roles that could be related,

using Oakley's descriptions, to those of Care Giver, Student, or Volunteer. As with Jackoway, Rogers and Snow (1987), the Role Checklist did not have a role corresponding to providing specialist advice to others. In addition, participants in this study identified another whole area of role performance that was most important to them and not mentioned in the Role Checklist, named variously as Stroke Recoverer, Person With a Disability and so on.

The results of this comparison between studies shows that each person will vary in the names they give their roles and the ways they define them according to their needs, choices and social and cultural backgrounds. Some of the differences identified can be explained in terms of the special needs of these participants. They had all had a stroke which left them with varying levels of disability and handicap. There are cultural differences between these men in Australia and the people that had been used to establish the role lists for the other assessments in America. These differences serve to demonstrate that assessments that use pre-determined role lists are of limited use, as it is likely that major roles will be missed.

Agreement on the naming of some roles involved a degree of discussion between interviewer and participant, generally led by the interviewer. The discussion related to what word or phrase would best describe the role, rather than uncertainty about the role itself. The roles provoking most discussion were generally the ones with less overt prescription. Attaching a role name was a need of the interviewer rather than the participant, and it seemed the name was perceived simply as a linguistic label by the participant. Providing a role name is useful only in that it facilitates conceptualisation by identifying a particular set of tasks and routines that is related to role activity. It does not assist with determining role level, and indeed where an activity fits with a role is very fluid.

In the present study, Family Member and Friend (or variations of those names) were the two most commonly identified roles. There is agreement between this finding and the findings of two Swedish studies on roles (Bränholm & Fugl-Meyer, 1992; Fugl-Meyer et al., 1991; Larsson & Bränholm) supporting the likelihood that Family Member and Friend are generally commonly identified roles for older people.

The Hierarchies of Role Repertoire:

As mentioned earlier, and reported in Chapter Four (section 4.2.1.1), participants discussed their roles in the context of their *role set or repertoire*. They were aware of how each role fitted with the others and used meaning to organise their role performance. Two

types of hierarchy that relate to perceived role meaning were evident in the way that participants discussed their roles. The first was in relation to *role value*. Participants identified some roles as being either more or less valued relative to other roles in their repertoire. This finding is consistent with results in studies using the Role Checklist (Oakley et al., 1986), where participants are able to rate their roles on a three-point scale for value. It is supported by continuity theory, which states that people have a set of roles that vary in importance and significance (Bell, 1976). It was not clear from the findings whether participants perceived any difference between *importance* or *significance* and *value*. These three terms have been assumed, in this study and others, to be interchangeable. For example, Heiss (1981), in discussing role identities, refers to a prominence hierarchy in terms of importance *or* value. Perhaps, however, there are self-perceived differences between these terms.

The second hierarchy related to *role level*. As described in Chapter Four, participants identified some roles that were very specific, with relatively few activities or routines associated with them. The same participants would have other roles in their repertoire that were comparatively broad and complex, with a range of routines and tasks associated with them. This finding is supported by Biddle (1979). He discusses the variation in level or complexity that can occur between roles. He describes the variation in terms of *breadth* - the number of different behaviours that can go to make up one role; *difficulty* - the degree to which skill and energy are required to perform the role; and *coherence* - the degree to which the components of the role fit together. This variation in level is clear in the roles identified in some occupational role assessments. For instance, Jackoway, Rogers and Snow (1987) identified seven roles that related to membership of a group or organisation. In this study, this category of role was given one name only by participants - club member. This variation in level is not available using the Role Checklist, which lists roles always at their highest or most all-encompassing level. Perhaps the age range of the participants means that this hierarchy is particularly evident in this study. Older people may have greater opportunities for choice in their role performance than younger people because they have fewer highly prescribed roles. For instance, none of the participants were still in paid employment. Their role repertoires had few 'institutional' roles. The majority of roles identified could be seen as 'tenuous' roles as described by Rosow (1976) and discussed in Chapter Two (section 2.5). Tenuous roles have few normative elements, and very little consensual expectation within their reference group. This leaves the holder of the role freer to determine the nature of the role and its performance than is the case with institutional roles which carry normative

consensual expectations within their reference group. This concept of choice will be discussed at greater length in relation to findings grouped under Personal Meaning (section 5.2.2.3).

The tenuousness of some roles made it difficult for the participant to tease out and separate two or more closely related roles. This was reported in Chapter Three (section 3.4.4) and in Chapter Four (section 4.2.1.1). There appeared to be some role overlap, with reduced role definition where the roles concerned had few *overt prescriptions*. There was difficulty in determining at what level the role should be named as a role. Perusal of the list of roles identified in Table 4.1 indicates a high proportion of roles that may not have had many overt prescriptions, leading to a higher degree of choice in terms of role performance. Participants generally discussed a number of their roles in ways that indicated they felt able to perform them in a manner of their choosing. It may mean that for these roles there was less need for role negotiation and therefore definition, as role partners were undemanding. This is not specifically discussed in the reviewed role literature, although Biddle maintains there are no natural boundaries for role performance (Biddle, 1979). The finding is supported in the same way as the finding about role levels, by Rosow's (1976) idea of the tenuous role - ill-defined, with few external expectations for performance. It is clear that further research is needed to investigate why some roles are well-defined and others less so, and whether any pattern or underlying reason can be discerned for variations in role level.

The role level hierarchy is problematic if occupational performance roles are considered to be made up of tasks and routines or activities in a hierarchy of complexity, as defined by many occupational therapy writers (Christiansen & Baum, 1997a) and discussed in Chapter Two. If role is part of this hierarchy, then where are the cut-off points? When does an activity or a routine become a role? The findings of this study provide greater insight into the non-observable characteristics of occupational performance roles which may assist researchers to better define what it is that differentiates an activity or routine from an occupational performance role.

Features of Participant 'Style' in Role Repertoire Performance

The second type of findings about the self-perceived role repertoire of the participants relate to the *style* of role repertoire performance. Three styles were identified and reported in Chapter Four (section 4.2.1.1). These were *planned and active*, *unplanned and active*, and

passive. There was no literature found to support these observations about variation in style of role repertoire performance. As already mentioned, little research has been reported regarding performance in the context of the whole role repertoire (Adelmann, 1994). The findings in this study represent an extension of the concept of choice in relation to occupational role performance as described by Burns (1991) and Chapparo and Ranka (1997a) and discussed in Chapter Two. They raise questions beyond the scope of this study. Are these three styles typical of others or peculiar to these participants? Would a larger study reveal other styles? Do people change their style in later life or persist with the same style that characterised their role repertoire performance in earlier years? What is the impact of role transition on style of performance? Is there any relationship between style of performance and self-perceived satisfaction with performance outcomes?

These findings reinforce the need for occupational therapists to be aware that each person's role repertoire is likely to be unique, not only in terms of the roles held, but in terms of the way they are interpreted and performed by the holder.

5.2.1.2 Temporal Perception of Occupational Role Performance

As reported in Chapter Four (section 4.2.1.2), participants in this study used the concept of role to organise their time. The stroke had meant they now spent more time performing in their role as a person with a disability, attending to personal care and rehabilitation needs. This meant that they had less time to spend in other, more preferred roles. This finding is supported by the literature. Barris, Kielhofner and Watts (1988b) discuss role as an organiser of time. Bell (1976) discusses the fact that people will always have a definite temporal orientation to their role set or role repertoire.

Those who were planned and active, with a role focus, were often strongly directive of their role performance in terms of time and appeared to be satisfied with their time use. Other participants who did not have a role focus but were actively engaged in their roles (unplanned and active), did not appear to organise their time so carefully, but expressed surprise at how quickly time passed for them. The more passive people in the study complained more frequently of needing to find ways to pass the time and appeared to be less satisfied with their time use. This finding is supported by the work of Yerxa and Locker (1990) who found a link between the meaning of particular occupations to the people in their study and their expressed satisfaction with time use. Hagerdorn (1992) supports this. She differentiated unstructured

time from leisure time, and said that unstructured time may be unpleasant for those who lack the roles and resources to fill it. The implication of the finding for occupational therapy clinicians who are working with clients on their use of time is that they need to discuss time use with them in the context of self-perceived occupational role performance priorities.

5.2.1.3 Occupational Role Performance Transitions and Continuity

Roles are reported to be dynamic in nature (Heiss, 1981) and every participant in this study had experienced some role loss due to their stroke (reported in Chapter Four, section 4.2.1.3). These roles were often spoken of as being of great importance to the participant concerned. The lost roles were replaced by an unwanted role. All had acquired the new role of Person with a Disability and were engaged in dealing with this role. It had been imposed upon them suddenly, rather than chosen. It could perhaps be described as a biologically ascribed role, which carried a negative change in social position, as perceived by the participants. Their disabilities made it difficult for them to continue with some of their other roles, leading to a dislocation in their sense of social fit and producing high levels of stress. This finding of role loss is supported by a number of studies which showed that the majority of people who experience brain injury experience the loss of major roles, leading to losses in social and leisure activities and a reduction in life satisfaction (Aström et al., 1992; Drummond, 1990; Hallett et al., 1994; Jongbloed, 1994; Labi et al., 1980; Månsson et al., 1995; Niemi et al., 1988; Viitanen et al., 1988). George (1980) states that where a role has been lost, it needs to be replaced by another if a person's self-esteem is to be maintained.

Successful transition in this study appeared to be linked to two factors. One factor was the ability to utilise previous knowledge derived from earlier life experiences in a way that was relevant to the participant and to their present situation. The other factor was participant ability to utilise various relevant resources to help them deal with the new role. Participants identified in this study as most successfully dealing with the acquisition of the role of Person With a Disability were planned and active in their role repertoire performance style. They were able to draw on previous experience and resources, and utilise problem-solving skills to assist in the adaptation process. Many participants spoke of their reliance upon their wife and/or family and friends to support and assist them. Some expressed concern at the lack of rehabilitation services available to them.

These findings are supported by a study that was carried out in Canada into how people with an ongoing disability experienced the transition from hospital to home. The people in the study emphasised the need to be resourceful and to be able to think out solutions to specific problems. They reported the need to depend upon the support of family and friends in practical as well as social and psychological ways. Some expressed frustration at the lack of rehabilitation services available to them, when they felt further improvement was still possible. Many respondents emphasised the importance of occupation or *doing* in achieving a successful transition from hospital to home (Gage, Cook, & Fryday-Field, 1997).

Participants in this study showed by the way that they discussed their roles that they were at various stages in the adaptation process. For some, role acquisition had really not yet commenced, and so the tasks associated with successful transition were not being done. Other participants had embarked upon the acquisition process and were totally preoccupied with the transition, spending a large part of their time problem-solving, performing and experiencing the new role. Others appeared closer to the stage where the new role had been integrated into their role repertoire. This finding is supported by Schlossberg's Model for Analysing Human Adaptation to Transition, discussed in Chapter Two (section 2.2.2.7). The model defines adaptation to transitions as "*a process during which an individual moves from being totally preoccupied with the transition to integrating the transition into his or her life*" (as cited in Forsberg-Wärleby & Möller, 1996 p. 117). In this model, three sets of factors are suggested to influence transition - the characteristics of the particular transition; the characteristics of the pre- and post-transition environment; and the characteristics of the person (as cited in Forsberg-Wärleby & Möller, 1996).

A number of factors from the three sets described were evident in this study. In particular, the role being acquired was not chosen but suddenly imposed and carried with it a high degree of stress. Some participants appeared not to be making effective use of the environmental resources available to them, and seemed unable to move on with this role, despite the fact that it affected the performance of almost every other role in their role repertoire. Perhaps the degree of stress and the characteristics of the person as identified by Schlossberg (as cited in Forsberg-Wärleby & Möller, 1996) were such that they were overwhelmed by the experience of the stroke and its aftermath, as evidenced by the fact that they expressed a strong wish to return to the past.

A second finding about the dynamic nature of roles and the impact of the stroke was that the majority of participants were able to *continue* with some of the roles held prior to the stroke. For some roles that were successfully continued, the participants had retained the abilities and skills, as well as the environmental resources the role demanded, and were able to continue with the role as before. For other roles, participants had to make changes to the way they performed in the role, utilising much the same resources as they were using in adjusting to role transition. Some participants lost the overt performance of a particular role but maintained covert performance in the form of reminiscence or by passing on role knowledge to others. No direct studies were identified in the reviewed literature that related to role continuity in the presence of disability. However, this finding is supported indirectly by continuity theory. This theory, as discussed in Chapter Two (section 2.5), states that, unless prevented by disability or external life events, people tend to continue with the same activity levels they have always had (Kelly, 1982).

These findings reinforce the need for a consideration not only of the resources available to assist with role transition, but of the person's motivation and ability to make effective use of those resources. In addition, they draw attention to the need for participants to retain as many roles as possible in the presence of injury and disability, and give some indication of the factors involved in achieving this.

It is beyond the scope of this study to suggest specific factors that would support successful role acquisition, role change or role continuity. Further research is needed, perhaps using Schlossberg's model (as cited in Forsberg-Wärleby & Möller, 1996) to establish the relevance of and relationship between the three major factors he describes and how they may be manipulated to facilitate successful role transitions and role continuity.

5.2.2 Personal Meaning

The second major theme identified in the findings described in Chapter Four was called Personal Meaning. Findings that are part of this theme relate to the meaning that motivates Active Engagement. It relates mainly to findings related to *being*, although there are elements of *knowing* and *doing*. Meaning is an important factor in making significant life choices (Frankl, 1963).

5.2.2.1 Participant Role Sorting

Participants sorted their roles in ways that were impossible for the researcher to predict, as reported in Chapter Four (section 4.2.2). Even roles that are apparently well prescribed social roles, such as Father and Husband, appeared under a number of occupational performance meta-role headings. Participants sorted their roles not only according to the relationships or role partnerships that the role conferred, but according to the nature of the role itself, and what aspect of the role and area of role performance it represented (as reported in Chapter Three, section 3.4.5). Some roles were seen primarily as being about relationships with others and were sorted under the socio-cultural heading. Other roles were seen primarily as related to a particular area of *doing* and were sorted under one of the occupational performance meta-role headings. Participants sorted their roles according to how they saw themselves performing in relation to their role partner(s) at the time of the interview. In other words, they were able to sort their roles in an *occupational* way, perhaps acknowledging their dynamic nature. The trend to sort generally accepted social roles such as Father under occupational performance headings went the other way too, with participants sorting roles such as business partner (commonly considered a Productivity role), stroke recoverer and home maintainer (commonly considered as Self-Maintenance) and bird watcher (commonly considered Leisure) under the Socio-cultural meta-role heading. It follows that some roles that are conventionally seen as strongly social in nature were seen by some participants as having social content, but being primarily occupational in nature. Other roles, while being seen as having occupational content were seen by some participants as being primarily social in nature.

The idiosyncratic placement in the present study is supported by two earlier studies discussed in Chapter Two (section 2.4.2) (Marino-Schorn, 1986; Yerxa & Locker, 1990). Participants in these studies were asked to sort activities rather than roles, but in the absence of research relating to role performance, their results are relevant. Both pieces of research used similar headings to those described in this study, and found that participants demonstrated a tendency to sort activities in an idiosyncratic manner. The findings are extended in this study to the role level. It is postulated by Chapparo and Ranka (1994) that not only may roles carry different occupational meanings for different people, but that the same person may view occupational performance belonging to a specific role as having a different occupational meaning if the context of performance changes (see Chapter Two, section 2.3.2.3). Because this was a 'snapshot' study participants were only asked to sort their roles once. It would be interesting to see how consistent role sorting for these participants was

over time, and, where change occurred, whether external and internal factors could be identified and linked to the change.

This type of ascribing of meaning is not part of social role theory for theorists such as Biddle who view role in terms of what is observable to others (Biddle, 1979). However, the finding is supported by the view of other role theorists such as Burns (1991) who points out that many roles are prescribed in terms of what is *not* acceptable, rather than what is desirable. It may relate to Rosow's (1976) idea of tenuous roles held in later life. Such roles would allow a greater degree of choice on the part of the role performer about the nature and meaning of performance.

A second finding related to role sorting, reported in Chapter Four (section 4.2.2), was that when the role sorting done by all the participants was represented together, the sorting followed a more expected pattern than it did for individual participants. This finding is supported by the study described above by Yerxa and Locker (1990) and has resonances with the work of Chiou and Burnett (1985), as discussed in Chapter Two (section 2.6.2.2). Chiou and Burnett found that occupational therapists had a good grasp of the priorities for Self-Maintenance activities of a group of clients when viewed as a whole, but had very poor agreement with the individual members of that group.

These findings demonstrate that many roles were considered occupational in nature by participants who were not bound by external expectations. Rather, they used the construct of role as a tool to conceptualise areas of occupational performance in a flexible manner. Further research is needed to determine how self-perceptions of role may change over time in response to contextual changes, and to further explore the factors that determine how specific roles are perceived in terms of meaning at any given time. In relation to clinical practice, it would be useful for therapists to know which roles in each client's role repertoire are perceived by him or her to be predominantly *occupational* in nature and which are considered predominantly socio-cultural. This would help to direct therapy towards the more occupationally orientated roles of the client, and perhaps ensure that the roles that the client experiences occupational problems with are included in therapy.

5.2.2.2 Fit - Self-identity and the Perceived Expectations of Self and Others

An important finding of this study (reported in Chapter Four, section 4.2.2.1) was that occupational role performance was a significant expression of self-identity for the

participants. Roles that were highly identified with were ones that were shared with role partners who had the same definition of the role. All the participants in the study indicated that they valued the roles of Family Member and/or Partner highly for example, reflecting a long and rewarding association and identification with these roles. They appeared to perceive a high degree of social congruence or *fit* in these roles. Some participants demonstrated that their self-identity was still tied up with past paid worker roles, speaking of these roles in terms which indicated they had experienced a satisfying sense of fit and of social recognition. These findings are supported by the work of the symbolic interactionists. Heiss (1981) states that a role that has been successfully held for many years, will form a strong part of that person's self-identity. People can be seen to have a hierarchy of identities, and an identity that is a passport to a network of relationships is likely to rank high in a person's hierarchy of identities. When the other people in the network share that person's role definitions, and when the identities which brought the others into the relationship are high on their own hierarchies, then the identity is likely to rank very highly, because these are the circumstances in which rewards are most likely to be forthcoming (Stryker, as cited in Heiss, 1981).

Another finding reported in Chapter Four (section 4.2.2.1) was that participants identified some roles that they acknowledged and performed in but did not see as part of their self-identity. They indicated that these roles were performed almost entirely because of the expectations of others. They perceived their performance was valued by others and they performed because of their sense of social obligation or social fit. For some there was a general disinterest in the role, while for others, a failure to perform to their own expectations prevented them from identifying with the role. It appears that personal beliefs and values are an important factor in determining a sense of self-identity and social fit and that it is possible to perform in a role that relates to a sense of fit, but not to a sense of self-identity. These distinctions are important in order to develop further research to understand the meanings ascribed by people to their roles.

Identity and social fit are constructs central to role theory and widely discussed (Biddle, 1979; Heiss, 1981). However, further research is needed to establish if it is possible to make the distinction between the self-perceived aspects of these two constructs. For therapists, being able to identify which roles are important to their client's sense of self-identity and which contribute to a sense of social fit is important. It would mean that they could ensure therapy was focused upon the restoration of occupational performance in roles that were appropriate to the client's specific problems with self-identity or sense of social fit.

There is a need for therapists to recognise how each client's beliefs and values may colour their view of their own role performance. Performance that may be considered acceptable by the therapist may be unacceptable to the client and vice versa.

5.2.2.3 Choice and Ideal Role Performance

As reported in Chapter Four (section 4.2.2.2), participants all demonstrated choice in relation to the nature of their role performance. As discussed earlier in this chapter, each of the participants demonstrated a role hierarchy. Most of the roles in this hierarchy, for most of the participants, had been chosen. One role they all shared had been imposed - Person With a Disability. Choices were made by all the participants about how to deal with this role. These choices were related to their beliefs and values. Some participants chose to work hard at their rehabilitation as a means of overcoming the effects of their stroke. They indicated that they believed that rehabilitation was the best way to achieve recovery of lost function and hence restore lost occupational role performance. Other participants chose not to be active in rehabilitation, even though they attended outpatients or Day Care. The majority of these participants indicated they did not believe that therapy would achieve the improvements they were seeking. This idea of choice - particularly in relation to the **nature** of role performance is supported by Burns (1991), as discussed in Chapter Two (section 2.2.2.6). The finding that participants chose whether to work at their rehabilitation or not is further supported by the work of Heiss who suggests that people will work hard at difficult or challenging roles only if they believe that once the associated identity is achieved (in this case, someone who has overcome disability) the costs are reduced, and there is a large reward. Those who do not believe the difficulties can be overcome will not work so hard at the role or rank it as highly (Heiss, 1981).

Participant responses revealed that interest was an important factor in the choices made by these men. Options for role performance that reflected the interests of the participant were chosen above those that did not. Such performance options were found rewarding by participants. This is supported by the work of Matsutsuyu (1969) who stated that interests are choice states, evoke affective responses, can sustain action and reflect self-perception. For example, participants did not appear to identify with or value the Self-Maintainer role, yet that is the role that is often the focus of therapy. If occupational therapists were able to identify the roles that were of significance for their clients, then performance in such roles could be more effectively linked to performance in Self-Maintenance. This could heighten

motivation to achieve in the Self-Maintainer role as a means of supporting occupational performance in other, more significant roles.

An important finding from this study is that participants demonstrated that they had a picture in their minds of the ideal way to perform in their roles. These internal images could be seen as pictures of *Ideal Role Performance*. Participants appeared to compare their performance to this internal ideal picture. It is anticipated that this picture of role performance is complex and built up over time as a result of experience and role learning, and is consistent with the person's beliefs and values and self-identity. This idea of a differentiation between the cognitive picture in the mind that is ideal and the actuality of role performance was suggested early on in the development of role theory by Linton, who proposed that role itself was an *ideal pattern of conduct*. He saw this ideal as only rarely being translated into actual role performance. This finding is supported by Heiss (1981) who suggests that the rare identities that a person manages to live up to are high on their hierarchy.

This concept of ideal role performance is related to the idea of the ideal self, which has been considered in the discipline of psychology for many years (Ogilvie, 1987b). Clinical psychology techniques such as those related to Personal Construct Theory are based upon the idea of encouraging people to experiment with the internal picture they have of ideal performance and ways of *being*, in relation to the relevant environmental context (Pervin, 1975).

It is important for clinicians to understand the ideal picture of role performance held by clients in order to more fully understand the level of performance that is acceptable to them. Further research is needed to determine how flexible this picture is, and to identify the factors that may influence changes in Ideal Role Performance as part of the adjustment process consequent upon acquiring a disability.

5.2.2.4 Self-expression and Satisfaction

The role ratings provide one means of considering levels of satisfaction in this study. There was a difficulty in looking at individual role ratings. High value roles were placed under the same meta-role heading as low value roles during the sorting process. Because it was not possible to ask participants to rate each role individually, (some participants became impatient with the process as it was), participants were asked to rate each meta-role as a

whole. This meant that participants were asked to rate a group of roles of quite differing nature in terms of what was being rated: perceived frequency, value and satisfaction with meta-role performance. The resultant ratings are perhaps distorted by the variety of roles that the person had to give a rating to. This makes discussion of individual roles in the light of these ratings difficult.

This study found that if a participant perceives his role performance to closely match his *ideal role performance* he will experience a greater degree of performance-related satisfaction than if the two do not match well. Self-expression - defined here as being able to perform in significant roles in a way that is largely self-determined, and achieve something that comes near to ideal role performance, seemed to offer the best opportunity for role performance satisfaction. This finding is supported by Heiss (1981) as described in the last section. Very few if any studies have been reported examining satisfaction with *role performance*. Related studies examining life satisfaction indirectly support the finding. Elliott and Barris (1987) found a relationship between performance in roles that were valued and higher levels of life satisfaction. Ogilvie (1987a) found that the more time people spent enacting higher order identities, the more satisfied they were (see section 2.4.5). If there is a link between ideal role performance and self-identity, then Ogilvie's findings would support what was found in this study.

A second finding relating to self-expression and satisfaction related to the perceived quality of performance. Participants sometimes spent a great deal of their time performing in roles that they did not particularly enjoy or value for their own sake, yet they expressed satisfaction with their performance. It is clear from this study that performance in a valued or significant role was not necessarily linked to a sense of pleasure or high quality of life, as is sometimes assumed. Being satisfied with role performance was not necessarily equated with a role of value or significance either. It seemed from what participants said that satisfaction with role performance was more likely to relate to the anticipation of a rewarding outcome (such as increased level of occupational role performance), either now or in the future. It was likely to relate to meeting the expectations of others and of self, as described in Heard's model (Heard, 1977) and in the extension of that model (Hillman & Chapparo, 1995a), both of which are described in Chapter Two (section 2.3.1.2 and 2.3.1.7). Rewarding outcomes have been described in this way by Heiss (1981) and by Biddle (1979).

This is an important finding in terms of developing further understanding of the **motivation** to perform. It reinforces the need for clinicians to have as clear an understanding as possible of Ideal Role Performance and a good contextual perception of what is perceived as rewarding for each person they work with. Research directly addressing satisfaction with occupational role performance is needed to further clarify the factors that influence the level of satisfaction that people experience.

5.2.2.5 Self-perceived Occupational Role Performance Viewed Over Time

One of the findings of this study in relation to time, was that participants who were role focused and had an *planned and active* style of role performance grounded their role performance in the present, as did those who were *unplanned and active* in style. Participants who were *passive* in style tended to ground their performance in the past, referring to past role performance often, and reminiscing. Reminiscing about past roles that were highly valued and in which the person had experienced success, rewards from peers and the achievement of personal expectations could be highly satisfying. In addition, it was possible to re-experience role performance in an idealised form. There was no reality check in the form of feedback about actual role performance. It was therefore easier to achieve a satisfying sense of fit through choice and approximation to Ideal Role Performance when reminiscing about past role performances than when dealing with the present. These participants appeared to still experience *being* through *doing* in valued roles even though no longer able to approximate ideal role performance in the present. Reminiscence can be a powerful means of experiencing satisfaction and self-expression in role performance. Literature on reminiscence confirms its self-affirming qualities (Bornat, 1994; Budge, 1989; Viney, 1993; Zingmark, Norberg, & Sandman, 1995).

A second finding in relation to time was that present meaning in a given role was built upon past life experience. Comparing past with present role performance appeared to have an influence upon the participant's view of present role performance. Often, perceived actual role performance did not come up to the level of perceived past performance. Participants expressed frustration about the things they were now unable to do, related to a range of different current roles. Other participants appeared to see meaning in their current role performance that was derived from past performance. This finding is supported by the literature on role learning (Biddle, 1979; Heiss, 1981), and is likely to be a determining factor in the person's present picture of Ideal Role Performance.

Finally, all participants attempted to predict the future and linked this to what was meaningful to them in terms of occupational role performance. Participants expressed the need to hope for improved occupational performance. Those participants who were strongly grounded in the past, seemed to wish to skip the present and looked forward instead to a meaningful future. When considering role performance in the future, it was again possible to experience ideal role performance. Fisher (1995), a developmentalist, identified a sense of future as an important feature of successful ageing. He stated that one of the distinguishing features of successful ageing was that it involved *"the individual's integration of prior life experiences with present circumstances and preparation for further developmental challenges"* (p. 239).

The findings related to occupational role performance over time provide further insight into *meaning* and *motivation* to perform in the context of past, present and future experience.

5.2.3 Perceived Control

The third major theme identified in the findings described in Chapter Four (section 4.2.3) is Perceived Control. Findings that are part of this theme concern the different types of knowledge that participants had about their occupational role performance, the manner in which they evaluated their occupational role performance and the estimation of self-efficacy they formed. This theme relates mainly to findings about *knowing*. It is suggested that participants put together the results of this *knowing* to give them a sense of Perceived Control. The literature related to environmental interaction indicates an inherent urge and need on the part of the person to experience control of their personal environment, as described in Chapter Two, (section 2.4.1). This is an important motivating factor in occupational role performance.

5.2.3.1 Occupational Role Performance Knowledge

Participants in this study demonstrated personal occupational role performance knowledge in a way that integrated present knowledge with past experience. Participants were identified as displaying knowledge about their current occupational role performance in four different ways:

- 1) *Knowledge about their own occupational role performance.* Findings related to participants' knowledge about their own role performances showed such knowledge was formed either through the experience of performing in the role, or through extrapolating knowledge of performances in other roles to give assumed knowledge of performance. This finding is supported by the literature on Learning Theory (Neistadt, 1998b).
- 2) *Knowledge about problem-solving outcomes.* Some participants spoke of attempts to problem-solve performance problems. Where these attempts were successful, it led to the development of knowledge about useful strategies for overcoming problems. Where strategies had not helped, it led to a greater conviction that the task in question could not be performed by the participant. Feedback from occupational performance provided opportunities for participants to learn about both their current level of ability and strategies that may or may not be successful in dealing with problems. This finding is well supported by both Learning Theory and occupational therapy literature on cognitive aspects of performance (Crepeau, 1998; Neistadt, 1998b; Wheatley, 1996).
- 3) *Knowledge about relevant role rules.* These rules were sometimes about how participants expected themselves to behave in carrying out all their roles and sometimes about how they felt people in general should behave in a particular role. The first type of role rule appeared closely related to self-identity. The second appeared to relate to role learning as described by Heiss (1981) or role prescription as described by Biddle (1979).
- 4) *Knowledge about the environmental context.* Participants had detailed knowledge of the physical and sensory environment relevant to their role performance, and the social context, including the expectations of others such as role partners. They put these together to inform their perception of environmental demand as well as what resources were present in the environment. This information was used as a reference in planning role behaviour, and assisted in identifying resources that could be utilised. It informed about perceived barriers to role performance. This finding is consistent with The Press-Competence Model developed by Lawton and Namehow (1973) and described in Chapter Two (section 2.4.1). Bell (1976) found that behaviour related to any given role is seen as being limited by such factors as time, energy and space.

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

It is proposed that participants used the four types of knowledge described above to create an *internal picture of the environment* that had personal relevance. Participants perceived the environment around them in terms of relevance to their self-identity, their beliefs and values and the relevant tasks of desired role performance. The idea of an internal picture of the environment is consistent with basic concepts of role theory, being part of the description classification of Biddle and Thomas (1966b) and described in Chapter Two (section 2.2.2.4).

This knowledge was very specific and personal, with information being filtered according to relevance and personal meaning. The personal nature of role performance related knowledge is supported by the work of Levine (1987), who suggests that people direct their attention, in any interaction with the environment, to those factors that have significance to them because of their cultural background and the ways of *being* that they have learned from their parents and peers.

The implication of this finding for occupational therapy clinicians is that clients may be operating from a knowledge base that leads to reasoning that is different to that of the therapist. This different reasoning will produce priorities and performance plans that differ from those envisaged by the therapist, even though goals for therapy have been agreed. It is important for the therapist to have some understanding of the knowledge base of each client and how this informs their reasoning. Such knowledge would enable a more focused and meaningful interaction between therapist and client, leading to greater efficiency and effectiveness in the therapeutic relationship.

5.2.3.2 Perceived Outcomes of Occupational Role Performance

As reported in Chapter Four (section 4.2.3.1), most participants demonstrated that they used the four types of knowledge described in the previous section in order to interpret

or make sense of the feedback they perceived about their occupational role performance. It is proposed that they used the knowledge to *evaluate* or judge whether the outcome from that performance was satisfactory or not. Perceived current occupational role performance was evaluated by comparing it with past performance, with *ideal role performance*, and by comparing role performance outcomes with desired outcomes. The judgements made as a result of this process formed the basis of a dynamic knowledge about perceived occupational role performance outcomes. This information then informed planning about future role performance. The collection and application of knowledge about role performance was dynamic and cyclical in nature, with earlier performance informing later performance. This cyclical cognitive process is similar to and supported by the work of Chapparo and Ranka (1997c; Fry & O'Brien, 1997) in developing the Perceive: Recall: Plan: Perform: (PRPP) System of Task Analysis. While this analysis was designed for use at the task performance level, the same pattern of cognitive processing could be extended and used to describe thinking at the role level. Briefly, the system reflects stages in the cognitive processing required for routine task performance. The first stage, Perceive, involves taking in information from the environment, sorting it and forming sensory images of self and environment. These images of self and environment are then classified and compared, in the next stage of the cycle (Recall), with relevant information already held. In the third quadrant (Plan) the processed information is used to problem-solve, evaluate strategies and make decisions about performance. Finally, the last quadrant (Perform) relates to carrying out of the decided course of action. As a result of this performance, more information is gained and the cycle can go around again (Chapparo & Ranka, 1997c; Fry & O'Brien, 1997).

Participants indicated that they thought about their roles and spent time reviewing role performance and attempting to problem solve difficulties. It may be that a lot of time is spent in the Recall and Plan quadrants at the role level, in the absence of overt occupational role performance.

The findings reported in Chapter Four indicate that participants compared perceived performance outcomes with *ideal role performance* to determine whether outcomes were satisfactory. Being able to achieve an outcome in a specific role-related task could be judged unsatisfactory if it did not in any way resemble this ideal picture. A number of participants were continuing in previously valued roles, but their performance had changed drastically - for some from physically performing the task themselves to advising others in its performance. Participants who had an ideal role performance that was strongly related to the

actual nature of performance in the role related tasks found that the changes brought by the stroke meant they were no longer able to perform in the manner specified. Their role performance was unsatisfactory, even if the desired outcome was achieved. Other participants, whose ideal role performance related more to outcome, demonstrated a greater acceptance of changes in the mode of role performance, provided the outcome was still satisfactory. The concept of *ideal role performance* meant that participants applied different standards for acceptable role performance to the different roles in their repertoire depending upon the personal meaning each role had to them. The concept of ideal role performance is supported by the literature on role theory. One of the earliest role theorists, Linton (as cited in Banton, 1965) saw a distinction between the concept of role that might be in a person's mind and the associated pattern of observable behaviour. He described an *ideal pattern of conduct* which was rarely fulfilled by actual role performance.

As reported, participants used the outcomes of role performance *evaluation* in order to predict future role performance. This was most important to them and many expressed the need to hope their performance would improve. Evaluation was an important means of informing the person about their performance and provided them with a sense of how in control of a specific role or sections of their role repertoire they were. Evaluation is part of the role classification produced by Thomas and Biddle (1966) and described in Chapter Two (section 2.2.2.4).

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

5.2.3.3 Perceived Self-Efficacy

As reported in Chapter Four (section 4.2.3.3), participants' evaluations of their own role performance led to a perception of self-efficacy. Perceived self-efficacy is defined by Albert Bandura as "... *beliefs in one's capabilities to organise and execute the courses of action required to produce given attainments*" (Bandura, 1997, p. 3). For participants in this study, perception was found to vary from a high level of self-efficacy for all the roles in the

repertoire of some participants to a low level for all roles for others. There were varying levels of perceived self-efficacy for different roles within the same role repertoire. Participants whose style was *planned and active* and who were *role focused* appeared to have high levels of belief in their own self-efficacy, and were prepared to persist despite difficulties - particularly in their role(s) of focus. Participants who were *passive* in their role performance style appeared to have the lowest levels of perceived self-efficacy. This finding regarding varying levels of belief in self-efficacy is supported by Bandura, who describes such beliefs as varying in several dimensions. First, they can vary in *level*. Perceived self-efficacy can relate to a simple task demand, all the way through to a highly demanding and very taxing area of performance. Efficacy beliefs can vary in *generality*. People may judge themselves efficacious across a wide range of activities or only in relation to a specific area of functioning. Efficacy can vary in terms of *strength*. Weak beliefs are easily negated by negative experiences, while strong beliefs will persist despite setbacks (Bandura, 1997). Gage and Polatajko (1994) cite the research of Holahan, Holahan and Belk and Davis-Berman who researched the relationship between perceived self-efficacy and psychological well-being. They found that higher levels of self-efficacy were associated with lower levels of depression.

It is proposed that Occupational Role Performance Knowledge and Perceived Outcome for role performance, are put together with this third factor of perceived self-efficacy to establish a level of Perceived Control of Active Engagement. This proposal is supported by the early work of Matsutsuyu (1971) who suggested, in considering productivity, that exploration, mastery, decision-making, achievement and competence were recurring themes of occupational role performance.

5.2.4 Summary Of Discussion Of Findings Relating To The Themes Of Active Engagement, Personal Meaning And Perceived Control

Findings from data analysed and presented in Chapter Four were discussed relative to Research Purpose One: **To describe the self perceived occupational performance roles of men over 65 who have had a stroke, in order to gain insight into the meaning, motivation for, and organisation of their occupational roles.**

The major findings were examined in the light of literature regarding occupational performance outlined in Chapter Two and further literature that was of relevance to the findings. Theoretical and/or empirical data was found to support the conceptual

interpretations of the qualitative data. Participants were able to discuss their occupational performance in role terms that were supported by the literature on role theory and in terms that clearly indicated the personal nature of role performance to each participant.

In terms of the *nature* of role performance, the finding that participants used role as a conceptual organiser to think about, plan and perform occupations in a meaningful way was an important part of this study and was supported by the role theory literature. The specific name given to a role was not as significant to participants as the conceptual nature or personal meaning of that role, and the names ascribed to roles varied widely, reducing the value of role assessments such as the Role Checklist (Oakley, 1981; Oakley et al., 1986) which rely on external, pre-determined role naming and definition.

The value hierarchy that was identified was evident in other studies, although the terms value, importance and significance are used interchangeably in ways that may not be justified. The existence of a hierarchy of level between different roles in the role repertoire has bearing upon the view of tasks, routines and roles as being in a hierarchy of complexity as defined by many occupational therapy writers (Christiansen & Baum, 1997a). Other findings in this study emphasise the conceptual nature of occupational performance roles, while the nature of tasks, activities and routines are defined in occupational therapy literature and practice in structural terms using a variety of task and activity analysis methods.

In terms of *meaning*, participants saw their roles as part of an interacting whole, organising them in terms of meaning, performance abilities and time. Occupational performance in relation to the role repertoire as a whole has not been well described in the literature.

Role performance was closely tied to self-identity and a sense of fit within the context of the various social environments inhabited by the participant. Participants demonstrated meaning in terms of the perceived nature of the role. Role sorting was idiosyncratic in nature, demonstrating that there was a high level of *personal* rather than *socially prescribed* meaning attached to each role. Choice was a major factor in determining occupational role performance. Participants demonstrated a variety of occupational role performance styles which had a bearing upon occupational role performance outcomes. Meaning in a given role was based upon past life experience, and judgements about the quality of occupational role performance were based upon what had previously been acceptable to the participant.

Attempts were made by all participants to predict the future in terms of meaningful role performance.

In terms of *knowing*, four types of knowledge about occupational role performance used by participants were discussed. Participants used this knowledge to form an internal picture of the environmental context relevant to desired tasks of occupational role performance. The use of this knowledge by participants to evaluate outcomes of perceived occupational role performance, and inform future role performance, in a cyclical manner was discussed. It was proposed that this cyclical process can be described by application of the Perceive; Recall; Plan; Perform system of task analysis (Chapparo & Ranka, 1997c; Fry & O'Brien, 1997).

The proposed picture of Ideal Role Performance, used as a bench mark by participants to evaluate their performance and guide their choices about future performance, is supported by the role theorists. It is an important finding in that it may guide further research into the reasoning that is undertaken by the occupational role performer in order to make choices about their roles and the nature of future occupational role performance. In this study it is proposed that comparisons with Ideal Role Performance influenced participants' perceptions of their current role performance, affecting their level of perceived self-efficacy and hence their motivation to perform.

It was proposed that occupational role performance knowledge and perceived outcome for occupational role performance were put together, along with perceived self-efficacy to form and overall sense of Perceived Control of Active Engagement.

5.3 DISCUSSION OF FINDINGS RELATING TO PARTICIPANT USE OF THE CONSTRUCT OF ROLE

The second purpose of the study was **to explore the possibility that role is a construct that is understood and utilised by these men in the planning and performance of meaningful occupations.**

Discussion of the findings in relation to Research Purpose One demonstrates that Participants understood and used the construct of role to *organise* knowledge, meaning and time in order to produce specific occupational performance that would, in the person's

personal judgement, best produce the occupational performance outcome they would like to achieve.

In order to further fulfil the second purpose of the study, it was proposed in Chapter Four that a preliminary structural model can be stated from the themes developed in the findings. The three major constructs of this model are Active Engagement, Personal Meaning and Perceived Control. These constructs and their sub-constructs interact in complex and reciprocal ways that it is beyond the scope of this study to represent. However, the constructs themselves were described in Chapter Four (section 4.3).

The model demonstrates the extended description of the personal aspects of occupational role performance that has resulted from this study. The identification and description of the various constructs that emerged from investigating a self-perceived view of role performance make this model of particular value to occupational therapists. It affords access to information about the *reasoning* of their clients in relation to the occupational performance of their role repertoire, and to the factors that may influence that reasoning. The model can enable clinicians to gain a clearer understanding of the nature of occupational performance roles in terms of the relationships between the *doing*, *knowing*, and *being* aspects of occupational role performance, although further research into those relationships is required. The model can be used as a guide by therapists in determining what factors to assess and prioritise in therapy in order to facilitate a satisfactory return to occupational role performance that is of personal significance to each of their clients.

In terms of research, the description of the constructs and sub-constructs provide an important foundation for future research designed to provide an extended and dynamic picture of occupational performance roles.

The findings of this study have extended the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997) in terms of its central construct of occupational role performance.

The next and final chapter will provide an overview of the study in relation to the research purposes, discuss the significance of the findings and draw conclusions from them.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.0 INTRODUCTION

The purpose of this final chapter is to consider the research study as a whole in order to determine what has been learned and what significance the findings have for the occupational therapy profession.

The chapter will provide a brief overview of the purposes, methodology and outcomes of the research. This will be followed by a discussion of the limitations of the study and of its theoretical, methodological, empirical and practical significance. The study has generated some hypotheses and some implications for future research and practice and recommendations will be made about these. Once the study has been reviewed, and its results placed in context, its conclusions will be stated.

6.1 OVERVIEW OF THE STUDY

The study was prompted by an interest in the concept of occupational role performance in the presence of aging and disability. A concern regarding the long term outcomes of stroke rehabilitation was instrumental in determining the nature of the study. The need for the study was based upon the commonly stated need for occupational therapists to ensure that their clients are able to resume occupational performance roles of personal significance and meaning following stroke. However, there is very little reliable information about the occupational performance roles of older people, or of those who have had a stroke. Very little is known about how people perceive their own roles and role performance in later life. As a result, occupational therapists are ill-informed about the nature of occupational role performance. The construct remains ill-defined, making therapy at the role level difficult. There is an emphasis in the occupational therapy literature upon how role places demands upon the person, with the accompanying view that occupational therapists need to work to enable clients to meet those external demands. Little consideration is given to the degree of choice exerted by the person in their occupational performance roles and occupational role

performance. In the light of these considerations, the research purposes of this study were stated as:

RESEARCH PURPOSE ONE:

To describe the self perceived occupational performance roles of men over 65 who have had a stroke, in order to gain insight into the meaning, motivation for, and organisation of their occupational roles.

RESEARCH PURPOSE TWO:

To explore the possibility that role is a construct that is understood and utilised by these men in the planning and performance of meaningful occupations.

Research Purpose One was addressed by means of a review of the literature and a naturalistic study. Literature reviewed concerned the concept of role in the social sciences and occupational therapy literature, and rehabilitation outcomes and occupational therapy rehabilitation for stroke in the health services and occupational therapy literature. The literature review provided a description of role theory and of occupational role content and process that had been identified prior to this study. Variables were identified that might impact upon the perceived occupational role performance of men who in later life had had a stroke. Very little literature was identified that described the self-perceived occupational role performance of men following stroke.

This literature review was followed by a naturalistic study that explored the content and process of the self-perceived occupational role performance of a number of elderly men who were living at home and experiencing ongoing disability following a stroke. Thirteen men were interviewed at home, using a semi-structured interview format designed for the study (see appendix A). Data was recorded in the form of field notes and tape recordings. Inductive qualitative analysis of this data revealed the following findings. First, there was evidence that the participants in the study did use role as a conceptual tool in order to organise their occupational performance in terms of meaning, personal abilities and time. Second, this organisation involved the exercising of choice about which roles would be performed and what form that performance would take. Third, the choice decisions were

made in the context of the participant's perceptions about current environmental demands and were informed by previous experience and personal standards for role performance.

Research Purpose Two was fulfilled through the development of a preliminary conceptual model that arose out the analysis of the data, completing the study. The model describes a number of constructs representing the factors that were identified as contributing to the meaning, motivation, planning and performance of the occupational roles of the participants in this study. This model consists of three major constructs and a number of sub-constructs. Construct definitions were produced, and possible relationships between the constructs were discussed. A transcript excerpt was used to illustrate how the model could be applied. The interactions between the constructs is considered to be complex, and at this stage, no definitive version of these interactions has been arrived at. The model requires further research to establish its validity.

The three major constructs were named Active Engagement, Personal Meaning and Perceived Control. The construct of Active Engagement described the nature of occupational role performance although this performance could be overt (observable to others) or covert (evident only to the performer). Active Engagement related principally to *doing*, while containing elements of *being* and *knowing*. It was found that Active Engagement was undertaken in relation to what had Personal Meaning to the participant. The construct of Personal Meaning related principally to *being*, while containing elements of *doing* and *knowing*. Personal Meaning was not observable to others and available only through the self-report of the participants. The last major construct was Perceived Control. This construct related to the reasoning of the participant about his role performance. Participants utilised past experience and personal standards of performance to make choices and plan Active Engagement in their occupational performance roles in the context of what had Personal Meaning to them. Perceived Control informed Personal Meaning in terms of the perceived outcomes of Active Engagement. The nature and process of occupational role performance for the participants in this study was in this way described.

6.2 LIMITATIONS OF THE STUDY

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

6.2.1 Limitations Associated With the Characteristics of the Sample

The number of participants chosen for the study was partly determined by a difficulty in obtaining participants; partly to the large amount of data produced by the thirteen interviews, and partly to a sense of repetition emerging from the data analysis of the participants interviewed later in the study. It is recognised that the findings relate only to the thirteen participants studied and that other participants may have reported a different set of self-perceptions in relation to role performance.

The participants represented a convenience sample, chosen by a small number of occupational therapy clinicians who assisted the researcher in this regard. Specific ethics committee requirements limited the researcher's ability to control the selection process. Although clinicians were given a set of guidelines for participant selection, some of the criteria that were requested by the researcher were not met. However, where participants were accepted for the study the unmet criteria were eliminated. For example, one or two of the participants had had more than one stroke, although one of the criteria requested by the researcher was for people who had recently had their first stroke. This was removed as a criteria for selection as a result. Given that this was a preliminary descriptive study of an area in which little information was previously available, it was considered difficult and inappropriate to set relevant criteria for selection to ensure a representative sample. Some of the clinicians who selected the participants made comments to the researcher that implied the people they had invited to participate were those they thought would be 'interesting' for the study. Again, as it would have been difficult to define a representative sample, a sample of convenience was considered satisfactory for the preliminary nature of this study.

The participants were all men. Women who have had a stroke may perceive their occupational role performance differently. The participants were all over 65. Younger people may perceive their occupational performance roles differently. It is recognised that the findings of this study relate only to this group of men and cannot be generalised to other groups of men, women or those under 65 years of age.

No attempt was made to limit participants to people from a particular social stratum or income level. In view of the literature on the relationship between health and income levels, this may have had an impact on the findings.

6.2.2 Limitations In Data Gathered

Because this study is about the self-perceived role performance of these men, the data gathered is intrinsically limited by the method of data gathering. It is not possible to gain complete access to another person's mind. Research at best can only gather external data and make inferences about the nature of participant thinking about occupational role performance. Efforts were made to verify information, by getting each participant to confirm his roles and to sort and rate them, and by subsequent comparison of this data and the transcript.

The data gathered in this study was limited by being a 'snapshot' study, gathering information about the self-perceived occupational role performance of the participants at the time of the interview only. It is likely that participant perceptions of their own role performance will change over time - particularly as their role performance is likely to change. For this reason, a 'snapshot' approach was considered appropriate for a preliminary descriptive study, and care has been taken to relate the data to a given moment in time, emphasising the dynamic nature of role performance.

6.2.3 Limitations Of The Data Analysis Techniques

It is recognised that in all qualitative research the perceptions of the researcher will affect the interpretation of the data to some extent. Another researcher may have interpreted the data that has been reported in different ways. However, a number of transcripts and related data were reviewed by another researcher using the same analysis techniques as the first researcher. Comparisons were made which indicated general agreement between the two analyses. Checks were made at the time of the interview with the participants regarding role identification and naming and by asking them to sort and rate their roles.

6.3 SIGNIFICANCE OF THE STUDY

In fulfilling both of the research purposes, this study has made a contribution to occupational therapy theory and to methodology, and has implications for occupational therapy practice in the area of occupational role performance.

6.3.1 Theoretical Contribution

This study is perhaps unique in gathering information on a number of different levels about people's view of their lives using the construct of role. The study provides information about what participants *do* in a given role, what participants *know* about their own performance, their environment and the expectations placed upon them, and how participants' feel about their lives as a whole in terms of their life roles, the interactions they perceive between their roles, and factors internal to specific roles and how they affect role performance - in other words *being*.

The study has developed a preliminary structural model of self-perceived occupational role performance to describe the role performance of the participants in this study, that may in part explain the relationship between the *doing, knowing and being* aspects of occupational role performance as described in the Occupational Role Performance Model (Australia) (Chapparo & Ranka, 1997b). The study significantly extends the central construct of occupational performance role in the Occupational Performance Model (Australia) (Chapparo & Ranka, 1997) (see Figure 6.1).

The major outcome of this study has been the detailed identification and description of a number of constructs that relate to both the internal (thinking and planning) and external (performance) aspects of *self-perceived* occupational role performance for the participants. This represents a major departure from much of the previous occupational therapy research carried out in regard to occupational role performance. Such research tends to be reductive in nature, and address the needs people have to comply with the demands or expectations of those around them, with little consideration given to the self-perceptions the role performer may have or the choices he or she may make.

6.3.2 Methodological Contributions

This study has developed a number of innovative methods of eliciting information about the participants' perceptions of their occupational role performance. In particular, the role sorting task proved to be a valuable tool in accessing the meaning participants attached to their role performance. The idea of a 'snapshot' view or a slice in time assisted in simplifying the interview and enabling interviewer and participants to remain focused on the task. Using a conceptual model to guide the structure of the interview and data analysis was a useful

Figure 6.1 Extended version of Occupational Performance Model (Australia) (Chapparo & Ranka, 1997)

contribution to the methodology, giving the interview greater form and clarity. In particular it gave shape and meaning to the role sorting task, therefore enabling data analysis to proceed more smoothly.

6.3.3 Empirical Contributions

The results of this study provide a detailed description of a number of constructs relating to the self-perceived occupational role performance of the participants. It provides insight into the meaning and reasoning behind role performance as well as describing the nature of that role performance.

The development of a preliminary theoretical model to describe the self-perceived aspects of occupational role performance provides hypotheses that could form the basis for further research into the constructs and how they might relate to each other. Many of the constructs in the model have been described before but have not been brought together in this way to form a conceptual model to describe self-perceived occupational role performance. The findings of this research extend knowledge of occupational performance at the role level.

6.3.4 Practical Contributions

The findings of this study provide an extended knowledge base about the complex nature of reasoning and meaning behind observable occupational role performance, which can be used by the occupational therapy profession.

6.3.4.1 For occupational therapy practice

As described in Chapter Two (section 2.6.2.2), one of the difficulties experienced by occupational therapists in dealing with rehabilitation at the role level for those who have had a stroke, is the lack of a reliable knowledge base with accompanying techniques for dealing with this level of occupational performance. This study provides descriptive information that can assist clinicians to gain further insight into this area of function.

The findings confirm the use of the construct of role as an organiser of personal meaning by every one of the participants. This has important implications for clinical practitioners seeking to bring about change at the role level in their clients. It means that

occupational therapists can talk directly to their clients about their role performance and gain an understanding of what is of particular significance and meaning to each of them. It reinforces the need for clinicians to clarify the knowledge base from which each client is operating to reduce possible confusion between therapist and client about the factors influencing client decision-making. It removes the need to use a standardised assessment, and indeed, the findings suggest that such assessments may provide misleading information about clients' role performance due to the assumptions that are made in these assessments about the definition of significant and meaningful roles for each client.

Participants had no difficulty sorting roles into those they considered to be primarily occupational in nature versus those that were primarily social in nature, confirming the existence of occupational performance roles for those in this study. This finding is significant in view of the controversy in some quarters within the profession about the use of the construct of occupational performance role in therapy. The findings reinforce the uniqueness of each participant's role repertoire, with each role interacting with the others in a hierarchical and complex manner.

Many of the participants were able to achieve role continuity following their stroke, in contradiction to the assumptions of some clinicians that stroke leads to the loss of all roles as described by Osberg, McGinnis, DeJong and Seward (1987) and discussed in Chapter Two (section 2.6.2.2). This reinforces the need for occupational therapists to assist in maintaining that continuity where possible.

Successful role transition in this study appeared linked to two factors - the participants' motivation and ability to utilise relevant past experiences and to utilise current available resources to assist them in making the transition.

6.4 RECOMMENDATIONS FOR FUTURE RESEARCH AND PRACTICE

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

6.4.1 Theoretical Recommendations

The preliminary model developed in this study has not been validated in any way. Further research to determine the validity of each of the constructs and to establish the relationships between the constructs would provide a valuable model for further theory development and testing in this area. The model could then perhaps be developed for use in clinical practice, to help guide therapists' knowledge and reasoning about the occupational role performance of their clients.

6.4.2 Methodological Recommendations

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

6.5 CONCLUSIONS

This study has focused upon the occupational role performance of a number of men with stroke, viewed from their own perspective. In this, it has departed from other studies on occupational role performance that have taken a more external view. It has demonstrated that all the participants in this study used role as an organising construct. It has provided a description of a number of internal factors determining occupational role performance and identified and defined a number of constructs that have become part of a preliminary model of occupational role performance for the participants.

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

Finally, this study has extended the concept of occupational performance role by demonstrating that it is a construct that is used by people that are typical occupational therapy clients. This demonstrates that the use of the construct of role by occupational therapists does not have to impose a system of external labelling or reductionism upon those whose roles are being investigated, as is suggested by those who oppose the use of the construct (Jackson, 1996; 1998a). On the contrary, it frees the researcher or therapist from the need to observe and interpret behaviour or self-report in terms of meaning and motivation. With further exploration and development of the hypotheses that have arisen from this research, it is likely that occupational performance roles will supply the therapist or researcher with a routine, systematic tool for the examination of self-perceived occupational role performance that can provide direct access to the unique reasoning used by each person to meaningfully organise their occupations.

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APPENDIX A

THE OCCUPATIONAL PERFORMANCE

ROLE ASSESSMENT

**A1: NOTES ON OPRA MODIFICATIONS AS A RESULT
SUCCESSIVE INTERVIEWS**

A preliminary version of an interview protocol was developed for this study. This underwent a process of change and development as the study proceeded.

Three trial interviews were carried out before the study commenced.

Trial Interviews

- * Wife present. She threw in comments and modified things that he said, which he then agreed with. She did not contradict him, but tended to expand what he had said further. Interview went frequently off the rails with stories about their children etc.
Action: Request to interview participant alone in future.

- * Got participant to rate every sub-role. He had 15. This meant he had to rate on a scale a total of 45 times. He was clearly not concentrating or interested by the end and told me he found that part very tedious.
Action: Score the role areas only. This means every participant will score on a scale 15 times. Decided to use a board to provide some sort of visual display of roles.

- * English was not his first language and he told me he had difficulty at times finding the words he wanted during the interview.
Action: Retain the condition that English be the first language.

Study Interviews:

Interview 1

- * Board for visual display worked quite well. Used Post-it stickers and wrote roles/activities on them and stuck them on board as information was given. Removed or rearranged as appropriate. Wrote comments on them eg. "role highly valued"
Action: Keep and develop so that it looks better and is easier to manage

- * Asked him to tell me how he spent his time. This produced a rather uncontrollable conversation. He never did really get what it was I was asking about I do not think. He decided as the interview progressed that I was seeking general information about what it was like having had a stroke and wound up recommending I visit St. George hospital to see what they do there.

Action: Be much more directive in interviewing and to be much more up front about what the interview was about.

- * Requesting to interview him alone worked well.

Action: Keep

- * Had difficulty with the rating scales - sorting out all that verbiage.

Action: Perhaps use a line with the two extremes at each end. Participant points on the line to where he feels he lies.

- * With my check questions "so how often do you .. " etc. I tended to get not his perceptions of frequency, but an explanation or a repeat explanation about what he did.

Action: Develop a further range of questions that address this difficulty

Interview 2

- * Interviewing alone worked well. This man was really labile, but we got through the interview quite well. I started by saying I wanted to ask him about his roles in life. eg. you are a husband - would you say that was a role you had? Floods of tears.

I feel he got the point of the interview better and he had a better grasp of what I was talking about.

Action: Use a more neutral role example, but continue with this way of starting.

- * My "why" questions are very messy particularly in part 3 (see eg. T2 pp. 12). I feel that guidance is needed about the terms of the why answer eg. "because I think it is worthwhile" does not help me to identify which performance area might provide the major motivation for that role. I then have to ask "why do you think it is worthwhile". I find participants get a bit edgy if you keep pursuing them with "why" questions.

Action: Try to avoid asking why questions too often.

Interview 14

This person had cognitive difficulties. Found tasks of interview difficult. Flexibility required on the part of the interviewer. However, gave valuable information and insights into how things were for him and what mattered to him. Concluded that part 3 is a valuable way to discuss role issues. Parts 4 and 5 can be difficult for such people.

Action: Maintain as is but be prepared to be flexible in administration.

Interview 15

Interview went well.

Action: Nil

Interview 16

Interview went well.

Action: Nil

Interview 17

Participant set the agenda. Interview took much longer than usual (2 1/2 hours), but still worked well. Did not have enough tape with me to tape whole interview.

Action: Specify at least three one-hour tapes required in equipment section of manual.

Interview 18

Went well.

Action: Nil

Problems that became obvious and ways interview may be changed as result of detailed preliminary analysis of transcripts

Interviews 1,2, 14, 15, 16, 17 and 18 were analysed and the preliminary results summarised for a conference paper and journal article. It was decided that further depth of response was needed especially in the area of satisfaction with role performance. As a result of this decision, the manual was rewritten to incorporate changes as above and Part 4 was expanded to include a sorting of roles by priority and the inclusion of more questions designed to obtain more in-depth information (see second version of OPRA manual).

Perhaps frequency definition should be changed so that regularly means two or three times a week and very often means daily or several times a day.

Rationale: Because participants live very circumscribed lives they have a reduced number of roles and enact the majority of their roles very frequently.

Interview 19

Interview went very well. New questions worked very well.

Interview 20

This participant set the agenda as participant 17. Interview took two hours, but did not use new questions and did not get reliable role sorting or role rating. Suspect cognitive and perhaps perceptual difficulties with these tasks, as well as tiredness and lack of motivation.

Action: Nil

A2: FINAL VERSION OF OPRA MANUAL

THE OCCUPATIONAL PERFORMANCE ROLE ASSESSMENT MANUAL

© Anne Hillman and Chris Chapparo, 26th August, 1996

Description

The Occupational Performance Role Assessment (OPRA) has six parts:

Part 1: Explanation of Purpose of interview and obtaining of consent.

The interview commences with a request to start tape recording. An explanation of the purpose of the study follows. This is done by a verbal explanation and the provision of an information sheet. Following this, the consent form is signed.

Part 2: Recording demographic information

The date of interview, project identification number, and details of participant's age, ethnicity, living status, mobility, communication and personal care are recorded.

Part 3: Gathering information about role performance

Participants are invited to identify their occupational roles. The interviewer provides minimal prompts and examples to facilitate discussion. As a role is identified, further questioning helps the interviewer to determine whether it belongs to the productivity, self maintenance, leisure, or socio-cultural role area (Chapparo & Ranka, 1992).

The information in this section relating to activities is included to clarify for both the participant and the interviewer that roles are active. It produces better role definition.

Part 4: Participant confirmation of roles

The interviewer seeks confirmation that roles have been identified and recorded accurately and to the satisfaction of the participant. The participant is then asked to sort his roles in order

of priority, and further probing is done to discover the meaning specific roles have for the participant.

Part 5: Sorting roles under occupational performance area and socio-cultural headings

Identified roles are sorted by the participant using a board and post-it stickers with the named roles written on them. Roles are sorted under the headings of productivity, self maintenance, leisure and socio-cultural. Sometimes a role is performed for a number of reasons and may be categorised under more than one role area heading. However, participants are asked to nominate which of these is the most important to them. If the participant is unable to categorise the role in this way it is recorded under "other".

Part 6: Participant rating of roles

The participant is asked to rate on a 5 point scale for each identified role how frequently they perform the role, how much they value the role and how satisfied they are with their performance in the role.

Equipment required:

- a) Aids to identification: Name badge and business card
- b) Aids to conducting interview effectively: OPRA manual
- c) Implements for recording information: Copy of OPRA, tape recorder, 3 blank tapes, microphone, batteries for tape-recorder.
- d) Administration:
 - Part 1: Clipboard, information and consent form and pen
 - Part 4: Post-it stickers, pen, Role Board (plain A4 size board covered in white contact).
 - Part 5: Role Sorting Board (white-board ruled up in columns with each role area and its brief description written at the top of each column.

Part 6: Scales (3 separate laminated sheets with scales for frequency, value and satisfaction).

ADMINISTRATION

When arranging the interview, ask that no third party be present. This is to ensure that the person's own perceptions are elicited and for reasons of confidentiality.

Try to start the tape recorder as soon as possible. Ask early whether the participant minds being recorded. Valuable information can be lost if not recorded.

Part 1: Explanation of purpose of interview and obtaining of consent

It is important that the participant is able to feel relaxed and can explain things in their own terms. Introduce yourself and ensure that he understands the purpose of the interview. In order to involve the participant in collaborative research, it is necessary to ensure that he or she is fully informed (Minichiello, 1990). Give a brief explanation on the telephone when contacting the participant to make the interview appointment. Do not assume that the participant therefore fully understands the purpose the interview. A full explanation must be given at the interview. This is done in two ways.

Firstly, give a verbal explanation. In particular it is important that the participant understands that it is his own perceptions that are required, rather than what he believes to be the perceptions of those around him. Tell him that the interview will probably take just over an hour and that you will be taking notes and tape recording during the interview. Tell him he can take a break at any time or end the interview if he has had enough. An example of a verbal explanation is as follows:

Interviewer:

What I am looking at is what people are doing once they have had a stroke and are living back at home again. You've been in hospital and you have had some rehabilitation. Now you are back home and you are getting on with your life again; and that's the stage that I am interested in asking about and talking about with you ... And I am particularly interested in the roles that you have in life, so that's what I will be focussing on. What roles you see that you have. If there is any problem at any stage with the interview - if you want to stop you just say so and we will stop. The contents of this interview are confidential - on the form I just write a number. I don't put your name anywhere so there's no way the information can be traced back to you. The information that you give me will be compiled along with the information from the others I am interviewing. I will be using it to write papers for publication and for my Master's thesis. I will also be using it for educational purposes.

Secondly, give him the Participant Information Sheet. Allow time for him to read this written material. Give him the opportunity to ask questions. If he appears satisfied with the explanation he is asked to sign the consent form.

Part 2: Recording demographic information

Note the following information:

- 1) date of interview.
- 2) identifying number (allocated by the researcher).
- 3) Age.
- 4) Living situation - alone, with partner, with son or daughter or other.
- 5) Ethnicity.
- 6) Self reported status for mobility, communication and personal self-care. Records status for each as level 1, 2 or 3 according to the attached definitions.

Record in Part 1 of the OPRA form.

Part 3: Gathering information about role performance

Ask single, simple questions.

Initial question or cue for the interview:

"Could you tell me about some of your roles?"

If the participant has some difficulty with this approach an alternative opening prompt could be:

"How do you spend your time?"

Jot down roles and activities as they are given. As the participant identifies a role or areas of activity ask follow-up questions. For example:

Would you say that it is a role for you?

So is it a role you actively pursue?

Do you work hard at this role?

Do you just let it take its course?

Does it just happen?

Do you spend much time doing that?

Do you spend much time thinking about this role?

Is it important to you?

Is it something you feel you need to do?

Is it something you want to do?

Does doing it make you feel good?

Use prompts to ensure that as many roles as possible are covered in the discussion. The attached role descriptions may be used for guidance on possible roles.

Examples of questions to ensure coverage of different life areas:

Do you see much of your family?

Do you have many friends?

Do you spend much time outside the home?

How do you get around when you go out?

Do you have any special interests or hobbies?

Are you studying anything at present?

Do you do any work?

Do you help others in any way?

Are you a member of any clubs or other organisations?

Do you do much around the house?

How about shopping?

Do you have any pets?

In the course of part (3) start identifying in your own mind possible roles if and when it occurs to you that different activities being discussed could be seen as being done for similar reasons. As possible roles are identified, jot them down and check out with the participant to see whether they agree. Try to determine which role area roles might belong to by further questioning if necessary (see attached role area definitions). As the interview progresses, try to ascertain the order or level of each role, that is, whether it can be made bigger or not. For example, does the participant see the roles of father and grandfather as separate, or as both being part of the larger role of family member. Use questions at this stage that relate mainly to doing. Ask him about frequency, value and satisfaction in this section. These questions help to sort out what is and what isn't seen at the role level by the participant. Sometimes you will see a role where the participant just sees a series of activities, or he may see these activities as part of another role.

When both you and the participant are satisfied that all the major areas of activity have been identified, bring this part of the interview to a close.

Make a list of the identified roles and place them under the role area heading you think most appropriate, given what the participant has been saying (see attached definitions of role areas).

Record this in the interviewer's table in part 3 of the OPRA form.

Part 4: Participant confirmation of roles

Discuss roles again with participant and write them on post-it stickers. put these stickers on a the role board where the participant can see them. They are not sorted at this stage.

Say something like:

While we have been talking, I have been recording information. It seems to me that I can sort the things that you do into different categories or groups. I call these occupational roles. I would like to go through with you what I have done. Could you tell me whether I have got it right or wrong, and also if we have missed anything?

As roles are identified, discuss each one further as necessary and possible.

Once all the roles have been confirmed, ask the participant to sort his roles in order of priority, from most important down to least important.

Record this in part 4 of the OPRA form.

Select a role and ask a range of the following questions about it. Then move on to another role. These questions relate to doing, knowing and being, in order to expand on information given in section (3) "Gathering information about role performance".

Some participants may have difficulty with the latter half of the interview because of cognitive difficulties or poor endurance. You cannot expect to grill these people. Questions

need to be judicious, and it is not possible to ask all the following questions systematically about each role or role area. The purpose is more to get a flavour than to acquire detailed information across the whole role repertoire for every participant. Try and ask specific questions about the roles identified by the participant as the most important and the least important and perhaps one or two others.

The following are examples of questions that you may ask at this stage:

FREQUENCY

Are you spending more time doing this role now?

Would you rather be doing more in this role?

VALUE

Does this matter to you?

How important is this to you?

Do you value being a ...?

What do you think are your reasons for doing this?

Do you find you are valuing this role more and more?

Do you find you are valuing this less and less?

Did you want to be a ...? Why? or Why not?

SATISFACTION

Does that make you feel good?

What are some of the good things about being a ...?

What are some of the things you don't like about being a ...?

What do you think makes a good ...?

Could you tell me about something that you did about this that made you feel good in the last week or two?

How do you know when things are going right?

So what is it like when things go wrong?

Has anything gone wrong in this role recently?

Do you have any difficulties with this role now?

In the best of all possible worlds, is there anything you would change about how you do this role?

Could you describe something that makes you glad you have this role?

Do you ever feel guilty being a ...?

What makes you feel that way?

If there appear to be any difficulties about role definition, ask:

So what do you think a role is?

Could you tell me how you would describe a role?

About the role repertoire as a whole:

Of all these roles, which one would you least like to lose?

Are there any roles you would rather not have?

Does this role fit in well with your other roles?

Do you see yourself primarily as a ...?

GENERAL SATISFACTION WITH LIFE

If you had more hours in the day what would you do with them?

Would you like there to be more hours in the day?

Is there anything in life you would like to do just now, just for your own satisfaction?

What prevents you from doing this?

What would you say is your main aim in life at the present time?

What would be your main worries at the present time?

What would you like to change in your present situation?

When you feel really happy these days, what kinds of things make you feel that way?

When you feel really down or depressed what makes you feel like that?

What do you do when you feel like that?

Would you describe yourself as generally satisfied with your life or not?

Do you ever feel resentful?

Do you ever feel angry?

Is there anything else you would like to tell me?

(Some of these questions used with the kind permission of Professor B. Wearing,
Social Work Department, University of NSW)

Part 5: Sorting roles under occupational performance and socio-cultural meta-role headings.

Ask the participant to take each role sticker in turn from the interviewer and place it under the appropriate heading on the role sorting board. Try and get confirmation of the reason for the position chosen as necessary. If the participant is unable to decide which role area the role is part of it may be sorted under "other". Try to obtain information about why it was difficult to place under one of the other headings.

Record each role under the appropriate role area in part 5 of the recording form.

Part 6: Participant rating of roles

Taking each role area in turn, ask the participant to report on the frequency of role area performance, how much he values the role area and how satisfied he is with his performance in this role, using the three five point scales included in this package.

For each role area, show the participant the three scales in turn, and ask him to indicate by pointing where his answer falls. If the participant is unable to read the scale, read it out and ask the participant to respond verbally.

Scales:

I do things in this role:

1	2	3	4	5
Almost Never			All the Time	

I consider this role:

1	2	3	4	5
Not at all			Highly Valuable	
Valuable				

I feel satisfied with my own performance of this role:

1	2	3	4	5
Almost Never			All the Time	

based on Salamon and Conte (1984)

Record the participant's responses for each role area in part 6 of the OPRA form.

DEFINITIONS

Definitions for Part 2

Mobility:

Level 1 - independent in community mobility. The person is able to move about their local community without assistance. This may include walking, driving a car and/or using public transport (including taxis).

Level 2 - able to move about the community with assistance. The person is able to move about their local community but requires the assistance of others. This assistance may be in the form of lifts in someone else's car, assistance in negotiating architectural barriers in the community and/or assistance in managing mobility aids.

Level 3 - the person is housebound. They are unable to move about their local community without the full assistance of others.

Communication:

Level 1 - independent in communication

Level 2 - able to communicate with difficulty

Level 3 - unable to speak, dependent on non-verbal communication

Personal Care:

Level 1 - independent in all aspects of showering, dressing, feeding and toileting.

Level 2 - independent in showering, dressing, feeding and toileting with minimal assistance from others. This may take the form of minimal assistance with transfers, verbal prompting or preparation and/or placement of equipment.

Level 3 - dependent upon others for one or all activities of showering, dressing, feeding and toileting.

Role Descriptions for Part 3

These definitions are taken from Jackoway, Rogers and Snow (1987, pp 25-27). The definitions have been revised to reflect the doing or occupational aspect of the role by inserting suggested activities or tasks that may relate to each role. Please note that this is not intended as a definitive list. It is up to the participant to nominate their own roles as much as possible. These definitions are included to give a starting point for the interviewer in understanding what the definition of a role might be. All roles may be carried out with or without assistance.

Role: A role is made up of a number of tasks and activities that may be grouped together because they are seen by the person as having a common purpose or meaning.

<u>Role</u>	<u>Definition</u>
Spouse or partner:	May be married and is living with or having regular contact with spouse or partner. Carries out a number of activities and tasks primarily related to this role.
Parent:	Has personal or telephone contacts with children and carries out a number of activities and tasks primarily related to this role.
Grandparent:	Has personal or telephone contacts with grandchildren or great-grandchildren and carries out a number of activities and tasks primarily related to this role.
Son/daughter:	Has personal or telephone contacts with parents and carries out a number of activities and tasks primarily related to this role.
Sibling:	Has personal or telephone contacts with siblings and carries out a number of activities and tasks primarily related to this role.

Other relatives:	Has personal or telephone contacts with other relatives such as nephews or cousins and carries out a number of activities and tasks primarily related to this role.
Friend:	Has personal or telephone contacts with a friend or friends and carries out a number of activities and tasks primarily related to this role.
Neighbour:	Has personal or telephone contacts with a person who would probably not be a friend if not living nearby and carries out a number of activities and tasks primarily related to this role.
Visitor:	Visits people who are not close friends or relatives in their home, hospital or nursing home. May shop for that person or do other small tasks for them.
Pet owner:	Owns and cares for a pet.
Worker for pay:	May include consultancy work, relief work, part-time work, self employment, making items to sell and odd jobs.
Volunteer:	Donates time in an organised way to assist social groups or individuals. May be reimbursed for transportation and meals. May be in or out of home. Does not include care-giver or baby-sitting duties.
Trustee/director:	Serves as a trustee or on a Board of Directors.
Care-giver:	Has regular responsibility for providing unpaid care to another.
Student:	Enrolled in one or more classes, workshops, or other structured learning opportunities in which participation is expected. Participation may take the form of attendance at classes and/or the submission of written work.

Cook:	Plans and prepares or participates in the planning and preparation of meals for self and/or others. May include laying table and clearing away afterwards and shopping.
Shopper:	May plan and budget for shopping expeditions, and obtain food, clothing, household and other items by going to the shops or by ordering by telephone.
House Cleaner:	May tidy, vacuum, sweep, dust, wipe down and scrub the home and shop for household cleaning materials and equipment.
Gardener:	May plan and care for the back yard, flower or vegetable garden and maintain indoor plants. May shop for plants, fertilisers and other gardening materials and equipment.
Launderer:	May hand or machine wash, dry, and iron as appropriate, clothing and bedding. May take clothing and bedding to dry cleaners and may shop for washing soap and other equipment and materials required for this role.
Personal carer:	May do tasks such as toileting, bathing, shaving, and brushing teeth/dentures, doing hair, putting on make-up with or without assistance. May feed self and put on and removes clothing.
Driver:	Drives car. Has valid driver's licence. May plan journeys and carry out car maintenance.
Repair person:	May perform minor home repairs, appliance, furniture and other repairs.
Religious participant:	May include private religious activities, membership and attendance at a place of worship or religious group.
Civic organisation member:	May attend meetings, carry out tasks (eg. typing) and subscribe to publications for community organisations such as Lions club, rotary, city council etc.

Political organisation member:	Membership in party-related organisations, advocacy groups, or lobbying groups. May attend meetings, write letters, or otherwise be an active participant.
Senior citizen's organisation member:	May attend senior centres, be a member and actively participate in organisations which are limited to senior citizens and are not primarily political or self-help in nature.
Social group :	Is a participating member of any organisation which exist primarily for social purposes.
Support/self help group member:	Is a participating member of group which exists to support and help members cope with specific issues, eg. arthritis support groups, widows' groups.
Professional Organisation member:	Is a participating member of a group with common professional interests.
Special Interest organisation member:	Is a participating member of a group which comes together because of common interest in a specific topic, eg. play reading, groups, dance groups, musical groups.
Hobbyist/crafts person:	May do needlework, woodwork, painting, and other crafts. Not done to make money.
Musician:	Regularly plays a musical instrument or sings. May practice regularly, perform, maintain instrument or voice and buy equipment.
Sports Participant:	May participate in dancing, exercises, bowling, swimming, golf, etc. May practice, compete, take lessons to improve game, shop for items of special clothing or sports equipment, maintain equipment and belong to a sports club.

Walker:	Walks for recreation or exercise, not just to get places. May plan expeditions alone or with others, drive or use public transport to get to more remote areas, buy and maintain equipment.
Collector:	Maintains and adds to collections of specific items such as stamps, coins, salt shakers, or clocks. May be a member of a special collectors club. May travel to obtain new items, correspond with others and read about their interest.
Traveller/tourist:	Travels for the purpose of seeing new places, meeting new people and having new experiences. Does not include travel as a means to an end such as business trips or visiting family.
Event attendee:	May attend movies, plays, operas, ballet, lectures, sporting events etc. May plan expeditions to venues, purchase tickets in advance and organise a group to go.
Observer:	Does sedentary activities such as watching television, bird watching, people-watching, reading, listening to music etc.
Game player:	Plays solitary or social card or board games. May entertain friends for the purpose of playing games. May study or read books about games.
Chronically ill:	Has a health problem which is controlled, but not cured which entails activities such as attending the doctor, getting prescriptions filled, taking medicine in accurate doses, taking extra rests, avoiding certain foods or activities etc.
Acutely ill:	Has a health problem with sudden onset and relatively short duration. May include staying in bed, being dependent upon others, being a hospital patient.
Episodically ill:	Has a health problem which is usually controlled but occasionally is problematic. Has had an episode in the last year. May include seeing the doctor, obtaining and taking medication accurately, making arrangements about your affairs in case you are sick etc.

Role areas (Part 5)

To simplify the list of roles identified, they are placed into role areas. These role areas appear on the recording form as guidance for the interviewer. The participant may or may not have roles in all role areas.

Roles are placed under a particular role area according to the participant's primary perception of that role. For example, one person may do volunteer work primarily because of the social nature of the role, with the outcome of their work being of secondary importance. Someone else may value the role primarily because it allows them to feel as though they are still a productive member of society.

A participant may feel that a particular role could be placed under more than one role area. For example, a person may consider the role of gardener to fall under the heading of self-maintenance because it is something that needs to be done; but they may place it under leisure because they enjoy it. In this case, the interviewer needs to help the participant identify which is their primary reason for performing the role.

Role area Definitions for Part 5

Productivity:

The productivity role area is made up of roles that are undertaken primarily to do work whether paid or unpaid. Work can be seen as providing a service or commodity to someone else or to our society or culture. It can include objects, new abilities, ideas, knowledge, or performances (Kielhofner, G. 1988, pp. 85).

Examples of roles that may be enacted primarily for productivity reasons:

worker for pay, visitor, volunteer, trustee/director, care-giver, student, cook, shopper, house cleaner, gardener, launderer, driver, repair person, civic organisation member, political organisation member, senior citizen's organisation member, professional organisation

member, special interest organisation member, musician, collector, event attender, hobbyist/crafts person.

Self Maintenance:

The self maintenance role area is made up of roles undertaken primarily to deal with the routine needs of the person. They relate to survival needs. They are not particularly valued socially, although they may be culturally. They become important if a problem with performance develops. Self maintenance roles are made up of the activities and tasks that we expect to be able to do for ourselves or that our culture expects us to be able to do.

Examples of roles that may be enacted primarily for self-maintenance

reasons:

cook, shopper, house cleaner, gardener, launderer, personal carer, driver, repairer, sports participant, walker, chronically ill, acutely ill, episodically ill, support/self-help group.

Leisure:

The leisure role area is made up of those roles that are primarily undertaken for fun, pleasure and relaxation.

Examples of roles that may be enacted primarily for leisure reasons:

pet owner, visitor, volunteer, student, cook, gardener, social group, special interest organisation member, hobbyist/crafts person, musician, sports participator, walker, collector, traveller/tourist, event attender, observer, game player.

Social

The social role area is made up of those roles that are undertaken primarily for social reasons. This means that the main reason for doing the role is to have contact of some kind with other people or because they feel it is what others in their social network expect of them.

Examples of roles that may be enacted primarily for social reasons:

spouse, parent, grandparent, son/daughter, sibling, other relatives, friend, neighbour, visitor, pet owner, volunteer, student, cook, religious participant, civic organisation member, political organisation member, senior citizen's organisation member, social group, support/self help

group, professional organisation member, special interest organisation member, sports participant, walker, collector, traveller/tourist, event attendee, game player.

Cultural

The cultural role area is made up of those roles that are carried out mainly for cultural reasons. This means that the role relates to the beliefs and values that the person has in common with their own cultural group. A cultural group may consist of people who have grown up sharing a common background or environment, for example, ethnic groups; or of people who share common beliefs and values for other reasons, for example university students or members of a religious group. Participants may carry out cultural roles because of shared beliefs and values, or because they feel it is what their cultural group expects of them.

Examples of roles that may be enacted primarily for cultural reasons:

friend, visitor, volunteer, care-giver, student, cook, religious participant, civic organisation member, political organisation member, senior citizen's organisation member, social group, support/self help group, special interest organisation member, hobbyist/crafts person, musician, event attendee.

Definition of Terms for Part 6

Scale A - Frequency

1 ("almost never"):	has not done it in the past 12 months
2:	once or twice a year
3:	once a month
4:	once a week
5 ("very often"):	every two or three days

Scale B - Value

1 ("not at all valuable")	This has no worth for me.
2:	If I had to lose a role, this is one that could go.
3:	This is something I would rather not use.
4:	This is something I need to do or I want to do.

5 ("highly valuable"):

I would not give this up. It is something I really need or want to do.

Scale C - Satisfaction

1 "almost never":

I am always unsatisfied with my performance.

2:

I am not pleased with my performance.

3:

I would prefer to do this better.

4:

I feel comfortable with my performance.

5 ("all the time"):

I am always satisfied with my performance

The interviewer takes the participant's own interpretation of meaning. These definitions are intended as a guide only.

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A3: FINAL VERSION OF DATA RECORDING FORM

THE OCCUPATIONAL ROLE ASSESSMENT

Devised by Anne Hillman

© Anne Hillman and Chris Chapparo, 1996

RECORDING SHEET

Date of Interview:

Name of Interviewer:

Part 1

Project ID No:

Age:

Living Situation:

Ethnicity:

Self reported status:

Mobility:

Communication:

Personal self-care:

Comments about the interview as a whole:

Part 2

Notes:

Part 3: Interviewer's naming and sorting of participant's roles

Productivity	Self Maintenance	Leisure	Socio-Cultural	Other

Part 4: Roles sorted in order of priority by the participant

Part 5

Participant's identification and sorting of roles:

Productivity	Self-maintenance	Leisure	Socio-cultural	Other

PART 6 - ROLE RATING

Role Area	Frequency of performance	Value of role	Satisfaction with role
Productivity			
Self maintenance			
Leisure			
Socio-cultural			

SCORING

Scores are recorded on this summary sheet. Points are allocated according to the position on the scale indicated by the respondent.

APPENDIX B

PARTICIPANT INFORMATION SHEET AND CONSENT

FORM

INFORMATION SHEET

Dear Mr.

OCCUPATIONAL ROLE PERFORMANCE RESEARCH STUDY

I am writing to ask if you would be willing to be interviewed for a study I am conducting into how people over 65 who have had a stroke spend their time. This information would be used to gain a better understanding of what is important for people in your situation. It would be used by occupational therapists who work with people such as yourself to try and improve the services they offer.

If you agree to participate, I will ring you and make an appointment so that I may come to your house to interview you once.

The interview is expected to take about an hour. You will be able to take a break at any time.

You will be informed if there are any changes to the above procedures and purposes. You will not be identified by name on any of the data sheets recording the information you give us. Strict confidentiality will be observed by all the researchers, and all documents relating to the study will be kept under lock and key.

Results of this study may be published for the purposes of ensuring as many people as possible gain access to the information.

An independent committee exists which has approved of this study

If you feel you would like to participate, please fill in the form overleaf. If you have any questions you would like to ask, please ring me on 646 6212.

Yours sincerely,

Anne Hillman,
Lecturer,
Faculty of Health Sciences,
University of Sydney.
tel. 646 6212

Chris Chapparo,
Senior Lecturer,
Faculty of Health Sciences
University of Sydney
tel 646 6386

CONSENT FOR PARTICIPATING IN RESEARCH STUDY

1. I, the undersigned _____ hereby consent to my involvement in the study titled, "An investigation of self-perceived occupational role performance in men aged 65 and over who have had a cerebrovascular accident".
2. I acknowledge that the nature, purpose and contemplated effects of the study as far as it affects me have been fully explained to my satisfaction by the investigator _____ and my consent is given voluntarily.
3. The details of the procedure I am to perform have been explained to me including the anticipated length of time it will take and the frequency with which it will be performed.
4. I understand that the purpose of this research study is to develop a way of measuring the overall structure of people's lives, and to find out more about how people are able to live their lives following a stroke.
5. I give consent to be interviewed in my home, and for data to be used for data analysis and publication.
6. I understand that I am free to withdraw from this study at any stage.

Signed: _____

Date: _____

I certify that I have reviewed the contents of the form with the individual signing the above statement, who in my opinion understood the information.

Witness: _____

Date: _____

Anne M. Hillman, B. BApSc. and Chris Chapparo, MA
School of Occupational Therapy
Faculty of Health Sciences
The University of Sydney
646 6212

APPENDIX C:
TRANSCRIPT EXAMPLE

Interview transcription: ID19 (8,302 words)

Interviewer: AH

Date: 6/11/96

Key: [*] = inaudible. Words within these brackets are a guess.

PART ONE: Explanation of Purpose of Interview

Q: Now.
First of all I would just like to ... that is my card just so that you know that I am who I say I am.

A: Wouldn't matter would it?

Q: (laughs)
Er ... and I'll just get this pen.
OK. Now. This interview as I said on the phone, will take about an hour - it's up to you how long it takes.

A: No ... whatever you like.

Q: So you can say if you're getting fed up just say so and we can stop. And if it takes longer, it takes longer. There's no ... sort of ... rules about it. Um...
So just ... I'll just first of all explain a bit more about what it's about. Um ... You know, you've had a stroke, and now you're back home ... How long ago did you come home by the way? How long have you been out of hospital? Do you remember?

Wife: [*but indicated that he should answer]

A: (to wife) You should know.

Wife: About 3 months isn't it?

Q: About 3 months

Wife: Yeah

Q. OK. Um ... The other thing I will say is, that - yeah, you're quite right, I'd like to have it just between the two of us...

Wife: Mm, that's right, so ...

Q. So ... (to A.) if you don't know, you know, it's up to you what you say.

A: Well I'm ... I'm ... I can't remember the dates, you know ...

Q. Yeah.

A. ... things like that.

Q: Yeah, but that's OK.

A: If I looked it up I probably could.

Q: Yeah, that's OK. I was just wondering, it's not ... not important.

A: I know that I went into hospital on the 16th April I can always remember that.

Q: Yeah. Stuck in your mind.

A: I was there for what 9 weeks, so you can work it out from there.

Q: Right, right. OK.

What I am interested in talking to you about today is how you've been going since you've been home. So, I'm going to be asking you things about your everyday life now, and about the things that are important to you and how you feel about how you are getting on with them. Er, and I am going to be talking to you about roles. The way I am going to do that is to ask you about your roles. So, that's the form it's going to take. There's a number of different parts to the interview, so I will explain each part as we go through.

And the reason I'm doing it is because I want to, er, get more ... Well, there's not much information about what happens to people once they've been through rehabilitation and have got back home, and how they're finding things - just in their everyday life, and in terms of the things that are important to them.

So that's why I am asking ... I'm talking to you about this. What I'll be doing is, um ... I've already published one journal article on some earlier work that I've done and I will be writing ... This is for my Masters degree ... So I'll be writing a Masters Thesis, but the information you give me will be anonymous. You're not identified in any way. So if that's ...

A: [* but to the effect of what a shame]

Q: (laughs) I won't be writing your name on the form or anything like that.

A: No, No.

Q: OK. Now the next thing I need to do is to get your consent, that you're happy to be interviewed. And this is the, um ... the information that, er ... I sort of told you verbally. There's a bit more information ...

A: Mm.

Q: ... and then over the page, if you are happy to sign it, there's a consent.

This is from Westmead. This, this research has been approved by the er, Western ... what's it called? the area ... Western Area Health Authority.

A: Mm.
(long pause while respondent reads and signs consent form)

A: Now ...

Q It's the sixth. Sixth of November.

OK, terrific. And seeing as you are here Mrs X ... Can I ask you just to sign that as a witness too. I mean do read the whole thing as well if you ...

Wife: No.

Q. ... want to.

It's just one of these paperwork things that we have to do.

A. Yeah.

Q. There's an ethics committee which is very strict about making sure we don't do anything wrong (laughs).

Wife. What is the other bit there.

Q: That is ... that number there is ... O

Oh, don't worry about that part. No.

Wife: Just sign it, OK. That's fine.

A: You're only witnessing my signature.

Q: Thank you very much. It is just a bit of paperwork.

A. So you can do your scribbling now.

Wife: Do you need me here? Or do you want me ... ?

Q: No, no I don't need you here so you ... Whatever you like. Stay, or you can get up and do other things.

Wife: Yeah. I feel silly sitting here doing nothing.

Q: (laughs)

A. Don't you want to learn?

Wife. No, I know I'll learn. Well, I'll get down and just check on a few things.

Q. Yes, OK.

PART TWO: Recording Demographic Information

Q. OK. Now, just a few details first of all. Can you tell me your date of birth?

A: Yeah, twenty-second of the tenth, twenty-nine.

Q: OK. And, were you born in Australia?

A: Yeah.

Q: Australian born?

A: Yeah [*]

Q: OK.

Now, um, can you tell me a bit about your mobility. About getting around. Can you walk around ... er, you get around here all right ... without ...?

A: Oh, get around, yeah. Shuffle around.

Q: Yeah?

What about if you go outside?

A: Well, I've never walked down the street or anything like that.

Q: Right.

A: No. I've been over to the trials. Over to the trotting trials ...

Q: Have you?

A: ... today. I was walking around over there.

Q: Yeah? So, you go by car?

A: I go by car, yeah.

Q: Yeah. Are you driving?

A: No I can't drive yet.

Q: Right.

A: No, I wouldn't ... wouldn't drive yet.

Q: Yep. So, around the house and around the yard. And if you're going somewhere - when you get there, you can get around.

A: I can yeah, if I feel well enough, you know.

Q: Right. And you don't use a stick or anything?

A: No, I try not to. I try not to use a stick.

Q: OK. Good.

A: I try to rely on myself if I can.

Q: Yes, yes. How about at the trials this morning, did you find that you get tired? Or ... you got tired?

A: Well, no I was all right this morning. Yeah. Although these, see these tablets I'm taking, make me tired.

(indicated a large pile of medication that took up the whole of one end of the dining table).

Q. Yeah.

A. They make me tireder than what I normally would be.

Q. Yeah.

A. See ... This, this one here ...

Q. Yeah.

A. That's 'cause I'm aching around the head here see.

Q: Right. It helps the ache, but makes you tired.

A: Not really, it hasn't helped yet. I've got to go back to the doctor next Monday.

Q: Right.

OK.

A: I can't walk for too long, you know.

Q: No, no. I can see that, yeah.
Now how about, um ... communication. Any difficulty with making yourself understood with anyone?

A: No, I don't think so.

Q. No.

A. A little bit ... little bit scratchy in the voice.

Q. Yeah.

A. Could be worse.

Q: And if you are talking for a long time ... do you get ...?

A: No.

Q: Does it get scratchier? Or is it OK?

A: No, I think I seem all right, yeah.

Q: Seem all right. Good. OK.

And, um ... your own ... with showering and dressing and all those personal things.

A: Ah, my wife's got to help me a bit.

Q: She helps. What sort of things does she do? Does she ...

A: Oh, she's there to make sure if I fall, you know ...

Q. Right.

A. Make sure I don't fall.

Q. Right.

So you do most of it yourself?

A: Yeah, I do most of it.

Q: So she's there really for safety reasons?

A: Just, just in case, yeah. I feel more confident if ... And er, I'm not too good at bending down, you know?

Q. Ah ha, ah ha.

A. But, all the rest I can do.

Q: So you're able to put on your own shoes and socks for yourself?

A: I can yeah.

Q: Great OK, thanks.

PART THREE: Gathering information about role performance.

Q. OK. Now we get onto the interview proper.

Um, and I just want to start by saying, er ... the first question. Can you tell me about some of your roles. What roles do you see that you have?

A: What sort of roles?

Q: Any roles at all, for instance I'm here because I'm a researcher.

A. Yeah.

Q. I have a role as a researcher. Anything that .. occurs to you ...

A: Well, I'm, I'm more or less finished - you know? When you're sixty-five, you're a 'has been' aren't you? See? You with me? I haven't got a job. I couldn't do a job now if I had one.

Q. Ah ha.

A. But I was quite good until I had the stroke.

Q: Right. Were you working until you had the stroke?

A: No. I'd been ... I'd retired. But I could do more than I can do now, I tell you.

Q. Yeah, yeah.

A. But I just ... I don't feel as if I've got a role.

Q. Right.

A. Just getting better's my role I suppose.

Q. Yeah.

A. It's my ambition.

Q: Mm. And do you do much towards that? Obviously taking all these tablets!

A: Oh yeah. I feel like not taking them sometimes.

No, I just walk around, poke around, you know. There's a brother next door - I walk up round to see him and ... walk up and down the yard, and have a sit down. Get up again and have another walk.

Q: And you're doing that because you are trying to build up your ...

A: Trying to get better, yeah. That's what I'm doing that for.

Q. Yeah.

A. And if I'm real tired I'll just ... Well, Melbourne Cup yesterday - I had an excuse see. I didn't do anything. I watched the Melbourne Cup all day.

Q: Yeah. Were you pleased?

A: Oh yeah.

Q: Yeah? You had a win?

A: No I didn't back anything, no. I didn't lose anything. (laughs)

Q: It was a good race, wasn't it?

A: Oh, Beautiful. Yeah, beautiful.

Q: A great race. And of course, Saintly was wonderful!

A: Super. Oh, super, yeah.

Q: Just took off!

A: Super race.

Q: Yeah.

A: That's what my role is. I, I don't know.

Q: Ah ha.
Um ... Do you go to outpatients still - or ...?

A: Not now, no.

Q: Not now, no. So you've been discharged completely from them.

A: Yeah.

Q: Did they give you a sort of home program of things to do?

A: Oh yes, some exercises. I try and do them.

Q: Yeah? So, do you do them very much?

A: No, when I think of it I do a few.

Q: When you think it, yeah.

A: When I think of it.

Q: Yeah, yeah.

A: I like stretching me legs on those pair of things I made up.

Q: Oh. You made those?

A: Yeah, I got to stand up on them and stretch my legs.

Q: Ah, to stretch your calves.

A: Stretch the back of your legs, yeah.

Q: Oh! That's good.

A: They're rough but they do the job.

Q: Yeah. So you find that you get very tight do you? In the ...

A: In the legs. Oh yeah.

Q: Mm hm.

So how do you spend your time?

You're doing these things that you told me about ...

A: Yeah. It seems to go pretty quick, remarkably. You know, you would think it'd be boring, but it's not boring.

Q: Yeah.

A: Not when you go out, you know. Well, today we went at ... oh, half past nine, and went over there till half past twelve, so that fills ...

Q: Yeah.

A: Fills in a fair bit of time.

Q: Yes.

So ... That's another interest that you have obviously, the trots.

A: Well, yeah. Well that's ... that was me interest, yeah. But I can't help - do anything with it now.

Q: Right. Did you go a lot to the trots?

A: Well, I used to help. The son's got the horses so ...

Q: Oh, has he? I see.

A: I used to help him all the time.

Q: Did you have horses of your own once?

A: Oh yeah. Well, I still got a couple. He does everything.

Q: Right.

I, um, actually have a trotter myself ...

A: Have you?

Q: ... only he's over in Western Australia, so he's [*] (laughs). Yes, so ... I know about the trots. It's good fun isn't it?

A: Good, yeah. Well, Friday night we got one in - Friday night.

Q. Did you? Oh.

A. This Friday night coming.

Q. Right. Oh, I see ... you're ... when he's going to race.

A. Yeah. He's outclassed but, he's in a field too strong for him.

Q: Yeah. Do you have many wins?

A: He has... Well, we've only just bought this one.

Q. Right.

A. He has won seven. Seven races.

Q: Right. That's good. More than mine did.

A: I think he might be all right.

Q. Ah.

A. There's some of our photos there.

Q: Oh, yes. Can I have a look?

A: Yeah.

Q: (sound of Q. getting up to look at the photos which were hung on the walls around the room.)

This is all at ... Harold Park is it?

A: No.

Q. No?

A. No. I think one's at Bulli, one's at Richmond and one's at Newcastle.

Q: Oh yeah, right. So it's the same system I guess as in Western Australia. You go around the country tracks ...

A. Oh yeah, oh yeah.

Q. ... and sort of wind up in Perth if you're getting anywhere with the horse. We certainly were at ... we .. the horse was down in the country anyway, so, that 's what happened with him. He never got as far as any of the big places.

A: No, that's what I say. There's not many that get there, is there?

Q: No, no. Especially now because there are so many people that put a lot of money into it.

A: Oh, yeah. It's pretty hard now.

Q: Yeah.

So, um ... how much do you have to do with the horses now? Like you were at the track this morning ...

A: Ah, nothing. I don't do anything.

Q: No, maybe not in actually handling the horses ... but ...

A: No, I just talk, you know.

Q: You talk.

A: Yeah. Talk. Make suggestions and get told to mind me own business.

Q. (laughs)

A. On Sunday I went out. We went to the trials Sunday morning, and then I went out to help him shoe the horse - show him how to do it, you know, because he'd never done 'em. Well, he sort of did 'em but I used to do all that. Shoeing and that.

Q. Yeah.

A. I had to show him how to do it because I couldn't do it.

Q: Yeah. So you stood there giving instructions?

A: No I sat down. (laughs)

Q: Sat down. And how did that go?

A: All right, yeah. Oh yeah, he's gettin' better.

Q: So did you feel good about doing it that way?

A: Oh yeah, yeah. Well he was happy.

Q: And he wouldn't have been able to do it otherwise?

A: Oh yeah, he still would have done it. I just explained things to do, you know.

Yes, like it's pretty hard to put on old experience isn't it?

Q. Yes.

A. See, I've been doin' horses - shoeing horses ... Shod me first one at twelve years old!

Q. Did you? Yeah.

A. And learnt all the time you know?

Q: Yeah.

So you've got a lifetime's experience to...

A: Well I'd say so, yeah. And I made it my business to learn how to do ... how to shoe horses, you know? I used to go around to all the old experts.

They're a lot better now.

Q: Mm. Because there are various schools of thought about shoeing horses aren't they?

A: Oh yeah, specially tryin' to ... well, mainly trotters, well they ... or pacers - that type of thing ... pacers ... that ... they're gettin' cleaner gaited now. Years ago you'd have to make the shoes and angle them and - oh ...

Q: Put more weight on the inside?

A: Oh, yeah, sometimes yes. Yeah! But now they're pretty clean gaited. Now and again you get one that goes wrong, but, well I know how to correct that.

Q: Yeah. So you're able to pass all that on to your son? Does your son accept that?

A: Oh yeah!

Q: He likes that.

A: Oh, yeah. He's willing to learn.

Q: Yeah. So you're still getting some satisfaction out of that?

A: Oh yeah, a little bit. I feel like doing it myself but ...

Q. Yeah! (laughs)

A. I can't. When I can do it myself I'll know I'm right.

Q: Yeah.

So, is that something that you spend a lot of time thinking about?

A: Oh yeah, I think about it, yeah. Oh yeah.

If I get a problem with one of them, well you think about it and then you come up with an answer to it.

Q. Mm hm.

A. It doesn't always work but the next time might work.

Q. Mm hm. Mm hm.

A. If you've had trotters you'll realise that.

Q: Mm hm. Yeah. Yep. I wasn't involved in the training of this horse. But um ...

A: No, but you'd know about it?

Q: Yes, I do. Yeah. So now, with the ... with the horses that your son looks after, you're still doing that?

You're seeing ... you know, problems coming up and you think about it and come up with ideas to try?

A: Oh yeah, yeah. Yeah, I ring up if he's got a problem.

Sometimes you can help, sometimes you can't.

Q: Yeah. So that'd take up a bit of your time, one way or another I should think. Does it?

A: Oh yeah. Oh ... He's got his horses twenty miles away but. So, it's ... You've got half a mile to travel - half an hour to travel and half an hour travelling home and then ... So that fills in time.

Q: Yeah. And how often would you do that? How often would you go out and look at the horses?

A: Oh, only in the last three weeks I've been doing that.

Q: Right. So you've just started getting back into that?

A: Well, I'm trying not too ...

Q. (laughs)

A. ... but I probably will have to.

Q: Mm. So you'd rather leave it ... to him.

A: Leave it to him so he can get confidence in himself, yeah.

Q: Ah ha. Ah ha.

OK. Um ... So, would you say that was another role that you had? It sounds like it is. It's something that you've been doing for a long time.

A: Well, yeah, well that's another ... yeah well, that's another thing. I don't know about a role ... that's another ...

Q: Yeah. So would you call it a horse trainer?

If we were to put a name on it?

A: You've got to put a name on it have you?

Q: (laughs) It's up to you what you call it. I don't mind what it's called, but it's just so I can write about it.

A: Oh well, instructor. Instructor I suppose.

Q: OK. Instructor of...

A: Blacksmith, farrier.

Q: Farrier and instructor, how does that sound ...?

A. Farrier.

I used to make the shoes and everything, you know. And now you don't have to. You buy 'em. Buy them already made.

Q. Yes.

A. Just shoe ... You just put them on.

Q: Get a size so and so and ...

A: Yeah, get a size 3 or a size 4 or a size 0. Whatever the horse size is.

Q. Mm.

A. It makes life easier.

Q: Mm.

Oops, there's something ...

(sound of car coming closer)

A. Yeah, my brother. My brother coming home.

Wife: He knows just where to put that.

(brother parks car in tiny space just outside the door close to where we were sitting)

Q. (laughs)

That's pretty good.

So what about family? You've got ... You've got one son, obviously. You've been telling me about him. Any other children?

A: One son that is all I've got.

Q. Right.

A. Er, That's all I've got, yeah ... around at home. And I've got ... two daughters.

Q. Mm hm.

A. And ... there's er ...

There's three other sons isn't there?

(asks wife)

Wife: Besides the one here? Yeah.

A: Yeah. Three other sons.

Q: So a big family.

A: Yeah, six altogether. There's them.

(shows picture)

Q. Oh, right.

Wife: Our grandson got married.

Q. Oh, really?

Wife: ... and that's all our family.

Q: Oh gosh, they look gorgeous. What a nice lot of people.

Wife: It was the first time we got everybody together.

Q: They look great.

Wife: Yeah it's good.

Q: So where are they all normally, the other children?

A: Oh, there's one at ... One daughter's at Plumpton.

Q. Yeah.

A. One daughter's at er ... Oh, what do they call that place...

Q: Out of town? Is she in New South Wales?

A: No, no, close, handy.

Q. Right.

A. Just off the freeway. What ... what do they call that place? Gosh!

Q: It doesn't matter where. Is, is it ...

A: No, I should remember it!

Q. (laughs)

A. Those little, little things - I have a little lapse like that.

Q. Yeah.

A. Er ... just up past Eastern Creek anyhow. Minchinbury.

Q: Minchinbury right.

A: Minchinbury isn't it? No?

Wife: Eastern Creek.

A: Eastern Creek is that her address?

She lives in Minchinbury Road?

Wife: Mm.

A. Yeah.

Q. Right.

A. Yeah. Minchinbury Road, Eastern Creek.

Q: Right.

And what about the boys? There's your son's ...

A: Well, one boy is at Taree.

Q. Yeah.

A. He's got a little farm up there. Another boy's at er ... Jervis Bay only back this way. Not Jervis Bay. Glendinning. No. Not Glendinning.

I know that you're only testing me out!

Q: Oh, no, I'm not actually. No, I'm just interested in whether they live within sort of easy driving distance or a long way away ...

A. Yeah well ...

Q. Because I want to know ... Um, my next question is how much you get to see them all.

A: Oh, he's two hours away and (Bson) is four and a half, five hours away at Taree.

Q: Yeah. So it's a bit of a distance isn't it?

A: Yeah. Telephone's there, but.

Q. Ah ha.

A. And (Mson) he's at Riverstone.

Q. Right.

A. So. He's got the horses, (Mson).

Q: Right.

So, how many of them would you see regularly, do you think?

A: I see (Mson) pretty regular.

Q. Yeah.

A. That's the one with the horses.

Q. Yeah.

A. And, er ... Well, (Gson)'s coming up, next ... he, he'll be up here Thursday. That's the one from ...

(taps table)

Hus ... er, no, no. Er Husskin er ... anyhow. I don't see him that often, but he'll be up because he is helping (Gson). do that car up.

(points to one the cars outside)

Q. Mm hm.

A. We don't see (Bson) too often. (Mson), see him a lot. And (Cdtr) and the two girls, we see them pretty often.

Q: Right. So pretty often - once a week? Or once a fortnight? Or ...

A: Oh, I see (Mson) once a week for sure.

Q. Yeah.

A. It might get three times a week sometimes.

Q. Yeah, yeah.

A: And (Mdtr)'s just gone! (Mdtr). And (Cdtr), I see her at least once a week.

Q: And then phoning? Do you talk to them pretty regularly?

A: Oh yeah. Every couple of days or three or four days.

Q: Right. So you're in pretty good touch with all ...

A: Oh yeah.

Q: And does that give you a lot of pleasure? Are your children ... er, are they a source of pleasure to you? Or ...

A: Oh, I think so.

Q: Yeah?

A: Yeah, I think so. As long I am no nuisance to them that's all that I ... that worries me.

Q: Yeah.

OK. Um, we'll call that one father then. That's another role. Would you agree that's a role? being a father?

A: Oh yeah, hell, it used to be. (laughs).

Q: OK.

A: It used to be over the years bringing them up.

Q: Yes, a lot of hard work with five children, I'm sure.

A: Six.

Q: Oh sorry, six children

A: Mm mm.

Q: Yes.

A: There's er ... no worries now, no hassles now.

Q: Yes. Do they all have children? Are they married?

A: Yeah, yeah, they got ...

Yeah, we've got twelve grand kids haven't we?

(asks wife)

One great grandchild.

Q: Oh really. So you're doing very well.

A: (Bson) the one, (Gson), the one who lives here - he's not married.

Q: So how about being a grandfather, is that something that you enjoy too? Do you like having the kids around?

A: Oh yeah, yeah! Oh yeah. I like to see the kids and that.

Q: Do you do ... er, what sort of things do you do as a grandfather?

Do you do much with them?

A: Not really, no, no.

Q: So they come and visit, or you visit them?

A: Just visit.

Q: Yeah.

A: Oh, we visit them sometimes.

Q: Yeah.

A: Birthdays and things like that.

Q: Yeah.

Any that you see pretty regularly?

A: Only (Mson)'s kids. We see them pretty regularly.

Q: So, you'd know them the best?

A: Yeah. Oh I know 'em all! (laughs) I know 'em all pretty good.
But one of the grandsons he's learning to drive, see. He's learning to drive the trotters.

Q: Right, right.

A: So, I see him a fair bit. I seen him this morning. You got to have twenty ... you got to have twenty drives before you get your license.

Q: Right.

Oh, he needs ... Yeah, so you're able to give him a lot of help.

A: Yeah.

Q: So did you do much driving yourself?

A: No, not a great deal no.

Q: But you had been training them and driving them.

A: I did do it yeah. I wasn't a good driver, so I give it away. (laughs).

You got to know your limits.

Q: (laughs) Yes, that's an important thing, isn't it?

A: Yeah.

Q: Yeah. OK. Um ...

Er, do you spend much time outside the home doing anything else? Do you have any other interests or hobbies?

Or do you belong to any clubs?

A: I belong to a few clubs.

Q: Yeah?

A: Oh, yeah. Parramatta Leagues. Granville. Granville there. Bankstown ... Bankstown Trotting and Recreation.

Q: Yeah?

A: Bankstown Trotting Club.

Q: Oh, that's a few. Do you go to them regularly?

A: Oh, not very often.

Q: No?

A: I went to the Leagues Club, oh, last week - didn't I?

(asks wife)

Yeah.

I'm not ... not much of a club man really.

Q: Mm hm. So, you go for special events do you? Or ...

A: Not if I can get out of it. (laughs)

No, I went for my birthday the other day, that is all.

Q: Oh, right.

A: My daughter came down. She said "Come on we're take you to the club". I didn't want to go but I went.

Q: Did you enjoy it?

A: Not really.

Q: No.

A: No. I can't see any sense in it.

Q: Oh?

What is it you don't like about it?

A: Well I don't like them poker machines for one thing.

Q. Right, yeah.

A. Once you've had your dinner - you have a nice meal there - what else? See one ... I know that if you put money in, they take it out!

Q. Yes.

A. Poker machines? No. I'm not saying I don't like a bet, but not on poker machines. That's not betting. That's giving it away. In my opinion. But (wife) likes to play it.

Q: Yeah. So, the reasons you go to the club are: to get a good meal and, so that your wife can...

A: Oh, to get a good meal and go with them if they want to go that's all, yeah.

Q: Yeah. So, in the last three months, how often would you have gone, do you think?

A: Only the once, I think. Only the once.

Q. Right.

A. No, no twice. I went to Bankstown ... no four times.

Q: Ah ha! (laughs)

Wife: Now it's coming out!

A: I went to Bankstown twice and the Trotting Authority - the trotting one once, then Parramatta Leagues once.

Q: But it doesn't sound like something you actively go...

A: No, it's not once a weeker, no.

Q: No. It's just something that happens every now and again. Just sort of happens ...

A: No, well ...

Q: Is that right?

A: Well if there is a trotting meeting at, say Bankstown ...

Q: Yeah.

A: ... we might go over to the recreational club and have our tea, then go to the races.

Q: Right.

A: If it's - you know, if it's convenient. But that's only ... well, that's only twice that happened.

Q: Yeah. So would you think that was a role? Being a club member? Is that something that you would be prepared to ... not a big role, from the sound of it but...

A: Yeah, I'd say so. Yeah, it would be ... It might be when I get a little bit better. I might ...

Q: So that'd be something that gets a bit bigger later on?

A: Yeah.

Q: Yeah. OK.

A: Yeah.

(dog comes inside.)

Get outside.

Wife. Outside. Go on.

A: (Gson)'s home.

Go on Brock.

Q: I don't mind. I mean if you're sending him out for me, don't worry.

A: Oh, I'll leave him then.

Q: Hello! There.

A: There you are. Meet Peter Brock.

Q: Is that right?

A: Brockie.

Q: Oh! You're nice! He's got a lovely face! Very sweet. All that terrible barking!

Wife: Yeah, I know, that's the worst part of him. (laughs)

END OF SIDE ONE

Q: So, I meant to ask you earlier, how often do you go to the trots? To meetings I mean?

A: Oh, whenever our horse is in?

Q: Whenever your horse is in.

A: Yeah. Oh, we've been a fair bit.

Q: So, about every 2 weeks or so? Or ...

A: No, once a week.

Q: Once a week. Regular.

A: Oh yeah! And that's a role.

Q: Yeah, yeah.

A: Put that down as a role.

Q: (laughs)

Yes. Yes. I ... I have to ... I would like ... that's all part of being a horse owner really isn't it?

A: Yeah. Oh, yeah.

Q: Horse owner and trainer perhaps we should call that. Still trying to get a nice neat name.

A: Yeah, well I'm not training now. Because I can't do it.

Q: Well, horse owner and adviser? Or what did we call it before? Instructor?

A: Yeah, well, horse owner anyhow.

Q: Something like that.

A: This is my son (Gson)

Q: Oh hello.

D: G'day.

Q: I'm Anne Hillman. Did you know ... Do you know why I'm here?

D: They said someone was going to come around and that.

Q: Yeah.

A: Outside Brockie, go on!

Q: I'm interviewing your father for my research.

Wife. (claps her hands)

(to dog) Get out!

A: Get out!

(sound of departing dog's paws on the linoleum)

Q: He has very kindly agreed to ...

Wife He won't get out because we're taped!

Q: (laughs)

Wife: You've got father yelling!

Q: (laughs)

OK. Um ... How about friends? Do you have a lot of friends that you see a lot? Or not that many?

A: Not that many.

Q: Not that many? Any real buddies?

A: (Points to wife)

She's the only one really.

Q: Yeah.

So do you see much of friends or... ?

A: When I get to the trots I do.

Q: When you get to the trots.

A: Oh, yeah.

Q: So that's the main place is it?

A: Folk'll come over and see you, yeah.

Q: People don't come around here very much or...

Wife: Not many no.

Q: Do you go out and visit anybody?

Wife: Not really no.

Q: So it's the family mainly?

A: Mainly the family. Yeah.

Q: OK. Um ... Are you, er ... do you do any work of any kind?

A: No.

Q: No? Not voluntary work or any ...

A: Well I can't really.

Q: No, yeah.

A: Couldn't do it. I wouldn't do it if I could. (laughs)

Q: No.

A: I've got enough to do around here if I ... if I could do it. I ...

I've got too much to do around here really.

Q: Yeah. What sort of things? What would you be doing around here if you could?

A: I've got all that wall down that side ... Outside. I've got to fix it up. I was in the ... I was in the motions of fixing up another shed there. And that's ... I can't do that. The kids'll come home and do it one day.

Q: Yeah.

A: But I can't do anything in the shed now so - I don't worry about it.

Q: Yeah. So you're just letting it go?

A: See what happens. I might get better.

Q: So you would like to get back to it?

A: Oh yeah! Oh I'll get better! I'll get right.

Q: Yeah. So do you think much about it, do you think much about what you would be doing if you could get into the shed and do it?

A: No, no not really, I don't pine on it. The doctor said you might get right and you might not. That's the advice he gave me.

Q: Yeah.

A: He said you've a lot to look forward to. (laughs)

Q: Yeah.

A: But I will, I'll get right. Once I get rid of this pain - down here.

Q: Yeah. So that really slows you down?

A: Oh, yeah. Makes you dizzy, you know? These tablets make you dizzy too.

Well, he told me they would.

Well, I'm lucky to some people. You've been through the hospitals and that?

Q: Yes.

A: Yeah. I'm lucky aren't I?

Q: Yes. And that is the way to look at it too, I think. You know?

A: Yeah, oh yeah. Yeah I am lucky to some of them.

Q: Yeah.

A: That's the way I look at it anyhow! (laughs)

Q: Yeah.

Um. What about er ... What other reasons for going out of the house? Do you go shopping, for example?

A: Oh I go shopping yeah.

Q: Yeah. Do you do that on your own? Or do the two of you...

A: No, I can't drive, see.

Q: No. That's right.

A: Sometimes I go, just sit in the car, if I ... you know? Just to get out of the place.

Q: Yeah.

A: Sometimes I go push the trolley. Sometimes I sit on the bench - let her go on her own. Sometimes I go with her. It depends just how you feel. That day. Every day is different.

Q. Yeah.

A. Yeah, every day is different.

Q. Uh huh. Uh huh.

A. Some days you feel terrific. Other days you've got to push yourself.

Q: Yeah.

OK. And you've got a dog. Would you think you had a role as a pet owner?

A: Yeah, I often go out and talk to him. Sit down and talk to him.

Q. Right.

A. Yeah.

Q: So he's a real friend?

A: Sit on the old chair there and pat him. He comes up and puts his head there and I pat him. Oh yeah!

Q. Yeah.

A. Ah ... He's a ... He is a help.

Q: OK. So we'll put down dog owner as well.

Right. Anything else that you can think of that you do? The other role which I haven't discussed is being a husband.

But, I guess you spend quite a bit of time doing that? Is that right?

A: Yeah, I think she reckons I am in her road all the time!

Q. (laughs)

A. No, I couldn't manage without her.

Q. Yeah.

A. Though, I'm not her husband - that way, you know? We're just ... We're good mates, that's all.

Q. Yeah.

A. Because I'm ... no good any more.

(taps the table)

Not that way.

(taps the table again)

Q: Yeah.

A. (taps the table some more)

Q. So you have a good ... You're happy with the relationship?

A: Oh my word, yeah!

Q. You've got a good relationship.

A. Oh, yeah!

Q: Great.

OK. Anything else that you can think of?

A: Not really, no. It's just ...

Q. Sorry? Anything else?

A. Just normal things, you know. Just ... sit around living, that's all there is.

Q. Yeah.

Alright. I'm, just going to stop this for a ...

BREAK IN TAPE

PART FOUR: Informant identification and confirmation of roles

Q: If you've been, um ...

I just realised I turned the tape off when your son came in. That's when I turned it off.
So I've lost all that!

Wife. Oh yeah!

Q. Oh, dear! Never mind.

PART FIVE: Sorting roles under performance area and sociocultural headings

Q. Um ... Now, what I've got here is a board, and, er ... I've these headings:
productivity, self maintenance, leisure and social and cultural. And what I'm going to

ask you to do is to sort these roles that we've identified. And put them under these headings according to the main reason that you do them.

So, this heading - productivity, is about work or giving a service to others or producing something that can be used by others. So it's not necessarily paid work. It's just anything that you do that you can see is of use to others.

A: Yeah, well I don't do anything.

Q: You don't do anything?

A: Well not now because I can't.

Q: Yeah. I could change tyres and everything before! I can't do that now.

Q: Yeah. OK.

A: See. I can't rub that car down. He wants to paint it. I could paint it or anything. But I can't now.

It makes you feel useless really.

Q: Yes, yes.

A: As I say, I'm better than a lot of people who's had a stroke and I am glad for that.

Q: Yes.

A: I am not glad that they're worse. I'm glad that I'm not as bad.

Q: Yes.

A: Some people can't walk or anything! When you go in there and see it all.

Q: No, it's true.

A: Twisted arms like that, and they're stopped like that, you know.

Q: Mm.

OK. This next one is called self maintenance and that is what you need to do to get by and to get on with the rest of your life. So it's the sort of things that we all do in order to survive. To be able to live, you know? The sort of everyday tasks that we all need to do.

A: Yes.

Q: Um. And then leisure is things we do for fun and enjoyment.

And this one, social cultural, is ... um, the things that you do because of the ... most important, or main reason is because of the relationships that you have, er, because it's

to be with other people, or because it relates to the beliefs or values that you hold.
OK. Does that make sense?

A: Not really.

Q: No really? OK. Beliefs and values. For instance, if you were a church goer, you might put that under that heading because it relates to your beliefs.

A: Yeah, well I haven't been to church since I've been crook see.

Q: Yeah. It's just an example. Um. You know, it's things that ... It might be that you do because it's important to you. You believe that you should. It's something that's right. Do you know what I mean?

A: There is nothing I can do, even if I believe it's right. Nothing physical I can do.

Q: Yeah. Anyway, let's try, sorting each role, and, er, see how you go. So we start with the first one husband. What heading do you think you put that under?

A: I can't put it under there any more.

[I do not remember which one he was indicating, but in view of my next remark, it may have been leisure]

Q: Well, it's just the main reason, so...

A: Well.

Q: If you still get fun out of it, it doesn't have to be ... the same as before.

A: I don't know where you put that.

(pause)

See, I can't do nothing to suit anyone else.

(pause)

I s'pose that'd have to go in with that.

Q. Ah ha.

A. Wouldn't it?

Q: Under self maintenance?

A: Well, I can't manage without her.

Q. Mm hm.

A. I shouldn't say that in front of her, or she'll ...

Q. (laughs)

OK.

A. Does that sound all right?

Q: Yep. It's up to you, where you think.

I'll just put this down flat actually, because it's easier for you.

It's up to you entirely. Where you think it should go. The main reason.

A. There.

Q. OK. The next one is father.

A: (pause)

I don't know where to put that one either.

(pause)

I s'pose that'd go in this one.

Q: Mm hm. Under social/cultural?

A: Well, there is more ... yeah.

Q: Uh huh.

So the main reason is relationships is it? That ...

A: Well, something like that. Yeah.

Q: Or because you believe that's something that you should do?

A: Well, I don't know.

Q. OK. That's alright.

A. That'll do.

Q: That'll do?

A. Yeah.

Q. Grandfather.

A: That'll have to go in there too.

Q: OK. And great-grandfather?

A: Yeah that'll do.

Q: OK, all the same.

Now, horse instructor and ... horse owner and instructor?

A: I suppose that is fun and enjoyment.

(laughs)

Wouldn't it? S'pose.

Q: Yup. Whatever. Whatever you think.

A: It's funnier than sometimes, but still ...

Q: Er ... Stroke recoverer?

A: That's in ... That's probably in this one.

Q: Uh huh. Self maintenance one. And ... why is that?

A: Well, it's what you need to do to get on with the rest of your life!

Q: So you have to deal with that in order to get anything else done.

A: Yeah! Get on with the rest of your life!

Q: Mm hm.

OK.

A: It depends on how long you're going to live! When I was in hospital I didn't know. I was hoping it wouldn't be long.

Q: Yeah.

A: Well. Actually, this .. this has got to go in here too.

Q: Yep. Fine.

OK, last one.

A: Club member. that doesn't matter where it goes. It's got to be in there too.

Q: OK.

A: That one's got none in it.

Q: No. That's the productivity one.

A: Well, I can't do anything so...

Q: Yes.

(pause)

The one that I, I am not trying to... we will leave everything where they are, but the one that I might have thought could go in productivity would be this one.

A. Mm. Yeah.

Q. I don't know what you think about that, but .. I mean the instructor part in particular. Because you are giving people the benefit of your knowledge.

A: Yeah. Used by others ... yeah. But they wouldn't get much out of me.

Q: It sounds like they get quite a bit out of you. (laughs). But, I mean that's ... I don't want to er ... I don't want to influence you. If ... if you er, think it's better under there.

A: Well, no. Actually there's no fun any more. Really there's no fun in it. Not now. It's all hard work.

Q. Mm hm.

A. Yeah, someone'd get something out of it I s'pose.

Q: So it is a bit of both, would you say?

I mean, you do get some fun out of it do you ? From what you've been saying?

A: Well, yeah. Really I do, yeah.

It's hard work but.

Q. Yeah.

A. Not for me now because I am not doing much.

Q. Yeah.

A. It's hard work for him.

Q: Well, I mean what's the main reason that you continue to be interested in the horses do you think?

A. Well, mainly for him.

Q. Ah ha.

A. Yeah.

Mainly for him. I could do without 'em now.

- Q: Yeah. So it is to help him keep going with it.
- A: Yeah. While he is interested in 'em, I got to be interested too.
- Q: Oh. So it comes back to being a father again.
- A: Yeah. That's right. That's about it. Yeah.
- Yeah. That's about what it boils down to.
- Q: Right. OK. Well I think that is about it, we've finished.
- A: Well. You didn't learn much.
- Q: Oh, I learned a great deal! No. Thank you! I learned a great deal. So um ... I'll just stop this now.

BREAK IN TAPE

PART SIX: Informant rating of roles

- Q. What we've got is that for each of these roles. I'd like you to rate them ... on a scale, by just pointing. So ... if we start off with, um, this one. The horse owner and instructor. Um, could you just point on this scale how often you do this? 'I do things in this role ...' And you see one of the scale is 'never' and the other is 'very often'.
- A. Yeah, yeah.
- Very often.
- Q. Very often. Five.
- A. Mm.
- Q. OK. I'll just write this down.
- (sound of heavy traffic outside)
- A. [*that's our D]
- Q. Where'd that form go? Oh it fell down. Sorry. I'm being so quick I'm being slow!
- OK. So. OK. The next one for that same role, is 'how much do you value it?' from this end of the scale 'not at all valuable' up to 'highly valuable'?
- A. Oh. What, the whole lot?
- Q. The whole horse, horse ...
- A. Well, I'm only doing part of it.

Q. Well, it's your part of it. It's all to do with what you do.

A. Yeah. Mm.

About the middle I s'pose.

Q. Ah ha. Two or three? Do you think?

A. Oh, it'd be three.

Q. Three. OK. And then, last one for that role is satisfaction. 'I feel satisfied with my own performance in this role' 'almost never' up to 'all the time'.

A. Yeah. I'd say all the time.

Q. All the time? That's good. OK.

A. Because I'm easy satisfied.

Q. (laughs)

Alright. The next one ... Er, we look at husband here.

A. Well, that's all the time.

Q. All the time. Sorry, this for both of these here. Husband and stroke recoverer.

A. Yeah, well, that'd be right. Yeah.

Q. Yeah. For both. OK. So that's ...

And, er, we look at value next.

A. Yeah. Value's, the top one.

Q. OK.

And then the last one. This is your own performance. This is how you do in it.

A. With what I do?

Q. Yeah.

A. Well, 100% with what I do.

Q. Right, so you're pretty satisfied with that?

A. I'm pretty satisfied with what I'm doing. Yeah.

Q. OK. So now we move on to the next heading. Which is um, these two. Dog owner and club member.

A. Yeah. I ...

Q. What about frequency?

A. Oh, about the middle there, I reckon. Bout ...

Q. Two?

A. What's this one?

Q. That's two, this one's three.

A. Oh, about two I think.

Q. About two.

A. I'm not very fussy about that.

Q. What about value?

A. Not really. About the same.

Q. About two.

And, what about satisfaction with what you do in those roles - dog owner and club member?

A. Yeah, about the middle. About three.

Q. About three. OK.

A. There's not much satisfaction in that.

Q. No.

A. Only clubs and that.

Q. No. But with the dog ...

A. With the dog, yes.

Q. And the last one. That's the social cultural ones. That's father, grandfather and great grandfather. What about frequency? How often?

A. What do you mean? Well I'm there all the time.

Q. All the time?

A. Yeah. Very often.

Q. Very often? OK.

Um. And what about valuing these roles?

A. Yeah, they got a good value in it. Highly valuable.

Q. Highly valuable. OK. And ... How about your own performance as father, grandfather and great-grandfather. How satisfied are you?

A. Well, I'm satisfied. I do everything I can for 'em. Yeah.

Q. So whereabouts on the scale would you ...

A. Well I'd say all the time.

Q. OK!

A. I'm satisfied I do a good job.

Q. Yeah. Great!

A. They mightn't think so, but I think so.

Q. (laughs) I'm sure they do.
Alright. That's it! Thank you. I'm sorry ...

END OF TAPE

APPENDIX D:
DATA ANALYSIS

D1: TRANSCRIPT ANALYSIS

SAMPLE SCRIPT SHOWING FIRST-LEVEL CODING

The full set of transcripts and data analysis documents are available on request.Error!

No index entries found.

**D2: FORM USED IN PRELIMINARY
TRANSCRIPT ANALYSIS**

TRANSCRIPT ANALYSIS FORM

Notes on transcript

Mobility, Personal Care and Communication:

Roles as agreed with informant =

Role distribution as agreed with informant:

Productivity	Self-maintenance	Leisure	Socio-cultural

Roles and role distribution as identified by the interviewer:

Productivity	Self-maintenance	Leisure	Socio-cultural

Notes written at time of interview:

Present roles identified by informant:

Present Roles identified by interviewer and clearly agreed to by the informant:

Past roles identified by informant:

Correlation of scale ratings with statements made in interview:

Productivity

Frequency-Rated

Value-Rated

Satisfaction-Rated

Self maintenance

Frequency -Rated

Value -Rated

Satisfaction -Rated

Leisure

Frequency -Rated

Value-Rated

Satisfaction-Rated

Socio-cultural

Frequency-Rated

Value-Rated

Satisfaction-Rated

Roles identified by researcher on analysis of transcript:

Researcher's notes on Interviewer's performance:

D3: SAMPLE OF PATTERN CODING ANALYSIS

NOTES ON TRANSCRIPT FORM:

Date of interview: 13.1.97

Lives with wife

Age: 68

Australian

Mobility, Personal Care and Communication:

Mobility: 1. Uses stick for long distances eg. out shopping, because he gets tired; or over uneven ground, for extra stability.

Communication: 1. No difficulties reported or observed

Personal Care: 2. Wife helps with drying his back and with dressing. He gets in a muddle on his own.

Roles as agreed with participant = Husband, father, surf club member, home maintainer, person dealing with a stroke, leisure, bowler, being a mate, friend.

Role distribution as agreed with participant:

Productivity	Self-maintenance	Leisure	Socio-cultural
Husband	Dealing with the stroke	Leisure	Being a Mate
Father		Bowler	Friend
Surf club member			
Home maintainer			

Roles and role distribution as identified by the interviewer:

Productivity	Self-maintenance	Leisure	Socio-cultural
Friend	Home maintainer	Surf Club member	Husband
	Dealing with a stroke	Leisure	Father
		Bowler	Being a mate
			(friend)

Error rate: 6/9 wrong = 66.5%

Priority order set by participant (from highest to lowest)

1 Husband	6 & 7 Bowler & Leisure
2 Father	8 Surf Club member
3 Dealing with stroke	9 Home maintainer
4 & 5 Friend & Being a mate	

Notes written at time of interview:

When I turned over the tape-recorder, it did not connect properly, so I missed a bit. He said he considered suicide once or twice but his husband and father roles pulled him back. This man very service orientated. He cannot feel good about himself unless he is doing things for other people. Badly needs to find means to continue this. After I had finished the interview and stopped the tape, he told me how he would like to start a new role as a counsellor (my term) to others who have had a stroke. He said he had already started with someone who he used to work with at the surf club and did not like then. He has now had a bad stroke. He got the idea for counselling from someone he know who cheered him up and talked to him, who had also had a stroke. He organised this person to come and see the surf club person with him. He said that when you get angry you often take it out on your nearest and dearest and this was a big mistake as you need them.

Mr. Twenty-three told good jokes: "How do they make holy water? They boil hell out of it". He called the hospital ward he was on Victa because it had four strokes. He said the good thing to come out of the stroke was that he was able to prove to his wife the he had a brain.

Much of the discussion about identifying roles was lost I think. He does not watch TV to pass time but to watch specific programs. He gets very upset about maintaining the house and garden and having to get his son to do it.

The good thing about being a husband was that they talked and shared things and worked together. The bad thing was not being able to help her by doing the things around the house he used to eg. maintaining the garden and pool and helping with the washing up. He feels very inadequate and frustrated about this and used to help out all the neighbours with their plumbing problems and feels bad he is no longer able to do this. He does not see himself as old. "Bowling is what old people do and I'm not old" Bowling was something he just tried at Lottie Stewart and found he enjoyed.

Although he did not cry, he got a bit choked up at various points in the interview. He seemed very "up" at the end of the interview as compared to the beginning, so I think I cheered him up!

After listening to the first part of the tape :

I think the missing bits were:

- 1) He has left hemianopia (slight)
- 2) He doesn't do much around the house but never did
- 3) Used to have two dogs but both had to be put down because of skin problems
"something in the back yard upset them. He enjoyed having a dog but would not have another pet now.

We discussed what his roles were and named them as per part 4. He disagreed that he had a role as a time passer because he did not feel he did anything just to pass the time - he always had a reason. So we decided on "leisure" to cover things like watching TV (because he wants to see a specific program) and sitting in the sun (because he enjoys it). He loves going down the beach, but his wife is not keen so he doesn't go. We kept coming back to the things that he could not do because he needed his wife to take him. He feels reluctant to ask too much of her. They looked after her parents, one of whom was quadriplegic, for many years and that was a difficult burden that put a strain on their marriage at times. Now they are dead, but no sooner do they get their freedom than he has the stroke and she has someone to look after again. He feels bad about this and therefore determined to become more independent. He felt they had got closer since the stroke and the role of husband had become more important

to him. Good relationship as described above. He felt that role of mate was different to role of friend, so we separated them. He has two mates and the way he described the relationships put them on a different plane to the rest of his friends. His two mates had known him from school days, they were in the surf club together and would do just about anything for each other. One takes him to the surf club once a week. The other lives in Canberra but rings when he is coming to Sydney and tells him to get a list of jobs ready. He drives from Canberra, arrives at 8.00 am., works all day flat out putting the garden in order, doing maintenance etc., then leaves about six p.m. to drive back to Canberra.

We discussed how "bowler" was a new role that he hoped would grow and develop. I wanted to put home maintainer and he didn't. I pointed out that roles weren't just the things we liked to do or did well and that he seemed to spend a lot of time fretting about what was not being done or not done right and feeling bad about not being able to do it. Didn't just let the place rip. He agreed with this. Dealing with a stroke he strongly agreed was a role.

We then moved on to arranging in order of priority which he did quickly and with hardly any apparent uncertainty.

I started to discuss his role as a husband as per above in notes. He told he had considered suicide once or twice, but the role of husband and father had pulled him back. He found the role father very satisfying as well as husband. Felt that had not changed since the stroke, but also said he felt the stroke had pulled the family together. I think everything else in on the tape.

My impression of him and his wife:

I really liked him. Devoted to service to others in terms of self-identity. Wife very pleasant. They seemed to have a good, easy relationship. Beautiful house.

He also told a story about going to the swimming pool with his son. The tiles were slippery and he slipped over on his face and couldn't get up again. Son hauled him up. Later, son decided to go for a run and he said he would stay in the pool. son said "promise me you won't try to swim again. Stay up this end of the pool. Don't go out of your depth" I thought Gee! How things have changed - because that's exactly what I would have said to him once. I don't like that."

House and garden were immaculately kept. It seemed there had been a bit of money until the recent past to spend on things to make the place look nice as well as a lot of hard work in maintenance and improvement.

Present Roles identified by interviewer and clearly agreed to by the participant:
Husband, father ...

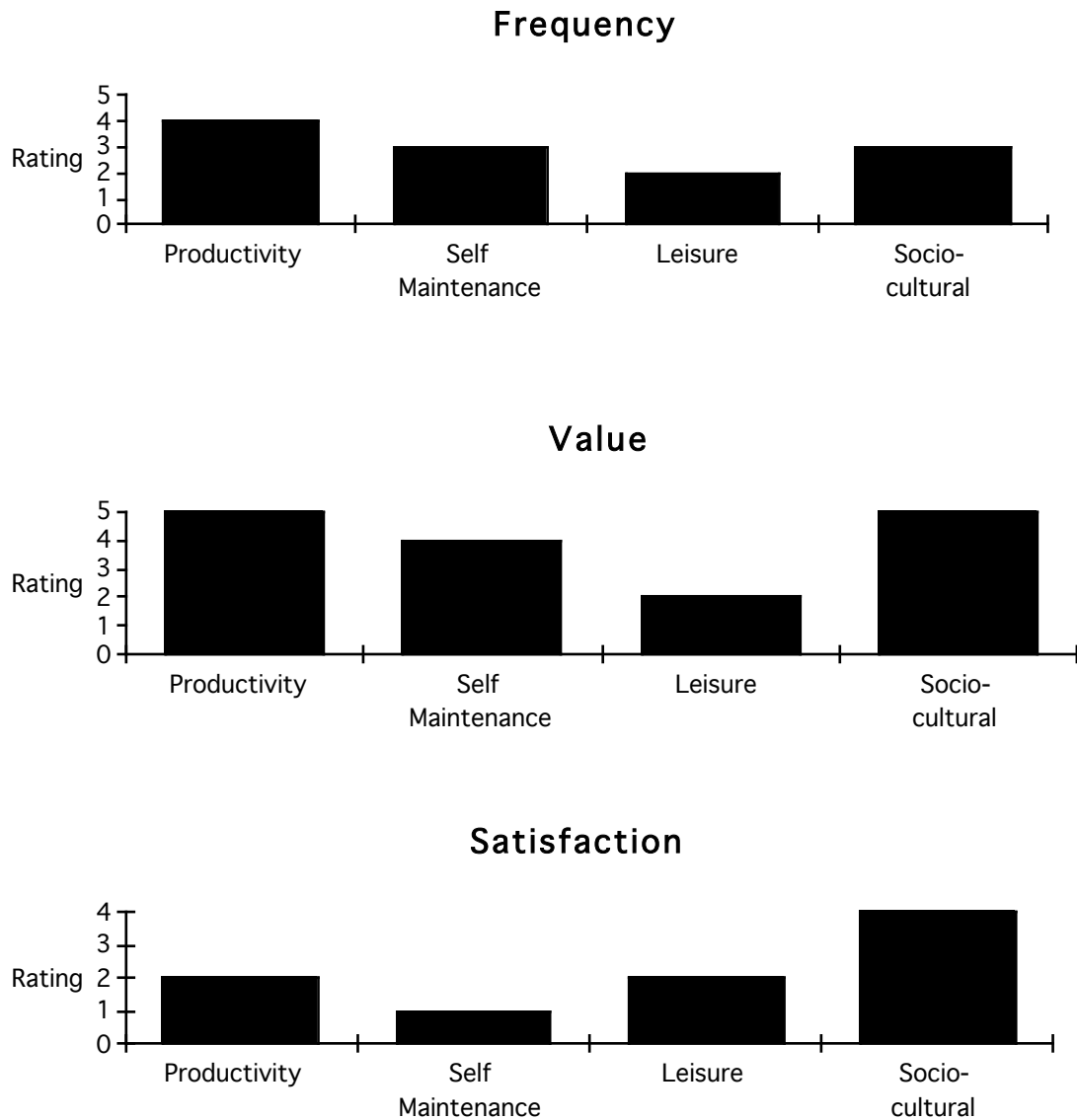
Past roles identified by participant:
Plumber, Surf Lifesaver, as opposed to club member as he is now. ...

Comment on role sorting

When sorting to roles under performance area headings, I reminded Mr. Twenty-three to look to the left-hand side of the board, which he needed to do because of his hemianopia. I do not know if this has any influence on the fact that he placed so many roles in productivity, but generally from the transcript it was clear that he had a strong productivity focus. I also

checked verbally and he was able to confirm that where he had sorted roles was where he meant to sort them!

Scale Ratings:



Correlation of scale ratings with statements made in interview:

PRODUCTIVITY - Husband, Father, Surf Club Member & Home Maintainer

Frequency-Rated 4

Daughter stays occasionally (p. 2). Son visits every day.

Value-Rated 5

Satisfaction-Rated 2

Commented when rating them "Because I can't do them very good now at the present moment". Feels a burden on his wife (p. 4). Worries particularly about maintaining garden and hates asking others to do it.

SELF MAINTENANCE - Person With a Disability

Frequency -Rated 3

Commented: "Hoping to get up to 5 as quick as I can"

Value -Rated 4

Satisfaction -Rated 1

Commented: "How satisfied am I? I'd come back to a ... I'd come back to a one there. I feel as though I'm not doing as much as I should."

LEISURE - Bowler, Leisure

Frequency -Rated 2

Value-Rated 2

Satisfaction-Rated 2

Commented:

A: Well, I feel as though I could do better.

Q: OK. Like sitting in the sun? (laughs)

A: Well, I find that ... You know, I'm wasting time there. ... Whereas, I could spend more time [*being outside] anyway.

Q: Yeah. So would you feel more satisfied with your leisure role if you were doing better in your productivity role? Do you think?

A: Yes.

Q: Would that be right?

A: Yes.

Q: So those two linked together?

A: Yep.

Q: One's dependent on the other? Like you can't ... You don't feel able to enjoy this without ...

A: Without getting on ... Without having this right.

Q: Yeah, yeah. You can't allow yourself to ...

A: No. I feel as though I'm ... What's the word I am looking for ... I'm ... **When I sit there, I feel as though - I'll put it crudely, as most others would, I feel as though I'm bludging on myself.** ... I feel as though I could be doing something.

SOCIO-CULTURAL - Being a Mate, Friend

Frequency-Rated 3

Value-Rated 5

Satisfaction-Rated 4

I noted at the time of the interview:

He had no hesitancy in rating and overall, and scored as I would have expected, although much lower on satisfaction than most others I have interviewed. However, he seemed to rate frequency oddly - look at this more closely with the transcript. eg. leisure Perhaps he does not want to admit this has increased so much. These frequency ratings seem more what they would have been while working, or prior to stroke.

Roles identified by researcher on analysis of transcript:

Researcher's notes on Interviewer's performance:

Using more contrast questions and getting good answers.

Was able to provide a bit of information to him at the end of the interview about specific self care problems he has and recommended that he asks to see OT as well as Physio when he returns to Westmead.

STAGE TWO OF PATTERN CODING ANALYSIS OF TRANSCRIPT

PRODUCTIVITY:

General comments :

He sorted Husband, Father, Surf Club Member, and Home Maintainer under this heading.

For husband and father he commented:

Well, yes, I think so yes. **They rely on me, and I enjoy the fact that they do rely on me. I enjoy the fact that I can do something to help them.**

This is the area of focus of Mr Twenty-three's life. Prior to his stroke he had just retired from his own plumbing business. He kept himself on call on weekends. He was also in the habit of doing all his neighbour's and friend's plumbing, lending a helping hand where needed. He was a very active life saver and still organises something once a year for his surf club. It seems that he feels the loss of independence he is experiencing not only in terms of loss of choice generally, but in particular an important loss is this loss of being able to do things for others.

p.13

A: Like with the stroke I had no idea. // ... The next thing I knew I was in Westmead Hospital. ... And after 50 years of work being very active to be told I'll never work again.

Q: Yes, because for you, you've had to take early retirement really, is that right? You weren't ... You were

A: Yes, I had retired. ... Yeah, we'd got out of the business. But I'd only just had a couple of months of retirement and then I had the stroke. // ... You see we had a business at Seven Hills and I had nine people working for us. And we downsized that. And I was just going to ... just continue on on my own doing little bits and pieces you know. **But that's all gone now.**

Husband:

He feels that he is a burden on his wife. He needs his wife to help his dress, and to drive him if he wants to go somewhere. He minds not being able to drive himself. When asked what was the most important thing he would like to be able to do at the beginning of the interview he said to be able to drive. He needs to be driven because he has a recent history of fitting. Also, with the changes brought about by the stroke, he does not know if he can drive.

p. 13

A: ... Only unless my wife takes me. **I never go anywhere on my own.** Because I had a ... I had a ... Oh, I had a set-back about 2 weeks ago where I started taking convulsions.

p. 3-4

A: Well, as the OT's used to say at Westmead, How do **you** wash your back? And I said well I couldn't do that when I had two hands, and I still can't do it. And, er, drying myself's the hardest part, like drying my back. Trying to get ... I throw the towel over my shoulder and try and lock it into this hand and work it this way. But drying, **I've got to get my wife to dry me.** All over the back. I can do all the front myself. And then, dressing, I find that I get into a hell of a muddle! ... I normally put my pants on

back to front. ... And my shirt on back the front. If I do it. Although I dressed myself this morning and I made it! ... But, yes **I do need assistance.**

P. 5

A: **I'd like to be able to drive again.**

Q: And why ... Why is that?

A: I ... Well, I feel as though I am ... I'm er ... I've lost my independence. Like ... And there's also ... **There are things that I want to do, that I've got to make my wife take me now. Or ask her to take me there to do them.** Just the things that ... like being ... being. Er, like before I had the stroke - I'd think of something, and I'd just jump in my truck, and away I'd go. And I'd do it. Now I can't. I've got to ask my wife to drive me there. And I feel ... **Sometimes I feel as though I'm such a burden on her.**

P.25-26

A: Well, the thing is, I don't know, whether ... If we stay in the area, it'd be Carlingford Bowling Club I'd be looking at. But, once again, **I've to get my wife to take me there, and my wife to come back and get me. ... Which restricts her.** You know? I know she'd do it quite happily, but ... Now, you take it on Monday when I go to Lottie Stewart ... when I go to Westmead. E's has got to drive me there, and I don't know how many hours I'll be there. But, and she'll come home, and she's got to come back and pick me up.

Q: So it comes back to this **driving** again doesn't it?

A: Well, being immobile, yes. ... **Now, I don't know whether I'll ever drive again. I'm not sure.**

He feels he is not keeping up his end of their jointly shared role of home maintainer;

p.5 -6

A: This is, you know, one thing that is frustrating, where we're ... We're selling the house because I can't look after it any more. ... **My wife can look after the inside but then I can't look after the outside.**

Q: Yeah. Your garden and everything?

A: Yeah, mowing of the lawns and things like that - vacuuming the pool.

(sound of wife's voice in the distance conversing with real estate agent)

Q: Yeah. Is that something that you took a lot of pride in before?

A: Yes we did, we tried. You know ... we did ... **We, er ... used to get quite a few compliments about, you know, the way the place looked.**

He feels his loss of independence is putting a strain on their relationship - not only because his wife needs to assist him more but because he can be difficult.

p. 9

A: I think you lose your independence, to a degree, you know. Like, my wife's very easy to get along with and she does everything to possibly help me. And ... But I've ... **I find sometimes I'm being ...a bit demanding.**

His motivation for working hard in rehabilitation is to restore the occupational aspects of his role of husband to their former status.

p.19

A: **Yes, I want to get back to the role that I had before as a full time husband and a full time father.**

Father:

He is currently relying on his son for garden maintenance.

p.6

Q: It's a beautiful house and a beautiful garden. Just looking from the front it looks wonderful.

A: (laughs) But, I find I can't do it. **Now I've got to ring up and rely on my son.**

p. 7-8

Yeah, well, you know ... **I've got to rely on my son coming over**, and he ... by the time he finishes his own lawns and then comes here, he's ... You know - OK Dad, I'll do it tomorrow. ... Sometimes tomorrow never comes. ... And then it becomes a big deal by the time he does get here and he spends a lot more time here than he should. ... And he ... It's getting harder and harder, because he's very tangled up with his job.

They are a close family, with a son and two daughters. None now live at home permanently, although the youngest one still stays there at times. Son visits every day. As a father, he spends time taking care of the financial welfare of his children, while they go to his wife to sort out emotional and social problems.

p. 11-13

A: Well, er ... I've got one daughter that lives at Cronulla, we don't see much of her. And our youngest one still lives here occasionally - she's at Uni. Our son lives at Epping and we see him every tea time because he's here. He comes over for ... He likes mother's cooking.

Q: So, fairly close relations with all of them.

A: **Yes. We're a very close family.**

Q: So that's another role that would be important to you is that right?

A: Yes very much.

Q: Being a father?

A: Yes.

Q: And how do you see that? How ... How ... What's ... I mean, it might sound like a silly question, but what's the nature of your role as a father? Do you ... Are you the sort of father who um ... they come and tell their troubles to? Or are you the sort of father that stays in the background and helps in more subtle ways or..

A: Yes, I think that'd be right, helps them. ... Especially financially. ... But no, they all go to their mother with their problems and then in turn she tells me. And between the two of us we try and help them. ... I've got daughters that are spendthrifts. And, er ... They get themselves into trouble occasionally and we've been able to get them out of trouble. But since this has happened, I've told them that ... the gravy train's stopped because we haven't got the money to do it! ... But no, we're a close family and we're very fortunate. They're very caring children, and they're very good to me. They're very good to their mother. ... But our eldest daughter, we don't see her much because she's a flight attendant with Ansett. ... She flies a lot. And she lives at Cronulla. And then the youngest one, well she's at Kuringai College and Macquarie University. And we see her quite a bit. And our son, he lives at Epping and as I say, we see him nearly every day of the week. Which is good.

He feels that having the stroke has drawn the family closer together, so that his role as a father has not changed, except perhaps to intensify.

- Q: So that's another relationship which has changed a bit? Would you say? Another role which has changed a bit?
- A: No, not, not so ... No it hasn't changed so much, only ... **I think it's brought us closer together, really.**
- Q: So, do you feel comfortable and satisfied with the way that role's going?
- A: Yes.

He wants to restore the occupational aspects of father to their former status. This is why he is so keen to work hard in rehabilitation.

p.19

- A: **Yes, I want to get back to the role that I had before as a full time husband and a full time father.** As the kids would say, well, you know, you're bloody hard enough to put up with now. (laugh) You're just the same as you were before! ... But, no, I find I was very strict with the children. My wife will back me up on that. I think it's paid off because they're all pretty normal. They're all working. And er, all got good ... Well M.'s at Uni. - she's going to be a primary school teacher. The boy's doing very well with Telstra, and J. is a flight attendant with Ansett. So they're all up and going, the lot of them, which we're very proud of.
- Q: Yes, that's terrific isn't it?
- A: **Well, it is, it's a fulfilling role.** And it's also fulfilling when your daughter comes home and says "Dad, you'll never guess what happened last night, we were all at the ... We were all having a get together at the Epping Hotel. You hear all the boys and girls saying well I'm going to see Mum today, or Dad, or spend so much time with one or the other". Well, she says "It just feels great that I know that I'm coming home and we'll all be together on Christmas Day".
- Q: Yeah. A proper family?
- A: Yes.

Surf Club Member:

He has been a keen surf club member all his life, but is no longer as active as he used to be. He still helps to organise and annual fund-raising swim, however.

- Q: Have you got any special interests or hobbies?
- A: Surf club.
- Q: And which surf club's that?
- A: Whale Beach. ... Fifty years this year.
- Q: Fifty years! Wow! That 's amazing! So you joined as a kid?
- A: I was a lot younger! (laughs) Well, I'm sixty-seven now, so, you can take fifty away from that. So I've been there a long time!
- Q: And a regular member all that time?
- A: Yes.
- Q: And an active ... I mean, were you a life-saver over there?
- A: Yes, I did. I did patrols for fourteen years, and then, after that I got onto the committee. Running things, you know. Like right now, I'm very involved in the ... our marathon swim next weekend - the weekend after next. When we have a swim from Palm Beach down the coast to Whale Beach.
- Q: Mm. I saw that, there's an article in the paper this morning about that.
- A: Is there?
- Q: I think so with Suzie Maroney, is it Maroney? The long distance swimmer? Is that right?

- A: Yes, I haven't seen today's paper, but er ... Yes, they do advertise it but er ... I'm on the er ... I help run it and I get a lot of mates, each surf club - guys and things like that, through our club that come down and volunteer to help. Because when we get something like a thousand to twelve hundred, fifteen hundred swimmers. Takes a lot of organising. ... And it's a very popular event. **I'd like to be more involved with the surf club now but my wife doesn't like the sand.** So she doesn't like the beach that much. And, er, **I've got no way of getting there unless she takes me there.**
- Q: Yeah. There's not another club member who could pick you up?
- A: No, not from around here, no.
- Q: So, er ... how often do you get to the club these days?
- A: Oh, once or twice a year now, that's all. ... Annual general meeting, and, er ... the marathon swim.
- Q: Right. So it's another role which has declined?
- A: Yeah, very much so.

He no longer attends the surf club regularly, but is still active in the club and maintains the friendships formed over the years there. The older surf club members use him to find out what is going on with the club, so he is quite active on the telephone. He also organises volunteers for the swim this way. He maintains a social tradition of gathering once a year at someone's house to watch the football grand final. Now people from this group are starting to die or acquire illnesses and disabilities like himself. He sees himself as an organiser. His enthusiasm for the club is so great that in the past, for thirteen years when he was living in Canberra, he maintained his share of patrols by driving to Sydney for the weekend and doing two patrols together.

p.28-30

- Q: So, to get to the surf club member, you were saying earlier that you only go twice a year now.
- A: Around about that yes.
- Q: Yeah. But that you also have a lot of friends from the surf club. And you'd see them more often?
- A: Yep.
- Q: And do you sort of keep up with the surf club activities through them? Do you talk to them about it?
- A: Well, no, **I think I am the focal point for them.** ... To keep up. They all contact me and find out what's going on. I got a phone call last night. Somebody wanting to know, can they wear a wetsuit in the race. ... I could answer that question for them.
- Q: So you know a lot about the rules and regulations and those sort of things?
- A: Well, Not a ..., not a ... Well, I wouldn't say I know a lot about them, but I do know a few things. But my main role is, with the marathon swim, is being able to supply volunteers.
- Q: I see, so you've got all the contacts, and you ...
- A: Yes, and I keep the old surf club guys going. My wife says only for me. we would drift apart. Like, one thing I do every year ... and there's - might be ten of us, or more. That we get together to watch the grand final of the football. Now, one year it'll be your turn. We'll all go to your house. ... And we'll go to my house, and come here, you know. And next year we'll go ... And unless I keep that momentum going it'll drop off. **But I make sure I keep it going, because it keeps us all together.** ... And ... Like the guy we were suppose to be going to this year, **unfortunately we buried him a couple of months ago.** So we won't be going there.
- Q: But you're a real ... Sounds like you're a real driving force there.
- A: Yeah, **I'm an organiser.** (laughs)

- Q: So, That's really ... important. That's a very active thing that you do.
- A: Yeah, I'd like to be much more active in that if I could. But I haven't been able to. I'll tell you how keen I was. When we lived in Canberra I used to come up on weekends to do patrols, from Canberra. ... Come all the way from Canberra. And, my wife and I would stay with her parents at Epping and then on Saturday afternoon I'd go down to the club and do a Saturday afternoon patrol, and then back up Sunday morning and do it again. Then we'd drive back to Canberra. Being able to do those two patrols meant I didn't have to come up as regularly but I could swap with somebody and do their patrol on a Sunday morning and then they'd do my patrol, when it was my turn in a month's - in a couple of week's time or something. ... So that's how keen I was with that and I've maintained that all through my life.
- Q: But you're still active on the phone aren't you?
- A: Yes.
- Q: From the sound of it. How often would you talk to people about surf club matters do you think?
- A: Oh, I'd say at least once a fortnight.
- Q: Right, yeah. So you really do know a lot about what's going on still don't you?
- A: Yeah.
- Q: And, you really are ... Are you actually still on the committee?
- A: I wouldn't actually say ... not actually on the committee. But, I'm actually er ... I'm on the er ... Yes, I suppose I could say I'm on the committee. ... But my main role is supplying volunteers. Like, you know, G. who runs ... well he's the head of the Committee ... he'll ring me up and say 'F. how many have you got this year'? And I'll say well, I got six, eight or ten, you know.
- Q: And you get them by ringing round and asking ...?
- A: Yeah, I just ring around and say "what are you doing Australia Day?" You know? Course, now, as the families grow up they've got other things to do, you know? But I've managed to keep ... Well, we got ... there's six of us going down the weekend after next. Normally I would have anything up to ten or twelve. But now other people have got other things. Like, one of our friends will be in New Zealand, on holidays. The other guy will be up at Foster, at his weekender. Some of them aren't as keen as I am, you know. I know they must think sometimes I'm a pain in the butt because I'm tying them up for the weekend to go down and do this. Because it's all voluntary.
- Q: They probably enjoy it when they get there. (laughs)
- A: Well, have the odd sip of Bonnington's Irish Moss and let our wives drive home. (laughs)
- Q: Yeah. Sounds good fun.
- A: Oh, it is. Because, you know, **I found that has been a big part of my life, the surf club. And the friends I've made in it I've maintained over the years.** Very much so.
- Q: Mm. Mm. So it really is a very important thing.
- A: Yes.
- Q: And it's something which has gone on right through your life. Is that right?
- A: Yes, from when I just came out of my apprenticeship, yes.

Home Maintainer:

Although this role was sorted as being of lowest priority by Mr. Twenty-three, he is unable to let it slide. Garden maintenance in particular is something he and/or his wife, and /or those around them appear to find must be done. By setting a high standard in the past, it seems this

standard must be maintained - to the point where they are going to move house because garden maintenance is causing so many problems. He feels unable to pull his weight in this role now, which he shares with his wife. Now he feels that what he used to do is thrown upon his son and friends.

p.5 -8

A: This is, you know, one thing that is frustrating, where we're ... We're selling the house because I can't look after it any more. ... **My wife can look after the inside but then I can't look after the outside.**

Q: Yeah. Your garden and everything?

A: Yeah, mowing of the lawns and things like that - vacuuming the pool.

(sound of wife's voice in the distance conversing with real estate agent)

Q: Yeah. Is that something that you took a lot of pride in before?

A: Yes we did, we tried. You know ... we did ... **We, er ... used to get quite a few compliments about, you know, the way the place looked.** ... And especially the way my wife kept it inside here. ... In fact, that's one of the bigger ... big factors of the ... reason that these people are having a building inspection now because we've got people pretty interested in selling.

Q: It's a beautiful house and a beautiful garden. Just looking from the front it looks wonderful.

A: (laughs) But, I find I can't do it. **Now I've got to ring up and rely on my son.**

p. 7-8

Yeah, well, you know ... **I've got to rely on my son coming over**, and he ... by the time he finishes his own lawns and then comes here, he's ... You know - OK Dad, I'll do it tomorrow. ... Sometimes tomorrow never comes. ... And then it becomes a big deal by the time he does get here and he spends a lot more time here than he should. ... And he ... It's getting harder and harder, because he's very tangled up with his job. As I said, people say to you, well, why don't you get somebody to come in to do it? You know. Well, when you have say \$25 to \$30 each time and maybe in the summer time it's once a fortnight, it takes a hell of a slice out of your living expenses. ... Plus the fact that **I used to like to do it myself. I had it the way I wanted to do it.** ... And I've tried to do it now and **I've had to ... get a different mower** because I can't ... The Victa I've got to pull the rope back, and as soon as I do that I fall over. Whereas the ... I've got a four stroke now, I can pull it straight up. I'm ... but I ... still find it difficult, er, putting the catcher on and off because you've got to lift it up with this hand and try and get the catcher in. These are the things that I find very frustrating.

Q: So you're ... It sounds like you really have to change the way ... your whole life.

A: Yes, yes you do. Yeah.

Q: And you've changed the way you're going to be living. You're going to move to a ... Well, what sort of place are you going to move to?

A: Smaller. ... Smaller house, and less grounds. We're just going to downsize, that's all.

Q: Yeah. Will you miss the grounds do you think?

A: No, I think I can adjust to that (laughs). We'll miss the pool, because the wife and I use that ... like once the children ... We put it in because we had young children and they used it all through their adolescence and then, er, now Mum and I use it a lot. We'll miss that, but I can live with that. ... **And it's just to ... try and make life a little bit easier.**

Q: So, so ... Maintaining the garden was a chore for you before? Or ...

A: No.

Q: No - it was a pleasure.

A: Not so ... Well, I wouldn't say it was a real pleasure, but it wasn't that ... I didn't find it difficult. I could ... you know, I could come home from work and then ... if it had been a hot day, because I was in the building trade, I could still ... like finish work and come home and then do the grounds and then dive into the pool and have a swim. ... And ... I didn't find it laborious but I wouldn't say I was overjoyed by it, but ...

He saw gardening as a chore, but something that must be done.

P. 26

A: When I was in business I would think to myself, you know, I've got to do this now. When I was in business it was a chore. Now that I have this time, I find it's frustrating, because I feel I should be doing something else, but because of this I can't do it. ... As I said, my wife's always said to me 'you were never a gardener'. You'd keep the lawns tidy, and turn the garden over. She's the gardener not me. ... I'd turn the thing - the ground... the ground over.

SELF MAINTENANCE

Only one role sorted under this heading. He commented:

I find that one of the hardest things.

Person With a Disability:

He needs his wife to help his dress and to drive him. He gets very frustrated with his loss of independence.

p. 3-4

A: Well, as the OT's used to say at Westmead, How do **you** wash your back? And I said well I couldn't do that when I had two hands, and I still can't do it. And, er, drying myself's the hardest part, like drying my back. Trying to get ... I throw the towel over my shoulder and try and lock it into this hand and work it this way. But drying, I've got to get my wife to dry me. All over the back. I can do all the front myself. And then, dressing, I find that I get into a hell of a muddle! ... I normally put my pants on back to front. ... And my shirt on back the front. If I do it. Although I dressed myself this morning and I made it! ... But, yes I do need assistance.

He finds his loss of independence very frustrating - particularly not being able to drive.

A: Very limited. I try to help when my wife washes up, I try to wipe up and I can't hold anything in this left hand because I've got no strength in it. But I, I do try, but not very successful. I find life at the present moment very frustrating.

Q: Yeah. What's the most ... the most important thing that you would like to be able to do that you are having trouble with?

A: Ah. (pause) I'd like to be able to drive again.

Q: Ah ha. And why ... Why is that?

A: I ... Well, I feel as though I am ... I'm er ... **I've lost my independence.** Like ... And there's also ... There are things that I want to do, that I've got to make my wife take me now. Or ask her to take me there to do them. Just the things that ... like being ... being. Er, like before I had the stroke - I'd think of something, and I'd just jump in my truck, and away I'd go. And I'd do it. Now I can't. I've got to ask my wife to drive me there. And I feel ... **Sometimes I feel as though I'm such a burden on her.**

He feels there have been severe consequences of his stroke.

p.5 -8

- A: This is, you know, one thing that is frustrating, where we're ... We're selling the house because I can't look after it any more. ... **My wife can look after the inside but then I can't look after the outside.**
- Q: Yeah. Your garden and everything?
- A: Yeah, mowing of the lawns and things like that - vacuuming the pool.
(sound of wife's voice in the distance conversing with real estate agent)
- Q: Yeah. Is that something that you took a lot of pride in before?
- A: Yes we did, we tried. You know ... we did ... **We, er ... used to get quite a few compliments about, you know, the way the place looked.** ... And especially the way my wife kept it inside here. ... In fact, that's one of the bigger ... big factors of the ... reason that these people are having a building inspection now because we've got people pretty interested in selling.
- Q: It's a beautiful house and a beautiful garden. Just looking from the front it looks wonderful.
- A: (laughs) But, I find I can't do it. **Now I've got to ring up and rely on my son.** Like, people say to me get your ... get your lawns mowed, you know. Well, **when you've got no income** ... it takes a hell of a lot out of the ... You know, my wife and I are on the pension now. And ... when I went into business I was too old to start superannuation, so we got none of that. I had every insurance company in Sydney trying to sell me insurance on super. Then they'd ask you the pertinent question, how old are you? I'd say I am forty-eight. Oh, we'll call back and see you. Well, they've never come back. ... And, er ... trying to live on nothing's pretty ... at the present moment we're finding it very different. Before that we had a pretty affluent lifestyle. ... Because of our business, you know, gave us a good lifestyle ... But er, ...
- Q: There's not enough left now.
- A: Yeah.
- Q: I mean that's ... yeah. Oh, that ... that must be very frustrating too.
- A: Yeah, well, you know ... **I've got to rely on my son coming over**, and he ... by the time he finishes his own lawns and then comes here, he's ... You know - OK Dad, I'll do it tomorrow. ... Sometimes tomorrow never comes. ... And then it becomes a big deal by the time he does get here and he spends a lot more time here than he should. ... And he ... It's getting harder and harder, because he's very tangled up with his job. As I said, people say to you, well, why don't you get somebody to come in to do it? You know. Well, when you have say \$25 to \$30 each time and maybe in the summer time it's once a fortnight, it takes a hell of a slice out of your living expenses. ... Plus the fact that **I used to like to do it myself. I had it the way I wanted to do it.** ... And I've tried to do it now and **I've had to ... get a different mower** because I can't ... The Victa I've got to pull the rope back, and as soon as I do that I fall over. Whereas the ... I've got a four stroke now, I can pull it straight up. I'm ... but I ... still find it difficult, er, putting the catcher on and off because you've got to lift it up with this hand and try and get the catcher in. These are the things that I find very frustrating.
- Q: So you're ... It sounds like you really have to change the way ... your whole life.
- A: Yes, yes you do. Yeah.
- Q: And you've changed the way you're going to be living. You're going to move to a ... Well, what sort of place are you going to move to?
- A: Smaller. ... Smaller house, and less grounds. We're just going to downsize, that's all.
- Q: Yeah. Will you miss the grounds do you think?
- A: No, I think I can adjust to that (laughs). We'll miss the pool, because the wife and I use that ... like once the children ... We put it in because we had young children and they used it all through their adolescence and then, er, now Mum and I use it a lot.

We'll miss that, but I can live with that. ... And **it's just to ... try and make life a little bit easier.**

Q: So, so ... Maintaining the garden was a chore for you before? Or ...

A: No.

Q: No - it was a pleasure.

A: Not so ... Well, I wouldn't say it was a real pleasure, but it wasn't that ... I didn't find it difficult. I could ... you know, I could come home from work and then ... if it had been a hot day, because I was in the building trade, I could still ... like finish work and come home and then do the grounds and then dive into the pool and have a swim. ... And ... I didn't find it laborious but I wouldn't say I was overjoyed by it, but ...

It has affected his friendships too (see more under Friend)

p.10

A: Well, it is when you ... you know, it's satisfying to have R. come around and pick me up and things like that. But, you know, he's got a bit of a demanding wife and she gets a bit cranky because instead of being home at six we might get home at six-thirty, or something like that, you know. ... And ... I feel sometimes I'm getting him into trouble at home, with his domestic life. Whereas years ago, he'd head off one way - he's got to pass his house to bring me home and then go back. Now, years ago, he'd just go straight home and I'd come straight home. ... Well ... I feel sometimes I could be causing trouble in his family.

He is experiencing some frightening symptoms in the aftermath of the stroke. Could be sapping his self confidence.

P. 13

A: Only unless my wife takes me. I never go anywhere on my own. ... Because I had a ... I had a ... Oh, I had a set-back about 2 weeks ago where I started taking convulsions. ... And er ... So I was on no medication, no nothing. And we were driving along out at Seven Hills, and all of a sudden I started this business in the car. Taking a convulsion. Fortunately, I was strapped in pretty tight with my seat belt and we were just outside the Seven Hills Police Station where my wife got two constables and they came out and pulled me through it. By the time the ambulance came and they took me back to Westmead ... er, they were very good to us. ... But **I don't go anywhere on my own unless ... No, I don't even venture down the street on my own.** If I do, I always let the wife know where I am and what I'm doing.

Q: It must have been rather frightening. That ... That convulsion.

A: Oh, it was! **Frightened the daylight out of the pair of us.** Especially when I had no idea what was wrong. All of a sudden I had these dreadful pains down my left arm and then I started vibrating violently. I had no idea. It'd never happened to me before. Like with the stroke I had no idea, I just got out of bed, walked down to my daughter's bedroom, says come on it's time to go to work. Walked back to bed and that was the end of me. I just sat down on the edge of the bed. The next thing I knew I was in Westmead Hospital. ... And **after 50 years of work being very active to be told I'll never work again.**

Q: Yes, because for you, you've had to take early retirement really, is that right? You weren't ... You were

A: Yes, I had retired. ... Yeah, we'd got out of the business. But I'd only just had a couple of months of retirement and then I had the stroke.

p. 17-22 for this whole section:

Dealing with his stroke is taking more and more of his time.

p.17

Q: So, we were talking about dealing with the stroke. And so, as far as time goes, are you finding you spend more time, now, doing this than ... As time goes on, are you spending more time dealing with the stroke or less time?

A: No, more.

Q: It is getting more time consuming?

A: Yes.

Q: Is that right? Why is that do you think?

A: Well ... I feel as though I want to do a lot more exercises. **I'm in a hurry.** That's the only way I can phrase it. **I'm in a hurry to get back to where I was before I had the stroke.** ...

He has had some discouragement in pursuing rehab. from health professionals

p.17

And, I've had a couple of negatives in people who I have dealt with. Like one was when I first went to Lottie Stewart, one of the physios. said to me "Oh, you are walking OK. I don't think you'll get any better with that". And then I had another one say "well, I don't think you will ever get your arm back". And **I found that very very negative from professionals.** ...

His aim is to restore function back to pre-stroke levels. He is prepared to do whatever it takes to achieve this.

p.17

Because as far as I'm concerned, I'm prepared to work ... as hard as I can. **As hard as they'll work me I'll work to get it back.** So if it means spending ... I would spend hours down at the end of the pool sitting on one of the chairs. I rigged up a ... an exer ... like a piece of rope where I'd have a bit of sponge rubber in there, and I'd sit there for hours going backwards and forwards trying to get the shoulder to work and then shift and get out and back. So I'd spend hours on that. ... Hours and hours. And then I'd spend hours ... I'd come in from that and I'd spend time on the exercise bike. And ... so yes, I'm spending a lot of time with this stroke. But, **I'm quite happy to spend as much time as it needs to get better.**

Q: And you felt that that wasn't being acknowledged by one or two people, is that what you are saying?

He is not prepared to be put off pursuing his goal of full rehabilitation.

P.17

A: Well, it was when I got these two negatives replies I came home and thought 'no, **I am not going to let that beat me,** I'm not going to sit down and let that ...'

He does not see that Lottie Stewart is able to offer him what he needs to meet his goal, and is delighted that Westmead are taking him back there as an outpatient.

p.17 -18

This is one thing that frustrates me down at Lottie Stewart. Some of the people that I'm in the group with have been going there fifteen years, some thirteen years. **Fifteen years, and they've made no progress whatever.** They're just prepared to go there. **It's like a social club. And that's not for me.**

Q: You want to actually get on with ...

- A: Well, **I want to get on with it**, that's why when Westmead rang this morning, I start back there next Monday. And I'm really looking forward to that.
- Q: So did you, er ... instigate that? How is that come about?
- A: No. One of the OT's at Westmead, C. We've become quite ... Even though she was working with me, we've become quite friendly with her. And she realised just how keen I was just to get on and do the exercises and she's spoken to me about Lottie Stewart and I told her about my disappointment that I can't get into the group to have the exercises done.

He has tried to get help himself, by going to the gym and persuading a Physio to give up her lunch hour to treat him, and by going to a private Physio.

p.18

The only girl that would ... that would try and help me there - she would do it in her lunch hour because they're so busy. And this business going down there just to sandpaper timber everyday was just not my scene. And I told C. that. I said I'd like to get on with ... I went to a private physiotherapist who had a heated swimming pool and I'd get in there and do the exercises in the heated pool. So I think they realise just how keen I am, and they've tried to help me along the way too. So, that is why C.'s been in touch with me and said I'm going to try and organise this for you to come back to Westmead. I mean, Lottie Stewart's very good, but you don't get the professional help. ... Because they are so busy with the other. I'd wander across from the carpenter's workshop to the physio, where they ... to the big area there, and I felt as though I was an outsider because I couldn't get somebody to work with me. And the only girl that would help me gave up her lunch hour and I felt ... well now, that's not right for her to have to do that!

Q: Yes, not a good situation.

A: No. And I felt that I'm not ... going to saddle up with another two or three years down at Lottie Stewart. Just going there and sandpapering timber. ...

Lottie Stewart has aroused his interest in bowls, however.

p.18

Even though I enjoy the Fridays, which is the bowls.

He was going two half days a week to Lottie Stewart and will be doing the same at Westmead.

p.18-19 (cut)

He found there was benefit for his wife in getting him out of the house so that she could have some time to herself.

p.19

We had a lunch ... we had lunch down there. ... But even though I wasn't finding it very helpful, it was good for E. because it got me out of the house and she could get on with what she had to do. Plus the fact she could jump in the car and go and do something. ... Without having to worry about me.

He wants recognition from his therapists that he will work hard, and for them to put in an extra effort on his behalf.

Q: Yes. But from your point of view, it wasn't a social outing for you, you wanted...

A: No.

Q: And so it wasn't very satisfactory.

A: Well, when I was in Westmead I was very fortunate that I had a physio. there called M. who realised how keen I was, and he gave me a program to work to. And, you know, I'd work to it. And he would say "well, let's finish" I would say "no, we'll do

it again". **And he realised how keen I was and as hard as I'd work, he'd work me.**
And that is the way I feel about it.

The reason he wants to work so hard is to stop being a burden to his wife, and to restore his dignity and self esteem. He wishes to restore the occupational aspect of his husband and father roles to their former levels.

p.19

I feel as though I'm a liability to my wife and I don't like being like that. I've never been that way in my life ... and I ... You know, I can't put my shirt on, as I say. I put the damn thing on inside out or back-to-front. I've got to wonder down here, and E'll be doing something and then she's got to stop. And I feel so ... well, I've never been that way, since I was a child, you know. **And now here I am, I'm back virtually a child again.**

Q: So you want to work on that.

A: **Yes, I want to get back to the role that I had before as a full time husband and a full time father.** As the kids would say, well, you know, you're bloody hard enough to put up with now. (laugh) You're just the same as you were before!

He is able to recognise progress in his rehabilitation efforts and take satisfaction from that.

p.20

Q: Now, when you are able to do things... er, positive things, in terms of dealing with the stroke. Like with this Westmead thing, how does that make you feel?

A: Good. ... Yeah, very good.

Q: Yeah, so you start ... you think "great we're getting somewhere".

A: We're getting somewhere. Yes.

Q: And when you're actually doing the therapy, do you find that ... Are you satisfied with how you go with that?

A: Yes.

He is also able to feel philosophical about things he is not achieving at present.

p.20

Q: So even when you can't do the things that they're asking you to do, you ... How do you feel about that?

A: Oh, the only thing I can say is "I tried and I can't do it" you know. And maybe I'll be able to do it in a week or so's time. Long as I keep at it.

Q: Right, so you've got a positive attitude about that.

A: Yes. I don't want to be like this for another two or three years.

*He finds it very hard to deal with the frustration he experiences, but finds that his roles as a husband and a father give him support and stop him from despairing. **NB look at this section further.***

p.20-21

Q: Um ... What about the other side of dealing with this, dealing with the stroke. Like at home - the frustrations that you've been talking about. How do you deal with those?

A: **Very difficult. I know there was a couple of times. This may sound rather extreme, but I have seriously considered suicide.**

Q: Have you?

A: Yep.

I haven't told anybody. But I have seriously considered it. But then I think of this and this (points to stickers with 'husband' and 'father' on them). ... And put it out of

my mind. I get that cranky with myself. I think to myself what do I have to look forward to. ((gets a bit teary)

Q: So you do get very down.

A: Yes, very.

Especially when I had this set-back the other day. I think to myself, you know, "here I go again".

Q: But this is what keeps you going? (points to stickers)

A: Yep.

Q: Being a husband and a father?

A: And a father, yeah. And a home life and everything, you know.

Q: So, do you think ... if you can work on things that will change, do you feel like ... ?

Being able to compare himself to others that he sees who have had a stroke help him to realise that things could be worse, and that he is making progress, but he still finds it very difficult.

p.21

A: Yes, if I can see ... I mean they keep telling me how well I've done. And I think to myself, well, when I look at other people that've had strokes I realise how well I've done. But, er, I still get very frustrated.

Q: So, when something goes wrong, when you try to do something, and it goes wrong, that really ... you find that very upsetting.

(sound of doorbell)

A: Very upsetting, yeah.

Q: What about when things go right? Do you give yourself credit for that?

A: Oh, well I feel good. Put it that way, I feel very good.

Q: Yeah. So, you actually do think: "Oh! I did it!"

A: "I did it" yes.

(sound of wife talking to real estate agent)

Q: Even though it wasn't ... You didn't manage to do it quite the way you might have done before?

A: No. **Even though it was a mundane chore I still feel good I managed to do it.**

He sees no benefit to having had to take on this role.

p.22

Q: Is there anything that makes you glad that you have this role? (points to dealing with a stroke)

A: No. Nothing. No.

Q: So this role is a total negative for you?

A: Yeah. **It's the big negative in my life.**

Q: Yeah. Even though you say it brought you closer to your May have brought you closer to your ...

A: Yeah. Well, we've always been close but, er, it has ... has been wonderful. But no, I could do without that in my life. I sure could.

LEISURE

General Comment:

He feels unable to enjoy leisure time or to see it as something positive in its own right. He seems to see it mainly as time wasted. At the end of the interview we discussed this further:

P. 41

Q: This productivity business and, um ... you are so, um ... At times, so disappointed with this, that you have difficulty enjoying the ... Like, this is interesting, I think, that

you can't allow yourself to enjoy your leisure things so much because you're still feeling frustrated with the productivity things, would that be right?

A: Yes. See, I've never been one that's had a lot of time, that I could, you know ... As I said, working. I never had time, the only thing I ever wanted to do was in this (indicates surf club on board). I never wanted to be a bowler or a golfer because I never really had the time for it, whereas I would make time for this.

Q: For the surf club, yeah.

A: Because I found it very satisfying.

Q: Yes. So that was the one big thing that you had outside work.

A: Yes. And since, you know, as I said, my wife's not that keen on the beach, she doesn't like the sand. And she's a big girl. She won't get in a costume, whereas she will at home here. She'll get in the pool. And I don't care what I look like when I am on the beach. (laughs) I just enjoy it so much. Plus I enjoyed the camaraderie with the guys in the club.

Q: Yeah. Yes. Well, it sounds like you still do a bit.

A: Yeah I still do my bit.

Bowler:

His stroke rehabilitation has generated a possible new role for him. He always thought it was for old people, (implication being that it would be therefore not be worthwhile or too easy or of no value?) but having tried it he has found there is more to it than he thought and he intends to pursue it, as he feels he might be good at.

p.?

Q: Anything else? Any other interests?

A: Ah no. 'Cause I ... 'cause being self employed, I never really had time. It's only since I have been like this, and Lottie Stewart takes us to Denistone Bowling Club, that I've started playing bowls. ... But I only do that on a Friday with the group from Lottie Stewart. But I've enjoyed it so much I might take it up. I always thought that bowls is for old people, you know. And at sixty-seven I'm not old. (laughs)

p.24

Q: Leisure ... and, what have we got under here? Being a bowler. Let's talk a bit about being a bowler, because that's just a small role at the moment isn't it?

A: Yes. [*] yes.

Q: That may become a bigger one do you think?

A: Oh, I think in years to come it could come, yes.

Q: Yeah. And what is it about bowling that attracts you?

A: I don't know, because when they first suggested it down there I thought, as I said. I would never go to bowls. Even a couple of mates from surf club that have been there in the club nearly as long as I have say, you know, "why don't you come up to Carlingford Bowling club. We play bowls up there". And I think, oh ... I'd rather play golf. That's more exercise, than standing there throwing a ball down the ... down the road, you know. ... And now ... I've thought of it, as I said, no, **that's only for old people**. But now I find that now that, I am doing it, it is very skilful. ... It's like golf. You can never get the ball in the same spot twice. You'd have one good shot, then the next one'd go into the trees. And I find that with bowls, you only have one good shot and then you try and do it again with the next one, and it goes somewhere else. (laughs)

Q: So, it offers you a challenge?

A: Yes.

Q: Would that be it?

A: Yes.

- Q: It's a challenging thing. It's something that you feel that you could get good at?
- A: Yes.
- Q: Is it?
- A: Yes, I think so. Well they tell me I'm ... you know. Even all the volunteers from the bowling club that help us, keep saying to me "you've played this before". And I say "no I've never played it before". **So it gives me an incentive to ... That I think that I could become good at it.**
- Q: Yeah. And where do you think you would play?
- (sound of telephone ringing)
- A: Is there a local bowling club? Oh, it depends where you move to I suppose, doesn't it?
- A: Well, the thing is, I don't know, whether ... If we stay in the area, it 'd be Carlingford Bowling Club I'd be looking at. But, once again, I've to get my wife to take me there, and my wife to come back and get me. ... Which restricts her. You know? I know she'd do it quite happily, but ... Now, you take it on Monday when I go to Lottie Stewart ... when I go to Westmead. E's has got to drive me there, and I don't know how many hours I'll be there. But, and she'll come home, and she's got to come back and pick me up.
- Q: So it comes back to this driving again doesn't it?
- A: Well, being immobile, yes. ... Now, I don't know whether I'll ever drive again. I'm not sure.

Leisure:

It was decided to call the things that Mr. Twenty-three did for and enjoyment his leisure role, as opposed to bowls, which was a more specific leisure role. In the past, Mr. Twenty-three did not have much time for leisure because he was so occupied with all his productivity activities. He is now experiencing enforced idleness. Finds it difficult to read.

P. 16

- Q: So now you've got a lot more time than you used to have.
- A: Yes.
- Q: Is that a problem? Do you find that time hangs ...
- A: Yes, I do find it a problem 'cause I can't read a lot because the stroke's affected both eyes. And I find if I read ... take like the newspaper, I've got to have a magnifying glass, because the lines all go into ... They inter-blend with each other, and I've got to ... keep coming back and starting again. ... And my eyesight hasn't deteriorated because I've had new glasses made...

In addition to that, he always believed that leisure should be earned. It seems that he spent all his time earning it without ever cashing in his earnings! Now he feels uncomfortable about sitting in the sun or doing something purely for pleasure because it goes against a lifetime of purposeful, productive activity.

p. 26-28

- Q: Now, these leisure things - sitting in the sun. Watching television. Watching the weeds grow! ... It's not very leisurely! But you were saying earlier that you found that when you were doing things like that you had this little voice saying "you should be doing something else". *(this refers to the section of interview not taped)*
- A: Yeah.
- Q: "You shouldn't be relaxing like this".
- A: Well, **I shouldn't be wasting time.** That's the way I put it.
- Q: Wasting time.

- A: Wasting time, yeah.
- Q: Has that always been ... Have you always been like that? About leisure things? //
- Before, did you feel like you had earned your leisure before?
- A: Yes. Yes.
- Q: Is that what it is?
- A: Yes.
- Q: And now perhaps...
- A: **Well, of course, before, we never had time for leisure.** ... I was always busy. Even on the weekends, you know, I'd get call-outs. ... Because I used to look after quite a few nursing homes and there's always something going wrong there, you know, and, I'd get called out. And some ... a lot of the factories that I looked after ... Fork lift drivers were my best friends because they'd always run into something such as the fire hydrant or something like that you know. ... I used to call them cowboys, but I earned a lot of money out of those people. ... And that was mainly on ... you know, it happened of a night time or on weekends. **And then you would look forward to your leisure time.** That's when I would look forward to this. (points to board)
- Q: Yes, the surf club.
- A: But then, I don't get down there at all now. Hardly ever.
- Q: Yeah. And, do you feel like you're entitled to leisure now?
- A: No.
- Q: You don't?
- A: No. **I feel you've got to earn your leisure.** ... I know I should take each day as it comes, and just let the day roll by and if it means I've got nothing to do - as they told me at Westmead - well, just do nothing! But I feel as though there ... I can look around and I can see things that I should be doing. Such as there's something under the house I want to get. Where I've stored it under there, and I wanted my son to get it for me last night. But by the time he finished dinner, he wanted to go home. That frustrates me that I can't climb up under the house. It's only to get a little tin box out, but it's got my bronze medallion in it which will tell me whether I've got forty-nine years up or fifty years. And I'll get my fifty years certificate, if it's what I think it is. And it's those sort of things. ... **So I sit down and think to myself, "no, I should be doing that. I should be getting under there to do that".**

SOCIO-CULTURAL

Being a Mate:

He misses being able to go to pub or club and have a yarn. This is important to him and seems a focus for his regret at his loss of independence, along with being more of a burden on his wife. He made a distinction between mates and friends (see friend role).

p.8-9

- Q: So, what ... what other things are important to you?
- A: Er ... I think **just being able to go out by myself**, or go with one of the mates at ... Go, go up to the club for a drink. You know, just go up there for an hour, or something like that.
- Q: Yeah, yeah. That ability to just take off, and do what you want.
- A: Yes, just ... Well, see what I used to be able to do ... Like finish working - like being self employed - I could ... I didn't have to sign on or sign off or anything ... I could duck into the club and have a beer on the way home. After this now I ... you know, come straight home or ... you know, **I'm here all the time** and ... I've got a mate that

comes around and picks me up on a Thursday afternoon and takes me up to the club for an hour, and I thoroughly enjoy that because we ... **We have a lot of fun together** and make a slight investment on the poker machines, very slight. ... And, er ... **It's being able to ... To mix with other men** too. You know? ... **Being with your wife all the time** ... I'm sure she's pleased to see the back end of me too. And er ... It's being able to mix with other fellahs and talk. ... You know, some of the factories I'd have done the maintenance on I'd had a really good rapport with the engineers, and some of them come to the club of an afternoon. We ... This one particular afternoon, and **it's good to sit there and chat with them and talk about things. ... About football, and things like that. You know. Things that I'm very interested in.**

Q: So that sounds like that's role that you ... that's gone, a lot.

A: **Yes. Important.**

Q: What would you call that? Being a mate?

A: Yes. **Being a ... being a male chauvinist pig .**

p.9

Q: OK. Now, I've got ... written down here, I've got a few ideas of roles, and we're going to talk a bit more about what roles you might have. But from what you've said, it seems like being a friend or a mate, you know, a male friend ... or a club member...?

A: I'm not ... Like, we're not clubby types. ... But I used to ... you know, I belong to the Parramatta Leagues Club and I used to call in there and ... I know a few other plumbers who drink there and ... you know, just to be with them, and bounce off a few things like how are you going for work? And what's your prices? And all this sort of thing. So it gives you an insight into how they're going, and what they are charging an hour and all those sort of things that ...

Q: Yeah, yeah. And, and even when you ... Even after you retired, that was still

A: Well, I still used to do that yes.

Friend:

It seems that for Mr Twenty-three, the role of friend has turned around from one in which he did things and provided services for his friends and neighbours (strong productivity aspect), to one in which he is now having to receive such services or favours from his friends. (self maintenance aspect) He finds this difficult.

For instance, he is happy with the arrangement that his friend picks him up on a Thursday afternoon and takes him to the club, which is the sort of thing they used to do, but now it takes longer for his friend because he has to be picked up and dropped off. He is concerned about causing upsets with his friend's wife because of this.

He has two categories of friends, those who help and those who do not. He was clear about the fact that there were some friends he would not ask for help.

p.10-11

Q: Yes. Still important, yeah, OK. But, would you say, I mean, you've still got friends, haven't you?

A: Oh yeah.

Q: You've got your friend who comes around and takes you up there on a Thursday.

A: Yeah.

Q: So it's changed. That ... that role has changed a bit? Would you say?

A: Yes.

- Q: I mean changed a lot obviously, but, but it's still there?
- A: Yes. Still there. Yes.
- Q: Yeah. **Just not so satisfying as it was.**
- A: Well, it is when you ... you know, it's satisfying to have R. come around and pick me up and things like that. But, you know, he's got a bit of a demanding wife and she gets a bit cranky because instead of being home at six we might get home at six-thirty, or something like that, you know. ... And ... **I feel sometimes I'm getting him into trouble at home, with his domestic life.** Whereas years ago, he'd head off one way - he's got to pass his house to bring me home and then go back. Now, years ago, he'd just go straight home and I'd come straight home.
- Q: Yeah. So it was less time - he'd be home earlier.
- A: Well ... **I feel sometimes I could be causing trouble in his family.**
- Q: Um ... Any other friends that um ...?
- A: **Oh, we have a multitude of friends call in. ... But I don't ask them to do anything, you know.**
- Q: Yeah. Are they just not the sort of friends that you would ask to do things or...
- A: Well ... Er ... Yes, they are not the ...
- Q: Yeah. And you don't like asking people anyway? Is that right?
- A: No. Well, see ... not patting myself on the shoulder or the back or anything, but ... **I used to look after a lot of houses around here for friends,** you know if they had problems with their building or plumbing or anything like that, I could fix it for them. I find that now that I can't do it you know, now that we've decided to sell and everything, they're all saying well, you know ... "we all know how bloody expensive plumbers are now that we've to get one and pay one". Where I used to do it all for free for them. **And I find that frustrating, that I can't get out and help these people.** As I said to E. when I first had the stroke: "God, who is going to fix all these things up if I'm incapacitated" you know. Her reply was "don't worry about it, it's not your worry". But ... **I used to get a great joy out of that. Being able to go down and help people.**
- Q: Yeah. So that whole aspect of the friendships ... er ... The friendships ... The nature of the relationships changed, right?
- A: Yes.

He sees his friends as very important. He feels that with the move, it will be difficult because they will lose many friends, and will have to start again. Currently, their friends are mostly neighbours or surf club people.

p.22-24

- Q: Now, what about these two, being a friend and being a mate.
- A: Yes, that's very important. ... It's very good that we do have a lot of friends. We've lived here for twenty-five years and all our ... We're blessed with good neighbours and we've had a lot of good friends and a lot of good times here. We're going to miss that when we do sell, no matter where we go, because we'll be starting again. But because we're together ... it won't be so hard, you know?
- Q: So most of your friends are from round here?
- A: Yes. And a lot from the surf club too. ... We still have a lot of ... maintain a lot of friends from the surf club.

The friendships have not changed over the years, or with the stroke.

p.23

- Q: And is ... They're good friendships that you feel good about?
- A: Yes.

- Q. Now?
- A. Yes.
- Q. That ... that they're still ... ?
- A. Yes.
- Q. Have they have stayed the same? The friendships?

He has two particularly good long-standing friends, both of whom provide valuable support now.. One gives him a spell at the club every week, while the other has twice drives in from Canberra for the day to do the garden and any other odd jobs that are needed.

p.23-24

- A: Yes. Oh, well, the one that picks me up on the Thursday, he's become very ... you know, we've grown very close. We have been close mates. We rowed together for years. ... You know, he was in the surf club with me and we rowed surf boats for years. He and his elder brother. We were in the crew together, the three of us. But he's become very close and very good.
- Q: And that's ... even more since the stroke? Or has that always been?
- A: No, it's always been.
- Q: So that's something you value very much?
- A: Yes. I have a very good mate in Canberra where we lived for 13 years. And, er, he's the type of mate that picks up the phone and says "look I am coming up for the day. Get a list of jobs you want me to do". He's an electrician, you know, and he's very handy with his hands. And he'll arrive at eight o'clock in the morning, which means that he's left Canberra about half past five or six or something. ... And he'll work all day. And at night time, he'll have a cup of tea and then jump in his car and go home. ... And that's, like that's a very close mate. ... And, er, he's done that a couple of times now. I get a list of things that I can't do - even changing a light globe in the light fitting or something like that, you know. Like ... he arrived here on Saturday - he usually plays seniors tennis. And he arrived here on Saturday, and one of our roller doors down stairs was sticking a bit. I said to him "mate, we're having a building inspection. Do you think you could fix that?" "No problems!" Straight out, opened the boot of his car, brought his tool box in and done it. Then he was on his way to Brisbane. ... He just called in for a quick cup of coffee! ... And, you know, he's ... I'd say he's as good as this one.

He is happy his friends help him out, although he worries a little bit about imposing.

p.24

- Q: And how does that make you feel when he does those things for you?
- A: **I feel good, but I feel as though I am imposing.** But he wouldn't look at it in that light. He ... you know, he'd be upset if I tried to do it and botched it. He'd say "leave it for me", you know?
- Q: So you can ... From his point of view, he wants to do it?
- A: Yes.

He values his friendships and feels satisfied about them.

- Q: So your friendships... Do you...
- A: **I value them very much.**
- Q: Yeah. You value them, right. Yeah. And you feel pretty satisfied about those relationships?
- A: Yes.

He is continuing to try and provide assistance to his neighbours who have plumbing problems, and has been successful at least once, but has also found he is unable to help any more.

P. 30-31

- A: Yes, **I still**, you know, **help a lot of people**. And, **I was pleased with myself the other day**. A chap two doors down was having troubles with his kitchen tap and I was able to go down and pull it apart and fix it for him.
- Q: Oh really! You were? So you still are able to do things like that?
- A: Yeah. As long as I can ... You know, I had to get him to hold the damn thing so it wouldn't twist around. ... And I was able to pull it apart, fix it and put it back together again. So I was very pleased with that. ... I came in and said to E.. 'well, **I'm very proud of what I've done**. I've been able to get that done. ... But, er ... Well, I did a lot of things that ... Like the lady across the road her toilet's running all the time, and I can't get ... I can't get both hands down there to pull the valve out. I mean, I know what to do, because I've done it hundreds of times, but it's physically to try and do it you know. And she's on her own, her husband's gone, and she hasn't got a lot of money and I was able to do those things to help her. ... Now I've got to ask another plumber mate of mine to come and do it, and he's got his own business, and he thinks ... 'well, what ...' you know ... "do you want me to do it for nothing or something?" ... They're things that I find very frustrating whereas **I used to enjoy helping all our neighbours**.
- Q: So you really valued being able to provide a service to your friends? Well, to your neighbours.
- A: Yeah. Yeah.
- Q: And you really miss that now.
- A: Yes, I do.

ANY FURTHER ROLES IDENTIFIED BY RESEARCHER ON TRANSCRIPT ANALYSIS

? Self Maintenance? - Financial manager

He discusses how, being a pensioner, he is not able to pay others to do the work he used to do. It seems this would be a possible satisfactory outcome for him to the problem of garden maintenance, but it is one they cannot now afford.

p. 6

- But, I find I can't do it. **Now I've got to ring up and rely on my son**. Like, people say to me get your ... get your lawns mowed, you know. Well, **when you've got no income** ... it takes a hell of a lot out of the ... You know, my wife and I are on the pension now. And ... when I went into business I was too old to start superannuation, so we got none of that. I had every insurance company in Sydney trying to sell me insurance on super. Then they'd ask you the pertinent question, how old are you? I'd say I am forty-eight. Oh, we'll call back and see you. Well, they've never come back. ... And, er ... trying to live on nothing's pretty ... at the present moment we're finding it very different. Before that we had a pretty affluent lifestyle. ... Because of our business, you know, gave us a good lifestyle ... But er, ...
- Q: There's not enough left now.
- A: Yeah.

p. 7

As I said, people say to you, well, why don't you get somebody to come in to do it? You know. Well, when you have say \$25 to \$30 each time and maybe in the summer time it's once a fortnight, it takes a hell of a slice out of your living expenses. ... Plus the fact that **I used to like to do it myself**.

Productivity

Possible continuation of his work role as a **plumber** in trying to continue to help neighbours with plumbing problems (see under friend).

3) FURTHER ANALYSIS

TIME

p. 5

Q: So, how do you spend your time?

A: I do a lot of **exercises**. And then, **sit out in the sun a lot**. And then, if there is anything decent on **TV** I'll watch that. But there's very rarely any thing decent. // I like the sports - if I could get the sports I'd be OK, but, er ...

p. 16

Q: So now you've got a lot more time than you used to have.

A: Yes.

Q: Is that a problem? Do you find that time hangs ...

A: Yes, I do find it a problem 'cause I can't read a lot because the stroke's affected both eyes. And I find if I read ... take like the newspaper, I've got to have a magnifying glass, because the lines all go into ... They inter-blend with each other, and I've got to ... keep coming back and starting again. ... And my eyesight hasn't deteriorated because I've had new glasses made...

Response to role question:

A: **Very limited. I try to help** when my wife washes up, I try to wipe up and I can't hold anything in this left hand because I've got no strength in it. But I, I do try, but not very successful. ... **I find life at the present moment very frustrating.**

Q: Do you?

A: Yes.

Q: Yeah. What's the most ... the most important thing that you would like to be able to do that you are having trouble with?

A: Ah. (pause) I'd like to be able to drive again.

Q: And why ... Why is that?

A: I ... Well, **I feel as though ... I've lost my independence**. Like ... And there's also ... There are things that I want to do, that I've got to make my wife take me now. Or ask her to take me there to do them. Just the things that ... like being ... being. Er, like before I had the stroke - I'd think of something, and I'd just jump in my truck, and away I'd go. And I'd do it. Now I can't. I've got to ask my wife to drive me there. And I feel ... **Sometimes I feel as though I'm such a burden on her.**

Response to "what is important to you" question

- A: I think **just being able to go out by myself**, or go with one of the mates at ... Go, go up to the club for a drink. You know, just go up there for an hour, or something like that.
- Q: Yeah, yeah. That ability to just take off, and do what you want.
- A: Yes, just ... Well, see what I used to be able to do ... Like finish working - like being self employed - I could ... I didn't have to sign on or sign off or anything ... I could duck into the club and have a beer on the way home. After this now I ... you know, come straight home or ... you know, I'm here all the time and ... I've got a mate that comes around and picks me up on a Thursday afternoon and takes me up to the club for an hour, and I thoroughly enjoy that because we ... We have a lot of fun together and make a slight investment on the poker machines, very slight. ... And, er ... It's being able to ... To mix with other men too. You know? ... Being with your wife all the time ... I'm sure she's pleased to see the back end of me too. And er ... It's being able to mix with other fellahs and talk. ... You know, some of the factories I'd have done the maintenance on I'd had a really good rapport with the engineers, and some of them come to the club of an afternoon. We ... This one particular afternoon, and it's good to sit there and chat with them and talk about things. ... About football, and things like that. You know. Things that I'm very interested in.
- Q: So that sounds like that's role that you ... that's gone, a lot.
- A: Yes. Important.
- Q: What would you call that? Being a mate?
- A: Yes. Being a ... being a male chauvinist pig .

Response to the "given you have had a stroke, what would you like to change" question p.32

- Q: ... But given that you've had the stroke, what would you like to be able to change?
- A: I'd like to be more physical. To be able to ... you know ... Like E. and I walk around the oval opposite there every night. We walk down the road and go right around there, but I find that I get terrible back pains because I must be walking incorrectly. I'd say to not be so reliant on other people and to being able to do things physically without having to ask people to help me. Because I've been a very independent person all my life. And I find it hard to ask people to do things for me.

Response to the "If you could do anything at all that you wanted, what would it be" question p. 32

- A: Travel.
- Q: Travel?
- A: We've planned a few trips together, but, you know, when the finances get better one day, there's things we'd like to do. But **the way I am at the present moment I'm afraid to do those things now**. Plus the fact that we **haven't got the finances** at the present moment. I suppose, over the years, we've poured a lot of money into the children. And er ... that's one thing that I'd like to do. One thing I'm looking forward to if we can do it sometime this year, is I want to go back to New Guinea. ... I have a mate of mine that's living up in Lae at the present moment. And, he rings me quite regularly. And I keep saying to him "well, as soon as I can afford it, we're going to go up there". We hoped to go up at Easter time but, we won't make at Easter time, we know that. That is one thing I would like to do, is go back there.
- Q: Very interesting place.
- A: But there are other things we want to do. We've travelled around Australia quite a bit. We've ... I want to go to Darwin. To Kakadu. My wife wants to go to Broome. They're things we'd like to do. And I find the stroke is very restricting, because it puts

so much onto E. Like, you know, I'm built like a ... I'm a big fellow. And then when you walk in somewhere and your wife's carrying the suitcases and people look at you and ... 'look at that lazy so and so' you know! (laughs) You think ... Like we had a funny incident here a while ago, seeing we've been in there area here for 25 years...

(break in tape)

A: ...beeping your horn and saying 'good one!' 'Saying good on you, F. you have finally got the old girl doing it!' You know. (laughs)

(This was a story about his wife working in the garden while he sat in a chair telling her what to do. This was related to him saying he felt bad about her having to do things in the garden that he used to do, and that people in the street sometimes did not understand what was going on and took it the wrong way. He felt people driving past were looking and condemning him for not doing the traditionally male things in the garden.)

Q: (laughs) Is that right?

A: Now, there's a lot of things in our life that we'd like to do, you know, like travel is one of them. And, since I've had these convulsions, the tablets I'm on make me terribly tired. I want to sleep all the time.

Considering this brought him back to the difficulties he faces because of his stroke.

Response to the "what kind of things make you really happy" question

p.33

Q: When you feel really happy these days, what kinds of things make you happy?

A: Er ... One big thing is to see my children successful. And when I'm able to do something that I used to be able to do before, without putting my shirt on back-to-front! (laughs) I'll think I've finally done it, you know? Being able to achieve something. ... And, and, from what you said earlier, it doesn't have to be a big something?

A: No, as long as I can do it myself.

Q: And then you feel really good?

A: Yes.

Response to "what makes you feel down" question:

p. 33-34

Q: And conversely, what makes you feel down?

A: When I can't do it. ... As I said I've been a very independent person. I hate asking people to do things for me. 'Cause I've been able to just wander in and do it and carry on with life. And then all of a sudden, you know ... when you have a doctor say to you, "look you'll never work again", where I've worked ever since I was fourteen and a half. I started my apprenticeship when I was fourteen and a half. Or I started working for a plumber, and then the apprentice ... put me through my apprenticeship, and I've been active working all that time. ... And also my wife's parents were very sick. Her father was a quadriplegic. And we were able to look after them. And that's one thing that I find very upsetting. That for thirty years my wife and I have toed the line with her parents, which was a very difficult time, and became very strained on our marriage at times. And now I find that we're ... They're both deceased and that chore has been taken off our shoulders, and then suddenly I have this, and she's back to square one again! That makes me very depressed. And that's why I am so keen to get back to Westmead. If I can get back into this ... having somebody telling me what to do with the exercises. Because all they've got to do is tell me. I'll do it!

Present roles identified by participant:

Right at the end of the interview, he confided that he may be starting a new role:

p.42-43

- A: See one thing that I ... I think I will ... When I do get better than what I am ah ... I would like to become ... Try and help other stroke victims. Which I'm doing at the present moment with an acquaintance of ours. Which I was never really friendly, that close to him. He is another surf club guy. He's had a stroke. He's in a very bad way. And, er ... even though I was never close to him, in fact I never liked him at one stage, I find that I am doing things to try and help him. ... I organised another mate of mine through the surf club, and we've gone and visited him. And his wife has been in touch with us to say how she appreciates that we called down to the hospital and that we lifted him in his spirits. But, er ... well, the reason that I do that is that J., who had a stroke the month before I did, used to call into Westmead and he's an ex inspector of police and a real heck of a nice guy, and he used to bounce around at the end of my bed, and say something like, you know, "come on F. get up. Only poofters and dunces can't dance, come on get up and dance with me" and that. Please don't put that in your quote!
- Q: (laughs)
- A: He was an inspiration to me. ... And I am trying to help this other guy. So I've rallied J. to the cause and he picks me up, we go down and see another J. who's had a stroke. And his wife is finding it very difficult to handle because he's a very ... You know, he used ... He used to do his own thing all the time. He had a very successful business and spent a lot of time playing golf. Going to the club every afternoon and playing golf. She said to him ... Said to E. and myself "we really appreciate the fact that F's come down and brought J. down and it's lifted him and it gets his spirits up". ... Because as I said a little while ago you can become very depressed. ... Feel very sorry for yourself. You ask the question why me? ... Because it always happens to somebody else. Then you say to yourself, I know I haven't been the best one on earth but, you know, I tried to do the right thing. Why did it happen to me? So I see that as a future role that I might try and get involved in something like that to try and help other people.
- Q: Yeah. Oh, that'd be a great thing to do. Because, no matter how much the OT or the speech therapist or the physiotherapist or whoever, doctor, talks to you about it - they haven't had a stroke. So, I think it does make a huge difference to have someone to talk to who's been through it.
- A: You can become ... **You feel sometimes you can become violent with people around you, because you become so frustrated and so annoyed with yourself**, like E. has often said to me "don't smash something because we can't afford to replace it", you know? **Sometimes I'll try to do something and if won't work so I'll throw it. And then you think "you silly bugger what did you do that for?"** And, er ... this guy's just come home from hospital, and they've had to alter the house to get the wheelchair up and down the corridor and to build a room on the back because he's going to live out there. **And one thing I find is that you have a tendency to take it out ... When things go wrong, you have a tendency to take it out on your mate. ... And this is something you shouldn't do. Because without your mate you've got nothing.** And I know this J. would be very much along those lines and I feel as though I could talk to him, and the other J. could talk to him too, because we've both been there. And fortunately for us, we have both come out a bit reasonably well, when you look at some of the others, that are stuck in wheelchairs for years and years and years. So that's one role that I think I would pursue in time to come.
- Q: Yes, I didn't ask you about future roles at all, yeah. Yeah, I think that would be very much appreciated.
- A: Well, it's something that I think would be fulfilling from my point of view too. But see, once again, I'd have to ... Hopefully I'd be able to drive, not having to rely on my

wife to take me everywhere. Now, I don't know whether that will ever come to fruition, as to whether I will be allowed to drive again.

STAGE THREE OF PATTERN CODING ANALYSIS - SAMPLE INTERPRETIVE SUMMARY

Generally, it was clear from his responses that Mr. Twenty-three had a very strong service orientation. His stroke had severely interfered with this and it seemed that the loss of this ability to do things for others caused him a great deal of distress.

PRODUCTIVITY

This is the area of focus of Mr Twenty-three's life. Prior to his stroke, he had just retired from his own plumbing business, employing other plumbers. Despite being the boss, he had kept himself on call on weekends right up until retirement, and had planned to continue working in a smaller way:

"Yes, I had retired. ...Yeah, we'd got out of the business. But I'd only just had a couple of months of retirement and then I had the stroke. ... You see we had a business at Seven Hills and I had nine people working for us. And we downsized that. And I was just going to ... just continue on on my own doing little bits and pieces you know. **But that's all gone now.**

He had also been in the habit of doing all his neighbour's and friend's plumbing without charge, lending a helping hand where needed. He had been a very active life saver in the past, and still organised something once a year for his surf club. It seemed that he felt the loss of independence he was experiencing as result of his disabilities particularly as a loss of being able to do things for others.

Mr. Twenty-three ranked four of his nine roles under the heading of productivity. He also gave two of them (husband and father) first and second priority when asked to prioritise his roles.

Husband

This was Mr. Twenty-three's most important role, ranked first in order of priority. In the past, he and his wife shared the role of home maintainer. She took care of the inside of the house and household tasks such as cooking and cleaning, while he took care of the garden, and any major home maintenance jobs. He now no longer felt able to do his share:

"This is, you know, one thing that is frustrating. We're selling the house because I can't look after it any more. ... **My wife can look after the inside but then I can't look after the outside.**"

"Your garden and everything?"

"Yeah, mowing of the lawns and things like that - vacuuming the pool."

(sound of wife's voice in the distance conversing with real estate agent)

"Is that something that you took a lot of pride in before?"

"Yes we did, we tried. **We, ... used to get quite a few compliments about ... the way the place looked.**"

Now neighbours see his wife out in the garden working and make jokes about how he has finally got his wife doing the work. He worries that people driving past will think he is a 'lazy so-and-so'. He feels that he is an unfair burden on his wife in many ways. They spent thirty years of their married life looking after her parents, both of whom were in need of care (her father was a quadriplegic). He recounted how difficult this had been for his wife, and

described the strain it had placed on their marriage. Now, just when they were free of that burden and able to enjoy life more, he has had the stroke. "... and she is back to square one again!" He needs his wife to help him dress, and to drive him if he wants to go somewhere. He feels his loss of independence is putting a strain on their relationship - not only because his wife needs to assist him more but because he can be difficult.

"I think you lose your independence, to a degree, you know. Like, my wife's very easy to get along with and she does everything to possibly help me. But ... **I find sometimes I'm being ... a bit demanding.**"

He described this further later on:

"You can become ... **You feel sometimes you can become violent with people around you, because you become so frustrated and so annoyed with yourself**, like E. has often said to me 'don't smash something because we can't afford to replace it', you know? **Sometimes I'll try to do something and if won't work so I'll throw it. And then you think 'you silly bugger what did you do that for?' ... And one thing I find is that you have a tendency to take it out ... When things go wrong, you have a tendency to take it out on your mate. ... And this is something you shouldn't do. Because without your mate you've got nothing.**"

His motivation for working hard in rehabilitation is to restore the occupational aspects of his role of husband to their former status.

"Yes, I want to get back to the role that I had before as a full time husband and a full time father."

He minds very much not being able to drive himself. When asked what was the most important thing he would like to be able to do at the beginning of the interview he said to be able to drive. He needs to be driven because he had a recent history of fitting. Also, with the changes brought about by the stroke, he does not know if he will be able to drive again. This was a theme throughout the interview:

"What's the most important thing that you would like to be able to do that you are having trouble with?"

"I'd like to be able to drive again."

"Why is that?"

"Well, I feel as though ... I've lost my independence. **There are things that I want to do, that I've got to make my wife take me now. Or ask her to take me there to do them.** ... Like before I had the stroke - I'd think of something, and I'd just jump in my truck, and away I'd go. And I'd do it. Now I can't. I've got to ask my wife to drive me there. And I feel ... **Sometimes I feel as though I'm such a burden on her.**"

But, once again, **I've to get my wife to take me there (to the Bowling Club), and my wife to come back and get me. ... Which restricts her.** You know? I know she'd do it quite happily, but ... Now, you take Monday when I go to Westmead. E. (*his wife*) has got to drive me there, and I don't know how many hours I'll be there. She'll come home, and she's got to come back and pick me up."

"So it comes back to this **driving** again doesn't it?"

"Well, being immobile, yes. ... Now, I don't know whether I'll ever drive again. I'm not sure."

"I'd like to be more involved with the surf club now but my wife doesn't like the sand. So she doesn't like the beach that much. And, er, I've got no way of getting there unless she takes me there."

I asked him what the good things were now about being a husband. He replied that they talked, shared things and worked together. I asked if there were any bad things. He said not being able to help her by doing the things around the house he used to do such as maintaining the garden and pool and helping with the washing up.

Father

They are a close family, with a son and two daughters. None now live at home permanently, although the youngest daughter still stays there at times.

One of his major goals in rehabilitation is to restore the occupational nature of his role as a father:

"Yes, I want to get back to the role that I had before as a full time husband and a full time father. As the kids would say, well, you know, you're bloody hard enough to put up with now. *(laughs)* You're just the same as you were before!"

He was proud of his children:

"I find I was very strict with the children. My wife will back me up on that. I think it's paid off because they're all pretty normal. They're all working. Well, M.'s at Uni. - she's going to be a primary school teacher. The boy's doing very well with Telstra, and J. is a flight attendant with Ansett. So they're all up and going, the lot of them, which we're very proud of."

"Yes, that's terrific isn't it?"

"Well, it is, it's a fulfilling role. And it's also fulfilling when your daughter comes home and says "Dad, you'll never guess what happened last night. We were all having a get-together at the Epping Hotel. I heard all the boys and girls *(talking about Christmas Day)* saying 'well, I'm going to see Mum. Or Dad. Or spend so much time with one or the other'. 'Well', she says 'It just feels great that I know that I'm coming home and we'll all be together on Christmas Day'."

"A proper family?"

"Yes."

As a father, he spent time taking care of the financial welfare of his children, while they went to his wife to sort out emotional and social problems.

"What's the nature of your role as a father? Are you the sort of father who they come and tell their troubles to? Or are you the sort of father that stays in the background and helps in more subtle ways ...?"

"Yes, I think that'd be right - helps them. ... Especially financially. ... But no, they all go to their mother with their problems and then in turn she tells me. And between the two of us we try and help them. ... I've got daughters

that are spendthrifts. They get themselves into trouble occasionally and we've been able to get them out of trouble. But since this (*the stroke*) has happened, I've told them that ... the gravy train's stopped because we haven't got the money to do it. ... But no, we're a close family and we're very fortunate. They're very caring children, and they're very good to me. They're very good to their mother.

He feels that having the stroke has drawn the family closer together, so that his role as a father has not changed, except perhaps to intensify.

"So that's another relationship which has changed a bit? Would you say?
Another role which has changed a bit?"

"... No it hasn't changed so much, only ... **I think it's brought us closer together, really.**"

"So, do you feel comfortable and satisfied with the way that role's going?"

"Yes."

His son visits every day. He is currently relying on him for garden maintenance, and feels this is an imposition.

"It's a beautiful house and a beautiful garden. Just looking from the front it looks wonderful."

"(*laughs*) "But, I find I can't do it. **Now I've got to ring up and rely on my son.**"

"Yeah, well, you know ... **I've got to rely on my son coming over**, and he ... by the time he finishes his own lawns and then comes here, he's ... You know - OK Dad, I'll do it tomorrow. ... Sometimes tomorrow never comes. ... And then it becomes a big deal by the time he does get here and he spends a lot more time here than he should. ... It's getting harder and harder, because he's very tangled up with his job."

Surf Club Member

The role of Surf Club Member was perhaps the formal expression of Mr. Twenty-three's orientation towards giving service to others. It has been a lifelong role, and he has been a member of the same surf club since he was seventeen. In the past he has gone to great lengths to maintain active membership.

"I'll tell you how keen I was. When we lived in Canberra I used to come up on weekends to do patrols, from Canberra. ... Come all the way from Canberra. And, my wife and I would stay with her parents at Epping and then on Saturday afternoon I'd go down to the club and do a Saturday afternoon patrol, and then back up Sunday morning and do it again. Then we'd drive back to Canberra. Being able to do those two patrols meant I didn't have to come up as regularly but I could swap with somebody and do their patrol on a Sunday morning and then they'd do my patrol, when it was my turn in a month's - in a couple of week's time or something. ... So that's how keen I was with that and I've maintained that all through my life."

He gave up being a lifesaver after fourteen years with the club and turned his hand to committee work. At the time of the interview, He no longer attended the surf club regularly,

going perhaps twice a year. He sorted it eighth in priority out of nine roles, reflecting its decline in significance and performance. He said:

"I'd like to be more involved with the surf club now but my wife doesn't like the sand. So she doesn't like the beach that much. And, er, I've got no way of getting there unless she takes me there."

"Right. So it's another role which has declined?"

"Yeah, very much so."

Nevertheless, he was still active in the role. He described how he was the driving force behind the maintenance of a social tradition whereby a group of club members gathered once a year at someone's house to watch the football grand final. Now he found people from this group were starting to die or acquire illnesses and disabilities like himself, making it hard to continue with this.

He saw himself as an organiser:

"And unless I keep that momentum going it'll drop off. **But I make sure I keep it going, because it keeps us all together.** ... Like the guy we were suppose to be going to this year, **unfortunately we buried him a couple of months ago.** So we won't be going there."

"But ... sounds like you're a real driving force there."

"Yeah, **I'm an organiser.**" *(laughs)*

He was also still involved, on an annual basis, in organising a sponsored swim from Palm Beach to Whale Beach. This event attracts up to fifteen hundred swimmers every year. He saw himself as a contact point for older members, and he worked to maintain the friendships he had formed over his many years with the club. The older surf club members used him to find out what was going on with the club, so he was quite active on the telephone. He organised volunteers to assist in running the annual swim this way.

"But my main role is supplying volunteers. Like, ... G. ... well, he's the head of the Committee ... he'll ring me up and say 'F. how many have you got this year?' And I'll say 'well, I got six, eight or ten', you know."

"And you get them by ringing round and asking ...?"

"Yeah, I just ring around and say "what are you doing Australia Day?" You know? Course, now, as the families grow up, they've got other things to do, you know? But I've managed to keep ... Well, we got ... there's six of us going down the weekend after next. Normally I would have anything up to ten or twelve. But now, other people have got other things. Like, one of our friends will be in New Zealand, on holidays. The other guy will be up at Foster, at his weekender. Some of them aren't as keen as I am, you know. I know they must think sometimes I'm a pain in the butt because I'm tying them up for the weekend to go down and do this. Because it's all voluntary.

"They probably enjoy it when they get there." *(laughs)*

"Well, have the odd sip of Bonnington's Irish Moss and let our wives drive home." *(laughs)*

"Sounds good fun."

"Oh, it is. Because, you know, **I found that has been a big part of my life, the surf club. And the friends I've made in it I've maintained over the years.** Very much so.

"So it really is a very important thing."

"Yes."

"And it's something which has gone on right through your life. Is that right?"

"Yes, from when I just came out of my apprenticeship, yes."

Home Maintainer

This role was sorted last in order of priority. Nevertheless, his perceived failure to perform in this role is the reason he and his wife are selling their house and moving to somewhere without a garden. Perhaps this is the reason for the sorting, because he sees that it will soon no longer be a problem to him.

"This is, you know, one thing that is frustrating, where we're ... We're selling the house because I can't look after it any more. ... **My wife can look after the inside but then I can't look after the outside.**"

"Your garden and everything?"

"Yeah, mowing of the lawns and things like that - vacuuming the pool."

(sound of wife's voice in the distance conversing with real estate agent)

"Is that something that you took a lot of pride in before?"

"Yes we did, we tried. You know ... we did ... **We, ... used to get quite a few compliments about, ... the way the place looked...** And especially the way my wife kept it inside here. ... In fact, that's one of the ... big factors of the ... reason that these people are having a building inspection now because we've got people pretty interested in selling." *(he may have meant to say buying)*

This role seems to be closely linked to his role as a husband (see above), as it was a role he shared with his wife. The appearance of the house and garden was important to both of them. The day I visited, the house and garden were immaculate and appeared to reflect years of hard work in home maintenance and improvement.

He described the problems he was experiencing in trying to continue with the role by sharing it with others. He did not like to trouble his son with it. Because of the stroke he now had no income coming in and found paying someone expensive. Perhaps most importantly, he did not feel it was done the way that he wanted it.

"Yeah, well, you know ... **I've got to rely on my son coming over**, and he ... by the time he finishes his own lawns and then comes here, he's ... You know - OK Dad, I'll do it tomorrow. ... Sometimes tomorrow never comes. ... And then it becomes a big deal by the time he does get here and he spends a lot more time here than he should. ... And he ... It's getting harder and harder, because he's very tangled up with his job. As I said, people say to you, well, why don't you get somebody to come in to do it? You know. Well, when you have say \$25 to \$30 each time and maybe in the summer time it's once a fortnight, it takes a hell of a slice out of your living expenses. ... Plus the fact that **I used to like to do it myself. I had it the way I wanted to do it.** ..."

He had made an effort to continue looking after the garden himself, but found it too difficult:

"And I've tried to do it now and **I've had to ... get a different mower** because I can't ... The Victa, I've got to pull the rope back, and as soon as I do that I fall over. Whereas ... I've got a four stroke now - I can pull it straight up. ... But I ... still find it difficult, putting the catcher on and off because you've got to lift it up with this hand and try and get the catcher in. These are the things that I find very frustrating."

It appeared that in the past he had not found the act of garden maintenance pleasurable, but necessary, and part of what was expected of him.

"Will you miss the grounds do you think?"

"No, I think I can adjust to that" (*laughs*) "We'll miss the pool, because the wife and I use that ... We put it in because we had young children and they used it all through their adolescence and then, now Mum and I use it a lot. We'll miss that, but I can live with that. ... And **it's just to ... try and make life a little bit easier.**"

"So, ... Maintaining the garden was a chore for you before?"

"No."

"No - it was a pleasure?"

" ... Well, I wouldn't say it was a real pleasure, but it wasn't that ... I didn't find it difficult. I could ... you know, I could come home from work and then ... if it had been a hot day, because I was in the building trade, I could still ... like finish work and come home and then do the grounds and then dive into the pool and have a swim. ... And ... I didn't find it laborious but I wouldn't say I was overjoyed by it."

I think he felt frustrated that now that he finally has time, he is unable to do the job justice as perhaps he had planned to do prior to retirement. A theme that appeared in relation to leisure (see below) was that he felt he had to earn his leisure. For example, perhaps in the past, he had felt able to have a swim because he had done the garden first.

"When I was in business I would think to myself, you know, I've got to do this now. When I was in business it was a chore. Now that I have this time, I find it's frustrating, because **I feel I should be doing something else, but because of this I can't do it.** ... As I said, my wife's always said to me 'you were never a gardener'. You'd keep the lawns tidy, and turn the garden over. She's the gardener not me."

LEISURE

A large part of Mr. Twenty-three's leisure time was spent sitting in the sun in the garden or watching sports on TV. Now that he was unable to work or do anything that he saw as productive, he seemed to see the time spent in leisure mainly as time wasted. At the end of the interview we discussed this further:

"This productivity business. At times, [you are] so disappointed with this, that you have difficulty enjoying ... This is interesting, I think, that you can't allow yourself to enjoy your leisure things so much because you're still feeling frustrated with the productivity things, would that be right?"

"Yes. See, I've never been one that's had a lot of time, that I could, you know ... As I said, working, I never had time. The only thing I ever wanted to do

was in this (*indicates Surf Club Member on the sorting board*). I never wanted to be a bowler or a golfer because I never really had the time for it, whereas I would make time for this. Because I found it very satisfying."

"Yes. So that was the one big thing that you had outside work?"

"Yes. And since, you know, as I said, my wife's not that keen on the beach - she doesn't like the sand. And she's a big girl. She won't get in a costume, whereas she will at home here. She'll get in the pool. And I don't care what I look like when I am on the beach. (*laughs*) I just enjoy it so much. Plus I enjoyed the camaraderie with the guys in the club."

"Well, it sounds like you still do a bit."

"Yeah I still do my bit."

There was an interesting slip in those last two lines. I meant that he still enjoyed the camaraderie. He took it that I meant that he still contributed to the club. If he could find something that he felt was a productive and that he also enjoyed, then he felt able to relax and get pleasure from it. If he felt it was not a productive activity, he did not feel comfortable and did not enjoy it.

He identified two roles that were sorted under the heading of leisure. One was a new role as a bowler and the other was a general role termed leisure to cover other activities that he did for enjoyment. Both these were sorted together as sixth in order of priority.

Leisure

We discussed the enforced idleness he was now experiencing.

"So now you've got a lot more time than you used to have. Is that a problem? Do you find that time hangs ..."

"Yes, I do find it a problem 'cause I can't read a lot because the stroke's affected both eyes. And I find if I read ... Take like the newspaper. I've got to have a magnifying glass, because the lines all go into - they inter-blend with each other, and I've got to ... keep coming back and starting again - and my eyesight hasn't deteriorated because I've had new glasses made"

He had always believed that leisure should be earned. It seems that he spent all his time earning it without ever cashing in his earnings! Now he felt uncomfortable about sitting in the sun or doing something purely for pleasure because it went against a lifetime of purposeful, productive activity.

"Now, these leisure things - sitting in the sun. Watching television. ... But you were saying earlier that you found that when you were doing things like that you had this little voice saying 'you should be doing something else'. (*this refers to the section of interview not taped*)

"Yeah."

"You shouldn't be relaxing like this".

"Well, **I shouldn't be wasting time**. That's the way I put it."

"Has that always been ... Have you always been like that? About leisure things? ... Before, did you feel like you had earned your leisure before?"

"Yes. Yes."

"Is that what it is?"

"Yes."

"And now perhaps..."

"Well, of course, before, we never had time for leisure. ... I was always busy. Even on the weekends, you know, I'd get call-outs. ... **And then you would look forward to your leisure time.** That's when I would look forward to this." (*points to board*)

"Yes, the surf club."

"But then, I don't get down there at all now. Hardly ever."

"And, do you feel like you're entitled to leisure now?"

"No."

"You don't?"

"No. **I feel you've got to earn your leisure.** ... I know I should take each day as it comes, and just let the day roll by and if it means I've got nothing to do - as they told me at Westmead - well, just do nothing! But ... I can look around and I can see things that I should be doing. ... So I sit down and think to myself, 'no, I should be doing that. I should be getting under there to do that!'"

Leisure was a role that he was obliged to take up because he needed to fill his time. This had never been a problem to him before, because he had always been so busy. He did not feel comfortable with the role and had not yet made the changes in his belief system necessary for him to successfully internalise and accept it. Possibly his wife also believed that being unproductive was wrong and thus reinforced his difficulties with accepting a passive leisure role.

Bowler:

His stroke rehabilitation has generated a possible new role for him as a Bowler. He was surprised to find that it required quite a lot of skill to play well. He had assumed that because it was usually older people who played that it must be easy and therefore not a challenge to him.

"It's only since I have been like this, and Lottie Stewart takes us to Denistone Bowling Club, that I've started playing bowls. ... But I've enjoyed it so much I might take it up."

"Let's talk a bit about being a bowler, because that's just a small role at the moment isn't it?"

"Yes"

"That may become a bigger one do you think?"

"Oh, I think in years to come it could come, yes."

"And what is it about bowling that attracts you?"

"I don't know, because when they first suggested it down there I thought, as I said. I would never go to bowls. ... And I think, oh ... I'd rather play golf."

That's more exercise, than standing there throwing a ball down the ... down the road, you know. ... And now ... I've thought of it, as I said, no, **that's only**

for old people. But now I find that now that, I am doing it, it is very skilful. ... It's like golf. You can never get the ball in the same spot twice. You'd have one good shot, then the next one'd go into the trees. And I find that with bowls, you only have one good shot and then you try and do it again with the next one, and it goes somewhere else." (*laughs*)

"So, it offers you a challenge?"

"Yes."

"It's a challenging thing. It's something that you feel that you could get good at?"

"Yes, I think so. Well, they tell me I'm ... you know. Even all the volunteers from the bowling club that help us, keep saying to me 'you've played this before'. And I say 'no I've never played it before'. **So it gives me an incentive to ... That I think that I could become good at it.**"

SOCIO-CULTURAL

Mr. Twenty-Three sorted two roles, that of being a mate and that of being a friend, under the Socio-cultural heading. He sorted them both as fourth in level of priority for him. He made a clear distinction between mates and friends, however.

Mate

Being a mate involved going to the pub or the club and have a yarn. He missed this as it was important to him and seemed a focus for his regret at his loss of independence, along with being a burden to his wife.

I asked:

"So, what other things are important to you?"

"I think **just being able to go out by myself**, or go with one of the mates ... go up to the club for a drink. You know, just go up there for an hour, or something like that."

"That ability to just take off, and do what you want?"

"Yes. Well, see what I used to be able to do ... Like finish working - like being self employed - I didn't have to sign on or sign off or anything ... I could duck into the club and have a beer on the way home. After this now I ... you know, come straight home or ... you know, **I'm here all the time** and ... I've got a mate that comes around and picks me up on a Thursday afternoon and takes me up to the club for an hour, and I thoroughly enjoy that because ... **We have a lot of fun together** and make a slight investment on the poker machines, very slight. ... **It's being able to ... mix with other men** too. You know? ... **Being with your wife all the time** ... I'm sure she's pleased to see the back end of me too. And er ... It's being able to mix with other fellahs and talk. ... You know, some of the factories I'd have done the maintenance on I'd had a really good rapport with the engineers, and some of them come to the club of an afternoon. And **it's good to sit there and chat with them and talk about things. ... About football, and things like that. You know. Things that I'm very interested in.**"

"So that sounds like that's role ... that's gone, a lot."

"**Yes. Important.**"

"What would you call that? Being a mate?"

"Yes. **Being a ... being a male chauvinist pig .**"

Friend

He sees his friends as very important. He feels that with the move, it will be difficult because they will lose many friends, and will have to start again. Currently, their friends are mostly neighbours or surf club people.

"It's very good that we do have a lot of friends. We've lived here for twenty-five years and ... We're blessed with good neighbours and we've had a lot of

good friends and a lot of good times here. We're going to miss that when we do sell, no matter where we go, because we'll be starting again. But because we're together ... it won't be so hard, you know?

At the time of the interview, He had two categories of friends, those who helped and those who did not. He was clear about the fact that he would not ask for help from most of their friends.

It seems that for Mr Twenty-three, the role of friend had turned around from one in which he did things and provided services for his friends and neighbours (a strong productivity aspect), to one where he was no longer able to do this. He was even now in the position of receiving such services or favours from two particularly close friends (a self maintenance aspect). He found this difficult.

"Oh, we have a multitude of friends call in. ... But I don't ask them to do anything, you know."

"Are they just not the sort of friends that you would ask to do things?"

"Well ... Yes, they are not the ..."

"And you don't like asking people anyway? Is that right?"

"No. Well, see ... not patting myself on the shoulder or the back or anything, but ... **I used to look after a lot of houses around here for friends**, you know if they had problems with their building or plumbing or anything like that, I could fix it for them. I find that now that I can't do it you know, now that we've decided to sell and everything, they're all saying well ... 'we all know how bloody expensive plumbers are now that we've to get one and pay one'. Where I used to do it all for free for them. **And I find that frustrating, that I can't get out and help these people.** As I said to E. when I first had the stroke: 'God, who is going to fix all these things up if I'm incapacitated?' You know. Her reply was 'don't worry about it, it's not your worry'. But ... **I used to get a great joy out of that. Being able to go down and help people.**

At the time of the interview, he had two particularly good long-standing friends, both of whom had provided valuable support since his stroke. One gave him a spell at the club every week, while the other had twice driven up from Canberra for the day to do the garden and any other odd jobs that were needed.

"Yes. Oh, well, the one that picks me up on the Thursday, he's become very ... you know, we've grown very close. We have been close mates. We rowed together for years. ... You know, he was in the surf club with me and we rowed surf boats for years. He and his elder brother. We were in the crew together, the three of us. But he's become very close and very good."

"And that's ... even more since the stroke? Or has that always been?"

"No, it's always been."

"So that's something you value very much?"

"Yes. I have a very good mate in Canberra where we lived for thirteen years. And, he's the type of mate that picks up the phone and says 'Look I am coming up for the day. Get a list of jobs you want me to do'. He's an electrician, you know, and he's very handy with his hands. And he'll arrive at eight o'clock in the morning, which means that he's left Canberra about half past five or six or something. ... And he'll work all day. And at night time, he'll have a cup of tea and then jump in his car and go home. ... And that's, like that's a very close mate. ... And, he's done that a couple of times now. I get a list of things

that I can't do - even changing a light globe in the light fitting or something like that, you know. Like ... he arrived here on Saturday - he usually plays seniors tennis. And he arrived here on Saturday, and one of our roller doors downstairs was sticking a bit. I said to him 'mate, we're having a building inspection. Do you think you could fix that?' 'No problems!' Straight out, opened the boot of his car, brought his tool box in and done it. Then he was on his way to Brisbane. ... He just called in for a quick cup of coffee!

He is happy his friends help him out, although he worries a little bit about imposing.

"And how does that make you feel when he does those things for you?"

"I feel good, but I feel as though I am imposing. But he wouldn't look at it in that light. He'd be upset if I tried to do it and botched it. He'd say 'leave it for me', you know?"

"So you can ... From his point of view, he wants to do it?"

"Yes."

He was also happy with the arrangement that his friend picked him up on a Thursday afternoon and take him to the club, which was the sort of thing they used to do. However, it now takes longer for his friend because Mr. Twenty-three had to be picked up and dropped off. He was concerned about causing arguments and tension between the friend and the friend's wife because of this.

He was continuing to try and provide assistance to his neighbours who have plumbing problems, and had been successful at least once, but had also found he limited in what he can do.

"Yes, **I still**, you know, **help a lot of people.** And, **I was pleased with myself the other day.** A chap two doors down was having troubles with his kitchen tap and I was able to go down and pull it apart and fix it for him."

"So you still are able to do things like that?"

"Yeah. As long as I can ... You know, I had to get him to hold the damn thing so it wouldn't twist around. ... And I was able to pull it apart, fix it and put it back together again. So I was very pleased with that. ... I came in and said to E.. 'well, **I'm very proud of what I've done.** I've been able to get that done. ... But, er ... Well, I did a lot of things that ... Like the lady across the road her toilet's running all the time, and I can't get ... I can't get both hands down there to pull the valve out. I mean, I know what to do, because I've done it hundreds of times, but it's physically to try and do it you know. And she's on her own, her husband's gone, and she hasn't got a lot of money and I was able to do those things to help her. ... Now I've got to ask another plumber mate of mine to come and do it, and he's got his own business, and he thinks ... 'well, what ... do you want me to do it for nothing or something?' ... They're things that I find very frustrating whereas **I used to enjoy helping all our neighbours.**"

SELF MAINTENANCE

The only role he sorted under this heading was the role of Person With a Disability (Dealing with the Stroke). He gave this role third highest priority after Husband and Father. This was a recently acquired role, and one he had been forced to take up by the externally controlled

circumstance of his stroke. It had pervaded all his other roles in ways discussed above. It had limited his ability to serve others - something which was the focus of his life. Instead, he now had to accept help from others, because it had taken away his independence, making him dependent upon his wife, his son and his friends in various ways. It had also required him to endure idleness, which he found difficult, having few leisure resources. He was very strongly motivated to work at his rehabilitation - especially his Physiotherapy.

His response to the grand tour role question was as follows:

"Can you tell me a bit about your roles now?"

"Very limited. I try to help when my wife washes up, I try to wipe up and I can't hold anything in this left hand because I've got no strength in it. But, I do try, but not very successful. **I find life at the present moment very frustrating.**"

"What's the most ... important thing that you would like to be able to do that you are having trouble with?"

"Ah." (*pause*) "I'd like to be able to drive again"

"Why is that?"

"Well, I feel as though ... **I've lost my independence.**"

Dealing with his stroke was taking more and more of his time.

"As time goes on, are you spending more time dealing with the stroke or less time?"

"No, more."

"Is that right? Why is that do you think?"

"Well ... I feel as though I want to do a lot more exercises. **I'm in a hurry.** That's the only way I can phrase it. **I'm in a hurry to get back to where I was before I had the stroke.**"

He was experiencing some frightening symptoms in the aftermath of the stroke, and it is possible this was sapping his self confidence.

"Oh, I had a set-back about 2 weeks ago where I started taking convulsions. ... So, I was on no medication, no nothing. And we were driving along out at Seven Hills, and all of a sudden I started this business in the car. Taking a convulsion. Fortunately, I was strapped in pretty tight with my seat belt and we were just outside the Seven Hills Police Station where my wife got two constables and they came out and pulled me through it. By the time the ambulance came and they took me back to Westmead ..., they were very good to us. ... But **I don't go anywhere on my own unless ... No, I don't even venture down the street on my own.** If I do, I always let the wife know where I am and what I'm doing."

"It must have been rather frightening. That convulsion."

"Oh, it was! **Frightened the daylight out of the pair of us.** Especially when I had no idea what was wrong. All of a sudden I had these dreadful pains down my left arm and then I started vibrating violently. I had no idea. It'd never happened to me before. Like with the stroke I had no idea, I just got out of bed, walked down to my daughter's bedroom, says 'come on it's time to go to work'. Walked back to bed and that was the end of me. I just sat down on the edge of the bed. The next thing I knew I was in Westmead Hospital. ...

And after 50 years of work, being very active to be told I'll never work again."

Although he had retired a few months before his stroke, he had planned to continue working in a smaller way. Work and being productive were so much part of this man's self image that he must have found the above statement hard to come to terms with. He had other problems with things that health professionals told him.

"And, I've had a couple of negatives in people who I have dealt with. Like one was when I first went to Lottie Stewart, one of the physios. said to me 'Oh, you are walking OK. I don't think you'll get any better with that'. And then I had another one say 'well, I don't think you will ever get your arm back'. And **I found that very very negative from professionals."**

The reasons he gave for being strongly motivated to work hard at his rehabilitation were so that he could stop being a burden to his wife, and restore his dignity and self esteem. He wished to restore the occupational aspect of his husband and father roles to their former levels.

"I feel as though I'm a liability to my wife and I don't like being like that. I've never been that way in my life ... and I ... You know, I can't put my shirt on, as I say. I put the damn thing on inside out or back-to-front. I've got to wonder down here, and E'll be doing something and then she's got to stop. And I feel so ... well, I've never been that way, since I was a child, you know. **And now here I am, I'm back virtually a child again."**
"So you want to work on that."
"Yes, I want to get back to the role that I had before as a full time husband and a full time father."

He resented health professionals who appeared to accept levels of function that he found unacceptable. His aim was to restore function back to pre-stroke levels. He was prepared to do whatever it took to achieve this, and needed staff who would help him instead of giving up.

"Because as far as I'm concerned, I'm prepared to work ... as hard as I can. **As hard as they'll work me I'll work to get it back.** So if it means spending ... I would spend hours down at the end of the pool sitting on one of the chairs. I rigged up ... like a piece of rope where I'd have a bit of sponge rubber in there, and I'd sit there for hours going backwards and forwards trying to get the shoulder to work and then shift and get out and back. So I'd spend hours on that. ... Hours and hours. And then I'd spend hours ... I'd come in from that and I'd spend time on the exercise bike. And ... so yes, I'm spending a lot of time with this stroke. But, **I'm quite happy to spend as much time as it needs to get better.**

"And you felt that that wasn't being acknowledged by one or two people, is that what you are saying?"

"Well, it was when I got these two negatives replies I came home and thought 'no, **I am not going to let that beat me ...**'"

He had found a therapist at Westmead who was prepared to work with him in the way that he wanted:

"Well, when I was in Westmead, I was very fortunate that I had a physio there called M. who realised how keen I was, and he gave me a program to work to. And, you know, I'd work to it. And he would say 'well, let's finish' I would say 'no, we'll do it again'. **And he realised how keen I was and as hard as I'd work, he'd work me.** And that is the way I feel about it."

He was able to see progress in his rehabilitation and felt very good about that. He was also able to be philosophical about lack of progress as long as he was continuing to try. However, he had been attending Lottie Stewart for rehabilitation, and was shocked at the low level of therapy.

"This is one thing that frustrates me down at Lottie Stewart. Some of the people that I'm in the group with have been going there fifteen years, some thirteen years. **Fifteen years, and they've made no progress whatever.** They're just prepared to go there. **It's like a social club. And that's not for me.**"

When he was expected to work in the carpentry shop sanding wood (which he did not see as therapy) he would wander across to the gym and try to do some work on his own. One of the physiotherapists noticed this and started giving up her lunch-hour to work with him. He felt bad that she had to do this in order for him to get therapy.

"I felt as though I was an outsider because I couldn't get somebody to work with me. And the only girl that would help me gave up her lunch hour and I felt ... well now, that's not right for her to have to do that! And I felt that I'm not ... going to saddle up with another two or three years down at Lottie Stewart. Just going there and sandpapering timber."

He has been attending a private Physiotherapist as well to try and get the therapy he feels he needs. The only advantage he could see to attending Lottie Stewart was that it gave his wife a break:

"We had a lunch ... down there. ... But even though I wasn't finding it very helpful, it was good for E. because it got me out of the house and she could get on with what she had to do. Plus the fact she could jump in the car and go and do something. ... Without having to worry about me."

Lottie Stewart had also introduced him to the sport of Bowling - something he thought he might pursue in the future.

The morning that I interviewed him, he was very happy because he had just heard he was to return to Westmead the following week for outpatient therapy. This, at last, was what he felt he needed.

I asked him:

"What about the other side of dealing with this. Like at home - the frustrations that you've been talking about. How do you deal with those?"
"Very difficult. I know there was a couple of times. This may sound rather extreme, but I have seriously considered suicide."
"Have you?"

"Yep. I haven't told anybody. But I have seriously considered it. But then I think of this and this (*points to stickers with 'husband' and 'father' on them*). ... And put it out of my mind. I get that cranky with myself. I think to myself what do I have to look forward to. (*gets teary*)

"So you do get very down."

"Yes, very. Especially when I had this set-back the other day (*the convulsions*). I think to myself, you know, 'here I go again'."

"But this is what keeps you going?" (*points to stickers*)

"Yep."

"Being a husband and a father?"

"And a father, yeah. And a home life and everything, you know."

However, he is able to give himself credit when things work:

"What about when things go right? Do you give yourself credit for that?"

"Oh, well I feel good. Put it that way, I feel very good."

"Even though it wasn't ... You didn't manage to do it quite the way you might have done before?"

"No. **Even though it was a mundane chore I still feel good I managed to do it.**"

He sees no benefit to having had to take on this role.

Is there anything that makes you glad that you have this role? (*points to 'Dealing With a Stroke' sticker*)

"No. Nothing. No."

"So this role is a total negative for you?"

"Yeah. **It's the big negative in my life.**"

"Even though you say it brought you closer to your ... [wife]"

"Yeah. Well, we've always been close but, it ... has been wonderful. But no, I could do without that in my life. I sure could."

THE FUTURE

During the course of the interview, there were three possible roles that Mr. Twenty-three saw he might develop further. One was that of Bowler (already discussed above). Another was that of Traveller. I asked:

"If you could do anything at all that you wanted, what would it be?"

"Travel. We've planned a few trips together, but, you know, when the finances get better one day, there's things we'd like to do. But **the way I am at the present moment I'm afraid to do those things now.** Plus the fact that we **haven't got the finances** at the present moment."

He also identified a third role that he had already started to develop. When he was in hospital, he was visited by someone who had recently had a stroke. This person really bucked him up and strengthened his resolution not to give in to his disabilities. This experience had inspired him to do the same. A few weeks ago, he organised another friend to go with him to visit a surf club member he had known for years, (and never liked very much) who has just had a stroke. He found, first that his visit was appreciated, and second, that he found it satisfying because he felt able to draw on his own experience to offer support. The

man's wife reported how he had lifted his spirits and made him easier to get along with. He discussed how having a stroke had made him feel:

"Because as I said a little while ago you can become very depressed. ... Feel very sorry for yourself. You ask the question 'why me'? ... Because it always happens to somebody else. Then you say to yourself, I know I haven't been the best one on earth but, you know, I tried to do the right thing. Why did it happen to me? So I see that as a future role that I might try and get involved in something like that to try and help other people.

"Yeah. Oh, that'd be a great thing to do. Because, no matter how much the OT or the speech therapist or the physiotherapist or whoever, doctor, talks to you about it - they haven't had a stroke. So, I think it does make a huge difference to have someone to talk to who's been through it."

"You can become ... **You feel sometimes you can become violent with people around you, because you become so frustrated and so annoyed with yourself**, like E. has often said to me "don't smash something because we can't afford to replace it", you know? **Sometimes I'll try to do something and if won't work so I'll throw it. And then you think "you silly bugger what did you do that for?"** And, er ... this guy's just come home from hospital, and they've had to alter the house to get the wheelchair up and down the corridor and to build a room on the back because he's going to live out there. **And one thing I find is that you have a tendency to take it out ... When things go wrong, you have a tendency to take it out on your mate. ... And this is something you shouldn't do. Because without your mate you've got nothing.** And I know this J. would be very much along those lines and I feel as though I could talk to him, and the other J. could talk to him too, because we've both been there. And fortunately for us, we have both come out a bit reasonably well, when you look at some of the others, that are stuck in wheelchairs for years and years and years. So that's one role that I think I would pursue in time to come. ... Well, it's something that I think would be fulfilling from my point of view too. But see, once again, I'd have to ... Hopefully I'd be able to drive, not having to rely on my wife to take me everywhere. Now, I don't know whether that will ever come to fruition, as to whether I will be allowed to drive again."

D4: TRANSCRIPT ANALYSIS

EXAMPLES OF THEMATIC CODING

THEMATIC CODING - SAMPLE

THEMES THAT HAVE EMERGED FROM THIS TRANSCRIPT

- * There are friends who are people that you just socialise with and some (very few) friends who you might ask to help, or who help without being asked. Two categories of friends.
- * You don't ask friends for help - rule
- * The role of friend appears to have moved from productivity to socio-cultural as a result of the stroke.
- * As a father, he cares for the financial wellbeing of his children, while his wife provides emotional support and assistance .
- * Role of father has a financial dimension (see Mr. 17).
- * He feels having the stroke has drawn the family closer together.
- * The stroke has put stresses on his relationship with wife.
- * Concern about dependency on wife and son.
- * Recounted bad experiences with rehab. staff, in terms of being told he would not make any more progress, or he should accept the level of function he had achieved at that point. He wanted on-going rehab., but was unable to get therapy at the level that he desired and felt he needed.
- * Was shocked that there were people attending Day Hospital who saw it simply as a social outing
- * Inability to drive a theme that occurs throughout.
- * Garden maintenance a big issue - reason for move.

D4 -THEMES/IDEAS FROM ONGOING DATA ANALYSIS

Level of Role

Some informants were very clear about what was just an activity vs what was a role eg ID14 and ID13. What level is a role?

Confidence in own role performance

A number of participants seemed to compare their role performance now to prior to stroke and find it lacking. A number of participants expressed concern at whether others found their role performance satisfactory - particularly in socio-cultural roles.

Those who are internally driven vs. those who are externally driven

Some men able to talk clearly about what they want to do in their roles and what matters to them eg. ID17. Others seem to see themselves in terms of what they believe society expects of them eg. ID 13.

Those who are role focused vs those who are role diffuse

eg. ID 17 role focused. ID 15 role diffuse.

Perception of Life Focus as Related to Roles and Performance Areas

The interview often reveals a clear focus to each person's life. eg. the sportsman who is now focused on his exercise program. The labile man who was focused on his personal relationships - whether good or bad. The Irish man who is content to potter or just sit (?). The minority eg ID 15 do not appear focused.

Level of Satisfaction

More men are reasonably content with their role performance or lifestyle generally than are unhappy with it. Try and look at whether those men who have a life focus and feel they are achieving in that area are more satisfied in ratings than those who do not have a focus or are not achieving. That is, do men who are able to spend time doing things that have meaning for them express higher satisfaction than men who don't? See Friedan pp. 563 and Ogilvie.

Difficulty with the concept of Role

They have no difficulty in grasping what level we are talking at, although some need a bit of initial explanation. If I talk activity, they talk activity. If I talk at the role level, they talk at the role level, by and large.

Justification of Client Centred Approach

In every case (I think) when the roles are identified and sorted by interviewer, they are sorted differently and the roles are different to when they are agreed and sorted by the participant.

Content Reliability

There appears to be a good correlation between what they say in the interview and the rating scales at the end.

Methods of Role Definition/Confirmation

They see roles as the parts of their lives that they value. They see their social roles as roles. They do not see self maintenance as a role.

They have a clear idea of what is and what is not a role for them. eg. the gardener who wasn't.

ID 15 Used time as a criterion (p. 11)

Role of Husband/Partner

The majority of men interviewed so far are married and all express how much they value that role.

With regard to role as husband or partner. Perhaps those who feel still able to contribute or offer some of the advantages of having them as a husband that they used to contribute to the marriage, then they feel more positive about themselves and their lifestyle in general. This is, after all, probably their main remaining role, in which they spend the majority of their time, and which they attach most value to??? eg. the labile man ID2 was frightened his wife might leave him. He may have felt that he was not offering her much reason to stay as he was dependent upon her. ID1, on the other hand, used to help his wife and seemed to feel that this helped a little bit now that she was helping him. He was not so dependent as ID2 and helped his wife with meal preparation etc. a bit.

Role of Time Passer

Can include both active and passive activities - ID15 describes attending day care and watching TV etc. as time passing.

Productivity

Some have a narrow focus (from my perspective) on productivity and see it only as paid work. However, I have not identified many productivity roles either, except in the trial interviews, when I was trying to have something under each heading.

Self Maintenance

Self maintenance is seen as a set of activities that have to be done by them or with someone else helping, but are sometimes dismissed as not being at the role level.

Leisure

There are two types of leisure roles - ones that give active pleasure and ones which are just time passers. There is more blurring in this area about what is a role and what is just an activity.

Socio-cultural

Socio-cultural roles are seen as important by all participants and are the most clearly defined.

Culture

Cultural issues colour the information I am getting:

These men are not used to speaking in personal terms about how they feel. They see themselves in terms of the expectations of others and whether they are meeting those expectations. When asked about role of husband (a sensitive area) the typical response is "oh well, you'll have to ask the wife that". or "my wife is the best wife a man could have".

Manner of Responding

Some of them respond by comparing their current situation with what they were doing when they were younger - as if this is what will give them an identity or validity. Not that they speak of the past in glowing terms or with longing. I think for a few of them their identity is still tied up in the work role eg. man writing letters.

The conversations rarely proceed in a straight line or even with a logical thread at times, but digressions do give information about what matters to that person as they tend to bring up what is important to them and often return to the same theme again and again.

Experiences of Stroke and Rehabilitation

Most people wanted to tell me about the stroke and about their rehabilitation (ID1,2, 16 ...). For some it was the main focus. Some appeared to assume that that was what the interview was about and would start to recount their stroke story before I had a chance to explain what I wanted to do (ID 1, 2, 16 ...)

View of Role

Several respondents eg have a clear idea of what is expected of them on formal or social roles eg father. They talk as though this is the only way to look at that role and that they carry out the role because they know exactly what is expected of them by society and they firmly concur with those expectations. I did not see this as a belief he had but a real fact. They have difficulty sometimes seeing or talking about what they get out of their own role performance - even when they say things like it is fun. I seemed to see the fun part as very secondary to what was important in that role's performance.

Interviewer's Performance

I am conscious that they all make judgements about me - my age, my class etc. which then colours what they say - maybe some things are censored or, vice versa, some things are said that would not be said to the next person doing the same thing.

I am getting better at asking the right questions, but slacker about keeping the interview on course. I allow a lot of digression because I find it interesting and because I am relaxing more and feel more like this is a genuine conversation. Perhaps I am enjoying myself too much!

I am still not getting past the "how do you feel ..." barrier.

Use this and highlight with same colour roles that recur across different performance areas.

Possible Themes from individual transcripts

Mr. One

- * He appears to have achieved a transition that he finds satisfying from the role of active sportsman to that of remedial exerciser, and to be maintaining continuity with the other aspects of his sportsman role.
- * While expressing concern for the changes forced by his disability on the role of husband, I think the fact he had cared for his wife for five years has made it easier for him to accept help from her now. In particular, he did not express the fear or knowledge that the relationship had deteriorated as a result of his recently acquired dependency that other participants have done, but seemed satisfied with how that role was continuing.
- * All his roles except for that of friend appear to have strong occupational aspects.
- * He did not identify or express regret for lost roles.
- * In terms of role balance, it seems that prior to the stroke, leisure was the focus of his life. This has continued, but the needs he has developed as a result of the stroke mean

that now there is a strong self maintenance requirement and performance that overlays this. NB this man did not sort his own roles.

- * He is actively pursuing his own rehabilitation, taking control of the situation in which he finds himself, and expressing confidence about his performance in this role, unlike some of the other participants.
- * He appeared internally driven rather than externally driven in that he spoke as someone performing his roles in terms of his expectations of himself, rather than being externally driven and doing what he thought others expected of him.
- * He appeared role focused rather than role diffuse. Despite my ineptitude, he had clear areas of his life that mattered to him (sportsman, husband).
- * He had a single clear focus in his life (sportsman/remedial exerciser) and was able to spend time doing things that had meaning to him.
- * He expressed level 4 satisfaction for all his role areas. Given his level of disability, he appeared to be experiencing ongoing satisfaction in all role areas.
- * There was a good (subjective) correlation between transcript content and role ratings.
- * Although I did not really discuss what he regarded as roles and what he did not, and did not ask a role question, he made some role statements.
- * I did not ask him to sort his own roles, but discussed with him my sorting. Despite this, roles were moved as a result of the discussions and there was still a discrepancy between my sorting and his, indicating he had a clear idea of the main reason he carried out each role and had no difficulty sorting it.
- * Leisure: He described watching TV as time passing, but actively sought out sporting programs - particularly golf.
- * Productivity: I suspect he would not have had anything under productivity if I had not put something there. From the transcript, paid productivity was not important to him and was not a role that he missed. He was able to continue with volunteering aspects of productivity.
- * Self maintainer: I tried to give him a role as a Personal Carer but he clearly did not see that as a role from the transcript. I think Disability Manager might have been something he would have agreed to. Do the participants generally see self maintainer as being a role or are roles only things that say things about you as an individual and provide opportunities for self-expression? Self maintainer underpins and supports performance in other roles, but may not be considered in its own right.
- * Socio-cultural: he considered these to be important and valued them.
- * Cultural issues. He was interested in informing me about his experiences with a stroke. His expectations of the interview were to pass on words of wisdom about recovering from a stroke (people with a stroke need to keep exercising, I should go to a hospital and see what people with a stroke are like and see what the therapists do for them etc.). He saw himself as an expert in this area, to someone like myself, as he was in the area of sport. He did not expect or wish or feel able to discuss how he felt. He was happy to tell me what he did, but not keen to get into areas of personal disclosure.
- * He did not respond to my questions by reverting to the past. He only spoke of the past in order to explain and answer my question as well as he could.
- * He briefly told his stroke story, but only to explain to me how he came to be in his present situation.
- * He expressed a role rule in relation to husband (partnership) and sportsman (giving advice if asked). He appeared to see these as his own rules rather than what 'everybody' did in that role. He clearly felt them to be important to gaining satisfaction from role performance.
- * He appeared confident of further recovery
- * He expressed no real affection or antipathy to the rehabilitation team (unlike others)

- * He did not seem concerned about being a burden to others, more that he was no longer able to assist his wife as before.
- * He did not have any roles that he performed to satisfy the expectations of others.
- * Not sure if he sees his disability role as transitional or permanent. He clearly expects more recovery.
- * No thoughts of death expressed. No apparent depression.

Mr. Fifteen

- * He did not tell a stroke story
- * Does not have the fear of dependency or not being wanted by partner/family seen in some of the others.
- * Seems to be marking time until he dies. No particular focus to this gentleman. His enthusiasms appear to be for stamp collecting and his pets. Spent a lot of time talking about the process of dealing with ongoing chronic problems with hearing, sight, prostate etc. Did not seem to spend much of his time doing things that he valued (apart from interacting with his pets).
- * No hesitancy in sorting roles.
- * Gave reasons for role performance that related to the expectations of others.
- * He sorted Pet Owner under Other
- * Talked of his roles in terms of role sharing eg. Father/Child
- * Self maintainer not a role clearly agreed to on tape. I think I remember him refusing to consider stroke recoverer as a role - it was just something he had to do.
- * He had a life focus - he was a campaigner.
- * Had role rules
- * Was from high socio-economic group - a lot of confidence
- * Tried to do as much as he could for himself
- * No active rehabilitation.
- * Dependent on wife, but did not discuss that.
- * Aware of deteriorating relationship with wife - short fuse
- * Using work skills and experience to assist his children
- * His role as a campaigner helped him with self esteem
- * His role as a campaigner gave him an occupation outside his disabilities.
- * He saw a need for follow-up from OT
- * He took active control of his life - and took responsibility for himself - not a victim

Mr Nineteen

- * Uncertainty about further recovery
- * Unhelpfulness of rehabilitation team (doctor telling him he had a lot to look forward to, medication that made him feel worse (tired))
- * Fearfulness of being a burden to wife and children
- * Roles being performed mainly because of expectations or wishes of family (horseman, club member)
- * Disability role evident but not formalised - seen as a transitional state
- * Using knowledge and experience to help others
- * Perceived discrepancy between IRP and ORP (horseman and handyman)
- * Roles in transition (horseman, husband, father)
- * Roles that are declining (handyman, ?horseman) and increasing (? club member)
- * New roles (person with a disability)
- * Thoughts of death, wishing for an end. (p. 30)

- * Roles sorted under the same role area heading were given very different priorities eg. Husband and Stroke recoverer both sorted under self maintenance, but Husband given no. 1 priority and Stroke recoverer no. 6 out of 8.

Mr. Twenty-three

- * There are friends who are people that you just socialise with and some (very few) friends who you might ask to help, or who help without being asked. Two categories of friends.
- * You don't ask friends for help - rule
- * The role of friend appears to have moved from productivity to socio-cultural as a result of the stroke.
- * As a father, he cares for the financial wellbeing of his children, while his wife provides emotional support and assistance.
- * Role of father has a financial dimension (see Mr. 17).
- * He feels having the stroke has drawn the family closer together.
- * The stroke has put stresses on his relationship with wife.
- * Concern about dependency on wife and son.
- * Recounted bad experiences with rehab. staff, in terms of being told he would not make any more progress, or he should accept the level of function he had achieved at that point. He wanted on-going rehab., but was unable to get therapy at the level that he desired and felt he needed.
- * Was shocked that there were people attending Day Hospital who saw it simply as a social outing
- * Inability to drive a theme that occurs throughout.
- * Garden maintenance a big issue - reason for move.

Mr. Twenty-four

- * Concern about the extra burden he is placing on his wife
- * Seems unhappy but accepting of his disability
- * Still an active outpatient. Only comment about staff was that they would not recommend the pool for him, while he felt it would be beneficial to him.
- * Wife very supportive of him
- * Does not seem particularly active in any of his roles.
- * Does not have a focus to his role repertoire.
- * Has completely lost some roles as a result of his stroke.
- * Not sure how much the balance has shifted in his role as a husband - suspect his wife was doing all the cooking, housework etc. and 'looking after him' before his stroke. He seems concerned about the extra work she has to do, but not about the nature of their relationship.
- * There seems no change in his role as a grandfather
- * Not sure of the changes in his role as a father, but he seems to see it as being reduced.
- * Seems to spend the bulk of his time passing - passive leisure or resting.
- * Feels rehabilitation is helpful and can see progress
- * Does not carry out home program of exercises
- * Perhaps his wife's unconditional positive regard means that he is under no external pressure to perform and does not therefore have the environmental demands to respond to - therefore remains unfocused and inactive???