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Life after stroke: the characteristics of those aged 18 to 55 years and an evaluation of a support service

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Summary

A common perception is that only old people have strokes. However this condition also occurs in adults under retirement age. Few studies have been conducted relating to this age group post stroke and there is a paucity of services available for them once they are discharged from traditional rehabilitation services. In July 1995 a Day Service Pilot Project was launched in Cardiff for people who were aged between 18 and 55 years and who had a stroke. This unique service aimed to provide them with the opportunity to identify and pursue meaningful and realistic opportunities within the community. It was established in the belief that these adults were not fully participating in society. This study is an in-depth analysis of the characteristics of those who attend this service and an evaluation of the service using quantitative and qualitative methods. Twenty-six participants were recruited to the study between June 1998 and January 2000. The findings suggest that attendance at the service increased participation in leisure activities, perceptions of increased occupational performance and feelings of independence. The environment was considered a 'safe' one which prevented isolation, promoted social interaction and aided general recovery. The findings also indicated that post-stroke these individuals were not fully independent in activities of daily living, over 50% were depressed and anxious, they had a poor quality of life, they did not retain the range of roles they had prior to the stroke and although they had a range of self-care, productivity and leisure occupations which were important to them, they had difficulty in performing them. Although there were some gains from attending the service there were also many unmet needs. The service providers need to reconsider the aims and structure of such services to target these needs. Further research is required to continue to identify how best to meet the needs of individuals post stroke under retirement age.

Declaration

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

Signed. ....(candidate)

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Statement 1

This thesis is the result of my own investigation, except where otherwise stated.

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Contents

Chapters

Appendices

List of Figures

List of Tables

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CHAPTER 1.

INTRODUCTION

1. INTRODUCTION

Participating in society and enjoying life fully are expectations that most adults would hold. According to literature these also contribute to perceptions of feeling healthy and considering quality of life to be good (Reed & Sanderson 1992, Blaxter 1995, Bogousslavsky et al 1998). Many factors can contribute to why an individual may not be achieving these expectations, one being an illness or disease. A stroke is an incident that can result in physical and psychological impairments. These impairments may be long term and may have an impact on the individual continuing to participate fully in society and enjoy life. It is recognised by the World Health Organisation (2001), for example, that individuals may be free of disease but continue to have health-related problems which have an effect on their ability to perform everyday activities (McLaughlin Gray 2001).

There is a common belief that strokes only happen to old people when, in fact, of the 130,000 incidents of stroke, 10,000 (7.7%) occur in those under 65 years (Stroke Association 1996). People who are between the ages of 18 to 55 years have various roles and responsibilities. They, like all ages, undertake a collection of occupations daily including self-care, productivity and leisure ones, of which some may be particular to their age group such as working, maintaining their home and caring for young children or ageing parents. The nature and consequences of stroke may mean that life is very different for them than prior to the stroke, and coping with normal living may be difficult as it would be for older people (Anderson, 1992). However, few studies have been conducted to investigate this.

The issue of how a stroke affects an individual in the long term, in the community, has been of interest to the researcher since conducting a randomised controlled trial investigating continued occupational therapy for stroke patients after hospital discharge (Corr 1994). Although that study involved a population whose mean age was 75 years, the range was 41 to 96. This gave the researcher experience of providing an intervention for a small number of individuals under the age of 55. Coming from an occupational therapy background the researcher is aware of the assumption that purposeful occupations or activities can positively influence a person's sense of well being and thus their state of health and level of functional independence (Wilcock 1993a). According to McLaughlin Gray (2001) there is growing recognition among healthcare providers that function and even occupations are important indicators of health and well-being. If the assumption is true it is possible that the effects of a stroke would result in poor occupational functioning or inactivity and thus poor health. How a stroke affects a younger individual in the long term in the context of their occupations is not known, while few studies have been carried out to enhance understanding of the relationship between occupational functioning and health.

Currently in the UK two voluntary organisations support individuals post stroke, while statutory services specifically for younger adults do not appear to exist. Different Strokes aims to change people's attitude to stroke and create awareness that it affects not just old people (Different Strokes, 2001). Networks and informal support groups have been established throughout England, with one of each in Scotland and Northern Ireland but none in Wales. The Stroke Association (1995) has a long history of developing services, support groups and funding research into all aspects of stroke. They established the only service that exists specifically for adults aged between 18 and 55 years, the Cardiff Day Service. This service meets weekly for full-day sessions with the aim to offer participants the opportunity to identify and pursue meaningful and realistic opportunities within the community. The purpose of these opportunities is to help individuals to meet their personal aspirations and enable them to develop to their full potential. There is no evidence to suggest that the Stroke Association conducted formal research prior to establishing the service to identity the needs of this group but the aim of the service suggests a belief that this group of individuals was not participating in occupations within society.

The Cardiff Day Service was established by the Stroke Association as a pilot service in 1995. In 1998 the Stroke Association wished to understand what, if any, benefits were obtained by users of this service and therefore commissioned an evaluation of the service. It is this evaluation that is reported in this thesis in addition to an in-depth analysis of the characteristics and needs of adults pre-retirement age, post-stroke. The two aims of this study were to identify the characteristics, problems and needs of people in the younger adult age group with a stroke and to evaluate the Cardiff Day Service.
Objectives:

- establishing the age, gender, living circumstances, levels of function in occupations, mood, quality of life and self-concept of this research sample;
- identifying the problems and needs of this population;

- comparing pre and post service of occupational performance, mood, social functioning, self-concept and quality of life levels (quantitatively);
- seeking stakeholders' perceptions of the service (qualitatively);
- establishing the effect of waiting to attend the service:
- identifying any maintenance of gain six months after attending the service;
- informing service planning for both statutory and voluntary agencies;
- contributing to a greater understanding of the relationship between occupational functioning and health in the context of adults with stroke.

The majority of research relating to stroke and stroke care focuses on in-patient rehabilitation although some current literature relates to community rehabilitation. However, there is a dearth of literature relating to services or studies relating to the impact of a stroke on an individual's life if they fall into the 18 to 55 years age group. This study therefore is original in providing information relating to this group for service planning and for contributing to a greater understanding of stroke from an occupational perspective. According to Kittner (1998) the study of stroke in young adults is a neglected area. There is the need for continued developments in stroke care and research to identify the effectiveness of services (Stroke Association 1996). This study contributes to both.

Following an introductory chapter, three chapters review literature relevant to the key issues of the investigation (Chapter 2 – Health, Chapter 3 – Occupation for Health, Chapter 4 – Stroke). A range of literature was accessed using computer databases such as Cumulative Index to Nursing and Allied Health Literature (CINAHL) and MEDLINE. Hand searches of British, American, Canadian, Australian and Scandinavian occupational therapy journals were also conducted. Keywords, used singly and in combination, included health, occupation, stroke, adults, occupational therapy, work, leisure, self-care, young, services, evaluation, quality of life and activities of daily living

Chapter 5 (Study Design) outlines the notion of evaluation research and justifies the study tools used including research approaches and techniques while Chapter 6 (Methods) outlines the exact procedures undertaken for this research. Chapter 7 (Post-stroke abilities – results and discussion) presents and discusses the findings of the in – depth analysis of characteristics and problems. Chapter 8 (Service evaluation – results) presents the findings of the multi-method evaluation of the Cardiff Day Service which are then discussed in Chapter 9 (Service evaluation - discussion). In Chapter 10 conclusions are drawn and recommendations made including suggestions for further research.

CHAPTER 2.

LITERATURE REVIEW - HEALTH

2. LITERATURE REVIEW – HEALTH

2.1 INTRODUCTION

This chapter will explore the broad range of concepts of health that exist. Well-being and quality of life are considered to be influenced by health. Attempts to identify what constitutes quality of life and well-being will be made in consideration of their relationship to each other and to health.

2.2 CONCEPTS OF HEALTH

Blair and Hume (1997) suggest that as health is a complex matter, it is a difficult concept to define. Seedhouse (1986) considers there to be a paradox when considering health. He suggests that

> health is a goal that is desired universally, but which does not have a universally shared meaning, and so cannot be desired universally (Seedhouse,1986:10).

A multifaceted phenomenon is how Aggleton (1990) describes health. Wright (1979) suggests that most of the debate on concepts of health is to be found in the medical sociology literature and that in the late 1970's several different ways of looking at health were outlined. These were health as an ideal, health as relating to illness and disease and health as the capacity to function socially. Each of these concepts will be presented in addition to concepts identified by other authors.

Health as an ideal state

According to Wright (1979) health was considered as an ideal or absolute concept. Seedhouse (1986) also considers health as an ideal state. This portrays health as an optimal level of well being that is aimed for, but in reality is virtually impossible to attain. Aggleton (1990) also identifies health as a state of being to which most aspire but one which money cannot buy.

Health as relating to illness and disease

Health as a relative concept that can be defined only in relation to illness and disease is another view presented by Wright (1979). Rogers (1982) considers health as the biomedical concept of order suggesting it refers primarily to the absence of biological signs, symptoms, and dysfunctions and therefore can be restored by removing disease by medical interventions such as drugs and surgery (Rogers, 1982). Bowling (2002) suggests that this view is based on objectivity and measurement, in particular of physical and chemical data. Blair and Hume (1997) however argue against this view suggesting that health is not just the absence of disease. The World Health Organisation (WHO) as early as 1946 (cited in Aggleton, 1990) defined health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. Aggleton (1990) suggests that this definition sets high targets to be achieved and is therefore too idealistic by expecting a state of being which it is impossible to attain. He also criticises this early World Health Organisation definition for suggesting

> that we are all unhealthy unless we have attained complete physical, mental and social well-being (Aggleton,1990:8).

Bowling (2002:20) considers this approach as potentially focussing

> too narrowly on the body and on technology rather than on people in the social context in which they live.

Wilcock (1998) considers this focus of health as the absence of disease not surprising. She suggests that

> in countries with advanced medical technology, people have been socialised to think about health and illness in terms of medical and physical sciences (Wilcock, 1998:97).

In May 2001, the World Health Organisation endorsed an International Classification of Functioning, Disability and Health. The purpose of this is to describe how people live with a health condition and it acknowledges that health relates to body functions and structures, activities, participation considering society and environmental issues (WHO, 2001). This illustrates that the World Health Organisation consides health in a wider perspective than previously; it acknowledges that people are surviving illnesses, but have health related problems which affect their everyday functioning, health and well-being (McLaughlin Gray, 2001).

Health as a capacity to function socially

A third view of health is as a capacity to function socially and thus maintain individual life styles as well as equilibrium of the social system (Wright 1979). A similar view is held by

Reed and Sanderson (1992), who consider health as encompassing the biological, sociological and psychological aspects of an individual. They consider health

> as a dynamic and changing phenomenon" and illness "to interfere with a person's ability to meet responsibilities because it alters an individual's potential methods of reaching a goal, changes the positions/roles a person has, and it reduces the number of occupations that a person can perform (Reed & Sanderson, 1992:84).

Seedhouse (1986) also considers health as a capacity to function. He suggests that

> a person's optimum state of health is equivalent to the state of the set of conditions which fulfil or enable a person to work to fulfil his or her realistic chosen and biological potentials (Seedhouse,1986:61).

He also outlines the foundations which make up health and outlines them in order of importance, including:

- The basic needs of food, drink, shelter, warmth and purpose in life.
- Access to the widest possible information about all factors which have an influence on a person's life.
- The skill and confidence to assimilate this information, and to be able to make reasoned decisions about what action to take in the light of their information.
- The recognition that an individual is never totally isolated from other people and the external world and that an essential condition for health is that individuals have an awareness of a basic duty they have because they are people in a community (Seedhouse,1986:62).

Tarlov (1996) also considers health in a social context suggesting that it can be defined in terms of functional ability and well-being within the social environment of an individual. He also considers good health to hold the highest value in every society and to provide the capacity for individual fulfilment. Because of this social context aspect, Tarlov (1996) considers this definition to be applicable to a population as well as to an individual. Aggleton (1990) argues that if health is defined as an 'optimum capacity'; anything other than this is obviously not health, which implies that ill-health is something that is intrinsically bad for society. The type of functioning may vary depending on age. Aggleton (1990:1) suggests that

> for many of those who are young, health may be associated with participation in a variety of activities, whereas for many people over 75, health may be the ability to undertake a more restricted range of actions.

Dubos (1995:9) also holds the view that

> health and disease cannot be defined merely in terms of anatomical, physiological or mental attributes.

He considers the ability of the individual to function within his life and society to be important.

Blaxter (1995), in an attempt to understand the concepts of health, carried out a survey of 9000 individuals asking them to consider someone they know who was very healthy and what made the respondents consider them healthy. Secondly the survey asked participants to consider the statement "at times people are healthier than at other times" and give their views on "what is it like when you are healthy?" Blaxter (1995) analysed the findings of ten per cent of the respondents and stated that for this random group the analysis was in-depth, looking at the precise language used and ideas expressed. She found that the way in which health was perceived differed with age. Younger men related to health in terms of physical strength and fitness, while young women related to ideas of energy, vitality and ability to cope. Concepts of health became more complex in middle age, with an emphasis being upon both mental and physical well-being. Older people, particularly men, related to health in terms of function, or the ability to do things. However, Blaxter (1995) also found that ideas of health as contentment, happiness, a state of mind, including situations where disease or disability were present, were expressed. In addition, Blaxter (1995) found that many women but few men, included social relationships in their definition of health. These findings provide a lay view of health as opposed to a health professional one. The use of just ten per cent of the responses for the findings is questionable, even if they were selected randomly as Blaxter suggests. There is no evidence that the selection was stratified, that is, where each member of the population had an equal chance of being selected in relation to their proportion within the total population (Denscombe 1998). This would have ensured that representative proportions of responses from men and women, young, middle aged and older individuals were selected. Without that information, it is not possible to appreciate the strength of views presented, although information suggesting the views are present does nevertheless contribute to understanding perceptions of health.

Health as reserve of strength

As previously stated Wright (1979) presented several concepts of health but the literature presents more. Seedhouse (1986:1) presents an additional concept and considers that

> health is a reserve of strength, or that health is an ability to adapt to changing circumstances, or that health is a resilient spirit.

No other literature was found with this concept, suggesting that Seedhouse may be alone in holding this view.

Health as a commodity

Aggleton (1990) adds an additional concept by considering health as a commodity. He suggests that health is viewed as

> something which can be bought (by investment in private health care), sold (via health food stores and health centres), given (by surgery and drugs) and lost (following accident or disease) (Aggleton,1990:11).

He suggests caution at accepting this view because it presents health as something that is removed from the person and that restoring an individual to health is a technical matter, such as the administration of drugs or by surgical intervention performed by experts.

Explaining health

In addition to literature presenting concepts of health, studies have been conducted to identify how individuals explain health. Two, both conducted in 1993, by Stainton Rogers and Crawford are outlined here.

Stainton Rogers (1993) conducted her study by using Q methodology to establish how people explain health and illness. Q methodology is a research tool that enables perceptions to be identified and is explained in greater depth in Chapter 5, as it was used in the evaluation of the Cardiff Day Service. Stainton Rogers (1993) developed a Q pack of eighty statements which seventy individuals sorted. The participants included individuals she describes as 'ordinary folk' as well as healthcare professionals, practitioners of 'alternative medicine' and individuals who might have unusual ideas such as members of religious sects and people suffering from congenital disease. From the data analysis eight different accounts of health were identified. These were:

- Body as Machine - a view expressed mainly by medical professionals, which supported the conventional medical view of health and illness, seeing modern therapeutic achievements as having made major contributions to health care and fighting disease. It portrayed the body as a machine that can either run well if properly fed, serviced and maintained or if neglected it may break down, needing medicine to 'fix' it;

- Body under Siege – a view expressed by 'ordinary people', where the individual was seen to be constantly under threat and attack from germs and diseases, interpersonal conflicts and the stress of modem life;
- Health Promotion – a view expressed by people actively involved in health education, which focused on health rather than illness, seeing it as a fundamental human right, and 'one of the most important things in life'. Good health was seen as a matter of lifestyle ;
- Inequality of Access – a view expressed by people who described their political views as 'left-wing', which illustrates their conviction of the benefits of modem healthcare. They also have concerns about the inequality of health and the lack of availability of services to those who need them most;
- Cultural Critique – a view which was concerned with power in terms of knowledge and resources of the medical profession;
- God's Power – a view expressed by a number of people who described themselves as religious, which illustrated a strong focus on the power of spiritual forces, God and prayer in healing. It strongly rejected luck as an influence and viewed health as a product of correct living, spiritual well-being and God's care;
- Willpower – a view expressed by several practitioners in 'alternative medicine', which considered the body's functioning as a resource upon which the individual could draw to promote health and fight off disease. Health, in this view, is something that is worked for, both in actions and also in state of mind;
- Robust Individualism – a view expressed by a variety of people who were far less concerned with explaining health and illness than with the importance of the individual's freedom to choose how to live his or her life. Health was portrayed as an 'investment'.

There are a few similarities between these eight views and the concepts already identified. Body as machine links with the concept of health relating to illness and disease, the biomedical view. The robust individualism may be considered to relate to the concept of health as a capacity to function socially as both are concerned with doing and with the individuals' choice or freedom to be able to do what they wish to do.

Stainton Rogers (1993) concludes that these eight accounts illustrate the variety of views held on health and illness. She suggests that health professionals need to be aware that people are not consistent when considering health and in fact some views are contradictory. Stainton Rogers conducted the study in the UK. The study conducted by Crawford used American participants. He interviewed sixty adults in the Chicago metropolitan area, each interview being between one and a half to two hours in length (Crawford, 1993). Almost two-thirds of the participants were white, middle class, under forty and female, thus large and important categories of the American population were not, or were only minimally, included. It is assumed that participants were not healthcare professionals as Crawford (1993:134) identifies the object of this research was to see things 'from the native's point of view'. Participants were invited to describe their health and to indicate how they defined the term. They were also asked about their explanations for their state of health: what they identified about themselves or their physical or social environments as important; what they perceived as a threat to their health; and what, if anything, they believed they could or should do to protect or enhance their health (Crawford, 1993). Two main themes were presented as findings: health as self-control and health as release. Crawford (1993:134) found the view that "to be healthy takes a little more discipline" and that issues such as self-discipline, self-denial, and willpower played a part in this. Stainton Rogers (1993) had also identified willpower as contributing to individuals' explanations of health.

Health as release was explained as enjoying life without worry and without a self-denying load of constraints. Being able to pursue a free 'lifestyle', and "being able to do what you want to do when you want to do it" (Crawford, 1993:138) were also given as explanations for health as release. This holds similarities to the earlier presentation of the concept of health as a capacity to function socially and Stainton Rogers' (1993) 'robust individualsim' view.

A smaller and more recent study was conducted by Bjorklund and Svensson (2000) in Sweden to establish how a group of experienced occupational therapists identify and characterise conceptions of health. Interviews were conducted with 21 (female) experienced occupational therapists who had a mean work experience of 6.7 years and were practising in various healthcare settings. They found three main themes – health as 'feeling fine', as ability to act, and as an objective state of body and/or mind (Bjorklund & Svensson, 2000).

Health as "feeling fine" related to the experiencing of positive value feelings such as to feel well, happy, strong, important or content. They found that these feelings were what the participants indicated as the meaning of health and not as indications of the presence of health. This positive value could be perceived as similar to Crawford's (1993) 'health as release' but it does not directly link with Stainton Rogers' (1993) accounts, 'robust individualism' being the closest possibility.

Health as the ability of an individual to act or to live a life how they would wish was a second theme explaining the meaning of health. The ability to have control over one's life was found to be important resulting in the ability to function in a way that "matches one's ambitions and life projects" (Bjorklund & Svensson:2000:29). They found that the occupational therapists identified the ability to be able to participate in activities of diverse kinds including work and leisure. Again, this ability to participate in life is reiterated as a concept of health. It is also similar to the views of Wright (1979), Seedhouse (1986), Aggleton (1990), Reed and Sanderson (1992), Crawford (1993), Dubos (1995) and Tarlov (1996).

The third theme Bjorklund and Svensson (2000) found was health as an objective state of body and/or mind. This theme contained statements on the meaning of health that tended to suggest objective, matter-of-fact characteristics as important parts of that meaning. For example they found that health was expressed in terms of the factual presence of a certain state of mind and/or body or the absence of some such state. Bjorklund and Svensson (2000:31) conclude that for their sample of occupational therapists health is

> something that applies to a person as a whole rather than to some part of his/her body, and something that is to be determined from the point of view of the person's own assessment.

The view of health as the capacity to function is the most commonly held in literature. The Canadian Association of Occupational Therapy (1994) also endorses the relationship between health and doing, and that health is more than the absence of disease. None of the studies described included a specific population of individuals who had a stroke. Their view of health is therefore unknown, but in light of the most commonly held view relating to the capacity to function, it is likely that if a stroke affects the ability to function, it will affect the individual's health. This literature supports the consideration of how a stroke affects individuals in terms of functioning when evaluating the Cardiff Day Service.

2.3 HEALTH, WELL-BEING AND QUALITY OF LIFE

Although the concepts of health have been explained in the last section, they will also be considered in relation to well-being and quality of life. Well-being according to Wilcock (1998) is a feeling and subjective. She describes it as "intangible and amorphous a concept as charm or style" (Wilcock, 1998:98). It is described as a pleasant sensation and can differ from person to person.

"Health and well-being are much more than just the absence of disease" (do Rozario, 1992:32). Edginton et al (1995:9) use the terms life satisfaction and well-being interchangeably. They identify the variables they consider to contribute to these. They include:

> self-esteem, satisfaction with self, standard of living, family life, work, mental and physical health, community, mood, place of residence, physical attractiveness, and leisure.

Other factors such as income, age, gender, race/ethnicity, employment, education, marriage and family, social contact, personality, creativity, and activities are also considered to contribute to well-being. They define an optimal lifestyle as

> the integration and balance of the physical, mental, emotional, intellectual, social, and spiritual aspects of a person

and consider this to have a great influence on well-being (Edginton et al, 1995:9). They believe that all individuals are capable of achieving an optimal level of life satisfaction or well-being.

The term quality of life is a difficult one to define, as it appears to have a range of different meanings. Bowling and Normand (1998) consider it to be a broad concept, greater than just health status and one that takes social well-being into account. Bogousslavsky et al (1998) suggest that there are many different issues to take into account when considering what constitutes quality of life. These include

> orientation, physical independence, mobility, occupation of time, social integration, and economic self-sufficiency (Bogousslavsky et al 1998:78).

Fallowfield (1990) and De Haan et al (1993) suggest that four domains make up quality of life. These are physical, functional, psychological, and social health. The physical health dimension refers to disease related and treatment related symptoms as well as pain and sleep. The functional dimension comprises self-care, mobility and physical activity level, as well as the capacity to carry out various roles in relation to family and work. The psychological dimension includes issues such as depression, anxiety and adjustment to illness, cognitive functioning, well being, life satisfaction and happiness. Finally the social health dimension includes qualitative and quantitative aspects of social contacts and interactions, such as relationships and participation in leisure and social activities. The inclusion of these dimensions reflects the need to ensure that, when thinking of quality of life as a concept, it is important to see it as a broad spectrum of consequences of disease, including elements of impairment, disabilities and handicaps, as well as individuals' perceived health status and well-being.

What is not clear is the required balance of the four dimensions that needs to be present in order to ensure quality of life. Diener (1984) suggests that part of the influence of health on quality of life is not simply the direct effect on how people feel physically, but also on what their health allows them to do. For example in two separate studies of stroke patients, Niemei et al (1988) and Wyller et al (1997) found that even when patients had a good recovery in terms of physical movement they reported a poor quality of life. Niemi et al (1988) studied the quality of life in 46 adults under the age of 65 in Finland who had a stroke four years earlier. Eighteen of the sample were aged 17 to 50 years and 78% of them indicated that their quality of life had deteriorated. This was less than the 51 to 64 age group where 87% indicated a deterioration. Although a small study, their findings of such high percentages of deterioration should be noted. In another Scandinavian study, Wyller et al (1997) recruited 60 individuals who had a stroke (median age 74 years) and 419 'reference' individuals (median age 75 years). They found a considerably lower quality of life in those who had a stroke. They acknowledged that a weakness in the study was the selection of individuals. Many were excluded for medical reasons, suggesting that those included may have been more able following their stroke. These studies show that the impact of a disease on health related quality of life is important but can be difficult to understand and to measure.

Although quality of life is a term used extensively, there are other expressions in the health context that are also used. These are health-related quality of life, subjective well-being, life satisfaction and happiness. Anderson (1988) proposes that an interest in quality of life by healthcare professionals has increased as a reflection of services being about caring, in addition to curing, and thus aiming to enhance well-being. He suggests that it allows consideration of the significance of an illness to everyday living in particular where there may be consequences for various aspects of life such as work and family. Fitzpatrick et al (1992) suggest that the term quality of life is misleading when used in a medical setting as it suggests an abstract and philosophical approach. They argue that in practice most approaches used in medical contexts make no effort to include more general notions such as life satisfaction or living standards, but instead concentrate on experiences that relate to health and health care. In light of this they advocate that the dimensions of quality of life should include

> physical function such as self care, mobility; emotional function such as depression, anxiety; social function such as intimacy, social support, social contact; role performance such as work, housework; pain; and other symptoms such as fatigue, nausea, disease specific symptoms (Fitzpatrick et al, 1992:1075).

Bennett (2000) also advocates the inclusion of an evaluation of an individual's satisfaction with their ability to participate in activities within the umbrella of quality of life.

Bowling and Normand (1998:14) use the term health-related quality of life and defines this as

> optimum levels of mental, physical role (e.g. work, school, parent, carer, etc) and social functioning, including relationships.

Because it is health-related quality of life Bowling and Normand (1998) suggest it should also include perceptions of health, fitness, life satisfaction and well-being and a patient assessment of their satisfaction with the health care they have received. What distinguishes it from just quality of life is the fact that it does not need to include wider issues such as income and adequacy of housing.

The Canadian Association of Occupational Therapists (1997) suggests that quality of life relates to people having choice and control in their lives. They perceive the North American concern for quality of life to be driven by medical philosophies that focus on preserving the quantity of life, which may have little quality. According to Iso-Aloha, (1980), the most important aspect of quality of life is perceptions. A person can be happy and satisfied with life if he/she so decides, no matter how much he/she owns or does. It is the individual's own perceptions that underlie their personal definition of the quality of life. Iso-Aloha (1980) suggests that it is the individual who decides and determines the importance of contributing factors such as material things to his quality of life. He considers that feelings of happiness, life satisfaction, and psychological well-being will result in high quality of life (Iso-Aloha, 1980:380).

Do Rozario (1992) conducted a qualitative study using autobiographies and in-depth interviews with 40 people to understand the subjective experience of a physical disability or chronic illness from the individuals with a range of different medical diagnoses. Five principal themes emerged which illustrate people's perceptions and experiences related to coping factors that facilitate health and well-being. These were:

- *the power of hope*

  Hope was seen as an essential life-affirming force that for most participants kept them living and growing
- *the need for personal control*

  Regaining personal control was found to be crucial in restoring personal identity and motivation to cope with adversity. Many participants indicated that having helpers created a sense of being 'taken over' or 'losing control' and can bring about feelings of passivity, lack of control and helplessness, a sense of just waiting to die in recipients of 'care'. The participants suggested that this can result in a lack of motivation to restore life and health. For some participants this lack of control led to feelings of anger and a subsequent desire to take back their sense of personal control.
- *the contribution of positive external support*

  Support from friends, families or others was found to be important as long as participants were accepted for who they were, and what they chose to do in their lives. They recognised the paradoxical nature of societal support where often strings are attached to the support networks, and invariably, the carers ask the person to change or invalidate beliefs or values. On the one hand, society reaches out and offers help, while at the same time creates stigma.
- *the need for meaningful activity and creative participation in life*

  The findings suggest that "creating, doing, interacting, learning and exploring challenges are essential for people to feel worthwhile, a part of something and contributing to society and their personal development" (do Rozario, 1992:31).

  All participants indicated that 'doing' needed to be meaningful and valued by the individual, thus helping people find interest in life.
- *and the healing ability of spiritual experiences*

> Participants described how the experience of an illness or disability offered them an opportunity to come to terms with themselves, and to discover inner determination, courage and self-love. This experience resulted in 'spiritual' discovery, where the goal was to reconcile the illness or disease and move towards integration and optimal health and well-being (do Rozario, 1992).

Although five themes emerged, do Rozario (1992) found that individual variations occurred in relation to individuals' success at coping. She found that coping strategies were dependent on many factors such as

> personal resources, religious beliefs, values and attitudes, current health status, valued external supports and active participation in life (do Rozario, 1992:29).

Ultimately, though, the five factors were found to facilitate health and well-being. Yet again the ability to function in society and carry out meaningful activities is linked to health.

Mayers (1995) also introduces a spiritual component to quality of life. Other factors which contribute to quality of life according to her are personal safety and privacy/personal space. Like health, quality of life and well-being have several meanings, some overlapping. However there appears to be a consensus that relationships and ability to function contribute to quality of life. The subjective perception of all three can also be considered key.

2.4 SUMMARY

Defining health, well-being and quality of life is difficult due to the variety of perspectives that can be considered. It would appear that the concept of health has broadened over time to be wider than the absence of illness and disease. Key considerations in defining health more recently relate to being able to carry out what activities an individual wishes to, to have an active part in society, and that is subjective. Well-being, life satisfaction and quality of life are acknowledged to be affected by illness or disease if it causes restrictions on an ability to function. When establishing the Cardiff Day Service it can be assumed that the Stroke Association was aware of possible restrictions in functional ability. They established the service to facilitate participation in society in a meaningful way. Based on the literature presented in this chapter it is suggested that the Stroke

Association had concern for the health, well-being and quality of life of adults who had a stroke. The next chapter will focus on the place of participating in occupations in relation to health.

CHAPTER 3

LITERATURE REVIEW – OCCUPATION FOR HEALTH

3. LITERATURE REVIEW – OCCUPATION FOR HEALTH

3.1 INTRODUCTION

A stroke can affect how an individual may carry out their everyday occupations. In order to have a greater understanding of occupations for everyday living it has been considered relevant to explore these issues. The Cardiff Day Service does not include occupational therapy. However, the content of the service is activity based. The aim of the service suggests a desire to enable individuals to participate in the community. Much of the literature relating to performing occupation stems from the occupational therapy literature, some of which is presented here. This section of the literature review will outline different definitions of occupation. Some of the literature relates to the study of the complex occupational nature of humans and the relationship between occupation and health (Ilott 1995, Jackson 1998a). In recent years there has been a growth in occupational science literature. Wilcock (1991:297) defines occupational science as

> the systematic study of all aspects of the relationship between humans and occupation, occupation encompassing people's goal-directed use of time, energy, interest and attention in work, leisure, family, cultural, self-care and rest activities.

Many believe that being engaged in occupations is necessary for health. This premise will be explored. In addition, literature exploring the human need to be occupied and the effects of being unable to participate will be reviewed.

Occupations are often categorised into three groups – self-care, productivity or leisure (Reed & Sanderson, 1992). These categories will be outlined as will the issue of having a balance of occupations. As the treatment media for occupational therapy is occupations the literature review will draw from occupational therapy literature to include the philosophical arguments for this concept.

3.2. OCCUPATIONS AND OCCUPATIONAL THERAPY

3.2.1 Definition

Wu and Lin, (1999) suggest that until recently, little attention had been given to defining the term "occupation". It was mainly in the 1990s that most discussion took place describing occupation in a way that indicated its complexity. According to the Collins Dictionary (1987:685) one of the definitions of occupation is

> a person's regular work, any activity on which time is spent or the act of occupying or the state of being occupied.

An even broader range of definitions is provided within the occupational science literature suggesting that it is considered as being much more than paid employment (Wilcock 1993b). The Canadian Association of Occupational Therapists (CAOT) define occupation as

> everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity) (CAOT, 1997:3).

According to Townsend (2000), this is a humanistic and social view of occupation rather than an industrial view in which occupation is defined as work. Christiansen (1991a:26) considers occupation as

> a general term that refers to engagement in activities, tasks, and roles for the purpose of productive pursuit (such as work and education), maintaining oneself in the environment, and for purposes of relaxation, entertainment, creativity, and celebration.

Christiansen (1991a:26) describes occupations as

> groupings of functional tasks and roles in which persons engage over a lifetime for a variety of purposes such as self-maintenance, self-expression and fulfilment.

He continues to outline the progression from action to tasks and to occupation. Action is the basic unit of occupation such as cutting vegetables. The purpose of the action e.g. cutting vegetables, can be to accomplish a task such as preparing a casserole. Tasks are groups of actions carried out for a specific purpose. Tasks can be grouped to make up the occupations required to fulfil roles. The occupation of meal preparation, for example, is composed of a number of tasks such as preparing a casserole and vegetables.

The context within which occupations are carried out, that is, the environment, is included in Goldstein's definition

> occupations are goal directed, self-initiated and involve roles, habits and skills we develop to facilitate our actions in the social and physical environment in which we live (1996:13).

The place of the context is crucial, according to McLaughlin Gray (1997), who suggests that occupations generally cannot be identified unless the context is addressed. Wu and Lin (1999:5) also consider the environment and the complexity of occupations in their definition

> Occupation must be considered as a complex dynamic involving individuals and their purposive behaviour within environmental contexts that have meaning and which change over time.

They introduce the changing nature of occupations which reinforces the dynamic concept. As occupation is used to describe what one is doing or the structure of what one does, both Christiansen (1990) and Breines (1995) consider it to be difficult to define. Yerxa et al, (1990) also consider occupation to be a complex multidimensional phenomenon. They suggest that its components are rules, habits, and skills. These are learned through the course of development and, when they are organised, allow individuals to fulfil their occupational roles.

Occupation and Activity

Until recently the term activity was used rather than occupation in the occupational therapy literature. Golledge (1998a) suggests that it is difficult to avoid using the term activity in an explanation of occupation. Earlier literature such as Turner (1996) and Wu et al (1994) use the terms ‘occupation’ and ‘purposeful activity’ interchangeably. Creek (1997:32) clarifies the two terms stating that

> an occupation has meaning for the individual and forms a part of her personal identity. Occupations provide a framework for organising activities.

The Canadian Association of Occupational Therapy (1997) support this difference by suggesting that occupation refers to groups of activities and tasks of everyday life. Pierce (2001) also argues that occupation and activity are two distinct concepts, suggesting that the individuals’ perspective is key for differentiating between the two. She suggests that

> an occupation is the experience of a person, who is the sole author of the occupation’s meaning, whereas activities are more general, descriptive categories whose meanings are culturally shared rather than originating with the person (Pierce, 2001:139).

Hocking (2000) also considers occupations to relate to the experience of an individual. Although the ultimate significance or meaning of the occupation is primarily determined by the individuals participating in it, others may have an idea of the meaning or significance of the occupation (McLaughlin Gray, 1997). In an attempt to distinguish between meaningful and purposeful, Trombly (1995:968) suggests that

> the purpose is the goal, the expected end result; the meaning is the value that accomplishment of that goal has for that person.

Therefore, although a meaningful occupation has purposefulness, a purposeful activity may or may not be meaningful (Trombly, 1995). She goes on to suggest that purposeful occupation can organise a person's time, while meaningful occupation can motivate an individual to participation in life.

How we occupy ourselves

Like the Collins Dictionary (1987) definition, Townsend (1997) considers occupations to relate to how we occupy ourselves. She sees this as on both an individual and a society level. She supports this argument by suggesting that

> occupations are both shaped by and shape the cultural ideas and habits, economic resources, political processes and physical environment that underpin the organisation of society (Townsend 1997:22).

Society can place boundaries on what can and cannot be done and which occupations have value. By carrying out their occupations individuals can gain recognition and value in society. Occupations are a mechanism for social interaction and this interaction with society facilitates a person to be organised and balanced (Kielhofner 1982, Wilcock 1993b). Society can also contribute to a situation of unfairness where there may not be occupational opportunities for everyone such as work for those with disability (Townsend 1997).

Ilott (1995) expresses concern that there is an acceptance of occupation as engagement in purposeful activities or meaningful doing which gives structure to life and time, for its face validity, rather like an act of faith, and argues the need to confirm or disconfirm these beliefs. More recently, Glass et al (1999:478) agree, suggesting that "the exact mechanisms through which activity acts on health and survival are not known". They conducted a study to examine any association between social, productive, and physical activity and 13 year survival in older people involving 2761 men and women aged 65 and older in the United States. Through the use of interviews they found that social and productive activities lowered the risk of mortality as much as fitness activities did. They consider this observation to be important because it suggests that activities that involve little or no physical exertion may also be beneficial. Glass et al (1999) outline the benefits of social and productive activities as leisure and enjoyment, reinforcement of social status, relationships, sense of worth and performing meaningful social roles. One major limitation with this study was the information collection. Glass et al established information about the number of activities in which people participate rather than information about the extent of that participation. They also only asked about a limited number of activities and those participated in during the previous month.

Necessary for health

The belief that occupation is necessary for health is fundamental to occupational therapy. Wilcock (1993b:21) justifies this premise by arguing that humans are occupational beings who have an innate need that is related to health and survival. She considers this concept, that is, to use abilities to enable maintenance and development of the individual as

> the most primary and least appreciated function of human occupation. The organism, and all its parts, have to be active in order to remain healthy.

Others such as Clark (1979), Kielhofner (1982), Hopkins (1998), CAOT (1997), Rebeiro and Allen (1998) and Turner (2002) agree that participating in occupations serves as a natural way of achieving and maintaining the well-being of individuals. Yerxa (1998) expresses concern that in modern society, participation in some occupations is often trivialized, demonstrating an ignorance of the contribution of occupations to health, and also to actual survival. This concept of occupation affecting health is discussed in greater detail later in this chapter.

A basic need

The idea that occupation is a basic human need is proposed by Kielhofner (1982), Wilcock (1993b), CAOT (1997), Townsend (1997), Wilcock (2001) and Turner (2002). Occupations enable survival by addressing needs of sustenance, self-care and shelter. If an individual is unable to perform the occupations necessary for survival they will need someone else to assist them (Reed & Sanderson 1992). Wilcock (2001) in an account of the history of occupational therapy suggests that thousands of years ago people lived naturally with nature imposing "an occupational regimen that maintained health". Then daily occupations were those that provided food, shelter, safety and superiority over predators. She suggests that Darwin's theory of evolution supports the view that an individual with a disability would be more likely to fail at survival if they were unable to conduct their occupations. Wilcock (2001:27) considers survival as

> the primary drive of humans and depends on occupations that provide for essential needs of the organism.

Providing meaning for life

In addition to being basic to life, occupations can enable individuals to develop, adapt and adjust and therefore flourish and realise aims and goals (Reed & Sanderson 1992, Wilcock 1993a, Townsend 1997). Providing meaning to life for an individual is another function of occupations (CAOT 1997). Trombly (1995) and Jackson (1998b) argue that each person, even if doing similar occupations to others, will have his or her own subjective meaning for participating in these occupations. Examples of meaningfulness include a sense of the importance of participating in occupations, or an expectation of reward in terms of success or pleasure (Trombly, 1995). Townsend (1997) sees occupations as an active process for discovering meaning, while Ilott (1995:368) reiterates the subjective nature of meaning of an occupation as individual and "something which cannot and should not be assumed". The Canadian Association of Occupational Therapists (1997) suggests that knowledge relating to occupation is developing all the time. This development is in order to understand occupation and its purposes

> for organizing time, creating balance, fulfilling particular purposes, prompting human development, expressing spirituality, coping with change, developing ability, enhancing performance, building competence, adapting the built environment, responding to stress, and transforming oppressive situations (CAOT 1997:34).

Requires participation

Considering occupation from a phenomenological perspective, McLaughlin Gray, (1997) presents it as a type of activity that involves some sort of participation by the individual. It usually, but not always, involves interaction with oneself, with others, and also the environment. Essentially, it is perceived as 'doing' by the individual (McLaughlin Gray, 1997).

3.2.2. Roles

Roles such as worker, friend or volunteer, are social positions but also have behavioural expectations and series of activities or tasks to be performed by the individual (Kielhofner 1985, Creek 1997, Christiansen & Baum 1997). Roles are recognisable positions in society, which have defined status. An individual may have multiple roles at the same time and during his or her lifetime have roles relevant to different stages of life (Creek 1997, Christiansen & Baum 1997, Matheson 2001). According to Kielhofner (1985), roles define who a person is and individuals internalise roles, that is, hold images of themselves occupying certain positions and undertaking the obligations associated with those roles. He suggests that when a role is internalised, it becomes part of an individual's self-image.

Blair and Hume (1997) consider an individual to be in a state of function when all the skills necessary for participating in expected roles have been learnt. Therefore, dysfunction occurs when the individual does not have the skills necessary for carrying out these roles. Christiansen (1991a:29) defines occupational dysfunction as an individual's "inadequate performance of social roles", and suggests that the reason for this may be

> either because of deficits in abilities and skills due to disease or disability, the conflicting demands of multiple roles (role conflict), or because of unclear role expectations (Christiansen, 1991a:30).

Golledge (1998a) considers occupations and roles to be interlinked because individuals adopt and develop their occupations to support their roles. Jackson, (1998a) however, suggests that there should be caution when considering roles and occupations as they may narrow the understanding of occupation. She states that

> bracketing occupation into various roles provides the illusion that life is partitioned into isolated segments which can be dealt with independently (Jackson, 1998a:53).

The impact of loss of roles on the lives of individuals may be great depending on their illness and this will affect their participation in occupations (Golledge, 1998a). This loss of role may be short or long term. If long term, it may result in the need to change some or all roles for the individual which will require adjustment and may be difficult. Roles, according to Kielhofner (1985) serve as a guide to behaviour that society expects, but also provide structure and purpose to everyday occupational behaviour. If there is role loss, there may be a loss of identity, purpose and structure to everyday life. Kielhofner (1985) also suggests that it is easier to adapt to role loss if there are other roles to take on more importance. For example, a student will lose that role but take on an important replacement when they become a worker. This process of taking up new roles may not occur if the role loss is due to illness or disability, such as a stroke. Role loss has implications to overall role balance.

3.2.3 Occupational performance

Occupational performance refers to the participation in occupations. The Canadian Association of Occupational Therapy (1997:30) define it as

> the ability to choose, organise, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after one's self, enjoying life, and contributing to the social and economic fabric of a community.

Earlier authors such as Fidler and Fidler (1978) refer to this as 'doing'. They consider 'doing' as a word which conveys the sense of performing in a purposeful way. They view doing as

> enabling the development and integration of the sensory, motor, cognitive and psychological systems; serving as a socialising agent, and verifying one's efficacy as a competent, contributing member of one's society (Fidler & Fidler, 1978:305).

Law and Baum (2001) also relate occupational performance to doing, suggesting that doing occurs to address life needs.

Rogers (1982) also considers the integration of the biological, physiological, social and environmental dimensions of man to be key to occupational performance. Therefore, through doing, an individual knows his or her potential and limitations and achieves a sense of worth. Wu and Lin (1999:5) also view occupational performance as "the doing, the action, the active behaviour or the active responses". Christiansen (1991a:27) refers to occupational performance as

> the day-to-day engagement in occupations that organize our lives and meet our needs to maintain ourselves, to be productive, and to derive enjoyment and satisfaction within our environments.

Occupational performance includes participation in both routine tasks such as dressing and more complex ones such as those related to one's work requirements (Christiansen, 1991a).

Breines (1995) refers to occupational performance as a period when both body and mind are engaged either simultaneously or alternatively, suggesting an integration of the mind and body. When the mind is occupied, the body performs. For example, when doing a crossword the mind is engaged and the body responds by filling in the words. However when the body is occupied, the mind may be distracted or engaged. For example, when playing a game of tennis the player may be engaged and concentrating on winning points, the score etc. or they may be distracted and although their body is responding by hitting the ball they may be thinking of other unrelated things.

The words 'function', 'performance' and 'occupational performance' are used interchangeably according to Law and Baum (2001). Occupational performance does not mean doing at an expert level; rather an individual may be competent in some performance areas and not in others or novice in some and expert in others (Rogers, 1982). Physical, psychosocial and environmental factors may facilitate or hinder performance. Law and Baum (2001) also consider the environment to play a part in occupational performance. They consider that individuals undertake their daily lives in a context and that 'doing' is influenced by the characteristics of a context or environment. Matheson (2001:103) relates occupational performance to roles and context and suggests it

> is developed in response to the stimulus of task challenges posed by role demands and by anticipated role demands.

Rogers (1982) suggests this illustrates a difference between the perception of health in medicine and in occupational therapy.

> In medicine health is perceived as the absence of a phenomenon labelled disease, while occupational performance is defined as the presence of a phenomenon called competence (Rogers, 1982:30).

This implies that health is passive while occupational performance requires activity.

Rogers (1982) describes dysfunction in occupational performance as the result of performance below capability, which may be caused by

> disease, injury, cultural deprivation, genetic abnormalities, the ageing process, inappropriate socialisation, and the absence of a sense of purpose in life.

The outcome is an inability for an individual to effectively carry out daily tasks and roles (Rogers,1982:31). Law and Baum (2001) see occupational performance as a dynamic situation involving relationships between individuals, occupations and environments. All parts are interdependent and individuals may alter performance based on their perceptions of changing conditions in the environment. They also see it as a process to shape self-concept and identity.

Occupational performance, according to Reed and Sanderson (1992:11) is "the result of developmental maturation and learning of many skills". They suggest that learning a combination of skills and the application of these skills at the right time and place and in the right amount contributes to occupational performance. This would appear to link with Rogers' (1982) view on ranges of ability from novice to expert.

Occupational performance is also the term occupational therapy practitioners use for function, according to Baum and Law (1997). They consider it to be

> the point when the person, the environment, and the person's occupation intersect to support the tasks, activities, and roles that define that person as an individual (Baum & Law 1997:281).

The term 'occupational performance', according to Baum and Edwards (1995), brings to the forefront the issues that occupational therapy has always valued: "the person's capacity to function in a community context" (Baum & Edwards, 1995:1019). Bing (1981) and also Law and Baum (2001:5) consider occupational performance as something to value suggesting it "provides opportunities for individuals to influence their well-being by gaining fulfilment in living". Law et al (1994) also add a value assumption to occupational performance by suggesting that occupational performance is not just about doing but also with satisfaction with doing.

3.2.4 History of occupational therapy

Occupational therapy emerged as a developing profession in the years during and following World War I and it formally began in 1917, when there were a number of chronically disabled soldiers returning from war (Pedretti & Zoltan 1990, Baum & Edwards, 1995). However, the origins of the profession come from the philosophy of moral treatment in the early nineteenth century (Pedretti & Zoltan, 1990). This philosophy was based on the belief that those with mental health problems needed to be active and participating in creative and recreational activity. One of the founders of occupational therapy, Meyer (1922), describes the development of its use;

> a pleasure in achievement, a real pleasure in the use and activity of one's hands and muscles and a happy appreciation of time, began to be used as incentives in the management of our patients, instead of abstract exhortations to cheer up and behave according to abstract or repressive rules. The main advance of the new scheme was the blending of work and pleasure – all made possible by a wise supplementing of centralization by individualization and a kind of re-decentralization (Meyer,1922:3/4).

Not only was it based on moral treatment, but it was developed in the period before drugs were used for treatment of mental illness. Individuals with mental conditions were institutionalised and professionals from various fields including medicine, neurobiology, nursing, social work and architecture believed that in-patients of mental institutions had needs that could be met by giving them meaningful work (Baum & Law, 1997). Crafts were used to reactivate the minds and motivation of individuals, thus beginning the process of work training (Pedretti & Zoltan1990).

Throughout its history, the value of occupation has been central to occupational therapy (Law & Baum 2001). However, the place of occupation at the centre of the profession became replaced by a focus on changing impairments such as mood, range of motion, and strength during the middle of the 20th century. Since the 1970s there has been a shift back to the profession's roots with renewed focus on intervention to facilitate occupational performance. This is still ongoing and is not complete as healthcare settings have demanded a focus on addressing impairments (Law et al 2001). Initially, there was concern that individuals in mental health institutions must be able to do and perform certain tasks or activities, at a certain time, with a certain level of performance or criterion (Reed & Sanderson, 1992). The profession has evolved since then to meet the needs of individuals with all kinds of disabilities. It now addresses the needs of individuals in a number of environments, including hospitals, schools and the community (Baum & Law, 1997).

3.2.5 Philosophy of occupational therapy

The Canadian Association of Occupational Therapists describe occupational therapy as

> a health profession whose members collaborate in enabling occupation with clients, who may be individuals, groups or organizations (CAOT, 1997:2).

By enabling occupation, they mean

> enabling people to choose, organize, and perform those occupations they find useful or meaningful in their environment (CAOT, 1997:2).

Its philosophy is based on the premise that occupation, or any form of human activity, has effects upon health and that by engaging an individual in occupations it is possible to enhance or maintain health, to reduce ill-health, or to help the adaptation process should the handicap appear irreversible (Wilcock 1991, Creek 1997). It is this therapeutic use of occupation and activity that is regarded as unique and the core element of the professional practice of occupational therapy (Golledge, 1998a). It has also been considered as a means of restoration, as a way to prevent further problems and restore function and speed recovery from injury or disease (Kielhofner 1982, Reed & Sanderson 1983).

As outlined in the history of the profession (Section 3.2.4), it has been suggested that from the 1940s to the 1980s, the profession moved away from its philosophy when occupation was not at its centre (CAOT,1997). It was at that time that occupational therapists used terms such as 'tasks' or 'activities', as in activities of daily living and the focus was on specialized equipment and techniques aimed at performance components of activities.

3.2.5.1 Effect on health

As outlined in Section 3.2.1, there is a body of belief that an individual's occupational performance influences their health status. Wilcock (1993a) argues that occupation is essential for health as it means that basic human needs are fulfilled. As a consequence, it provides the mechanism for people to exercise, to keep all body parts and functions at maximum efficiency, to adapt to environmental situations, to flourish as individuals and to maintain social relationships (Wilcock, 1993a). Keilhofner (1982) argues that a second premise follows logically. This is that an illness which affects an individual's ability to conduct occupations leads to a deterioration of health.

In Chapter 2 it was noted that the concept of health has many different meanings. Yerxa (1998:412) views health

> not as the absence of organ pathology, but as an encompassing, positive, dynamic state of "well-beingness", reflecting adaptability, a good quality of life, and satisfaction in one's own activities.

The Canadian Association of Occupational Therapists (1997:31) believe that

> health is more than the absence of disease, is strongly influenced by having choice and control in everyday occupations and has personal dimensions associated with spiritual meaning and life satisfaction in occupations and social dimensions associated with fairness and equal opportunity in occupations.

Both these views correlate with and expand on the 1946 World Health Organisation definitions (cited in Wilcock 1993a:200)

> health is a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity.

Occupation has been linked with health for many years. Work and leisure activities have been used with those with mental health difficulties for centuries. In the 20th century, soldiers returning from World War I were rehabilitated into employment (CAOT, 1997). However, Yerxa et al (1990) consider understanding the relationship between occupation and health as one of the greatest challenges society faces today. Despite this, Christiansen and Baum (1997) reiterate that although the relationship between occupation, health and well-being is not yet well understood, they inspired the development of innovative practices based on the idea that occupations influence health.

Within gerontology, Diener (1984) suggests that the view of being active affecting happiness has been a popular idea rather than a research based conclusion. Diener

(1984) argues that involvement in certain types of activities must enhance subjective well being. However, he acknowledges that to date there is little understanding of this relationship. Yerxa (1998:417) also suggests a link between occupation and happiness considering engagement in occupation to be

> an essential mediator of healthy adaptation and a vital source of joy and happiness in one's daily life.

In an attempt to establish evidence, Law et al (1998) conducted a critical review of research examining the relationship between occupation and health and well-being. They found from occupational therapy and health and social sciences literature that 23 articles focussed on the relationship between occupation and health and well-being. They used the following criteria to review the articles:

- The focus of the study included self-care, productivity and leisure occupations, not simply one of these categories;
- outcomes in the study centred on health and well-being as defined for this paper, rather than components of health and well-being;
- the article described a research study, not simply a case example description (Law et al:1998: 82).

The findings of the 23 studies showed that the removal of occupation leads to increased stress, physiological changes and decreased health indicating that occupation has an important influence on health and well-being. Law et al (1998) conclude that the performance of everyday occupations is an important part of everyday life and that changes in occupations have a significant impact on a person's self-perceived health and well-being. However, caution needs to be taken when interpreting the conclusions as most of the evidence is from cross-sectional studies. The majority of these studies focused on individuals without disabilities, and therefore the findings cannot be generalised to individuals with disabilities (Law et al 1998). As a result, Law et al (1998) suggest that the most that can be concluded is that there are strong relationships between engagement in occupations and health and well-being, not that occupation causes health and well-being.

In concluding the review, Law et al (1998) also identified factors which enhance the experience of participating in occupations. They suggest that the experience of occupation enhances the effect of occupation on health, and that the following factors

> such as perceived control, intrinsic motivation, sufficient complexity and achievement of a balance between the task challenge and a person's skills, are important influences

on the experience of occupation (Law et al 1998:90). According to the Canadian Association of Occupational Therapists (1994:294)

> health flourishes when occupations give meaning and purpose to life' and when 'people's occupations hold personal meaning and are publicly valued by the society in which they live.

Csikszentmihalyi (1993:41) describes a fully meaningful life as opposed to a healthy one and considers occupation to be a key component. According to him, such a life 'depends on the ability to find occupations that are challenging, yet within the scope of our abilities'. According to him, what the occupation is, is irrelevant. What provides most enjoyment is the situation where the skills of an individual are well matched to those required by the occupation. Csikszentmihalyi (1993) describes a state of flow – when there is deep concentration, too busy for the individual to think of themselves and the awareness of time disappears. He suggest that flow is "so enjoyable that a person will want to repeat whatever activity has produced it" (Csikszentmihalyi, 1993:39). Yerxa (1993:7) considers flow to involve an individual totally in what they are doing giving a high degree of satisfaction. It is the ongoing intrinsic rewards that Suto (1998) identifies as contributing to the experience of flow.

In contrast to flow, Farnworth (1998:142) describes boredom as

> a state where the person perceives the challenges of the occupation engaged in to be less than the skills that they bring to the situation.

As Csikszentmihalyi (1993) sees flow as essential for a fully meaningful life, as opposed to a healthy one, it could be concluded that a life that is not full of engagement in appropriately challenging occupations is one of boredom but not necessarily an unhealthy one.

Yerxa (1998) suggests that people who have no organized leisure activities and are unemployed often become depressed. She suggests that not only does it affect their health, but also their sense of identity and purpose in life and concludes that work facilitates health, even if the working conditions are poor. A study by Platt (1986) supports this. He investigated the relationship between unemployment and parasuicide ('attempted suicide') in Edinburgh during the years 1968-83. Parasuicide is defined for the study as a non-fatal act in which an individual causes self-injury or ingests a substance in excess of any prescribed or generally recognised therapeutic dosage. The parasuicide rate for the number of male patients aged 15 years and over was calculated. The findings were that unemployment was associated with sharply reduced well-being, and that employment was associated with a substantial increase in well-being. He concludes that unemployment is a cause of parasuicide.

3.2.5.2 Balance of occupations

In addition to the suggestion that participation in occupations has a positive effect on health, many theorists propose the need for some sort of balance in the categories of occupations, that is self-care, productivity and leisure (Christiansen 1996, Yerxa 1998, Jackson 1998b). Yerxa (1998) suggests that this balance is learned through organizing one's own actions, while Jackson (1998b) considers it as an individual's interpretation of a particular configuration of daily occupations.

Balance time

Christiansen (1996) offers a perception of balance in occupation relating to time. This perspective is that of a time budget approach to balance in occupation. This is based on the belief that daily activities can be categorised and that if equivalent time is spent within each category, the result will be improved well-being. Yerxa et al (1990) suggest that individuals are not pre-programmed as to how they spend their time doing their daily occupations. Conscious decisions are made about what they will and will not do resulting in choices in time. They suggest this results in a blend of work, rest, play, leisure or self-care occupations.

According to Reed and Sanderson (1992), maintaining health and a satisfying life is facilitated by having a balance of occupations. Stanley (1995) conducted a study of 68 individuals (mean age 75.65, SD 4.78) using a cross-sectional survey study design to investigate time spent in valued occupations. She did not find a relationship between participation in valued occupation and life satisfaction. Only one occupation category approached a significant correlation with life satisfaction and that was social occupations. Other factors investigated such as health, socioeconomic status and perceived satisfaction with health and finances were not found to be predictors of life satisfaction in this study (Stanley,1995). In addition a link was found between having a driver's licence and increased life satisfaction. Stanley assumes that the ability to drive a car is a key component in maintaining community activity. She also acknowledges that considering the value of an occupation is an extremely difficult thing to do as it depends on a range of issues including the environmental and social context of the occupation and the mood of the individual.

Balance categories of occupations

In addition to balance relating to time, it can relate to engagement in occupations from different categories. The three most commonly used categories for occupations are self care, play/leisure and productivity/work (Creek,1997). An occupation may be perceived as belonging to different categories depending on an individual's perspective (Creek,1997). For example, cooking may be self-care if it is to satisfy an individual's hunger, it may be work if it is to feed a family, or it may be leisure if it is to give a dinner party for friends. It is a balance of occupations in the three categories of self-care, play and work that Creek (1997) considers important. This balance is fluid and changes at different times of life and varies from individual to individual (Creek, 1997). It is determined

> by personal interests and abilities, social expectations, age, environment and personal circumstances (Creek, 1997:35).

Christiansen (1991a) also identifies that one occupation can fall into different categories and gives the following example to illustrate his point:

> writing could be classified as a leisure activity, as a work-related or educational activity, or an act necessary for self-maintenance, such as in writing a cheque to pay household expenses (Christiansen, 1991a:27).

However, Creek (1997:27) suggests that it is the participants' perspective that dictates in which category an occupation belongs while Christiansen (1991a) says that it is through knowing the context of an occupation "that one can discern into which domain a given activity falls". He does not clarify who "one" is – the participant or for example an occupational therapist who may be working with the participant.

Balance roles

Blair and Hume (1997:31) suggest that occupational therapists view health as

> the ability to function adequately in a balanced variety of roles, and achieve a sense of satisfaction from them.

They acknowledge that roles change throughout the life cycle but argue a flexible balance of roles is necessary to maintain health. Backman (2001:213) suggests that the reason that balance of roles changes is

> our perception of what is important, meaningful, and deserving of our time and energy changes.

Branholm and Fugl-Meyer (1994) conducted a study of 201 adults in Sweden using self-reported questionnaires to establish non-work activity preferences. They found that individuals participate in activities in which they were not interested. Most of the women and the 45-year old men reported carrying out car maintenance with no interest while about 20% of the 35- and 45-year old men appeared to toil without interest in their gardens. They also found that the different age groups had similar levels of activity preferences, although they found that physically demanding activities (e.g. soccer and jogging) are relatively rarely enjoyed by older participants. In addition they found that older women preferred social occupations more than men, in particular a higher female than male preference for party-going, travelling, reading, and listening to classical music. This is a small study and has cultural context to consider. The researchers acknowledge that their population came from a sparsely populated area where many regularly participated in outdoor physical exercises. The findings from a population in a more urban area such as Cardiff may be very different. Stanley (1995) in her study mentioned earlier, found that women spent more time doing housework occupations such as cleaning and meal preparation, whilst men spent more time doing outside domestic tasks such as home repairs and car maintenance.

If there was a greater understanding of how people conduct their daily occupations and integrate roles, Yerxa et al (1990) suggest there would be greater knowledge as to what configuration of occupations represents a balance which is optimal for health, a question also asked by Backman (2001). Blair and Hume, later in 1997 (p31) still do not identify what configurations are required; they just state that "a flexible balance of occupations is necessary to maintain health". More recently Backman (2001) recognises the need to measure the way in which individuals balance occupations but suggests that it is difficult to identify precisely what a reasonable balance of occupations is. She considers a balance of occupations to be subjective with individuals defining their balance

> in terms of how they choose to spend time on valued, obligatory, and discretionary activities (Backman, 2001:203).

This knowledge would assist when enabling individuals to find a more healthful balance of occupations in their daily lives.

The literature suggests that occupations are categorised into self-care, productivity and leisure. Theorists believe that a balance of these occupations is necessary to achieve optimal health. However, it is unclear as to how to measure such a balance. It is suggested that this balance changes over life stages and the balance is defined subjectively by individuals.

3.2.6 Occupation as a Means to Health

Occupation as a means to health is effectively what occupational therapy is. Occupational therapists' client group includes people who face emotional, physical or social barriers to being independent. The aim is to enhance quality of life and increase satisfaction in daily living and to use meaningful occupations as a way to develop their abilities and roles (Blair & Hume 1997, Golledge 1998b, CAOT 2000). Yerxa (1988) argues that occupation is not only the means of treatment in occupational therapy but also the outcome of treatment. The occupations used as intervention are those that the individual has an interest in and that will enable them to support his or her current lifestyle (Golledge, 1998b). Baum and Edwards (1995) describe the occupations used in intervention as "meaningful and productive" for the individual, which increases their occupational performance and consequently their function. By using occupations that interest a person, this allows the person to experience intrinsic satisfaction and personal pleasure in the occupation itself and will lead to increased performance of an occupation which subsequently

> facilitates the integration of physical, emotional and cognitive systems and the organization of self and environment (Wu et al. 1994:679).

Reed and Sanderson (1992:2) break down the meaning of the words 'occupation' and 'therapy' to suggest they are meant to convey that the practice

> involves treatment of illness or disability through the analysis and use of the occupations that fill up a person's time and space and engage the individual in activity.

<u>The clients</u>

Occupational therapists work with individuals with a wide range of mental and physical disabilities who, for some reason, are currently unable to lead satisfying and productive lives including individuals who have had a stroke (Reed & Sanderson 1992). Blair and Hume (1997:31) outline four different groups of occupational performance dysfunction:

- failure to develop and mature normally due to physical abnormality or environmental deprivation, for example, Down's syndrome;
- environmental changes that the individual cannot cope with, such as bereavement;
- new physiological or psychological needs, such as maternity, which cannot be met using existing skills;

- pathology or trauma causing loss of skills, for example, head injury.

Rather than treat the pathology of diseases or injuries, occupational therapy is concerned with how these conditions affect a person's ability to function (Blair & Hume, 1997). Cynkin and Robinson (1990:35) describe the work of occupational therapy as helping individuals with impairment to "turn from dysfunction toward function".

Occupation as treatment

Intervention is through using occupation as a therapeutic medium (CAOT, 1997). The use of occupations in this way is fundamental to the practice of occupational therapy (Golledge, 1998a). The type of occupations used may include those that the individual has an interest in or ones that are necessary to be able to do in order to support his or her current lifestyle.

Participation in occupation or activity according to Doble (1988) is not in itself particularly therapeutic or beneficial. She suggests that it is the participation in occupations that are meaningful which serves to validate an individual's sense of worth and value that can be used as treatment. The selection of occupations as treatment for an individual should include his or her values and interests.

Reed and Sanderson (1992) consider the use of directed, purposeful occupations as treatment as a way to influence positively an individual's sense of well-being and, thus, their state of health. If the occupations are directed and purposeful, they can enable an individual to assume responsibility for meeting their own needs. It can do so by increasing the individual's occupational performance levels and then the individual can perform self-care, work, and leisure occupations. Reed and Sanderson (1992) also suggest that in order to use occupations as treatment, occupational therapists need a knowledge of occupational areas, performance components of occupations and the impact of the environment on performance. This is a view shared by Turner (2002:41) who suggests that

> using occupation as therapy involves an understanding of the many elements that contribute to a successful occupational performance.

In addition to the use of occupations to increase performance, Rebeiro and Cook (1999) explored the concept of occupation being a means to other gains. In their study of eight members of The Women's Group, an outpatient women's mental health group in

Ontario, they used in-depth interviewing and participant and non-participant observation. They found a perception of a link between what the individual did at The Women's Group and how they perceived themselves and their mental health. The participants identified increased self-confidence, competence and subjective well-being as spin-offs to participating in occupation at the group. Rebiro and Cook (1999) suggest that these spin-offs identify independence in occupational performance as not just an end, but also a means to feeling better, more competent and confident over time. They conclude that these feelings may increase an individual's desire to participate in occupations further in order to continue to feel better. This study is very small and included only eight of the twelve group participants. The views of the remaining four are not known, therefore caution needs to be taken in generalising the findings. It does however begin the process of exploring the benefits of using occupation as treatment.

Process of Occupational Therapy

Intervention requires occupational therapists to be enablers thus identifying the practice as participatory and action-based. The occupational therapist facilitates individuals rather than doing things for them (CAOT, 1997). Abberley (1995) notes the difference between occupational therapists and other healthcare professions, such as nurses and social workers, suggesting that their patient or client is passive in treatment while the occupational therapist aims to provide the individual with a degree of power and autonomy. Rogers (1982) describes the intervention of occupational therapists as person-orientated and that the process for gaining or restoring occupational performance is through learning. Law and Baum (2001) also state that occupational therapists use learning but they identify adaptive strategies as another tool they use to support the individual to perform meaningful occupations. Feaver and Creek (1993) refer to the flexibility required by occupational therapy because it requires the ability to change to meet changing needs.

A problem-solving process, used in occupational therapy as well as other healthcare professions involves assessment, planning, implementation and evaluation (Reed & Sanderson, 1992). In addition to using a problem solving process, Reed & Sanderson (1992:10) identify unique aspects of occupational therapy that contribute to the treatment of individuals. These are:

- concern for a person's ability to perform the occupations of self-maintenance, productivity, and leisure throughout the life-span.
- knowledge of the development, integration, interrelatedness, and role of occupations in the life cycle;

- application of the knowledge of occupations to assist persons to develop, learn, and maintain occupational performance;
- methods of adapting a person's behaviour to human and nonhuman environments or adapting the environment to a person's needs.

Occupational therapists have developed methods both to modify the individual's behaviour and to change the environmental response to the individual (Reed & Sanderson, 1992: 11).

Outcome of intervention

As can be seen from the previous section, the role of the occupational therapist is an enabling one. As a consequence the outcome of intervention should be increased ability for the individual. This role as enabler has been part of the profession since its founding. According to Meyer (1922:7), one of the founders, the role is about

> giving opportunities rather than prescriptions. There must be opportunities to work, opportunities to do and to plan and create, and to learn to use material.

Treatment may need to enable individuals to clarify their values and interests, or to develop more appropriate ones, ensuring that they can begin to discover what it is that is important, useful and relevant to them (Doble, 1988). The success of occupational therapy, according to Branholm and Fugl-Meyer (1994) is enabling an individual to proceed towards the achievement of optimum satisfaction with life as a whole or happiness and these may be achieved by engaging the individual in new meaningful occupation preferences or goals. Blair and Hume (1997:32) describe the outcome as enabling the individual

> to enact a balanced range of occupations which will enable him to maintain physical and mental health.

Yerxa (1998:6) like Reed and Sanderson (1992), Branholm and Fugl-Meyer (1994) and Law et al (2001) consider the satisfaction of the individual to be part of the outcome of occupational therapy. She considers the goal of occupational therapy to

> enable the individual, regardless of extent or type of disability, to function in his or her environment competently and with personal satisfaction; to be a productive participant in the world.

Reed and Sanderson (1992) also recognise the need for outcome to focus on the individual being enabled to live a productive life. This reinforces the need for individuals to participate in society. According to Law et al (2001:279), enabling individuals to undertake a productive role is key to the functioning of society. They suggest that "society's problems become exaggerated when its citizens cannot work".

In addition to the outcomes of intervention for individuals, Reed and Sanderson (1992:19) suggest that the wider community may gain from occupational therapy in the following ways:

- A greater number of individuals who are more able to perform daily tasks for themselves and thus require less expensive help from others;
- Increases productive potential because the injured or ill person is able to return to work for the first time, or is able to contribute in unpaid service, such as volunteer work;
- A decrease in the number of individuals who feel hopeless or helpless and who may have been using many hours of a physician's or other service person's time for very little constructive purpose;
- A safer community, which is accessible to all, because barriers have been reduced or eliminated;
- A healthier community because more people are aware of the relationship of performance capacity to physical and emotional well-being;
- An increased sense of commitment to the quality of life as well as the quantity of life through recognition that dignity and self-worth are part of the rights of each individual regardless of individual limitations (Reed & Sanderson, 1992:19/20).

3.3. SELF-CARE

3.3.1 Introduction

As already indicated, self-care is one of three main categories of occupations. It is also considered the first category that occupational therapists focus on when enabling an individual to be independent. It is often the focus of rehabilitation in the early stages of recovery from stroke, while an individual is an in-patient and therefore has limited relevance to the evaluation of the Cardiff Day Service. As a consequence this section provides a brief outline of self-care. Subsequent sections on productivity and leisure are more comprehensively addressed due to their greater relevance to the Cardiff Day Service.

3.3.2. Definition

The category of self-care relates to the occupations for looking after the self and enabling the individual to survive. These include personal care, that is such occupations as eating, sleeping, keeping clean and keeping warm, personal responsibilities, that is cooking, dressing, shopping, maintaining one's living environment and keeping fit (Creek, 1997 and Turner 2002), and organisation of personal space and time (CAOT 1997, Creek 1997). They are also identified in literature as activities of daily living (Foti, 2001). Basic daily living activities are considered different from instrumental activities of daily living which, according to Foti (2001), require more advanced problem-solving and social skills and include activities such as home management and community activities.

According to Soderhamn (2000), the aim of self-care activity is to aim to maintain, restore or improve health and well-being. She identifies it as an activity individuals do for themselves. Once an individual has reached a stage of maturity when they can undertake purposeful action they perform self-care activities.

3.3.3. Occupational therapy and self-care

Occupational therapy has a role in assessing individuals' ability to perform activities of daily living and subsequently enabling independence in these activities (Foti 2001). Assessment is an important aspect of occupational therapy intervention in virtually every health and social care service. Intervention may include removing or reducing physical, social, cultural and emotional barriers. Thompson and Morgan (1990) also consider establishing independence in activities of daily living as a key aim for occupational therapy.

According to a study conducted by Drew and Rugg (2001) self-care activities were the most regularly used or observed by occupational therapy students while on placement in physical settings. This study surveyed 54 second and third year students from one occupational therapy school in the UK. There are several shortcomings with this study. The students were required to recall activities both used and seen during their fieldwork experience. For the third years this required recall of up to 2 years. The students from only one school were used representing a very small proportion of all clinical area where occupational therapists work.

One study has been conducted looking at the intervention by occupational therapy for one aspect of self-care, dressing. This study investigating the benefit of dressing practice by an occupational therapist for individuals post-stroke was conducted by Walker et al (1996). They conducted a randomised crossover design with 15 individuals in each of two groups with a three month treatment phase followed by three months with no treatment or vice versa. They found that both groups showed a statistically significant improvement (p=0.002) during the treatment phase, while neither improved during the non-treatment phase. They also noted that those who received treatment first maintained their improvement providing further evidence of benefit from dressing practice. This small study was conducted rigorously; there were no differences between the groups' abilities at the start of the study and a blind assessor was used for all assessments. The treatment took place in the normal context of dressing – that is in the individual's own home. The impact of a stroke on self-care abilities will be discussed further in the next chapter.

3.4. PRODUCTIVITY

3.4.1. Introduction

Productivity is one of three categories of occupation that is believed to make up an individual's balance of occupations. This section will define it predominantly from occupational therapy literature. The impact of the loss of a productive role will be considered as will the role occupational therapy has in enabling individuals to retain a productive role. As the Cardiff Day Service provides a service to those under 55 years, exploring this literature is relevant.

3.4.2. Definition

Within occupational therapy literature productivity is defined as

> any productive activity, whether paid or unpaid, that contributes to the maintenance or advancement of society as well as to the individual's own survival or development (Creek,1997:34).

The Canadian Association of Occupational Therapists (1997) also suggest that not all work activities result directly in financial gain, giving examples such as volunteer work, caring for others and home management as activities that are also considered work. Other examples include play in childhood, studying and parenting.

Marmot and Feeney (1996) and Yuill and McMillan (1998) suggest that work is a very important feature of everyday life because from it individuals draw an income and have opportunity for social contacts, status and a structure to their lives. Although work is regarded positively within most societies, it is also highly contradictory because it is something that is actively sought, even though it can also be a source of boredom and frustration (Yuill and McMillan, 1998). Kelly (1990) also suggests that people work because they want to and that they gain satisfaction from being productive. He does however acknowledge that all employment may not be satisfying work. Most people "work to live" rather than "live to work". Kelly (1990:75) found that

> most adults who are employed find some satisfactions in their employment, are quite concerned about the monetary rewards and have a clear sense of the relationship of employment to home, security, and the future of their families.

Pettifer (1993) suggests that the nature of work has undergone and will continue to undergo rapid change and therefore challenges the way in which work is defined. He defines work as

> a primary source of developing and maintaining a person's identity, feelings of competence, sense of belonging and physical well-being, as well as playing a major role in structuring society and the individual's position within it (Pettifer, 1993:20).

Like Yuill and McMillan (1998), Pettifer (1993) considers that just being in any job may not be adequate to maintain an individual's well-being, as they may not gain satisfaction from the job. They may, however, get benefits other than job satisfaction such as payment, companionship, social respect and a sense of structure in their lives.

The concept that work plays a key role in structuring society is acknowledged by Kelly (1990), Pettifer (1993), Creek (1997) and Krupa et al (1998). Work does this through the production of goods and services and by defining a person's social identity. Different social values are given to different jobs resulting in people with certain jobs being considered to be more important than others (Creek, 1997:34). There may be issues of esteem and social approval as well as social status with different jobs (Marmot & Feeney, 1996). Work not only provides society with structure, it provides structure for people's lives (Matheson, 2001).

The link between work and health is focused on the social aspects of health by Marmot and Feeney (1996). They give three reasons why work is crucial. Firstly, it generates prosperity which allows the development of social conditions conducive to health, such as reductions in unemployment and job insecurity and improved working conditions. Secondly, it has an impact on the individual, the family and the social environment. Thirdly, there may be impacts from the general physical environment surrounding the workplace.

3.4.3. Disability and productivity

Krupa et al (1998) consider work to be one aspect of an individual's life that will be affected if they have a disability. Yerxa (1998) agrees and suggests that it is only when the opportunity to work is affected by impairment that there is acknowledgement of the potential impact of unemployment and the loss of a work role on health. According to Richards (1998) there are 2.2 million people of working age with a disability or long-term illness in the UK and over half of these want to work. Matheson (2001) suggests that the opportunity to work becomes complicated for individuals with chronic disease and disability. The British Society of Rehabilitation Medicine outline the obstacles to re-employment that can occur quickly as

> deterioration in physical and mental health, adaption to life on benefits, financial gain from returning to work feels unacceptably small (BSRM 2000:12)

They also acknowledge that, if out of work for some time, individuals may be satisfied with their new lifestyle which allows the pursuit of other interests.

Wellwood et al (1994) suggest that the person with an illness or disability and their family's attitudes may affect return to work. The impact of a stroke on work is outlined in detail in the next chapter.

3.4.4. Occupational therapy and productivity

Bumphrey (1987) considers the occupational therapist to have a role in enabling individuals to return to work. This role includes

> helping employers to understand more fully the needs of disabled people and encouraging them to widen the range of opportunities open for them, as well as ensuring that the disabled person is aware of his real skills and has the confidence of applying them in a work situation (Bumphrey 1987:244).

Richards (1998:296) states that work must be on the occupational therapy agenda, because it "provides the opportunity of moving from dependency to economic freedom". Wilcock (1986) also agrees that when treating individuals that returning to work should be considered by occupational therapists. According to Matheson (2001), a focus on returning to work has been integral to occupational therapy since it began; even early founders provided opportunities for the development of work skills and behaviours. However, the British Society of Rehabilitation Medicine (2000) reports that few occupational therapists, although they have an important role, are employed to address the issue of returning to work.

Wilcock (1986) and Warlow et al (1998), suggest that returning to a previous job may not be possible. In these situations occupational therapy needs to be aimed at improving skills required for different jobs or enabling the individual to return to part-time work. Another possibility is employment at a sheltered workshop or doing voluntary work, or

> alternatively, the occupational therapist may help the patient to explore the possibilities of self or homebound employment, perhaps on the basis of previous skills or leisure interests which are still possible despite a stroke or using new skills learned during rehabilitation (Wilcock 1986:224).

3.5. LEISURE

3.5.1 Introduction

This section will consider the third occupational category, that is, leisure. As well as defining it, it will outline the benefits of leisure and the range and type of leisure occupations undertaken by adults. Finally leisure, in the context of occupational therapy, will be outlined. As leisure is not the sole province of any particular discipline, this section draws on literature from various disciplines including sociology, psychology and occupational therapy. The activities carried out at the Cardiff Day Service are predominantly leisure ones, therefore it is relevant to explore this literature.

According to Murphy (1981) over recent decades there has been an increase in leisure activities. He suggests this growth has been influenced by

> increases in free time, higher level of educational attainment, increasing affluence, more favourable attitudes toward pleasure, population mobility, advancements in technology, expansion of human and social services, and expanded opportunities of minority, disabled, and nonaligned groups (Murphy, 1981:12).

3.5.2. Definition

There have been many attempts to define leisure including considering it to be freedom, satisfaction, use of time, not work and a social symbol. Evidence for each of these concepts will be discussed. According to Drummond, (1990:157) leisure is notoriously difficult to define but she does offer the following definition that leisure is

> activity chosen primarily for its own sake after the practical necessities of life have been attended to.

Edginton et al, (1995) also consider it difficult to define and suggest that it is an elusive term and that individuals for centuries have been trying to understand its meaning.

Freedom

Leisure is often considered freedom. Kraus (1990), Pettifer (1993), Edginton et al (1995) and Lobo (1998) suggest that freedom relates to having choices when considering leisure activities. Edginton et al (1995) also suggest that freedom relates to being free of the obligations that might arise from normal life such as family, work, or home activities and therefore places constraints on leisure that may inhibit participation or involvement. Kelly (1990) also considers leisure in terms of freedom and suggests that the activity or the people it is done with, are freely chosen. He goes on to suggest that "leisure is, in some sense, what we choose to do rather than what we have to do" (Kelly, 1990:420). Edginton et al (1995:7) suggest that the freedom associated with leisure is "relatively free from constraints". The characteristics of leisure according to Pettifer (1993) include time free of work, freedom of choice and freedom of obligation. However, she argues that this does not mean that the majority of unemployed people's time is spent in leisure because their free time is not chosen or voluntary and there are many additional financial and social constraints. These constraints can increase their feelings of restriction and obligation and the financial ones can result in people being priced out of leisure.

Life satisfaction

Several authors consider leisure to be a means to achieve life satisfaction (Edginton et al 1995, Cheek & Burch 1976, Murphy 1981, Connolly & Law, 2001). More specifically, Edginton et al (1995) consider leisure to provide more opportunities for pleasure, which lead to increased life satisfaction. Cheek and Burch (1976:2) describe satisfaction from leisure as "having fun, playing, letting go, easing off". Murphy (1981:3) provides a different view suggesting that satisfaction is gained from leisure because it allows for "a greater degree of understanding of oneself as a person". Edginton et al (1995) also suggest that feelings of satisfaction are gained if participation in leisure is intrinsically motivated, where there is engrossment or commitment. They consider these motivators to be more powerful than external motivators.

Edginton et al (1995:33) see leisure as "a way of bringing balance into one's life". By balance they mean it provides the opportunity for escape, excitement and fantasy as well as relaxation and these can provide a counterbalance to the stressful aspects of an individual's life. They acknowledge that for each individual, leisure may have a different meaning. Iso-Aloha (1980) considers intrinsic motivation for leisure activities and the selection of a personally meaningful one to contribute substantially to life satisfaction.

In a different study looking at passive activities Farnwoth (1998) found that boredom can occur. In her study of how 36 young criminal offenders on probation spent their time, and how they experienced their use of time, she found that

> boredom was experienced significantly more when engaged in passive leisure and personal care occupations, and was less likely to occur when engaged in education, labour force or active leisure occupations (Farnworth 1998:140).

Riddick (1986) conducted a study to examine whether or not there are significant age group differences in leisure satisfaction and to identify precursors to leisure satisfaction. She recruited 400 participants, 40 from each of 10 age groups (18, 22, 28, 33, 40, 45, 50, 55, 60, and 65 years old) from students and staff within a university located in the United States of America. The response rate to questionnaires was 55%, that is 221 respondents but she did not indicate the distribution of these to each of the ten age groups. Using analysis of variance Riddick (1986) established the overall mean satisfaction score for the total group as 82 (SD = 6.0), with actual scores ranging from 24 – 111. The lowest mean score on leisure satisfaction was found in the 50 year old group (m = 77.3), while members of the 22 year old age group registered the highest leisure satisfaction (m = 87.6). Despite this finding, the 10 age groups did not significantly differ in leisure satisfaction ($p = 0.19$). Two variables, knowledge of leisure resources and leisure values emerged as having a significant positive effect on leisure satisfaction ($p<0.01$), while other factors including mate/spouse's leisure attitude, income, gender, age, and best friend's leisure attitude had no significant effects on leisure satisfaction (Riddick, 1986). The generalisability of this study is questionable, due to the small numbers in each age group.

Use of time

The use of time is another way in which leisure is defined (Kelly, 1990 and Pettifer, 1993). Edginton et al (1995) suggest that viewing leisure as time comes from the Industrial Revolution. Work time, free time, and time to maintain bodily functions were ways in which time was viewed then and leisure was considered free time when individuals were free to rest or pick an activity they wanted to do. Murphy (1981) describes this free time as the portion of time available after work and other activities required for existence had been completed. Pettifer (1993) refers to these other non-work activities as obligatory ones; once these and work are undertaken, the residual time is for leisure.

Not work

A common definition of leisure is that it is not work. Kraus (1990:57) states that leisure is that portion of an individual's time not devoted to work or work connected responsibilities or to other forms of maintenance or self-care. Kelly (1990) considers leisure to be just one activity in a nonwork category, others being necessary activities of maintenance and unfilled time. He defines nonwork as "activity outside work commitments" (Kelly, 1990:75). Murphy (1981:17) proposes that leisure is "an opportunity to get relief from work", while Edginton et al (1995) suggest that it is easy for people to separate work and leisure especially if their job is monotonous

> Work is that which is done at the office, factory, or plant, while leisure is that which is done outside of the job (Edginton et al, 1995:40).

However, they also suggest as does Pettifer (1993) that there can be a lack of a clear distinction between work and leisure and what may be considered work for one person may be leisure for another and vice versa.

Both Murphy (1981) and Kelly (1990) suggest that leisure can be related to people's work, but acknowledge that a number of additional factors influence choice of leisure. These factors include

> educational experiences, neighbourhood friendships, leisure socialisation habits inherited from the parental family, community opportunities, costs and income, and a host of personal elements (Kelly, 1990:73).

Shaw (1985) conducted a study with a random sample of 60 married or living-together couples using interviews to establish factors which best differentiate leisure from non-leisure. Those interviewed ranged in age from 21 years to 62 years with a mean of 39.6 years. In addition to being interviewed all were asked to keep a 2-day time-budget diary including one Sunday and one typical workday during the week. During the interview participants were asked to classify all the activities listed in their diaries as 'work' or 'leisure', or 'a mixture of work and leisure,' or 'neither work nor leisure'.

Shaw found that the great majority of events (95.2%) were designated as either work (28.5%), leisure (50.0%), or a mixture of work and leisure (16.8%). Only 196 events

(4.8%) were defined in terms other than work or leisure, with most of these being 'personal care' activities such as getting up, washing, shaving and getting dressed.

Shaw found that very few activities were consistently defined as leisure or as work with some activities experienced as leisure in some situations but considered as work in other situations. Shaw (1985:11) argues that

> these results indicate the problems associated with using any type of activity definition of leisure if leisure is conceptualized in terms of individual experience.

Shaw (1985) also found that both the majority of leisure situations and work or non-leisure situations were non spontaneous. However the leisure situations were more likely to have high levels of enjoyment and relaxation, while the non-leisure situations did not.

Shaw (1985) concluded that enjoyment, freedom of choice, relaxation, intrinsic motivation, and the lack of evaluation were the factors that best differentiate leisure from non-leisure. Each of these factors alone cannot be considered to define the concept of leisure, but Shaw (1985) suggests that

> the combination of three or more factors leads to accurate predictions of the definition of situations as leisure" (Shaw, 1985:1).

Social status

Another definition of leisure is as a symbol of social status. Edginton et al (1995:37) suggest that it has been as such since the beginning of agricultural civilisations when "*leisure classes*" emerged. They consider this emergence to be a result of changes in the social organisation and functions of agricultural societies. It is also argued that leisure as a social symbol was evident in the 1970s. As societies became highly industrialised, leisure was seen as a prized value and contributed to the social value placed on individuals when leisure was part of their life style (Murphy,1981). According to Edginton et al (1995), participation in leisure may be motivated by the desire to gain status in society.

3.5.3. Benefits of Leisure

Leisure is considered to provide benefits to individuals (Murphy 1981, Kelly 1990, Kraus 1990, Christiansen 1991a, Edginton et al 1995, Henry 1998). These benefits relate to health, psychological well-being, social interaction and intellectual development. Today's society is full of stress and pressures which individuals need to escape or recover from. These stresses can be escaped from temporarily through leisure. Edginton et al, (1995:21) believe that

> participation in positive, constructive forms of leisure provides an excellent alternative to negative forms of escape such as substance abuse.

Health

The spectrum of activities that are considered leisure is wide. Some are physical activities and these can have a positive effect on health. Kraus (1990) identifies these as such issues as control of obesity and preserving cardiovascular fitness. While Edginton et al (1995:12) consider participation in leisure to be maintaining a healthy vigorous lifestyle, rest, relaxation, self enrichment and pleasure are considered benefits of leisure by Kelly (1990) and Kraus (1990). According to Suto (1998) participating in leisure neither cures nor removes the effects of ageing or chronic health problems, but it does have the potential to change the quality of life for many individuals.

Psychological well-being

Psychological benefits can also be gained as leisure can

> contribute to the psychological well-being of individuals and nurture the human spirit by enhancing stability, growth, health, self-esteem, self-confidence, and feelings of competence (Edginton et al, 1995:17).

Kraus (1990) suggests that leisure can help avoid emotional distress and mental illness because it is an emotional outlet which provides feelings of pleasure and satisfaction. If these are repressed, illness may occur. Joy, happiness, increased mood, a natural high, self actualisation and "just to feel good" are additional psychological benefits from leisure (Riddick 1986, Kraus 1990, Kelly 1990, Christiansen 1991a, Edginton et al 1995, Henry 1998).

In order to feel positive following a leisure experience, Edginton et al (1995:33) suggest that individuals must perceive themselves to have the skills necessary for the activity. By matching the challenge of the activity with skills, then the experience will be satisfying and not frustrating or discouraging. It would appear that here Edginton et al are referring to flow, as defined by Csikszentmihalyi (1993) and outlined in Section 2.2.5.1. Murphy (1981) considers leisure to provide each person with an opportunity to realise his or her full potential, or as Kelly (1990:2) puts it "we need some freedom to become and to be ourselves", and this can lead to their fullest development as a human being (Murphy, 1981). There is a relationship between the range of activities participated in and psychological well-being according to Iso-Ahola (1980) who suggests the more extensive the range of activities, the better the psychological state.

Social interaction

Another aspect of leisure is the social gain. Kraus (1990:3) suggests that leisure

> is highly social and provides the opportunity for making new friends or co-operating with others in group activities.

Edginton et al, (1995) consider it to be of benefit to social interactions and society. They state that

> leisure offers opportunities to teach sporting behaviours, fair play, team work, citizenship, social skills and conflict resolution (Edginton et al, 1995:16).

They also suggest that it allows individuals the opportunity to learn and practise their social skills as well as interacting with others. It can provide opportunity for companionship and building relationships (Kelly 1990). According to Christiansen (1991a), leisure is an important means of facilitating social transition through life stages. It can provide continuity with the past and a satisfying use of time during retirement.

Intellectual development

Leisure is also believed to have cognitive benefits as often new learning takes place. Mental and cognitive skills are engaged and it can influence values of achievement and success (Kraus, 1990). Pettifer (1993) suggests that leisure activities can improve or enhance an individual. This is also the view of Creek (1997) who suggests that through leisure, new skills are learned more thoroughly and integrated more successfully into the pattern of daily life because the individual will be approaching the learning in a playful and explorative manner.

3.5.4. Leisure in Adulthood

As the age group for those attending the Cardiff Day Service spans 18 to 55 years, consideration has been given to the variety of different levels of participation and types of leisure activities. Adulthood, according to Edginton et al, (1995) includes three age bands; that is early adulthood (ages 18 to 30), middle adulthood (ages 31 to 50) and late adulthood (ages 51 to 65). Edginton et al (1995) describe early adulthood as between the ages 18 and 30. During this time individuals establish independence from their parents and begin to consider relationships and family. Individuals usually complete formal schooling and focus on their career.

Settling down and being established in career and family life are part of middle adulthood, according to Edginton et al (1995). This spans from 31 to 50 years and during that time there may be commitments, such as caring for parents and helping children to mature. Mid-life crisis may occur as physical maturity begins to decline and there may be an awareness of one's own mortality, recognising the "limited amount of time left to find fulfilment" (Edginton et al, 1995:150).

Late adulthood (ages 51 to 65) is when there may be fulfilment or failure of life goals (Edginton et al 1995). Also the "empty nest syndrome" may occur – that is when children leave home and couples need to adjust to each others' company. Late adulthood is also a time when physical deterioration begins and bodies take longer to recover from exhaustion and show lack of endurance. It is usually a transition time from job to retirement which may result in anxiety over loss of work role and concern over issues such as finance and health care.

Although these stages of adulthood represent times of change, Kraus (1990) acknowledges that adults are usually able to meet their leisure needs as they tend to be physically capable, mobile and financially able to purchase equipment or drive to leisure venues. However Kelly (1990) argues that adulthood may include a number of traumas and transitions such as mental and physical health problems for the individual, the death of a spouse or parent, divorce or unemployment. These would affect leisure activities, in particular the opportunity for them to make social contacts.

During adulthood, Edginton et al (1995) suggest that leisure activities are likely to be ones which require the individual to be self-motivated. Kraus (1990) concludes that during middle age, adults change their leisure pursuits away from family centred activities and develop their own interests while later, according to Edginton et al (1995:149), when people enter retirement "they tend to seek less novelty and thus tend to participate in previously tried activities". However Iso-Ahola (1980), while acknowledging that leisure participation generally decreases with age, suggests that this does not mean that the importance of leisure diminishes as age increases.

A broad range of activities are participated in by adults. Leisure activities can be grouped into three categories: quiet recreation such as hobbies, crafts and reading, active recreation such as sports, outings and travel, and socialisation such as visiting, phone calls, parties and correspondence (Law et al 1994). Cheek and Burch (1976) identified a range of leisure activities in which adults in the USA participated in one month. The most frequently conducted activities were reading a paper (90%), watching TV (88%), visiting friends and relatives (86%) and reading for pleasure (75%). A much smaller proportion took part in going to a museum (13%), taking a class for enjoyment (10%), making a collection (10%) motorcycling (5%) and horseback riding (5%). It is acknowledged that this is not a recent list although activities identified are similar to those referred to by Edginton et al in 1995. Kraus (1990:3) agrees that the range of leisure pursuits is broad

> including travel and tourism, cultural entertainment or participation in the arts, hobbies, membership in social clubs or interest groups, nature related activities such as camping or hunting and fishing, attendance at parties or other special events, or fitness activities.

Kelly (1990) and Drummond (1990) consider even daydreaming to be a leisure activity. By daydreaming

> we enter a normally inaccessible environment, acquire previously unattainable skills, and interact with formerly distant others, we transcend some of our normal limitations to try out identities outside our normal reach (Kelly, 1990:43).

Not all activities are equally participated in by all adults and there are several reasons for this such as age, the person's health, economic status and educational background (Cheek & Burch 1976, Kraus 1990, Edginton et al 1995).) During early adulthood (ages 18 to 30) leisure activities such as outdoor pursuits and team sports are important (Edginton et al 1995). Other activities that this age group participate in include movies, concerts, music, dancing, dating and bars as well as shopping, television and watching videos.

During middle adult (ages 31 to 50) there is less involvement in team sports and continued or increased participation in golf, tennis, swimming, bicycling, volleyball, bowling and exercising (Edginton et al 1995). Other activities include gardening, hobbies, crafts, television, driving and socialising including trips. Edginton et al (1995:148) suggest that

> physical activities and exercise are important to maintaining good health as individuals begin to realise their mortality during this time.

During late adulthood (age 51 to 65) there is increased group participation, socialising and involvement in social organisations often increases (Edginton et al 1995). Active pursuits include fishing, bowling, golf, tennis, walking, exercise, bicycling and swimming. Also there is participation in gardening, relaxing, reading, church related activities, picnics, television, hobbies, travel and volunteering.

Kraus (1990) also considers personality and gender to influence choice of leisure activities. He suggests that

> outgoing, enthusiastic, sociable people are likely to engage in a wide variety of active games, sports, and group pastimes. Others more introverted or intellectually grounded may choose to be involved in quieter, less group-oriented activities, possibly of a cultural nature (Kraus, 1990:60).

With regards gender he suggests that males have more freedom to participate in leisure activities than females. Also traditionally males have been encouraged to participate in activities that are physically active, challenging and competitive, while females are expected to take part in leisure activities that are "centred around domestic functions, or that were artistic but relatively quiet or passive in nature" (Kraus, 1990:107).

Even an individual's level of education can influence leisure behaviour (Murphy 1981). He argues that educated individuals have a greater potential for leisure since they are better equipped to do what they want, both on the job and in free time and may have a high income which aids choice.

3.5.5. Disability and leisure

There is evidence to suggest that participating in leisure activities if disabled can be difficult. Kraus (1990) suggests that coping with matters such as raising a family, time pressures and financial situation may make it difficult for those with a disability to participate in leisure activities without support. Edginton et al (1995) also identify constraints such as limitations or restrictions but suggest that these may be constraints placed on individuals themselves or by society or their environment.

Fougeyrollas et al (1998:128) identified different levels that can present obstacles for participating in leisure. One level relates to environmental factors, such as

> the physical or intellectual demands of particular activities, the adaptability of equipment required and willingness of participants to accommodate.

The second level relates to the

> physical accessibility of recreational facilities and the availability of information about accessible leisure activities.

Murphy (1981) agrees that architectural barriers such as curbs, stairs, narrow doors and high counters can be a factor in limiting mobility and independence of some disabled people and thus limit their use of leisure facilities.

Another factor affecting people with disabilities, according to Murphy (1981:162) are professionals such as special educators, rehabilitation counsellors, physiotherapists and occupational therapists promoting segregation and which, he considers

> ironically, may in some cases be encouraging the dependency and continued limited participation of these individuals they seek to serve, the disabled.

He goes on to suggest that reasons given for this segregation are that professionals believe it is

> for their own good" because the disabled receive individual attention, and it protects them from unwarranted daily frustrations, concerns and failures (Murphy, 1981:162).

Another argument relates to how the local community view disabled people with suggestions that they may be embarrassed by the disabled, or the leisure services are not equipped to provide services to the disabled. These arguments highlight the need to ensure access to public facilities including the removal of architectural and physical barriers and provide support so that people with disability may participate in leisure activities of their choice (Murphy, 1981).

Murphy (1981) also raises the issue of the types of activities that disabled people are not expected to participate in such as skiing, horseback riding, motorcycling, gymnastics and mountain climbing. Architectural barriers are again a major obstacle to providing an opportunity for excitement for disabled people.

Albert et al (1994) conducted a study of 72 men with HIV (mean age 42) to establish how they spent their time. Participants completed a time budget which they brought with them to their next scheduled clinic visit. For each activity, subjects reported a start and finish time, whether they were alone or with someone, and whether they were at home or out of the home. Albert et al (1994) found that respondents reported an average of 15.5 activities in their diaries, with a range of 6 to 41 activities. Of these work occupied the largest percentage of the day (22%), followed by passive leisure

(18%) and 5% of the day in personal care (i.e., grooming, bathing, dressing). They found the percentage of the day in passive leisure activities (which they define as listening to the radio, watching TV, reading) was most highly correlated with poor function and poor performance on tests of memory, attention, executive function, and verbal fluency were all associated with a greater proportion of the day in passive leisure. In addition, the presence of neurological dysfunction and cognitive symptoms were associated with more time at home and in passive leisure, and less time at work. They concluded that in the case of HIV

> more severe disease is associated with restrictions in activity (more time at home, less time at work, more time resting); reconfiguration of the day to stress activities still within the capability of respondents (more passive leisure time) or made necessary by disease (increased medical time); and alterations in activity that may indicate adaptation to disease (more time resting, less time awake in a day) (Albert et al, 1994: 28).

These associations are sustained across a number of indicators of disease severity, including immune status, symptom status, and clinical measures of neurological and neuropsychological deficit. They acknowledge that this relationship has been demonstrated in the case of HIV only, but consider it likely that similar associations may be found for other diseases too.

3.5.6. Occupational therapy and leisure

According to Henry (1998), leisure, in addition to work and self-care is considered one of the major occupations of human beings and therefore is appropriate to be considered within occupational therapy. Hopson et al (1983:213) outline the aims of occupational therapy in the area of leisure as to:

- provide all patients with the opportunity to relax and enjoy themselves,
- encourage concentration, orientation, memory and participation with others,
- combine physical and proprioceptive skills through certain games played in a seated position e.g. carpet bowls,
- ease tension and encourage a competitive spirit with team activities,
- help the patients and their relatives plan towards discharge, and therefore encourage personal interests which can be pursued at home, offer advice regarding potentially suitable leisure pursuits for the individual.

According to Kraus (1990:190), initially, the primary purpose of leisure activities in treatment settings was to

> provide diversion, contribute to the morale of patients, and make them more receptive to other forms of therapy.

In more recent times it has been acknowledged that many individuals with disability have serious problems of conducting their leisure activities. The focus changed so that individuals are helped to use leisure effectively and participate in leisure activities in the community. Therapeutic goals can be achieved through the use of leisure activities (Suto, 1998).

Drummond and Walker (1996) carried out a study involving 65 individuals post-stroke to assess the effects of a leisure rehabilitation programme on functional performance, psychological wellbeing and mood. Each of the participants was randomly allocated to either a leisure rehabilitation group, a conventional occupational therapy group or a control group. The participants in all three groups were similar in terms of demographic characteristics except for age. The mean age for the leisure group was 58.95, while for the other groups it was 70.10 and 68.65. Following the use of statistical measures to control the influence of age on the results, Drummond and Walker (1996) found that age was not as important a factor as might have been expected. The findings suggest that leisure rehabilitation improved psychological wellbeing as measured by the total Nottingham Health Profile score. Although this improvement was significant at 3 months (p=0.02) there was only a trend towards significance at 6 months (p=0.06). This indicates that the effect of leisure rehabilitation reduced with time (Drummond & Walker, 1996).

3.6. SUMMARY

This section of the literature review has introduced literature relevant to occupation and health. The belief that participation in occupations can have an effect on health is not new. There are perceived to be many benefits from being active both at individual and societal levels. The desire to understand the exact influences on health and the nature of occupation has led to the creation of a new science, occupational science. The occupations are used as a treatment medium and it is suggested that a balance of occupations is required for health. There are three major categories of occupations, self-care, productivity and leisure. The balance of participation in each of these categories to achieve optimal health is not yet known. The study reported in this thesis includes the investigation of what occupations and roles individuals post stroke carry out or have difficulties with as well as their quality of life. This should add to the current knowledge of participation in occupations and health. The next section of the literature will focus on the specific condition of stroke and its impact on the occupational performance of individuals.

CHAPTER 4

LITERATURE REVIEW – STROKE

4. LITERATURE REVIEW - STROKE

This aspect of the literature review will outline what a stroke is, the incidence of stroke and the effects of a stroke on the human body both physiologically and psychologically. However, the main focus of the review will be on exploring the impact and consequences of a stroke on the individual concerned, in particular in relation to their occupational roles, their family and carers and on hospital and community services. The majority of the literature relating to stroke and studies conducted concern the older population. As the focus of this research is on a younger age group (18 to 55 year olds) efforts have been made to highlight literature of particular relevance to this age group.

4.1. INTRODUCTION

Stroke is the acute onset of neurological deficit lasting more than 24 hours or leading to early death, the cause being of a presumed vascular origin (Aho 1980, Bogousslavsky et al 1998). As the cause is likely to be secondary to a primary disease involving the vessels and circulation it can be ischaemic or haemorrhagic (Bogousslavsky et al 1998). In younger adults, around half of strokes are caused by blood clots and half by haemorrhages (Stroke Association 1996). Stroke is a complex condition that potentially disrupts all aspects of motor, sensory, language, cognitive and social functions (Falconer et al 1993).

The Stroke Association (1996) consider a stroke to be a life-threatening illness and to constitute a major life event for families and carers as well as for the patients. They suggest that approximately one-third of stroke survivors recover to their former level of physical function whereas one-third of patients die within the first six months after the stroke. The remaining third of patients will recover a proportion of their function but will be disabled to some degree for the rest of their lives (Stroke Association 1996). According to Phipps (1991), of those who survive a first stroke, 50% are expected to be alive in 5 years.

You et al (1997) suggest that stroke in the young is particularly tragic because of the potential for a lifetime of disability. A stroke is often considered a personal disaster, which hits the patient suddenly and leaves him or her with distressing and disabling consequences (Wyller et al 1997).

Even after the most severe stroke some kind of recovery usually occurs (Birkett, 1996). The most rapid amount of recovery occurs spontaneously during the first three months (Freemantle et al, 1992 Bogousslavsky et al, 1998). This spontaneous recovery can be impressive, though the rate of improvement diminishes, and it is most unusual for improvement to continue beyond six months to one year after stroke (Freemantle et al, 1992, Bogousslavsky et al, 1998). However recovery can be interpreted in two ways. The first is neurological recovery, that is, the largely spontaneous processes of physiological reorganisation of the neural system which is perhaps being referred to by Freemantle et al 1992, Birkett 1996 and Bogousslavsky et al, 1998. The second type of recovery is adaptive recovery; that is the development by the person of adaptive techniques to use to compensate for residual impairment of functional abilities (Chang & Hasselkus 1998). According to Thompson and Coleman (1988), if the individual who had a stroke is young and has no major complications they are likely to regain some previous skills more quickly than an older person.

4.2. INCIDENCE AND PREVALENCE

Stroke is the third most common cause of death in most Western populations after coronary heart disease and cancer (Stroke Association 1996, Warlow et al 1998). It is also the most common life threatening neurological condition, the commonest disease of the central nervous system to warrant admission of a patient to hospital and the most important single cause of severe disability in people living in the United Kingdom (Stroke Association 1996, Warlow et al 1998, Bogousslavsky et al 1998).

Someone in Britain has a stroke every five minutes and about 130,000 first ever strokes occur in Britain each year (Kings Fund 1988, Freemantle et al 1992, Sharma 1999). In Wales in 1999, the Welsh Health Survey was carried out on 28,992 adults and reported (National Assembly for Wales, 1999). It found that 1.2% of the population had a stroke. This was a decrease on the proportion reported in 1995 when it was 1.6%. The incidence was less in the 18 to 44 age group (0.4%) than those aged 65 to 74 (2.7%). There are slight differences in the reported rates of stroke although all agree that stroke affects all ages and that the rate increases with age (Bevan et al 1990, Birkett 1996). According to Kings Fund (1988) and Office of Health Economics (1988) half of all first strokes occur in people aged 75 and over. Freemantle et al (1992) suggest that one in four strokes occur in people under 65 years old whereas Zuber and Mas (1991) and Bogousslavsky et al (1998) suggest that less than 15% of stroke patients are under the age 45 and at least two-thirds are older than 60. The Stroke Association (1996) predicts that at the current rate one woman in five and one man in four aged 45 or over can expect to have a stroke if they live to be 85. They also state that every year around 10,000 people under retirement age in England and Wales will have a first stroke, that is almost 200 per week (Stroke Association 1996). It would appear from the literature that over time either the awareness of stroke in young adults has increased or the actual incidence has increased. According to Hilton-Jones and Warlow, in 1985 stroke in young adults was uncommon but by 1996 the Stroke Association were reporting an incidence of 10,000 per year.

In 1996, the Stroke Association canvassed 230 people who had had strokes under the age of 55 and found that 68% were aged between 41 and 55, 30% were aged between 18 and 40 with two percent being younger than 18. This reflects the findings that the incidence of stroke increases with age. The gender of the Stroke Association group was balanced with 52% being male. This contrasts with other studies. Allen et al (1988) found that men have a 30% higher incidence of stroke than women do and that this difference was greatest before the age of 65 years.

4.3. EFFECTS

Stroke is a complex condition that can affect each individual in a different way and to a different degree. Most of the literature refers to the effect of stroke on older people but Bevan et al (1990) suggest that there are differences in how the stroke impacts on the lives of young people and that these may be different for older adults. Kittner (1998) identifies these as issues such as career development and bringing up a family. Often the obvious physical limitations of a stroke such as hemiplegia, are the only effects that are acknowledged. Langton-Hewer (1982) believes that there is a growing awareness that those who have had a stroke also experience severe psychological problems.

The development of a chronic physical illness in adulthood is often expected to result in a loss of physical independence and increased dependence on others (Gignac & Cott 1998). Individuals may seek assistance for some tasks (e.g. housekeeping), in order to leave themselves with the time and energy to focus on other tasks (e.g. socializing with friends). In other words, independence in some domains of life may only be possible by accepting some level of dependence in other areas of life. This section of this chapter outlines the multiple impairments that can occur following a stroke first before considering the impact of these impairments on the individual, their family and carers and services.

4.3.1. Physical

Motor, sensory and language loss can occur with a stroke. According to Wilkinson (1999), the particular loss of function depends on the area of the brain affected by the stroke. Some of the resulting impairments are outlined below.

Motor

Common motor effects of stroke are paralysis of the face, arms, and legs (Mathias et al 1997). Hemiplegia, that is paralysis of one side of the body, is often the most observable sign of stroke, and according to Wilcock (1986:29) receives "more attention than other symptoms which may be equally dysfunctional". In addition there may be a reduction of mobility (Bogousslavsky et al 1998, Pound et al 1998). Soderback et al (1991) found that 80% of survivors reported sensori-motor impairments. This is consistent with the Stroke Association (1996), which found that many younger people have serious residual physical disability. Other motor problems that may be present include poor head control, trunk control, facial weakness and impaired balance (Wilcock 1986, Gillen 2001). As a result individuals may appear asymmetrical, or may lean or fall to the hemiplegic side, or uncoordination, clumsiness or involuntary movements may occur (Gresham et al 1995).

Sensory

Both sensation and perception may be affected by a stroke and Wilcock (1986) acknowledges that it is sometimes difficult to differentiate between the two. She considers sensation to be impaired when the individual experiences distorted information from themselves and the environment, and perception to be impaired when the individual experiences difficulty in understanding and interpreting information from themselves and their environment.

Sensory loss together with motor dysfunction can result in the loss of functional activity. The most common types of sensory loss from stroke are proprioception and tactile sensation (Wilcock, 1986). Proprioception relates to the sensory awareness of the position of body parts and impairment affects anti-gravity and postural mechanisms resulting in individuals having

> difficulty maintaining balance, appearing to forget affected body parts, being unable to describe the position or movement of limbs, and being susceptible to joint damage (Wilcock, 1986:31).

Tactile sensation relates to the indentification and discrimination of stimuli on the skin such as light touch, texture, temperature and pain. Loss of tactile sensation can result in an individual having

> a lack of awareness of body parts simply because people tend to forget what they cannot feel (Wilcock, 1986:31).

Language

As well as affecting motor and sensory functions, stroke may often lead to impairment of communication and cognitive function (Wellwood et al 1994, Mathias et al 1997, Pound et al 1998). The Stroke Association (1996) found, in their survey of 230 young adults, that 38% said they could not communicate adequately and a further 30% said they could not communicate well. There are three main communication problems following stroke: dysphasia, dysarthria, and dysphagia (Wilkinson 1999). Dysphasia refers to the difficulty understanding what is said, expressing things verbally, reading and writing. Dysarthria is when the muscles used when speaking are affected resulting in slurred or unintelligible speech. Dysphagia results in difficulty swallowing, including chewing and tongue movement in preparation for swallowing.

4.3.2. Psychological

A broad range of psychological effects may occur following stroke. These include depression, anxiety, emotional problems, poor cognitive processes and loss of self-concept. The nature and severity of psychological problems are influenced by many factors including the extent of the neurological deficit, the person's premorbid personality and previous quality of life (Langton-Hewer 1982). Friedland and McColl,

(1989) suggest that poor psychological adjustment after a stroke can manifest itself in many forms but the most common form is depression.

Depression

There is substantial evidence to suggest that depression does occur following a stroke (Feibel and Springer 1982, Lipsey et al 1984, Evans et al 1989, Angeleri et al 1993, Gompertz et al 1993, Pound et al 1998, Watkins et al 2001). The Stroke Association, (1996) suggest that depression occurs in 20% to 60% of people with a stroke. It is often severe and long-standing (Lipsey et al 1984, Price 1990). In the mid 1980's, it was assumed that depression following stroke was an understandable response to the traumatic and disabling effects of the illness (Stroke Association 1996). It was also believed that people recovered spontaneously after several months and therefore did not need antidepressant treatment. More recent evidence suggests that depression is highly prevalent after stroke, that the incidence increases over time and that it impacts on regaining normal lifestyles (Robinson et al, 1984, Bacher 1990, Stroke Association 1996, Watkins et al 2001).

Depression is recognised not only to occur but to be present some time after the stroke. Wade et al (1987) found, in a study of 976 individuals who had a stroke, that over 50% of those who were depressed at three weeks remained so at one year. Collin and Lincoln (1987), also looking at long-term outcome, found that out of 111 participants in their study, 47 (42%) were depressed between one and two years post stroke. Robinson and Price (1982), in a study of 103 individuals post stroke, found that the prevalence and severity of depression was significantly higher in those who were between 6 months and 2 years post-stroke ($X^2 = 6.01$, $p < 0.02$). Combined, these three studies include over 1100 participants. This could be considered as a large enough population to support the argument that depression occurs post stroke.

Folstein et al (1977) and Fedoroff et al (1991) studied depression as a specific complication of stroke. Folstein et al (1977) conducted a small study involving 20 individuals with a stroke and 10 with orthopaedic problems They found that those who had a stroke were more depressed than those with orthopaedic problems (45% versus 10%) even though the level of functional disability in both groups was the same. They concluded that depression is more than simply a response to the motor disability of stroke although it could be argued that the study is too small to draw any conclusions.

Fedoroff et al (1991) also conducted a small study involving 44 individuals with stroke, 25 who had a myocardial infarction and 12 with acute spinal cord injury. They found that the stroke group scored significantly higher for generalised activity (p = 0.012) and for depression (p = 0.004). They conclude that the cause of depression associated with myocardial infarction or spinal injury is different from that following a stroke. Again, this is a small study, but it begins to identify a difference in depression depending on the condition the individual has.

Robinson and Benson (1981) found depression to be common in those with speech problems following a stroke and Allman (1991) suggests that making a diagnosis of depression in this group of people with stroke can be particularly difficult. Signs such as unexplained weight loss, sleep disturbance or irritability might be the only pointers to the diagnosis (Allman 1991). It therefore may be difficult accurately to identify the incidence of depression if speech is affected.

There are only two studies that surveyed the incidence of depression in young adults. The first was carried out by The Stroke Association in 1996. They surveyed 230 individuals and of these 45% said that they were depressed at the time of the stroke and at the time of the survey they were still depressed. They did not state how long after the stroke the survey was conducted and therefore do not provide a time range post-stroke when depression occurs. The Stroke Association surveyed these adults using a questionnaire. It does not state that within the questionnaire was a standardised assessment of depression as opposed to an open question on mood after stroke. The incidence of depression may be different if a standardised assessment was used.

A second study was conducted in France by Neau et al in 1998. Seventy-one young individuals (aged 15-45 years) affected by a stroke were included in the study if it was at least one year since hospital discharge. They found that post stroke depression was common, with 48.3% of the individuals classified as depressed. This depression was associated with the type of stroke, a severe disability, a bad general outcome, and an absence of return to work.

In addition only one study has compared the incidence of depression following a stroke in men and women. Angeleri et al (1993) conducted a study of 180 individuals who were at least one year post stroke. Sixty-five per cent of the study population were men.

They found that depression was greater in women than in men and that the difference was significant (p<.001). As this is the only study to look at gender differences it is not possible to conclude that these findings are generalisable.

All these studies, with the exception of Wade et al (1987) are small with populations of less than 20 to 230. Also the methods used varied from standardised assessments such as Hospital Anxiety and Depression Scale to non-standardised open questions. However they continue to provide evidence that depression occurs post stroke. Another small study was conducted by Hindfelt and Nilsson (1992). They followed up 74 young adults (age 16-40 years, mean age at stroke 29.5 years) at least 13 years post stroke. Of the 62 survivors at follow-up, there were few recordings of major psychiatric complications and only 7 (11%) had suffered from depression. This falls short of the Stroke Association's estimate of 20% to 60% of individuals suffering from depression post stroke.

Anxiety

Evans et al (1989), Warlow et al (1998) and Mathias et al (1997) suggest that it is not surprising to see symptoms of anxiety in most people who have had a stroke, as even a minor stroke can represent a considerable threat to most people. A stroke can induce feelings of fear in relation to dying, being left disabled or having another stroke. However, there are no studies to specifically support the incidence of anxiety following stroke.

Cognitive ability

Impairment of thought processes, confusion, impaired cognition and memory problems may be present following a stroke (Evans et al 1989, Mathias et al, 1997 and Pound et al 1998). Soderback et al (1991) in a study of 195 individuals three years post stroke found that 80% reported intellectual impairments. The definition of intellectual impairments was based on 15 questions in a questionnaire completed by participants.

Negative Self-concept

Self-concept is the multidimensional nature of the self and the term 'self-esteem' is often used interchangeably with self-concept (Ben-Shlomo and Short 1983, Kersten 1990). Several authors define self-concept as an individual's perception of him or herself (Shavelson et al 1976, Brinkman and Hoskins 1979, McClelland 1982, Ben-Shlomo and

Short 1983). A number of studies have been conducted to identify changes in self-concept following a long term disability or chronic illness. Charmaz (1983:170) suggests that serious chronic illness provides a unique area in which to study the self because those with an illness

> often become highly aware of previously taken-for-granted aspects of self because they are altered or gone.

Brinkman and Hoskins (1979) conducted a study of seven individuals with a stroke. Their aim was to determine the effect of a rehabilitation programme on the level of physical fitness, function and self-concept in these patients. Prior to the rehabilitation programme they found that these individuals had a low level of self-esteem, a diminished view of their own worth, a negative view of their body, state of health, physical appearance, skills, and sexuality, and a diminished sense of personal worth and adequacy as a person. Brinkman and Hoskins (1979) concluded that a self-concept reflecting a diminished view of self can result in lowered aspirations and behaviour that reinforces the feelings of negative self-concept and that participation in rehabilitation programmes resulting in achieving goals such as improved physical and functional status can have a positive influence on self-concept.

Kersten (1990:457) conducted a study on 37 individuals with Chronic Obstructive Pulmonary Disease (COPD) attending a pulmonary rehabilitation programme and defined negative self-concept as

> the crumbling away of former self-images without the development of equally valued new ones.

The findings of this study indicate that self-concept changes from negative to positive during pulmonary rehabilitation. Although some decrease in self-concept was found after discharge, it was not to a significant level ($t = -0.92$, $p = 0.39$). Men were more likely than women to have a reduction in self-esteem after discharge. Kersten (1990) concludes that negative self-concept comes from either living a restricted life, social isolation, poor definitions of the self from, for example, unmet expectations or becoming dependent and a burden to others. The self-concept of a normal adult remains relatively stable; however it can be affected by major life events changes such as a COPD or stroke.

Tyerman and Humphrey (1984) conducted a study of the self-concept of 25 individuals with severe head injury. They found that the individuals perceived a typical head injured person to be significantly more bored, unhappy, helpless, forgetful and clumsy and significantly less attractive, hopeful, active and clever compared with a typical person without a head injury. They found that many individuals described a reduced sense of personal worth and were self-conscious about their various disabilities.

Sarason et al (1983) suggest that social support has an impact on self-concept. They define social support as

> the existence or availability on whom we can rely, people who let us know that they care about, value and love us (Sarason et al, 1983:127).

They suggest that people who have a lot of social support not only seem to have positive self-concepts, but also have a belief in their own ability to control aspects of their lives.

Feldman (1974) also acknowledges the impact of a serious illness on the individual including their self-concept. He suggests that with the onset of an event like a stroke, periods of depression are regularly encountered. "Mourning the loss of the pre-morbid self and its potential is to be expected" (Feldman 1974:288). This mourning process facilitates the consideration of the future which may not be possible until what has been lost has been grieved for. He suggests that

> the possibility of continued membership in highly valued groups increases the ability to cope with the crisis of serious illness (Feldman, 1974:288).

He defines valued groups as family, close friends, and, in the instance of prolonged hospitalisation, fellow patients and considers both the mourning process and the involvement in these groups as a way of developing a new self-concept, new self-meaning, and a new 'mode of being'.

Other effects

A range of other psychological effects of stroke has been reported in the literature including emotional problems, loneliness and abnormal illness behaviour. Soderback et al (1991) in a study of 195 individuals found that about 80% of people had emotional problems after a stroke. The emotional problems included stress, lability, restlessness, fatigue, worry, listlessness and anger. The most prominent problems were feelings of sadness and changes in personality. The Stroke Association (1996) found that terrible frustration was the most common emotional problem. This was often caused by the inability of individuals to express themselves as they wished following a stroke. Loneliness and isolation have also been identified as a consequence of stroke especially if the person is house-bound or unable to resume their normal leisure or work activities (Charmaz 1983, Warlow et al 1998, Pound et al 1998).

Clark and Smith (1997) suggest that Abnormal Illness Behaviour is a psychological effect of stroke. They describe abnormal illness behaviour as illness behaviour that is disproportionate to the effects of stroke and the person persists in the sick role. They describe a person adopting a sick role as someone who

> is not held liable for incapacity, and is granted relief from normal social responsibilities, provided the person agrees that this is undesirable and actively seeks to regain health (Clark & Smith, 1997:162).

In their study of 94 individuals (mean age 70.3, SD=10.6), they found that about one person in eight on admission showed signs of abnormal illness behaviour, while one in four did during rehabilitation, at six months and 12 months. They also found that the abnormal illness behaviour group had significantly poorer mood, greater depression, and more neurotic symptoms as well as poorer levels of performance in activities of daily living. They conclude that this psychological response ultimately leads to an increase in dependence and suggest that rehabilitation needs to include the psychological and social needs of the individual if long-term dependence is to be avoided.

4.3.3. Consequences to the individual

Stroke has a major impact on lives. However there are conflicting views to suggest that the consequences can be particularly devastating when it is a younger person who has had the stroke (Stroke Association, 1996). The adulthood age span (18 to 55 years) can be times of different changes. During young adulthood, people normally leave their family and establish different social roles. Leisure and work activities are important and people may set up their own households, form long-lasting partnerships and start new families (Ravetz, 1998). During middle age people often gain more personal independence, greater financial security and increased social stability (Ravetz, 1998). A disability such as a stroke will disrupt these normal expectations of roles and activities. However, Evans et al (1989) found that age was not a factor when looking at adjustment post stroke. They found that younger and older people experience similar disruptions in their lifestyles.

The consequences of stroke are multi-layered. Some people describe their concerns about the stroke in terms of its impact on their sense of self, while most refer to the changes in their lives in terms of loss of function (Pound et al, 1998). In addition, Charmaz (1983) suggests that a serious chronic illness, such as stroke, can result in financial crises, family strain and stigma. Studies identifying the impact of a stroke on an individual in terms of their ability to carry out normal occupations such as self-care, work and leisure are outlined below. Evidence is also presented to suggest that there is an impact on their physical and social environments.

An altered use of time is another way in which the impact of an illness such as stroke can be seen and according to Albert et al (1994:21), "time use can serve as a measure of disability in disease". They suggest three possible changes in time use, recognising that firstly some activities will become more difficult than they would otherwise be, and individuals no longer spend time on them, such as work and active leisure. Secondly, some activities may require more time than usual (e.g., personal care tasks) because individuals simply lack the ability to perform them as fast as they once did; therefore they use others for help to speed up time spent on them. Thirdly, other activities may begin to take up larger amounts of time for activities which facilitate recovery, (sleep, rest) or there may be a greater proportion of the day spent on activities which they continue to have the ability to do, passive leisure thus replacing activities that have become more difficult (Albert et al, 1994).

The use of special aids and equipment may also relate to people's subjective perception of their independence. For example, relying on an aid rather than another person may contribute to feelings of subjective independence (Gignac & Cott 1998). It is possible, however, for individuals using assistive devices to report a loss of independence and subjective perceptions of dependence. This may relate to perceptions of lost control and to resentment at having to rely on a piece of equipment to accomplish tasks that were once performed without difficulty (Gignac & Cott 1998).

4.3.3.1. Occupations

Earlier aspects of this literature review have outlined some of the impairments that occur post stroke. This section outlines the impact of these impairments in terms of individuals' ability to carry out their everyday occupations following a stroke.

Occupations have already been defined in Chapter 3. Occupations are frequently divided into the categories of self-care, productivity and leisure. Angeleri et al (1993) suggest that most studies focus on the acute phase of stroke which results in less information about the later consequences. One study that addressed the longer term situation found that none of the 195 individuals in the study thought that they had regained the same level of occupational performance as before the stroke (Soderback 1991).

In contrast to the situation where a stroke can result in limited occupational performance, Feldman (1974) introduces the concept of the sick role. He states that

> illness is the only condition that permits the giving up on responsibility by an adult, and condones his dependency in a work-orientated culture (Feldman, 1974:289).

He does go on to clarify that this is acceptable if based on the 'temporary' nature of the illness. He acknowledges that individuals may have

> powerful incentives to continue in the sick role, particularly in those illnesses in which one does not 'get well' in the ordinary sense (Feldman, 1974:289).

These include being cared for and not having to respond to others' expectations. He considers the essence of moving from sick to different is to discover a new meaning in life, to accept the difference imposed by the illness and still to maintain one's dignity and worth.

Self-care

Self-care occupations include those activities required to carry out personal care such as dressing and washing, functional mobility such as walking indoors and community management such as shopping and managing one's finances (Law et al, 1994). Gerhart (1998) suggests that self-care is about having essential, basic, human needs met and it is an area that can be greatly disrupted by a disability such as stroke.

Mathias et al (1997), Bogousslavsky et al (1998) and Pound et al (1998) report that stroke can affect self-care and lead to a reduction in independence in daily activities and thus the ability to live independently. The Stroke Association (1996), when surveying 230 younger adults, found that 78% needed help with their day-to-day living, 60% used disability aids and 42% had adaptations in their home. The Stroke Association do not indicate the time since stroke for the respondents. This contrasts with Warlow et al (1998) who found that one month post stroke, between 50% and 60% of their 515 participants were functionally independent. Information on the amount and type of rehabilitation received by these participants is not provided. The rehabilitation process may have an impact on levels of function. Soderback et al (1991) in their study of 318 individuals post-stroke found that age influenced independence in domestic activities. They found that an older group (mean age 65) were more limited in self-care than those who were middle aged (mean age 49) or younger (mean age 26). The findings of these studies provide an inconsistent picture of the level and frequency of difficulty in self-care activities post stroke.

Belcher et al (1982) compared the needs of those who were single (n = 31) and had a stroke with those who were married (n = 42) and also had a stroke. They found that those who were married required more assistance with personal care than those who were single (p = 0.01). When looking at gender difference in a study of 170 people one year after stroke, Harwood et al (1997:208) found that women had greater handicaps in comparison to men in “economic self-sufficiency, mobility and social integration”. There were similar numbers of each gender in the study.

Other self-care restrictions have been found such as difficulty leaving the house and managing financially and more time may be needed for such activities as bathing, dressing, eating and sleeping (Ware Davidson & Young 1985, Pound et al 1998). Although more time may be required, Belcher et al (1982) found that both single and married people following stroke spent a comparable amount of time shopping for groceries. No comparison was given of this time compared with someone who had not had a stroke.

Physical limitations are not the only factors that influence performance in self care occupations. Schubert et al (1992) found that depression lowers functional ability because it increases fatigue, hopelessness and decreases motivation. Towle (1988:149) studied depressed mood after stroke in a group of 44 individuals and found that participants who

> were depressed were unwilling to do much for themselves. They were often capable of carrying out an activity but never actually did it.

This study was small and drew its conclusions from the rank order of the Extended Activities of Daily Living Scale. Towle found that under the mobility section individuals indicated independence climbing stairs, an item which is ranked more difficult than walking outside, and which fewer individuals indicated as independent. She therefore surmised that if individuals rank themselves independent in climbing stairs they must also be independent walking outside due to the ranking nature of the scale even if they did not indicate that. This indicates that the conclusions were not based on objective testing.

Productivity

Productivity occupations include those activities required to carry out paid or unpaid employment such as finding or keeping a job and volunteering, household management such as cleaning, laundry and cooking and education/college work such as studying and homework (Law et al, 1994). Several studies have highlighted the effects of a stroke on work and household management with none on education.

A stroke in a younger person often results in a change in their employment circumstances. It can devastate their career and result in a reduction of professional activities (Stroke Association 1996, Bogousslavsky et al 1998). A number of studies have been conducted to identify if return to work occurs. Getting back to work after a stroke, according to Burningham (2001), is not just a milestone in recovery, it is a means of boosting confidence, self-esteem and having a sense of acheivement. Many people hold the belief that people should rest after a stroke and that activity will bring on another stroke but Warlow et al (1998) argue that this misconception may result in ruling out the possibility of returning to work. There are conflicting findings from studies looking at return to work following stroke. According to Wilcock (1986) only a small proportion of stroke patients return to the work force because many are beyond working age and have already retired, and others have residual impairment which prevents them returning to a previous field of employment. However as Warlow et al (1998) found out, about one-third of patients who have a stroke are of employment age, therefore the issue of returning to work is an important one. In a study carried out in Oxfordshire, 76

(24%) of 318 men and 39 (11%) of 357 women were in paid employment before their stroke (Warlow et al, 1998). Of these, 68 (59%) returned to work at some stage, the majority within 6 months of the stroke. Several issues affected this return to work including, obviously, the nature of previous employment, residual impairments and disabilities, and the person's own wishes. Kittner (1998:176) also found factors that contribute to return to work including the

> premorbid level of function, motivation, workplace demands, and social and workplace support systems.

The American Stroke Association (2000c) suggest that the real issue is overcoming the fear of joining an able bodied workforce.

The Stroke Association (1996) survey showed that many younger people are trying to cope with the loss of their career and have financial hardship as a result. Of the 230 people surveyed, 80% of those who were in full-time employment at the time of their stroke had given up their jobs, 10% had to give up their jobs but had since found other employment, and only 10% were able to continue in their jobs. Seventy six per cent had not received any careers advice on retraining, while 27% felt they had been discriminated against in the job market (Stroke Association 1996). In tandem with the reduction in employment was a fall in income as a result of the stroke, with 87% reporting a 25% or more drop in income and 58% were relying on state benefits (Stroke Association 1996).

Angeleri et al (1993) produced similar results and reported that 21% returned to work. They did not indicate how many of their population of 180 people were under 65 years; the mean age for the total population was 65.29 (SD 11.22). They found that communication problems did not necessarily rule out a return to work unless there was an inability to understand language.

Howard et al (1985) also found a small number had returned to work. Out of their study of 379 individuals, 73 (19%) reported employment outside of the household at the 3-, 6-, or 12-month follow-up. They attempted to identify factors that influence return to work and conclude that

> people with higher incomes, more education and more skilled forms of employment have a greater probability of returning to work after a stroke (Howard et al, 1985:230).

They also suggest that those aged 55 or younger are most likely to return to work following a stroke especially if their disability is not severe. Jonkman et al (1998) found that none of the 35 participants in a study of a relatively young stroke age group returned to their original level of work.

Holbrook (1982) in another study also found that a small number returned to work. In her study, 30 out of 92 people were working prior to their stroke. Only eight of these 30 returned to work, three of whom left work later for health reasons. At follow-up, two to three years later, five people were still in work. She also looked at the impact of the stroke on the spouses' or main carers' working pattern. Out of 59 spouses, 26 were working when their partners had a stroke. Sixteen of those returned to work, two worked part-time and the remaining eight did not return to work. In explaining these findings, Holbrook (1982) states that for those whose strokes left them with minimal residual disability, and whose employers wanted them back, they were able to go back to work. The three who went back to work and then gave it up, did so because one had another stroke, and the other two found they could not cope. Poor motor function and or communication problems were factors that contributed to not returning to work. A slightly higher percentage (25%) of younger (n=41, mean age 26 years) and middle aged people (n=112, mean age 49 years) had returned to work in Soderback et al's (1991) study. They also found of those who had returned to work, one third were not doing their original jobs. In contrast Adunsky et al (1992) found that 81% of those aged between 18 and 40 had returned to their previous or alternative jobs six months following discharge from hospital after their stroke. The remaining 19% had given up their jobs due to physical or psychological disabilities. However, there were only 30 participants in this study. A study conducted by Neau et al in France (1998) also found a high proportion of the seventy-one young individuals (aged 15-45 years) affected by a stroke. After one year, forty six individuals (73%) had returned to work.

A third study indicating a high incidence of return to work is Hindfelt and Nilsson's study (1992). They followed up 62 individuals for many years following a stroke and found that within a few years after the stroke, some 80% had resumed full-time work and a decade or more later still 63% remained in full-time work. They consider this to be evidence that the prognosis of stroke in the young can be favourable (Hindfelt & Nilsson, 1992).

It is evident that many studies consider the issue of returning to work. As can be seen the reported percentage of those returning to work varies greatly from 10% to 73%. In addition, the majority of the studies relate to small numbers. On the whole, quantitative measures were used in the studies to record return to work. There is little qualitative data indicating individuals' views on returning to work, the importance of the work role to them, the support they require or would like to receive in returning to work or whether a leisure or other role replaces the lost work role.

The ability to carry out household management tasks is also affected by a stroke (Bogousslavsky et al 1998, Pound et al 1998). Anderson (1992) found that 80% of 90 individuals with a stroke were doing less housework than they were prior to the stroke. Belcher et al (1982) found that those following a stroke who were single (n=31) spent significantly more time doing housework tasks than those who were married (n=42) and that single people were more able to carry out the tasks. Soderback et al (1991) found that older people (n=165, mean age 65 years) had greater disability in carrying out domestic and housework activities than younger (n=41, mean age 26) or middle aged people (n=112, mean age 49) with a stroke.

Evans et al (1989) found a link with psychological problems and activity levels. They found that those who were depressed, confused and anxious carried out fewer household management activities. Pound et al (1998) also consider the wider implications of being unable to do household tasks. They suggest that the inability to do household tasks means that the household is not under the control of the individual. For the women in their sample the household was a domain which they had largely controlled. By losing this degree of power and their mechanism for using their skills they experienced considerable unhappiness.

In a study of 84 individuals post-stroke, where 64% were over 60 years of age, DeJong and Branch (1982:652) found that the ability to get in and out of a car "proved to be the most important predictor of a person's ability to lead a productive lifestyle". They suggest that these results are not too surprising because of the dependency on cars in today's society. The consequence for someone with a stroke may be that they

> remain homebound and refrain from participating in activities commonly associated with a productive lifestyle (DeJong & Branch, 1982:652).

Atler and Gliner (1989) also identified transport as a key factor in the decline of participation in such productivity activities.

Leisure

Leisure occupations include those activities required to carry out quiet recreation such as hobbies, crafts and reading, active recreation such as sports, outings and travel and socialisation such as visiting, phone calls, parties and correspondence (Law et al, 1994). After a stroke, there is often a reduction in the participation of previous leisure activities (Atler & Gliner 1989, Bogousslavsky et al 1998, Neau et al 1998 and Pound et al 1998). Soderback et al (1991) suggest that as many as 50% of people who have had a stroke do not maintain the leisure activities they used to have, based on the findings of their study of 195 individuals.

Belcher et al (1982) conducted a study of 73 individuals, 42 married and 31 single, to establish what activities people participate in following a stroke. They found that those who are not married tended to listen to the radio, study, participate in hobbies and crafts, and go to church more often than those who were married. Also those who were married spent more time watching television, playing solitary games, attending sports events, and visiting exhibits or museums. Belcher et al (1982) also found that both single and married people following a stroke were rarely participating in activities such as going to sports events, exhibitions, the theatre, the cinema or on outings. However, they found that all were dining out and grocery shopping fairly frequently. They speculated that although their subjects had the abilities needed to shop or dine out choosing to participate in other active recreation activities may have been influenced by age. They suggest that age influences preference for certain activities rather than disability. The mean age of the single people in their study was 57 years and of the married people was 62 years (Belcher et al, 1982).

More recently, Drummond (1990) carried out a study to identify the leisure habits of individuals prior to their stroke and compare this to their lifestyle post stroke. The study included 109 subjects with a mean age of 71 (range 43–90) and their mean time since stroke was 59 weeks (range 40–78). The Nottingham Leisure Questionnaire, which contains 37 activities and allows respondents to add more, was used. Drummond found that the frequency of participation in three activities ("watching TV", "day-dreaming", and "just sitting") increased (p=0.01). Exercise also increased in frequency, but not to a statistically significant level (p=0.84), while all other activities listed decreased in frequency of participation and all except 4 decreased (p=0.05) (Drummond, 1990).

These findings showed that passive activities were ranked more highly after stroke, and suggest that individuals who are disabled following stroke are less likely to continue with leisure pursuits (Drummond 1990). It is not stated if this is due to physical impairments or difficulties in using transport, getting help and financial constraints. Although she noted that more than half the subjects had varying degrees of mobility and hand function difficulties, the results could suggest that individuals following stroke have difficulty modifying or replacing their previous leisure activities. This may have an effect on other aspects of their lives.

Morgan and Jongbloed (1990) undertook an exploratory study using semi-structured interviews to identify leisure activity involvement for those who had had a stroke. Their sample included twenty men and ten women whose mean age was 69.6, ranging from 42 to 86. All had had their stroke within the previous 15 months and were not on anti-depressant medication. They found that age influenced what type of activities people found meaningful. Participants who had retired before the stroke (80%) were happy to be aiming at resuming leisure activities, while those who were in employment when they had a stroke (20%) were less satisfied doing self-maintenance and leisure activities and identified the need to do something important with their lives. The extent to which individuals could participate in an activity had an impact on the results. A third (n=10) were willing to resume an activity at a lower degree of competence than before, while twelve had no interest in doing an activity unless they could perform to a previous standard (Morgan & Jongbloed, 1990). Previous participation was another factor for resuming leisure activities. Morgan and Jongbloed (1990:226) found that

> those who had participated in a wide variety of activities before the stroke (n=13), had an increased likelihood of being able to continue performing a previous activity.

All participants reported some alteration of their normal routines. Generally participants who had been working when they had the stroke, experienced a greater number of role changes than those who were retired at the time of the stroke. Younger individuals may have been forced to retire, as well as give up more leisure activities: or may have had very little time for leisure activities in the past, and so had very limited knowledge when they tried to assume new roles and activities (Morgan & Jongbloed, 1990). Like

Drummond (1990), they suggest that a physical impairment may not be the only contributing factor to inability to participate in leisure activities following a stroke. The availability of transport and the distance to a leisure venue were important considerations. Support from family and friends was also influential. This depended on how the individual was previously perceived. In some situations they were valued simply for being, while in others they were valued for what they did such as making meals. If they were no longer able to carry out these activities or perfom them as well as before, Morgan and Jongbloed (1990) found that they were no longer valued as much. Due to the small population size of this study (n=30) it is not possible to generalise from this study. However, it introduces issues that may help understand why, despite good physical recovery, leisure activities are not resumed. These include depression, marital status, education and extent of physical disability

Socialisation activities are also affected by a stroke (Bogousslavsky et al 1998). Belcher et al (1982) found different levels of participation in social interaction activities between single and married people with single people participating in more. They suggest that married people participate less often in these activities because they can rely on their spouses for social interaction. Angeleri et al (1993) in a study of 180 individuals with stroke, 117 men and 63 women, found that the reduction in social activity was significantly greater (p=0.001) in women than in men following a stroke. The Stroke Association (1996:3) acknowledged the effects of a stroke on a younger person by suggesting that "*it can devastate their social life*". In contrast the study of Evans et al (1989) on the effect of a stroke on this aspect of life, compared 80 individuals post-stroke and community norms for involvement in social activities and found no significant difference. However, Soderback et al (1991) found that more than one third of the 195 subjects in their study reported altered social roles indicating a change in their participation in social activities.

Sjogren (1982) and Drummond (1990) suggest that restriction may also be caused by psychological factors and there may be a fear that an activity may bring on a further stroke. Furrie (1998) suggests that one of the key influencing factors that impacts on the participation in social activities is spontaneity. A spontaneous offer to, for example, have a coffee can only be considered if arrangements such as transport can be accommodated. The fact that this may be difficult for an individual post stroke may greatly reduce participation. Ware Davidson and Young (1985) also acknowledge this lack of spontaneity by suggesting that planning is required. Issues such as new situations or environments can be stressful. They found, in a study of 29 individuals post stroke that many had not tried any new activities and that many previous activities, especially those which involved leaving the home, were discontinued. Individuals reported timing their activities carefully to ensure they would avoid the stress of using public conveniences.

Depression is also a factor that influences socialisation (Bacher et al 1990).

> Social ties and activities have a complex relation to depression, and poor social functioning is more likely a result of depression than a cause of it (Price 1990:13).

Johnson (1991) agrees with Price (1990), suggesting that the link between social functioning and post-stroke depression is not fully understood. A lack of confidence and lack of motivation, according to Wright and Telford (1996), also contribute to a decrease in the participation of social activities.

Another barrier to participating in leisure activities may be the need for assistance to carry out previously enjoyed activities. Gignac and Cott (1998) suggest that hobbies and leisure activities are examples of activities where it may not be possible or practical to get help from others. Reduction in leisure activities following stroke may contribute to exacerbate social isolation, lower mood and adversely affect relationships with carers (Feibel & Springer 1982, Sjogren 1982, Warlow et al 1998).

4.3.3.2. Environments

People live their lives not just in physical environments, but also social and cultural ones (Yerxa et al 1990). As occupations are what individuals do all the time, the context or environment within which they take place is important. Ware Davidson and Young (1985) suggest that an illness such as stroke causes changes in the individual and therefore affects his interactions with his environment. The environment in which the individual functions can ultimately affect the degree of well-being which can be attained. Christiansen and Baum (1997) argue that occupational performance is always influenced by the environment in which it occurs. Yerxa et al (1990:7) suggests that "occupation requires the interaction of the individual with his or her particular context". Law et al (1998) agree with Yerxa et al by suggesting that the interaction between the individual and the environment will either facilitate or hinder that individual's occupational performance.

Physical

The physical environment is the most tangible of the environments. It relates to within the home and within the local community. It can impact on an individual's ability to perform occupations according to Christiansen and Baum (1997). They consider the physical properties of environments to be easily identified, such as steps, and therefore most likely to be considered in relation to influences on performance. If the mobility of an individual post stroke is poor and there is need to use a wheelchair, physical barriers such as stairs can severely impact on the nature and frequency of activities and social interactions (Furrie, 1998).

Pound et al (1998) also acknowledge this by suggesting that physical environmental barriers can imprison people in their homes. Governments, businesses and communities have begun to address the issues of physical barriers and attempt to remove them thus making a wider community available to individuals, although an individual's own home environment may still have barriers (Furrie, 1998).

Social

The social environment relates to attitudes found in an individuals' wider community and society. Christiansen and Baum (1997:62) suggest that

> social attitudes, the behaviours and the presence or lack of support from others can enhance or limit performance.

The consequences of stroke can affect all aspects of an individual, such as their roles and relationships. Banet (1994) and Pound et al (1998) suggest that those who have had a stroke are not well supported by others.

Soderback et al (1991) found that more than one third of them thought that their role in the family had changed. Blair (1998) also argues that the loss of role and the adaptation to new roles occurs following an illness such as stroke. An individual may lose their role in society as a worker whereas a daughter or son of an individual may have to take up a new role, such as that of carer. Singer (1974) suggests that age makes a difference in the social environment,

> younger people are also more likely than older ones to feel that they are socially unacceptable because of their illness (Singer, 1974:149).

Christiansen and Baum (1997) also discuss the importance of being accepted in society; they acknowledge that social rejection and isolation can have devastating psychological consequences. Therefore there may be intolerance of differences and ignorance in the social environment.

Cultural

The cultural environment refers to the values, beliefs, customs and behaviours that are passed on from one generation to the next (Christiansen & Baum 1997). Individuals with disabilities such as stroke are not a homogeneous group (Furrie, 1998). They are people first and as a consequence, come from a variety of backgrounds, beliefs and customs. It is the attitudes of this environment that may give rise to attitudinal barriers which impact on an individual's participation in community activities. This cultural environment can influence an individual's choices regarding both what occupations to participate in and how to participate in it (Christiansen & Baum, 1997).

4.3.3.3. Quality of Life

Stroke is perceived as a serious disease that has a negative impact on an individual's quality of life (Horner, 1998). In 1988 it was recognised by Niemi that the quality of life of those who have had a stroke needs to be studied. She found in a study of 46 individuals, four years after stroke, that in spite of a good recovery in terms of discharge from hospital, activities of daily living, and return to work, the quality of life of most of these individuals had not been restored to the level they were at prior to the stroke. The factors that correlated with a decrease in the quality of life included paresis, co-ordination disturbances, dependence in activities of daily living and an inability to return to work.

Jonkman et al (1998) conducted a study to identify factors that are important for quality of life in the period 3-12 months after a stroke in 35 people between 25 and 70 years of age. They found that for the majority of the study population, even for those with a good neurological recovery, their quality of life was not restored to the level it had been before the stroke. None of the group had returned to their original working levels. Anderson (1992) also found a reduction in quality of life but in a smaller proportion (36%) of the study population (n=90). Angeleri et al (1993) conducted a study of 180 individuals to assess the quality of life after an active post-stroke period of rehabilitation. The mean age of the study population was 65 years and they found that the higher the ability of the person in activities of daily living the better their quality of life.

The Stroke Association (1996), in their survey of 230 younger adults with a stroke, found that their participants' quality of life was perceived to be dramatically reduced. Ware-Davidson and Young (1985) also found that younger adults with a stroke demonstrated a much greater reduction in quality of life than older adults.

This impact on quality of life for a younger population is not unique to those who have had a stroke. Singer (1974) in comparing differences between young and older Parkinson patients found that younger patients had more negative evaluations of their health. The younger patients experienced relatively greater role curtailment and this was accompanied by greater boredom and loneliness than that experienced by the older patients.

In a study by Charmaz (1983), looking at the chronically ill person's experience of time, 73 in-depth interviews were conducted with 57 chronically ill individuals in Northern California who had various diagnoses such as stroke, diabetes, cancer and multiple sclerosis. The age range of participants was from 20 to 86 years, with the largest proportion ranging from 40 to 60 years and two thirds were women. Charmaz (1983:172) found that those in the study who were homebound

> live narrowed, restricted lives, which contrast sharply with the lives of other adults, who have more possibilities for constructing valued selves.

The findings suggested that for the homebound, the focus of their lives was their illness and their days were filled with mundane activities. Because this study included individuals with different diagnoses, a small proportion may have been those with a stroke. Therefore caution needs to be taken in generalising these findings to individuals post stroke.

Knutas and Borell (1995) conducted a qualitative study which involved in-depth interviews with two former patients who were treated in a rehabilitation setting after stroke. The interviews were conducted one year after discharge. Three themes emerged which related to:

> a) occupational experiences of living with diminished abilities; b) the person's feelings and thoughts about the diminished abilities; and c) whether the person perceived himself as being ill or functioning well, and the meaning each person saw in life as a stroke survivor (Knutas & Borell,1995: 57).

They found contrasting scenarios for each individual. Participant A's activity pattern had changed in many positive ways one year after discharge. He had started work-training at his old working place and had continued doing most of the things that he had learned in the rehabilitation setting. His work appeared to play an important part in his perception of himself as functioning relatively well in society. He was very motivated to go on with his life and fulfil his roles.

Participant B had changed in a negative way even though he had less motor impairment than participant A. One year after discharge he hardly ever went outside the house and he had stopped doing some of the things he used to do while receiving rehabilitation. The stroke for participant B and for his wife was perceived as

> something that prevented them from getting on with their lives, in terms of doing things they liked and wanted to do (Knutas & Borell, 1995: 60).

It had caused them a lot of emotional pain and sadness. His old lifestyle was replaced by a new one, based on the role of being sick and he stated that he perceived himself as "being very ill and unable to do the things he used to do" (Knutas & Borell,1995: 61). Although just a study of two individuals, this study illustrates the differences in how an individual responds to a stroke and in their motivation.

4.3.4. Consequences to Carers and Family

An illness such as stroke involves not just the individual but all family members (Stroker, 1983). Holbrook (1982:100) also acknowledges the effect on more than just the individual and states

> stroke is a family matter. It disrupts family life, work patterns, financial status and general life-style.

Literature suggests that the effects include changes in roles and strain on carers. The main source of help and support for an individual is his or her family (Anderson 1992, Ebrahim 1990, Greveson & James 1992, Stroke Association 1996, Van den Heuvel et al 2001). These issues will be explored in this section.

Jongbloed (1994) argues that the literature on stroke does not place any emphasis on the role of the family, and that little is known about the influence of family members on roles and activities after a stroke, both for the person who experienced a stroke and his or her spouse. She conducted a study of one couple over a period of two years. In depth interviews were conducted on five occasions with this couple (a woman aged 55 years, with a right stroke, and her husband, aged 61 years). Jongbloed (1994) found that the man's roles and retirement plans had to change after his wife's stroke. The couple acknowledged that how the husband responded to these changes had influenced his wife's experience of dependence and resulted in her reduced physical function. Although small, this study was in-depth, using qualitative methods and serves to introduce some of the issues pertinent to adjustment over a period of time from both the individual's and the carer's perspective.

Birkett (1996) suggests that returning home after a stroke involves revelation of issues such as the reality of the extent of handicap, the strains on family relationships and the economic effects that are all part of life after a stroke. Northamptonshire Health Authority (1994) acknowledges that relatives and friends of stroke sufferers who provide informal care incur costs but that these costs are not estimated in any calculation. They suggest that this is due to a lack of detailed information on care being provided and difficulties in establishing methods of how such services should be costed. Evandrou (1996) sees this informal caring as pivotal in maintaining disabled people in the community but this has only been formally recognised in the mid 1990s in the policy arena. There is now a formal responsibility for state service providers to assess and support carers.

Evandrou (1996:205) defines informal caring as

> additional family responsibilities due to looking after someone who is sick, handicapped or elderly. It is provided within households and is usually unpaid.

She suggests that care may be physical help or practical, personal, social or emotional support. There may be a direct effect of caring on a carer's health such as physical or emotional strain, or the impact may be indirect, such as loss of earnings or reduced space if the individual has moved in with the carer (Evandrou, 1996). Positive effects of caring on health may be present such as increased physical activity and/or mental well-being, and the fulfilling of spousal duty. These benefits are difficult to quantify. Evandrou (1996:206) identifies six factors that may affect carer health. These are:

- the intensity of caring, such as the number of hours of caring carried out per week;
- the type of care tasks carried out, physical, personal or practical;
- the nature and extent of the incapacity of the dependant, whether they are physically and/or mentally impaired, or whether their level of independence is related to old age infirmity;
- the duration of the caring experience, number of months or years, such as whether the caring is done within or outside the carer's own household, whether or not the experience of caring is shared, distinguishing between sole, joint or peripheral caring;
- the nature of the caring relationship: caring for one's spouse may be very different from the experience of caring for one's elderly parent/parent-in-law, or one's incapacitated child

Ebrahim and Nouri (1987) in a study of 120 carers found that over two-thirds of relatives and friends living with individuals who had had a stroke were giving support and the majority found that this burden had an adverse effect on their lives. They identified those needing most assistance to be those who were more disabled, more cognitively impaired, had spent longer in hospital, and were more likely to suffer with speech impairment and urinary incontinence. These findings are supported by a more recent study. Van den Heuvel et al (2001) interviewed 212 caregivers, the majority of whom were female, their mean age was 64 years and the individual they were caring for had a stroke on average 3.5 years previously. They also found that the carers taking care of an individual with severe emotional, cognitive and behavioural problems following a stroke, had the strongest negative consequences to caring. They found that good social support, good knowledge of stroke and using coping strategies such as finding time for themselves frequently resulted in a positive caregiving experience.

It should be considered that carers may not be adults. With young adults having strokes it is possible that children may be carers. There are few targeted community services to assist child carers, and fear of stigma may cause disabled parents to remain quiet about the responsibilities undertaken by their child or children (Evandrou, 1996). The Van den Heuvel (2001) study described above found that younger carers experience more strain. The age range for their study was not stated, although it was stated that the age of those who had a stroke was 45 years or older and the mean age for caregivers was 64 years.

4.3.4.1. Psychological

There is evidence that a stroke has an impact on the psychological aspects of the individual who may suffer from depression, anxiety, poor self concept or other problems as already outlined in this chapter. However, it is not just the individual who may have subsequent problems. In their study of 60 individuals in the community, Brocklehurst et al (1981) found that seven (12%) of the carers were being treated for anxiety state or depression by the end of a year. It was the carer's relationship with the individual which seemed to have contributed to the stress involved, rather than the individual's physical disability. The individuals' behaviour, the need for constant supervision and loss of sleep contributed to the stress on the relationship. Carnwarth and Johnson (1987) also identified depression in carers. They conducted a study of 103 spouses of an individual with stroke and 51 controls. They found that the carers of those with stroke were more likely to be depressed ($p < 0.005$). The controls were matched for age and sex and there were no significant differences between the groups for past medical history.

Carers also experience emotional problems (Horner, 1998). In a survey of 181 carers carried out by the Stroke Association (1996:12) they found that one-third (33%) of carers described themselves as "at breaking point". Another issue they noted carers struggled with was the feeling that the person they had known before the stroke had gone forever. Two-thirds (64%) of carers reported a personality change in the person they cared for and more than four in five (83%) said they were not receiving adequate support to deal with these emotional problems (Stroke Assoc., 1996).

These issues have a profound impact on family life and relationships. Coping with the burden of care also causes frustration. The stresses of caring had led 14% of 181 carers to become ill themselves (Stroke Assoc., 1996). They also found that a quarter (25%) admitted getting frustrated or angry with the person they were caring for and one in five (19%) said they felt aggressive towards the person. Brocklehurst et al (1981:39) also conclude from their study that

> while the contribution made by relatives of stroke patients to their care in the community is enormous, nevertheless, this does not happen without a significant toll on their health and interference with their overall lives.

They found that the proportion of 97 carers in their study reporting poor health increased during the first year after stroke from 33% to 40%.

An additional strain is feelings of guilt. Warlow et al (1998) suggest that carers worry that they contributed to the stroke, perhaps by giving the person the wrong diet or because of some petty incident which the carer feels they should have avoided. The sort of issues carers worry about include whether the individual will fall, have another stroke or even die unless they are in constant attendance. They suggest that these fears may cause the carers to become overprotective towards the individual. Stroker (1983) found that the attitudes of the carer can influence recovery, in that if the carer is positive it can lead to a more positive rehabilitation outcome for the individual. There may also be a negative effect however. She found that wives felt somewhat overprotective of their husbands. Wives also experienced guilt feelings based on the belief that they were the only ones who could take care of the patient and therefore would feel guilty if they did not undertake the burden of care.

Evans et al (1989) studied anxiety in 80 stroke carers and found significantly high levels ($p = < 0.01$) compared with normative age-matched samples. The mean age of this group of caregivers was 59.7 (SD = 11.6). In addition to anxiety and depression, Birkett (1996) found that carers report sleep problems, social isolation, and financial worries. They also worry about whether the care they are providing is adequate. He suggests that the psychological effects of stroke cause more stress for family caregivers than the physical effects.

Warlow et al (1998) also identify that the impact of caring for an individual with a stroke changes over time. Immediately after the stroke the carer and family have to come to terms with what is a potentially life-threatening event. Later, during the weeks and months following hospital discharge when professional support dwindles, Warlow et al (1998) found that friends stop calling and the carers become physically and emotionally exhausted. In Van den Heuvel et al's (2001) study of 212 caregivers, they compared the effect of caregiving with the length of time carers had been in the role and found that the duration in the role did not influence the carers' strain, mental health or vitality.

4.3.4.2. Occupations

A stroke can also impact on the occupations of carers, in particular their productivity and leisure occupations (Warlow et al, 1998). The Stroke Association (1996), in their survey of 181 carers found that while 21% had to give up work to become carers, 16% of carers had to take on the role of family breadwinner because of the stroke. Brocklehurst et al (1981) found that only 35 (36%) carers were working at the time the individual had their stroke and of these only five (14%) gave up their jobs during the subsequent year. Carnwarth and Johnson (1987) found that because of depression, carers had given up jobs and interests, had social and financial problems and felt isolated from friends and relations.

There is evidence to suggest that gender affects the impact of the burden of caring. Ebrahim and Nouri (1987) found that wives looking after husbands bore a larger burden than husbands caring for wives, in particular with regard to employment outside the home. In other studies, the proportion of women carers is far higher than men. Anderson (1992) found that 70% of carers were women; the Stroke Association (1996) found that 60% were women and in Brocklehurst et al's study (1981) the largest group of carers (64%) were younger females.

Robinson (1983) reports that women are not only portrayed as the main caregivers but as providers of more extensive care than men. This is explained by Stroker (1983), who suggests that men have great difficulty with their new roles and responsibilities as carer. It is suggested that this relates to the fact that in traditional family arrangements, men are the providers of goods and women the providers of nurturence and care. Stroker (1983) found that women felt somewhat overprotective of their spouses, thus providing more extensive care. Stroker (1983) is not alone in identifying over protective carers. Birkett (1996) suggests that carers can help or hinder recovery. If they are overprotective, they may undertake many tasks for the individual and thus create dependency. He considers that those living alone sometimes do better because they do not have an over-protective family doing too much for him or her. It is not just employment occupations that are affected by caring. Jones and Vetter (1985) in a study of formal and informal caregiving by 256 carers to elderly patients living at home found that the more disabled or mentally infirm the dependent the less likely the carer was to have breaks or holidays.

4.3.5. Consequences to Health, Social and Voluntary Services

As already stated, a stroke has a major impact on the life of the individual affected. Such individuals require not only the support of their family and friends but also require support from statutory and voluntary agencies. This section of the literature review will outline the impact of the incidence of stroke on such services. Holbrook (1982) suggests that stroke incurs a heavy workload on both hospital and community care services. This study, the evaluation of the Cardiff Day Service, relates to the longer term aspects of life following a stroke. As a result this section will focus not on acute and intermediate rehabilitation but on services available post discharge and within the community. Normand (1991) in the consideration of service provision suggests that there is a need to identify priorities. Resources are often scarce and therefore services should be selected to maximise the potential benefit for any spending. According to the Office of Health Economics (NHS Executive 1996), the expenditure on stroke for 1992/1993 was 4.2% of NHS hospital expenditure, 1.5% of NHS primary care and 7.1% of community health and social care. Due to the morbidity and disability of stroke, the Office of Health Economics (1988) sees the provision of services in the community as a major issue for concern. The NHS Executive (1996) suggests that any disease presents two different forms of burdens on society. Firstly there is the loss of duration and quality of life due to the consequences of diseases and secondly there is the cost of health, social care and other services concerned with assisting individuals to cope with their diseases and in addition the prevention and treatment of disease.

4.3.5.1. Hospital Based Services

The focus of hospital based care for individuals with stroke is rehabilitation which aims to increase an individual's opportunity to achieve a high quality of life and full community reintegration (Bacher 1990). The World Health Organisation (1981:9) defines rehabilitation as

> all measures aimed at reducing the impact of disabling and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration.

Gresham et al (1995) view rehabilitation as a restorative and learning process to achieve the same aim as that outlined above by the World Health Organisation, that is, to enable the reintegration of individuals as fully as possible to community life. Noad et al (1998) acknowledge that admission to hospital results in better provision of rehabilitation services regardless of an individual's disabilities. However surveys conducted by the Stroke Association (1996:5) indicate that service provision is "haphazard, fragmented and often sub-optimal". Currently there are geographic inequalities in the services that individuals receive (Ebrahim & Redfern, 1999).

There are several consequences of stroke for health services, one being the cost of providing care. According to Terenet et al (1994) and Phillips (1999) accurate economic data on stroke is not available. The Stroke Association consider it virtually impossible currently to estimate the true cost of stroke. In 1999, Phillips estimated that the lifetime costs of stroke to be around £46,000 and an annual cost to be around £13,000. These do not include financial and quality of life costs to the individual and their family and carers. The Stroke Association (1996) estimate 4 to 5% of NHS budget is spent on stroke services and Sharma (1999) also estimates stroke costs as 5% of NHS resources. He suggests that the percentage of NHS budget spend on strokes

> is set to rise as our population grows older and the number of people having strokes increases (Sharma, 1999:1).

Thompson and Coleman (1988) estimated that 18,000 hospital beds were occupied daily by individuals who had a stroke with about 55,000 new patients admitted every year. It is anticipated that although these figures are over a decade old, these numbers would not have decreased since. They may however have increased due to the population living longer.

Greveson and James (1992) suggest that contact with hospital services tails off over time and found that few individuals or their carers were in contact with hospital services three years after suffering a stroke. Most support came from informal carers. Gresham et al (1995) recommend that follow-up should occur at regular intervals after discharge to ensure the individual is maintaining the gains made during rehabilitation, to assist with problems encountered after discharge and to reinforce expectations of long-term progress.

Greveson and James (1992) conducted a study of 68 survivors three years post stroke. They investigated the provision of information about stroke considering both the type of information needed and the optimal timing for receiving information. They found that most individuals and carers could not assimilate the information presented to them in the few days after a stroke when they were still in a state of shock. Although they do not provide exact figures, thirteen (21%) were unaware of available sources of help, appropriate financial benefits or how to obtain advice.

4.3.5.2. Community Based Services

The Office of Health Economics, (1988) suggest that the provision of an adequate domicillary-care service would seem to be an essential part of the overall management of stroke patients. They assume that the decrease in hospital expenditure, as a result of fewer admissions, would more than cover the additional spending that would be required on community services such as physiotherapists and occupational therapists. Robinson (1983) suggests that a shift in long-term care from institutional to community-based services had begun to occur.

Warlow et al (1998) suggest that individuals who are not admitted to hospital after their stroke, or who remain in hospital for just a few days do not have opportunities to ask questions and obtain advice and information. Services to address these needs should be provided.

McKevit and Wolfe (2000) conducted a qualitative study to establish from individuals who had a stroke and carers the main problems they faced, and to get their views on what they thought a stroke specific community service should offer. Twenty qualitative interviews were conducted where participants were asked to describe their experiences and raise issues of concern. Participants were recruited from those discharged from the local district general hospital. Those living outside the study area, in residential care prior to the stroke, or with severe speech or cognitive impairments that would make interviewing difficult were excluded. This study involved small numbers (n=20) and there was a range in when the interviews were conducted in relation to the length of time after discharge (six to ten months). McKevit and Wolfe (2000) considered that more gaps in service provision may have been identified if the interviews had been conducted earlier.

The researchers indicate that some of their findings were what they were expecting, that is individuals identified lack of information and emotional and/or psychological difficulties following the stroke. In addition there were concerns about lack of access to on-going physiotherapy and long term monitoring of their progress (McKevit & Wolfe, 2000). The participants identified the need for long term monitoring as a means of providing hope and the desire to continue to be actively working for one's own recovery. Although the study did not aim to quantify need, McKevit and Wolfe identified a diversity of problems people face, suggesting the need for sensitive targeting of a community service to address these. Such a service should take into account individuals' needs and McKevit and Wolfe (2000) acknowledge that it may not be possible for any one service to address the needs of individuals and their families. The question of how best to support individuals and families in the community following stroke remains unresolved (McKevit & Wolfe, 2000). The evaluation of the Cardiff Day Service should begin to address this, as it will examine a service in existence and establish if it is addressing the needs of individuals.

The Stroke Association (1996) in their survey of 230 individuals found general dissatisfaction with the support received from social services. Common complaints were that services on offer were inadequate, long delays were experienced in receiving them, and many services were insensitively delivered. More specifically, 35% reported problems in obtaining services they needed, 30% reported problems in getting disability aids required and 73% reported that the services they received were not geared to younger people (Stroke Assoc., 1996)

Greveson and James (1992) in their three year follow-up of 68 individuals found that 36 (58%) had received at least one community service. Jones and Vetter (1985) in their earlier study of carers of elderly dependants found that home helps, community nurses and day hospitals were the accessed community services, while occupational therapists, physiotherapists and volunteers were rare visitors.

Several studies have been conducted to evaluate community services. In 1988 Townsend et al reported a study comparing a post discharge care attendant service with standard care. They conducted a randomised controlled trial with 903 individuals post stroke. The treatment group (n=464) received care on the first day at home and for up to 12 hours a week for two weeks. They found that re-admissions within 18 months of discharge were significantly higher (p=0,014) in the control group. They conclude that investment in such a service could yield considerable benefits by keeping individuals at home and thus reducing demand for unnecessary re-admissions to hospital.

A more recent study conducted by Corr and Bayer (1995) in the UK also found a reduction in re-admissions. The study was a randomised controlled trial comparing occupational therapy for individuals discharged from a stroke unit with standard care. The treatment group (n=55) were visited and reviewed by an occupational therapist at 2, 8 16 and 24 weeks post discharge. Intervention was provided as required. They found few significant differences between the groups although the number of pieces of adaptive equipment received by the intervention group was greater (p=0.05) and their incidence of re-admission was smaller (p=0.03). Several arguments are presented for the small number of significant differences including the small study size (110 participants) and the inclusion of individuals with severe disabilities who were discharged to residential and nursing homes. The lack of sensitivity of the measurement tools used to identify small changes in function was also considered a factor.

Gilbertson (1998) conducted a similar study but did not include individuals who were discharged to residential and nursing homes as the Corr and Bayer study had done. Gilbertson (1998) aimed to establish if a brief programme of domiciliary occupational therapy could improve the recovery of individuals with stroke discharged from hospital. This single blind randomised controlled trial involved 138 patients with stroke who received six weeks domiciliary occupational therapy or routine follow up. The results showed a significant (p=0.08) increase in independence in the intervention group in activities of daily living as measured by the Nottingham extended activities of daily living scale. By eight weeks the mean in the intervention group was 4.8 points (95% confidence interval –0.5 to 10.0, p= 0.08) greater than that of the control group. There were similar, though still not statistically significant, results at six months. Those in the intervention group were more likely to report satisfaction with a range of aspects of services. This demonstrates that a brief occupational therapy programme can improve occupational performance when carried out in the individual's home. Gilbertson et al (2000) warn, however, that benefits may not be sustained over long periods of time. They also acknowledge that the population was relatively small and thus had limited power to detect a modest effect on functional outcomes. The findings from these studies lend support to the principle of extending rehabilitation from the inpatient period to a post-discharge period based in the community.

The Stroke Association in 1996 recommended that commissioners of health and social services should review the suitability of the services for younger people who have had strokes. They believe they should be made to provide more day care services, including employment training, advice on parenthood and counselling for emotional problems and that these services should be available in the community.

In a study in Colorado, USA of 21 women with acquired brain injury, Sample and Darragh (1998) used interviews to establish the women's experience of rehabilitation support and services as they attempted to continue their lives and re-enter their communities. They found that all the women experienced barriers to accessing care including lack of information or services, lack of care co-ordination and difficulties travelling to services. In this study all service providers were criticised by the participants. They also identified that their information about services came via family, friends and word of mouth. The researchers note that the findings represent the perceptions of the participants. They did not seek corroboration of information from relatives or supporters. They conclude that

> whether or not the information is completely accurate in all cases is secondary to the impressions the women had of the services they did or did not receive (Sample & Darragh, 1998:872).

4.3.5.3. Voluntary Services

Voluntary organisations such as the Stroke Association provide support for both the individual and their carers. This support tends to occur after discharge and when individuals have returned to their own homes. One initiative set up by the Stroke Association was the post of Family Support Worker (Pound & Wolfe 1998). This was set up to address the needs of people with stroke and their carers living in the community and to bridge gaps in statutory support. Their role is

> to provide emotional support, advice and information to people with stroke, and their carers with the ultimate aim of reintegrating people into their communities and to discuss risk factors and encourage the adoption of preventative health measures (Pound & Wolfe, 1998:482).

In addition they establish links with GPs and relevant agencies, and have a role in developing support groups and clubs for people with stroke in the community.

Another support service, the Volunteer Stroke Scheme is outlined by Geddes and Chamberlain (1994). In their small study of 30 individuals, 17 participated in the Volunteer Stroke Scheme. They found that after one year the carers of users were consistently more positive than the others. They also found that users increased their activities to a significant level ($p<0.01$) as measured by the Frenchay Activities Index and users had better social recovery. Also the carers of those receiving the service reported that they had more free time for themselves when compared with carers of individuals not receiving Volunteer Stroke Scheme support. However, the numbers in this study are small and there were differences in user and comparison groups making findings vulnerable to Type II errors.

Stroke clubs and carer support groups are another source of services available. Pound et al (1993) suggest that there are great varieties in the activities and roles of stroke clubs and carer support groups. They suggest that

> the acceptability and relevance of interventions are likely to differ according to social, cultural, economic, and educational background (Pound et al, 1993:504),

but among the working class carers they found little enthusiasm for carer support groups. Warlow et al (1998) also support the view that not everybody wants to attend a group and suggest that support needs to be tailored to the individual. Based on the findings of their study, Van den Heuvel et al (2001) advocate support programmes, but suggest some specific content for these. They suggest that programmes for carers should include education on using coping strategies, the importance for carers of retaining their own interests and activities and on how to identify and access social support that provides satisfactory support for the individual carer.

Servian (1996) suggests that service users need to be empowered by services. He argues that if users have been able to

> follow their own interests, to feel fulfilment or to meet their own material needs, an assumption is that they have displayed their own power in doing so – they are empowered (Servian 1996:8).

He sees needs and empowerment as related and suggests that empowerment is best defined as “moves towards autonomy” (Servian 1996:8). He also considers professionals and carers as those who tend to reinforce the powerlessness of individuals with a disability.

The American Stroke Association (2000b) identify support groups to be key in providing peer support. They suggest that individuals need peers to facilitate getting the most benefit from the group, to participate in similar activities and to demonstrate that recovery can occur.

In 1995 the Stroke Association established a new support service, a Day Service Pilot Project in Cardiff, UK. A Day Service Organiser was employed to establish the service to run one day a week to provide support for those who had had a stroke during adulthood. The aim for the Service was established from the beginning. The Service was to offer people who have a stroke and are aged between 18 and 55 years, the opportunity to identify and pursue meaningful and realistic opportunities within the community. These opportunities would help them to meet their personal aspirations and enable them to develop to their full potential.

More specifically the aim was broken down as:

1. to provide information on the Day Service to those who may be eligible to participate in the service and their carers;
2. to assist individuals to consider their capabilities and potential;
3. to examine ways of meeting their development and social needs;
4. to provide individuals with as much real choice as possible and help them set personal and achievable goals within the context of a needs led development programme of opportunities.

The staffing of the service consists of one employed member, namely the Day Service Organiser, and relies heavily on volunteers. The activities undertaken are mainly leisure and social ones. It is an evaluation of this service that constitutes a major aspect of this current study. The methods used, findings and discussion follow in subsequent chapters.

4.4. SUMMARY

Stroke affects younger people in addition to older individuals. The consequences affect all aspects of life including the individual's ability to care for themselves, work, and participate in leisure occupations. Spouses, children and other carers are also affected. In order to support these individuals hospital, community and voluntary services are required. The current focus of these services is on the in-patient phase of recovery and there is a need for longer term support and monitoring to address the array of disabilities and handicaps that occur post stroke and to promote quality of life. One such service, the Cardiff Day Service, has been established and the evaluation of it aims to establish if it is addressing the needs of young adults (18 to 55 years) post stroke. The next chapter outlines the choices of research methods and measurement tools available and selected to identify the impact of a stroke in this study.

CHAPTER 5

STUDY DESIGN

5. STUDY DESIGN

5.1. INTRODUCTION

The aims of this study are to identify the characteristics, problems and needs of people in the younger adult age group with a stroke and to evaluate the Cardiff Day Service. In order to achieve this a range of research methods has been used. This chapter provides details of the study design and its components in preparation for the methods chapter which outlines the specific processes undertaken. The overriding umbrella of study design for this research is evaluation research. The chapter outlines what this is before describing specific methods or tools drawn on to conduct the evaluation. The chapter however begins with some arguments for conducting research to understand individuals as occupational beings.

5.2. RESEARCH RELATED TO OCCUPATIONS

Over recent years there has been an increase in the amount of research in the areas of both occupational therapy and occupational science. This section draws on literature to outline why research should be conducted in these areas, the priorities for research and presents arguments for ways in which it could be conducted. These arguments informed the selection decision of methods to identify the occupations of adults under 55 years who have had a stroke.

Reasons for research

According to Ilott (1995) and Abreu et al (1998), the need to conduct research is critical to the survival of the profession of occupational therapy. Parham (1998) suggests that undertaking research on occupations may not be easy and considers it challenging because occupation is a complex, multi-layered phenomenon for which there are contextual influences and personal meanings.

Fossey (1992) suggests several reasons for conducting research to investigate occupations and occupational therapy. She suggests that although years of clinical experience have provided a wealth of opportunities for occupational therapists to observe the direct and indirect effects of occupations on health, much research is still required to support the assumption that there is a relationship between health and participation in occupations. In addition, research is required to establish the requirements for a healthy balance of occupations at different stages of life, the outcome of which would enable occupational therapists to assist people to adjust to changes in their life styles and patterns of occupations (Fossey, 1992).

Another area where there is need for research, according to Fossey (1992), is understanding people's subjective experiences of participation in occupation. This is supported by Stewart (1997:60) who states that until recently very little research has been undertaken "about the nature of 'occupation' and its significance to humans", although there is an acknowledgement that occupational science is beginning to provide the vehicle for addressing this by qualifying and quantifying the effect of occupation on various parts of individuals' lives. Stewart (1997:48) argues that research is

> now required in order to place occupational therapy on a similar footing to other professions and to increase the evidence for theoretical underpinnings.

Parham (1998) sees the profession as having a responsibility to contribute to the knowledge of society in the area of the nature and uses of occupation. She, like Stewart, believes this research will "strengthen the identity of the profession in the eyes of those outside the profession". Gutman (1998) suggests that the profession has not generated a body of research that supports the efficacy of occupational therapy practices even though it has maintained high entry level educational standards. There are few researchers at the doctoral and advanced master's degree level who are able to undertake studies and have the skills to compete for highly sought-after research grant monies (Gutman 1998).

As already stated, the aim of this study is to evaluate a day service with specific reference to occupational functioning. As the study identifies what occupations individuals are engaged in, areas of difficulty in these occupations and the importance of those occupations to the participants, it is research conducted for reasons supported by Fossey (1992), Stewart (1997) and Parham (1998). The study does not involve occupational therapy intervention and therefore it will not inform the efficacy of practice. However, by identifying problems in areas of occupational performance it will inform service planning.

Priorities for research

According to Parham (1998), the proper domain of occupational therapy research is in the study of occupation and its applications to health care. She goes on to add that a key element is "the study of the occupational nature of the human being" and "the study of the influence of occupation on the person" (Parham,1998:485). If these were undertaken there would be benefits for occupational therapy.

Although Wilcock (1993b) acknowledges that research is urgently required, Ilott (1995:369) suggests that "there is so much to do to unravel the mysteries of occupation that it is difficult to know where to start". She does however go on to suggest there is a need for a greater knowledge of what constitutes effective occupational performance, across the life span and in different environments. Wilcock (1991:229) also agrees that research relating to occupation and health should be a priority and offers the following questions to be addressed:

- how important is occupation to health?
- what are the results of occupational deprivation on health?
- what are the long-term effects of different types and combinations of occupations upon health?
- what is a healthy balance of work, play, rest and sleep?

It is the cultural meanings of occupations that Hocking (2000) considers to be a potential area for research, while Mounter and Ilott (1997) suggest that the findings of research on understanding the relationship between occupation and health will inform services offered to different client groups. Trombly (1995:960) also supports this suggesting that

> it would be to our advantage also to discover how therapeutic occupation brings about those changes so that we can treat more effectively.

By acknowledging Ilott's (1995) observations that knowing where to start is not easy, a starting point for understanding individuals post stroke is to identify their current participation in occupations. By collecting this data and additional data relevant to the concept of health, it may be possible to start to address some of Wilcock's (1991) questions. It should facilitate Mounter and Ilott's (1997) suggestions of gaining greater understanding of the relationship between occupation and health and thus inform services that are or perhaps should be offered to adults post stroke. It should also add to knowledge of the use of occupations as a therapeutic intervention. By identifying occupations that are perceived important for adults post stroke, this study will inform occupational therapists of a range of relevant occupations that are relevant and appropriate for use in stroke care.

Appropriate methods

There are differing views on which research methods should be used when conducting research relating to occupations. For example, Robertson (1988) advocates qualitative methods and argues that issues occupational therapists are concerned with, such as the meaning and purpose clients place on occupations, cannot be readily analysed by quantitative methods. However, Parham (1998) suggests that occupational therapists should use whatever methods they consider necessary, even diverse and innovative ones, when studying occupation and its applications to healthcare. Fossey (1992) and Stewart (1997) both agree that different research methods may need to be used. Custard (1998) also advocates a breadth of methods and sees the justification for both experimental designs and qualitative approaches. She considers experimental methods to be of value when supporting any hypothesis regarding the benefit of occupational therapy and qualitative approaches of value when promoting an awareness of meanings of occupations. She suggests that

> primary concern should not be which research methodologies occupational therapists should or should not use, but be the defence of the value of occupation as a therapeutic medium (Custard 1998:682).

Wright (1998) considers qualitative research to be appropriate because of its emphasis on the meaning of experience which relates well to occupational therapy but also because occupational therapists possess some of the tools of qualitative research such as listening and taking a holistic and client-centred view.

The various arguments regarding methods were considered when planning this study relating to adults' participation in occupations post stroke. The context of this study, a service evaluation, will be discussed in the next section of this chapter. However, the context influenced the choice of methods and tools used resulting in both quantitative and qualitative methods with techniques such as semi-structured interviews and measurement scales via questionnaires being used. These are described later in this chapter.

5.3. EVALUATION RESEARCH

As already indicated, the umbrella for the design of the study being reported is evaluation research. This section will define this type of research; outline strategies that can be used; identify key players who have a role in evaluation research as well as some potential limitations.

5.3.1 Defining evaluation research

Over two decades ago Shortell and Richardson (1978:14) defined the evaluation of a service or programme as

> the use of scientific method (or an approximation) in judging the worth of a particular programme to provide information to decision-makers and policy-makers in a position to improve the programme, extend it to other sites, or cut back or abolish the programme so that resources may be allocated to other efforts.

Twenty years later Murphy et al (1998:215) consider evaluation as "an essential part of any intervention or programme of action in health, education, and social services". These authors are therefore suggesting that evaluations should be integral to service provision. They are for ensuring that organisations are explicitly accountable for the services they deliver. According to Robson (1993:170) an evaluation is a study "which has a distinctive purpose". Its purpose can be to assess the effects and effectiveness of either a policy, practice or service and it typically provides strong implications for change. Although an evaluation may indicate that changes are needed, the findings are likely to be just one of a complex set of influences on the future development of the service programme (Robson, 1993). Shortell and Richardson (1978) suggest that if a service appears to be associated with a beneficial effect, it is important to establish whether the effects can really be attributable to the service or whether they result from some other factors. An additional function of evaluations is that they can provide feedback for improvement and can shape and focus a service (Shortell & Richardson, 1978, Rossi et al, 1999). This aspect of feedback appears to be crucial according to Robson (1993), who suggests that unless there is the prospect of an evaluation being useful it should not be carried out. Phillips et al (1994) suggest that by involving users in an evaluation their expectations will be raised and will stimulate a prospect of change. This requires a commitment by stakeholders to act upon the findings of evaluation research.

Murphy et al (1998) describe two types of evaluation – outcome and process. Outcome evaluations focus on assessing the effects produced by services. Robson (1993) defines this as measuring how far a service meets its stated objectives or goals. Outcome evaluation requires an accurate description of the characteristics (goals and objectives) at issue and the assessment of them against relevant standards or criteria (Rossi et al,1999). Process evaluation focuses on understanding the internal dynamics of a service, that is, how it is organised, delivered and used (Murphy et al, 1998, Bowling, 2002). Palfrey et al (1992) suggest that processes as indicators of efficiency and effectiveness are not often considered.

Robson (1993) and Landry and Matthews (1998) describe an additional form of evaluation – an economic evaluation, or cost-benefit evaluation. This is an evaluation "which attempts to determine the value of an outcome, given the cost of the service" (Landry & Matthews 1998:161). As in outcome evaluation, economic evaluations require the identification and delineation of the goals, objectives, and relevant resources of programmes and services in measurable terms. This highlights the constructs that should be measured and compared (Landry & Matthews 1998).

In addition, Shortell and Richardson (1978) suggest that it is important to know the degree to which different levels of service intervention produce different levels of benefits and the time period over which such benefits will accrue. They consider the most difficult theoretical and empirical problems encountered in undertaking this type of evaluation are deciding what to include in measuring benefits, how to measure the benefits, and how to take into account the effect of time while they consider the calculation of service costs to be generally much more straightforward.

Evaluations are however not without their difficulties. Shortell and Richardson (1978:xi) state that "evaluations are exciting but difficult to do well". They suggest that practical considerations come into play when doing research in health care settings which can be complex. Another limitation is that many evaluations require data beyond that which is already available or currently being obtained, thus imposing on the day to day running of the service (Shortell & Richardson 1978).

Robson (1993:172) outlines some of the practical problems of doing real world evaluation research: "evaluation tends to work to short time-spans and tight deadlines".

It can be difficult to contact participants if they are busy or prefer not to be contacted. Gatekeepers may appear such as middle management and they may be obstructive. The Service Administrators may decide to make alterations or changes and external events ranging from national strikes to bad weather may occur Robson (1993). Rossi et al (1999) also acknowledge that evaluations present many challenges to the evaluator. The circumstances and activities of the service may change during the course of an evaluation. As the purpose of evaluation of the Cardiff Day Service was to establish if the service was resulting in benefits and the cost of these benefits, both outcome and economic evaluations were undertaken. The strategies considered to conduct these are outlined in the next section, while the processes used are reported in Chapter 6.

5.3.2. Strategies used in evaluation research

According to Smith and Cantley (1985), Palfrey et al (1992), Robson (1993), Phillips et al (1994) and Rossi et al (1999), a range of methods such as experimental, survey, case study or a combination of strategies can be used in evaluation research. Although a variety of methods are available the most appropriate method(s) for a given evaluation depend on a range of factors, including the nature of the service being evaluated, the variables being measured, the cost and time involved (Shortell & Richardson, 1978). Robson (1993) advocates an open mind to the most suitable strategy and best methods for an evaluation while requiring the data collection to be rigorous and systematic. Phillips et al (1994) support this view. They consider all strategies to have merits and limitations and suggest that methods should be chosen if they are appropriate to the situation and context of the evaluation. In addition to ensuring that the methods used are appropriate there is the need to ensure the usefulness of the data for the purpose of the evaluation.

A major paradigm shift was underway in the late 20th century as seen in trends to value qualitative as well as quantitative research (CAOT, 1997:17). Regardless of the methods selected Robson (1993) states that an evaluation should only be done if the evaluator can demonstrate that it will be carried out fairly and ethically. It also should only be carried out if it is feasible to conduct it in political, practical and cost-effectiveness terms. Rossi et al (1999) support Robson by suggesting that the political and organisational context of the programme to be evaluated must be considered.

Qualitative strategies

Qualitative methods draw on the experiences of the subjects and involve the collection, analysis and interpretation of data that is not easily reduced to numbers. The data relates to the social world and the concepts and behaviours of people within (Stewart 1997, Murphy et al 1998). Qualitative methods may also be used to interpret, qualify or illuminate the findings of quantitative research (Murphy et al 1998). Murphy also suggests that it can be used to test hypotheses while Wright argues that it leads to hypothesis generating rather than testing as it is

> interpretive, with themes and concepts tending to arise from the inquiry and follow rather than lead the data (Wright,1998:420).

Qualitative methods have a place where the questions are about processes rather than outcomes. They, according to Murphy et al (1993:3) are particularly suited to answering "How does this come to happen?" questions rather than "How many?" "How much" or "How often" questions. They are also useful in studies that are concerned with

> understanding events and behaviour, holistically, in the context in which they occur in everyday life, and to those that seek to understand the process by which such events and behaviours come about (Murphy et al,1998:86).

In addition, Robertson (1988) considers this approach to take into account participants' beliefs, their comprehension, their social situation or their cultural influences. There are four main approaches in qualitative research: *ethnography*, which is concerned with the culture and customs of groups of people and studies "the interrelation of groups, families, economic systems, religions, social organisations and the like" (Wright, 1998:419); *phenomenology*, which is concerned with how individuals and groups perceive their worlds and how they interpret what happens to them; *symbolic interactionism*, which is concerned with what events mean to those experiencing them and with the symbols that they use to convey that meaning; and *grounded theory*, which is the development of theory based on findings of data collected by researchers without being influenced by present knowledge of the particular phenomenon being studied (Wright,1998:419). During data analysis the researcher reflects on emerging theories many times before offering firm theoretical proposals (Wright,1998).

Single-case studies, surveys and interviews, life histories and illuminative studies based on letters, documents, field notes and observation, are all qualitative methods of data collection (Stewart 1997, Robertson 1988). According to Pound et al (1998) qualitative data usually takes longer to collect and analyse than quantitative data, resulting in smaller and more focused samples being used, while still generating data which is rich, detailed and meaningful.

The findings of qualitative research are based on the reality of the subjects under study and therefore a limitation is that findings are usually not open to generalisations. However they can be helpful in offering insights into subjective experiences and where the issues are complicated, numbers small or research subjects unusual (Stewart, 1997, Murphy et al, 1998). Grembowski (2001) suggests that qualitative methods are used in service evaluations to understand what is happening at the service. It was for these reasons that qualitative methods were considered. However, as the purpose of the evaluation was outcome and economic, a purely qualitative approach was not appropriate.

Quantitative strategies

According to Murphy et al (1998) quantitative strategies seek facts in an objective manner with little regard for the subjective state of participants. Controlled and measurable tools are used and the data is reliable and can be generally applicable. Quantitative research is outcome orientated, reductionist and leads to confirming, verifying, inferring or hypothesis testing. Designs used include experiments and quasi experiments and tools include standardised scales, surveys and questionnaires. The sample size is usually large with randomisation (Krefting, 1989). The data can be subjected to statistical analysis to provide a gauge for the outcomes of future interventions and services (Stewart, 1997). Quantitative strategies can be used to demonstrate change over time (CAOT,1997).

According to Shortell and Richardson (1978) the use of experimental designs in evaluation results in the random allocation of subjects to treatment and control groups. Randomisation increases the probability that treatment and control groups are alike ruling out alternative explanations for service evaluation results such as selection bias. Although it has advantages, randomisation raises ethical and administrative concerns. According to Shortell and Richardson (1978:48) opponents of randomisation contend that

> it is unethical to withhold treatment or services from groups of people who might benefit from them, or, in contrast, it is unethical to expose people to a particular experimental treatment or program that might be harmful to them.

Of course withholding a particular treatment or service does not mean that the control group receives no services at all (Shortell & Richardson, 1978). (The ethical issues considered for the evaluation of the Cardiff Day Service are outlined in Chapter 6).

According to Rossi et al (1999:305), randomised experiments are "the flagships of evaluation" as they generally provide the credible conclusions about the impact of services. They suggest that policymakers, stakeholders, and the general public are likely to treat findings from true experiments respectfully, because they may be familiar with at least the outlines of such designs from an awareness of the way laboratory studies are conducted. The randomised controlled trial (RCT) is the most common randomised experiment where participants are allocated randomly either into a treatment group or a control group (French et al 2001).

A cross-over design is a design where each participant receives two or more sequences, for example a treatment phase and a no-treatment phase, or vice versa (Bowling, 2002). Comparisons are made 'within participant' and therefore participants act as their own controls (French et al, 2001). In order to avoid bias, random allocation of phases should take place and consideration given to any carry-over effect or natural improvement over time (Bowling, 2002). Order-effect can occur as participants take their experiences from the first phase to the second. Random allocation provides some control for this (French et al, 2001). Measures of outcome taken before and after an intervention, or at fixed time periods if in the control group can provide estimates of effects of the intervention and help to understand how the intervention worked over time (Rossi et al,1999). A cross-over design overcomes the potential ethical problem of withholding services (Phillips et al 1994). As the Cardiff Day Service was established prior to the commencement of the evaluation, a cross-over design was considered appropriate and the details of its use is reported in Chapter 6.

However, despite their rigour, Rossi et al (1999) suggest that randomised experiments have several limitations, for example:

- Randomisation is sometimes perceived by stakeholders as unfair and even unethical because of the differential intervention given to experimental and, especially, control groups.
- The way in which intervention is delivered in the experimental condition may not resemble intervention delivery in the implemented programme.
- Experiments are costly and time-consuming.
- Because experiments require tight controls, the results may be low in generalisability and external validity (Rossi et al,1999:306).

Combined strategies

The case study is an example of where combined strategies are used. It is a detailed examination of one particular setting, such as a service, organisation or community or it can be one single subject or one set of documents (Robson 1993, Murphy et al 1998). It involves

> an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence and is flexible and interactive (Robson 1993:5).

Denscombe (1998) agrees with Robson (1993) suggesting that the case study research strategy emphasises the particular rather than the general, considers the natural environment of the case and allows for the use of multiple methods depending on the needs of the situation. The case is studied in its own right, not as a sample from a population and uses multiple sources of evidence that are both qualitative and quantitative data. The Cardiff Day Service, a unique pilot service, can be considered as a case in its own right. As there are no other such services in the UK the users are not a sample from a larger population.

Stewart (1995), Robson (1993) and Robertson (1988) acknowledge that many research initiatives use combinations of qualitative and quantitative methods while Murphy et al (1998) acknowledge an ongoing debate regarding the collaborative co-existence of qualitative and quantitative methods. Murphy et al (1998) suggest that using both is contested by those who advocate quantitative methods as they dismiss qualitative approaches as not proper science, while enthusiasts for qualitative methods reject quantitative approaches for not understanding the social world. They suggest that the question to be asked should be "will qualitative or quantitative methods provide the answers to this question most effectively and efficiently" (Murphy et al, 1998:58). They also advocate the combination of qualitative and quantitative methods when appropriate thus seeing each approach as contributing something to the overall knowledge of a particular issue. Stewart (1997:55) describes this as

> both offer different perspectives leading to different kinds of knowledge which can inform each other. The qualitative approach gives rich understanding while quantitative methods give hard data for subsequent verification of the theory.

Murphy et al (1998) recommend that researchers should establish which approach is likely to answer the question at hand in the most effective and efficient manner. The two approaches are suitable for different and complementary purposes (Rossi et al,1999:439). Smith and Cantley (1985:13) support the view that a combined strategy is appropriate. They state that

> the constant use of as great a variety of different kinds of data as possible ensures, so far as is possible, that the research reflect the full range of interests, ideologies, interpretations and achievements abroad within the agency.

Grembowski (2001:146) considers the use of both methods as "essential for understanding programme performance", while Phillips et al (1994) consider a combined approach as the most useful method for evaluation in health and social care.

As has been indicated, there is much support for using a combination of quantitative and qualitative strategies in evaluation research. This is the approach that was taken to evaluate the Cardiff Day Service for adults post-stroke. In addition to evaluating the outcome and cost-benefit the evaluation included establishing perceptions of the benefits of the service. Therefore a flexible approach as described by Robertson (1988) was taken using a quantitative method to establish if the service was effective and using a qualitative method to take into account the key players' perspective. The main design was a randomised cross-over design with questionnaire and interview techniques. In addition, Q methodology (which is explained later in this chapter in Section 5.4) was used to establish the perceptions of the benefits of the service. The details of these processes are reported in Chapter 6.

5.3.3. Key players in evaluation research

There are groups of people who play a role in service evaluation according to Shortell and Richardson (1978), Smith and Cantley (1985), Martin (1986), Thomas and Palfrey (1996), Murphy et al (1998) and Rossi et al (1999). These include the organisation, often the commissioners of the service, the programme administrators, those who usually deliver the service, the consumers of the service and the evaluator(s). Rossi et al (1999) suggest that with this range of stakeholders there may be conflicting needs, interests, and perspectives and that the existence of different perspectives should be acknowledged. Identifying who the key individuals are may be difficult if these individuals (or groups) are not readily identifiable or if they do not recognise their role for providing the information needed for the evaluation, nor share ownership of the programme and its goals (Murphy et al,1998). It is possible that not all will want the service to be evaluated and/or be willing to participate in the process, especially if the results are seen as a threat rather than as advice or guidance (Murphy et al,1998).

The organisation

The organisation that provides a service will have an interest in an evaluation of the service. According to Shortell and Richardson (1978), their interest may be in demonstrating that the programme is effective, justifying expenditures, establishing costs, gaining support for expansion, and determining future courses of action. Robson (1993) suggests that all evaluations have a political dimension to them, where for example a positive evaluation may lead to the expansion of a service, and thus make major differences to the lives of users involved.

The organisation may be the funder of the service being evaluated. If this is the case they may wish to know the efficiency and effectiveness of the programme and have "value for money" expectations (Thomas and Palfrey 1996). In the case of the evaluation of the Cardiff Day Service, the organisation is the Stroke Association who fund the running of the Service.

Programme administrators

This group includes those who actually run and staff a service. According to Shortell and Richardson (1978) they may have some positive views about the evaluation such as seeing it as a means to bring favourable attention to the service, provide a means for advancement in status in the organisation or towards promotion. They may also consider it as providing a means of gaining greater control, or providing evidence to support a proposal for future developments. Staff running services may have much to gain or lose from particular outcomes of an evaluation and jobs may be on the line. In the case of the evaluation of the Cardiff Day Service, the programme administrator is a Day Service Organiser who is supported by a group of unpaid volunteers.

The consumers

The consumers have a key role in an evaluation. Their perspective may focus on efficiency of spending or the need for information on specific benefits that may be obtained (Shortell & Richardson, 1978). Thomas and Palfrey (1996:127) suggest that they are

> interested in receiving timely, courteous and effective service and will often feel grateful if the service makes him or her feel noticeably better.

In the context of this current study relating to the Cardiff Day Service, both the users of the service and their carers are considered the consumers of the service. Martin (1986) suggests that consumers usually do not contribute to the planning and designing of the evaluation, but make their first contribution at the implementation stage by answering questions or otherwise providing information as required by the research methodology. Phillips et al (1994) support making efforts to obtain consumer viewpoints because their perceptions should help to counteract professional perceptions and therefore provide a balance of views.

For some time it has been argued that consumers have a right to have their perceptions considered (Martin, 1986). Martin also argues that by involving consumers in the evaluation of services, this may be a means of increasing their involvement in other aspects of the service's ongoing operations, such as present management and planning for future development. Phillips et al (1994) also support the involvement of users in the assessment of service provision and relate it to quality of life. They suggest that increasingly, service provision relates to improving quality of life. However, as quality of life is subjective and a judgement of it can best be made by the individual users, they argue that it is paramount that users are involved in evaluations.

There can also be difficulties when involving consumers in any effective or useful way in a research-based evaluation as there are long-standing traditions of client dependence upon the decisions of service staff, consumers' unquestioning respect for professional expertise, and the viewpoint of some consumers that those paid to deliver services should carry out their responsibilities without calling upon unpaid assistance (Martin 1986).

The evaluator(s)

Rossi et al (1999) suggest that evaluators deal with conflicting perspectives and therefore need to be prepared for criticism even from the sponsors of the evaluation, and tailor their communication to meet the requirements of the variety of stakeholders. The role of the evaluator is to gather information in various ways which are seen to be appropriate to the particular situation (Robertson 1988). Once gathered they need to understand what is going on and suggest ways in which desirable change might take place (Robson, 1993).

According to Shortell and Richardson (1978:11)

> the evaluator's perspective is likely to include
> - the desire to contribute to disciplinary and applied knowledge.
> - an opportunity for professional advancement.
> - a sympathy with the program's goals.

- a strong belief in the importance of sound evaluation to make progress toward agency and societal goals.

According to Shortell and Richardson (1978), even if good communication and interpersonal relationships exist it is inevitable that the evaluator will be at odds with the administrators to some degree from start to finish. One factor that contributes to this is the design of the service evaluation, which is likely to directly impinge on the conduct of the service itself. The evaluation may require the administrator to undertake additional tasks such as to spend time completing forms or to follow a protocol that seems unnatural to them. The evaluation may also require the deferment of making changes during the course of the evaluation that would appear to improve care or be more efficient. An additional conflict recognised by Shortell and Richardson (1978:105) is that the evaluator is required to be objective and even hold "a degree of scepticism". The evaluator should be committed to maintaining the integrity of the design and to the scientific value of the study, while in contrast, the administrator is service orientated (Shortell & Richardson, 1978:105).

5.3.4 Summary

The processes involved in the evaluation of the Cardiff Day Service are outlined in Chapter 6. They include details of the quantitative and qualitative techniques used and the involvement of different key players in the study. The Q methodology and measurement scales used are outlined in the remainder of Chapter 5.

5.4. Q METHODOLOGY

5.4.1. Introduction

One of the methods used for the evaluation of the Cardiff Day Service study was Q methodology. It was selected as an appropriate tool to use to identify individual perceptions of the service. The process involved in Q methodology is outlined below, while the processes conducted for this study are detailed in Chapter 6.

William Stephenson first introduced Q methodology in the 1930s (Wigger & Mrtek, 1994). He had studied both psychology and physics and had been a student of the statistical theorist Charles Spearman. He became concerned about the amount of reductionism that was evident within social science and psychological research and subsequently had the

> desire to understand what made the individual person unique rather than what characteristics could be found across large populations of individuals (Stephenson cited in Wigger & Mrtek, 1994:9).

The method Stephenson developed grew from quantitative and qualitative backgrounds. It used a unique method of data collection and statistical analysis techniques, and it measured attitudes (Brown, 1996). Q methodology enables researchers to gain a greater understanding of individuals. It is possible to examine life as lived from the standpoint of the person living it, to identify characteristics of individuals who share common viewpoints and to measure arrays of attitudes at a certain point in time or measure attitudinal changes over time (Dennis 1986, Brown 1996, Mrtek et al 1996). Wigger and Mrtek (1994:9) suggest that the purpose of using Q methodology is "to focus on discovery and understanding of individuals as complex, holistic beings", which according to Dennis (1986) is unique. However, qualitative methods such as phenomenology and hermeneutics also attempt to understand the meanings individuals place on experiences (Doordan, 1998).

Q methodology according to Wigger and Mrtek (1994) opens a wide range of creative research opportunities. Stainton Rogers (1995:180) suggests that "the range of topics which can be studied using this technique is almost unlimited". Wigger and Mrtek (1994) believe that whenever subjective matters are at the centre of the research question, Q methodology can be used. It would help identify attitudes to illness and disability from a client's perspective and has already been used to attempt to explain health and illness (Stainton Rogers, 1991).

Q methodology was selected for use in this current study, evaluating the Cardiff Day Service, as it provided an opportunity for all those involved in the service (such as users, volunteers, carers and organisational personnel) to participate,. The method allowed the attitudes towards the benefits of the service to be identified. Phillips et al (1994) suggest that conventional data collection methods have limitations in establishing the intensity of opinions and they advocate considering alternative methods to establish subjective views.

5.4.2. The Q method process

This methodology has four distinct phases, developing the Q sort pack, administering the Q sort, factor analysing the data and interpreting factors. The stages are outlined below while the processes undertaken for the evaluation of the Cardiff Day Service are outlined in Chapter 6.

Developing the Q pack

The first step in Q methodology is the development of the Q sort pack. This is a pack of, ideally, between 40 and 80 statements related to the research topic (Dennis 1986). These statements can be generated from several sources including preliminary interviews with potential participants, relevant literature or any sources that provide information and opinions connected to the study (Dennis 1986, Brown 1996, Wigger & Mrtek, 1998). According to Barbosa et al (1998), there should be enough statements with a variety of opinions to cater for the widely different subjective feelings the participants may have about the research topic.

Administering the Q sort

The Q sort pack, that is the final pack of statements, consists of a pack of cards with each statement on a separate card. Participants are asked to sort the various statements indicating the degree of agreement they place on each of the statements, from 'most disagree' through 'neutral' to 'most agree' (Dennis 1986, Leary et al 1995, Brown 1996). Stainton Rogers (1995) suggests that it is easier to firstly separate the statements under three headings 'disagree', 'neutral' and 'agree'. Prior to administering the sort pack, the researcher needs to develop a grid layout of the distribution pattern reflecting the number of statements to be placed in each position. From this it will be clear how many statements should be placed in the extreme 'most disagree' box, the extreme 'most agree' box and all other positions in between.

Statements of importance, that is, with which the participant has strongly agreed and strongly disagreed, should firstly be placed at the extreme ends of the distribution pattern. Statements which hold little importance for the participant would therefore be found near the midpoint of the grid (Mrtek et al 1996). All statements can be moved about and exchanged until the participant is completely satisfied with his or her choices as there is no right or wrong way to do a Q sort (Brown 1980, Stainton Rogers 1995).

Q methodology is based on the belief that this behaviour (allocating of statements) is an expression of the participants' subjectivity (Wigger & Mrtek, 1998). It is therefore a technique which can be used to study the ranking a participant gave the statements relating to a range of concepts (Robson, 1993). The population size for Q methodology can be small, as it is the viewpoints of participants that is being studied rather than the character traits of a large group of participants (Mrtek et al, 1996). Twenty-one was the population size for both Wigger and Mrtek's (1998) study of professional understanding in pharmacy students and the study carried out by Leary et al (1995) of stress and coping strategies in community psychiatric nurses. The fact that the population size can be small was a favourable influence on its selection as a method for the evaluation of the Cardiff Day Service.

Analysing the data

Analysis of the data gathered by Q methodology can be carried out by a general statistical package (such SPSS (SPSS inc. 1998)) or by a dedicated Q package (such as PQMethod (Schmolck, 2000). The rank-ordering pattern (Q sort) of each participant is entered into the statistical package. It is then analysed for its meaning (Mrtek et al, 1996). The Q sorts are correlated indicating the extent to which participants' viewpoints are similarly expressed.

If all participants sort the statements similarly, then the correlation coefficient will be high and only one factor (viewpoint) will be identified. Normally more than one but less than seven factors (viewpoints) are identified in Q studies (Dennis, 1986). When participants load together significantly on the same factor, it is because their Q sorts are similar, that is, they have sorted the same statements that they most agree with and most disagree with (Dennis, 1986).

Interpreting the factors

The final stage of a Q methodological study is to interpret the factors that have emerged. This is achieved by looking for interesting patterns when comparing and contrasting between the positioning of statements in each factor. Theory, previous research and cultural knowledge may aid interpretation (Stainton Rogers 1995). At this stage often the factors are given labels which best describe the patterns of statements in the given factor.

5.4.3 Strengths

There are a number of benefits to using Q methodology. Most importantly it allows people to express their own views. Turner (1996:5) suggests that one element of the philosophy of occupational therapy is that "people are individuals of worth and inherently different from each other". If used with clients, occupational therapy researchers, for example, could establish the different views that individuals hold (Corr, 2001a). Establishing the client's views of any service, enables the service to ensure the service is client centred.

Sorting the Q pack requires active participation of the research participant which, although not unique, is unusual in the research process. As a result of this active participation it is rare to have missing data and undecided responses (Dennis 1986). Also the ranking of the statements during the Q sort requires participants to make fine discriminations they otherwise might not make (Dennis 1986). In other research methods, such as Likert scales, participants are asked to indicate their levels of agreement on a range of statements. However, the advantage of Q methodology over one such as Likert, is that the participant has to identify their level of agreement in a statement in relation to all the other statements. It also allows researchers to clarify the range of constructs present in viewpoints on the research topic (Barbosa et al 1998).

In Q methodology the content validity of each of the statements is derived from the rank order in which they are placed and the vicinity to other statements as determined by the participant (Wigger & Mrtek, 1998). The face validity of Q methodology relates to the degree of satisfaction a participant feels about how accurately his or her ranking of the statements reflects their personal feelings (Barbosa et al 1998). Dennis (1986) suggests that the data tend to be highly reliable.

Another strength to Q methodology is that only a small number of participants are needed (Mrtek et al, 1996). It also reveals how many different viewpoints are present among the group of participants (Mrtek et al 1996). It is like other qualitative methods in that it generates qualitative data; however, it is different in that it provides a way to quantify and analyse such information (Mrtek et al 1996).

5.4.4. Limitations

Q methodology has several limitations. The main ones relate to the process involved. Time is required for each participant to sort the statements – this amount of time can add up depending on the number of participants in the study. Also, explaining the process to the participants can be time-consuming as the instructions are comprehensive and participants may need to be shown how to proceed (Dennis 1986). It is necessary to invest this time if participants are to represent their perspectives accurately and adequately.

A second limitation is that it does not show how many people exist in the population who have a specific viewpoint (Mrtek et al 1996). Also as Barbosa et al (1998:1039) point out "no claim is made that other viewpoints do not exist in the broader population". Although stated earlier that validity is present, it could be affected if the participants did not comprehend the Q sort task, leading to a misrepresentation of his or her views (Dennis 1986). Alternatively there is the potential for participants to make mechanical rather than conceptual choices to complete the process, particularly if they find the process tiring which may be the case with some client groups (Dennis 1986). Another limitation is the fact that the meanings are given to factors by the researchers and therefore could be influenced by researcher bias (Barbosa et al 1998).

5.4.5. Summary

Despite its limitations, Q methodology is a research tool that is appropriate to use in the study of peoples' perceptions. It was therefore considered an appropriate tool to establish the range of viewpoints held by the key players in the Cardiff Day Service that was evaluated in this study. McKevit and Wolfe (2000) state that it is rare for the views of individuals who have had a stroke or their relatives to be sought, but the use of Q methodology in this study does so. It combines the strengths of both qualitative and quantitative methods (Brown, 1996) and allows the qualitative, subjective aspects of the participants to be identified. How it was conducted is outlined in Chapter 6.

5.5 MEASUREMENT SCALES

5.5.1. Introduction

As discussed in the literature review, stroke has an impact on an individual's life in a broad spectrum of ways, including a person's ability to carry out their occupations, their cognitive state and social interactions. A broad range of measurement scales exist to assess these various issues. This section will outline the range and provide detail of those used within the evaluation of the Cardiff Day Service. The general principles of measurement scales will be outlined first followed by a discussion on measurement scales for functional status, leisure, quality of life, mood, occupational performance, self-concept and carer's strain. These concepts were considered valid to the participants of the study both as occupational beings and as users of the Day Service.

Gompertz et al, (1993) suggest that broad issues such as mood, perceived health, movement loss and functional status are issues that should be measured post-stroke. However, Williams (1998) argues that despite its frequency and impact, the best method for measuring the outcome of stroke is not clear. He suggests that most stroke trials assess outcome in terms of general and specific activities of daily living, stroke-specific impairment and health-related quality of life. According to Pound et al (1998), objective outcome measures are used to assess the consequences of stroke. She suggests that these have traditionally focused on impairment and disability and argues the importance of obtaining a comprehensive picture of the aftermath of stroke which is grounded in the experience of people with stroke. Wilkinson et al (1997:130) support the need for a range of assessments

> in order to achieve a truly comprehensive assessment of the long term outcome of stroke.

In order to ensure all aspects of occupational functioning and health were addressed in the study being reported in this thesis a broad range of scales has been used. The ideal would be to use a single comprehensive tool but all the scales outlined in this chapter have limitations. In order to minimise these limitations a collection has been used.

5.5.2. General principles of measurement scales

5.5.2.1. Validity and reliability

The reliability and validity of a measurement scale needs to be considered when selecting a scale (Corr, 2001b). Validity of a measurement scale relates to whether it measures what it is intended to measure (Bowling & Normand 1998). Pound et al (1998:339) urge that attention is paid to content validity when choosing measures and note that

> while many measures have been used in the field of stroke, few are specifically designed with stroke in mind.

In terms of content validity the scales may not be comprehensive enough to encompass all aspects of the experience of stroke.

Scales also need to be reliable, that is, consistent at producing the same results whether at repeated intervals (test-retest), by the same rater at different times (intra-rater) or by different raters (inter-rater) (Gompertz et al, 1993). If a measurement scale has high inter-rater reliability, different raters when measuring the same individual will produce the same results (Burton, 1989). It is also necessary to ensure the sensitivity of the measurement scale. This question addresses whether the measure is able to identify changes that may occur over time or whether the scale is relevant to the population being measured (Bowling & Normand 1998, McDowell & Newell 1996).

The King's Fund (1988) recommends that measurement should be undertaken using standard scales. Although this is desirable, Barer and Nouri (1989) suggest that the use of formal measurement by a professional may show what the person can do under test conditions, but informal measurements made by carers are more likely to indicate what the person does in real life. They go on to suggest that postal surveys or interview of patients at home may reveal what they think they can do. Williams (1998) acknowledges that for those who have had a stroke measurements need to be reliable for completion by proxy as well, since language or cognitive effects of the stroke may interfere with the completion of the scale. Other problems that might affect self completion include aphasia, right-sided paralysis, and visual distortion or loss (Price 1990).

5.5.2.2. Methods of scoring

There are several different ways in which a measurement scale may be scored such as interval, ordinal and nominal scores. Interval measurements are when the distance between two numbers on the scale are of a known size like exact degrees of movement or length in centimetres (Bowling & Normand 1998). Ordinal scales are a description to identify, for example, how able an individual is to carry out an activity such as dependent or independent or a continuum of agreement based on verbal expressions such as disagree, unsure or agree. The ranges of response options are in some kind of order and have a relationship to each other (Bowling & Normand 1998). The Likert scale, which is a summative rating scale is an example of how ordinal responses may be arranged (Robson, 1993). A third type of scale are nominal scales where numbers are used just for labels such as male or female and the numbers have no value in relation to each other. Most of the scales used in stroke research are ordinal and nominal ones.

The scoring system used needs to be straight forward and quick. Also, Law and Letts (1989) suggest that scoring needs to be easy to interpret so that the results can be used for treatment planning or measuring the outcome of treatment.

5.5.2.3. Data Collection Methods

Data collection using measurement scales can be via questionnaires and interviews. Robson (1993) supports the use of questionnaires, especially self-completed ones which participants fill in for themselves, suggesting that they are very efficient in terms of time and effort. If used in research, a questionnaire that has been well constructed can reduce the time needed to code and analyse responses, especially if computer coding or analysis is being used (Robson 1993). They also allow the quantitative assessment of the participants' performance on each construct. However, both Robson (1993) and Pound et al (1998) highlight limitations of questionnaires. According to them the data may be superficial with lack of depth and detail. Also "there is little or no check on the honesty or seriousness of the responses" (Robson, 1993:243). This is balanced by the advantage of being able to collect large amounts of comparable data from groups of people (Pound et al, 1998).

When standardised measurement scales are used via questionnaires, the questions will be specific with minimum range of interpretations by respondents (Robson, 1993). Gompertz et al (1993) advocates a postal method for questionnaires as it may reduce test-retest variability.

Interviews, in particular structured interviews, are used to measure concepts related to stroke care. Structured interviews consist of specific items which an interviewer asks in a standardised manner. With the case of measurement scales the scale provides the structure for the interview including the number of questions and range of options for responses. Semi-structured interviews, according to Britten (1995:251)

> are conducted on the basis of a loose structure consisting of open ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge in order to pursue an idea in more detail.

Semi-structured and in-depth interviews can cover issues in greater depth. Robson (1993:205) describes the fully structured interview as "effectively a questionnaire where the interviewer fills in the responses". The structured interview uses closed or scale items (Robson, 1993). The closed questions force the respondent to choose from two or more fixed alternatives, whereas scale items ask for a response in the form of degree of agreement or disagreement such as strongly agree, neutral, strongly disagree.

In noting advantages of interview over questionnaire, Robson (1993) states that

> the refusal rate for personal interviews is typically very much smaller than the non-response rate for postal questionnaires.

There is, with both methods, a lack of knowledge about the views and characteristics of those who do not respond, which impacts on the ability to generalise. Wellwood et al (1994) suggest that one reason why individuals do not respond or provide incomplete responses to questions is that they may be difficult to answer accurately. Robson (1993) suggest that the 'demand' made on a respondent with questionnaire or structured interview is typically very small in terms of time and effort.

Both questionnaires and interviews were used in the study being reported in this thesis. The structure and process of these is detailed in Chapter 6. However, the content includes the standardised measurement scales being outlined in the remainder of this chapter.

5.5.3 Measurement scales for functional status

There are several different interpretations of functional status. According to the Collins dictionary (Harper Collins 1987:406) function means "a natural action". This can be interpreted in humans as the natural everyday actions that are carried out by individuals such as walking, toileting and eating. By developing scales to measure an individual's functional status the expectation is that it will be possible to get a current picture of the individual's ability to carry out the actions that are natural to all. According to McDowell and Newell (1996) an individual is healthy if he or she is physically and mentally able to do the things he or she wishes and needs to do.

A large number of scales have been developed over the last few decades, mainly in rehabilitation medicine. Two were used in this study and will be outlined below with justification for their selection. The Barthel Activities of Daily Living (ADL) Index measures activities of daily living and the Nottingham Extended ADL Scale measures extended activities such as community based activities.

5.5.3.1. Barthel Activity of Daily Living Index

Background

One of the most widely known and used measures of activities of daily living is the Barthel Activity of Daily Living (ADL) Index. It was developed in 1965 by Mahoney and Barthel, as a simple index of independence to score the ability of patients to care for themselves, and by repeating the test, to assess their improvement (Mahoney and Barthel 1965). It contains 10 items and measures the ability to carry out activities.

Scoring

The original scoring system was from 0 to 100, now modified so that scores range from 0 to 20 with higher scores signifying better functioning (Bacher et al 1990, Collin et al 1988). The Barthel ADL Index is not hierarchical in that it does not result in a total score that gives a clear indication of the level of disability (Gibbon 1991). As a result it is not possible to assume two people who score the same are both independent in the same activities. The items are not in an order that reflects the complexity or difficulty to carry out particular activities.

When the scores are totalled there is no single way of interpreting this total. Granger and Hamilton (1990) found that no specific score could be regarded as adequately specific or sensitive to be used as the criteria for admission for rehabilitation services or as an indication of readiness for discharge. Rodgers et al (1993) suggest that the Barthel ADL Index is most useful in assessing individuals who are moderately or severely disabled. There is a ceiling and flooring effect, meaning that those scoring the maximum (20) may still be significantly handicapped with the potential of improvement beyond the limits of the scale. As a result the Barthel ADL Index lacks sensitivity to change in its upper range (Rodgers et al 1993). The same occurs at the lower end. To overcome this people with high Barthel ADL Index scores should subsequently be assessed with an ADL scale that assesses a broader range of activities.

Reliability and Validity

The Barthel ADL Index has been shown to be reliable for use in clinical settings and also for use in formal research, by post and over the telephone (Wade 1992). Law and Letts (1989) indicated that more specifically it has been shown to have adequate observer and test-retest reliability. It is a valid measurement scale for function in activities of daily living and is sensitive to measure changes in ADL after treatment in controlled research settings.

Eakin (1993:185) suggests that the appeal of the Barthel ADL Index

> lies in the fact that it is simple and quick to use; its results can be easily understood and communicated between different professions; and its content is perceived as relevant to both clinicians and individuals.

However, it is limited by the number of items it contains being insufficient to account for the impact of rehabilitation and that the grading system is not sensitive enough to reflect change, particularly in the short term. Bearing these limitations in mind, the Barthel ADL Index was selected as a baseline tool in the evaluation of the Cardiff Day Service and not a tool to measure outcome from attendance at the service. In addition, its limitations of few items relating to activities of daily living relevant to community living led to the selection of the Extended ADL Scale as outlined below. Wilkins et al (1997) in a study to establish whether the Barthel ADL index alone provides sufficient information about long term outcome of stroke concluded that other measures are required in order to conduct a comprehensive assessment.

5.5.3.2. Extended Activities of Daily Living Scale

Background

The Extended ADL Scale was developed in Nottingham by Nouri and Lincoln (1987) to assess the activities which may be important to those who had a stroke and are living in the community. It includes activities that relate to carrying out domestic tasks and other activities that take place outside the home environment. It consists of a questionnaire of 22 activities divided into four groups: mobility, kitchen, domestic and leisure.

Scoring

The Extended ADL Scale is a ranked scale, therefore all individuals with the same scores are independent in the same items. The score 'one' is given if activities are performed by individuals on their own or on their own with difficulty. For activities which individuals are unable to perform or for which they require help the score is zero. The scores for each item are calculated and summed to make sub-sectioned scores, that is, mobility, kitchen, domestic and leisure sub totals are generated. These scores are summed to create the Extended ADL total score.

Lincoln and Gladman (1992) found that an overall total score could provide an indication of overall independence in the activities if comparing groups of people. They recommend that with individual section scores, for example, mobility or leisure scores, rather than overall totals should be used when identifying progress or change over time. They recommend this as they found discrepancies when using the total score. They suggest that the scale is appropriate to use in research into the evaluation of rehabilitation.

Reliability and Validity

It has been validated for administering by interview and post (Lincoln & Gladman 1992, Nouri & Lincoln 1987, Wade 1992). Towle (1988) used the Extended Activity of Daily Living Scale (EADL) as part of a study on depressed mood after stroke, and found that individuals scored what they did rather than what they were capable of doing. Due to depression, individuals were unwilling to carry out activities themselves even though they were often capable of carrying them out. This highlights the point that issues of reliability as a self report method may not be consistent with, for example, a carer reporting.

5.5.4. Measurement scales for leisure

Bundy (1993) suggests that our play and leisure activities may be some of the purest expressions of who we are as persons, because we freely choose them. A wide range of activities may be defined as leisure including golf, running, building with blocks or playing computer games.

According to Drummond and Walker (1994), there are no standardised assessments available to measure exclusively the leisure participation of those who have had a stroke, which led them to develop the Nottingham Leisure Questionnaire. Bundy (1993) suggests that when assessing leisure activities a range of issues need to be defined, including

> (a) in what activities the client becomes totally absorbed;
> (b) what the client gets from those activities;
> (c) whether or not the client engages routinely in activities in which he or she feels free to vary the process, product, and outcome in whatever way he or she sees fit;
> (d) whether or not the client has the capacity, permission, and support to do what he or she chooses to do;
> (e) whether or not the client is capable of giving and interpreting messages that "this is play; this is how you should interact with me now." (Bundy, 1993: 219).

As leisure activities are the key activities that are undertaken at the Cardiff Day Service, it was considered appropriate to measure levels of activities pre and post service. In addition, understanding an individual post stroke from the perception of an occupational being requires the collection of data relating to their engagement in leisure activities. The Nottingham Leisure Questionnaire was selected for use and is outlined below.

5.5.4.1. Nottingham Leisure Questionnaire

Background

The Nottingham Leisure Questionnaire was developed by Drummond and Walker (1994). It was developed in order to monitor changes in the leisure habits of those who have had a stroke. It has subsequently been used by them in a randomised controlled trial of leisure rehabilitation. More recently, Drummond et al (2001) have conducted a further validation study of the measure. The original version of the scale was used in the study reported in this thesis.

Scoring

A total of 37 activities are in the original scale. The frequency of participation in each activity is indicated either as regularly (at least once a week), occasionally (every few weeks/monthly), or never. A total score is then calculated by adding up the number of activities an individual does, irrespective of the frequency, giving a Total Leisure Activity score (Drummond 1994). As this score does not include the frequency, it does not establish if an activity is carried out regularly. It is further limited in that it does not identify the qualitative issues identified by Bundy regarding participation in leisure activities. No conclusion can be drawn such as an individual's motivation or the reward they gain from participating in their leisure activities. However it has been developed for use with those who have had a stroke and it is appropriate to use to identify the range of activities in which individuals participate. Following the further recent validation study, the scale was reduced to 30 activities and the layout and instruction simplified for self-completion (Drummond et al, 2001). The activities that did not represent positive activities eg. 'daydreaming' and 'just sitting' have been removed.

Reliability and Validity

In addition to developing the scale, Drummond and Walker (1994) conducted an inter-rater reliability study and found the level of agreement was either 'excellent' or 'good' for all categories (Drummond & Walker, 1994:417). They also found it sensitive to monitoring change following occupational therapy intervention. In the recent study (Drummond et al, 2001), test-retest reliability was examined by sending the scale to 137 participants and again two weeks after receipt of the first one completed. They found satisfactory test-retest reliability. They also acknowledge that the scale has been developed in an elderly British population and suggest caution when used with other age groups or cultures. They also wonder about its relevance to current leisure activities as they do not include computer use in it, an activity that many more participate in for leisure than in the 1990s when the scale was being developed.

5.5.5. Measurement scales for quality of life

As discussed in Chapter 2 (Health), quality of life is not easy to define and according to Bogousslavsky et al (1998:78) "measurement of quality of life in people who have had a stroke is difficult". This is a view supported by Pound et al (1998). Fallowfield (1990) and De Haan et al's (1993) suggestion is that four domains, physical, functional, psychological and social health make up quality of life. These include the consequences of disease, including elements of impairment, disabilities, and handicaps, as well as individuals' perceived health status and well-being. In view of the potential different understandings of quality of life, measuring the concept can also pose problems.

Quality of life measures "attempt to evaluate directly the impact of a disease or treatment" (Donald 2001:1) and range from being broad general health profiles (generic) to disease specific scales. The broad health profiles are those which have not been developed for specific target populations. A strength of these is that comparisons of quality of life results across populations can be made (Fitzpatrick et al, 1992). A limitation is that they do not always focus on the specific problems of a given group. Examples of these are the SF36 (Ware & Sherbourne 1992) and the Nottingham Health Profile (Hunt et al,1985). Disease specific quality of life scales exist for a range of specific patient groups including those who have had strokes (Holbrook & Skilbeck 1983), who have rheumatic disorders (Liang et al 1990), and cancer (de Haes & Van Knippenberg 1985). Disease specific scales do not allow cross disease comparisons but are often more sensitive to the quality of life issues particularly relevant to specific populations of patients.

Most of the available quality of life scales depend on individuals to rate themselves. Quality of life is a very personal issue and therefore getting the individual to rate themselves is the preferred method of administration. It is also possible to use structured interviews or written questionnaires. It can be difficult for people with serious cognitive, and speech and language disorders to complete these (De Haan et al 1993), a fact that was considered in selecting a tool for the evaluation of the Cardiff Day Service.

Quality of life measures can be used for a number of reasons. They may be useful for people with chronic conditions where recovery is not expected and where success of treatments may best be measured in terms of maintaining an acceptable quality of life for the person as the disease progresses (Talamo et al, 1997, Fitzpatrick et al, 1992). They can also be used to facilitate the process of identifying who is likely to benefit from which type of rehabilitative procedure (Mathias et al, 1997). Treatment from a multidisciplinary team may include a range of interventions which individually are difficult to measure directly or demonstrate outcome, or for which there is no sensitive measure. In these situations a quality of life measure may be the most appropriate option to demonstrate outcome from the treatment. Quality of life measures can also be used to evaluate treatment programmes (Fitzpatrick et al, 1992). Baker and Intagliata (1982) suggest that if a person's life situation is not improved in some way and they are not happier or more satisfied after participating in treatment then it is difficult to ultimately justify the treatment.

The ideal stroke-specific health-related quality of life instrument would be reliable for individual or proxy completion, have appropriate content validity, and would be responsive to meaningful within-participant changes for those with stroke within all ranges of severity (Williams, 1998). Williams notes that the SF36 is increasingly being used in stroke studies. This was the tool selected for use in the evaluation of the Cardiff Day Service and is outlined below. In addition to its selection being based on evidence of its use in other stroke studies, and its administration by post, the fact that normative data is available for the tool was an additional consideration. This allows the comparison of data with normal populations.

5.5.5.1. The Short Form 36

Background

The Short Form 36 (SF-36) Health Survey has been developed from a longer Medical Outcomes Study questionnaire, which has had the number of items reduced to 36. Hence the title Short Form 36 (SF-36). The aim of reducing the items was to develop a scale that could be conducted in a short period of time and therefore lend itself to be used in a broad range of settings (Ware & Sherbourne 1992).

The SF-36 was developed to be an indicator of quality of life for population studies as well as an outcome measure in clinical practice and research (McDowell & Newell, 1996). It is suitable for use with all in receipt of healthcare as the measure addresses aspects of health that are important to all, rather than just those with a particular condition. It is a questionnaire that can be completed by anyone over 14 years of age in a clinical setting or at home. It can also be administered in an interview. The fact that it is easy to use and takes between five and ten minutes to complete has made it popular (Larson, 1997).

The SF-36 categorises the 36 items into eight areas relating to health concepts. These are physical functioning (10 items), role limitations due to physical problems (four items), social functioning (two items), bodily pain (two items), general mental health (five items), role limitation due to emotional problems (three items), vitality (four items) and general health (five items), perceptions (Larson, 1997). The inclusion of bodily pain and vitality as concepts of health is unique to the SF-36 scale (Ware & Sherbourne 1992). The final item asks about health change over the past year.

Each of the eight different sections produce individual section scores ranging from 0-54. For each item, there is a choice of responses on a Likert scale, ranging from 'limited a lot' to 'not limited at all' or 'all of the time' to 'none of the time' (Brazier, 1995). Although, according to Bowling and Normand (1998), these are not combined to form an overall score which make it hard to make comparisons, it is possible to calculate two combined scores – the physical component score and the mental component score. This reduces the eight scale profile to two summary measures without substantial loss of information (Ware et al, 1993). Higher scores indicate a perception of good quality of life (Talamo et al, 1997).

Reliability and Validity

There is considerable evidence for the validity and reliability of the SF-36 and its ability to measure changes in health status over time (Brazier et al 1992, Garratt et al 1994, Jenkinson et al 1994, Ware & Sherbourne 1992). This supports its use as a routine scale for monitoring and assessing quality of life both in clinical practice and research. Anderson et al (1996) found it to be valid for use in stroke rehabilitation. However like other measurement scales ceiling and flooring effects can occur. Williams (1998), like Anderson et al (1996), considers the SF-36 to have some limitations when used in stroke care. He suggests that it does not encompass several domains potentially important to stroke patients, such as upper extremity function, communication, cognitive function, and self-care. Also, some individual items within the SF-36 may not be sufficiently sensitive to post-stroke symptoms to measure important changes in function, walking being one example. The three levels of function for walking are more than a mile, several blocks, or one block. They may not include enough responses to note changes in mobility immediately after stroke (Williams, 1998).

5.5.6. Measurement scales for mood

Mood, according to Gelder et al (1983) denotes emotional status. Changes in the notion of emotion can be towards anxiety and depression. Wade (1992) suggests however that the phenomena that contribute to mood are very difficult to define. As a consequence there are few measures available for assessing mood. When considering the measurement of mood three questions arise:

- Are these feelings a realistic response to the situation?
- Is there a single underlying change such as depression?
- Are the various problems seen as a direct consequence of brain damage? (Wade 1992:67).

According to Sutcliffe and Lincoln (1998), there are several ways to identify depression. These include "informal judgements, self-report measures and structured psychiatric interviews" (Sutcliffe & Lincoln, 1998:507). There are advantages and disadvantages to self-report questionnaires. They can be relatively cheap, easy to administer and not time-consuming, and easy to repeat. However they do depend on the respondent's literacy skills and ability to concentrate. They are also open to bias, because when the test is used postally, no control exists over who completes the questionnaire (Sutcliffe & Lincoln 1998). Another aspect of bias might be the respondent wishing to present himself in a particular light (Snaith et al 1971). The measurement of mood was considered appropriate for the evaluation of the Cardiff Day Service. As stated in Chapter 4, depression and anxiety occur post-stroke. It was important to establish the levels of these and compare levels pre and post-service. In order to do so, the Hospital Anxiety and Depression Scale was selected for use in this study and is outlined below.

5.5.6.1. Hospital Anxiety and Depression Scale

Background

The Hospital Anxiety and Depression (HAD) scale was designed to assess mild degrees of two common components of mood disorder that is, anxiety and depression (Zigmond & Snaith, 1983). It was designed to detect the presence and severity of these in individuals who are outpatients and not receiving psychiatric care (Wilkin et al,1992).

The HAD scale has 14 items, of which seven are concerned with anxiety and seven with depression. It is completed by the individuals themselves and, according to Walker and Rosser (1993) and Wilkin et al (1992), it is easy and quick to administer. For each item there is a choice of four responses and the order of responses to the items have been arranged so that the first response may indicate maximum severity while for another item the first response may indicate minimum severity (Zigmond & Snaith, 1983).

Scoring

The respondents need to consider the responses in relation to their feelings during the past week and give their immediate reaction. According to Wade (1992) it is easy to use and score. Item scores for each sub-scale are summed and indicate non-cases (7 or less), doubtful cases (8 to 10), and definite cases (11 plus) (Wilkin et al, 1992).

Reliability and Validity

The reliability and validity of the scale has been tested. Zigmond and Snaith (1983) found it to be reliable for screening for clinically significant anxiety and depression in outpatients aged 16 to 65 years attending a general medical clinic. They also found it to be a valid measure of the severity of these disorders of mood. Wilkin et al (1992) suggest that it is valid when tested against other measures and can differentiate between anxiety and depression.

Sutcliffe and Lincoln (1998) consider the anxiety questions of the HAD scale to have a relevance to the problems of stroke. As a stroke is an unpredictable and devastating event, an individual may justifiably feel 'a frightened feeling as though something awful is about to happen'. They may also be aware of preventative measures to take in the light of the possibility of further strokes and therefore aware of the possibility of a recurrence.

According to Zigmund and Snaith (1983), Aylard et al (1987), Walker and Rosser (1993) and Bowling and Normand (1998), it avoids the use of somatic symptoms such as tiredness, dizziness and headaches which could be due to both physical illness and mood disturbance. By separating the anxiety and depression items it also deals with another common objection to mood disorder questionnaires, that is, there is insufficient distinction between one mood disorder and another (Zigmond & Snaith, 1983).

In a recent study, Mykletun et al (2001) examined the psychometric properties of the HAD scale in a large population. In Norway, 51,930 participants, ranging in age from 20 to 89 years, completed the HAD scale as part of a large health study. Using principal component analysis, the researchers found evidence to support the two (anxiety and depression) factor structure of the scale. They also found that items 6 (I feel cheerful) and 7 (I can sit at ease and feel relaxed) are not unique to either depression or anxiety. They conclude by suggesting their results support the HAD scale as an instrument "with good psychometric properties" (Mykletun et al, 2001:543).

5.5.7. Measurement scales for self-concept

As per the definition in Chapter 4 (Stroke), self-concept is an individual's perception of himself or herself and is multi dimensional in nature (Shavelson et al 1976, Brinkman and Hoskins 1979, McClelland 1982, Ben-Shlomo and Short 1983, Kersten 1990). It was considered an appropriate concept to measure in the evaluation of the Cardiff Day Service as there was potential for the self-concept of users to change through attending the service. The Semantic Differential Self Concept Scale was the only scale identified that had previously been used with individuals with a stroke (Ellis-Hill, 1998) and therefor was chosen for this study.

5.5.7.1. Semantic Differential Self Concept Scale

Background

A 20-item semantic meaning differential scale for measuring self-concept was originally developed by Osgood et al (1957 cited in Kersten, 1990), and later adapted by Tyerman and Humphrey (1984). Tyerman and Humphrey (1984) adapted the original scale to use it to assess self-concept in 25 young adults after head injury. According to Kersten (1990), the advantages of the scale are its brevity, ease of administration and interpretation, and potential clinical usefulness. The test takes only 5 to 10 minutes for an individual to complete.

The instrument has 20 pairs of opposite adjectives called concepts. For each concept, such as happy-unhappy, the individual is asked to judge his or her self (Kersten, 1990). The individual can indicate on three separate scales his or her past, present and future self. Each scale has seven spaces for responses, with one end representing extremely unhappy, for example, the middle a neutral position, and the other end extremely happy. The individual marks a response by placing an X in one of the seven spaces, the format is such that some left hand spaces will be both positive and negative, ensuring that an individual does not automatically choose one side.

Scoring

To determine changes in self-concept for each individual, the administrator allocates a one to seven value appropriately to represent the marks made by the individual on the semantic differential scale (Robson 1993). The 20 scores are totalled, yielding the total self-concept (TSC) score. If using the scale for past, present and future self, there will be three TSC scores. In the interpretation of results, a TSC score greater than 80 indicates a positive self-concept. A TSC score of less than 80 indicates a negative self-concept (Kersten, 1990:450).

Reliability and Validity

Osgood et al (1957 cited in Kersten 1990) established the instrument's face validity and satisfactory test-retest reliability using short and long time intervals (three minutes to three hours). Cronbach's alpha was used by Kersten (1990) to estimate internal-consistency reliability of the tool when used in a study of 37 individuals. Coefficients were found to be high for each of the three scales on the admission evaluation (alpha for past self = 0.96; present self 0.94; future self = 0.93) and remained in the same range on the other two evaluations.

5.5.8. Measurement scales for occupational performance and roles

The development of models of occupational therapy, the need for evidence based practice and the requirement to identify the outcome of intervention has led to the introduction of occupational performance scales (Ward et al, 1996). This has led occupational therapists away from using measures that assess impairment to developing measures that are specific to occupational performance.

According to Law and Baum (2001:15),

> the measurement of occupational performance involves assessment of self-care, work, other productive pursuits, play and leisure

and Toomey et al (1995) consider measurements as means to describe individuals' occupational problems and to evaluate treatment intervention. Ward et al (1996:448) suggest that assessments of occupational performance

> are often more indicative of the impact of illness or disability on people's lives than objective biochemical measures or measures of times walking or strength.

The Canadian Occupational Performance Measure which is based on the Canadian Model of Occupational Performance, and the Role Checklist which is based on the Model of Human Occupation have been used in the evaluation of the Cardiff Day Service due to their relevance to the participants as occupational beings and the potential for change in occupations following attendance at the service.

5.5.8.1. Canadian Occupational Performance Measure

Background

The Canadian Occupational Performance Measure (COPM) was developed as a measure designed for use by occupational therapists "to detect change in a client's self-perception of occupational performance over time" (Law et al, 1994:1). This involves assessing individuals' perception of their performance of daily activities and their satisfaction with their performance (Chan & Lee, 1997). Toomey et al (1995) support its use to ensure that the problems identified have relevance to the client, as does Ward et al (1996) who claim that most measurements do not focus on what is important to the individual nor are they sensitive to small changes. It was designed for use with individuals with a variety of disabilities and across all developmental stages. The measure is based on the Canadian Model of Occupational Performance, and is concerned with occupational performance in areas of self-care, productivity and leisure (Law et al, 1994, Ward et al, 1996).

An unusual aspect of the measure is that occupational performance is measured in terms of the person's satisfaction with their performance (Ward et al, 1996). Bodiam (1999) sees this as supporting the belief that individuals have responsibility for their health.

The COPM uses a semi-structured individualized interview approach. Ottenbacher and Christiansen (1997) suggest that the primary areas being measured are self-care, productivity and leisure, but there can also be an assessment of performance components in order to gain an understanding of why the individual may be having difficulty in a particular area.

Scoring

The COPM is administered using a semi-structured interview, by asking the individual if they need, want or expect to carry out an occupation by asking about their daily routines. Problems are noted under headings of self-care, productivity and leisure. Each of these problems is rated by the individual in terms of importance to his/her life on a score of 1 (not al all important) to 10 (extremely important) (Ward et al, 1996). The individual then rates the problems for their ability to perform the occupations identified (Performance) and their satisfaction with their performance level (Satisfaction) (Law et al, 1994, Bodiam, 1999).

It should take 20 to 30 minutes to administer (Law et al, 1994). If the individual is unable to identify problems for cognitive or speech reasons a carer or other appropriate person may answer on their behalf (Law et al, 1994). A total performance score is established by summing the performance scores and dividing by the number of identified problems. Similarly, a total satisfaction score is established by summing the satisfaction scores and dividing by the number of problems. These scores will range from 1 to 10 and scoring is simple (Law et al, 1994, Law et al, 2001).

The COPM is an individualised measure, where individuals' scores are compared against their own reassessment scores, unlike some norm-referenced tests where the individual scores are compared against a population norm (Law et al, 1994). This characterises the client-centredness of the COPM (Chan & Lee, 1997). Changes of 2 or more points on the COPM measure are viewed to be important clinically (Law et al,1994). Bodiam (1999) suggests that an increase in the scores for satisfaction may relate to the achievement of an increase in occupational performance, or could indicate that the individual is coming to terms with their disability or situation.

Reliability and validity

The COPM is a reliable and valid assessment (Law et al, 1994, Bodiam, 1999, Law et al, 2001). It is standardised with specific instructions and methods for administering and scoring the measure. It is not norm-referenced because occupational performance has been conceptualised as individually determined (Law et al, 1994). It has been found to have good to excellent reliability (Law et al, 2001).

Ward et al (1996) highlight that the COPM can identify areas of functional deficit which are not perceived as a problem by the individual. An individual may rate their ability to perform an activity as "not at all able", although they may express satisfaction with this. In these cases someone else may be performing the activity for them, hence they did not need to do it themselves and therefore it was not perceived as a problem. The reasoning behind the scores may require investigation to understand the individual's perceptions.

Ottenbacher and Christiansen (1997) suggest that the COPM is sensitive to perceived changes in occupational performance as they found that the average change scores for performance and satisfaction were approximately 1.5 times the standard deviation of the scores. With regards to the clinical utility to the measure, Ottenbacher and Christiansen (1997) state that comments by those involved in the pilot studies were generally favourable.

Toomey et al (1995) highlight however that specific client skills are required in order to complete the COPM. They suggest that the client needs to be ready or able to make a choice and needs to be willing to assume responsibility for the process. This is dependent on client insight, cognitive ability, emotional state and whether the client is English speaking. The outcome of the assessment is dependent on the ability of the interviewer. According to Letts and Bosch (2001:133) "it does take a good interviewer to administer this well"

5.5.8.2. Role Checklist

Background

The Role Checklist is a self-report instrument (Christiansen, 1991). It was designed specifically to assess an individual's involvement in a range of roles, the perceived importance of each role, and the balance of current roles. The instrument also provides information about the expectations of individuals regarding future role involvement (Kielhofner, 1985, Kielhofner, 1992).

Scoring

There are two parts to the Role Checklist. In Part I ten roles are listed: student, worker, volunteer, caregiver, home-maintainer, friend, family member, religious participant, hobbyist/amateur, and organisational participant. There is also a space for the individual to insert a relevant unlisted role. For each of these, individuals are asked to indicate their previous, current or expected performance. Christiansen (1991:409) states that "roles in this section were chosen specifically because of their implication for productive use of time". Part II of the test invites individuals to indicate the value they place on each of the ten roles. The choices for indicating value are "not at all valuable, somewhat valuable", and "very valuable".

Reliability and Validity

According to Christiansen (1991), the test-retest reliability for the checklist was estimated in a study of 124 adults without ill-health who were living in the community. The findings were that percent agreement for each role averaged 87%, with a range of

77% to 93%. For the value component (Part II), agreement was 70%, suggesting acceptable reliability for the checklist, albeit with individuals who do not have health problems. Kielhofner (1985) reports that preliminary research suggests discriminant and concurrent validity and that the checklist has content and face validity although full details of how these were tested are not reported.

5.5.9. Measurement scales for carer's strain

The literature clearly indicates that carers are affected by having a family member who has had a stroke (Anderson, 1992, Stroke Association, 1996). There are few measures of the care-giver's strain. The Care-giver Strain Index was selected as it had previously been used in studies in stroke care (Bugge et al, 1999). However there also is little literature available about this index.

5.5.9.1. Carer-giver Strain Index

Background

The Carer-giver Strain Index was developed by Robinson (1983) as a tool for clinicians to asses carer-giver perceived strain. It comprises 13 stressors which reflect caregiver strain affecting roles and activities outside the caregiving situation. The strains include perception of caregiving, emotions problems, job/caregiving conflict, constriction of social life and economic problems (Bugge et al, 1999, Connolly & O'Dowd, 2001).

Scoring

The Caregiver Strain Index (CSI) is calculated by totalling the 0 (no) and 1 (yes) responses for the 13 items. Therefore, CSI scores ranged from 0 to 13 (Robinson, 1983).

Reliability and Validity

It is a valid scale (alpha = 0.84) and has internal consistency (alpha = 0.86). Also when developing the scale, Robinson (1983) found high internal reliability suggesting the tool is appropriate for use in research and for screening. It was not tested for test-retest reliability.

5.5. SUMMARY

This study has been conducted using evaluation research as its umbrella. Both quantitative and qualitative strategies were considered appropriate for this evaluation. Q methodology enabled the perceptions of key players in the service to be obtained and standardised measurement scales enabled the identification of changes in abilities over time. The economic evaluation was conducted to identify the cost of the service and to facilitate the comparison of cost with benefit gained. This chapter has provided the background to the processes undertaken in the evaluation of the Cardiff Day Service. The next chapter will provide the detail as to how the study was conducted.

CHAPTER 6.

METHODS

6. METHODS

6.1. INTRODUCTION

Chapter 5 outlined the range of methods used in this study and the justification for their use. This chapter will outline the various processes undertaken in detail. The research team consisted of the researcher and a research administrator. The researcher undertook all aspects of the study except those duties that are indicated in this chapter as being conducted by the administrator.

6.2. POPULATION

The focus of this study is the Cardiff Day Service. It is a unique service established by the Stroke Association. It was established as a pilot service in recognition of the need to support younger people post stroke. Therefore the population for this study is unique, the service is a case in its own right and the users are not a sample from a larger population of service users. They are, however, in addition to being users of this unique service, adults who have suffered a stroke while younger than 55 years. According to the Stroke Association (1996), the incidence of stroke in the UK in individuals under 65 is 200 per week or 10,000 per year. The most current prevalence data for this, the incidence of stroke in Wales, is from the Welsh Health Survey 1998 (National Assembly for Wales, 1999). Its findings are based on 30,000 computed health questionnaires from across Wales by adults aged 18 years and over. The incidence of stroke was 1.2% throughout Wales (0.7% of 18 –24 years, 1.0 % of 24 – 34 years, 1.0 % of 35 – 44 years, 1.0% of 45 – 54 years). It does not provide the incidence in age groups for the different geographical areas in Wales.

The Stroke Association established the following criteria for attendance:

- aged between 18 and 55 years
- independent using and transferring on/off toilet
- living within a catchment area of approximately five miles or able to use private transport to access the service.

Referral routes to the service are various including self-referral, via health and/or social care professionals, via family or friends, or other services within the umbrella of the Stroke Association, such as family support worker or information officer.

The Cardiff Day Service is staffed by one paid employee (an organiser) who works three days a week. The role of the organiser includes ensuring the smooth running of the service on the actual day it runs as well as all the necessary administration. These duties include renting the facilities, engaging sessional instructors as appropriate, fund raising, organising transport, recruiting and managing volunteers and meeting with potential users and their carers. Additional support on the day is provided by volunteers. The venue for the service is a large multi-purpose room with a range of facilities including kitchen, practical activity area, social area and computer area. An additional small meeting room and toilet facilities are close by and available.

The evaluation of the Cardiff Day Service occurred from April 1998 to April 2001. All new referrals to the service from June 1998 to February 2000 participated in the evaluation. In total 26 participants were recruited. Of the 28 people referred to the service during the evaluation period two did not continue with their referral (one person did not fit the criteria for the service and another was too ill to participate).

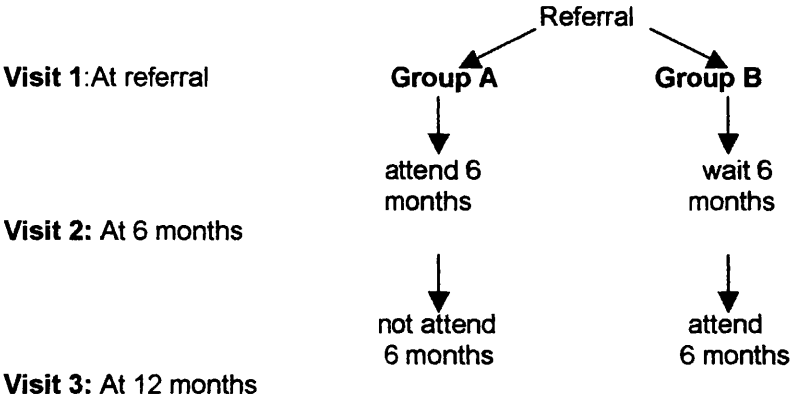
The average rate of referrals for the first two years of the service (1995 to 1997, the period before the evaluation) was 24 per year, and the estimated recruitment for the evaluation based on that referral rate was 40 to 48. The actual number of participants recruited over the 21 month recruitment period of the evaluation was 26. However data analysis indicates that at first the service recruited users who had their stroke some time before they attended the service (median 10 months). This contrasts with the recruitment during the evaluation when most users were being referred sooner after their stroke (median 5 months). This suggests that initially the service recruited both individuals who had recently had a stroke as well as those who had had their stroke some time previously. By the time the evaluation was carried out it has been assumed that the service had exhausted the population of individuals who had their stroke some time ago and were recruiting mainly those who had recently had their stroke.

6.3. CROSS-OVER DESIGN AND RANDOMISATION

Both cross-over design and randomisation have been outlined in Chapter 5. The cross-over design was selected as it enabled all individuals referred to the Cardiff Day Service to attend the service and thus receive both an intervention and control phase, each of six months' duration. It was considered unethical to conduct a randomised controlled trial as the service was already in existence. Therefore to randomly allocate individuals to a control group would have led to them not receiving the service at all. The design also allowed the investigation of the effect of delayed intervention and the effect of a six month follow-up period. Randomisation was used to allocate individuals into each group (Figure 1). The crossover design enabled all to attend. However, in order to complete the evaluation a time period of six moths for attendance was agreed. Less than six months was considered too short to show change. From the outset it was acknowledged that maximum change may not have been achieved by six months.

Randomisation was carried out by a research administrator using pre-prepared envelopes from random number tables, independent of the researcher and the Day Service Organiser. As suggested by Roberts and Togerson (1998) the main purpose of randomisation is to avoid bias and therefore the process distributed the users so that both groups were similar. The researcher was blind to which groups the users were allocated to. All clients (n=26) referred to the service during the recruitment process were randomly allocated to either Group A (attend service immediately for six months and then not attend for six months) or Group B (attend after a period of six months). Irrespective of their group allocation all those referred received a visit from the researcher at referral, at six months and at one year (Figure 1).

Figure 1. Randomisation and assessment process



As envisaged, a third group emerged (Group C) consisting of those people who were referred to the service but who chose not to attend. Each also received three visits from the researcher. There were nine participants in Group A, ten in Group B and seven in Group C. All clients who were referred to the service, for the purpose of reporting will be called participants of the evaluation. The term 'users', when used will denote only those in Groups A and B, those who actually attended during the evaluation period.

All individuals who were referred to the service during the recruitment period were assessed by the researcher at referral, at six months and at one year. The assessment schedule included both quantitative and qualitative tools (questionnaire and interview) to establish the levels of social, psychological and occupational functioning of the individuals such as social function, leisure activities, quality of life, mood, valued roles and occupations and self-concept, that is the measurement scales outlined in Chapter 5. The specific contents of the questionnaire and interview schedule are detailed in the next section. The assessments took place in the participants' homes. Prior to each visit by the researcher, a questionnaire for the potential user and a carer's questionnaire were sent out. An interview was conducted at the visit.

6.4. QUESTIONNAIRES

Two questionnaires were developed for this study – one for the participants and one for carers, where one was identified. Both questionnaires comprised several standardised assessment tools which had already been tested for postal self-completion use as indicated in Chapter 5. The participants' questionnaire consisted of the Extended ADL Scale, Nottingham Leisure Scale, SF36 and the Hospital Anxiety and Depression Scale. The carer's questionnaire consisted of the SF36 and the Carer's Strain index. Figure 2 shows a summary of the content of each measure. The questionnaires were designed to be filled out easily. This is vital according to Robson (1993). Large print was used and the format was tick boxes all in the same position on the right hand side of the page (Appendix A.). The order of the questionnaire was planned so that questions relating to mood were at the end. They might have influenced the individual's perception of ability if they had been at the beginning.

The questionnaires were sent by the research administrator to the participants approximately one week prior to each of the researcher's three visits to them. A letter accompanying the questionnaire invited them to complete the questionnaire prior to the forthcoming researcher's visit. This allowed them time to complete the questionnaire. If they needed assistance, it also allowed time for a carer or other person to help them. They were asked to indicate who had completed the forms. A further justification for sending the questionnaires in advance was to attempt to secure the researcher's blindness. The participants may have indicated that they had undertaken activities at the Cardiff Day Service thus giving an indication to the researcher regarding the groups they were in. It was considered vital that all efforts possible were made to ensure the researcher's blindness. It was therefore preferable that the researcher did not assist in completing the questionnaire.

Figure 2 Outline of questionnaire and interview contents

Assessment tool	**Measures**
Questionnaire	
Extended ADL Index	22 extended activities including domestic and leisure
Nottingham Leisure Scale	Frequency of participation in a range of leisure activities
Hospital Anxiety and Depression Scale (HAD)	Generates an anxiety and a depression scale
Short Form 36 (SF36)	A quality of life scale which generates eight subscores and two capacity scores – physical health capacity score and mental health capacity score
Interview	
Barthel ADL Index	10 items of activity of daily living
Canadian Occupational Performance Measure	Problem occupations under the headings of self-care, productivity and leisure
Role Checklist	Identifies past, current and future roles as well as perception of the value of 10 different roles
Semantic Differential Self-concept Scale	Components of self-concept with total score for self-concept
Carers' Questionnaire	
Carer's Strain Index	Indicates level of strain experienced by carer

The questionnaires were piloted with two individuals who were users of the service prior to the evaluation commencing. They were therefore representative of the individuals who would subsequently be taking part in the evaluation. Both were able to complete the questionnaire on their own and they found the layout easy to follow. They suggested clarifying some of the instructions, for example with the Nottingham Leisure Scale they asked for clearer instructions as to what 'regularly', and 'occasionally' meant. Explanations of these were subsequently inserted. Both individuals found the questionnaire do-able but long and also noted some duplicate questions. Consideration was given to reducing it but as it was made up of standard assessments, to reduce it and to remove the duplicate questions would have resulted in invalid tools. It was decided to retain the full questionnaire so that all sub and total scores of the scale could be calculated. By posting the questionnaire a week prior to the visit it was anticipated that this would allow time for the individuals to complete it at a relaxed pace.

Enclosed within the envelope with the participant's questionnaire was a letter and questionnaire for carers (Appendix B). This invited a carer or individual who had regular contact and provided support to complete the carer's questionnaire. The participants' third questionnaire had some additional questions inserted. These related to use of a range of health, social and voluntary services. Participants were asked to indicate any use of these services over the previous 12 months and to indicate any hospital admissions and length of stay if appropriate.

6.5. INTERVIEWS

Each participant received a visit to their home by the researcher on referral, at six months and at one year (total of 78 visits). The letter that accompanied the questionnaire informed the participant of the date and time of the researcher's visit (Appendix A). They were invited to contact the research administrator if the time was not convenient. The research administrator routinely telephoned the participants several days after posting the letter to confirm that the visit time was convenient. If it was not, an alternative time, usually within a week was arranged.

The interview conducted was structured, consisting of the Canadian Occupational Performance Measure (Appendix C), the Role Checklist (Appendix D) and the Semantic Differential Self Concept Scale (Appendix E). During the first visit only, information on activities of daily living was collected using the Barthel ADL Index (Appendix F). This was used as a baseline for all participants. It was not used subsequently because the intervention of the day service did not consist of formal rehabilitation or focus on activities of daily living. The initial questions relating to the Canadian Occupational Performance Measure (COPM) were open questions, that is, they allowed the participants to respond without restriction to the manner in which they replied but were restricted to the topic area (Robson 1993). During the first visit, the participants were invited to outline their normal current and previous occupations. While doing so the researcher noted those mentioned under the appropriate headings of COPM (self-care, productivity and leisure). She also prompted the participants if no occupations under headings were mentioned. Once this process was completed the researcher introduced the rating of importance, performance and satisfaction aspects of the measure and these were completed. During the second and third visits the participants were invited to re-score each occupation for importance, performance and satisfaction. They were also invited to add new occupations if appropriate.

Both the Role Checklist and the Semantic Differential Self Concept aspects of the interview used scale systems. Robson (1993) describes this as requiring a response in the form of degree of agreement or disagreement. In the case of the Role Checklist the agreement options for Part I (whether they had a particular role in the past, currently or hope to in the future) were 'yes' or 'no' and Part II (the value they placed on each role) were 'not at all valuable', 'somewhat valuable' or 'very valuable'. In the case of the Semantic Differential Self Concept Scale it was level of agreement on a 7 point scale with opposite adjectives at each end of the scale.

The interview schedule was piloted with two individuals who were users of the service prior to the evaluation. It was considered important to pilot the interview with an individual with speech problems as it was intended to ensure that data could be collected from all participants including those with speech problems. The pilot interviews comprised the Canadian Occupational Performance Measure (COPM), Role Checklist and Semantic Differential Self-Concept Scale. The carer of the individual with speech problems was present at the interview. The individual without the speech problem completed all aspects of the interview without difficulty. The individual with speech problems required their carer to identify their normal occupations and those they carried out prior to the stroke. The individual themselves subsequently was able to rate the importance and performance aspects of those occupations. The carer occasionally assisted with aspects of the remainder of the interview. All aspects were completed despite the individuals' expressive difficulties. The most difficult aspect for the individual was the semi-structured open question initially part of the COPM. For the remainder he responded appropriately and appeared satisfied that an accurate representation of his view had been recorded. It was decided to continue to use the interview schedule for the study. It was acknowledged that individuals with both expressive and comprehension problems would rely on carers greatly for this aspect of data collection. However it was also acknowledged that if individuals just had expressive difficulties, and if a carer assisted with the initial aspect of data collection, the individual themselves could indicate their own ratings on the interview tools.

Each visit lasted approximately forty-five minutes. This allowed the researcher to introduce or reacquaint herself and the study as appropriate, to collect the questionnaires and confirm there were no difficulties in completing them or no missing data before commencing the structured interview. If a carer was present they were invited to stay if they wished but were requested not to respond on behalf of the individual unless there were comprehension difficulties. The carer's questionnaire was also collected during the interview. The interview for the first and second visits concluded with the researcher reminding the participant that she would visit again in six months and that as before they would receive a letter and questionnaire beforehand. At the end of the third visit the participants were thanked for their participation in the study.

6.6. Q METHOD

The users' views regarding the benefits of the service and those of the referring professionals, funding agencies and others were established by using the Q methodology. As outlined in Chapter 5, this is a method for the scientific study of human subjectivity and facilitates the quantification of qualitative data (McKeown & Thomas 1988). This method provided an opportunity for the users to have an active role in the evaluation, an important issue according to Martin (1986). The processes used for this study are outlined below. As indicated in Chapter 5, there are four stages to Q method. The first three – developing a sort, administering a pack and analysing the data are described here. The fourth stage, interpreting the factors is the finding which is reported in Chapter 8 and discussed in Chapter 9.

Developing the Q pack

Group interviews were carried out to generate statements of perceived benefits of the Cardiff Day Service. The groups consisted of representatives of the users of the service, their carers, volunteers, fund holders and those who referred clients to the service. Each group was asked what it thought the benefits of the service to be. Literature was also explored, especially that relating to the provision of day services and the service's own documentation which outlines its aims. In total 360 statements were initially generated. Stainton Rogers (1995) suggested that the initial pool of statements is typically around three times the size of the aimed-for final Q sort pack.

The 360 statements for the Day Service study were analysed and categorised. Statements were initially checked for duplication. All statements that described the processes involved in the Day Service, as opposed to the benefits gained, were removed. This procedure is supported by Martin (1986:94) who states that

> questions about the process of service, and particularly about the consumers' opinions of staff and intervention procedures, must be clearly separated from questions about the effects of the service as judged by the consumers. Positive feelings expressed about the efforts of staff to help can too easily appear to be positive assessment of results achieved; confusion of the inputs and outputs of service may be generated by gratitude, loyalty or personal regard for dedicated practitioners.

The categorisation process involved grouping statements of similar content together. The following are the content themes that emerged – respite for carers, social benefit, normalisation, psychological benefit, access to community services, support for developing skills, helping recovery, security, counselling, campaigning for rights and mutual support. Under each theme statements were combined and, if necessary, rephrased, to ensure that they were clear and easy to read while still relevant to the study. Care was taken at this reduction phase to ensure that the final statements were appropriate and applicable to the study, and comprehensive enough to include all relevant aspects of the study (Stainton Rogers, 1995). The Q sort pack prior to piloting contained 47 statements (Appendix G).

Administrating the Q sort

As stated in the previous section, the statement pack prior to piloting contained 47 statements. Piloting for this aspect of the study was undertaken in two phases. The first phase focused on the validity and clarity of the statements, and the second on the administration process. In the first phase, the 47 statements were sent in questionnaire format to eight individuals, two of whom were users of the service prior to the commencement of the evaluation, two were carers of service users, two were volunteers at the service, one was an information officer for the Stroke Association who referred potential users to the service and finally an independent researcher in stroke rehabilitation. All eight were returned; one was completed incorrectly and therefore not used. The respondents were invited to comment on the appropriateness of the statements in relation to perceptions of service benefits. They were invited to indicate their level of agreement with each statement, comment on wording, identify duplication of statements and comment on comprehensiveness (Appendix H). As a result of comments received (Appendix I) the changes were made to the statement pack. Incidences of duplication had been highlighted and therefore the pack was reduced further to 41 statements (Appendix J). In addition, comments raised in relation to ambiguous language were noted and some statements were re-phrased to ensure clear understanding.

Phase two of the pilot process involved three users and one carer. The carer had no difficulty understanding the task of sorting the statements and completed the sort in 15 minutes. Each of the users however struggled and became tired. Even those with communication difficulties understood the concept of indicating their level of agreement with the statements but had difficulty concentrating for the period it took to undertake the task. They also struggled to be negative or critical of the service and therefore had difficulty placing statements in the 'most disagree' category. In response to these difficulties the statement pack was reviewed and again reduced to include just 33 statements (Appendix K). In addition the parameter of agreement was changed so that instead of being from 'most agree' to 'most disagree' it went from 'most agree' to 'least agree'.

All Q sorts were administered by the research administrator. Each user conducted the Q sort close to the end of their six months attendance of the service. The research administrator conducted this approximately two weeks prior to their finishing at the service. In the case of the two users who had only attended for a short period, the research administrator conducted the sort at approximately the time they were due to finish the service. The non-users, that is the carers, volunteers and other key players conducted the sorts at times convenient to them over a 12 month period.

Analysing the data

The factor analysis for the Q method was carried out using a data inputting package (Qcom), which allows the entering of data in the distribution pattern format and SPSS into which the data is imported and factor analysis is conducted. When imported each participant is a variable rather than each statement. Factors were identified if the eigen value was one or greater (Wigger and Mrtek 1994). Principal Component Analysis was the extraction method used and Varimax with Kaiser Normalisation the rotation method used. Components that loaded above 0.6 in each factor were merged as long as they did not load more than 0.3 on other factors (Mrtek et al 1996). The interpretation of the factors is presented in Chapter 8 and discussed in Chapter 9.

6.7. ECONOMIC EVALUATION

The data collection for the economic analysis involved two processes. Firstly, data was collected regarding all activities available at the service, running costs, equipment, staffing and overhead costs. Three forms were developed in order to collect the data (Appendix L). The first form collated all the activities that occur at the Cardiff Day Service. Once this was collected a second form was used to identify the cost per each activity. This included collecting data on the costs of materials and equipment, staffing, transport and any additional costs. By estimating the number of users who would participate in each activity and the number of hours for the activity a cost per user per hour was computed. A third form was used to collate costs of running the service that were not related to specific activities. These included such things as salaries, rent for the room used by the service, volunteer costs, refreshments, transport and miscellaneous.

The Day Service Organisers inputted the data on the three forms which were then sent to the research administrator. During the process of the study there was a change of Day Service Organiser. This resulted in two sets of data being collected and merged. With the exception of the individuals' participation in activities sheets, both organisers presented data for a 12 month period, ensuring consistency.

The second process of data collection was via mapping the activity participation of eight users of the service during the evaluation period. The data was collected via a fourth form, which recorded an activity cost for the eight individual users. This enabled the collection of relevant data for each of their attendances during a six month period. What each individual did during each day of attendance was recorded in 15 minute units. Standard costs such as transport and attendance fee were also collected. The collection of data for the economic evaluation commenced after the other aspects of the evaluation. It depended on the Day Service Organiser and volunteers to input data. This required explanation and gaining their support. They were invited to complete the individual activity sheets for as many users in the evaluation as possible. However, they did not commence this process until 12 months into the evaluation. As a consequence the activity record for individual users was only collected for eight participants. As these eight were part of the evaluation, outcome data was collected in the form of the questionnaires and interviews for them.

6.8. ETHICAL CONSIDERATIONS

The population for this study was not receiving an NHS service nor were they attending the service as NHS patients. The Cardiff Day Service is funded and run by the voluntary agency, the Stroke Association. However the researcher wished to ensure that formal LREC approval was not required and therefore sent a copy of the proposal for the study for advice to the Bro Taf Health Authority Research Ethics Committee. The researcher was advised that the study did not need to be submitted for their approval (Appendix M). Although the study did not need to go through this formal process, the following ethical issues were considered and dealt with in the study.

Confidentiality

At all stages throughout the study the confidentiality of subjects was maintained. Each subject was given an identification number and this code was used in all stages of the data collection and analysis. Any identifying information was kept secure by the researcher and research administrator.

Benefits to participation

The greatest ethical consideration of this study was conducting an objective evaluation of a service already in existence and therefore current practice. It was considered unethical to withhold the opportunity to attend the service. However, there was the need to compare outcomes relating to attending the service with non-attendance. This situation informed the design of the study and resulted in the cross-over design outlined in Section 5.3. The use of this study design allowed individuals to both attend and not attend for a fixed period of time. Six months was established as an appropriate time frame as it allowed for benefits to be gained (although it is acknowledged that it may not be sufficient to gain maximum benefit). It also allowed the evaluation to be undertaken within a period of three years. This would not have been possible if attendance had been longer. A shorter attendance might have resulted in individuals not settling into the service and gaining benefit.

When an individual was referred to the service they were informed in writing that attendance would be for a maximum six month period. They were also informed that they might be invited to attend immediately or that they might have to wait six months before attending.

Throughout the study the researcher clearly indicated, both verbally and through the letters relating to the researcher's visits to each subject, that the results of the study would facilitate the planning of future services for young adults following a stroke. It was indicated that the subjects themselves may not benefit directly from their participation, but were assured that the data collected would enable the Stroke Association to gain an insight into the needs of this group and thus help with the refinement of current services and the development of future ones. Many of the participants indicated an awareness that information is available regarding stroke in younger populations. They expressed a willingness to contribute to the collection of this data in order to increase awareness and assist in the development of services.

Consent

All subjects were notified in writing of the forthcoming visit by the researcher. This was followed up by a phone call to confirm the visit. It was considered that consent had been given if the researcher's visit was confirmed. In addition if the questionnaire was completed or the individual was happy for the researcher to complete the questionnaire with them, it was considered that consent was given. This is supported by Seale and Barnard (1999:373) who state that

> it is not always necessary to obtain signed consent from respondents of self-administered questionnaires.

Harm

None of the procedures of this study were invasive and therefore there was no risk of harm. The researcher was aware that some of the questions required the identification of lost roles and occupations and could have led to participants becoming upset. If this occurred, the subjects were assured that they did not have to continue with the interview.

6.9. DATA ANALYSIS

The analysis process for the Q method aspect of the study has been described in Section 6.6. Data analysis for the other aspects of the evaluation has been carried out using SPSS (SPSS inc. 1998). All data was inputted to SPSS by the researcher. No analysis was conducted until the final pieces of data had been inputted.

Both descriptive and inferential statistics have been used. A p value of $p = 0.05$ or less was judged appropriate to identify statistically significant changes. Altman and Bland (1995) state that by convention a p value of greater than 0.05 is considered not significant. Both parametric and non-parametric tests were used depending on the type of data to be analysed. Wilcoxon test (z) and t-test (t) were used to compare same subjects at two different points (such as pre and post service). Friedman test (X^2) was used to compare Group C at three different points. Fishers' Exact Test was used when comparing Group A with Group B.

6.10. ISSUES OF RIGOUR

Reliability

The reliability of the individual tools used in the questionnaires and interviews was outlined in Chapter 5. This indicated that the questionnaire content had previously been tested and was reliable for use by postal self-completion method.

There was consistency with the interviews as the researcher conducted all of these. The research administrator administered all the user Q sorts again ensuring consistency. The research administrator also conducted all but one of the non-user Q sorts. The researcher administered this one sort to a key person from the Stroke Association as she had access to him while the research administrator did not.

The data collection for the economic evaluation was conducted by the Day Service Organiser in conjunction with a small number of volunteers. Explanation was given to them as to the data required. However, the researcher had to rely on them to record the data reliability.

Validity

According to Denscombe (1998:241), validity in terms of research data hinges around "whether or not the data reflect the truth, reflect reliability and cover the crucial matters". The validity of the questionnaires was based on selecting measures that would reflect possible outcomes from attending the service. This was informed by the aims of the service and by Stroke Association management personnel, the Day Service Organiser, volunteers and users prior to the commencement of the evaluation.

No data analysis was conducted during the evaluation period and therefore no changes were made to the service as a result of findings. One change that did occur related to a change in Day Service Organiser. The first organiser was in post for 19 months during the evaluation. She planned the programme for the service for 6 months beyond her leaving date. After a gap of three months the second Day Service Organiser was in post and remained in post for the remainder of the evaluation period. At appointment she was informed of the evaluation and the need for consistency. She continued to run the service along similar lines to that of the first organiser. It is possible that these changes affected the content of the service during the evaluation. However, as the two organisers were not in post for equal lengths of time, two comparable groups of users did not exist, and therefore it was not valid to make comparisons. The funders of both the service and the evaluation were not prepared to extend the evaluation in order that two groups could be established. This situation reflects what Rossi et al (1999) consider the challenges of evaluation where circumstances and activities of the service may change during the course of the evaluation.

The use of multi-methods (questionnaires, interviews, Q method and economic evaluation) in this study resulted in different kinds of data being produced on the same topic, allowing for corroboration. According to Denscombe (1998), this opportunity to corroborate findings enhances the validity of the data.

6.11. SUMMARY

This chapter has outlined how the multi-methods of data collection were carried out for this study. The data collected and subsequent analysis provide a breadth of information regarding the occupational functioning of adults aged 18 to 55 after stroke and the effects of attending the Cardiff Day Service. Issues such as ethical considerations and reliability and validity were also presented. The next chapter will report and discuss the characteristics of the population in this study. Chapters 8 and 9 report and discuss the findings of the evaluation component of this study.

CHAPTER 7

POST STROKE ABILITIES – RESULTS AND DISCUSSION

7. POST STROKE ABILITIES – RESULTS AND DISCUSSION

7.1 INTRODUCTION

This chapter presents the characteristics, problems and needs of the total population referred to the Cardiff Day Service during the study period, gathered from data collected by questionnaire and interview at Visit 1. Predominately descriptive and some inferential analysis have been conducted although complex analysis was not valid due to the relatively small size of the study group. The later half of the chapter discusses the findings.

7.2 RESULTS

7.2.1 Demographic details

The data collection process ensured a good response and resulted in little missing data. Twenty six individuals participated in this study. Table 1 shows some baseline data relating to all of the participants.

Table 1: Details of demographic characteristics of all participants

Characteristic	**Total n = 26**	**Characteristic**	**Total n = 26**
Age		**Sex**	
Mean	48	Men	15
Standard Deviation	7	Women	11
Median	50		
Range	34-55	**Barthel scores**	
No. 34 to 44 years	7 (27%)	Mean	17.5
No. 45 to 55 years	19 (73%)	Standard Deviation	2.3
		Median	17.5
		Range	12-20
Months since stroke		No. score ≤12	1 (4%)
Mean	21	No. score 13 – 16	7 (27%)
Standard Deviation	32.55	No score >16	18 (69%)
Median	5	**Body side affected**	
Range	1-141	Right	16 (62%)
0-12 months	16 (61%)	Left	10 (38%)
13-24 months	3 (12%)	**Speech affected**	
more than 24 months	7 (27%)	Yes	18 (69%)
		No	8 (31%)

The youngest individual referred to the service was 34 years old; however the majority (73%) were aged between 45 and 55 years. On average participants were referred to the service 21 months following their stroke. Although the time ranged from one month to over 11 years post-stroke, 16 (61%) were referred within a year of their stroke. For one individual it was over 7 years (91 months) since their stroke while for another it was over 11 years (141 months). There was no association between the time since stroke and age ($X^2=1.26$, df=2, p=0.531) or gender ($x^2=1.028$, df=2, p=0.598).

The Barthel ADL Index scores for the total group (mean=17.5, median=17.5) indicate a relatively high level of functioning among those referred (maximum possible is 20). Only one individual scored 12 or less indicating a high level of dependency while two thirds scored 17 or more. The individual who scored 12 was female, lived alone and had her stroke five months previously. The left side of her body had been affected by the stroke and speech was not. Although data was not collected about perceptual impairments, it is possible that these may have been present and may have contributed to her low Barthel score. However, this individual scored '0' for the mobility subscore of the EADL, suggesting in fact that severe physical impairment was present. Eight individuals scored 20, the maximum score for the Barthel ADL scale. Five (63%) were male and six (75%) were aged between 45 and 55 years. All except one had very recently had their stroke (in the previous three months). Two individuals (25%) had previously had a stroke, for six (75%) the stroke affected the right side of the body and seven (87.5%) reported their speech being affected. Their overall EADL scores ranged from 12 to 19 (22 is maximum) and seven of the eight (87.5%) regularly carried out seven or more leisure activities.

A higher proportion of men than women were referred to the service during the evaluation period. The majority of participants (16, 62%) had suffered a stroke affecting their right body side compared to 10 (38%) that had a stroke affecting their left side. Eighteen (69%), compared to 8 (31%) felt their speech was affected. For some, they did not have expressive or comprehension problems but said they were unable to concentrate on conversations, cope in a large group setting or had lost their confidence in social settings which for them indicated that their speech was affected. There was no association between the number of previous strokes individuals in the younger age group had compared with those aged 45 to 55 years (x^2 = 6.94, df=4, p=0.139). There was also no association between body side affected (Fishers Exact Test, p=1.00) for the two age groups.

Participants, when completing the questionnaires, were asked to indicate if they self-completed them or if they received assistance. Table 2 indicates that self-completion increased with time rising from 10 (38%) to 16 (64%). The help provided by others included an occupational therapy student, an occupational therapy technician, a social worker and Citizen Advice Bureaux. If the researcher found the questionnaire not completed when conducting the visit she offered to assist with its completion.

Table 2: Details of who completed participants' questionnaire

Completed by	Visit 1 (n = 26)	Visit 2 (n = 26)	Visit 3 (n = 25)*
Own	10 (39%)	14 (54%)	16 (64%)
Spouse	6 (23%)	5 (19%)	3 (12%)
Other relative	3 (12%)	4 (15%)	2 (8%)
Paid carer	1 (4%)	-	-
Other	2 (8%)	1 (4%)	1 (4%)
Researcher	4 (15%)	2 (8%)	3 (12%)

* One participant did not complete the questionnaire of visit 3

Living with a spouse was the most frequent home circumstance for those referred (Table 3). Three (12%) lived with their children. These children were mainly younger than 30 and could be categorised as young carers. There was no association between the home circumstances of those aged 34 to 44 years compared with the older group (x^2 =4.861, df=4, p=0.302).

Table 3: Details of home circumstances for participants

Circumstances	n = 26
Alone	6 (23%)
With spouse	11 (42%)
With own age friend/relative	4 (15%)
With children	3 (12%)
Supported accommodation	2 (8%)

Six individuals were living alone, and a trend towards an association was found between living alone and gender (Fisher's Exact Test, p=0.054) suggesting that individuals were more likely to be living alone if female. Five had had their stroke recently, within the previous six months and it was the first stroke for all. The range of Barthel ADL index scores was 12 to 20. Mobility levels also ranged from 0 to 5 (EADL) with half scoring 4 or 5 and the maximum score gained on the total EADL was 16 (out of 22). This profile of those living alone suggests that it is those with a range of abilities and not just those with high levels of mobility who are in the community living on their own. There was also an association found between living alone and higher social function scores of the SF36 instrument (x^2=17.55, df=7, p=0.014).

7.2.2 Social functioning

Social functioning was measured using the Extended Activities of Daily Living Scale (EADL). Table 4 shows the number and percentage of those able to carry out each task, the sub total scores for mobility, kitchen, domestic and leisure functioning as well as an overall score. The mean score for domestic functioning was lower than the other subscores (1.5). The total score range indicates that no participants were fully independent, the maximum score obtained by the group being 19, out of a possible 22.

Over half the individuals managed walking outside, however, only seven (27%) indicated that they could use public transport and just two could drive a car. Nineteen (73%) of individuals indicated that they could use the telephone, although 18 (69%) (see table 1) had reported that their speech was affected by their stroke. This would suggest that even if they lacked confidence, they could still conduct a conversation using the telephone.

There was no association between social functioning in the younger participants (34 to 44 years) and the older participants (45 to 55 years) when comparing mobility subscores (x^2=5.50, df=6,p=0.481), kitchen subscores (x^2=2.11,df=5,p=0.834), domestic subscores (x^2=7.57, df=5, p=0.181), leisure subscores (x^2=4.591, df=5, p=0.468) and total EADL scores (x^2=12.27, df=13, p=0.505). There were also no association between ability to perform in all individual items, subscores, overall EADL scores and gender except carrying a drink from room to room (Fisher's Exact Test, p=0.038).

Table 4: Details of abilities, subtotal and total scores for Extended ADL Scale

Scale	n = 26
Walk outside	17 (65%)
Climb stairs	16 (62%)
Get in/out car	22 (85%)
Walk on uneven ground	15 (58%)
Cross roads	15 (58%)
Use public transport	7 (27%)
Mobility subtotal Extended ADL	
Median	4
Range	0-6
Manage to feed self	24 (92%)
Make hot drink	21 (81%)
Carry drink from room to room	18 (69%)
Wash up	15(58%)
Make hot snack	13(50%)
Kitchen subtotal Extended ADL	
Median	4
Range	0-5
Manage own money	15 (58%)
Wash small items	9 (35%)
Housework	7 (27%)
Do shopping	10 (29%)
Full clothes wash	8 (31%)
Domestic subtotal Extended ADL	
Median	1.5
Range	0-5
Read papers	22 (85%)
Use telephone	19 (73%)
Write letters	12 (46%)
Go out socially	7 (27%)
Manage garden	1 (4%)
Drive a car	2 (8%)
Leisure subtotal Extended ADL	
Median	3
Range	0-5
Extended ADL Total Score	
Median	13.5
Range	3-19

7.2.3 Leisure

Participation in leisure activities in recent months was measured using the Nottingham Leisure Scale (NLS). Tables 5 and 6 show the level of participation in 36 activities.

Table 5: Details of numbers of participants taking part in different leisure activities either regularly or occasionally

Activity	Combined	Regularly	Occasionally
Watching TV	26 (100%)	19 (73%)	7 (27%)
Just sitting	24 (92%)	23 (88%)	1 (4%)
Read newspaper	24 (92%)	14 (54%)	10 (38%)
Listening to radio	23 (88%)	13 (50%)	10 (38%)
Visiting family/friends	20 (77%)	6 (23%)	14 (54%)
Daydreaming	19 (73%)	12 (46%)	7 (27%)
Walking	19 (73%)	8 (31%)	11 (42%)
Going to pubs	15 (58%)	1 (4%)	14 (545)
Eating out	12 (46%)	1 (4%)	11 (42%)
Read books	11 (42%)	4 (15%)	7 (27%)
Pleasure shopping	11 (42%)	1 (4%)	10 (38%)
Indoor games	10 (38%)	1 (4%)	9 (34%)
Caring for pets	9 (35%)	5 (19%)	4 (15%)
Cooking for pleasure	8 (31%)	1 (4%)	7 (27%)
Taking exercise	8 (31%)	3 (12%)	5 (19%)
Entertain at home	8 (31%)	0	8 (31%)
Singing	6 (23%)	0	6 (23%)
Gardening	6 (23%)	1 (4%)	5 (19%)
Attend sports event	6 (23%)	1 (4%)	5 (19%)
Going to plays	5 (19%)	0	5 (19%)
Church activities	5 (19%)	4 (15%)	1 (4%)
Meditation	5 (19%)	1 (4%)	4 (15%)
DIY	4 (15%)	1 (4%)	3 (12%)
Crafts	4 (15%)	0	4 (15%)
Going to parties	4 (15%)	0	4 (15%)
Volunteer work	4 (15%)	0	4 (15%)
Collecting things	3 (12%)	0	3 (12%)
Swimming	3 (12%)	2 (8%)	1 (4%)
Driving	3 (12%)	1 (4%)	2 (8%)
Activities at clubs	2 (8%)	1 (4%)	1 (4%)
Photography	2 (8%)	0	2 (8%)
Attend classes	1 (4%)	0	1 (4%)
Dancing	1 (4%)	0	1 (4%)
Sports	1 (4%)	0	1 (4%)
Bicycling	0	0	0
Fishing	0	0	0

The only activity all participants undertook was watching television, while most (92%) also indicated that they just sat and read newspapers. None of the participants went fishing or bicycling. The average number of activities each individual participated in was 11, although regular participation was restricted to 5 activities on average. There was no association between participating in activities regularly and being aged 34 to 44 or 45 to 55 years (x^2=12.27, df=8, p=0.139); being able to walk outside (x^2=3.31, df=8, p=0.913), gender (x^2=5.379, df=8, p=0.716) or if depressed (x^2=20.42, df=16, p=0.202). However, a relationship was found between being male and occasionally going to the pub (x^2=10.03, df=2, p=0.007).

Although the individuals participated in 34 of the 36 leisure activities identified in the NLS, ten of the activities are only participated in occasionally, that is, every few weeks or monthly. It is interesting to note that when responding to the EADL, two individuals indicated that they drove, while on the NLS one indicated driving regularly and two occasionally. More individuals reported reading the newspaper in the NLS than EADL (24 versus 22 respectively). It is not possible to compare other items of the scales as they do not ask about exactly the same activities, for example, 'managing the garden' (one individual in EADL) was obviously perceived differently from 'gardening for leisure' (one regularly and five occasionally in NLS).

Table 6: Details of the frequency of leisure activities from Nottingham Leisure Scale

		n = 26
Total no. of leisure activities carried out	Median	11.5
	Range	6-24
Activities carried out regularly		
	Median	5
	Range	1-10
Activities carried out occasionally		
	Median	7.5
	Range	2-17
Activities never carried out		
	Median	24.5
	Range	8-31

Fourteen individuals indicated that they regularly undertook five or more leisure activities. Seven were male (50%), two thirds (9, 64%) were in the 45 to 55 age bracket, while the majority (10, 71%) had had their stroke within the previous 12 months. Eleven of these individuals had not had a previous stroke (79%), five (36%) lived alone and the majority had high levels of independence, with 10 (71%) scoring between 17 and 20 on the Barthel ADL index. Of the fourteen, five were not depressed, while six were, as indicated by the Hospital Anxiety and Depression Scale. The scores for the remaining three suggested 'doubtful' depression.

7.2.4. Quality of life

The Short Form 36 was used to establish quality of life. Table 7a shows who responded positively to the frequencies of those individual items and 7b shows the eight subscores for the scale in addition to the Physical Health Capacity Score and Mental Health Capacity Score. As 'change in health' is nominal data, the median and range are presented. A third of the participants (12, 31%) consider their general health to be good or very good. Only four (16%) consider themselves able to walk a mile, although most (17, 65%) can manage a flight of stairs. All bar one individual (96%) felt limited in the kind of work activities they could do and had difficulty performing tasks while 24(93%) did not consider themselves to be full of life most of the time.

Table 7a: Details of responses to individual items of SF36

Scale	N=26	Scale	
General Health		**Less careful**	
Good/ Very good	12(31%)	No	5 (19%)
Health now		**Health interfere with activities**	
Somewhat better/ Much better	5(20%)	Slightly/ Not at all	4(16%)
Vigorous activities		**Bodily pain**	
Not limited at all	3 (12%)	Mild/ None	10(39%)
Moderate activities		**Pain interfere with activities**	
Limited a little/ Not limited at all	11(43%)	Slightly/ Not at all	10(39%)
Lifting groceries		**Full of life**	
Limited a little/ Not limited at all	10(39%)	Most of the time/ All of the time	2 (8%)
Several flights		**Nervous person**	
Limited a little/ Not limited at all	9(35%)	A little of the time/ None of the time	12(46%)
One flight		**Down in the dumps**	
Limited a little/Not limited at all	15(60%)	A little of the time/None of the time	5(20%)
Bending		**Calm and peaceful**	
Limited a little/Not limited at all	10(39%)	Most of the time/All of the time	3(12%)
Walk more than a mile		**Lot of energy**	
Limited a little/Not limited at all	4(16%)	Most of the time/All of the time	2(8%)
Walk half mile		**Downhearted**	
Limited a little/Not limited at all	11(43%)	Some of the time/A little of the time	10(39%)
Walk 100 yards		**Worn out**	
Limited a little/Not limited at all	17(65%)	Some of the time/ A little of the time	8(31%)
Bath self		**Happy person**	
Limited a little/Not limited at all	15(60%)	A good bit of the time/Most of the time	7 (27%)
Cut down time		**Feel tired**	
No	5 (19%)	Some of the time/A little of the time	7 (27%)
Accomplished less		**Limited social activities**	
No	2 (8%)	A little of the time/None of the time	3 (12%)
Limited kind of work		**Ill more easily**	
No	1 (4%)	Mostly false/ Definitely false	10(39%)
Difficulty performing		**Healthy as anyone**	
No	1 (4%)	Mostly true/ Definitely true	6(19%)
Cut down time		**Expect to get worse**	
No	7 (27%)	Mostly false Definitely false	8(31%)
Accomplished less		**Health is excellent**	
No	7 (27%)	Mostly true/ Definitely true	5 (19%)

Table 7b: Details of sub scores and capacity scores for Short Form 36 (SF36)

Scale	n= 26
Physical function	
Mean	26.15
Standard Deviation	23.42
Range	0-85
Role limitation due to physical problems	
Mean	8.65
Standard Deviation	21.15
Range	0-100
Role limitation due to emotional problems	
Mean	24.36
Standard Deviation	41.69
Range	0-100
Social functioning	
Mean	30.34
Standard Deviation	28.03
Range	0-100
Mental Health	
Mean	42.46
Standard Deviation	22.14
Range	0-80
Energy/vitality	
Mean	28.27
Standard Deviation	19.85
Range	0-70
Pain*	
Mean	51.85
Standard Deviation	29.61
Range	0-100
General Health Perception	
Mean	43.85
Standard Deviation	17.69
Range	10-80
Change in Health	
Median	25
Range	0 – 100
Physical Health Capacity Score	
Mean	32.5
Standard Deviation	8.23
Range	18.5-54.6
Mental Health Capacity Score	
Mean	33.1
Standard Deviation	11.5
Range	14.6-58.5

* Information missing for 2 participants

The mean score for 'role limitation due to physical problems' was the lowest of all items. Scores generally range from 30 and 60 with higher scores indicating better health (National Assembly for Wales, 1999).

7.2.5. Mood

The Hospital Anxiety and Depression Scale was used to measure mood. As can be seen from Table 8, over half of the participants had definite anxiety and depression. Although the range of scores spanned 20 points the median scores for both indicate a presence of both anxiety and depression.

Table 8: Details of anxiety and depression from Hospital Anxiety and Depression Scale

Scale	n=26	Scale	n=26
Anxiety Aspects		**Depression**	
Tense		**Enjoy things**	
Not at all	3 (12%)	Definitely as much	1 (4%)
From time to time	8 (31%)	Not quite as much	5 (19%)
A lot of the time	7 (26%)	Only a little	6 (23%)
Most of the time	8 (31%)	Hardly at all	14 (54%)
Frightened		**Laugh**	
Not at all	7 (27%)	As much as I always could	7 (26%)
A little but it doesn't worry me	5 (19%)	Mot quite so much now	8 (31%)
Yes but not too badly	6 (23%)	Definitely not so much now	8 (31%)
Very definitely and quite badly	8 (31%)	Not at all	3 (12%)
Worrying thoughts		**Feel cheerful**	
Only occasionally	4 (15%)	Most of the time	5 (19%)
From time to time	7 (27%)	Sometimes	10(38%)
A lot of the time	8 (31%)	Not often	8 (31%)
A great deal of the time	7 (27%)	Not at all	3 (12%)
Sit at ease		**Slowed down**	
Definitely	3 (12%)	Sometimes	1 (4%)
Usually	8 (31%)	Very often	10 (38%)
Not often	10 (38%)	Nearly all the time	15 (58%)
Not at all	5 (19%)	**Lost interest**	
Butterflies in stomach		Just as much care as ever	13 (50%)
Not at all	8 (30%)	Not quite as much care	3 (12%)
Occasionally	9 (35%)	Don't take as much care	8 (30%)
Quite often	2 (8%)	Definitely	2 (8%)
Very often	7 (27%)	**Look forward to things**	
Feel restless		As much as ever	4 (15%)
Not at all	3 (12%)	Rather less	8 (31%)
Not very much	7 (27%)	Definitely less	8 (31%)
Quite a lot	9 (34%)	Hardly at all	6 (23%)
Very much indeed	7 (27%)	**Enjoy a book**	
Feelings of panic		Often	7 (27%)
Not at all	5 (19%)	Sometimes	10 (39%)
Not very often	8 (31%)	Not often	4 (15%)
Quite often	6 (23%)	Very seldom	5 (19%)
Very often indeed	7 (27%)		
Anxiety score		**Depression score**	
Median	12.5	Median	11.5
Range	2 – 21	Range	1 – 20
No anxiety	10 (38%)	No depression	6 (23%)
Doubtful anxiety	2 (8%)	Doubtful depression	6 (23%)
Definite anxiety	14 (54%)	Definite depression	14 (54%)

Fourteen (54%) individuals indicated that they had definite depression; that is they scored 1 or more. Half (7) were male, most (10, 71%) were aged between 45 and 55 and eight (57%) had their stroke in the previous 12 months. Only two lived alone while 8 (57%) lived with a spouse. In contrast to those who were not depressed, only three individuals (21%) scored 20 on the Barthel scale and only four (29%) were regularly participating in seven or more leisure activities.

Of the six (23%) individuals who were not depressed (scored seven or less), four were male and two female; most (5, 83%) were aged between 45 and 55 and the same number had their stroke within the previous 12 months. Two were living alone, two were living in sheltered accommodation and of the remaining two, one lived with a spouse and the other with a relative. Five indicated that they had not had a previous stroke, had a stroke affecting their right side and four indicated that their speech was affected following the stroke. Five had a Barthel score of 20, suggesting a high level of functioning in activities of daily living, however their overall EADL scores did not suggest that they were fully independent in other activities, as their scores ranged from 12 to 17 (maximum score is 20). Most (4, 67%) were participating in seven or more leisure activities regularly, that is at least once a week.

There was no association between depression and age, gender, home circumstances or EADL scores. There was an association between depression and the social function score of the SF36 (x^2=25.3, df=14, p=0.031) and the mental health score (x^2=40.4, df=24, p=0.019). These suggest that a low depression score relates to a high social function score, whereas a high depression score relates to a low mental health score. However, this association was not found with the SF36 mental health capacity score.

7.2.6 Roles

The Role Checklist provides information on past, current and hopes for future roles as well as values placed on each role. Tables 9 and 10 show that the vast majority (92%) of participants had roles of worker, home maintainer, friend, family member and hobbyist prior to their stroke. The current role profile is low while many indicate a hope to resume some of these roles in the future. Being a friend and family member was very valuable to most 24 (92%) of the participants with 20 (77%) also indicating the value of their work role to them.

Table 9: Details of number of participants who indicated having specific present, past and future roles

	Past roles n / %	Present roles n / %	Future roles n / %
Student	9 (35%)	0	3 (12%)
Worker	24 (92%)	1 (4%)	20 (78%)
Volunteer	11 (42%)	0	11 (42%)
Carer	17(65%)	5 (19%)	14(54%)
Home maintainer	25 (96%)	11 (42%)	22 (85%)
Friend	26 (100%)	22 (85%)	25 (96%)
Family member	26 (100%)	20 (77%)	24 (92%)
Religious participant	11 (42%)	3 (12%)	9 (35%)
Active hobby	24 (92%)	4 (15%)	20 (77%)
Participant in organisations	13 (50%)	3 (12%)	8(31%)

There were no gender differences in those conducting present roles, however the individual who returned to work was male.

Table 10: Value placed on each role by participants

Role	Very valuable	Somewhat valuable	Not very valuable
Student	1 (4%)	1 (4%)	24 (92%)
Worker	20 (77%)	4 (15%)	2 (8%)
Volunteer	6 (23%)	6 (23%)	14 (54%)
Carer	11 (42%)	10 (39%)	5 (19%)
Home maintainer	18 (70%)	8 (30%)	0
Friend	24 (92%)	0	2 (8%)
Family member	24 (92%)	1 (4%)	1 (4%)
Religious participant	4 (15%)	6 (23%)	16 (62%)
Active hobby	16 (62%)	9 (34%)	1 (4%)
Participant in organisations	6 (23%)	5 (19%)	15 (58%)

7.2.7. Occupations

The Canadian Occupational Performance Measure was used to establish problems experienced by the participants. All individuals were invited to identify problems they experienced in the areas of self-care, productivity and leisure. As indicated by Table 11, the area where most occupational problems were identified was self care with 84 problems identified. In total, 77 productivity problems were identified and the 26 participants identified 81 leisure problems. When identifying the problems, participants indicated out of ten how important the problems were to them, 10 being extremely important. Of the 84 self care problems 61 (73%) were rated eight or more for importance. Of the 77 productivity problems 60 (78%) were rated eight or more for importance and of the 81 leisure problems 69 (85%) were rated eight or more for importance.

Table 11: Details of total numbers and importance ratings of self-care, productivity and leisure problems experienced.

	n = 26		n = 26		n = 26
Self-care		**Productivity**		**Leisure**	
Total no. of problems	84	Total no. of problems	77	Total no. of problems	81
Problems rated 8 or more	61 (73%)	Problems rated 8 or more	60 (78%)	Problems rated 8 or more	69 (85%)
Problems each		Problems each		Problems each	
Median	3.5	Median	3	Median	3
Range	0-9	Range	0-9	Range	1-7

Tables 12a, 12b and 12c outline both the range of occupations under the headings self-care, leisure and productivity that were identified as problems and the number of participants who identified them as problems. Participants identified problems under each of the three headings and the problems were recorded under the category they perceived them to be; some therefore considered shopping to be self-care, whilst others considered it productivity.

Table 12a : Details of number of participants who identified specific self-care problems

Self-care occupations	Total
Shopping ***	10
Dressing**	9
walking outside***	9
bathing**	8
showering*	6
using public transport**	8
in/out bath*	5
walking far**	4
cooking ***	4
get up stairs**	4
managing money**	2
in/out bed***	2
driving***	2
getting out/about*	2
doing/washing hair	2
washing self	2
getting lost if out alone**	2
going to town	1
shoe laces***	1
washing clothes***	1
hoovering	1
walking fast	1

*Up to 50% of participants rated this 8 or more out of 10 for importance
** 51% - 75% of participants rated this 8 or more out of 10 for importance
*** 76% - 100% of participants rated this 8 or more out of 10 for importance

The most common problems identified in self care were shopping (10), dressing (9) and walking outside (9). In addition, according to the participants for whom shopping, walking outside, cooking, getting in and out of bed, driving, doing up shoe laces and washing clothes were problems, 75% to 100% rated these as very important problems to them.

Table 12b: Details of number of participants who identified specific productivity activities as problems

Productivity occupations	Total
previous job***	19
cooking**	9
DIY***	7
driving***	6
laundering***	5
household jobs*	5
hoovering*	5
cleaning house	3
shopping	3
using public transport**	3
ironing***	2
gardening*	2
committee activities***	2
managing club***	2
giving lectures***	1
cleaning windows***	1
charity activities***	1
writing***	1
managing finances***	1
A level English	1
carrying hot drink	1

*Up to 50% of participants rated this 8 or more out of 10 for importance
** 51% - 75% of participants rated this 8 or more out of 10 for importance
*** 76% - 100% of participants rated this 8 or more out of 10 for importance

The most common productivity problems identified (Table 12b) were conducting their previous job (19), cooking (9) and DIY (7). Twelve of the 21 productivity activities that were identified as problems were considered by 75% - 100% of the participants to be very important. The most common leisure problems (Table 12c) were reading (11), socialising (7) and going for a drink (5). In total 38 activities were identified as previous leisure occupations by the participants indicating the breadth of variety in leisure activities they previously engaged in.

Table 12c: Details of number of participants who identified specific leisure activities as problems

Leisure occupations	Total	Leisure occupations	Total
reading***	11	holding long conversations***	1
socialising**	7	attending functions***	1
going for a drink*	5	sewing	1
visiting friends/family***	4	travelling***	1
gardening***	4	bingo***	1
watching sport**	4	dancing***	1
swimming***	3	taking children to park***	1
watching films/TV***	3	playing cards***	1
knitting**	3	snooker***	1
walking/lookingafter dog***	3	keep fit classes***	1
fishing*	3	holidays***	1
bowls/bowling*	2	weightlifting***	1
walking***	2	writing***	1
driving***	2	golf***	1
going for a meal	2	aquarium	1
caravanning*	2	baking	1
rugby	2	making models	1
photography*	2	cycling***	1
crosswords	2	playing football	1

*Up to 50% of participants rated this 8 or more out of 10 for importance
** 51% - 75% " " " " " "
*** 76% - 100% " " " " " "

Tables 12a, 12b and 12c illustrate the breadth of occupations individuals previously carried out and also how they are perceived. For two individuals gardening was seen as work or productivity, while for another two it was considered a leisure occupation. Two individuals considered driving as self-care, six as productivity and two as leisure. Regardless of the category into which it was allocated, 75%-100% of the participants rated driving as very important.

7.2.8 Self-concept

The Differential Self-concept Scale was used to measure self concept. Table 13 shows the median total score was 70 (range 40 – 124) which indicates a negative self concept. (According to Kersten (1990) a score of less than 80 indicates a negative self concept). Feeling friendly was positive (median = 6.5) while feeling satisfied, attractive and self-confident scored lowest (median = 2). Nine individuals scored 80 or more suggesting a postitive self-concept. Two thirds (6) were male, had had their stroke in the previous 12 months, while most (7, 78%) were aged 45 to 55 years, did not live alone and had a high level of independence, scoring between 17 and 20 on the Barthel ADL index, although none scored very highly on the EADL scale, the maximum score being 16 out of 22. Eight of the nine participated in nine or more leisure activities regularly. In addition, seven had no anxiety, while two had definite depression as indicated by the Hospital Anxiety and Depression scale.

Table 13: Details of self-concept

Adjective	Score	Adjective	Score
Interested		**Unaggressive**	
Median	4	Median	5.5
Range	1 – 7	Range	1 – 7
Happy		**Calm**	
Median	3	Median	3
Range	1 – 7	Range	1 – 7
In control		**Caring**	
Median	3	Median	5
Range	1 – 7	Range	1 – 7
Relaxed		**Capable**	
Median	3	Median	4
Range	1 – 7	Range	1 – 7
Satisfied		**Independent**	
Median	2	Median	3.5
Range	1 – 7	Range	1 – 7
Attractive		**Active**	
Median	2	Median	2.5
Range	1 – 5	Range	1 – 7
Hopeful		**Co-operative**	
Median	4	Median	4
Range	1 – 7	Range	1 – 7
Self-confident		**Talkative**	
Median	2	Median	4
Range	1 – 7	Range	1 – 7
Stable		**Friendly**	
Median	4	Median	6.5
Range	1 – 7	Range	1 – 7
Of value		**Patient**	
Median	2.5	Median	3
Range	1 – 7	Range	1 – 7
		Total score	
		Median	70
		Range	40 - 124

7.2.9. SUMMARY

This section presented data relating to the 26 participants in this study. On referral to the Cardiff Day Service, the average age of the participants was 48 and 16 (61%) had their stroke within the previous 12 months. They were not fully independent in activities of daily living and most participated in quiet leisure activities such as watching television or just sitting. The average number of leisure activities they carried out regularly was five. Their quality of life scores were low and over 50% had both anxiety and depression. Few had retained the range of roles they had prior to the stroke with most considering work, family, friend, home maintainer and hobbyist as valuable roles. They identified a range of self-care, productivity and leisure occupations which were of importance to them but which they had difficulty in performing. Although they presented as feeling friendly overall the average self-concept scores indicated a negative self-concept.

7.3. DISCUSSION

7.3.1 Characteristics

The population for this study included all individuals referred to the Cardiff Day Service during a 21 month period. Their ages reflect the general incidence of stroke; that is, it increases with age (Bevan et al, 1990, Birkett,1996). No individuals aged 18 to 33 were referred to the service, seven aged 34 to 44 and 19 aged 45 to 55 years. Although measures for sensori-motor, perceptual and speech impairments were not carried out in this study, the participants reported a larger proportion (16,62%) having left CVA, right body side affected and 18 (69%) reported that their speech was affected. This finding is similar to that of the Stroke Association Survey (1996) where 38% of 230 participants said that they could not communicate adequately and a further 30% said they could not communicate well. Another similarity with the Stroke Association survey (1996) is a higher incidence of stroke in men. Both their survey and this study found 58% were men.

The majority of participants (16, 61%) had their stroke within the previous 12 months. Some individuals may still have been recovering spontaneously from their stroke which, according to Freemantle et al (1992) and Bogousslavsky et al (1998), is most rapid in the first three months, but can continue to occur for up to a year post stroke. The findings of this study suggest that mobility was affected, although two thirds (60%) could still manage to climb a flight of steps, but only 4 (16%) could walk a mile or more.

Only a quarter of the individuals (6, 23%), were living on their own. The remainder lived with a spouse, friend or relative of similar age or with their children, while two lived in sheltered accommodation. Those living alone were more likely to be female and to have higher social function scores than those living with others.

The incidence of depression post stroke has been well documented in stroke literature for two decades (Feibel & Springer 1982, Lipsey et al 1984, Pound et al 1998, Watkins at al 2001). The findings of this study are consistent with other studies, as over 50% of participants were suffering from depression and anxiety, as the median scores were greater than 11, a score that reflects definite cases. According to Watkins et al (2001) depression impacts on regaining a normal lifestyle. The findings of this study suggest that the absence of depression is associated with increased social functioning, however the score for social functioning (SF36) for 50% of those not depressed was still low at 44 (out of 100). With this population, no association was found between gender and depression, unlike Angeleri et al's (1993) study, where they found a greater incidence of depression post stroke in women. Their population had had their stroke more than a year previously. Van de Wey (1999) in a study in the Netherlands of 85 individuals (mean age 61 years) post stroke found no relationship between sex, age or presence of a partner and depression. He found that depression is associated with increased disability following stroke. No such association was found it this study.

A negative sense of self was an additional characteristic of these participants, with 16 (62%) scoring less than 80 on the self-concept scale. This is similar to Brinkman and Hoskins (1979). Ellis-Hill and Horn (2000) in their UK study of 26 individuals post stroke (mean age 71.4 years) found that the participants reported a negative sense of self and reduced social activity.

According to Kielhofner (1985), Creek (1997) and Christiansen and Baum (1997) roles define who a person is and are recognisable positions in society which give status. Roles also provide structure and purpose, The roles most individuals had were as friends (22, 85%) and family member (20, 77%). Most did not value the student role (24, 92%), although they indicated that they might take up this role in the future. Over half did not value being a volunteer, religious participant or a participant in organisations. However, 11 (42%) considered they might undertake the role of volunteer in the future. Sixteen hoped to take up an active hobby role in the future. Despite these wishes it could be suggested that the participants in this study lacked identity and purpose to everyday life. Their lack of work role is discussed in the next section (7.3.2. Problems).

The leisure activities participated in by this group were similar to those participated in by adults without disability (Edginton et al 1995). Although not a recent study, Cheek and Burch in 1976 reported that 88% watch TV (100% in this study), 86% visit family and friends (vs 77%) and 90% read a newspaper (vs 92%). The inability to drive may be a contributory factor to participating in activities. Being unable to drive was rated as very important on the COPM by those who identified it as a problem. Some considered driving as leisure, while others considered it self-care, perhaps an essential to basic life, other as productivity, perhaps as a role they previously undertook as driving others where they need to go. Lister (1999) in a small phenomenological study in Australia of three individuals aged 70 post stroke found that loss of driving resulted directly in an altered lifestyle, feelings of loss of control and loss of independence. The participants' experiences reflected great variety in the accessibility and availability of transport alternatives.

7.3.2. Problems

The Canadian Occupational Performance Measure identified problems in occupational performance areas for the study population. Between the 26 participants they identified 84 self-care, 77 productivity and 81 leisure problems. The percentage of these problems that were rated as very important (rate of 8 or more) was 73% of self-care, 78% of productivity and 85% of leisure problems.

The participants in this study had a median Barthel Activities of Daily Living (ADL) score of 17.5. This indicates a good level of functional ability (maximum possible score is 20). This level of functioning reflects the criteria for attending the service, in particular the criteria that users must be independent as regards to toilet use. By fitting this criterion an individual would have the ability to transfer safely and have a level of independent mobility which may include wheelchair mobility. The fact that participants had this level of ability is also reflected in the mobility sub-score of the EADL scale; the median is 4 (maximum is 6). However, participants' physical function score on the SF36 indicates a much lower level of ability compared to the normal population. The mean score was 26.15 whereas the mean score for normal population based on an American study aged 33 to 45 years was 89.7 (n=503) and for those aged 45 to 54 years was 84.6 (n=338) (Ware et al 1993). A more recent finding in a South Wales population of the Welsh Health Survey (aged 18 to 75+)

indicated a mean score of 77.8 (n=6785) (National Assembly for Wales 1999). This substantial reduction in the level of functioning and the fact that self care problems were identified by all participants indicates a gap between levels of physical function and being independent in all activities of daily living. Although participants may not fully recover in terms of motor function, individuals can be enabled to be independent through providing adaptive equipment or by being taught new ways to do activities.

Both the Canadian Occupational Performance Measure and the Extended Activity of Daily Living identified participants' levels of dependency. The COPM also enabled individuals to identify what occupations were most important to them and which they wanted to carry out independently. Shopping, dressing and walking outside were the most common self-care problems identified.

Occupations which came under the umbrella of productivity, include employment, volunteer work, participating in organisations and home maintenance activities. In total, two individuals of the 26 indicated they had not had a work role in the past, only one had returned to work and 20 (78%) wished to return to work. The majority (24, 92%) considered the work role to be valuable with most suggesting it to be very valuable to them. This issue is important for the participants judging by their value rating of the role and the importance rating they gave to work via the Canadian Occupational Performance Measure. As individuals under the age of 55 years they do not have the opportunity to earn an income, to make social contacts, have status and structure in their lives, all products of work according to Marmot and Feeney (1996), Yuill and MacMillan (1998) and Matheson (2001). The other findings of this study may have an impact on returning to work such as poor self-concept and the presence of depression. Warlow et al (1998) and Kittner (1998) suggest that the nature of the individual's previous employment, residual impairments and disabilities, the person's own wishes and social and workplace support were important factors for returning to work. This study did not identify the nature of previous employment or workplace support but the data collected does suggest individuals do wish to return to work, therefore their residual impairments such as low mood may have effected their return to work.

The participants of this study are not alone in wanting to return to work however the Stroke Association (!996) and Jonkman et al (1998) also found a small number returned to work. A recent study undertaken by Bryan et al (2002) surveyed 3000 stroke survivors (under 55 those who were working reported statistically significantly fewer unmet needs than those who no longer worked.

7.4 SUMMARY

This chapter has outlined the characteristics, problems and needs of 26 individuals aged 34 to 55 who have had a stroke and who are living in the community. These findings indicate that the majority had recently had their stroke; they had difficulty in performing a range of self-care, leisure and productivity occupations; they had a negative sense of self and most were depressed. The findings suggest that these individuals have several needs including the need for an individual assessment of their problems and needs, provision of intervention for both residual problems following their stroke such as depression and poor mobility but also intervention that helps them to overcome the problems they encounter with self-care, productivity and leisure activities. The next chapter will present the findings of the service evaluation of the Cardiff Day Service and will identify if this has addressed their needs.

CHAPTER 8

SERVICE EVALUATION – RESULTS

8. SERVICE EVALUATION - RESULTS

This chapter reports the findings of the evaluation. It is divided into three sections. The first section presents the findings of the multi-method evaluation using both descriptive and inferential statistics. It presents pre and post service data, control phase data for both groups, findings from the Q methodology and the economic evaluation. The second section presents the findings from the carers' questionnaires and the final section reports on Group C – those individuals who during the period of the evaluation were referred to the service but who chose not to attend it.

8.1 DAY SERVICE ATTENDANCE

This section of the results chapter presents the comparisons of functioning pre and post service and during the control phase, the findings from the Q method and economic evaluation.

8.1.1 Background data

Group allocation

As previously indicated, 26 participants were recruited to this study. On referral each was allocated randomly to either Group A (14) or Group B (12). Of the 14 in Group A, two did not attend the service and therefore were transferred into Group C. Of the remaining 12 participants in Group A, three were unable to attend the service at the time of referral due to health reasons. Consideration was given to removing these individuals from the evaluation. However, due to the small sample size that option was not desirable. It was decided to retain them in the study. If they did not start attendance at the service within six weeks of their start date they were offered the opportunity to commence in six months time and they joined Group B. Three individuals took this opportunity, resulting in nine of the original 14 remaining in Group A. Of the 12 participants allocated to Group B, five chose not to attend the service, and thus joined Group C. The remaining seven attended the service six months after referral with the three participants from Group A who transferred into Group B, resulting in a total of 10 participants in Group B.

Table 14 shows there were no differences between the groups at referral point for age gender, time since stroke, Barthel ADL Index scores or effects of the stroke. It shows the breakdown of the demographic details for Groups A and B. This suggests that despite reallocating three individuals into Group B, the two groups remain similar with no statistically significant differences between them. The demographic details for Group C are presented later in Section 8.3 of this chapter.

Table 14: Details of demographic characteristics at referral

Characteristic	Group A n = 9	Group B n = 10	Comparison	
Age				
Mean	49	46	95% C I of difference	t = 0.990
Standard Deviation	6	7	-3.48, 9.63	p = 0.336
Median	51	48		
Range	39 –55	34 – 55		
Sex				
Men	6	7	Fisher's test	p = 1.000
Women	3	3		
Months since stroke				
Mean	34	12	95% of C I of difference	t = 1.324
Standard Deviation	49	17	-12.89, 56.31	p = 0.203
Median	14	5		
Range	2 –141	1 – 53		
Barthel scores				
Mean	18	17	z = -0.993,	p = 0.356
Standard Deviation	1.8	2.3		
Median	18	17		
Range	15 –20	12 – 20		
Body side affected				
Right	4 (44%)	7 (70%)	Fisher's test	p = 0.370
Left	5 (56%)	3 (30%)		
Speech affected				
Yes	4 (44%)	8 (80%)	Fisher's test	p = 0.170
No	5 (56%)	2 (20%)		

Researcher blindness

As it was the administrator who dealt with randomisation process the researcher was blind to the group allocations including the changes of allocation. However it was possible that during visits the participants would indicate which group they were in. After each visit the researcher indicated if she was aware which group the participant was in. She did not check data from previous visits six months earlier. She was unaware of group allocations for all individuals at first visit. However, she was aware of group allocation for 13 (49%) of participants at visit 2 and 8(32%) at visit 3.

8.1.2 Pre and post-service abilities

The data presented in this section relates to the abilities of users (those in Groups A and B) in terms of social function, leisure activities, quality of life, mood, valued roles, occupations and self-concept. This relates to the abilities of the users prior to attending the service for six months and their abilities at the end of that period. For those in Group A, their pre-service data was that collected at the first visit and for Group B it was that collected at Visit 2. The post-service data for Group A was collected at Visit 2 and for Group B at Visit 3 (see Figure 1, Chapter 6). Data from the questionnaires is presented first, followed by data from the interviews.

8.1.2.1. Questionnaires

The data collected via the questionnaires related to social function, leisure, quality of life, mood and other services accessed.

Social function

The Extended Activities of Daily Living Scale (EADL) was used to measure social function. Table 15 shows the subtotal scores and total EADL score pre and post-service. There was a statistically significant improvement ($p = 0.008$) in leisure ability following attendance at the service. The average (median) mobility and domestic subscores remained the same and the kitchen subscore decreased. The average (median) total score of EADL pre-service was 10 (out of 22) and 12 at post-service. This is not a statistically significant change.

Table 15: Details of subtotal and total scores for Extended ADL Scale

Scale	Pre-Service (n = 19)	Post-Service (n = 19)	Comparison*
Mobility subtotal Extended ADL	4	4	z = -0.479
Median	1-6	1-6	p = 0.632
Range			
Kitchen subtotal Extended ADL	4	3	z = -0.086
Median	0-5	0-5	p = 0.931
Range			
Domestic subtotal Extended ADL	1	1	z = -0.096
Median	0-5	0-5	p = 0.942
Range			
Leisure subtotal Extended ADL	2	3	z = -2.652
Median	0-5	1-5	p = 0.008
Range			
Extended ADL Total Score	10	12	z = -0.884
Median	4-18	4-19	p = 0.377
Range			

* Wicoxon test

Leisure

Both the Extended Activities of Daily Living Scale and the Nottingham Leisure Scale were used to identify the leisure activities of users pre and post-service. Table 16 shows a statistically significant change with users doing more leisure activities after attending the service. Further analysis has been carried out to show the change in the frequency of participation in leisure activities.

Table 16: Details of the frequency of leisure activities from Nottingham Leisure Scale

	Pre-Service (n = 19)	Post-Service (n = 19)	Comparison*
Total no of leisure activities			
carried out Median	10	15	z = -2.305
Range	7-24	8-23	p = 0.021
Activities carried out regularly			
Median	5	6	z = -2.410
Range	1-13	3-14	p = 0.016
Activities carried out occasionally			
Median	6	8	z = -1.038
Range	3-17	2-19	p = 0.299
Activities never carried out			
Median	27	22	z = -2.305
Range	13-30	14-29	p = 0.021

* Wilcoxon test

By attending the service, users increased the total number of leisure activities they participated in significantly (z=-2.305, p=0.021). They also significantly increased the activities they did regularly (z=-2.410, p=0.016) and there was a reduction in the number of activities they never carried out (z=-2.305, p=0.021). There was not a statistically significant finding on the activities carried out occasionally. Table 17 outlines the numbers of users participating in activities post-service in relation to pre-service.

Table 17: Details of numbers of users and changes in number of users participating in different leisure activities

Activity	Pre-service (n = 19)	Post-service (n = 19)
Watching TV	19	same
Just sitting	17	increase by 1
Daydreaming	16	same
Listening to radio	16	increase by 2
Visiting family/friends	15	increase by 1
Walking	15	increase by 2
Read newspaper	14	increase by 4
Going to pubs	11	decrease by 1
Indoor games	9	same
Eating out	9	increase by 4
Read books	6	increase by 4
Taking exercise	6	increase by 2
Pleasure shopping	6	increase by 2
Entertain at home	6	decrease by 2
Singing	5	same
Caring for pets	5	decrease by 1
Cooking for pleasure	4	same
Gardening	4	decrease by 1
Activities at clubs	4	increase by 2
Going to plays	4	same
Church activities	3	same
Meditation	3	increase by 4
DIY	3	increase by 2
Crafts	2	increase by 1
Attend sports event	2	increase by 2
Attend classes	2	decrease by 1
Collecting things	2	increase by 3
Going to parties	2	increase by 2
Swimming	1	increase by 4
Volunteer work	1	increase by 3
Dancing	1	same
Photography	1	increase by 5
Fishing	1	increase by 1
Driving	1	increase by 2
Sports	1	increase by 2
Bicycling	0	same

Of the 36 activities in the Nottingham Leisure Scale, the number of users participating in swimming and photography have statistically significantly increased post stroke (p=0.046 and p=0.025 respectively) and there was a trend towards a significant finding for collecting things and volunteer work (both p = 0.083). Users' participation in 22 of the 36 activities increased post-service, participation in nine of the activities stayed the same, and in five of the activities the numbers participating decreased.

Quality of life

The SF36 was used to measure quality of life (Table 18).

Table 18: Details of sub scores and capacity scores for Short Form 36 (SF36)

Scale	Pre-service	Post-service	95% confidence interval of difference	Comparison
Physical function				
Mean	28.7	31.6	-15.4, 9.63	t = -0.485
Standard Deviation	23.3	19.7		p = 0.633
Role limitation due to physical problems*				
Mean	9.7	11.1	-14.5, 11.7	t = -0.223
Standard Deviation	21.2	21.4		p = 0.826
Role limitation due to emotional problems*				
Mean	20.3	20.3	-24.1, 24.1	t = 0.000
Standard Deviation	36.4	36.4		p = 1.000
Social functioning				
Mean	28.0	40.3	-25.3, 0.70	t = -1.987
Standard Deviation	23.2	29.7		p = 0.062
Mental Health				
Mean	42.1	50.1	-22.9, 6.94	t = -1.124
Standard Deviation	24.0	22.7		p = 0.276
Energy/vitality **				
Mean	39.0	33.8	-10.8, 21.4	t = 0.701
Standard Deviation	18.9	19.7		p = 0.494
Pain***				
Mean	48.4	44.4	-4.18, 12.8	t = 1.072
Standard Deviation	29.8	26.1		p = 0.299
General Health Perception				
Mean	46.0	48.9	-15.2, 9.48	t = -0.491
Standard Deviation	20.2	21.1		p = 0.629
Change in Health				
Median	25	50		z = -1.766
Range	0-100	25-100		p = 0.077
Physical Health Capacity Score				
Mean	33.8	33.0	-2.81, 4.29	t = 0.442
Standard Deviation	5.9	8.1		p = 0.664
Mental Health Capacity Score				
Mean	33.5	35.2	-7.38, 4.11	t = -0.604
Standard Deviation	10.5	11.8		p = 0.555

* information missing for one person post-stroke

** information missing for three people pre-service

*** information missing for one person pre-service

When comparing pre and post-service mean and median scores using the t-test and Wilcoxon, the average score for role limitation due to emotional problems remained the same pre and post-service. The scores for physical function, social function, role limitation due to physical problems, mental health, general health perception and change in health increased, showing improvement by post-service. However only the social function and change in health improved, although not significantly (p=0.062, p=0.07 respectively). This indicates that following attending the service users perceived their social function to have improved and their health to have improved from what it was a year previously. The average scores for energy and vitality and pain decreased indicating a decrease in levels of energy and increase in pain. These changes are not statistically significant.

Mood

Mood was measured using the Hospital Anxiety and Depression Scale. As can be seen in Table 19, the average (median) anxiety score was 13 pre-service and 12 post-service. The anxiety depression score was 13 pre-service and 11 post-service. Although there is a decrease in both cases this is not statistically significant. According to the authors of the Hospital Anxiety and Depression Scale scores of 11 or above indicate definite cases of anxiety and/or depression.

Table 19: Details of anxiety & depression from Hospital Anxiety & Depression Scale

Scale	**Pre-Service (n = 19)**	**Post-Service (n = 19)**	**Comparison**
Anxiety			
Median	13	12	z = -0.590
Range	2-20	3-20	p = 0.555
No anxiety	8	5	
Doubtful anxiety	1	4	
Definite anxiety	10	10	
Depression			
Median	13	11	z = -1.542
Range	1-20	2-21	p = 0.123
No depression	3	4	
Doubtful depression	3	5	
Definite depression	13	10	

Other Services

While participating in the evaluation, participants had access to other services. Data was collected on services used via the Visit 3 questionnaire. Table 20 shows that the family support worker and social worker were most frequently accessed by those in Group A while also for Group B the social worker was most frequently accessed along with stroke clubs. When asked to identify any other services used a range of additional services were identified and mainly accessed by Group B.

Table 20: Details of other services used during the evaluation

Service	Group A	Group B	Comparison*
Family Support Worker	3	4	p = 1.000
Stroke Clubs	2	5	p = 0.367
Dysphagic Support Group	1	1	p = 1.000
Speech Therapy	1	1	p = 1.000
Occupational Therapy	2	2	p = 1.000
Physiotherapy	0	4	p = 0.103
District Nurse	0	2	p = 0.477
Health Visitor	0	0	-
Chiropodist	2	2	p = 1.000
Home Care	1	3	p = 0.603
Meals on Wheels	1	1	p = 1.000
Social Worker	3	6	p = 0.637
Highfields Day Centre	1	2	p = 1.000
Others include:			
Headway Day Group	0	1	
Mental Health Day Care	-	1	
Community Psychiatric Nurse	1	1	
Community Mental Health Team	0	1	
Health Care Assistant	0	1	

*Fisher's Exact test used

8.1.2.2. Interviews

The data collected via the interviews related to roles, occupations and self-concept.

Roles

Users, using the Role Checklist, were invited pre and post-service to outline their previous roles, their current roles and roles they hoped to have in the future. Table 21 outlines the number of past, present and future roles as indicated by the users.

Table 21: Details of number of roles users identified using Role Checklist

	Pre-Service	Post-Service	Comparison
Past Roles			
Median	7	8	z = -1.748
Range	5-7	5-10	p = 0.080
Present Roles			
Median	3	3	z = -0.960
Range	0-5	0-7	p = 0.337
Future Roles			
Median	6	6	z = -0.203
Range	3-8	3-10	p = 0.839

Data missing for one person throughout

There was no significant difference between the number of roles users had pre or post service. Prior to their stroke all users had the roles of worker, home maintainer and friend as shown in Table 22. Attending the service did not have the effect of increasing the number of new roles to a significant level. What was significant was the difference between their previous (past) roles, their current and their hope for future roles. At post-service users indicated that the average number of roles they had in the past was 8, whereas their current average was 3 (z=-3.742, p=0.001). This current average was much smaller than the number of roles they would like to have in the future (median=6), another statistically significant finding (z=-3.542, p=0.001). In addition to there being no significant difference to the number of roles users had through attending the service there was no significant change in the type of roles they had. The numbers of users having the role of volunteer, carer, home maintainer, family member and hobbyist only increased by one, while the numbers of users with the role of religious participant and participant in organisations increased by two. These increases are not statistically significant thus it is not possible to conclude that attending the service had any impact on them. Although all (18, 100%) of the users had a work role prior to their stroke, 13 (72%) hoped to resume a work role in the future. However only one had returned to work.

Table 22: Details of number of users who indicated having specific present, past and future roles

	Past roles (pre-service) n / %	Present roles (pre-service) n / %	Present roles (post-service) n / %	Future roles (post-service) n / %
Student	7 (39)	1 (6)	1 (6)	4 (22)
Worker	18 (100)	1 (6)	1 (6)	13 (72)
Volunteer	6 (33)	0	1 (6)	9 (50)
Carer	11 (61)	4 (22)	5 (28)	9 (50)
Home maintainer	18 (100)	7 (39)	8 (44)	16 (89)
Friend	18 (100)	13 (72)	13 (72)	18 (100)
Family member	16 (89)	11 (61)	12 (67)	15 (83)
Religious participant	9 (53)	2 (11)	4 (22)	3 (17)
Active hobby	17 (94)	5 (28)	6 (33)	15 (83)
Participant in organisations	8 (44)	1 (11)	3 (17)	7 (39)

Data missing for one person throughout

Table 23 shows the value users placed on each of the ten roles pre and post-service. The most valuable roles to the users were that of worker, home maintainer, friend and family member. There are small changes in views pre and post-service including less users considering having a hobby as very valuable post-service. There were also changes in views towards the role of carer and volunteer with more users considering these to be very valuable post-service.

Table 23: Details of the value placed on each role

Role	Pre-service	Post-service	Role	Pre-service	Post-service
Student			Friend		
Not valuable	16	15	Not valuable	-	1
Somewhat valuable	2	3	Somewhat valuable	3	2
Very valuable	-	-	Very valuable	15	15
Worker			Family member		
Not valuable	1	-	Not valuable	-	-
Somewhat valuable	2	5	Somewhat valuable	2	2
Very valuable	15	13	Very valuable	16	16
Volunteer			Religious participant		
Not valuable	11	7	Not valuable	13	13
Somewhat valuable	5	7	Somewhat valuable	4	3
Very valuable	2	4	Very valuable	1	1
Carer			Active hobby		
Not valuable	7	6	Not valuable	1	3
Somewhat valuable	6	7	Somewhat valuable	4	5
Very valuable	5	5	Very valuable	13	10
Home maintainer			Participant in organisations		
Not valuable	-	2	Not valuable	11	10
Somewhat valuable	3	2	Somewhat valuable	3	6
Very valuable	15	14	Very valuable	4	2

Occupations

Using the Canadian Occupational Performance Measure, users indicated the occupations that were important to them and that they had difficulties in carrying out under the headings of self-care, productivity and leisure. Once problems were identified, users indicated how important it was to them to be able to do each occupation, their perceptions of their ability to perform the occupations and their satisfaction with their ability. Table 24 outlines the pre and post-service performance and satisfaction scores. Users perceived an increase in their ability to carry out occupations post-service which was significant (z=-2.652, p=0.008). Their perception of satisfaction does not match their increase in ability and is not statistically significant.

Table 24: Details of pre and post-service COPM performance and satisfaction scores

COPM	Pre-service	Post-service	Comparison
Performance			
Median	2.3	3.2	z = -2.652
Range	1.5 - 5.3	2 – 7.6	p = 0.008
Satisfaction			
Median	1.5	2.6	z = -1.345
Range	1.0 - 4.9	1.0 – 7.9	p = 0.179

Self-concept

Self-concept was measured by the Differential Self-Concept Scale. The median score pre-service was 69 (range 48 – 111) and the median score post-service was 79 (range 38 – 128). This increase indicates a trend for a more positive self-concept post-service although this was not statistically significant (z=-1.710, p=0.087). To investigate this further pre and post-service comparisons were made between each individual item of the Differential Self-Concept Scale. When completing this, users indicated how they felt most of the time on a scale of 1 (negative) to 7 (positive). Table 25 illustrates that there was a statistically significant change at post-service indicating that users were feeling happier (p=0.047), feeling more independent (p=0.031) and a trend towards feeling more hopeful (p=0.084). Although these are the only statistically significant changes in a positive direction it can also be noted that for the other issues there was not a statistically significant change in a negative direction.

Table 25: Details of pre and post-service self-concept

Scale	Pre-Service (n = 19)	Post-Service (n = 19)	Comparison
Interested			
Median	3	4	z = -1.237
Range	1-6	1-7	p = 0.216
Happy			
Median	4	4	z = -1.909
Range	1-6	1-7	p = 0.047
In control			
Median	4	3	z = -0.126
Range	1-7	1-7	p = 0.899
Relaxed			
Median	3	4	z = -0.837
Range	1-7	1-7	p = 0.403
Satisfied			
Median	3	2	z = -0.190
Range	1-7	1-7	p = 0.849
Attractive			
Median	3	3	z = -0.071
Range	1-7	1-7	p = 0.944
Hopeful			
Median	4	5	z = -1.729
Range	1-7	1-7	p = 0.084
Self-confident			
Median	2	4	z = -1.356
Range	1-7	1-7	p = 0.175
Stable			
Median	4	4	z = -0.770
Range	1-7	1-7	p = 0.442
Of value			
Median	3	3	z = -1.232
Range	1-7	1-7	p = 0.218
Unaggressive			
Median	4	4	z = -0.286
Range	1-7	1-7	p = 0.775
Calm			
Median	3	3	z = -0.871
Range	1-7	1-7	p = 0.384
Caring			
Median	5	6	z = -1.071
Range	1-7	1-7	p = 0.284
Capable			
Median	2	2	z = -1.281
Range	1-7	1-7	p = 0.200
Independent			
Median	2	4	z = -2.161
Range	1-7	1-7	p = 0.031
Active			
Median	3	4	z = -1.093
Range	1-7	1-6	p = 0.274
Co-operative			
Median	5	5	z = 0.200
Range	1-7	1-7	p = 0.841
Talkative			
Median	4	4	z = -0.080
Range	1-7	1-7	p = 0.936
Friendly			
Median	6	6	z = -0.955
Range	4-7	1-7	p = 0.339
Patient			
Median	3	4	z = -1.206
Range	1-7	1-7	p = 0.288

For two issues on the Differential Self Concept Scale, the median was lower (thus more negative). These were feeling in control and feeling satisfied. Attending the service either changed some aspects significantly in a positive direction or did not have a great influence on them. The median for ten items remained the same pre and post-service. A score of four or greater indicates a positive view and therefore post-service the users felt interested, happy, relaxed, hopeful, self-confident, stable, unaggressive, caring, independent, active, co-operative, talkative, friendly and patient. They also felt helpless, dissatisfied, unattractive, worthless, irritable and incapable.

8.1.2.3. Comparison of Groups A and B at post service

Statistically significant increases in function were present for the leisure subscore of Extended ADL (p=0.008), total leisure activities (p=0.021) and activities carried out regularly (p=0.016) as measured by Nottingham Leisure Scales, performance scores of Canadian Occupational Performance Measure (p=0.008) and feeling independent as measured by Self-concept Scale (p=0.031).

Table 26: Comparison of functional increase post service

	Group A			Group B*		
	Pre	**Post**	**Comparison**	**Pre**	**Post**	**Comparison**
Leisure (EADL)						
Median	3	3	z = -1.930	1.5	2	z = -2.000
Range	0–5	1-5	p = 0.054	1-4	1-4	p = 0.046
Total leisure (Nottingham Leisure Scale)						
Median	13	17	z = -1.404	10	11	z = -2.032
Range	7-24	13-21	p = 0.160	7-17	8-23	p = 0.042
Leisure activities regularly (Nottingham Leisure Scale)						
Median	5	8	z = -1.973	5	5	z = -1.354
Range	3-8	5-11	p = 0.049	1-13	3-14	p = 0.176
Performance Scores (COPM)*						
Median	2.0	3.2	z = -2.431	2.6	3.25	z = -1.262
Range	1.8-5.3	2.5-7.6	p = 0.015	1.3-4.8	1.2-5.3	p = 0.207
Feeling independent (Self concept scale)						
Median	3	3	z = -1.265	3.5	1.5	z = -1.811
Range	1-7	1-7	p = 0.206	1-6	1-4	p = 0.070

* Data missing for two individuals in Group B

Further data analysis has been carried out to compare these individual aspects for the separate groups to establish if the increase in function occurred more in the intervention phase for Group A as opposed to Group B. Table 26 shows that there is a statistically significant change for both groups for leisure ability (EADL), for Group A an increase in leisure activities conducted regularly and perception of occupational performance, and for Group B for the increase in the number of leisure activities carried out. There were no statistically significant differences in the months since stroke at the time of starting the service (as opposed to at referral point) for the two groups (t=0.958, p=0.351).

8.1.3. Control phase data

This section will report on findings of analysis of the data for both groups during the control phase. For Group A, who attended immediately, this relates to Visit 2 (at the end of service attendance) and Visit 3 (at the end of the control phase). For Group B this relates to the data collected at Visit 1 (beginning of the control phase) and Visit 2 (end of the control phase pre-service). The analysis was conducted to look for increases of functional levels during the control phases.

Group A

This section relates to Group A. The users in this group attended the service immediately after referral. In addition to an assessment post-service (at six months) data was also collected at one year (six months post-service). No statistically significant improvement in any subscores or the total EADL score were evident, as shown in Table 27. There is a trend towards significant improvement for leisure activities (z = -1.730, p = 0.084). The level of definite cases of anxiety, as measured by the Hospital Anxiety and Depression Scale remained the same (n=4) by Visit 3, while the incidence of definite depression increased from five to six by Visit 3. There is no significant increase or decrease in the level of anxiety or depression amongst those in Group A six months after attending the service. The trend for increased leisure found in EADL is not present in the Nottingham Leisure Scale. There is no significant increase or decrease in leisure activities. Although not significant the median performance and median satisfaction scores both increased as measured by the Canadian Occupational Performance Measure.

Table 27: Details of EADL, Nottingham Leisure Scale, Hospital Anxiety and Depression Scale and COPM for Group A at Visit 2 and Visit 3

Scale		Visit 2 (n = 9)	Visit 3 (n = 9)	Comparison
Extended ADL*				
Mobility subtotal Extended ADL				
	Median	5	4.5	z = -0.638
	Range	2-6	3 – 6	p = 0.524
Kitchen subtotal Extended ADL				
	Median	4	3	z = -1.633
	Range	1-5	1-5	p = 0.102
Domestic subtotal Extended ADL				
	Median	1	1.5	z = -0.816
	Range	0-5	0-5	p = 0.414
Leisure subtotal Extended ADL				
	Median	3	4	z = -1.730
	Range	1-5	1-6	p = 0.084
Extended ADL Total Score				
	Median	14	13	z = -0.586
	Range	4-19	6-12	p = 0.558
Nottingham Leisure Scale				
Total no of leisure activities carried out				
	Median	17	18	z = -0.284
	Range	13-21	8-27	p = 0.777
Activities carried out regularly				
	Median	8	7	z = -0.171
	Range	5-11	5-10	p = 0.865
Activities carried out occasionally				
	Median	9	12	z = -0.845
	Range	5-13	3-17	p = 0.398
Activities never carried out				
	Median	20	19	z = -0.284
	Range	16-24	10-29	p = 0.777
Anxiety, Hospital Anxiety & Depression Scale				
Anxiety	Median	10	10.5	z = -0.135
	Range	5-17	4-17	p = 0.893
No anxiety		3	1	
Doubtful anxiety		3	3	
Definite anxiety		4	4	
Depression	Median	11	12.50	z = -1.194
	Range	2-19	5-19	p = 0.233
No depression		2	1	
Doubtful depression		2	1	
Definite depression		5	6	
COPM				
Performance	Median	3.2	4.2	z = -0.841
	Range	2.5-7.6	3.1-7.1	p = 0.400
Satisfaction	Median	3.1	3.5	z = -0.676
	Range	1.7-7.9	1.8-7.3	p = 0.499

* information missing for one person at visit 3

There was no significant change in the SF36 sub-scores or the Physical Health Capacity score or the Mental Health Capacity Scores between the end of the attendance period and six months later as seen in Table 28. Therefore there was no difference in quality of life between the end of attendance at the service and six months later at follow-up for Group A.

Table 28: Details of subscores for SF36 for Group A at visits 2 and 3

Scale	Visit 2	Visit 3	Confidence interval	Comparison
Physical function				
Mean	25.00	28.75	-19.67 – 12.17	t= -0.557
Standard Deviation	16.69	18.66		p = 0.595
Role limitation due to physical problems				
Mean	7.14	21.43	-51.70 – 23.13	t = -0.934
Standard Deviation	12.20	36.00		p = 0.386
Role limitation due to emotional problems				
Mean	23.81	19.05	-36.71 – 46.23	t = 0.281
Standard Deviation	31.71	26.23		p = 0.788
Social functioning				
Mean	40.28	41.67	-17.43 – 14.65	t = -0.205
Standard Deviation	22.17	27.70		p = 0.844
Mental Health				
Mean	53.00	48.50	-10.50 – 19.50	t = 0.709
Standard Deviation	19.80	13.43		p = 0.501
Energy/vitality				
Mean	37.50	36.25	-13.70 – 16.20	t = 0.198
Standard Deviation	27.65	23.26		p = 0.849
Pain				
Mean	50.00	48.61	-26.45 – 29.23	t = 0.118
Standard Deviation	31.43	34.60		p = 0.909
General Health Perception				
Mean	53.13	49.38	-9.80 – 17.30	t = 0.655
Standard Deviation	20.86	22.75		p = 0.523
Change in Health				
Median	50	62.50		z = -1.134
Range	25 - 100	50 - 100		p = 0.257
Physical Health Capacity Score				
Mean	32.41	35.41	-8.33 – 2.31	t = -1.384
Standard Deviation	7.04	8.52		p = 0.216
Mental Health Capacity Score				
Mean	37.74	34.90	-5.31 – 11.00	t = 0.853
Standard Deviation	10.07	9.08		p = 0.426

There is no significant change in the overall self-concept score six months post-service (Table 29). When observing individual components the only significant change is in the concept of caring (z=-2.000, p=0.046). Members of Group A rated themselves as less caring six months post-service.

Table 29: Details of self-concept for Group A at visit 2 and visit 3

Scale	Visit 2 (n = 9)	Visit 3 (n = 9)	Comparison
Interested			
Median	4	4	z = -0.552
Range	1-6	2-5	p = 0.581
Happy			
Median	4	4	z = 0.000
Range	1-7	2-7	p = 1.000
In control			
Median	4	3	z = -0.996
Range	1-7	1-6	p = 0.334
Relaxed			
Median	4	3	z = -1.089
Range	1-6	1-3	p = 0.276
Satisfied			
Median	2	2	z = -0.345
Range	1-7	1-5	p = 0.730
Attractive			
Median	3	4	z = -0.921
Range	1-7	2-5	p = 0.357
Hopeful			
Median	5	3.5	z = -1.063
Range	2-7	2-7	p = 0.288
Self-confident			
Median	4	3.5	z = -0.477
Range	1-7	1-5	p = 0.655
Stable			
Median	4	4	z = -0.425
Range	1-7	2-6	p = 0.671
Of value			
Median	4	2.5	z = -1.057
Range	1-7	1-6	p = 0.290
Unaggressive			
Median	4	3.5	z = -0.816
Range	1-7	1-6	p = 0.414
Calm			
Median	3	3	z = -0.378
Range	1-7	2-5	p = 0.705
Caring			
Median	6	5.5	z = -2.000
Range	1-7	1-7	p = 0.046
Capable			
Median	2	2.5	z = -1.414
Range	1-7	1-5	p = 0.157
Independent			
Median	4	4	z = -0.422
Range	2-7	2-7	p = 0.673
Active			
Median	4	4.5	z = -1.035
Range	1-5	2-6	p = 0.301
Co-operative			
Median	6	4.5	z = -0.954
Range	3-7	2-7	p = 0.304
Talkative			
Median	4	4	z = -0.412
Range	3-7	2-7	p = 0.680
Friendly			
Median	7	6	z = -0.333
Range	3-7	3-7	p = 0.739
Patient			
Median	4	3	z = -1.725
Range	1-7	1-6	p = 0.084
Total			
Median	81	73.5	z = -0.986
Range	61-128	57-87	p = 0.325

* information missing for one person at visit 3

The rating scale for the self-concept is one (negative) to seven (positive). The median rating for the following items was four or greater indicating that Group A members felt happy, interested, attractive, stable, caring, independent, active, co-operative, talkative and friendly. They had negative views on the other concepts indicating that they were feeling helpless, worried, dissatisfied, despondent, lacking confidence, worthless, aggressive, irritable, incapable and impatient.

Group B

This section relates to Group B. The users in this group waited six months before attending thus had their control phase first. As a consequence Visits 1 and 2 related to the beginning and end of their control phase.

Table 30 shows no statistically significant change of levels of abilities for social function, participation in leisure activities, mood or occupational performance at the two time frames as measured by the Extended Activity of Daily Living Scale, the Nottingham Leisure Scale, the Hospital Anxiety and Depression scale and the Canadian Occupational Performance Measure. Although not significant the incidence of anxiety decreased by one while numbers with definite depression increased by two.

Table 30: Details of EADL, Nottingham Leisure Scale, Hospital Anxiety and Depression Scale and COPM for Group B at Visit 1 and Visit 2

Scale		Visit 1	Visit 2	Comparison
EADL				
Mobility subtotal Extended ADL				
	Median	3	4	z=-0.997
	Range	0-6	1-6	p=0.319
Kitchen subtotal Extended ADL				
	Median	3.5	3	z=-0.276
	Range	1-5	0-5	p=0.783
Domestic subtotal Extended ADL				
	Median	1.5	1	z=-0.542
	Range	0-5	0-5	p=0.588
Leisure subtotal Extended ADL				
	Median	3	1.5	z=-1.382
	Range	0-4	1-4	p=0.167
Extended ADL Total Score				
	Median	12.5	10	z=-0.051
	Range	4-16	4-18	p=0.959
Nottingham Leisure Scale				
Total no of leisure activities carried out	Median	9.5	10	z=-1.268
	Range	7-21	7-17	p=0.205
Activities carried out regularly				
	Median	5	5	z=-0.491
	Range	1-10	1-13	p=0.623
Activities carried out occasionally				
	Median	7	6	z=-1.430
	Range	2-11	3-10	p=0.153
Activities never carried out				
	Median	25	27	z=-1.474
	Range	8-30	20-30	p=0.141
Hospital Anxiety and Depression Scale				
Anxiety	Median	11.5	8	z=-1.016
	Range	3-20	4-19	p=0.310
No anxiety		4	5	
Doubtful anxiety		1	1	
Definite anxiety		5	4	
Depression	Median	11.5	12.5	z=-0.635
	Range	5-19	1-19	p=0.526
No depression		1	1	
Doubtful depression		3	1	
Definite depression		6	8	
COPM				
Performance	Median	2.6	2.6	z=-0.169
	Range	1.2-4.1	1.3-4.8	p=0.866
Satisfaction	Median	1.8	1.9	z=-0.526
	Range	1.3-4.3	1.0-4.9	p=0.599

Using the Short Form 36 (SF36) there are no significant changes in Group B's quality of life between Visit 1 and Visit 2 as seen in Table 31.

Table 31: Details of subscores for SF36 for Group B at visits 2 and 3

Scale	Visit 1	Visit 2	Confidence interval	Comparison
Physical function				
Mean	19.0	34.5	-42.50	t=-1.299
Standard Deviation	19.2	28.13	11.50	p=0.226
Role limitation due to physical problems				
Mean	5.0	12.5	-26.45	t=-0.896
Standard Deviation	10.5	27.0	11.45	p=0.394
Role limitation due to emotional problems				
Mean	16.6	20.0	-44.56	t=-0.183
Standard Deviation	36.0	35.8	37.89	p=0.859
Social functioning				
Mean	26.6	26.6	-16.33	t=0.000
Standard Deviation	29.7	24.1	16.33	p=1.00
Mental Health				
Mean	42.8	43.6	-14.61	t=-0.131
Standard Deviation	17.8	26.2	13.01	p=0.899
Energy/vitality				
Mean	31	37	-23.75	t=-0.765
Standard Deviation	22.5	22.0	11.75	p=0.464
Pain				
Mean	53.0	48.15	-13.73	t=-0.610
Standard Deviation	32.2	27.7	23.61	p=0.559
General Health Perception				
Mean	43	50.5	-25.04	t=-0.967
Standard Deviation	13.3	19.7	10.04	p=0.359
Change in Health				
Median	25	37.5		z=-0.552
Range	0-100	0-100	-	p=0.581
Physical Health Capacity Score				
Mean	31.8	33.9	-5.77	t=-0.99
Standard Deviation	6.89	6.25	2.299	p=0.350
Mental Health Capacity Score				
Mean	30.5	32.9	-9.77	t=-0.303
Standard Deviation	9.67	8.70	7.50	p=0.770

There is no significant change in overall self-concept scores for Group B during their control phase (Table 32). However, significant increases in feelings of satisfaction (p=0.008) and feeling attractive (p=0.042) occurred. In addition there was a statistically significant change in feeling independent (p=0.042) during the control phase.

Table 32: Details of self-concept for Group B at Visit 1 and Visit 2

Scale	Visit 1	Visit 2	Comparison
Interested			
Median	3.5	3	z=-0.284
Range	1-7	1-6	p=0.776
Happy			
Median	3	4	z=-0.184
Range	1-7	1-6	p=0.854
In control			
Median	2.5	4	z=-1.340
Range	1-6	1-7	p=0.180
Relaxed			
Median	3	3.5	z=-1.025
Range	1-7	2-7	p=0.305
Satisfied			
Median	1	4	z=-2.661
Range	1-5	1-7	p=0.008
Attractive			
Median	2	3.5	z=-2.032
Range	1-5	1-7	p=0.042
Hopeful			
Median	3.5	4	z=-0.795
Range	1-7	1-7	p=0.427
Self-confident			
Median	1.5	2.5	z=-1.342
Range	1-7	1-7	p=0.180
Stable			
Median	4	4	z=-0.424
Range	1-6	1-7	p=0.671
Of value			
Median	2.5	3	z=-1.103
Range	1-7	2-7	p=0.270
Unaggressive			
Median	5.5	4.5	z=-1.403
Range	1-7	1-7	p=0.161
Calm			
Median	3.5	3	z=-0.632
Range	1-6	1-7	p=0.527
Caring			
Median	6	4.5	z=-0.828
Range	1-7	3-7	p=0.408
Capable			
Median	4	2	z=-1.252
Range	1-7	1-7	p=0.211
Independent			
Median	4	1.5	z=-2.030
Range	1-7	1-4	p=0.042
Active			
Median	1.5	2.5	z=-1.000
Range	1-6	1-7	p=0.317
Co-operative			
Median	4	5	z=-1.552
Range	1-7	3-7	p=0.121
Talkative			
Median	3	3.5	z=-1.378
Range	1-7	1-7	p=0.168
Friendly			
Median	5	5.5	z=-0.897
Range	1-7	4-7	p=0.370
Patient			
Median	2	2	z=-0.341
Range	1-5	1-7	p=0.733
Total			
Median	65.5	68.5	z=-1.276
Range	41-100	53-111	p=0.202

8.1.4. Q methodology

The perceptions of both users and non-users of the benefits of the service were sought using Q methodology. All users at the end of their attendance were invited to take part. Seventeen of the 19 users who attended the service participated (one did not complete the Q sort and the other was too ill to take part). In total 18 non-users also participated. This group consisted of Stroke Association personnel including the Director and Assistant Director of Community Services, Local Management, Day Service Organisers, Information Officer and Family Support Worker. In addition, Day Service Volunteers, other Day Service personnel (such as music therapist) and also carers participated. The users sorted a pack of 33 statements (Appendix K) while the non-users sorted a pack of 41 statements (Appendix J).

Six particular viewpoints (factors) were presented by the users and five by the non-users. These reflect 71% and 70% of the variance of views held by users and non-users respectively. These are outlined below with the most and least agreed ratings for each statement indicated in brackets, as well as each statement number. For the users factors the 'most agree' rating was +4 and 'least agree' was –4. For the non-users factors the 'most agree' rating was +5 and 'least agree' was –5. All factors have been given a factor label to reflect the statement contents of the factor.

Users factors

Users Factor 1: New experiences

Users Factor 1 identified 'new experiences' as benefits to the service, in particular opportunity to make new friends and try new activities.

Most/least agree	No.	Statement
(+4)	24.	*The service has enabled me to make new friends*
(+4)	31.	*It gives carers a regular break*
(+3)	11.	*There is an opportunity to try new activities*
(+3)	19.	*I learn from others*
(+3)	13.	*It encourages people to communicate with each other even if there are speech problems*
(-3)	16.	*Going to the service is the only time I get out of the house*
(-3)	7.	*Counselling is available for users and their carers*
(-3)	26.	*I now use community services that I discovered through the service*
(-4)	9.	*The service provides information relating to benefits*
(-4)	33.	*The service helps me to fight for my rights*

The least agreed aspects of this factor reflect a view that the service did not facilitate participation in the wider community including helping to know one's rights and entitlements. However for this viewpoint there was not a dependence on the service for contact with the community.

Users Factor 2 Feeling valued

Users Factor 2, 'feeling valued', identified psychological benefits to the service including an environment where users felt of value and had a sense of purpose. The least agreed aspects of this factor reflect a view similar to Factor 1 but with the addition that the service did not provide a sense of security nor did it respite for carers.

Most/least agree	No.	Statement
(+4)	23.	*I feel of value*
(+4)	14.	*The service stops me just thinking about myself and makes me think of others*
(+3)	21.	*It's drawn me out of myself*
(+3)	24.	*The service has enabled me to make new friends*
(+3)	10.	*The service gives me a sense of purpose*
(-3)	9.	*The service provides information relating to benefits*
(-3)	26.	*I now use community services that I discovered through the Service*
(-3)	31.	*It gives carers a regular break*
(-4)	16.	*Going to the service is the only time I get out of the house*
(-4)	2.	*Our carers know we are safe*

Users Factor 3 Social recovery

Users Factor 3, 'social recovery', identified the chance to get out of the house and help with overall recovery from their stroke as benefits to the service. The least agreed aspects of this factor reflect a view that the opportunity to get support to return to work or counselling were not available.

Most/least agree	No.	Statement
(+4)	22.	*Going to the service has helped my recovery from my stroke*
(+4)	16.	*Going to the service is the only time I get out of the house*
(+3)	28.	*It gives me something to talk about when I get home*
(+3)	19.	*I learn from others*
(+3)	24.	*The service has enabled me to make new friends*
(-3)	26.	*I now use community services that I discovered through the Service*
(-3)	12.	*Carers get support at the service*
(-3)	1.	*The activities at the service are mainly focused on leisure and hobbies*
(-4)	7.	*Counselling is available for users and their carers*
(-4)	15.	*There is the opportunity to train/retrain for work*

Users Factor 4 Security

Users Factor 4, 'security', identified a feeling of security as a benefit of the service, in particular feeling safe and sharing similar experiences as others. The least agreed aspects of this factor reflected a view that the service did not facilitate independence, it did not enable users to be less reliant on others or facilitate abilities to do more activities or return to work.

Most/least agree	No.	Statement
(+4)	18.	*You see others improve and deal with similar situations*
(+4)	17.	*I feel safe there*
(+3)	33.	*The service helps me to fight for my rights*
(+3)	24.	*The service has enabled me to make new friends*
(+3)	5.	*People don't feel alone*
(-3)	16.	*Going to the service is the only time I get out of the house*
(-3)	31.	*It gives carers a regular break*
(-3)	3.	*I am now able to carry out some everyday activities*
(-4)	29.	*Attending the service encourages me to be less reliant on carers*
(-4)	15.	*There is the opportunity to train/retrain for work*

Users Factor 5 Prevents isolation

Users Factor 5, 'prevents isolation', identified the service as having the benefit of preventing isolation as reflecting in the statements of not feeling alone and being encouraged to communicate with each other despite difficulties. It also illustrated the benefit of opportunities to try new activities, in particular hobbies and leisure activities. Despite the service preventing isolation, the least agreed view suggested a reflection that the service did not prevent users from focusing more on themselves and less on others.

Most/least agree	No.	Statement
(+4)	11.	*There is an opportunity to try new activities*
(+4)	5.	*People don't feel alone*
(+3)	13.	*It encourages people to communicate with each other even if there are speech problems*
(+3)	1.	*The activities at the service are mainly focused on leisure and hobbies*
(+3)	2.	*Our carers know we are safe*
(-3)	12.	*Carers get support at the service*
(-3)	24.	*The service has enabled me to make new friends*
(-3)	3.	*I am now able to carry out some everyday activities*
(-4)	14.	*The service stops me just thinking about myself and makes me think of others*
(-4)	29.	*Attending the service encourages me to be less reliant on carers*

Users Factor 6 General recovery

Users Factor 6, 'general recovery', identified a contribution to users' general recovery following their stroke as a benefit to the service. In addition it encouraged communication and provides information. This factor reflected a positive view with regard to the service allowing views to be expressed without judgement while at the same time a least agreed view indicates the service did not draw users out of themselves. This factor also identified the service as not facilitating the use of community services or opportunities to return to work.

Most/least agree	No.	Statement
(+4)	22.	*Going to the service has helped my recovery from my stroke*
(+4)	6.	*It's a place to express views without being judged*
(+3)	20.	*Detailed information on stroke and its prevention is available*
(+3)	13.	*It encourages people to communicate with each other even if there are speech problems*
(+3)	2.	*Our carers know we are safe*
(-3)	15.	*There is the opportunity to train/retrain for work*
(-3)	28.	*It gives me something to talk about when I get home*
(-3)	26.	*I now use community services that I discovered through the service*
(-4)	8.	*It's the only time I feel a sense of achievement*
(-4)	21.	*It's drawn me out of myself*

Non-user factors

Nonusers Factor 1 Psychological gains

Non-users Factor 1,'psychological gains', identified psychological benefits to attending the service including gaining confidence and feeling of value. The least agreed views saw the service as not providing specific therapeutic assistance, be that rehabilitation, information, counselling or support for carers.

Most/least agree	No.	Statement
(+5)	38.	*Users develop confidence*
(+5)	23.	*Users feel of value.*
(+4)	6.	*It's a place to express views without being judged*
(+4)	13.	*It encourages people to communicate with each other even if there are speech problems.*
(+4)	31	*It gives carers a regular break*
(-4)	36.	*Users are able to use their arms and legs better since coming to the service.*
(-4)	12.	*Carers get support at the service*
(-4)	9.	*The service provides information relating to benefits.*
(-5)	8.	*It's the only time users feel a sense of achievement*
(-5)	7.	*Counselling is available for users and their carers*

Nonusers Factor 2 Social confidence

Non-users Factor 2, 'social confidence', reflected a viewpoint that the service facilitated the development of confidence in particular in a social context such as making new friends and participating in leisure activities. The least agreed view suggested that the service was not providing rehabilitation.

Most/least agree	No.	Statement
(+5)	24.	*The service has enabled users to make new friends*
(+5)	38.	*Users develop confidence*
(+4)	1.	*The activities at the service are mainly focused on leisure and hobbies*
(+4)	13.	*It encourages people to communicate with each other even if there are speech problems*
(+4)	31.	*It gives carers a regular break*
(-4)	7.	*Counselling is available for users and their carers*
(-4)	3.	*Users are now able to carry out some everyday activities*
(-4)	33.	*The service helps users to fight for their rights*
(-5)	15.	*There is the opportunity to train/retrain for work*
(-5)	36.	*Users are able to use their arms and legs better since coming to the service*

Nonusers Factor 3 Encourages communication

Non-users Factor 3 'encourages communication', presented a view of encouraging communication as a benefit to the service. This is reflected in statements that suggest that the environment was safe and therefore even those with speech difficulties were encouraged to communicate. However, there did not seem to be a carry over to bring these new abilities out into the community according to the least agreed view.

Most/least agree	No.	Statement
(+5)	13	*It encourages people to communicate with each other even if there are speech problems.*
(+5)	18	*Users see others improve and deal with similar situations*
(+4)	24	*The service has enabled users to make new friends*
(+4)	17	*Users feel safe there.*
(+4)	22	*Going to the service has helped users recovery from their stroke.*
(-4)	34	*The service has increased users awareness of community services*
(-4)	39	*Users have had the chance to learn basic skills that enable them to be independent.*
(-4)	6	*It's a place to express views without being judged*
(-5)	26	*Users now use community services that they discovered through the service*
(-5)	15	*There is the opportunity to train/retrain for work*

Nonusers factor 4 Respite for carers

Non-users Factor 4, 'respite for carers', reflected a view that the benefit of the service was respite for carers, allowing carers to have a break. Despite being supportive to carers in this way, this factor suggested more could be done as the spouse/partner was safe, nor did they believe the service to be encouraging users to be less reliant on carers.

Most/least agree	No.	Statement
(+5)	41.	*The service provides an essential function in the recovery from a stroke*
(+5)	31.	*It gives carers a regular break*
(+4)	13.	*It encourages people to communicate with each other even if there are speech problems*
(+4)	25.	*Attending the service brightens up life and makes users feel happy*
(+4)	6.	*It's a place to express views without being judged*
(-4)	15.	*There is the opportunity to train/retrain for work*
(-4)	29.	*Attending the service encourages users to be less reliant on carers*
(-4)	2.	*Carers know that the users are safe*
(-5)	8.	*It's the only time users feel a sense of achievement*
(-5)	35.	*It's a place to forget troubles*

Nonusers factor 5 Sense of purpose

The final non-users factor, 'sense of purpose', considered providing a sense of purpose to be a benefit to the service along with acceptance as it was perceived as a place where views could be expressed. Despite these positives, the least agreed views suggested that it did not provide security or a sense of achievement.

Most/least agree	No.	Statement
(+5)	38.	*Users develop confidence*
(+5)	10.	*The service gives users a sense of purpose*
(+4)	6.	*It's a place to express views without being judged*
(+4)	13.	*It encourages people to communicate with each other even if there are speech problems*
(+4)	18.	*Users see others improve and deal with similar situations*
(-4)	20.	*Detailed information on stroke and its prevention is available*
(-4)	8.	*It's the only time users feel a sense of achievement*
(-4)	40.	*Users can get things 'off their chests' there*
(-5)	17.	*Users feel safe there*
(-5)	28.	*It gives users something to talk about when they get home*

The statements

When considering how each statement was rated in each factor the following was found (Appendix N). Statement 3 *(I am now able to carry out some everyday activities)* was not rated highly indicating that there was neither strong agreement nor disagreement that the service enabled users to do everyday activities more independently. There is a contrast of placing for statement 6 (*I am now able to carry out some everyday activities*), with five out of the six users factors rating it '0'. The non-users factors 1, 4 and 5 rated it strongly (+4) with factor 3 rating it -4, and factor 2, +1. Although most ratings for statement 8 (*It's the only time I feel a sense of achievement*) were negative, two non-user factors rated this very negatively (-5). This indicates that some view that a sense of achievement is gained at the service, although for users the service is not the only place it happens. Non-users rated the free environment for communication much higher than the users (statement 13: *It encourages people to communicate with each other even if there are speech problems*). The ratings of statement 15 (*There is the opportunity to train/retrain for work*), indicates that this was an issue not being dealt with according to both users and non-users.

The non-users did not consider the service to be the sole opportunity for users to get out of the house whereas one user factor loaded this highly, indicating for some that this was the case. Learning from others (statement 19: *I learn from others*), was not perceived as an important benefit by both users and non-users. Two factors, one user and one non-user indicated feeling of value (statement 23: *I feel of value*) as very important whereas the remainder were ambivalent about it. One non-user factor indicated strongly that community services discovered through the service were not being used (statement 26: *I now use community services that I discovered through the service*). The other factors rated it as negative with only one rating it positive (+1). In total, three factors, two user and one non-user rated statement 29 (*Attending the service encourages me to be less reliant on carers*) as least agree.

There are mixed views on the place of the service in providing respite for the carers (statement 31: *It gives carers a regular break*). One user factor and three non-user factors rated it very highly, however the remaining users views do not reflect the view strongly held that the service provided respite. Of the additional statements in the non-user pack, statement 38 (*Users develop confidence*) is one worthy of comment as three factors rate this very highly and consider it a key benefit to the service.

8.1.5. Economic evaluation

For the purposes of the evaluation, information for eight users, who were consecutive users during a time frame, was collected mapping their participation in activities during their attendance at the service. Table 33 outlines the activities that they participated in, the number of users who did so and the total hours spent in each activity by this sample population. The activities have been grouped under the following headings to reflect the range of types of activities taking place at the service: crafts, indoor games, new skills, outings, social activities and quiet activities. Each of the eight users had the opportunity to attend for 6 months (24 weeks). Two users attended for 24 sessions, the range was 9 to 24. Each session was 5 hours, so the attendance in hours ranged from 45 to 120 hours (mean = 91).

Table 33: Details of activities and participation by 8 users at the service

Activity	Participation n / %	Total hours for that activity
Crafts		
Art	1 / 13	0.5
Indoor games		
Quiz	7 / 88	12.25
Cards/chess/pool	3 / 38	5.25
New skills		
Music	8 / 100	49.25
Computers	6 / 75	37.35
Hydrotherapy/swimming	1 / 13	3.5
Teaching Welsh	1 / 13	0.75
Meditation	2 / 25	2.0
Outings	8 / 100	161.25
Social activities		
Socialising	8 / 100	149.0
Party	4 / 50	20.0
Quiet activities		
One to one with staff	6 / 75	29.5
Individual counselling	1 / 13	1.0
Smoking	2 / 25	3.25
Evaluation	5 / 63	13.0
Sleeping	1 /13	0.75
Reading newspaper	1/13	4.25
Other		
Helping others	3 / 38	21.25
Group discussion	6 / 75	33.5
Talks – self confidence/benefits	5 / 63	17.25
Filling in form	1 / 13	1.0

All eight users participated in music, socialising and trips. These were also the activities that the users spent most time doing.

Table 34: Details of users' time in hours spent in different activities

	hours spent	
Activity	**Mean**	**Range**
Crafts	0	0 – 0.5
Indoor games	2.3	0 – 6
New skills	11.7	3 – 44.5
Outings	20.8	9 – 34.5
Social activities	21.1	7 – 45
Quiet activities	15.1	5 – 32
Total hours	92.5	45 – 120
Hours not accounted for	21.2	8 – 43

Table 34 indicates the mean and range of hours spent by the eight users participating in the different categories of activities. Although time spent on activities such as having lunch are not indicated there is still an average of 21 hours per user where the users are not recorded as participating in the variety of activities occurring at the service.

In addition to the time spent in activities, information was also collected on the overall costs of the service. The overhead costs for the service are outlined in Table 35 and were considered as the total costs per annum. Miscellaneous costs refers to stationery, postage and other costs. Group materials relates to materials required for the various activities that occurred at the service. During the evaluation process there was a change in Day Service Organiser and information was gathered for two 12 month periods. These were averaged to give approximate costs of the running of a service such as the Cardiff Day Service. The number of users attending the service on any particular day ranged from 12 to 20. The nature of the activities varied. Some were seasonal and thus occurred annually eg. Christmas party, others occurred for a set series of sessions while others occurred every week. The variety of activities and the fluctuating attendance numbers mean it is not possible to calculate an average cost per user for attending the service.

Table 35: Details of overhead costs for a day service per annum (2000/2001)

	Cost in £
Salary: Day Service Organiser	14,214
Rent for venue	1,837
Volunteer costs	1,691
Refreshments	233
Transport	5,469
Miscellaneous	1,482
Group materials	565
Total cost	**£25,491**

8.2. CARERS

Where an individual had a carer they were invited to complete a carer's questionnaire. This included the Carer's Strain Index and the SF36. Carers ranged from being a spouse, children, other relative or friend. The number of carers who completed the forms pre-service was 12, while post-service 13 carers completed it. Table 36 outlines how carers responded. There were no statistically significant differences on any of the items pre and post-service. However, there was a trend towards change for both the carer's strain and role limitation due to physical problems. The level of strain was beginning to reduce (p=0.08). Although the reduction had not reached a statistically significant level, the median score reduced from eight to five, and a score of seven or more indicates strain.

Table 36: Details of Carer's SF36, Carer's Strain

Scale	Pre-Service (n = 12)	Post-Service (n = 13)	95% confidence interval of difference	Comparison
Carer's Strain				
Median	8	5	–	z = -1.706
Range	0-12	0-12		p = 0.088
Missing	2	3		
Physical Function				
Mean	84	81	-30.3, 35.3	t = 0.243
Standard Deviation	21	19		p = 0.824
Missing	8	4		
Role limitation due to physical problems				
Mean	52	70	-39.5, 3.18	t = -1.896
Standard Deviation	33	38		p = 0.087
Missing	1	1		
Role limitation due to emotional problems				
Mean	21	42	-51.7, 9.28	t = -1.550
Standard Deviation	34	50		p = 0.152
Missing	0	1		
Social Function				
Mean	69	75	-15.7, 4.65	t = -1.198
Standard Deviation	24	24		p = 0.256
Missing	0	0		
Mental Health				
Mean	55	60	-15.7, 5.07	t = -1.127
Standard Deviation	25	21		p = 0.284
Missing	0	0		
Energy/vitality				
Mean	42	48	-15.4, 2.9	t = -1.495
Standard Deviation	21	21		p = 0.163
Missing	0	0		
Pain				
Mean	76	69	-9.44, 24.2	t = 0.968
Standard Deviation	23	25		p = 0.354
Missing	0	0		
General Health Perception				
Mean	64	60	-5.20, 13.2	t = 1.208
Standard Deviation	17	19		p = 0.294
Missing	7	5		
Change in Health				
Median	50	50	–	z = -1.00
Range	25-50	25-75		p = 0.317
Missing	7	4		

8.3. GROUP C

This section of the results chapter reports the data analysis at questionnaire, and interview data collected for Group C. This group is made up of those participants in the evaluation who although originally were happy to be referred to attend the service, they chose not to attend. They continued to have each of the three visits.

Table 37 : Details of demographic characteristics of Group C

Characteristic	**Group C** **n = 7**
Age	
Mean	49
Standard Deviation	6
Median	51
Range	36 – 55
Sex	
Men	2
Women	5
Months since stroke	
Mean	16
Standard Deviation	20
Median	5
Range	1 – 49
Barthel scores	
Mean	18
Standard Deviation	2.4
Median	20
Range	15 – 20
Body side affected	
Right	5 (71%)
Left	2 (29%)
Speech affected	
Yes	6 (86%)
No	1 (14%)

Table 37 outlines the demographic details of the group. The mean age is the same as that for Group A. Unlike Groups A and B, Group C comprises more women than men. The mean time since stroke, at 16 months is greater than Group A (34 months) and greater than Group B (12 months). Group C has a higher median Barthel score, being the maximum at 20. The proportion of participants with right bodyside and speech affected is similar to Group B.

8.3.1. Questionnaires

Social function

The following are the results of comparing the group at all three assessment points. Table 38 outlines the subscores and total scores for Extended ADL.

Table 38: Details of subtotal and total EADL scores and comparisons for Group C

	Visit1 (n = 7)	Visit2 (n = 7)	Visit3 (n = 7)	Comparison*
Mobility subtotal Extended ADL				
Median	5	5	4	$X^2 = 0.000$
Range	0 – 6	0 – 6	0 – 6	p = 1.00
Kitchen subtotal Extended ADL				
Median	5	5	5	$X^2 = 5.6$
Range	1 – 5	1 – 5	0 – 5	p = 0.061
Domestic subtotal Extended ADL				
Median	2	4	2	$X^2 = 1.6$
Range	0 – 4	0 – 5	0 – 5	p = 0.449
Leisure subtotal Extended ADL				
Median	3	5	4	$X^2 = 7.05$
Range	0 – 4	0 – 6	0 – 6	p = 0.029
Extended ADL Total Score				
Median	14	16	13	X = 2.273
Range	3 – 19	3 – 22	1 – 22	p = 0.321

* Friedman test

There were no significant differences for mobility, domestic and overall EADL scores. The leisure subscore increased significantly (X^2=7.053, p=0.02) with participants being more independent in leisure activities at Visit 2 and 3. The kitchen subscore indicates a trend to decrease but not significantly (X^2=5.6, p=0.061).

Leisure

There was no change in number or frequency of participation on leisure activities when measured by the Nottingham Leisure Scale (Table 39).

Table 39: Details of frequencies of leisure activities from Nottingham Leisure Scale for Group C

	Visit 1 (n = 7)	Visit 2 (n = 7)	Visit 3 (n = 7)	Comparison*
Total no of leisure activities carried out Median	11	9	17	$X^2 = 0.519$
Range	6 – 22	6 – 26	8 – 29	p = 0.772
Activities carried out regularly				
Median	4	3	4	$X^2 = 0.583$
Range	2 – 8	3 – 14	4 – 14	p = 0.747
Activities carried out occasionally				
Median	7	6	13	$X^2 = 0.080$
Range	4 – 15	3 – 17	4 – 15	p = 0.961
Activities never carried out				
Median	26	28	20	$X^2 = 0.519$
Range	15 – 31	11 – 31	8 – 29	p = 0.772

* Friedman test

Quality of life

The only significant change in SF36 scores between Visits 1, 2 and 3 was change in health (X^2=6.50, p=0.39). Group C perceived their health to have improved.

Table 40: Details of SF36 subscores comparisons for Group C

Item	Comparison		
Physical function	F = 2.664	df = 2	p = 0.091
Role limitation due to physical problems	F = 1.606	df = 2	p = 0.224
Role limitation due to emotional problems	F = 0.245	df = 2	p = 0.785
Social functioning	F = 1.215	df = 2	p = 0.315
Mental Health	F = 0.629	df = 2	p = 0.542
Energy/vitality	F = 0.953	df = 2	p = 0.400
Pain	F = 0.198	df = 2	p = 0.822
General Health Perception	F = 0.363	df = 2	p = 0.700
Change in Health	Mean ranks: visit1 = 1.43, visit 2 = 2.14, visit 3 = 2.43 $X^2 = 6.50$ p = 0.39		

Mood

Table 41: Details of anxiety and depression level for Group C from Hospital Anxiety and Depression Scale

		Visit 1 (n = 7)	Visit 2 (n = 7)	Visit 3 (n = 7)	Comparison*
Anxiety					
	Median	9	14	13	$X^2 = 0.960$
	Range	4 – 21	0 – 18	0 – 17	p = 0.619
No anxiety		3	1	1	
Doubtful anxiety		1	1	1	
Definite anxiety		3	5	5	
Depression					
	Median	8	9	10	$X^2 = 0.087$
	Range	1 – 20	0 – 19	0 – 19	p = 0.957
No depression		3	2	2	
Doubtful depression		1	2	2	
Definite depression		3	3	3	

* Friedman test

There were no significant changes in levels of anxiety and depression for those in Group C over the evaluation period (Table 41). The median score for anxiety at Visit 1 was lower than 11, the score the authors suggest is a definite case of anxiety. The median for both Visits 2 and 3 was greater than 11 although the increase is not significant. For all three visits the depression score is less than 11.

Other services

Group C used a range of additional services, both statutory and voluntary (Table 42). The Family Support Worker, a service provided by the Stroke Association was most frequently used.

Table 42: Details of other services used by Group C during the evaluation

Service	Group C
Family Support Worker	4
Stroke Clubs	1
Dysphagic Support Group	1
Speech Therapy	3
Occupational Therapy	1
Physiotherapy	3
District Nurse	3
Health Visitor	0
Chiropodist	2
Home Care	2
Meals on Wheels	1
Social Worker	2
Highfields Day Centre	1
Others include:	
Diabetic Clinic	1

Three participants in Group C were admitted to hospital during the evaluation period. The mean number of days in hospital was 15 (range 14 – 70) which is the same as the mean number of days for those in Group B and less than those in Group A (mean = 22 days).

8.3.2. Interviews

Roles

The participants in Group C had a range of roles prior to their stroke and during the evaluation process (Table 43). The number who had roles at Visit 2 was greater than that at Visit 1, with an increase in those who had the role of worker, volunteer, home maintainer, religious participant, hobbyist and participant in organisations. Only one individual had a work role. This was indicated at Visit 2 but not at Visit 3; however information was missing for four individuals at Visit 3.

Table 43: Details of roles for Group C

	Visit 1 (n = 7)/%	Visit 2 (n = 5)*/%	Visit 3 (n = 3)**/%
Student			
Past	1 / 14	1 / 20	1 / 33
Present	0	0	0
Future	1 / 14	1 / 20	0
Worker			
Past	6 / 86	5 / 100	3 / 100
Present	0	1 / 20	0
Future	5 / 71	3 / 60	1 / 33
Volunteer			
Past	5 / 71	3 / 60	2 / 67
Present	0	2 / 40	1 / 33
Future	4 / 57	3 / 60	1 / 33
Caregiver			
Past	6 / 86	4 / 80	3 / 100
Present	2 / 29	2 / 40	1 / 33
Future	4 / 57	3 / 60	2 / 67
Home maintainer			
Past	6 / 86	5 / 100	3 / 100
Present	3 / 43	5 / 100	1 / 33
Future	5 / 71	5 / 100	1 / 33
Friend			
Past	7 / 100	5 / 100	3 / 100
Present	7 / 100	4 / 80	3 / 100
Future	7 / 100	4 / 80	3 / 100
Family member			
Past	7 / 100	5 / 100	3 / 100
Present	7 / 100	5 / 100	3 / 100
Future	7 / 100	5 / 100	3 / 100
Religious participant			
Past	4 / 57	4 / 80	2 / 67
Present	1 / 14	2 / 40	1 / 33
Future	3 / 43	2 / 40	1 / 33
Hobby			
Past	7 / 100	4 / 80	3 / 100
Present	1 / 14	3 / 60	2 / 67
Future	5 / 71	3 / 60	2 / 67
Participant in organisations			
Past	5 / 71	3 / 60	3 / 100
Present	1 / 14	2 / 40	1 / 33
Future	3 / 43	3 / 60	1 / 33

* Data missing for 2 participants
** Data missing for 4 participants

Occupations

Table 44: Details of COPM performance and satisfaction scores

	Visit 1 (n = 3)	Visit 2 (n = 3)	Visit 3 (n = 3)	Comparison
Performance				
Median	3.1	4.8	3.9	$X^2 = 6.00$
Range	1.5 - 5.0	4.4 - 7.8	3.9 - 6.7	$p = 0.05$
Satisfaction				
Median	2.8	4.1	3.6	$X^2 = 4.66$
Range	2.6 - 5.2	3.1 - 7.6	3.3 - 9.3	$p = 0.09$

Information relating to both performance and satisfaction scores of the Canadian Occupational Performance Measure was only available for three of the seven participants in Group C (Table 44). There was a significant change in performance. The mean rank scores suggest that there was an increase in performance between Visit 1 and Visit 2. Although there was in increase in mean rank for satisfaction, this increase was not significant.

Self-concept

Data was missing for three of the seven participants for the Differential Self-Concept Scale (Table 45). There were no significant changes in the scores of individual items or the total score during the evaluation period. For several aspects the median score at all three visits was greater than four indicating a positive feeling. These included feeling happy, in control, satisfied, hopeful, self-confident, stable, of value, unaggressive, caring, capable, active, co-operative, friendly. Feeling patient was the only aspect where the medians for all three visits was below four suggesting that participants felt impatient consistently.

Table 45: Details of self-concept for Group C

	Visit 1 (n = 4)	Visit 2 (n=4)	Visit 3 (n = 4)	Comparison*
Interested				
Median	5	3	5.50	$X^2 = 0.667$
Range	1 – 7	1 – 6	1 – 7	$p = 0.717$
Happy				
Median	6.50	6.50	5.50	$X^2 = 2.00$
Range	1 – 7	1 – 7	1 – 7	$p = 0.368$
In control				
Median	6	6	6.5	$X^2 = 2.00$
Range	4 – 7	4 – 7	4 – 7	$p = 0.368$
Relaxed				
Median	5	3.5	4	$X^2 = 1.07$
Range	1 – 7	1 – 6	1 – 7	$p = 0.584$
Satisfied				
Median	4.5	5	5.5	$X^2 = 0.545$
Range	2 – 7	4 – 7	3 – 7	$p = 0.761$
Attractive				
Median	3.50	4.5	5.5	$X^2 = 4.00$
Range	2 – 5	4 – 7	3 – 7	$p = 0.135$
Hopeful				
Median	6.5	5.5	4.5	$X^2 = 1.40$
Range	1 – 7	3 – 7	2 – 7	$p = 0.497$
Self-confident				
Median	5	4.5	7	$X^2 = 2.60$
Range	5 – 7	3 – 7	4 – 7	$p = 0.273$
Stable				
Median	5.5	6.0	4.5	$X^2 = 4.00$
Range	3 – 7	5 – 7	2 – 7	$p = 0.135$
Of value				
Median	6	5.5	6	$X^2 = 0.00$
Range	1 – 7	3 – 7	2 – 7	$p = 1.00$
Unaggressive				
Median	6.5	4.5	6.5	$X^2 = 0.800$
Range	1 – 7	4 – 7	3 – 7	$p = 0.670$
Calm				
Median	2.51	4.51	3.5	$X^2 = 4.667$
Range	2 – 7	4 – 7	2 – 7	$p = 0.97$
Caring				
Median	5.5	7	7	$X^2 = 1.40$
Range	2 – 7	4 – 7	6 – 7	$p = 0.497$
Capable				
Median	5.5	4	5	$X^2 = 0.286$
Range	1 – 7	2 – 7	2 – 7	$p = 0.867$
Independent				
Median	3.5	4.5	5	$X^2 = 0.200$
Range	1 – 7	2 – 7	1 – 7	$p = 0.905$
Active				
Median	5	4.5	4.5	$X^2 = 0.00$
Range	1 – 7	1 – 7	1 – 7	$p = 1.00$
Co-operative				
Median	5.5	5.5	5.5	$X^2 = 0.286$
Range	3 – 7	3 – 7	2 – 7	$p = 0.867$
Talkative				
Median	3.5	4	4.5	$X^2 = 1.273$
Range	1 – 7	3 - 7	1 – 7	$p = 0.529$
Friendly				
Median	7	5	7	$X^2 = 4.677$
Range	7 – 7	1 – 7	6 – 7	$p = 0.097$
Patient				
Median	3.5	2	2.5	$X^2 = 1.00$
Range	3 – 4	1 – 4	1 – 4	$p = 0.607$
Total Self-Concept Scale				
Median	95.5	93.5	96	$X^2 = 1.50$
Range	66 – 124	65 – 128	69 – 135	$p = 0.472$

* Friedman test

8.4 SUMMARY

By attending the Cardiff Day Service users significantly increased their participation in leisure activities, their perception of their performance abilities and feelings of independence. The users considered that attending the service 1) provided them with opportunities for new experiences; 2) offered a place to feel valued; 3) contributed to social recovery; 4) offered a place to feel secure, prevent isolation and to generally aid recovery. The non users perceived the service to facilitate psychological gains, to provide confidence in social contexts, to encourage communication, to provide respite for carers and to provide users with a sense of purpose.

For Group A there was no significant carryover of these gains in the subsequent six month period although there was a trend towards a continued increase in leisure ability. At the end of the six month control period they considered themselves less caring.

For Group B (who waited six months to attend) there were no significant differences in most functional areas during this waiting period. There were, however, some statistically significant changes for aspects of self-concept. At the end of the six month waiting period they had an increased feeling of satisfaction, feelings of attractiveness and a decrease in feeling independent.

The provision of such a service requires staffing, materials and other costs. The range of activities taking place includes crafts, indoor games, learning new skills, outings, social activities and quiet activities. The total cost per annum for the service is calculated at £25,491.

A number of carers of users also participated in this study. There were no significant changes in either their strain levels or quality of life as a result of the individual they cared for attending the service.

Although invited to attend the service a number of participants in the study did not do so. However, they continued to participate in all the data collection procedures. Their median Barthel score at referral was 20, higher than the other two groups suggesting that they were a more able group in terms of everyday functioning. Over the year from referral to the end of data collection their ability in performing leisure activities increased to a significant level. Their quality of life did not change, although the incidence of anxiety increased over time. The level of depression remained constant. They perceived their performance in occupations to have increased to a significant level with also an increase in satisfaction but not to a significant level. There was no change in their self- concept.

All these findings will be discussed in the next chapter in relation to the study objectives, the literature and the current context of service delivery.

CHAPTER 9.

SERVICE EVALUATION - DISCUSSION

9. SERVICE EVALUATION - DISCUSSION

This chapter will firstly consider the changes in pre and post service abilities and perceptions of benefit. The second section will relate to the control phase of the study and discuss this in relation to service provision. The third section discusses the activities and environment of the Cardiff Day Service. The next two sections will discuss the findings in relation to the carers. The sixth section will discuss the findings in relation to occupational performance and health. A final section will discuss the research process in relation to the findings. A subsequent chapter will draw conclusions and make recommendations.

9.1. BENEFITS OF ATTENDING THE SERVICE

The Cardiff Day Service aims to provide the opportunity for users to identify and pursue meaningful and realistic opportunities in the community which would help them to meet their personal aspirations and enable them to develop to their full potential. The findings from both the qualitative and quantitative methods used will be drawn together to discuss the extent of gains achieved by attending the service.

The participants of the evaluation were all those referred to the service during the recruitment period of the evaluation process. The population size was 26 with each individual randomly allocated to Group A or Group B. Group C emerged as those who declined the opportunity to attend although they fitted the service criteria. Overall these groups were similar in terms of demographic characteristics. The number of months since stroke was greater in Group A than the other two groups. This would suggest that although members of Group B did not attend for six months they were still attending on average sooner after their stroke than those in Group A. It was reported in Chapter 8 that three individuals originally allocated to Group A were unable to attend at the allocated time or for a considerable number of weeks due to health reasons. This reflected the real life situation of conducting a research study which can cause challenges as suggested by Shortell and Richardson (1978). It was undesirable to lose these participants from the study due to the small population size. The findings, that both groups were similar in demographic terms and in months since stroke at the pre service point, supports the decision to continue to include these individuals, but to move them to Group B. This move did not cause any difference in the groups.

The median Barthel Activity of Daily Living Index score for Group C was 20 (the maximum possible) compared with 18 and 17 for groups A and B respectively. This suggests that those in Group C on average had greater physical ability and therefore may have felt they would not gain from the service. Five individuals in Group C were originally allocated to Group B. They may have reconsidered their desire to attend the service in light of how they had continued without the service during the waiting six months. This may have led them to decline the opportunity to attend.

The nature and breadth of the measurements and methods used in this evaluation allow a range of findings relating to occupational performance to be discussed. Some relate to categories of occupations such as self-care, leisure and productivity, while others relate to issues associated with occupational performance such as the environment, mood, self-concept and quality of life. In addition, the findings relating to carers will be discussed.

9.1.1 Occupational Performance

The findings from the Canadian Occupational Performance Measure indicate that users had a perception that their ability to perform occupations increased significantly following attendance at the service. This increase was not matched when users indicated their satisfaction with their abilities. Although users saw their performance improving, they still may be unable to perform at previous levels such as they had before their stroke. This supports Soderback's (1991) findings where none of the 195 individuals in a study of long term outcome following stroke thought they had regained the same level of occupational performance as before the stroke. This would suggest the necessity for an increase in performance to result in levels of independence close to pre stroke levels in order for satisfaction to increase.

The service appears to have begun to reduce the number of problems participants had. The activities carried out at the Cardiff Day Service focus on leisure activities, with a few on developing new skills that could contribute to increased performance in self-care and productivity occupations. The aim of the service relates to providing individuals with opportunities to meet their personal aspirations. However, these findings suggest that in the areas of self-care and productivity this is not occurring. Several issues may have contributed to the reason why the reduction was not greater. The length of time attending the service during the evaluation process was six months. A greater reduction may have been evident if attendance had occurred for longer than this. An additional factor may be the small numbers in this study. Another consideration is whether the service was equipped to assist in this reduction. To facilitate such changes may require a wide range of rehabilitation skills and resources. During the evaluation, no occupational therapists, physiotherapists or speech and language therapists were employed to provide rehabilitation although the Day Service Organiser for the latter period of the evaluation had a social work background. The findings may have been different if these professionals had been employed. Gilbertson (1998) conducted a randomised controlled trial to investigate if occupational therapy could improve recovery after stroke. She found, using the Canadian Occupational Performance Measure, that with occupational therapy there was a significant increase in both performance (p=0.002) and satisfaction (p=0.01). Some users did receive formal rehabilitation. In addition to attending the Cardiff Day Service, which does not have any members of a rehabilitative multi-disciplinary team providing an input, five individuals (19%) received occupational therapy, five (19%) received speech and language therapy and seven (27%) received physiotherapy. Over 80% of those receiving these services had had their strokes in the six months prior to being referred to the Cardiff Day Service and thus were still receiving rehabilitation services.

Between the 26 participants they identified 62 self-care, 58 productivity and 58 leisure problems. The percentage of these problems that were rated as very important (rate of 8 or more) was 68% of self-care, 65% of productivity and 57% of leisure problems. The self-care and productivity problems are perceived to be more important to participants than leisure ones.

These findings suggest that for individuals post stroke there is a need for gaining independence in self-care and productivity first before addressing leisure needs. This suggests that similar to Maslow's hierarchy of needs (cited in Chiou & Burnett 1985), the most important needs are primary needs such as food, shelter, and safety with belonging, esteem and self actualisation needs to be less important. Chiou and Burnett (1985) suggest that satisfying lower needs has greater value then satisfying deprived higher needs.

Other studies also found a similar pattern. Bodiam (1999) conducted an investigation involving seventeen participants who were patients on a neurorehabilitation unit. Using the COPM, she noted that during the acute stage of admission participants focused more on self-care activities, but over time productivity and leisure activities became more significant to them. The seventeen participants between them identified 46 (54%) self-care problems, 13 (15%) productivity problems and 26 (31%) leisure problems.

Chan and Lee (1997) also conducted a study, in this case of thirty-nine adult clients with orthopaedic (30) and stroke (19) disabilities, all of whom were assessed using the COPM, again, a relatively small sample size which needs to be interpreted cautiously. Also, similar to Bodiam's study, Chan and Lee (1997) found that most problems were with activities under the occupational performance category of self-care (56%). Productivity had greater importance than Bodiam's study (22% vs 15%) and leisure had less importance than Bodiam's study (22% vs 31%). A study conducted by Ward et al (1996) also found that, when assessing 29 orthopaedic patients while on wards, most of the problems identified were self-care ones. However, at a 6-month re-assessment point, additional problems in the areas of productivity and leisure were identified which were not being addressed by any professional intervention. They conclude that these needs do not appear to be being met within the community.

In total, two individuals of the 26 indicated they had not had a work role in the past, and only one had returned to work (data missing for 6), and 13 (72%) wished to return to work. The majority (17, 85%) considered the work role to be valuable with the most suggesting it to be very valuable to them.

There is currently no specific support available for individuals post stroke to return to their previous jobs or to consider and facilitate taking up new employment. Gresham et al (1995) argue that facilitating return to work should be done in a client centred manner which offers the flexibility to change objectives and strategies as the individual's capacities increase or the work environment changes. Any return to work programme in their view should enable the development of skills and offer opportunities for retraining, and promote links with employers if the individual is to return to work successfully.

The British Society of Rehabilitation and Medicine (BSRM) (2000:6) in a report on vocational rehabilitation considers the NHS to have "lost the culture and skills of facilitating employment as a key element of effective health care". The BSRM (2000) recommend a multi-professional approach to individuals in assessment and treatment from the onset of illness until the return to work – surprisingly, they do not advocate this support to beyond the initial return to work point. They do however, acknowledge the need for undergraduate healthcare professions to be aware of the importance of employment to good health and the need to promote vocational rehabilitation, that is

> the concept of enabling individuals with either temporary or permanent disability to access, return to, or remain in employment (BRSM, 2000:11).

The BSRM (2000) supports rehabilitation being available to an employee at their normal work environment, thus maintaining them in a worker role even if on reduced or modified duties. They consider this better for employers, health services and societies as well as for the individual as it should avoid low self-esteem and lack of confidence. They suggest that support from supervisors and employers results in the best outcome for those returning to work.

The fact that users increased their level of leisure activity has just been discussed. The service appears to provide opportunities for this. However what is interesting to consider is the fact that these leisure activities are not perceived by users as roles. Seventeen (94%) of the 19 users indicated that being actively involved in a hobby was a role they had in the past, before their stroke. Only 6 (33%) had such a role post service. Fifteen (83%) expressed a wish to have such a role in the future. This finding is consistent with other studies which suggest that there is a reduction in leisure activities after stroke (Atler & Gliner 1989, Bogousslavsky et al 1998, Neau et al 1998, Pound et al 1998). This would suggest that although doing more leisure activities, there might be various reasons why this has not led to resuming or taking up a new hobby role. Participation in leisure activities may be driven more by the need to fill time or participate in any activity they are capable of doing. This level of involvement may be superficial and not the level of the activity becoming a role which would require a greater depth of involvement and where 'flow' may occur (Csikszentmihalyi 1990). Having a hobby role was perceived by nearly all the users as valuable with the majority considering it to be very valuable. These views would suggest an appreciation of the benefits of leisure by the participants such as improved health, psychological well-being, social interaction and intellectual development as identified by Murphy (1981), Kelly (1990), Kraus (1990), Christiansen (1991), Edginton et al (1995) and Henry (1998).

9.1.2 Leisure

Increased participation in leisure activities was a gain from attending the service. This was identified through the Extended Activity of Daily Living Index, the Nottingham

Leisure Scale and the Q study. There was an increase in both the number of leisure activities that users participated in and the frequency of carrying them out post service. The activities that were most frequently participated in by the users included watching television, just sitting, daydreaming, listening to the radio and visiting family or friends. Cheek and Burch (1976) found that the majority of adults from a normal population participate in similar activities. They found the activities most frequently participated in were reading newspapers, watching television and visiting friends and relatives. Edginton et al (1995) suggest that in this age bracket there is less involvement in team sports. Only three participants post service indicated that they were participating in sports activities. However the scale does not give more detail of the type of sports activity. Prior to attending the service only one person participated in photography and one person in swimming. Post service these increased to six (p=0.046) and five (p=0.025) people respectively, a significant increase.

The User Factor 1 (new experiences) presents a view that the service did provide opportunities to try new activities. However, also within this factor and four other factors including one non-user one, was a view that attending the service did not result in users being enabled to use community services themselves. There are inconsistencies as participation in swimming, attending plays and attending sports events, all community based activities, increased but only for swimming was this increase significant. However participation in other community based activities, including going to the pub and attending classes decreased. The fact that the numbers participating in each of these activities may be a reason why this decrease was not significant. This would suggest that although the service ensured users were introduced to activities that were community based it was not consistent in facilitating users to access these independently.

As reported in the literature, leisure contributes to health, psychological well-being, social interaction and intellectual development (Murphy 1981, Kelly 1990, Kraus 1990, Christiansen,1991, Edginton et al,1995, Henry 1998). The findings suggest that although the participation in leisure activities increased, the participants may not be achieving all the potential gains from leisure such as social interaction if they are not undertaking these in the community.

Edginton et al (1995) suggest that during middle adulthood (31 to 50 years) – the age span of most of the participants – the commitments of a career or caring for elderly parents or young children reduce the amount of time available to carry out leisure activities. Only one of the participants in this study returned to work, thus it can be assumed that time constraints were not the most influential barrier to conducting leisure activities in the community. Stanley (1995) in her study of 68 individuals investigating participation in valued occupations found that having a driver's licence was important. She assumes that the inability to drive greatly influenced the ability to participate in community activities. In two other studies, the availability of transport was highlighted as important to individuals post stroke being able to carry out leisure activities (Drummond 1990, Morgan & Jongbloed 1990). At post-service only three users had returned to driving. The cost of hiring transport or an inability to use public transport may have also contributed to the small number participating in leisure activities. This would suggest that the service needs to place more focus on facilitating users to access community facilities.

9.1.3 Self-concept

Following attendance at the day service the overall score for Differential Self-Concept Scale indicated a trend towards better self-concept (p=0.08) although the total median score post service (79) still reflects an overall negative self-concept as it is less than 80. The two components that increased significantly were feeling more independent (p=0.031) and feeling happier (p=0.047). There was also a trend towards more positive feelings of hope. Although not significant, the median score for confidence increased post stroke. Increase in confidence is also identified by Non-user Factor 1 (psychological gains) as a benefit to the service. In addition, following attendance, users increased their levels of social function significantly and their perception of a change in health in a positive direction was found as measured by the SF36. A further finding that links to more positive feelings is the User Factor 2 (feeling valued). This identified benefits to the service in terms of feelings such as feeling of value and having a sense of purpose.

These findings support those of Brinkman and Hoskins (1979) and Kersten (1990) who found that rehabilitation programmes can have a positive influence on self-concept. It is acknowledged that their services were formal rehabilitation (for individuals with Stroke and Chronic Obstructive Pulmonary disease respectively) while the Cardiff Day Service did not provide formal rehabilitation. Ellis-Hill (1998) also found that individuals after a stroke have a lower self-concept than prior to the stroke. She found this reduced self-concept was also present at six months and one year. Brinkman and Hoskins (1979) consider a negative self-concept to result in lower aspirations.

9.1.4 Psychological Benefits

Attending the service did not reduce the levels of anxiety or depression. This study, like many others such as (Feibel and Springer 1982, Lipsey et al 1984, Evans et al 1989, Angeleri et al 1993, Gompertz et al 1993, Pound et al 1998) has found a high incidence of depression. At the post-service assessment 10 of the 19 users had definite anxiety and 10 definite depression. This proportion of over 50% fits into the Stroke Association's (1996) suggestion that depression occurs in 20% to 60% of people with a stroke.

The presence of depression in the participants of this evaluation study may contribute to the low level of functioning in other areas including roles. This presents an argument that it is important to enable individuals and carers to understand stroke and depression and anxiety and the effect they may be having on their motivation, self-concept and ability to function, so where appropriate other interventions may be required. Despite the high prevalence of depression, only four participants in this study were receiving community or outpatient mental health services at the time of this evaluation.

A range of psychological benefits attributed to attending the service were identified through the Q process. There was agreement that counselling was not available and one user, when participating in the Q process, commented on the need for individual structured counselling to assist with the emotional problems following a stroke. In addition to adjusting to life after their stroke, participants had life events occurring such as the break up of relationships, death of parents and coping with and bringing up children. In light of the high incidence of depression, it would appear that expert psychological support is required for individuals post stroke.

9.1.5 Social interaction

According to User Factor 3 (social recovery) and User Factor 5 (prevents isolation) the service provides benefits relating to social interaction. It is seen as an important, and in some cases, the only venue outside the home where users go. It provides the conversation material when outside the service and enables individuals to meet new people and to make friends. It also provides social contact so people don't feel alone and encourages communication even if speech problems are present. The Nonuser Factor 2 (social confidence) also presents the view of the service as the venue to promote confidence in social circumstances. Loneliness and isolation, according to Charmaz (1983), Warlow et al (1996) and Pound et al (1998) are consequences of a stroke. It would appear that the Cardiff Day Service contributes to a reduction in these feelings as identified through qualitative measures. It is not therefore possible to quantify the extent to which this is the case.

9.1.6. Roles

As reported in the findings chapter, the service did not increase the number of roles that users had. However it did change views on the value of roles, in particular the role of carer and that of volunteer. There was an increase in the number of users who saw these roles as very valuable following attendance at the service. This change of value may have resulted in users seeing volunteers contribute to the running of the service and thus had insight into the role and its value.

It is interesting to note that within the self-concept scale, those users in Group A, at the end of their control phase (six months after attending the service) increased in their feelings of caring to a significant level. Volunteering, according to Rebeiro and Allen (1998) can be considered a valued and socially acceptable occupation which allows for the individual to contribute to, and be a productive member of society. This may explain the attractiveness of it as a new role to undertake by individuals post stroke. Again there does not seem to be adequate support to enable individuals to undertake these roles.

All users had a role in maintaining their homes in the past. The occupations related to this role varied and included such activities as DIY, gardening and housework. The service did not provide an opportunity for users to retain this role; only one person felt that they had gained this role following attendance at the service. Ninety per cent wanted to be able to take up this role again. This may be a role where they could regain status within their own family, and with it feelings of purpose and increased self-image (Kielhofner, 1985).

Eight users were actively involved in organisations in the past. Three were participating in organisations post service while seven hoped to be engaged in this in the future. It would appear that the loss of roles for an individual had an impact on both their status in society and their need for support as suggested by Creek (1997) and Christiansen and Baum (1997).

Users considered themselves to hold roles that they could conduct in a passive manner such as family member and friend. In these roles others can interact with them to ensure they participate in these roles. For other roles carrying them out may be more complex and requiring a range of behaviours and skills. Many roles have activities or tasks that need to be performed by the individual, but Blair and Hume (1997) consider an individual capable of conducting a role only when they can undertake the necessary skills. The desire to regain these roles is present but to a lesser extent to pre-stroke levels. Individuals post stroke need support in order to gain the skills to conduct these roles.

9.1.7 Environment

The additional perceived benefits that emerged include the provision of a secure environment. This suggests an environment where people felt accepted as they are with whatever difficulties have arisen from their stroke. Statement 6 (*it's a place to express views without being judged*) was rated highly in one user factor and three non-user factors contributing to an agreement that the environment of the service was a secure one. Also the placing of statement 24 (*the service has enabled users to make new friends*) adds to this view of a secure environment as it was rated highly in three factors. No other literature refers specifically to the importance of providing a secure environment. The American Stroke Association (2000b) acknowledges the benefits of peer support in particular to demonstrate that recovery can occur. Servian (1996), rather than considering the need for a secure environment suggests the need for an empowering one where individuals are empowered by services. He suggests that professionals and carers are those who reinforce the powerlessness of individuals. By describing the environment as secure, the users of the Cardiff Day Service may be suggesting that although they feel safe and not judged, they may also be discouraged from gaining independence by fellow users, carers and volunteers. The findings of the self-concept scale support this as they indicate that users feel less in control post-service. This raises questions as to how the service empowers users to meet their personal aspirations and to enable them to develop to their full potential as suggested in the service aims. A range of factors can influence this from the skills, environment, equipment and attitudes of the service to the level of depression and perception of the future by the users. To address the broad needs of all users so that they are specific to each user requires skills and resources. As the areas of need cross psychological, physical, social and occupational dysfunction, expertise in all of these areas are required to provide a truly needs led service.

9.1.8 Carers

Perceptions of benefits to carers were also addressed through the Q method. As stated earlier all users did not have carers. Those without carers may have felt statements in the Q pack irrelevant to them, although they were encouraged to consider the statements from the perspective of potential benefits to other users if they had a carer. Despite this, of the five statements relating to carers, only statement 31 (*it gives carers a regular break*) was rated highly by any of the factors. The non-users rated it highly in three factors, indicating a strong perception on their part that the service has a respite role. There was strong rating of this statement in only one user factor indicating that there are other more important benefits from their perspective. It could be suggested that the non-users were aware of the effect of caring on carers as stated in the literature (Ebrahim & Nouri 1987, Evandrou 1996, Van den Heuvel et al 2001). They therefore considered the service to provide respite for carers. This would suggest that the users were clear that the service was not focussed on carers' needs and therefore not of great benefit to carers. The aims of the service do not in any way suggest that the service addresses carers' needs. The non-users acknowledge that the service gives carers a break. If the service was to provide more constructive and specific support to carers it should consider the findings of Van den Heuvel et al's (2000) study of 257 carers. They suggest services for carers should be aimed at "teaching them appropriate coping strategies and providing relevant information" (Van den Heuvel et al 2000:119). Bugge et al (1999) also advocate support for carers and recommend that service providers should help carers deal with situations that cannot be changed and issues such as family relationships. They found service utilisation to be low and therefore recommend the investigation of carers' thoughts about services and the need to plan services that carers would actually use.

9.1.9 Overall Recovery

A final perceived benefit identified through the Q method is that of the service as essential to overall recovery from a stroke. User Factor 3 (social recovery) and User Factor 6 (general recovery) rated statement 22 (*going to the service has helped users' recovery from their stroke*) as the most important view from their perspective. In addition Non-user Factor 4 (respite for carers) rated statement 41 (*the service provides an essential function in the recovery from a stroke*) as the most important benefit. Literature suggests that some kind of recovery usually occurs after stroke but the most rapid recovery occurs in the first few months after stroke (Freemantle et al 1992, Birkett 1996, Bogousslavsky et al 1998). However, adaptive recovery, where individuals develop techniques to compensate for long-term impairments is a longer term process (Chang & Hasselkus 1998). It may be this type of adaptive recovery that users refer to, both in relation to physical abilities but also in relation to the psychological adjustments that inevitably are required in order to cope with life changes as a result of the stroke.

9.1.10 Costs

As has been indicated, the service does provide some gains for users. The total cost of the service per annum was £25,491. It could be argued that the benefits gained are small considering the costs. In addition, the findings suggest that the service does not, as stated in its aims, facilitate meaningful participation in the community. This suggests that the costs of the service do not result in a decrease in dependency and therefore individuals continue to be a burden on community health and social care. There is a dearth of literature on the long term costs of stroke (Phillips 1999). According to the NHS Executive (1996) stroke already accounts for 7.1% of the community health and social care budget while Phillips (1999) suggests the cost of treating stroke annually is £13,000 but this does not include the financial and quality of life costs to the individual and their carers. Consideration should be given to ensuring maximum benefit for the cost of the service.

9.1.11 Summary

Although there is evidence from both the quantitative and qualitative methods of benefits to the service, these could be considered small. The evidence also suggests that the aim of the service, that is, to offer the opportunity to identify and pursue meaningful and realistic opportunities within the community which meet individuals' personal aspirations and enable them to reach their full potential, is not being met.

9.2 CONTROL PHASE

In addition to the benefits gained following attendance at the service, analysis was carried out to establish if changes occurred while waiting to attend the service and if benefits identified were still present at six months post service.

9.2.1 Waiting period

Due to the cross over design element of the evaluation, those allocated to Group B waited for six months to attend the service. When comparing data at the beginning and end of this period no significant changes in social functioning, participation in leisure, mood, occupational performance or quality of life were found, although levels of anxiety decreased and feelings of independence decreased significantly (p=0.042). These individuals also increased their feelings of satisfaction (p=0.008) and feeling attractive (p=0.042). These findings suggest that it does not matter if users attend the service immediately on referral or six months later. This has implications for service planners as it suggests that the service should be made available for all individuals post stroke, regardless of the time since stroke. It also supports the argument that the benefits found from attending the service can actually be considered as a result of attending the service. This supports Gresham et al's (1995) recommendation that long-term follow up and support should be available.

9.2.2. Six month follow up

The data relating to maintenance of benefits was gathered for Group A during their third visit, six months after they finished attending. When comparing the data at the beginning and end of this period the findings indicate that for the Extended Activity of Daily Living Scale there was a trend for a continued increase in leisure activities. This suggests that the exposure to leisure activities during the users' time at the service continued to have an impact on their leisure activities. No other increase in ability was found on the other sub sections of the EADL. For the Nottingham Leisure Scale there was no change in leisure activities indicating that post service and six months later levels were similar. Similarly there was no change in Group A's levels of depression, anxiety, self-concept, occupational performance and satisfaction at six months post service. The only significant change on aspects relating to self concept was a decrease in feelings of caring. Despite this decrease, the median score for caring was 5.5 at six months post service, which still reflects a positive feeling. These findings suggest that Group A maintained the gains achieved during their attendance for a period of six months.

9.2.3 Summary

There are no definite recommendations in the stroke care literature about how and for how long, on-going support should be provided. The findings of this study suggest that after a six month period of attending the Cardiff Day Service users increased their levels of functioning to a small extent and these gains were maintained for a six month follow-up. For service planners this would suggest that a reasonable time to wait for a review of an individual could be a minimum of six months. Gresham et al (1995) recommend that one purpose of follow-up is to reinforce expectations of long-term progress. By monitoring individuals at this time frame, service providers can review individuals, ensure gains made during service provision are maintained, identify new goals and provide appropriate services to address them. They can facilitate the individual to identify realistic goals thereby assisting with what Chang and Hasselkus (1998) call the adaptive recovery process where they are adapting to all aspects of life post stroke.

9.3 SERVICE ISSUES

9.3.1 Service Environment

The environment of the Cardiff Day Service also contributes to individuals' progress. The Q method indicated beliefs that the environment was a safe one, the activities carried out suggest the predominant focus for activity were outings and socialising. This would suggest an environment with more focus on providing opportunities for participating in activities in the community as a group than providing opportunity for users to meet individual goals and empower them to pursue activities independently. It may be that the environment is too safe in that users feel so comfortable that they are cushioned from taking responsibility to use the skills they already have or to try to gain new skills. There is little agreement on statement 21 (*the service draws users out of themselves*). An implication of this is that the service is not encouraging or enabling users to rise to levels that could be possible. The Q process established that the service does not result in users using community services they discovered through the service (statement 26). In addition there was not agreement for the statement that attending the service encourages users to be less reliant on carers, again emphasising that the environment is not one that focuses on users taking responsibility or control.

9.3.2 Service Activities

A range of activities took place at the service. These included craft activities such as art, activities focused on learning new skills such as computer skills and meditation, indoor games such as quizzes, outings such as visits to tourist sights and meals out, social activities such as parties, quiet activities such as reading newspapers and other activities including group discussions. The average time spent per user learning new skills was 11.7 hours, less than the time spent in social activities (17.8 hours) and outings (20.15 hours). This is further evidence that the greater focus at the service is social support with lesser emphasis on enabling new skills. The range of new skills being taught at the service is limited.

All eight users whose activity levels were recorded participated in outings, socialising and music. Different numbers of users participated in the other activities available. Opportunity and interest of the users may have influenced their choice whether to participate in a particular activity. Some of the benefits identified by users, such as gaining social recovery and preventing isolation, may be the result of participating in the social activities. The non-users also support the benefit of these activities in acknowledging gains such as social confidence and encouraging communication.

The total cost of the service per annum was £25,491. This included the costs of materials for activities as well as overhead costs. It is difficult to equate money to gains when they are concepts that do not traditionally have monetary value. These include gains such as respite for carers, enabling carers to work and increased confidence in social interaction for the users.

Currently one member of staff is employed to organise the service, with experts employed sessionally to input specifically for example to run sessions on art or music. Volunteers provide the remaining support. The overall costs would be greater if the volunteers did not provide the support they do and if other staff had to be employed.

The current staffing arrangement may have an impact on the range of activities that can be facilitated at the service.

As the Cardiff Day Service is a pilot service, it is not possible to compare its content, costs and staffing with other day services. In addition, the service has been established by the voluntary sector and therefore is not part of statutory health and social care provision. Traditionally, stroke care is provided by interdisciplinary teams in hospitals (Ebrahim & Redfern, 1999) and in two thirds of cases in stroke units. The teams usually include clinical psychologists, medical staff, nurses, occupational therapists, physiotherapists and speech and language therapists. In a survey of commissioners of health services, concerns were expressed about the lack of community support, community-based services and rehabilitation in the community (Ebrahim & Redfern, 1999). This would suggest that the Cardiff Day Service is a welcome initiative, but the findings of the evaluation suggest that further development of the aims, content and staffing of the service is required to ensure it addresses the needs of adults post stroke. In addition consideration needs to be given to the period of attendance as gains may have been greater if the users attended for longer than six months.

9.4 CARERS

Although the service was not specifically targeting carers, there was an expectation that carers would benefit from users attending. The group of carers for the participants are varied due to the age range of the participants. Therefore some carers are elderly parents, spouses, siblings and teenage children. According to the findings from the SF36 and the Carers Strain Index the impact of service on carers was not statistically significant, although there was some reduction in carer's strain. The service was seen to give carers a break as indicated by Non-user Factor 4 (respite for carers) but needs such as providing counselling and support for carers were not perceived to be addressed. The carers' mean scores on the SF36 were higher in all areas than the participants. The carers' scores however were lower in all aspects in comparison to an American normal population aged 45 to 54 years (Ware et al, 1993). When compared with data from a Cardiff Population in Wales (aged 18+), there were some differences. The carers had a similar mean score for physical function (80 vs 81), lower for role limitation due to physical problems (70 vs 77), substantially lower for role limitation due to emotional problems (42 vs 80), similar for social functioning (75 vs 78), lower for mental health (60 vs 72) lower for energy and vitality (48 vs 57), similar for pain (69 vs

72) and lower for general health perception (60 vs 67) (National Assembly for Wales, 1999). This suggests that caring for a spouse, close friend or relative who has had a stroke affects quality of life and has an impact on mental health when compared with a similar aged population in Cardiff. This supports the need to provide support for carers.

9.5 GROUP C, THE NON-ATTENDERS

The seven participants who chose not to attend this service were placed into Group C. Unlike the other groups there were more women than men in Group C. Their length of time since stroke was comparable to Group B having the same median of 5 months post stroke. Group C's median score for the Barthel ADL Index was higher than Groups A and B. Their median score was 20, the maximum score for the Index. This difference in Barthel Score raises the question whether they were a more able group than those who attended the service and they may not have perceived the service to provide particular benefits for them.

Even though this group did not attend the service they also increased their leisure abilities as measured by the Extended Activity of Daily Living Scale significantly during the evaluation period. There was also a trend towards a difference in kitchen scores, this time indicating a decrease in ability over time. However the significant increase in leisure ability was only evident in EADL as there was no significant change in leisure activities using the Nottingham Leisure Scale. However, the small numbers in Group C may be a factor in there not being a statistically significant difference.

The findings from both the Hospital Depression and Anxiety Scale and the SF36 indicate little changes over the evaluation period. The anxiety and depression scores for Group C did not change significantly. The median depression score at each visit was less than 11, suggesting that the individual may have had mild depression as opposed to definite depression. These median scores were lower than the pre and post service score for groups A and B. The only significant change identified by the SF36 was for the sub-scale 'Change in Health'. This suggests that those in Group C perceived significant improvements in their health.

The Canadian Occupational Performance Measure scores indicated a significant change in performance scores with an increase from Visit 1 to Visit 2. This increase may have contributed to those originally in Group B (waiting six months to attend) deciding not to attend. They may have felt they were improving in ability as it was.

The median total self-concept score for Group C was 95.5 at Visit 1, 93.5 at Visit 2 and 96 at Visit 3. This was considerably higher than both the pre service score (median 69) and post service (median 79) for groups A and B. This would suggest that a higher self-concept influences the decision to accept an invitation to attend a service such as the Cardiff Day Service. The median scores for each aspect of the self concept scale suggest that Group C had more positive feelings than those in Groups A and B. Group C felt happier, in control, satisfied, hopeful, self confident, stable, of value, unaggressive, caring, capable, active, co-operative and friendlier to a greater extent than those in Groups A and B. They also had a lower median score for patience suggesting they felt more impatient than those who attended the service.

Participants in Group C had a broad range of roles through the evaluation process. The number of those with roles as worker, volunteer, home maintainer, religious participant, hobbyist, participant in organisations increased from Visit 1 to Visit 2. Although only five participants identified roles at Visit 2 the proportion of those participating in all roles except the student role was higher for Group C compared with the roles of Groups A and B post service.

These findings for Group C raise questions about the perceptions of who the Cardiff Day Service is for and what it can offer. This group present as more able, confident and in control, and participating in more roles than those in Groups A and B. It would appear that this group did not perceive the service as having the potential to be of benefit to them. This group were not fully independent (median Extended Activities of Daily Living score of 13 at third visit) and had not resumed all previous roles. This would suggest that they may have benefited from specific support and rehabilitation which the Cardiff Day Service did not provide. In order to gain from participating in occupations such as attending the day service, the occupation has to have meaning and purpose (Trombly 1995, McLaughlin Gray 1997, and Pierce 2001). Participants in Group C may not have seen attending the service or the activities carried out of the service as having meaning for them or as having a purpose.

9.6. OCCUPATIONAL PERFORMANCE, HEALTH AND QUALITY OF LIFE

The findings from the evaluation of the Cardiff Day Service relate to the functioning of individuals under 55 years post stroke. Many would consider these individuals to be unhealthy by virtue of their stroke, if they consider health to be a biomedical concept (Rogers 1982). The World Health Organisation (2001) consider health as relating to not just body functions and structures, but also to activities and participation in society, while Seedhouse (1986) considers health as a capacity to function, the optimum state of health being able to undertake everyday functions. The findings of this evaluation suggest that these participants are not able to function independently or carry out desired occupations. They identified a range of occupations that they wished to carry out, were able to carry out previously but could not now carry them out. This ability to perform occupations is viewed as a basic need for survival by Kielhofner (1982), CAOT (1997), Townsend (1997), Wilcock (2001) and Turner (2002a). Providing a meaning for life is another gain from participating in occupations. The dearth of roles being carried out by the participants of this study would suggest that they have reduced purpose in life and little structure. The loss of the work role is evident but as there is no increase in other roles, this work role is not replaced. This would suggest that the participants do not have a balance of occupations. There is no definitive suggestion as to what balance of occupations is or should be. Suggestions are that it should be a balance of time spent on different categories of occupations, a balance of different categories or a balance of roles (Christiansen 1996, Creek 1997, Blair & Hume 1997).

In addition to establishing that the participants of this study have occupational performance difficulties, few roles and apparent loss of balance of occupations, they also suffer from depression. This study cannot explain whether the lack of participation in occupations has resulted in low mood, or whether existing low mood including decreased motivation combined with residual impairments from the stroke, results in a lack of desire or ability to participate in occupations. The study of the nature of occupations, their significance to individuals, and their therapeutic benefit is still new (Fossey 1992, Stewart 1997 and Parham 1998) and no research is available to explain the relationship between low mood and poor occupational performance. The findings suggest that there is a relationship between occupations and health but not whether occupations causes health and well-being. This is similar to the findings of Law et al (1998).

Although acknowledged as difficult to define, Fallowfield (1990) and De Haan et al (993) suggest that the domains of physical, functional, psychological and social health make up quality of life. The multiple findings of this study illustrate poor levels of these and thus poor quality of life even after attending the Cardiff Day Service. The mean scores for all aspects of the SF36 are lower than a large scale Welsh population (n=22843) (National Assembly for Wales 1999). The mean physical component score for the Cardiff population (n=2599) in the Welsh Health Survey was 49.4 compared with 33.0 for the users post service (n=19), while the mental component score mean was 48.8 compared with 35.2 for the users. This supports the argument that for the participants of this study their quality of life is poor.

A common issue between participation in occupations and quality of life is subjectivity. Creek (1997) and Wu and Lin (1999) suggest that occupations that individuals participate in should have meaning for them and according to Goldstein (1996) they should be goal directed and initiated by the individual. This illustrates the importance of the participant's view in the engagement in occupations. Quality of life is also considered subjective (Wilcock 1998) and can only be identified by the individual themselves. Individuals having choice and control in their lives are important to the perception of quality of life (CAOT 1997). It is not clear what degree of choice or individual goal direction took place during the evaluation of the Cardiff Day Service. The findings would suggest little as many of the activities were outings or trips where presumably all members either had to go or not attend the service that day. Also the breadth of problems and the importance of them identified by the participants and the low rate of increased function and even lower level of satisfaction would suggest that individual goals were not set and therefore there was not much opportunity to participate in meaningful occupations. When comparing the data from the COPM and the activities that occurred at the service, it can be seen that the activities conducted under the headings of crafts, indoor games and new skills were not identified as problem occupations via the COPM. Some of those under the headings of outings and social activities were. Also a large range of activities that were identified as a problem were not conducted at the service.

The skills and qualifications among the Day Service Organiser and volunteers suggest that to expect change in participation in the community that is meaningful (as stated in the service aims) was unrealistic and would not be achieved unless appropriate skilled staff were employed at the service. This suggests that in order to achieve the aim of the service it needs to consider the activities it provides but more importantly needs to ensure the skills of staff are adequate to facilitate increases in function so that users are enabled to perform occupations that are meaningful to them and thus increase their quality of life. As occupational therapists enable individuals to perform meaningful occupations their potential role in the day service provision should be considered.

9.7 RESEARCH PROCESS

A number of factors influence the generalisability of the findings of this evaluation. The population for this study consisted of all individuals referred to the Cardiff Day Service during the recruitment period. As a result they can be considered as typical of individuals post stroke. The criteria for attending the service demand a certain level of physical functioning and independence in toilet use. As the participants meet these criteria, they could be perceived as being 'more able' post stroke, and therefore not representative of all individuals who have a stroke. The service base is Cardiff and therefore the group is assumed to be reflective of the cultural and societal make-up of that area. This may be different if the service was elsewhere. In addition the age criterion is from 18 to 55 years. The age range for the participants was 34 to 55 years so the findings cannot be considered to relate to those aged 18 to 34 years.

From the outset it was anticipated that the numbers of participants in this evaluation would be small based on previous attendance information. However the population was even smaller than expected as the number of potential users referred to the service dropped. The average rate of referrals for the first two years of the service (the period before the evaluation) was 24 per year, and the estimated recruitment based on that referral rate was 40 to 48. The actual number of participants recruited over the 21 month recruitment period was 26. However initial data analysis indicates that at first the service recruited users who had their stroke some time before (median 10 months). This contrasts with the recruitment during the evaluation as most users were being referred sooner after their stroke (median 5 months). This suggests that initially the service recruited both individuals who had recently had a stroke as well as those who had had their stroke some time previously. By the time the evaluation was carried out the service had exhausted the population of individuals who had their stroke some time ago and were recruiting those who had recently had their stroke.

The size of the population may have influenced the ability to detect significant changes in the quantitative measures used. As a result Type I and Type II errors may have occurred, that is significant changes may have occurred but not been detected, or changes that have been reported as significant may not be so (Polgar & Thomas, 2000). In addition, due to the volume of data collected a considerable number of comparisons have been made. The volume of these may have resulted in some differences occurring by chance.

Consideration was given to carry out further analysis to calculate numbers needed to treat. The event rate identified related to the key gain from attending the service, which was the increase in leisure functioning. This was based on the findings reported earlier indicating an increase in leisure functioning following attendance at the Cardiff Day Service (Nottingham Leisure Scale p=0.021). However, on further investigation of the measure, it was found that the authors had not identified an acceptable indication of clinically significant change. It was not reported as to how many activities an individual needed to increase their participation in for that increase to be meaningful; therefore it does not allow an accurate calculation of proportion of success.

The information regarding the costing of the service relates to the total cost per annum (£25,491). The varied nature of the activities carried out and the fluctuating attendance numbers prevents an accurate individual cost being generated. Regardless of the number of individuals attending (within maximum limits of 20 for the Cardiff Day Service) some costs such as hire of venue and salary costs would remain the same but would have to be divided proportionally to the number attending. An estimate of the average cost per user if 15 users were attending the service is £1,700. However, for the reasons just given, this estimate has to be treated with considerable caution.

Efforts were made throughout the evaluation to ensure that the researcher was not biased. She was unaware of the allocation of individuals to groups although on occasion the users themselves informed her which group they were in. The quantitative tools used in the evaluation were standardised and by using them in questionnaire format and to be completed prior to her visit she did not influence their completion. This added to the objectiveness of the evaluation and its findings. In addition no data analysis was conducted until the end of the evaluation, ensuring that trends were not identified and the service influenced and changed as a result. Also on the whole the research administrator was responsible for the administration of the Q sort. This also ensured objectivity.

The research process resulted in a limited attendance period of 6 months at the service. At the outset of the evaluation that was considered long enough for change to occur although it was acknowledged that further change might occur if users attended for longer. Therefore the findings may have been different if attendance had been for a longer period of time.

Organisational issues could be considered to have influenced the research process. The organisation (the Stroke Association) had an interest in the evaluation and considered it vital for informing service provision and future developments. Although co-operative in the process, the Day Service Organisers and volunteers may have considered the evaluation a threat, a possibility suggested by Murphy et al (1998). They may have considered the service to be good and therefore not in need of evaluating while the organisation required objective data on the benefits of the service as well as perceptions of benefit. In addition, an organisational change occurred during the evaluation where there was a change in Day Service Organiser. It is possible that the personality or skills of the organisers influenced the content, culture and environment of the service. The data collected however does not suggest that this occurred. In-depth briefing was provided to ensure the understanding of the purpose and processes involved in the evaluation.

9.8. SUMMARY

This chapter has discussed the benefits gained and perceived benefits of the Cardiff Day Service. The needs of younger adults who have a stroke have been considered in relation to the findings and other studies. Service provision issues have been highlighted including staffing, the environment, the aim of the service and the timing of attendance. The next chapter will draw conclusions and make recommendations.

CHAPTER 10

CONCLUSIONS AND RECOMMENDATIONS

10. CONCLUSIONS AND RECOMMENDATIONS

The findings of both strands of this study have been presented and discussed in previous chapters. Conclusions will be drawn and recommendations made in this chapter.

10.1 CONCLUSIONS

This study illustrated the needs of those who have had a stroke in adulthood and the benefits the Cardiff Day Service provided. An important part of the service was the social support it provides and the benefits users received from the social interaction at the service. Through participation at the service, users also increased their participation in leisure activities, their performance in occupations and had higher self-concept. In addition the service offered carers a break and both users and non-users saw the service as an important aspect of recovery from a stroke. Despite these gains there was a presence of depression amongst users, a low level of social functioning, poor integration into the community, a loss of roles and a range of needs that were not addressed. The participants' levels of functioning and quality of life were lower than that of the normal population. It can therefore be concluded that the gains achieved through the service are small in comparison to the needs of the individuals. On the whole the gains achieved at the service were still present six months later but the needs identified were also still present.

These findings indicate that the service was not enabling users to draw on community services once they finished attending the service. It therefore was not achieving its aim. The service should review both its aim and its service provision to establish if given its resources (in particular staff skills) its aim is realistic. Palfrey et al (1992) suggest that aims and objectives of services should be targeted at meeting the needs of the users of the service. They recommend that they should be "explicit, specific, measurable, scheduled, prioritised, owned by a worker or team, related to each other and communicated to all" (Palfrey et al 1992: 91). The current aim of the Cardiff Day Service does not suggest that specific objectives for individual users are established and that they are scheduled for achievement. Prior to the evaluation process no review or discharge policy was in place. The current aim may be owned by the organisation, that is the Stroke Association, but needs to be reviewed in light of the findings of the evaluation in order to ensure it targets meeting the needs of the users. The fact that individuals, at a considerable time since stroke, benefited from the service suggests that there should not be a criterion for attending the service relating to time since stroke.

The study highlighted the broad spectrum of needs of individuals following a stroke. The service aimed to provide the opportunity for users to identify and pursue meaningful and realistic opportunities in the community which would help them to meet their personal aspirations and enable them to develop to their full potential. The findings of the evaluation require the service to consider how it currently identifies individual need, and then matches these needs specifically to the activities available, thus ensuring it is adhering to its aim of providing opportunities to pursue meaningful and realistic opportunities. The quality of life, health and occupational science literature all emphasise the importance of ensuring all occupations have meaning for individuals if participating in them. There was no evidence in the evaluation to suggest that the activities of the service focused on individual need. Although leisure and social interaction were the focus of the service, users rated self-care and productivity problems as of greater importance. For them it may be more important that their self-care and productivity needs are given priority. Only one of the 26 participants had returned to work, when resuming a work role was identified to be of great importance to the majority of the participants.

Different skills and resources and a more rehabilitative approach are required. A range of health and social care professionals and the voluntary sector would make valuable contributions to this process, including psychologist, occupational therapist, speech and language therapist, physiotherapist, social worker, community psychiatric nurse, family support worker and work resettlement input. The skills of these staff are required to reduce the incidence of depression, increase occupational performance, facilitate return to work and provide specific individual support.

The evaluation also identified that the service provided carers with a break but not with other support that they require such as counselling. The service could have a greater role in supporting carers more formally.

Group C were those who chose not to attend. They were more able in terms of functional ability, were less depressed and had higher self-concept. They also had a range of needs. However their perception may have been that the service would not be able to offer them the appropriate level of support to facilitate them to address their needs. If the service were to develop more detailed individual needs assessment and a broader range of activities, those with higher levels of ability, but still with needs, may perceive the service to have benefits for them.

The findings of the evaluation suggest that some changes are required to broaden the scope of provision at the service and thus address the wider spectrum of needs of those who have had a stroke. Any changes made to the service need to accommodate the retention of the important social support that it currently offers. As suggested in the literature there are sparse services for adults in the pre-retirement age group post stroke. The Cardiff Day Service is a positive step in addressing these individuals' needs. With the findings of this evaluation it should be able to refine its aims and activities to focus more accurately on the needs of these individuals.

10.2. RECOMMENDATIONS

It is acknowledged that the population size for the study was small. However, the literature relating to health, quality of life, occupational science and the findings of the evaluation support the need to focus on enabling individuals to perform occupations that are purposeful and meaningful to them and enable them to participate in society. The recommendations following this study are therefore focused on addressing the needs of individuals who have had a stroke. They have resource implications but if carried out would lead to true adjustment for an individual into society, being able to pursue meaningful roles and achieving a sense of control back into their lives. These are all requirements for the perception of good health and quality of life.

The findings of the study call for the establishment of a comprehensive needs identification process so that individual needs and priorities can be identified when an individual is referred to the service. The service could establish which of these it can address and also act as a catalyst to other services that may help address needs.

However the service should be such that it can address most, if not all, of the needs so that individuals do not have to access numerous services to gain the support they require. This would involve expanding the provision of the service.

A recommendation of the evaluation is that the service considers separating the social and enabling aspects of the service. The social aspects could be considered as long term and continuous while the enabling aspects should be goal driven and time limited, reviewed and revised continuously. As there was carry-over of gains it would be reasonable to recommend that a review time scale could be not less than at regular six months intervals after the initial attendance period.

In order to create a truly enabling environment the service requires more skills and resources. It should pilot the input of the various health and social care professionals to assess specific psychological, physical, social and occupational needs and to facilitate achievement of goals in these areas. The findings provide justification for at a minimum the input of occupational therapists and mental health care workers such as community psychiatric nurses and psychologists. Occupational therapists use occupations as treatment and aim to facilitate individuals to perform those occupations they need or want to perform (CAOT 1997).

Returning to work was a desire of the majority of the users of the service. The establishment of a return to work programme is recommended. This should include work assessments, linking with employers, benefit agencies, providing full-time support to users as they begin the process of returning to work, with gradual withdrawal of support as appropriate. The service should make links with agencies who have a role in providing return to work services.

Return to work may not be a desired or realistic goal for all individuals. However regaining roles was a desire of all participants in the evaluation. It is recommended that previous roles, skills and responsibilities are recognised and used within the service. By using the previous skills of individual they may regain some status within society, which is usually gained through a work role.

An informative exercise would be to consult those in Group C (those who were offered the opportunity to attend but who declined). The findings suggest that Group C had needs, although they were more able than Groups A and B. This consultation may give insight into their perceptions of the service and its place in their adjustment following a stroke. It would also allow them to express their views on what they would require from the service.

Establishing the specific needs of carers was not part of this evaluation process but would be a valuable exercise. Such an exercise would assist in identifying the best way to provide support for carers to meet their individual needs. The young carers may have different needs to spouses or elderly parents.

The current service is for individuals aged between 18 and 55 years. It also accommodates those who fit the criteria and thus have some level of physical functioning. There may be individuals who are older than 55 or who have greater needs but who could still benefit from a service such as this. Consideration should be given to these individuals so their needs can also be addressed. In addition, the service is a pilot service. The findings of this evaluation should be used to facilitate the planning of new services throughout the UK.

Further research should be carried out with a larger population to test the findings found in this evaluation. This, however, would lengthen the evaluation period. For this study the data collection took place over 22 months. In addition, research should be conducted to monitor services to ensure they are providing services to address individual needs. A longitudinal study of the participants of this evaluation study using the same questionnaires and interview schedule would assist in understanding the long-term effects of stroke on this age group. This would continue to inform service provision. In order to further understand how stroke impacts on life it would be valid research to conduct a comparative study of matched adults for age and gender, who have not had a stroke. This, if it included studying mood, quality of life, social function, self-concept, roles and occupational performance would facilitate comparison of both groups.

A qualitative study to investigate what occupations previously were meaningful to individuals would inform service provision and facilitate a greater understanding of individuals as occupational beings prior to their stroke. By investigating what occupations led to the experience of 'flow', that is involving a high degree of satisfaction. As flow is considered to be the opposite of boredom, it should be a goal to enable individuals to participate in activities to achieve flow. In order to do this occupations should result in enjoyment if the skills of the individual are well matched to those required by the occupation (Csikszentmihalyi 1993). This type of research would add to the little literature that exists to understand the nature of occupation.

These recommendations suggest that further research is required to understand the experience of stroke for an adult pre retirement age and that although services for this group are in their infancy the focus needs to be on ensuring that service meets the needs of these individuals.

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Appendix A

Letter to participant and questionnaire

Date

Dear ,

Your name has recently been given to The Stroke Association as someone who is between the ages of 18 and 55 years and who recently had a stroke.

The Stroke Association are keen to gather information about this group of people so that in the future they can develop appropriate services. As a consequence they hope you will agree to Miss Susan Corr, an Occupational Therapist, to come and visit you on three occasions over the forthcoming year.

The purpose of her visits will be to establish what your abilities and needs are, at the present time. Her first visit to you at your home will be on at . It would be very helpful if you would complete the enclosed questionnaire before Susan's visit. If you are unable to complete all the questionnaire yourself, please ask someone to help you.

There is also a brief questionnaire addressed to a relative or friend (someone else who knows you well) and it would be helpful if you could pass it on to them. Susan will collect the completed form from you when she visits.

I will contact you in a few days time to confirm that Susan's visit is convenient.

Yours sincerely

Jo Cresswell
Research Administrator