The Invisible Contract: Care-giving in home-based rehabilitation

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ABSTRACT

Home-based rehabilitation is one of a number of initiatives in Australia that have reduced hospital length of stay and transferred health care from the hospital to home. This study took a critical feminist approach to the analysis family care-giving in home-based rehabilitation in Victoria, Australia. The main aim of this study was to make visible the contribution of family care-givers in the implementation of home-based rehabilitation in Victoria so that this contribution could be adequately recognized and compensated in the development of these early discharge initiatives.

Family care-giving of older and disabled persons has been extensively researched. However, most of the research that engages directly with care-givers has focused on the stress, strain, or burden associated with the role. This study was unique in three ways. A feminist theoretical approach had not previously been applied in home-based rehabilitation research. Second, most care-giver research is a-contextual, but this study captured the experiences of a group of care-givers within the context of a particular health service which was an example of a current and universal (nationally and internationally applicable) health policy. Thirdly, a qualitative approach had not previously been used to investigate the impact of an early discharge initiative on the lives of care-givers. This study combined qualitative and quantitative approaches with two levels of analysis (care-givers and programs), allowing for triangulation of data sources and data collection strategies. Twenty-four care-givers and twenty-three staff were interviewed and data were collected about 102 home-based rehabilitation clients admitted to one of eight home-based rehabilitation programs in Victoria that were established with the aim of reducing or replacing hospital length of stay.

The study found that there were considerably more female than male care-givers (88% of care-giver sample, and 59% of program sample) involved in home-based rehabilitation. Eighty-one per-cent (81%) of home-based rehabilitation clients had a primary care-giver. The care-givers were not offered and/or did not allow themselves any other alternative but to provide care for their friends or relatives. Avoidance of more restrictive modes of care was a prime motivator. Care-giving had both an immediate and longer term impact on the social and material well-being of care-givers. Both program staff and care-givers reported that some care-givers (41% according to program staff, and 75% according to care-givers) were providing 24-hour a day care. The most common care activities were meal preparation, housework, supervision, and keeping the care recipient company. Despite this contribution, both care-givers and program staff reported that care-givers were excluded from the information loop and decision-making processes of both the hospitals and the home-rehabilitation programs.

This study proposes that home-based care-giving represents an new mode or context of care. This new mode shares some of the features of the formal or institutional mode and the community or household mode identified by previous authors (Abel & Nelson,1990; Fisher & Tronto, 1990). However, it differs from the modes of care previously identified in that care-givers in home-based rehabilitation are impacted upon by both the private and public modes of patriarchy and have lost some of the autonomy previously associated with the household context of care.

This study argues that for informal care-givers, early discharge results not only in a shift of care from hospital to home, but in an invisible contract which transfers labour and responsibility without transferring rights, recognition, or compensation. The study recommends that the contribution of these care-givers be acknowledged. This acknowledgement should not take the traditional form of treating care-givers as part of the client system and therefore seen as stressed, coping, or not coping. Rather care-givers should be seen as an integral part of the health service system with the right to information, training, input into decision-making, and financial compensation for their work.

STATEMENT OF AUTHORSHIP

Except where explicit reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part for a thesis by which I have qualified for or been awarded another degree or diploma. No other person's work has been relied upon or used without due acknowledgement in the main text and in the bibliography of the thesis.

Signed..........B... Dow.................... Date....9..10..03...

Briony Dow

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Chapter One - Introduction

1.0 INTRODUCTION

This study builds on the research that was conducted by the author for her Masters of Arts Degree (Dow, 1999). That study was an evaluation of the Ballarat Health Services Rehabilitation in the Home Program (BHS – RHP) from the perspectives of the clients, staff, and care-givers involved in the program. The findings of the study relating to care-givers were narrow and inconclusive, focussing only on care-giver strain. The study recommended that *"further research be undertaken to explore the impact that home-based hospital type programs have on carers"* (Dow, 1999, p.125). The present study was undertaken as a PhD research thesis at the University of Ballarat, in the state of Victoria, Australia. The author was enrolled full-time over a three-year period, and funded by an Australian Post-graduate Award. This chapter will describe the context of the study, define the terms used in the thesis, and outline the structure of the thesis. This study adopts a feminist theoretical perspective and takes up the question of the impact of early discharge on family care-givers involved in home-based rehabilitation programs in Victoria.

1.1 HISTORICAL, POLITICAL, AND ECONOMIC CONTEXT OF THE STUDY

Since 1995, when the first Australian home-based rehabilitation program was established at the Greenvale campus of North-West Hospital (National Ageing Research Institute, 1998), there have been a further nine home-based rehabilitation programs established in Victoria that reduce or replace hospital-based rehabilitation. There are many more that provide rehabilitation services in the home, but were not established as a substitute for hospital-based care (see Chapter 7 for a full list, and description of programs). Similar programs have also been established in other Australian states and overseas (for example, in Western Australia, Bairstow, Ashe, Heavens, & Lithgo, 1997; and in Sweden, Widén Holmqvist, de Pedro Cuesta, Holm, & Kostulas, 1995).

Home-based rehabilitation as an alternative to inpatient rehabilitation is part of a national and international trend towards early discharge from hospital and the provision of alternative health services in the client's home (Grant, 1998; Philp, 1996). Other examples of this trend are hospital in the home programs (Gunnell, Coast, Richards, Peters, Pounsford, & Darlow, 2000) and domiciliary midwife services offered to women discharged early from maternity care (Thompson, Roberts, Currie, & Ellwood, 2000). This trend towards shorter hospital stays, and service provision in the home is the result of a convergence between the need to curtail health spending, consumer demand for home-based care (McCallum & Geiselhart, 1996), and the development of technologies that make home-based care a safe alternative to hospital or institutional care (Clayton, 1995). There is a concern expressed in much of the recent rehabilitation literature about the ageing of the population, and the implications that this might have for health service demand (Currie, Tierney, Closs, & Fairtlough, 1994; Farnworth, Kenny & Shiel, 1994; Widén Holmqvist, de Pedro Cuesta, Möller, Holm, & Sidén, 1996). This has led program developers and policy makers to look for cheaper alternatives to hospital rehabilitation. As hospital care accounts for a major proportion of health care expenditure on rehabilitation (Anderson, Mhurchu, Brown, & Carter, 2002), reducing hospital length of stay has become an important strategy in containing this expenditure. There is also an emerging belief, reinforced by empirical evidence, that people recover better in their own homes (Mayo, Wood-Dauphinee, Côté, Gayton, Carlton, Buttery, & Tamblyn, 2000). Furthermore, most people, and especially older people, prefer to receive treatment at home, rather than in a residential or hospital setting (Philp, 1996).

Home-based rehabilitation started in Victoria with the funding of the North-West Hospital program, based at Greenvale in 1995. Several other programs were funded within the following twelve months (Butler & Charlton, 1998; Dow, 1999). Although some of these programs received additional funding to set up the new program, for others ongoing funding was dependent on the closing down of rehabilitation beds (Dow, 1999). At the time that these programs were established, there was no specific government policy on home rehabilitation. For accountability and funding purposes, these programs were considered part of the inpatient rehabilitation program (Service Redevelopment Unit, Aged, Community and Mental Health Division, Human Services Victoria, 1999). The first government publication that considered the emergence of home-based rehabilitation in Victoria was the Report of the Pilot Study into the Continuum of Care Funding Model (1999). This document reviewed the impact of the Continuum of Care funding model on three sites that were included in the pilot. The Continuum of Care funding model did not increase the budgets of the participating agencies but provided them with funds calculated according on their existing total service targets, based on a 100% occupancy rate. Rather than funding the location of care, that is an inpatient bed or a Community Rehabilitation Centre (CRC[1]) place, funds were used for a sequence of care. This meant that the participating agencies could use their bed day funds to provide services in the home. Rehabilitation in the home was established as a service option by two of the agencies that participated in the pilot (Ballarat Health Services and Bundoora Extended Care Centre). The report found that this funding model enabled flexibility of service delivery based on clients' needs and that throughput increased and length of stay decreased. Its authors recommended that attention be given to the impact on carers of the trend towards home-based services; that throughput targets be refined; that reporting systems be expanded; and that continuum of care funding be applied to *"all services in the sub-acute and rehabilitation category"* (Human Services Victoria, 1999, p.25). However, Continuum of Care funding was not the only way in which home-based rehabilitation programs were funded. By the late 1990s in Victoria, there was a group of programs, all funded by the state government department responsible for health and welfare in Victoria, the Department of Human Services, Victoria, (DHS). However, each of these services was funded in different ways and developed a slightly different model of service delivery. To some extent this is still the case, as will be described in Chapter

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[1] A Community Rehabilitation Centre is a hospital-based outpatient facility that provides multi-disciplinary rehabilitation to eligible clients.

Seven. In 1997, the managers of these programs discovered each other through their professional networks and started to meet to discuss and develop their services. At that time the impetus for the development of standards and guidelines came from the program managers themselves, rather than DHS. More recently, however, the Sub Acute Service Unit of DHS has initiated meetings with the managers and staff of the home-based rehabilitation programs operating in Victoria to develop an understanding of current practice in home-based rehabilitation (Race, personal communication, 2003). It is expected that in the near future there will be clear guidelines, practice standards, reporting procedures, and policy developed by the Department of Human Services in conjunction with the people working in this area, but at the time of writing this had not yet occurred.

In Victoria, the trend to shorter stays in hospital was prompted, at least in part, by the casemix funding system that was introduced in public hospitals in Victoria in 1993/94. This type of funding attaches a dollar amount to each diagnosis, known as DRGs or Diagnostic Related Groups (Swerissen & Duckett, 1997). The dollar amount is based on an expected resource use over an average length of hospital stay (LOS), including the cost of procedures and hotel services. Considering that an overnight stay in a public hospital ward costs $500 to $600, there is a considerable financial disadvantage for the hospital if the patient outstays the designated time. Conversely, if the patient goes home early, the hospital saves money on that patient and can admit another patient, attracting another DRG based dollar amount. Furthermore, if the hospital can reduce its waiting list by increasing the throughput of patients, then it attracts bonus funding for complying with the government's goal of reducing the waiting time for public hospital treatment. Thus, there are significant financial incentives for early discharge. From 1989-90 to 1997-98 the throughput of patients in Australian public hospitals increased from approximately 2 million to 3.7 million within the same bed day capacity (Swerissen & Duckett, 2002), illustrating the success of case mix funding models. During the course of this study, a similar funding model was extended to most of the home-based rehabilitation programs that act as alternatives to inpatient care. The new funding model is called Clinical Rehabilitation and Funding Tree (CRAFT), and will be further discussed in Chapter Seven.

Some evaluative research has been conducted into the effectiveness of early discharge programs both in Australia and overseas. Rehabilitation in the home has been evaluated in terms of patient outcomes (Meeds & Pryor, 1990; Farnworth et al., 1994), participant satisfaction (Dow, 1999) and cost effectiveness (Anderson, Mhurchu, Rubenach, Clark, Spencer & Winsor, 2000). The research has shown that for many clients – from 100% of all patients post orthopaedic trauma (Currie et al., 1994) to 50% of all stroke patients (Widén Holmqvist et al., 1995) – home-based rehabilitation results in functional outcomes that are as good as if not better than hospital-based care. Clients are generally satisfied with the care they receive at home, and there are savings to be made in terms of reduced hospital length of stay (Anderson et al., 2002). Home-based rehabilitation has also been found to increase the active involvement of the patient in setting their own rehabilitation goals and planning their rehabilitation program, when compared with inpatient rehabilitation (von Koch, Wottrich & Widén Holmqvist, 1998). Thus, for a significant proportion of rehabilitation clients, these programs are a viable and preferable alternative to inpatient care.

However, these alternatives to hospital care rely on the client's family and friends in order to make them work. Thompson et al. (2000) found that women discharged early after childbirth did not have an increased risk of developing symptoms of postnatal depression (PND) during the following six months. They concluded that the high levels of support from partners, family members, mothers, mothers-in-law, and friends may account for the difference between the findings of this study and others that found higher levels of PND in women who were discharged early. In Hospital at Home programs the patient cannot be discharged home early unless there is a care-giver present (Guillemin, 1999). If a family care-giver is not available, the health system has to retain the client in hospital or provide 24 hour nursing care at home – both very expensive alternatives. It may be that that there has been a shift of costs and responsibility for care from hospital to home, from paid staff to care-givers, and to the clients themselves. One of the aims of this study is to investigate whether this shift has occurred in home-based rehabilitation. Is this initiative, like Hospital in the Home and domiciliary midwifery programs, reliant on family care-givers for its successful implementation?

Given the potential reliance on the work of unpaid family care-givers, there has been surprisingly little research on the impact that these programs have on care-givers. Where care-giver outcomes have been included in the program evaluations, the focus has been on the emotional and psychological state of the care-giver, as will be discussed in the next chapter. The amount of work that care-givers have been required to undertake, and the impact that this undertaking had on their lives, have been the focus of only one study to date (Kane, Reinhardy, Penrod, & Huck, 1999). Furthermore, most of the economic appraisals that have been conducted into home-based rehabilitation fail to include the cost of family care-givers' time (Anderson et al., 2000; Beech, Rudd, Tilling, & Wolfe, 1999).

1.2 THE INVISIBILITY OF WOMEN'S CARE-GIVING WORK

Feminist authors (for example, Browne, 1998) have critiqued the way in which women's work in general, and care-giving work in particular, has been rendered invisible by the prevailing definitions of what constitutes productive activity. Marilyn Waring (1996) revealed a gender bias in the method of calculating a nation's gross domestic product (GDP); that is, what has been included and excluded from the United Nations' System of National Accounts (UNSNA) definition of economic activity. Most domestic activities undertaken by women are excluded unless payment is exchanged (for example, preparation of food for the family is not included but preparation of food for sale is included). This exclusion also applies to the work of family care-givers. In the 1993 System of National Accounts (United Nations, Department of Economic Affairs Statistical Office, New York, cited in Waring, 1996, p. 54) *"the care of the sick infirm or old people"* when produced and consumed within the same household was specifically excluded from production. These services were only included when they are done for payment or when provided by a government or voluntary agency. Thus, unpaid care-giving work undertaken by family members or friends within a domestic setting is not formally considered to be productive work.

This lack of recognition of the work of care-givers has huge implications for international investment and the development of government policy in each country. The work that is undertaken by family members to care for the sick or injured is not considered to be part of the formal primary health care system. Yet the bulk of primary health care services, including tending ill children, applying bandages, transporting people to and from medical and dental appointments, and coordinating care for older and disabled people, is done by family members, primarily women. Waring (1996) estimates that up to two-thirds of all primary health care in New Zealand is carried out by women. While this work is effectively invisible as far as recognition, compensation, or adequate support is concerned, it is heavily relied upon by the formal health service system (Guillemin, 1999). The current trend towards early discharge and home-based care presumably places even higher expectations on family care-givers. It has been argued that most of the current health care reforms – the reduction in hospital and institutional care; shifting to home and community-based care; privatising the delivery of health care services, and the adoption of private sector management practices – impact upon women more than men (Grant, 1998; Bryson, 1995). This is because women are more likely to be clients of health services, more likely to be employed in health services, and more likely than men to provide the informal care when formal care is restricted. As one Canadian writer stated, *"When the health care system is cut back women get hit with a triple whammy. First, women tend to be the health care workers who are losing their jobs or are being run off their feet by understaffing. Second, women and their children tend to be the heaviest users of the health care system. Finally, women have to pick up the slack when the state no longer funds health care services"* (Dusel, 1987, p. 4).

If care-giving is not seen as work, or productive activity, what is it? Is it the natural, nurturing, caring activity of women, or a social obligation like donating to charity or attending church? If care-giving is seen as a social obligation rather than work, it is legitimate for society to assume that it is a family's (and therefore women's) obligation to undertake this care. It is the contention of the author that the construction of care-giving activity as a social obligation rather than a community (or state) responsibility means that it remains within the private (domestic) sphere. Hence, it will continue to be seen as a woman's duty rather than an essential public service with associated recognition and pay. Furthermore, the construction of care-giving work as a social obligation rather than a community responsibility means that it is not considered to be a legitimate activity for men. Most informal care is undertaken by women. The ways in which the modes of patriarchy interconnect around the issue of care-giving will be further discussed in Chapters Three and Eight.

In recent years there has been considerable policy attention paid to informal or family care-givers (Creelman, 2002). This has led to the development of carer support services and advocacy groups, such as the Carer's Association of Australia. However, most of this policy and service development centers on the ways in which care-givers can be supported (to continue) in the role, rather than providing a critical analysis of their position as part of the health service system. The Carer Payment (formally known as the Carer's Pension) does represent some recognition of and support to care-givers. However, like most income security payments in Australia, it is designed to alleviate poverty and is based on the principles of economic need rather than income replacement or compensation for the work of care-giving (Rosenman & LeBroque, 1996). Further, the eligibility requirements are restrictive. The 1993 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (ABS, 1993) found that only 7.4% of care-givers received a Carer's or Wife's Pension. It is expected that most of the care-givers in the present study would not be eligible for the Carer Payment because it is only available where care is likely to be required for at least six months (Centrelink[2], 2000) while it is expected that the episode of care required for home-based rehabilitation clients will be less than six months. Furthermore, care-givers who are employed for more than 10 hours

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[2] Centrelink is the name of the Commonwealth Government Department responsible for income security payments, such as, Aged and Disability Pensions and Carer Payments.

per week are ineligible for the pension, which excludes the many care-givers who are engaged in the paid workforce.

1.3 SUMMARY AND STUDY AIM

In summary, there are some unanswered questions about the impact of the current trends in health policy and service delivery. Does the trend to early discharge and the provision of health services in the home mean that there has been a transfer of work and responsibility from paid care-givers in the hospital setting to unpaid care-givers at home? If such a shift has occurred, what are the forces that are driving it, and whose interests do they serve? What might the consequences of such a shift be for unpaid informal or family care-givers? Does the exclusion of care-giving work from global definitions of productive activity and economic appraisals of home-based care mean that the current contribution of care-givers goes unnoticed and unrewarded? How do provisions, such as the Carer Payment, compensate for the work of care-giving? Are these provisions accessible to care-givers taking on short-term or emergency care responsibilities brought about by the early discharge of their relative or friend?

The aim of this study is to employ a feminist theory and methodology to explore the involvement of (family and informal) care-givers in home-based rehabilitation in Victoria, so the study findings can be used to inform the future development of early discharge policies and programs. To achieve this aim, this study examines the perceptions of both care-givers and staff at the interface between the hospital and the home; between the public and private realms of care.

1.4 DEFINITION OF TERMS

1.4.1 Care-giver

The terms care-giver, family care-giver, informal care-giver, and carer are used inter-changeably in this study. To provide a definition of these terms, the model proposed by Schofield et al. (1998) in their study of care-giving in Victoria has been adapted to differentiate home-based rehabilitation care-givers from other informal care-givers. Figure 1, below, shows the Schofield et al. (1998) model and Figure 2, illustrates the adapted definition. According to the definition proposed by Schofield et al. (1998), care-givers are unpaid but are not volunteers. They are usually family members or friends for whom there is little choice about providing the care. The relationship between care-giver and care recipient is not one of mutual dependence, and there is a transgression of the usual expectations. Care-giving according to this definition does not include parents of non-disabled children where it is considered normal to expect that they will care for their dependent children. The present study accepts this definition to this point, although care-givers will not be excluded from the study if they are receiving a payment, and the amount and type of payment that they receive will be investigated. However, this study will only include care-givers who have been recently involved in providing care for a client of a home-based rehabilitation program. The care-giver may be co-resident or living elsewhere and it is acknowledged that there may be more than one care-giver according to this definition.

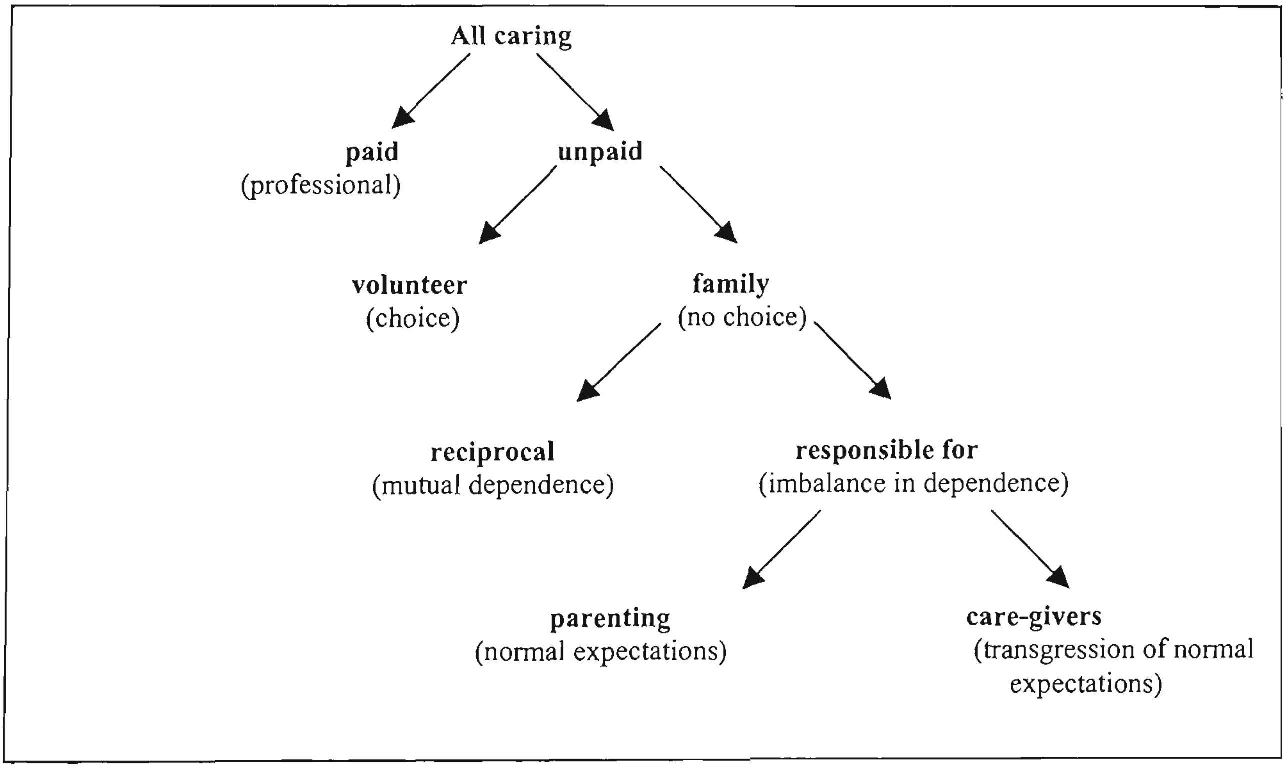

Figure 1 – Definition of family care-givers (Schofield et al., 1998, p. 12)

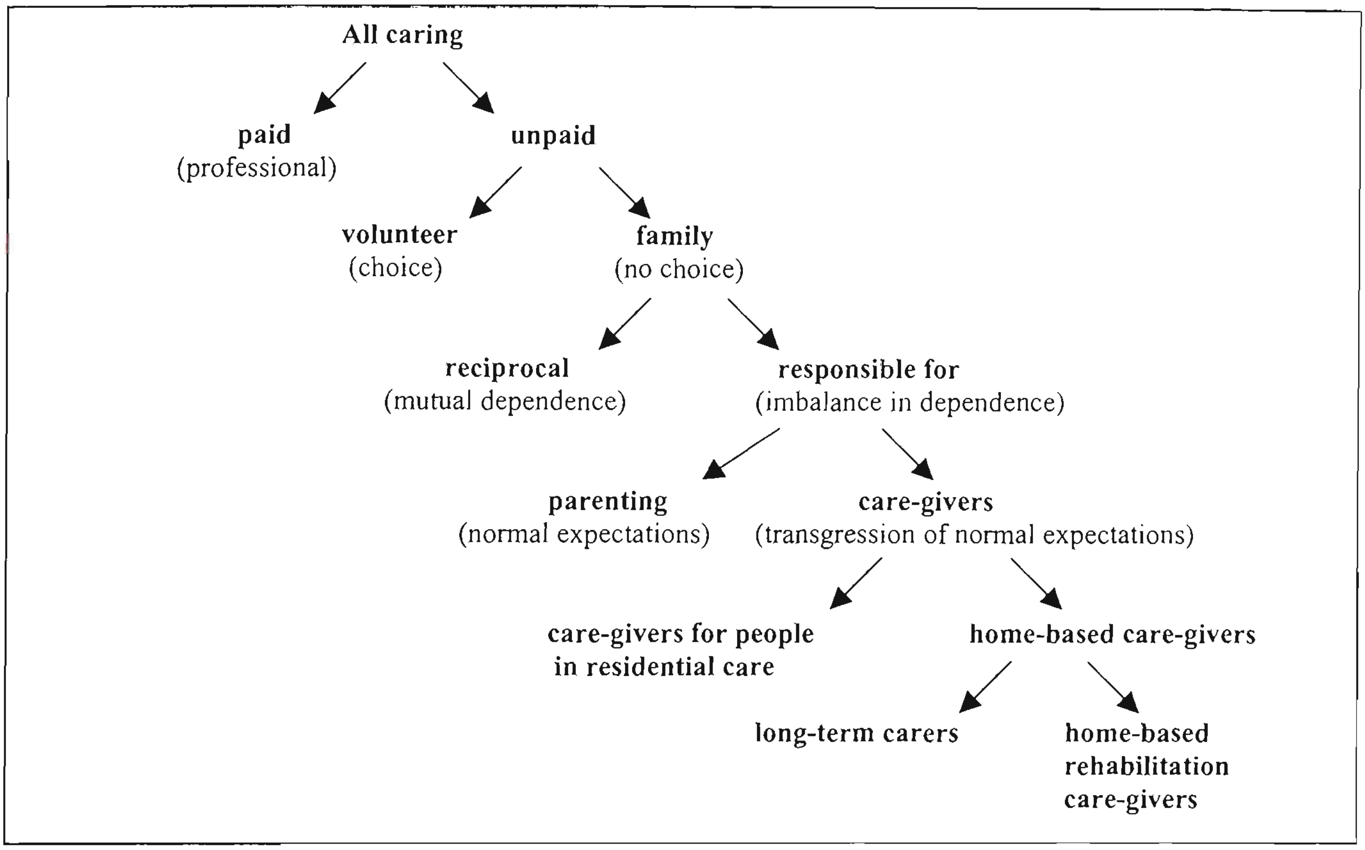

Figure 2 – Definition of care-givers in home-based rehabilitation

1.4.2 Home-based rehabilitation

The focus of this study is on physical rehabilitation, that is on the rehabilitation of disabilities and handicaps that are associated with organic conditions, including neurological, orthopaedic, and other medical conditions. Psychiatric rehabilitation is not included in this study. Although one of the physical rehabilitation programs included in the study had a psychiatric rehabilitation service, clients of that service were not included in the data collection process. However, it is likely that some of the physical rehabilitation clients included in the study would also have had a psychiatric condition, and these clients were not excluded from the study. The reason that psychiatric services were not included is that the purpose of this study was to examine home-based rehabilitation as an example of the recent trend to early discharge. The deinstitutionalisation and community rehabilitation of people with psychiatric illness has a much longer history and involves a much more complex service system than physical rehabilitation. It has also been extensively studied elsewhere (for example, Holloway, Carson, & Davis, 2002).

For the purposes of this study rehabilitation will refer to *"...interventions aimed at enabling a person to reintegrate into his or her usual community life and to realise his or her fullest physical, psychological, social and vocational potential in line with his or her preferences"* (Dow, 1999, p. 17). Home-based rehabilitation refers to a service where allied health and other rehabilitation staff visit the client at home for the purpose of facilitating his or her rehabilitation. There are three kinds of home-based rehabilitation programs, described in Chapter Seven. For inclusion in this study, however, a rehabilitation program had to meet the criteria of replacing a hospital-based rehabilitation service. See further discussion of inclusion and exclusion criteria in Chapter Four, Methodology.

1.4.3 The three elements of hospital care

In examining the transfer of hospital care into the home and community, it is necessary to break hospital care down into its component parts, some of which can be transferred and some of which still have to be restricted to within a hospital in order to maintain patient safety. For example, physiotherapy treatment can usually be conducted in the client's home, but surgery cannot. As noted earlier, there are two main elements that need to be considered in the cost of hospital care. The first is the cost of procedures and treatment, and the second is the cost of hotel-type services. A third element is personal care. All three elements are defined below.

1.4.3.1 Treatments and procedures

'Treatment and procedures' in this context refers to the activities that are undertaken by professional staff in a health setting in order to keep the person receiving care alive and/or restore them to health. The World Health Organisation (WHO) International Classification of Impairment, Disability, and Handicap (ICIDH) is useful in identifying those treatments and procedures that can be successfully transferred from a hospital environment to home. In the ICIDH, impairment is defined *as "any loss or abnormality of psychological, physiological or anatomical structure"* (WHO, 1980, p. 27). Disability is defined as *"any restriction or lack (resulting from an impairment) of ability to perform an activity within the range considered normal for a human being"* (WHO, 1980, p. 28). Handicap is defined as *"a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, social and cultural factors for that individual)"* (WHO, 1980, p. 29). The treatments and procedures associated with impairment are usually conducted within a hospital or clinic. However, the care and treatment associated with disability or handicap can be successfully conducted at home. Rehabilitation is generally focussed on disabilities and handicaps. Impairments, for example, a hip fracture or the acute phase of a stroke, are treated in the acute hospital setting with medical and surgical procedures. Disabilities, for example, the limited movement that results from a fractured hip, and handicaps, which are the restrictions in ability to carry out personal care activities independently, can be successfully treated at home.

1.4.3.2 Hotel-type services, tasks, or care.

Although "hotel type" is a common expression in the health care field (see Gardner & Barraclough, 2002, p. 7 for example), it has not been defined in any formal text. For the purposes of this study, hotel type services refer to the provision of the following –

- accommodation, including, heating, or cooling, bathing facilities, a comfortable chair, television and so on; the provision of meals;
- services, such as bed making, washing of clothes and linen, and house cleaning services; and
- caretaker services, such as making sure that someone is available in case any services are required and maintaining security over the accommodation.

These services are to be distinguished from personal care services, described below.

1.4.3.3 Personal care services

Personal care services are more personal or intimate in nature than hotel-type services, as defined above. For the purposes of this thesis, personal care services include – assistance with bathing, dressing, toileting, shaving, hair dressing, teeth cleaning, or any other personal activity that is usually undertaken independently by non-disabled adults.

1.4.3.4 Nursing-type care

Nursing-type care activities are defined here as those activities that are usually seen as requiring the services of a trained nurse. In this study, this care includes –

- wound care;
- management of peg feeding;
- monitoring and management of bed-sores;
- management of incontinence, including catheter management; and
- monitoring of symptomatology associated with the condition experienced by the care recipient, for example, looking out for signs of another stroke.

1.4.3.5 Case management or care coordination

The terms case management and care coordination have been used inter-changeably in this study to refer to the process of coordination of the care received by the care recipient. This process may include the following interventions –

- acting as a central contact point for communication between the various people providing care to the client, and the client;
- assessing the client's overall care needs and arranging services as required by the client;
- monitoring the client's ongoing care needs and terminating or activating services as required;
- acting as a counsellor or advocate for the client;
- assisting the client to plan his or her rehabilitation regime;

- evaluating the care provided to the client and providing feedback to the various personnel and agencies involved; and
- providing information to the client about services, the condition that he or she is recovering from, and his or her rights and entitlements.

The terms case management and care coordination have been used in this study to refer to a role that may be undertaken by professional staff, care-givers, or the clients themselves.

1.4.4 Carer Payments

There are two main payments that care-givers can receive from the Commonwealth Government, through Centrelink. These are the Carer Payment, which is equivalent to a pension ($421.80 per fortnight at 10th May, 2002) and the Carer Allowance. The Carer Payment is means and asset tested and subject to additional eligibility criteria including the personal provision of *"full-time care to an adult whose level of disability is long term and severe and would otherwise require full-time professional care…or constant care…from both you and another person."* This care must be provided in the person's own home (or while temporarily in hospital), and be likely to be required for at least six months (Centrelink, 2000, p. 5). It is often known as the Carer Pension. The Carer Allowance is a payment of approximately $82 per fortnight, and can be paid in addition to the Carer Payment or the Age Pension.

1.5 STRUCTURE OF THE THESIS

The thesis consists of a further seven chapters (see Table One, below). Chapter Two is a critical review of the literature about care-giving in home-based rehabilitation, and identifies the gaps in the literature that this study will address. Chapter Three extends the literature review into a theoretical review of the social work care-giving literature and a review of the feminist literature on family care-giving. It concludes with a description of the feminist theoretical framework that will be tested in this study, which is an adaptation of the work of Abel and Nelson (1990), Fisher and Tronto (1990), and Walby (1990). Chapter Four outlines the study aim, the questions, and the hypotheses that were tested in this study, and then describes the methodology that was used to answer the study questions and test the hypotheses. Chapter Five is the first of two chapters that document and discuss the findings of the care-giver interviews. This chapter focuses on the ways in which care-givers perceive their entry into the care-giving role, the nature of the care-giving relationship, and the impact that it has on their lives. Chapter Six focuses on the interface between the care-givers and the formal care system, including the home-based rehabilitation program, community support services, income security measures, and the hospital system. Chapter Seven documents and discusses the findings of the state-wide data collection and the interviews with program staff. Finally, Chapter Eight concludes the discussion of the findings. This chapter also outlines the study recommendations, outcomes, and a discussion of the extent of achievement of the study aim.

Table 1 Structure of the thesis

Chapter	Title	Summary of content
1	Introduction	Context, definitions, summary of thesis
2	Literature Review: care-giver stress and coping	Critical review of the literature on care-giving in home-based rehabilitation and identification of gaps relevant to this study.
3	Theoretical framework: The invisible welfare state	Theoretical review of the social work literature on care-giving. Review of the feminist literature on care-giving. Presentation of a theoretical framework for understanding care-giving in home-based rehabilitation.
4	Methodology	Research aim, questions and hypotheses. Study methodology, including study design, sampling, procedures, ethical considerations, and framework for analysis of data.
5	Results 1: "As you do" – Family care-giving in home-based rehabilitation.	Findings of care-giver interviews in relation to the assumption of care, the nature and duration of care, and the impact of care-giving on the care-giver. Discussion of findings in relation to the literature, theoretical framework, research questions, and hypotheses.
6	Results 2: Interface with the formal support system.	Findings of the care-giver interviews in relation to their experiences of the home-based rehabilitation program, the hospital system, community supports, and the income security system. Discussion of findings in relation to the literature, theoretical framework, research questions, and hypotheses.
7	Results 3: Caring for the state – Informal care in home-based rehabilitation across Victoria.	Findings derived from the data collected from eight home-based rehabilitation programs across Victoria. Findings of the staff interviews. Discussion of findings in relation to the literature, theoretical framework, research questions, and hypotheses.
8	Conclusion : A new context of care: Policy, program and theoretical implications.	Conclusions derived from the results and discussion outlined in the previous three chapters. Study recommendations and outcomes. Discussion of study aim.

Chapter Two – Literature review: Care-giver stress and coping

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2.0 INTRODUCTION

This literature review examines the literature concerning care-giving for people with conditions that are considered responsive to physical rehabilitation, mainly stroke and orthopaedic surgery. The review is restricted to those studies that relate to care-giving in the home, rather than in an institutional or hospital setting. The studies reviewed have been divided into three groups. The first group includes those studies that focus on the emotional and physical health of care-givers who are caring for clients with rehabilitation conditions (see Table 2, below). The second group includes those studies that investigate outcomes for care-givers in the evaluation of home-based rehabilitation or other programs designed to assist care-givers of rehabilitation clients, including one study that examined the way in which care-givers were perceived by rehabilitation staff working in the client's home (Table 3, below). Like the studies in Table 2, many of the studies in Table 3 examine outcomes such as the physical and emotional health of the care-giver, but they have a particular focus on the impact of a particular program or intervention on these outcomes. Finally, a third group of studies includes four qualitative studies that investigated the experience of care-giving for rehabilitation clients in a more open-ended way, rather than in relation to the effectiveness of a particular program or intervention (Table 7, below).

2.1 CARE-GIVING IN HOME-BASED REHABILITATION

This review was bound by the following parameters. The EBCSO Host data bases Academic Search Elite, Australian and New Zealand Reference Centre, CINAHL, Health Source Consumer Edition, Health Source Nursing/Academic Edition, Health Business Full Text Elite, the Psychology and Behavioural Sciences Collection, and PsychInfo; the Wiley, ProQuest, WebSpirs, Austrom Family, and Medline data bases were searched for peer reviewed, English language papers, published between 1990 and the end of 2002, relating to human subjects only. The literature reviewed in this chapter was located using the key words "home rehabilitation", "rehabilitation care-giver", "rehabilitation carer", "stroke rehabilitation", "family care-giver", "orthopaedic rehabilitation", "hip replacement", and "hip fracture". Further papers and books were located using the reference lists from the articles derived from the data base searches.

Through the search methods outlined above, the author located 44 empirical studies that included a sample of care-givers who were caring for people who were still in the rehabilitative stage after a stroke or an orthopaedic condition. The majority of these studies (36) included stroke care-givers only (three in conjunction with dementia care-givers); three included orthopaedic rehabilitation care-givers only; and five included both stroke and orthopaedic care-givers. There were also four literature reviews on the impact of stroke on informal care-givers (Biegel, Sales, Schulz, & Rau, 1991; Evans et al., 1992; Han & Haley, 1999; Low, Payne, & Roderick, 1999). Those studies that examined care-giving for people who had a psychiatric or chronic medical condition only, such as Alzheimer's disease, were not included in this review as the home-based rehabilitation programs that are the focus of this study do not generally cater for people with these conditions. The rationale for restricting the search to publications after 1990 was that an earlier literature review conducted by the author (Dow, 1999) located only one study about home-based rehabilitation published prior to 1990.

Table 2 Rehabilitation care-giving studies that focus on the emotional and physical health of the care-giver

Author (date)	Country	Study aim/design	Care-giver sample	Main outcome measures	Key findings
Anderson, Linto & Stewart-Wynne (1995)	Australia	To determine the effect of caring for a stroke survivor one year post stroke. Quantitative Longitudinal	N=84 Stroke	Impact and subjective distress – SBAS* Burden and emotional distress – HADS Psychiatric Illness – GHQ *The acronyms are explained at the end of the table	The areas of care-giver's life most affected were- - social activities (79%) - emotional health (79%) - leisure time (55%) 55% above the cut-off score for emotional illness on either the HADS or GHQ Emotional distress related to - dementia in care recipient - need to assist with bathing, grooming and feeding. Use of services not related to emotional distress.
Béthoux, Calmels, Gautheron, & Minaine (1996)	France	To determine the most pertinent factors of stroke spouse's QOL. Quantitative Cross-sectional	N=9 Stroke	Quality of life	Spouse's QOL scores were correlated with severity of patient disability as measured by the Barthel Index and the FIM.
Bugge, Alexander, & Hagen (1999)	Scotland	Quantitative Longitudinal To identify the level of strain experienced by care-givers in the early months after stroke, and to assess the relationship between strain, patient and care-giver characteristics, and service inputs.	N=110 Stroke	Strain (CSI)	Increase in strain related to - Time spent with care recipient - Time helping care recipient - Care-giver health - Stroke severity - Time since stroke

Author (date)	**Country**	**Study aim/design**	**Care-giver sample**	**Main outcome measures**	**Key findings**
Draper, Poulos, Cole, Poulos, & Ehrlich (1992)	Australia	To compare care-giver burden and psychological distress in stroke and dementia care-givers. Quantitative Cross-sectional	48 stroke and 51 dementia	Health – GHQ, number of GP visits, use of psychotropic medication. QOL Life satisfaction Social support Use of community resources Stress	Care-givers in both groups experienced high levels of burden and psychological morbidity. Burden and psychological morbidity were associated with behaviour and mood disturbance in the care recipient 80% of care-givers were satisfied with their current life. 17% reported an improvement in their relationship with the care recipient
Elmståhl, Malmberg, & Annerstedt (1996)	Sweden	To assess care-giver burden 3 years post-stroke To test validity and reliability of novel care-giver burden scale (CB scale) Quantitative Cross-sectional	N=35 Stroke	Burden - CB scale Psychopathology – CPRS) Questions about aggression and depression in care recipient	Factor analysis of the CB scale gave 5 indices of burden - general strain - isolation - disappointment - emotional involvement - environment Higher burden related to - closer relationship - improvement in ADL Lower burden related to - care recipient extraversion - care recipient QOL
Greveson, Gray, French, & James (1991)	UK	To assess the functional, emotional and social outcome of stroke after 3 years. Quantitative Cross-sectional	N=49 Stroke	Strain – CSI Subjective Health – NHP Level of support from informal, voluntary, and statutory services	30% of care-givers showed marked strain – CSI > 6. Strain was partly related to care recipient dependency, and appeared more frequently when care recipient attended day care.

Author (date)	**Country**	**Study aim/design**	**Care-giver sample**	**Main outcome measures**	**Key findings**
Hodgson, Wood, & Langton-Hewer (1996)	UK	To develop a predictive model for "at risk" stroke care-givers in the first year post-stroke. Quantitative Longitudinal	N=50 Stroke	Well-being Stress appraisal Care-giver health Level of activity (FAI) Satisfaction with formal and informal support services Family functioning chronic illness index Perception of loss Ways of coping index	Three predictive variables were - care-giver appraisal of care-giving stress - care-giver's physical health - care-giver's satisfaction with the provision of formal services Accounted for 53% of the variability in care-giver well-being 12 months post-stroke.
Kinney & Stephens (1995)	USA	To identify the specific stresses (hassles) and satisfactions (uplifts) of care-giving post stroke and to document the relationship between uplifts, hassles and three indices of care-giver well-being. Quantitative Cross-sectional	N=78 Stroke	Care-giver hassles and uplifts scale. Physical and cognitive limitations – revised London Psycho-Geriatric Scale Social activity restriction and negative personal relations – Caregiver Social Impact Scale Depression (SCL-90-R)	More uplifts than hassles were reported by care-givers. Appraisals were more strongly predicted by care recipient than care-giver characteristics. More physically impaired, cognitively confused or socially withdrawn – more hassles reported. Younger care-givers reported more uplifts. Hassles were negatively associated with well-being. When net uplifts outweigh hassles, care-givers less depressed and experienced better social relationships.
Macnamara, Gummow, Goka, & Gregg (1990)	USA	To characterize the development of care-giver strain in a sample of "successful" stroke-patient care-givers. Quantitative and qualitative Cross-sectional	N=41 Stroke	Strain (CSI) Anxiety, hostility and depression (POMS) Open-ended discussion	Care-giver anxiety, but not strain, hostility or depression, increased with time since stroke.

Author (date)	**Country**	**Study aim/design**	**Care-giver sample**	**Main outcome measures**	**Key findings**
Matson (1994)	UK	To examine the relationship between care-giver stress and depression and coping strategies. Quantitative Longitudinal	N=36 stroke, 37 dementia care-givers	Depression – BDI Hassles Belloc health measure Coping strategies	Higher levels of care-giver stress and depression were associated with - non-confronting coping - behavioural disturbance of care recipient Lower levels were associated with - tactical coping with specific hassles
Nieboer, Schulz, Mathews, Scheier, Ormel, & Lindenberg (1998)	Netherlands	To identify the relationship between disruption of life activities and depressed affect. Quantitative Longitudinal	N=127 stroke, hip fracture, congestive heart failure and myocardial infarction patients	Depression – HADS	Increase in care-giving demands resulted in increase in depressive symptoms. Activity restriction resulted in higher depression over time.
Periard & Ames (1993)	USA	To assess the perceptions of lifestyle changes and coping patterns of 20 care-givers of first time stroke survivors in the early post-stroke phase. Quantitative and qualitative Cross-sectional	N=20 Stroke	Semi-structured interview on lifestyle changes	Most care-givers experienced at least one lifestyle change, due to physical restriction or lack of time. Younger care-givers had higher levels of care-giver strain.
Purk & Richardson (1994)	USA	To test the relationship between morale of care-givers and morale of care recipients and care-giver's positive view of the care providing situation. Quantitative Cross-sectional	N=44 Stroke	Morale Care-giver impressions – closeness, household responsibilities, enjoyment of spending time with spouse, bother at the spouse's limitations.	Morale of care-giver and care recipient were positively correlated. Lower care-giver morale associated with having to provide assistance with transfers or personal care. Impressions of care-giving and care-giver morale were positively correlated.

Author (date)	Country	Study aim/design	Care-giver sample	Main outcome measures	Key findings
Reese, Gross, Smalley, & Messer (1994)	USA	To compare the psychological distress and immunological status of Alheimer's disease (AD) and stroke care-givers and non-care-givers. Quantitative Cross-sectional	3 groups of 25 Stroke AD	Depression – Zung Self-Rating Depression Scale Burden –Zarit Burden Interview Services and social support – OARS, PSSFR, PSSFA. Health Immune system function	No immunologic differences Both AD and stroke care-givers reported more symptoms of depression and fewer social resources and contacts than non-care-givers. No difference on self-reported health outcomes of care-givers and non-care-givers. AD care-givers had greater impairment in social functioning and more burden than stroke care-givers
Riedel, Fredman, & Langenberg (1998)	USA	To examine the associations between self-reported rewards and difficulties of caregivng and burden Quantitative Cross-sectional	N=200 64 stroke, 84 hip fracture and/or replacement, 32 other rehab.	Burden – Zarit Burden Interview	Burden was associated with - physical difficulty - emotional difficulty - social difficulty - multiple difficulties Higher level of burden with multiple difficulties. Care-givers who reported more rewards reported fewer difficulties. Rewards and difficulties - not mutually exclusive - their relationship affected burden.
Salz, Zimmerman, Tompkins, Harrington, & Magaziner (1998)	USA	To describe the stress reported by care-givers caring for someone up to one year post hip fracture, and identify the factors associated with the stress. Longitudinal Quantitative	N=230 Hip fracture	Strain - CSI	>4 considered indicative of strain. If the patient did not fall, strain reduced over time. Greatest degree of strain at 2 months post hip fracture (43% reported 4 or more strain items). Two of the 13 items were reported at increased rates when the patient fell during the 12 month study period.
Scholte op Reimer, de Haan, Pijinenborg, Limburg, & van den Bos (1998a)	Netherlands	Determine the reliability and validity of SCQ Quantitative Longitudinal	2 studies N=166 N=47 Stroke	Burden (SCQ)	Higher burden associated with - Higher impairment level of care recipient - Burden perceived as - feeling heavily responsible, constantly worried, and that care recipient relies on care-giver only.

Author (date)	**Country**	**Study aim/design**	**Care-giver sample**	**Main outcome measures**	**Key findings**
Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos (1998b)	Netherlands	Quantitative Cross-sectional To describe the level and nature of care-giver burden and estimate the relative contributions of patient and care-giver characteristics.	N=115 Stroke	Burden (SCQ)	Higher burden explained by - Care-giver emotional distress ($R^2 = 16\%$) - Care recipient impairment level ($R^2 =14\%$) - Care-giver loneliness ($R^2 =6\%$) - Care-giver's unmet needs for psychological care ($R^2 =4\%$) - Care-giver disability ($R^2 =3\%$) - Amount of care provided ($R^2 =2\%$) Care-giver's unmet needs for assistance with ADLs ($R^2 =2\%$)
Schulz & Tompkins (1990)	USA	Quantitative Longitudinal Identification of the impact of life stressors the relationships between stroke patients and their primary support persons.	N=150 Stroke	Depression Quality of social contacts Structural social networks	Care-givers who were at risk of depression - had higher initial depression scores - were less optimistic - had fewer networks - had poorer quality social contacts.
Segal & Schall (1996)	USA	To examine the relationship between care-giver life satisfaction and patient disabilities and handicaps Quantitative Cross-sectional	N=38 Stroke	Life satisfaction – LSIA Stress – QRS	Care-giver's satisfaction was - somewhat lower than that of the general population - directly associated with care-giver stress scores which were in turn associated with patient handicap.
Thompson, Bundek, & Sobelow Shubin (1990)	USA	To determine the factors associated with poorer care-giver adjustment. Quantitative Cross-sectional	N=40 Stroke	Depression – geriatric depression scale	Depression associated with - physical disability of care recipient - poor family functioning - care-giver's negative perception of care recipient - care-giver's loss of meaning about life.
Watson, Modeste, Catolico, & Crouch. (1998)	USA	To examine the relationship between the self-care deficits of patients and care-giver burden. Quantitative, cross-sectional	N=52 Stroke	Burden – Zarit Burden Interview	Higher burden associated with - greater impairment in self-care capacity and cognition in the care recipient - younger care-giver age.

Author (date)	**Country**	**Study aim/design**	**Care-giver sample**	**Main outcome measures**	**Key findings**
Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russell, & Beech (1997)	UK	Investigate the long-term outcome of stroke, for residents of a deprived inner city area. Quantitative Cross-sectional	N=38 Stroke	Strain – CSI Anxiety and depression (HADS)	5/37 care-givers had elevated anxiety, 8/38 had CSI scores >7. Over 50% of respondents agreed that aspects of the care-giving situation were upsetting. - Changes in the care recipient - Care recipient behaviour - Changes to personal plans.
Williams (1993)	USA	To pilot test questionnaires designed to examine the well-being of care-givers of stroke survivors. Quantitative Cross-sectional	N=28 Stroke	Depression Psychological distress Burden Health	45% of care-givers showed signs of depression and 40% had high levels of hostility. Mainly associated with dealing with cognitive and language impairment, demanding behaviour and incontinence.
Williams, Oberst, Bjorklund, & Hughes (1996)	USA	Quantitative and qualitative Longitudinal To examine the amount and type of care provided and the extent to which psychological distress changed over time and the expectations of recovery	N=57 Hip fracture	Care-giving demand scale POMS Semi-structured interviews	The location of the care recipient was a major factor in determining the type but not the amount of care required. Mood distress did not change over time. Care-givers seemed to have unrealistic expectations about recovery time.

BDI	Beck Depression Inventory
CSI	Care-giver Strain Index
FAI	Frenchay Activities Index
FIM	Functional Independence Measure
GHQ	General health Questionnaire
HADS	Hospital Anxiety and Depression Scale
LSIA	Life Satisfaction Index A
OARS	Older Americans' Resources and Services Multidimensional Functional Assessment Questionnaire, Social Resources Scale
NHP	Nottingham Health Profile
POMS	Profile of Mood States
PSSFA	Perceived Social Support from Family
PSSFR	Perceived Social Support from Friends
QOL	Quality of life
QRS	Questionnaire on Resources and Stress
SBAS	Social Behavioral Assessment Schedule
SCQ	Sense of Competence Questionnaire
SF-36	Self reported general health
SIP	Sickness Impact Profile

2.1.1 Negative outcomes for rehabilitation care-givers

The primary focus of the research into stroke care-giving has been on care-giver depression or burden of care (Han & Haley, 1999; Low et al., 1999). This was also the case for most of the orthopaedic studies located (Nieboer et al., 1998; Riedel et al., 1998; Salz et al., 1998). Although a number of different measures have been used to assess these outcomes, there have been consistent findings of elevated depression (Han & Haley, 1999) and high levels of burden (Bugge et al., 1999; Evans et al., 1992) among care-givers of stroke survivors.

In the studies reviewed here ten different negative outcomes for care-givers' emotional health were surveyed. The negative outcomes measured were –

- depression (twelve studies);
- burden (eleven studies);
- strain (five studies);
- stress (five studies);
- anxiety (four studies);
- psychological distress (two studies);
- psychiatric illness (two studies); and
- subjective distress, hassles, morale, and fatigue (each measured in one study).

Most studies claimed that there were elevated levels of these measures in the care-giver populations studied. However, only one study included a control group of non-care-givers for comparison. The authors found that stroke care-givers had more symptoms of depression than the general population but lower levels than care-givers of people with Alzheimer's disease (Reese et al., 1994). This finding was not supported by Draper et al., (1992) who found that care-givers of stroke survivors and people with Alzheimer's disease had similar levels of psychological morbidity. Some studies took a more holistic perspective and examined care-givers' quality of life (QOL) (Béthoux et al., 1996; Draper et al., 1992) or life satisfaction (Segal & Schall, 1996; Gladman, Lomas, & Lincoln, 1991), or examined positive as well as negative outcomes. For example, Kinney and Stephens (1995) examined both hassles and uplifts associated with the care-giving experience. The predominant focus of the literature, however, was on negative outcomes for the care-giver.

Identification of the factors associated with these negative outcomes was the purpose of much of the research (see Table 2, above). For the purpose of this review, the findings in relation to these factors have been grouped into three categories – factors associated with the care recipient, including the type of care required and the relationship factors; factors associated with the care-giver, for example coping strategies; and the impact of formal interventions, such as home-based rehabilitation (see Tables 3, 4, and 5 below).

Table 3 Studies that found that an increase in negative outcomes for care-givers was associated with care recipient characteristics

Factors associated with care recipient	Studies
Severity of disability or impairment, dependency (10 studies)	Bethoux et al. (1996); Bugge et al. (1999); Greveson et al. (1991); Kinney & Stephens (1995); Scholte op Reimer et al. (1998a, 1998b); Segal & Schall (1996); Thompson et al. (1990); Watson et al. (1998); Kotila, Numminen, Waltimo, & Kaste (1998)
Cognitive deficit/dementia, psychological or behavioural disturbance (8 studies)	Anderson et al (1995); Draper et al. (1992); Kinney & Stephens (1995); Matson (1994); Purk & Richardson, 1994); Watson et al. (1998); Wilkinson et al. (1997); Williams (1993)
Amount and/or type of assistance required (5 studies)	Anderson et al. (1995); Bugge et al. (1999); Nieboer et al. (1998); Purk & Richardson (1994); Scholte op Reimer et al. (1998b)
Improvement in ADL	Elmståhl et al. (1996)
Relationship type	Riedel et al. (1998)
Care recipient falling	Salz et al. (1998)
Incontinence	Williams (1993)
Sleep disturbance	Santamaria & McKenzie (2000)

Table 3 (above) illustrates that the care recipient factors most often associated with negative outcomes for care-givers were the disability or dependency level and psychological state of the care recipient and the type and amount of care-giving required. There is an obvious relationship between the three variables. The more physically or cognitively impaired the care recipient, the more assistance they are likely to require, and the assistance is more likely to be physically intimate and/or emotionally demanding. Assistance in personal activities of daily living was associated with poorer care-giver outcomes in two studies (Anderson et al., 1995; Purk & Richardson, 1994). However, these findings were not universally supported. Reese et al. (1994) did not find any association between depressive symptoms or burden experienced by the care-giver and the severity of stroke or dementia of the care recipient. Elmståhl et al. (1996) found a relationship between higher levels of care-giver burden and *improvement* in the patient's ADL status.

Two studies identified the duration of the care-giving (time since stroke) as an important factor in accounting for higher levels of stress in care-givers (Bugge et al., 1999; Macnamara et al., 1990) but a further two studies found that there was no change in care-giver outcomes over time (Kotila et al., 1998; Purk & Richardson, 1994). The timing of the four studies was different. The Bugge et al. (1999) study examined care-giving in the early stages post-stroke (1, 3, and 6 months), while Kotila et al.'s study (1998) looked at care-giving at 3 and 12 months post stroke and the care-givers in Purk and Richardson's (1994) study had been caring for a stroke survivor for up to four years. The Macnamara et al. (1990) study used a cross-sectional design to examine changes over time, which weakened the validity of their findings.

The timing of the study post stroke is important as there are likely to be changes in the outcomes for care-givers as they become experienced in the role, as they adjust to care-giving or become worn out, and as the care recipient's health status improves or deteriorates. Han and Haley (1999) also identified the timing of research post stroke as an important factor in determining care-giver outcomes in their review of 20 studies relating to care-giving for stroke patients. As with the studies reviewed here, the length of time that had elapsed between the stroke and the data collection varied considerably between the studies that they reviewed. For three predictors of depression reported in their review, there were different findings for the acute and chronic phases of care-giving. First, concern for future care was found to be an important predictor of depression only at the acute phase; second, a relationship between the patient's disability, measured by the Barthel Index, and care-giver depression was found only at the acute phase; and third, three studies (one specifying the acute phase) found a relationship between patient depression and care-giver depression and one did not (at the chronic stroke phase).

Furthermore two studies found that care-giver depression was more likely at the acute care phase (Schulz, Tomkins, & Rau, 1988; Tompkins, Schulz, & Rau, 1988 in Haley & Han, 1999) but no relationship was found between longer duration of care and care-giver depression. Unfortunately these phases were not adequately or consistently defined across the 20 studies reviewed. Definitions of the acute phase ranged from the time spent in hospital to six months post-discharge, and the chronic phase from seven months to four years post stroke. The research reviewed by Haley and Han suggests, however, that care-givers are more likely to be depressed in the early stages post stroke and that there are more known predictors of depression at this stage than at later stages of stroke care-giving.

This 'acute' phase in caring for a stroke survivor seems to be a very difficult time for the care-giver due to uncertainties about the future and the extent of recovery that the stroke survivor will make. As the care-giver and staff interviews conducted in this study will focus on the time immediately post-discharge from hospital, this study will provide qualitative data about care-givers' experiences of this phase of care. Furthermore information will be sought about about the care-givers' experiences of the transition of the care recipient from hospital to home from the perspectives of both care-givers and staff. As the focus of this study is not on care-giver depression, it will not seek to identify the factors associated with care-giver depression at this phase. However, this study should shed light on the ways in which care-givers are affected by the actions of the health service system at this early post-stroke stage.

The type of relationship, specifically being the daughter, rather than the spouse or other relative, was found to be significantly related to higher levels of burden in one study (Riedel et al., 1998). The relationship type has also been identified as important in other (non-rehabilitation) care-giver research (Schofield et al., 1998; Ungerson, 1987) but did not emerge as an important variable in the rehabilitation care-giving literature.

Table 4 **Studies that found that an increase in negative outcomes for care-givers was associated with care-giver characteristics**

Care-giver characteristics	Studies
Appraisal of situation (4 studies)	Hodgson et al. (1996); Purk & Richardson (1994); Schulz & Tompkins (1990); Thompson et al. (1990).
Health/disability (3 studies)	Bugge et al. (1999); Hodgson et al. (1996); Scholte op Reimer et al. (1998b).
Emotional distress/depression (2 studies)	Scholte op Reimer et al. (1998b); Schulz & Tompkins (1990).
Younger age of care-giver (2 studies)	Periard &Ames (1993); Watson et al. (1998).
Coping strategies – non-confronting coping	Matson (1994).
Loss of meaning about life	Thompson et al. (1990).
Loneliness	Scholte op Reimer et al. (1998b).

More studies found care recipient factors were associated with an increase in burden or strain for the care-giver than factors associated with the care-giver (see Table 4, above), or the provision of support. As Table 4 illustrates, however, the main care-giver factor that was associated with negative outcomes was the care-giver's appraisal of the situation. For example, Purk and Richardson (1994) examined care-giver morale and found that impressions of care-giving, such as feelings of closeness to the care recipient and enjoying the company of the care recipient, were correlated with higher care-giver morale. The four studies that recorded this finding examined well-being (Hodgson et al., 1996); morale (Purk & Richardson, 1994); and depression (Schulz & Tompkins, 1990; Thompson et al., 1990). A difficulty with these studies is that there is a conceptual overlap (and in some cases measurement overlap) between appraisal and outcomes. Both are aspects of the care-giver's subjective experience. For example, in the Purk and Richardson (1994) study the morale of the care-giver was found to be positively correlated with the care-giver's impressions of care-giving. It is difficult to determine whether low morale is an outcome of or a contributor to the care-giver's impressions of the situation, but, in either case, the care-giver is not happy with the situation. In this author's opinion, it is likely to be the situation that needs to be addressed rather than the care-giver's (possibly accurate) perception of it. It is acknowledged that cognitive behavioural approaches to counselling are based on the premise that altering a client's perception of their situation can alter their psychological distress. However, this study argues that applying these approaches to care-giving has resulted in too great a focus on the individual rather than society as the source and therefore the focus of resolution of care-giver distress. This issue is further discussed in the following chapter.

The health or disability level of the care-giver was also an important factor in accounting for elevated stress, strain, and burden. Three studies found that the health status of the care-giver contributed to poorer outcomes on these measures.

2.1.2 Positive outcomes for rehabilitation care-givers

Although positive outcomes were not the principal focus of the literature, there were some studies that examined the positive as well as the negative aspects of care-giving. These outcomes were explored both in their own right and to identify whether positive outcomes had any protective effect against the negative impacts of care-giving. Kinney and Stephens (1995) asked the 78 care-givers in their study to identify uplifts and hassles associated with the care-giving role, using the Care-giver Hassles and Uplifts Scale. Most care-givers reported both positive and negative appraisals of care-giving and overall more uplifts than hassles were identified. Kinney and Stephens (1995) also looked at the relationship between hassles and uplifts and care-giver well-being. They found that when net appraisals were positive, that is when uplifts outnumbered hassles, care-givers were less depressed and experienced better social relationships.

Riedel et al. (1998) conducted a study of 200 care-givers of rehabilitation patients (64 with stroke, 84 with hip fracture/replacement, and 32 with another rehabilitation condition). They examined associations between care-giver burden and self-reported rewards and difficulties of care-giving. They found that care-giver burden was influenced by rewards as well as difficulties. Care-givers who reported more than one type of difficulty reported higher burden scores, and, as care-giving rewards increased, burden scores decreased, regardless of the number of difficulties. They classified some types of rewards, including perseverance and learning experiences, as hardship rewards. These types of rewards were associated with increased burden. In conclusion, the study suggested that rewards counteract the effect of care-giving difficulties on burden and distress.

Draper et al. (1992) also measured the positive and negative aspects of care-giving in their comparison of the experiences of stroke and dementia care-givers. They found that caring for people with stroke and dementia produced similar levels of burden and psychological morbidity, but they also found high levels of life satisfaction. Eighty per cent (80%) of the care-givers interviewed stated that they were currently satisfied with their life, and 17% reported an improvement in their relationship with the care recipient since the onset of the illness. However, 90% of their sample were spouse care-givers so this finding may not be generalisable to other relationship groups.

The three studies discussed above found that care-givers experience both positive and negative outcomes in the care-giving role. There is also some evidence that positive outcomes provide some protection against negative ones. Consistent with the research about other (non-rehabilitation) care-givers (Stull, Koloski, & Kercher, 1994), these studies suggest that the positive and negative aspects of care-giving are different dimensions and are not mutually exclusive.

2.1.3 The impact of services on rehabilitation care-givers

There were three papers that reviewed the literature on family care-giving for stroke patients (Evans et al., 1992; Han & Haley, 1999; Low et al., 1999). All three reviews called for further research into the effectiveness of interventions to relieve care-giver strain and to improve the care-giver's quality of life.

This review located 15 studies that examined the impact of formal support services on outcomes for rehabilitation care-givers (see Table Five, below) and these have been divided into two categories. The first group of studies evaluated the outcomes for care-givers where the care recipient was involved in a home-based rather than hospital or clinic-based rehabilitation service (Anderson et al., 2000; Gladman et al., 1991; Rink, Sims, Walker, & Pickard, 1998; Slauenwhite & Simpson, 1998; Widén Holmqvist et al., 1996; Widén Holmqvist, von Koch, & de Pedro Cuesta, 2000; Young & Forster, 1992). The second group includes those studies that evaluated the effectiveness of a particular intervention, such as social work support (Dennis, O'Rourke, Slattery, Staniforth, & Warlow, 1997), outreach nursing (Forster & Young, 1996), or a volunteer support scheme (Geddes & Chamberlain, 1994), and those that included service use as a variable in assessing negative outcomes for care-givers (Anderson et al., 1995; Greveson et al., 1991; Hodgson et al., 1996).

Most (4) of the studies that compared home-based rehabilitation with a more conventional alternative found that there were no differences in outcomes for care-givers between the two program types. Three that compared home-based rehabilitation with hospital care found that there were more negative outcomes for care-givers in the home-based program. Anderson et al. (2000) conducted a randomized controlled trial comparing early hospital discharge and home-based rehabilitation with the usual inpatient rehabilitation and follow-up treatment and found that care-givers in the home rehabilitation group had significantly lower mental health scores. However, the same study found that there were no differences in satisfaction between the two groups of care-givers. This finding is consistent with that of Widén Holmqvist et al. (1996), which was the only other study to find reduced health outcomes for home-based rehabilitation care-givers. They also found that home-based rehabilitation suited the preferences of care-givers, despite the temporary decrease in subjective health status. Slauenwhite and Simpson (1998) examined the impact of "enhanced early discharge" from the perspectives of 23 care recipients and their families. They found that clients and their families were not satisfied with aspects of their interactions with the health system, specifically communication with nursing staff during the transition from hospital to home.

Table 5 Evaluation of the impact of home-based rehabilitation and other support services for rehabilitation care-givers

Author (date)	Country	Study aim/design	Sample	Main outcome measures	Key findings
Anderson et al. (2000)	Australia	To examine the effectiveness of an early hospital discharge compared with a home-based rehabilitation scheme for patients with acute stroke. Quantitative. Cross-sectional	N=49 Stroke	General health – SF-36 satisfaction	Care-givers in the home-rehabilitation group had significantly lower mental health scores. There was no difference in care-giver satisfaction between the two groups.
Braithwaite and McGown (1993)	Australia	To examine the effects of distress on the capacity of care-givers to absorb information about stroke and care-giving. Quantitative Cross-sectional	N=37 Stroke	Psychological health Burden Stroke knowledge Psycho-social loss	Caregiver's psychological state did not affect their capacity to take in information from a stroke seminar.
Dennis et al. (1997)	UK	To compare the outcomes for care-givers with and without social work support. Quantitative Cross-sectional	N=231 Stroke	Psychological well-being – GHQ, HADS Burden Activity level – FAI Social adjustment Satisfaction	Care-givers in the treatment group had better outcomes in mood symptoms than the control group.
Forster & Young (1996)	UK	To compare outcomes for care-givers with a specialist outreach nurse with those with no additional support. Quantitative Cross-sectional	N=139 Stroke	Psychological health – GHQ Health – NHP Activity level - FAI	There were no significant differences between the groups in psychological or physical health.
Geddes & Chamberlain (1994)	UK	To compare the outcomes for care-givers involved in the Volunteer Support Scheme with those with no additional support. Quantitative Longitudinal	N=27 Stroke	Anxiety and depression - HADS	There were no significant differences in anxiety or depression levels between the two groups.

Author (date)	Country	Study aim/design	Sample	Main outcome measures	Key findings
Gladman et al. (1991)	UK	To compare the effectiveness of day hospital with domiciliary physio and occupational therapy. Quantitative Cross-sectional	N=180 Stroke	Life satisfaction Social engagement	No significant difference in life satisfaction or social engagement between the two groups.
Kotila et al. (1998)	Finland	To determine the incidence and severity of depression in patients and care-givers at 3 and 12 months post stroke. Assess the impact of the existence of home-based rehabilitation programs on depression. Quantitative Longitudinal	3 months – 195 12 months – 184 Stroke	Depression - BDI	At 12 months the care-givers with no active home rehabilitation program were more severely depressed. Care-giver depression was associated with higher patient impairment. Half of all patients and care-givers were depressed at 3 months, no decrease at 12 months.
Logan, Ahern, Gladman, & Lincoln, (1997)	UK	To determine whether stroke patients benefit from the enhanced service compared with the usual service. Quantitative Longitudinal	N=55 Stroke	Psychological health – GHQ Adjustment to stroke Stroke information	There was no significant relationship between family education and family adjustment.
McLean, Roper-Hall, Mayer, & Main, 1991	UK	To investigate the perceived needs of care-givers and to test and identify outcome measures for future studies. Quantitative Qualitative Cross-sectional	N=20 Stroke	Anxiety and depression – HADS Semi-structured interviews about perceived needs.	Most care-givers identified unmet needs in areas of personal-emotional advice.
Slauenwhite & Simpson (1998)	USA	To examine the impact of enhanced early discharge on families experiencing repaired hip fracture in an older adult. Qualitative and quantitative. Cross-sectional	N=23 Hip fracture	Strain – CSI Questionnaire	Need for improved communication between nursing staff and patients and families especially during transition from hospital to home.

Author (date)	Country	Study aim/design	Sample	Main outcome measures	Key findings
van Veenedaal, Grinspun, & Adriannse (1996)	USA	To identify the information needs of stroke survivors and their family members. Cross-sectional Quantitative	N=39 Stroke	Educational needs	Care-givers were more concerned with information on how to avoid another stroke than with information about their current situations. Preferred source of information was hospital medical practitioner.
Widén Holmqvist et al. (1996)	Sweden	To assess the impact of home rehabilitation on care-givers. Longitudinal Quantitative	N=8 Stroke	Subjective well-being- SIP	Some decrease in care-givers' subjective health, but it was temporary and home rehabilitation suited care-giver preferences.
Widén Holmqvist, von Koch, & de Pedro Cuesta (2000)	Sweden	To assess the impact of rehabilitation at home after stroke on family care-givers. Quantitative Longitudinal	N=35 (at discharge) Stroke	Subjective well-being - SIP	No significant differences between the home-rehabilitation group and the routine rehabilitation (longer hospital stay) group in subjective well-being or amount of time devoted to helping the patient.
Young & Forster (1992)	UK	To evaluate the effectiveness of a domiciliary stroke rehabilitation service compared with day hospital rehabilitation. Quantitative Cross-sectional	N=63 Stroke	Stress - GHQ	There was no significant difference in care-giver stress between the two groups

BDI	Beck Depression Inventory	NHP	Nottingham Health Profile
CSI	Care-giver Strain Index	POMS	Profile of Mood States
FAI	Frenchay Activities Index	PSSFA	Perceived Social Support from Family
FIM	Functional Independence Measure	PSSFR	Perceived Social Support from Friends
GHQ	General health Questionnaire	QOL	Quality of life
HADS	Hospital Anxiety and Depression Scale	QRS	Questionnaire on Resources and Stress\
LSIA	Life Satisfaction Index A	SBAS	Social Behavioral Assessment Schedule
OARS	Older Americans' Resources and Services Multidimensional Functional Assessment Questionnaire, Social Resources Scale	SCQ	Sense of Competence Questionnaire
		SF-36	Self reported general health
		SIP	Sickness Impact Profile

Table 6 Impact on care-givers of home-based rehabilitation and other support services

Service Intervention	Outcome	Studies
Home-based rehabilitation compared with hospital or clinic based.	No difference in care-giver outcomes	Anderson et al., 2000 (satisfaction); Gladman et al., 1991; Widén Holmqvist et al., 2000; Young & Forster, 1992.
Home-based rehabilitation compared with hospital or clinic based.	Improved care-giver outcomes	Rink et al., (1998)
Home-based rehabilitation compared with hospital or clinic based.	Negative impact on care-giver outcomes	Anderson et al., 2000 (mental health); Slauenwhite & Simpson, 1998; Widén Holmqvist et al., 1996
Provision of support compared with no support	No difference in care-giver outcomes	Anderson et al., 1995; Braithwaite & McGown, 1993; Forster & Young, 1996; Geddes & Chamberlain, 1994; Logan et al, 1997;
Provision of support compared with no support	Improved care-giver outcomes	Dennis et al., 1997; Hodgson et al., 1996.
Provision of support compared with no support	Negative impact on care-giver outcomes	Greveson et al., 1991
Lack of support	Negative impact on care-giver outcomes	Kotila et al., 1998; Scholte op Reimer et al., 1998b; Schulz & Tompkins, 1990

Only one study found a positive outcome for home-based rehabilitation care-givers (Rink et al., 1998). This study conducted open-ended interviews with care-givers to find out about their experience of the program. The 26 care-givers included in this study were involved in the "Going Home Service", an early discharge support service for orthopaedic patients. The care-givers were mainly positive about the service and although they found that they had to do more for the care recipient at home than in hospital, they specifically identified not having to visit the patient in hospital as a positive outcome of home-based care.

Studies that examined the impact of other services, or included service use as a variable in explaining care-giver burden, reported similar findings to the home-based rehabilitation studies. Most (5) reported no differences in care-giver outcomes, two reported improved outcomes, and one reported a negative outcome, that the care recipient's attendance at the day centre was associated with higher levels of care-giver strain (Greveson et al., 1991). There were three further studies that identified lack of services as a problem for care-givers.

2.1.4 Staff perspectives of care-givers in home-based rehabilitation

Only one study examined the ways in which care-givers were perceived by program staff (Tamm, 1999). This study, conducted in Sweden, consisted of 30 interviews with 18 occupational therapists working in home-based rehabilitation and adopted a grounded theory approach. Tamm (1999) identified six categories of care-giver as perceived by occupational therapists. In three categories, the care-giver was regarded as a help (the rehabilitator, the creative problem solver, and the information bearer), and in the other three categories, the care-giver was regarded as a hindrance (the emotionally overheated party, the stopper, and the home protector). The interaction between the occupational therapist and the care-giver depended on the role of the family care-giver as perceived by the occupational therapist. Where care-givers were perceived as helpful, the occupational therapists found that their role was better defined and distinct.

In another paper by the same authors as the Rink et al. (1998) study described above, the roles and attitudes of the staff who were involved in the development of a home-based rehabilitation program in a hospital in London were examined (Sims, Rink, Walker & Pickard, 1997). Although this paper did not focus solely on care-giver issues, there were some interesting findings about the staff perceptions of the care-givers' experiences. Staff identified the need for improved communication within the "Going Home Service" team, between the team and hospital staff, and between all professional staff and patients and care-givers. Other care-giver related problems perceived by staff were having to communicate the "new culture" of the service to patients and care-givers; concern about the invasion of care-givers' privacy; and the additional burden on care-givers. This study will further explore the expectations and perceptions that home-based rehabilitation program staff have of care-givers.

2.1.5 Qualitative studies

Most of the studies reviewed here collected quantitative data. There were, however, three studies that investigated the experiences of rehabilitation care-givers using qualitative methods (Macnamara et al., 1990; Periard & Ames, 1993; Williams et al., 1996), and three studies that included some open-ended interview questions in the evaluation of a particular service (McLean et al., 1991; Rink et al., 1998; Slauenwhite & Simpson, 1998). The findings of these studies have been discussed above. There were an additional three studies that took a phenomenological approach to the examination of care-givers' experiences and one that conducted an open-ended investigation of the experiences of a large group of care-givers over a 12 month period after the care recipient was discharged from hospital (see Table Seven, below).

Grant and Davis (1997) interviewed 10 family care-givers and asked them to identify the problems associated with care-giving. The authors identified four major losses: the loss of the familiar self, due mainly to taking on different tasks to those with which they were familiar; the loss of the autonomous self, due to restrictions in personal freedom; the loss of the affiliate self, due to changes in relationships with family and friends; and the loss of the knowing self, due to taking on a role with which they were not familiar. Some similar themes emerged in a case study of a daughter care-giver of a stroke survivor which described her experiences over a six and a half month period (Fraser, 1999). The themes that emerged over this time were: changing relationships; becoming a care-giver then stepping back; enduring emotional turbulence; taking one day at a time; and struggling to hang on to hope. *"A new way of being in the world was experienced"* (Fraser, 1999, p. 9).

Table 7 **Exploratory studies of rehabilitation care-giving**

Author (date)	Country	Study aim/design	Sample	Key findings
Fraser (1999)	USA	Qualitative Longitudinal Single case study design	N=1 Stroke	Themes of - changing relationships - becoming a care-giver then stepping back - enduring emotional turbulence - taking one day at a time - struggling to hang onto hope
Grant and Davis (1997)	USA	To describe and categorise personal losses revolving around the self that care-givers experienced in caring for stoke survivors, qualitative, longitudinal	N=10 Stroke	Identified four major losses - loss of familiar self - loss of autonomous self - loss of the affiliate self - loss of the knowing self
Kane et al. (1999)	USA	To document the experiences of family members who were not necessarily already designated primary care-givers, in the aftermath of hospitalization. Qualitative Longitudinal	N=307 Stroke or hip fracture	Median time spent care-giving 2 weeks after discharge was 28 hours. Tasks diminished over time but shopping, transport, and supervision remained high for the whole year. Average time spent in care-giving for people living in the community was twice that of those in nursing homes. Low usage of formal services, and those largely during the first two weeks post-discharge. More negative effects when care recipient in a nursing home. Restrictions on their lives, stress and problems in the relationship with the care recipient were the most often identified problems. Positive effects when care recipient in the community mainly related to increased closeness, seeing the care recipient improve, and sense of achievement.
Wood (1991)	USA	To describe the activities and the inherent meaning of those activities in the care-giver role . Qualitative Cross-sectional	N=10 Physical rehab.	Care-givers reported that - they felt that they were the only person who could provide the care - the change in relationship had both positive and negative results - the transition from hospital to home was difficult - many care recipients had already progressed to their maximum potential in hospital so had deteriorated since coming home - care-giving had an impact on their work. Negative aspects of care-giving included –time commitments, physical and emotional demands and the inability to get out. Positive aspects included – a sense of fulfillment and an appreciation of life in general.

Wood (1991) interviewed a sample of 10 care-givers who were providing care for clients who had been recently discharged from a physical rehabilitation program (within the two months preceding the interview). All interviewees were relatives of the care recipients and believed that care-giving was their responsibility because of that relationship or because there was no-one else to take on the role. Like Wood (1991), other researchers have found that the transition from hospital to home is a particularly difficult time for care-givers (Slauenwhite & Simpson, 1998; Kane et al., 1999).

Kane et al. (1999) recorded the experiences of 307 care-givers of older people who had been hospitalised for stroke or hip fracture at six weeks, six months, and 12 months after the care recipient's discharge from hospital. This study investigated the amount and type of care-giving activities undertaken, the care-giver's use of formal services, the difficulties, learning needs and satisfactions associated with care-giving, the effects of care-giving on the relationship between the care-giver and the care recipient, and the care-giver's work and financial situation. Three interviews with each care-giver were conducted by phone using open-ended questions intended to elicit the care-givers' stories. The study was designed to address a gap identified by the authors in the existing care-giving literature, which was to document the experiences of family members who were not necessarily already designated primary care-givers, in the aftermath of hospitalization. The major findings of this study were that family care-givers experienced both satisfactions and difficulties associated with the care-giving role. The difficulties were associated with managing the emotional and social aspects of the role, rather than the physical tasks. There were more negative aspects associated with caring for someone in a nursing home than with home-based care, although community based care recipients required a high level of care, especially during the first two weeks post-discharge. As with other (non-rehabilitation) care-giver studies, service use was found to be low, with about 50% of care-givers using only one or two services, and these only during the first two weeks after discharge. The impacts on the care-givers' employment and financial situation were considerable, with care-givers reporting reducing or rescheduling their hours of work, giving up opportunities for promotion, and experiencing stress in attempting to balance work and care-giving.

Some of the issues identified in Wood's (1991) study and Kane et al.'s (1999) study are pertinent to this project. This study will focus on the experiences of care-givers in the time immediately post-discharge from hospital. The way in which care-givers (who may not already be primary care-givers) take on or are allocated the care-giving role will be examined, as will the amount and type of work they undertake, the positive and negative aspects of the role, and the impact that care-giving has on their family relationships, employment and leisure opportunities, and financial status. Although some of these issues have been examined in the general care-giving research, they have not yet been extensively explored with care-givers involved in a home-based rehabilitation program.

2.1.6 Summary and critique of rehabilitation studies

2.1.6.1 Study Findings

In summary, there are three main areas of focus in the rehabilitation care-giving literature to date. The first and most dominant area has been the impact of care-giving on the psychological state of the care-giver and identification of factors that contribute to or ameliorate negative outcomes for the care-giver. A second and related area of focus has been on more positive outcomes for the care-giver, both as a separate dimension of care, and as a protective factor against care-giver burden. The third area of interest has been the impact on care-givers of formal interventions, particularly home-based compared with hospital-based care. However, investigations into the impact on care-givers of home-based rehabilitation have also been limited to measuring whether these forms of intervention are detrimental to the psychological health of the care-giver. Apart from the study by Kane et al (1999), there has been little research into other outcomes for care-givers; for example, the impact on their employment opportunities.

Given that psychological health is the main focus of the literature, it is not surprising that some degree of strain, burden, or other psychological dysfunction has consistently found to result from the care-giving role. At the same time positive consequences of care-giving have consistently been found where these have been investigated. However, the lack of a point of comparison makes it difficult to interpret these findings. As George (1994) points out, it is not possible to compare care-givers and non-care-givers on care-giver burden indices. There is no 'normal' level of care-giver burden, nor is there a universal cut-off point. This methodological problem was evident in the studies reviewed here that used the CSI as a measure of strain. Threshold scores used to identify elevated strain included seven (Macnamara et al., 1990), six (Greveson et al., 1991), and four (Salz et al., 1998). The CSI is a 13 item index that asks the care-giver to indicate whether or not they have experienced sleep disturbance, inconvenience, confinement, family adjustments, physical strain, changes in personal plans, emotional adjustments, upsetting behaviour, work adjustments, financial strain, feelings of being completely overwhelmed, and whether they perceive the care recipient as a difficult person to care for (Robinson, 1983). The index has been validated for use as a screening tool to detect strain. However, it may be that a score of only one on this index (for example, the care-giver indicating that they feel completely overwhelmed) could be indicative of an unacceptable level of strain, depending on the context in which the care-giver reports this experience. Thus, not only is there a problem of identifying what constitutes an acceptable or normal level of strain in the literature, but there is also a problem of separating the strain index, designed as a screening tool, from the care-giver context. The focus on stress, strain, and burden and the factors that contribute to these outcomes can result in the care-givers' lived experiences becoming obscured. The complex interplay between positive and negative aspects of the experience, the relationship and family context, and the impact that care-giving has on the care-giver's work life and friendships can be lost in the quantitative findings. Furthermore, as will be discussed further in the theoretical sections of this thesis, the focus of the care-giving research and the consequent interventions has remained on the individual care-giver or the care-giver-care recipient dyad, rather than on the community and societal context in which care-giving takes place.

The studies in which depression was measured should have been able to compare care-givers with a matched control group. However, only one study used a control group to assess depression (Reese et al., 1994). Without a control group for comparison, it is not known whether the claims of elevated depression among rehabilitation care-givers are due to other factors, such as aging and restriction of physical activity for example, rather than the impact of care-giving.

Furthermore, in quantitative studies, the factors that are found to be associated with adverse psychological outcomes for the care-givers depend on the variables that are entered into the equation, rather than employing a more open examination of the care-givers' perceptions of the factors that contribute to stress, strain, or burden. For example, Nieboer et al. (1998) were interested in the relationship between increasing demands, activity restriction, and depression and so these were the only variables studied. Scholte op Reimer et al. (1998a), in validating the Sense of Competence Questionnaire, assumed that a higher level of burden would be associated with the impaired functional health of the patient. This assumption is not always supported by the findings of other studies.

Most of the rehabilitation care-giving literature examines the experiences of care-givers of stroke survivors. There are few studies that examine orthopaedic or other diagnostic groups in physical rehabilitation. This is perhaps due to the expectation that caring for people with these conditions is short-term, which is consistent with the paucity of research into short-term care-giving in general. However, one of the few studies that did investigate care-giving for people who had experienced a hip fracture (Slauenwhite & Simpson, 1998) found that the care-givers' expectations of recovery were met. Short-term care-giving and care-giving for people with orthopaedic and other rehabilitation conditions are investigated in the current study.

2.1.6.2 Study methodologies

There was considerable variation in the methodologies and the sampling strategies employed in the rehabilitation care-giving studies. Even studies with a similar focus investigated a range of different outcomes (depression, strain, burden, stress, morale, and anxiety) and employed different measures to do so. For example, five different measures were used to assess burden. These were the Hospital Anxiety and Depression Scale (Anderson et al., 1995), the subjective burden (CB) scale (Elmståhl et al., 1996), the Sense of Competence Questionnaire (Scholte op Reimer et al., 1998a; Scholte op Reimer et al., 1998b), the Zarit Burden Interview (Reese et al., 1994; Riedel et al., 1998; Watson et al., 1998), and the Questionnaire on Resources and Stress (Segal & Schall, 1996). These outcomes were also examined at different points in time. In the stroke literature the timing of administration of measures ranged from one month (Bugge et al., 1999) to five years (Wilkinson et al., 1997) post-stroke.

The dominance of quantitative methods in this field of enquiry has also led to inadequate exploration of several key questions. For example, the process of entry into care-giving has not been extensively addressed. Is there an assumption within the health care system that families can and will enter into the care-giving role? The sorts of decisions that are made within a family in order to manage the need to care for one of its members have not been explored. Is it assumed that the women within the family will provide the care or are other options canvassed? There has been no exploration of the inter-relationships between care-givers and home-rehabilitation programs that intervene in the care-recipient's home. This study will address these questions using qualitative methods.

2.1.6.3 Theoretical frameworks

Very few of the studies reviewed here have explicitly identified a theoretical framework. An implicit empiricist approach was used in the bulk of the literature. An empiricist approach is based on the assumption that through careful observation it is possible to collect objective data that are independent of the process of observation. The data thus generated can then be used to generalise about and predict future events (Crotty, 1998). An empiricist framework in this context assumes that care-giver strain is the result of the care-giving role, and that it is possible to identify the factors associated with greater or lesser amounts of this strain. One of the problems with this approach to care-giving is that the assumption of cause may be flawed. Further, it is very difficult to separate cause and effect or to determine the direction of the relationship. For example, the study by Scholte op Reimer et al. (1998b) found that higher levels of care-giver burden could be explained by care-giver distress, loneliness, and disability. However, each of these three factors could also be explained by care-giver burden, especially as the care-givers in this study were partners of people who had experienced a stroke three years previously.

Two studies that did identify a theoretical framework used a stress-coping (Reidel et al., 1998) or transactional stress (Kinney & Stephens, 1995) model in which it was expected that that positive appraisals of care-giving (coping) would mediate against the experience of burden or strain (stress). The stress-coping model has been widely used in care-giving research (for example, Wells & Over, 1998) as researchers have looked for a way to explain and alleviate the stress associated with care-giving. In the rehabilitation literature reviewed here, there has been much more emphasis on the stress aspect of the model than the coping aspect. However, a further review of the social work care-giving literature, discussed in the next chapter, has identified some studies that examine care-giver coping, service evaluation, and service use. It has been found that care-givers are often reluctant to use support services. The study by Kane et al. (1999) described in this chapter also found that care-giver service use is low.

Most (5) of the studies included in this review that examined the outcomes for rehabilitation care-givers who received support services compared with no support services found that the provision of the service made no difference to care-giver outcomes. However, two studies found that there were improved outcomes for care-givers who used services and one study found that there was a negative outcome (see Table Five). From the literature reviewed for this study, including the social work literature discussed in the next chapter, it would seem that support services may not address what care-givers want, or what is most effective in reducing the stress and strain associated with care-giving. Furthermore, the stress-coping model focuses on the individual and their immediate family and community support network. It does not critique the social and economic structures of class, race, and gender, which often serve to maintain individuals within a stressful occupation regardless of their personal and family coping mechanisms.

Although all studies of rehabilitation care-givers collected data on the gender of the care-givers and care recipients, this did not emerge as an important predictor of care-giver strain or depression. None of the studies took a feminist perspective, despite the fact that there were significantly more women than men in the care-giver samples; for example 82% women (Anderson et al., 1995) and 83% women (Macnamara et al., 1990). The only studies in which female care-givers did not predominate were those of spouse care-givers where the ratio was closer to 50:50 (for example, Draper et al., 1992). This is a major gap in the literature that will be addressed by this study. As will be discussed in the next chapter, this study takes a feminist perspective to examining the experiences and position of home-rehabilitation care-givers.

2.1.7 Conclusion and implications for this study

The main issues identified in this review of the literature on care-giving in rehabilitation to date are: the restriction of focus to the psychological outcomes for the care-giver; the restriction of the unit of analysis to the care-giver and the care-recipient; the lack of diversity in theoretical approaches; and the emphasis on quantitative methods of enquiry.

This study takes a different approach to any of the previous studies in this area. A feminist theoretical framework will be used to explore the experiences of care-givers in an open-ended way and the level of analysis will be expanded to include the interactions between care-givers and program staff. This will be done within the context of the implementation of a specific government policy, that of early discharge and the provision of rehabilitation services in the home.

As with most feminist research, the link between the personal (experiences of care-givers) and the political (the implementation of the policy of early discharge for rehabilitation) will be examined. The next chapter will provide a rationale for and a description of the feminist theoretical framework adopted in this study.

Chapter Three – Theoretical Framework: The invisible welfare state

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3.0 INTRODUCTION

In this chapter, the theoretical approaches to care-giving underpinning the research literature to date will be summarised and critiqued. The case for a feminist theoretical approach to care-giving in home-based rehabilitation, based on the theories of care-giving proposed by Abel and Nelson (1990) and Fisher and Tronto (1990), and the theories of patriarchy proposed by Walby (1990), will then be presented. The chapter has been divided into four sections. Section One outlines the assumptions on which the theoretical framework is based and the definitions that are pertinent to this chapter of the thesis. Section Two is a theoretical review of the social work literature on care-giving. Section Three presents the case for a feminist approach to care-giving and includes the criticisms that have been leveled at previous feminist literature on care-giving. Finally, Section Four outlines the feminist theoretical approach that will be tested in this study.

3.1 SECTION ONE: ASSUMPTIONS AND DEFINITIONS

There are a number of assumptions that underpin the theoretical approach taken in this study. The assumptions relate to the author's understanding of the nature of the social world, the relationship between individuals and society, and the way in which knowledge is acquired.

This study takes the position that the social world is essentially conflictual and that there are universal social structures that serve the interests of some at the expense of others. These social structures and relationships are seen as being continually constructed and reconstructed through human endeavour, power, and knowledge. Mulally (1997) describes social structures as consisting of *"boundaries, barriers, expectations, regulations and so on"* (p. 138). Connell (1987) defines social structures as "collective social arrangements" that are linked to personal life in a *"fundamental and constitutive way"* (p. 16). Some social structures are formal and visible, such as, legislation enacted by the state, and some are ideological and more subtly enforced, such as the ideology of the traditional male-headed nuclear family. All social structures restrict individual freedom to some extent and a functionalist view is that this restriction of individual freedom is in the best interests of the whole of society. A conflict view, however, argues that some sections of society (for example white, heterosexual, married, employed men) benefit from the way in which society is organized at the expense of others (for example, people of colour, lesbians and gay men, the unemployed, and women). The power and status of the dominant groups is maintained through oppression. Oppression occurs where the restriction of individual freedom is based not on individual behaviour, such as failure to adhere to the law, but on the individual's position as a member of a particular group or category of people (Mulally, 1997). Oppression is perpetuated by the dominant groups in society and is *"systematic and continuous in its application"* (Mulally, 1997, p. 138).

In this study, knowledge is understood as being socially constructed, rather than as objective (existing independent of human consciousness), or as subjective (existing only as perceived by the subject). In a constructionist epistemology, meaning is derived from the interplay between subject and object (Crotty, 1998). Knowledge is generated by human activity and is constituted in the interests of those who produce it. Knowledge is not natural or fixed; rather it is the result of the meanings generated through social interactions. These meanings are dependent on the historical, political, and cultural contexts in which the social interactions occur. The conflict view taken in this study is that certain dominant groups have constructed the knowledge that is commonly taken for granted. From a feminist perspective, most knowledge produced to date is seen as having been produced by and on behalf of men (Eisenstein, 1984). The key terms used in this chapter are patriarchy, gender and gender relations, the state, capitalism, and the family. These terms are defined below.

In this study, Walby's (1990) definition of patriarchy, as a *"system of social structures and practices in which men dominate, oppress and exploit women"* (p. 20) will be adopted. Her definition deliberately includes the notion of social structures in order to reject both biological determinism and the idea that every individual man is in a position of dominance over every individual woman. Further, Walby identified six structures which make up the system of patriarchy. These are paid work, housework, sexuality, culture, violence, and the state. She argued that the inter-relationships between these structures create different forms of patriarchy.

Gender is understood to be culturally and socially constructed, as opposed to sex, which refers to the biological characteristics of the individual. Gender relations refer to the division of *"responsibility, opportunity, and privilege, and the patterns of psychological interdependence"* between men and women (Dinnerstein, in Eisenstein, 1984, p. 80).

In this chapter, the state refers to the set of institutions including the legislature, federal, state, and local government, judiciary, police, and the armed forces (adapted from Abercrombie, Hill & Turner, 1994). The role of the state in constructing and reinforcing the social relations of gender is outlined in section 3.8 below.

There are many forms of capitalism, and capitalism is subject to constant historical change. However, for the purposes of this study capitalism, which is understood to be the basis of the Australian economy, has been defined as consisting of the following characteristics. Capitalism is characterized by the private ownership of the means of production, that is the resources, equipment, and capital required for exploitation of natural resources, manufacture, or exchange. Capitalism is concerned with the acquisition of profit, that is, the surplus of revenue over costs, in order to benefit the owners of the means of production. The existence of a free market as the regulator of economic activity is fundamental to capitalism as is the provision of labour by waged workers (adapted from Abercrombie, Hill & Turner, 1994). Capitalism has been both moderated and supported by the workings of the state. For example, Equal Opportunity Legislation is an attempt by the state to soften the workings of the market place. At the same time, the state provides much of the infrastructure costs of capital production, for example, roads, education and training, and medical care of the labour force.

One of the key contributions made by feminism has been to redefine the notions of 'public' and 'private'. In classic liberal political theory, the term 'public' referred broadly to that which was the concern of the state. The private realm, on the other hand, referred to the market or those parts of the economy that were seen as separate from the civil or state realm (Bryson, 1995). Family and personal domains were largely ignored by classic liberalism. Feminist theory, however, has redefined the public realm to include both the market and the state. The family has been included as a key element of the private domain. As Bryson (1995) states, *"transformation of the relationship between the public and private realms... in relation to such issues as violence and caring, is fundamental for feminist political theory as well as feminist activism*"(p. 22-23).

The definition of the family has also been subject to considerable debate and historical change and the varying definitions of family have social and political consequences for different sections of society. Eligibility for some entitlements and services provided by the state rely on definitions of the family that lead to inclusion and exclusion of certain groups, for example, homosexual spouses. One of the commonest and broadest definitions of a family is *"two or more people living together and connected by blood, marriage or adoption"* (Hartman, 1995). However, even this broad definition excludes some families; for example, single people who are part of a family who live elsewhere and homosexual couples. In this chapter, the family will mainly be referred to in the context of the ideology of the family or the family ethic, which are defined in section 3.4.2 below.

3.2 SECTION TWO: A THEORETICAL REVIEW OF THE SOCIAL WORK LITERATURE ON CARE-GIVING

As there was very little literature on care-giving in home-based rehabilitation that specified a theoretical framework, a further review of the social work literature on care-giving was conducted. The social work literature was chosen because it was expected that it would include some structural analysis of care-giving as well as individualistic and systems approaches. Social work education in Australia has a strong if not dominant tradition of radical and structural approaches (Fook, 1993; Mulally, 1997). Further, social work as a profession focuses on the interface between the individual and their political and social milieu (Compton & Galaway, 1999) so it was expected that there might be some theoretical literature on care-giving that would be relevant to this study.

As discussed in the previous chapter, there is an absence of explicit theory testing in most of the literature on care-giving in home-based rehabilitation. Implicit in the bulk of the research, however, is a stress-coping framework. Similarly, a review of the social work literature on care-giving revealed that, despite the social justice concerns of social work, most of the research into care-giving takes an individualistic stress-coping theoretical perspective (Dow & McDonald, in press[3]). Although this approach has helped social workers to identify the coping strategies associated with managing the care-giving role, it is seen here as having the following limitations. Firstly, it focuses on the problems associated with care-giving experienced by the individual care-giver. This has the potential to problematise the care-giver; seeing his or her inability to cope as the problem, rather than structural factors, such as the contraction of state-funded care, as the problem. This, in turn, restricts the way that care-giver concerns are dealt with. Support services are seen as the key to maintaining care-givers in the role. This solution to care-giver problems has not always been seen by care-givers as helpful. Care-givers have been reluctant to use support services (Cox, 1999; Kane et al., 1999; Ganzer & England, 1994) associating them with a sense of failure (Heenan, 2000), or being unwilling to entrust the duties of care-giving to

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[3] This paper has been accepted but not yet published by Australian Social Work.

others (Ganzer & England, 1994). Finally, a stress-coping approach tends to view the care-giving relationship as uni-dimensional, in which the care-giver is burdened by the demands of caring for the care recipient, resulting in a negative view of the care-giving relationship.

Interpretivist approaches have also been used to understand the experiences of care-givers. These approaches are less prominent in the social work literature than the stress-coping approach discussed above. However, a number of studies by nurses have taken these approaches (Grant & Davis, 1997; Fraser, 1999; Wood, 1991). These approaches are concerned with the meanings and interpretations that care-givers give to their experiences and with honouring and exposing these alternative perspectives. This approach has led to some alternative ways of working with care-givers. For example, Ganzer and England (1994) recommended that social workers adopt a narrative approach with their care-giver clients. They suggest allowing clients to tell their stories brings order and coherence to their experiences and eventually enables them to construct new stories that will assist them to move forward. The problem with these approaches is that, like the post-modern or post-structuralist approaches, they do not challenge the broader social structures within which the care-giver is located.

A third approach identified in the social work literature on care-giving was a systems or ecological perspective. However, despite the influence of this approach on social work practice (Compton & Galaway, 1999) it was not the dominant approach in the care-giving literature, appearing in only 10 of the 102 articles reviewed by Dow and McDonald (2003). Like the other approaches discussed above, the systems approach offers some alternative ways of working with care-givers and their families but does not advocate any radical changes to the care-giver situation.

Finally, there were eight articles located by Dow and McDonald that took a structural or feminist approach to care-giving. Three of these studies were policy analyses (Barusch, 1995; Butler & Weatherley, 1992; Scheyett, 1990), three examined race and care-giving (Delgado & Tennstedt, 1997: Gelfand & McCallum, 1994; Purdy & Arguello, 1992), one looked at the care-giving experiences of lesbians and gay men (Fredriksen, 1999), one examined the interface between employment and care-giving for female breadwinners (Gibeau & Anastas, 1989), and one was an editorial examining aging as a feminist issue (Hartman, 1990). There were no empirical studies that examined the experiences of individual care-givers from a feminist perspective.

The three policy analyses provided a critical analysis of the current position of female care-givers from an international perspective. Barusch (1995) conducted an international survey examining the ways in which families are encouraged or required by the state to undertake care-giving. She identified three existing strategies for increasing family care of older relatives. These were: filial support legislation, where there are legal requirements for the family to care for their elderly relatives; incentives for family care-givers, such as, tax concessions or direct care-giver payments; and services rationing, whereby services are only made available to people without family members who are deemed to be capable of providing care. Each of these approaches was criticized by Barusch for ineffectiveness and lack of social justice. Butler and Weatherley (1992) examined social policy in the United States as it affected poor women at midlife and concluded that this group of women was particularly vulnerable to the categorical and residual approach to welfare of the United States government. They too argued for a more socially just society in which men and women have equal rights to contribute and be cared for.

Sheyett (1990) examined the policy of de-institutionalisation of people with mental illness and argued that there had been a transfer of care from the state to women. She contended that *"the culture of caring, disguised as a "natural" virtue and duty, is a form of oppression for women because it is non-optional, unrecognised, unrewarded labour that limits women's choices and opportunities and restricts self-exploration and self-determination"* (Scheyett, 1990, p. 33). All three of the studies discussed above called for a more socially activist stance for social work. Butler and Weatherley (1992) argued for social workers to adopt structural and feminist approaches and to join with oppressed groups to explore ways with them to advocate for change. Scheyett (1990) made a number of recommendations for social work practice including the development of social policy that recognizes the special requirements and contributions of care-givers. She suggested that social workers should be engaged in: urging the state to provide financial support; advocacy for support services, particularly respite care; training in gender issues; feminist research; and addressing women's oppression in society as a whole. However, in the ten to twelve years since the publication of these three papers, most practice interventions, at least those reported on in the social work literature, have continued to focus on individual coping and social supports. At the same time, advocacy for the development of socially just policies and feminist research and training in this area have all been sadly neglected. This study takes up the issue of the lack of feminist research in this area by taking a structural feminist approach in its examination of care-giving in home-based rehabilitation.

3.3 SECTION THREE: THE CASE FOR A FEMINIST APPROACH TO CARE-GIVING RESEARCH

It is generally agreed in the literature that family care-givers are mostly women. Where the study sample is not restricted to particular kinship groups, this is certainly the case, with estimates ranging from 65% (UK General Household Survey) to 78% (Victorian Care-giver's Program) (Schofield et al., 1998). However, where the sample includes only spouse care-givers, the male to female ratio becomes more balanced. For example, Wells and Over (1998) found that in their sample of 100 couples, there were 42 husbands caring for wives and 58 wives caring for husbands. Arber and Gilbert (1989) identified four types of kinship relationships between the care-giver and care recipient. In three out of four categories, women outnumbered men. In the fourth category, spouse care-givers, there were as many men as women. Arber and Ginn (1990) found that from age 30 to 69 there was a higher proportion of women care-givers, but from 70 onwards, there was a higher proportion of men. The higher proportion of men in this age group would seem to suggest that men are more likely to engage in care-giving when they are no longer engaged in the workforce.

There has been some debate in the literature as to whether spousal care, unlike other kinship groups, represents an equal and reciprocal exchange of care between men and women. Gibsen and Allen (1993) argue strongly against this view. They examined evidence from Australian research (Kendig, 1983; 1986; the Australian Council of Social Services (ACOSS) & Department of Community Services (DCS) report, 1985, in Gibsen & Allen, 1993) on spouses who cared for one another and found that, far from an equal distribution of work, 50% of women who became frail and disabled still prepared meals for their non-frail spouses and one third still took responsibility for the housework. The reverse was not true for men. However, men did take more responsibility for home maintenance tasks. As Gibsen and Allen (1993) point out, these tasks do not need to be undertaken daily and can often be put off if necessary, unlike meal preparation, errands and cleaning. This point is also made by Jutras and Veilleux (1991) in their analysis of the types of assistance provided by male compared with female care-givers. Female care-givers were more likely to be engaged in activities that were *"essential, recurrent, and must be undertaken with little or no delay"* (p. 15). Furthermore, Gibsen and Allen (1993) found that marriage provided men with greater protection from institutional care than women, with men being less willing or able than women to look after their frail spouse at home. This finding is also supported by Arber's analysis of the most recent UK General Household Survey, reported on in a paper presented at Victoria University, July 2002. In her analysis of the relationship between marital status and well-being in older age, she found that the group least likely to enter institutional care were married men.

Some of the literature that examined gender differences in care-giving has found that men take on different tasks than women, and do less than women when they take on the care-giving role. Arber and Ginn (1990) in their examination of the UK General Household Survey found that female co-resident care-givers provided on average 57 hours of care per week, and male co-resident care-givers provided 46 hours per week. Non-resident care-givers provided ten and seven hours respectively. Stommel, Collins, and Given (1994) also found a gender difference in the types of activities taken on by male and female care-givers. Men were inclined to take on case management while women were more likely to take on "hands on" activities, such as personal care. However, these findings have not been universally supported, with some studies reporting no gender difference in the amount of help provided to the care recipient (Braithwaite, 1990; Tennstedt et al., 1992; Williamson & Schulz, 1990).

Gibsen and Allen (1993) recommended the rejection of a gender neutral analysis of care-giving, arguing that women's labour, not men's, maintains older couples in their own homes, representing a significant saving to the public purse. They examined the different types of services that men and women need and use. They found that men use a disproportionate amount of community services compared with women. The types of services that men required are also more freely available than those required by women. Male care-givers have less trouble accessing services than their female counterparts because they are seen as less able to do these things for themselves. Arber and Gilbert (1989) also found a gender difference in the receipt of community services, particularly Meals on Wheels, with men being more likely to receive help than women. This finding was supported by an Australian study of the costs of community care for Linkages clients. Being a male carer was found to be one of the predictive factors of increased costs, regardless of the disability level of the client or carer residence (Kendig, Wells, Swerrissen & Reynolds, 1999). However, some studies do not support the view that men receive a disproportionate amount of community services. For example, Thompson, Futterman, Gallagher-Thompson, Rose, and Lovett (1993) found no difference in service provision by gender. On the basis of their review, Gibsen and Allen (1993) concluded that the welfare system is "parasitic" on women and "phallocentric". The long-term care system, they argued, is reliant on the free labour of older women but is more responsive to the needs of older men.

Thus, there is consistent evidence in the literature that, with the possible exception of older male spouse care-givers, the majority of care-givers are women. In most cases women provide more assistance than men, and are engaged in different care-giving activities from men. Furthermore, most of the literature indicates that men who do provide care receive more help from community services than female care-givers. Clearly a gender inequality is perpetuated in the area of informal care, and for this reason there is a strong case for a feminist theoretical perspective in care-giving research. A feminist perspective offers more than just a focus on the individual women providing care. It also shifts the focus away from individualised solutions to structural ones. As Hooyman and Gonyea (1995) argued, *"to frame care-giving as a feminist issue is to make explicit the underlying social, economic, and ideological structures that devalue caring across populations and limit women's choices across the life span, both within the home and in the labor market, thereby systematically disadvantaging them economically. Bringing to bear a feminist perspective defines care-giving as a societal, not an individual responsibility"* (p. 20). Despite the lack of feminist research within the rehabilitation and social work literature, in the broader care-giving literature there has been a significant contribution from feminist scholars, which is outlined in the next section.

3.3.1 Feminist analyses of care-giving to date

The feminist analyses of care-giving in Britain and Scandinavia developed in response to government policies of the 1960s and 70s, which shifted the responsibility for care of older and disabled people away from institutions to the community (Finch, 1990). Ungerson (1997) identified three phases of feminist analysis. Initially, in Britain, feminist analyses were concerned with describing care, and counting the number of care-givers (Ungerson, 1997). Following this was an analysis of the government policies of de-institutionalisation and community care. This work led to the exposure of the assumption by policy makers that families, and therefore women, would provide care in the community (Finch, 1990; Wærness, 1990). Some work was then done by feminists to promote alternative policies that lessened the exploitation of women, for example, collective care provisions (Finch, 1990) or payment for care-givers (Ungerson, 1990).

There were also some early psychoanalytic explanations of the gendered nature of care-giving (Ungerson, 1987). For example, Gilligan (1982, in Ungerson, 1987) argued that the different Oedipal stages that boys and girls go through result in the development of different moral frameworks in mature men and women. Men are more oriented to rights, *"which are subject to public and rational assessment"* and women to responsibilities, *"which are private and sensitive to individuals and their particular relationships"* (p. 146). Women are therefore more concerned with human relationships than men and more attuned to recognizing and catering for the needs of others. As both Graham (1983) and Ungerson (1987) point out, these arguments run dangerously close to essentialism; that is, the view that care-giving reflects women's fundamental nature and fulfils her needs.

The relationship between care-giving and class has also been subject to feminist analysis. Arber and Ginn (1992) pointed out that in all the literature that had been written about care-giving prior to the early 1990s, there had been virtually nothing written about the class dimensions of care. They examined the 1985 UK General

Household Survey and found that while informal care-givers as a whole are drawn from all classes, co-resident care-givers are more likely to be working class. They identified a number of ways in which class impacts upon informal care-givers and, conversely, ways in which disability and being an informal care-giver impact upon class. They argued that due to the poorer health status of the working class, working class women are more disadvantaged by the demands of providing informal care than middle class women. While most older people are likely to experience periods of ill health prior to death, it happens at an older age for middle class than working class people. This means that middle-class female care-givers are likely to be older and more likely to have retired from paid employment when their care-giving services are required. The demands of caring for younger working class care-givers, however, are more likely to impact upon their work opportunities, thus compounding their disadvantaged position. Furthermore, middle-class care-givers are more likely to be able to alter their work arrangements to meet the requirements of care-giving than working class care-givers (Abel, 1990). Mutschler (1989, in Krach & Brooks, 1995) found that care-givers who were executives or professionals were more likely to rearrange their work schedules than production workers who were more likely to take unpaid leave. In another study that examined the relationship between class and care-giving, Butler and Weatherley (1992) examined the lack of policy response in the United States to women who are poor at mid-life. They argued that these women are often poor because their productive roles as care-givers, both for dependent children and older relatives, have limited their opportunities to participate in paid employment, except in care-giving roles such as nursing attendants in residential care settings or home care workers in the community. These roles, they argued, are devalued and poorly compensated, both in the paid workforce and through social supports provided by the welfare system. There is also a class factor in the ability to purchase paid, formal care. Caldock (1992, in Arber and Ginn, 1992) found that only the middle class elderly purchase private home help. Stommel et al. (1994) found that gender and employment status do not influence the tendency to purchase services. However, they did find that reliance on paid services is 5% higher with each additional US$10,000 household income.

There is also a relationship between care-giving, employment, and financial security in later life. The impact of care-giving on the employment opportunities of care-givers has been well documented in the literature (Arber & Ginn, 1992; Guillemin, 1999; Rosenmann & LeBroque, 1996). Schofield et al. (1998) found that care-givers of working age are less likely to be in paid employment than non-care-givers. Having to take time off work or alter work arrangements are common outcomes of the dual role of care-giver and employee (Guillemin, 1999). Glezer & Wolcott (2000) examined the impact of care-giving on work and work on care-giving in the Australian context. In their review of the Australian Bureau of Statistics (ABS) data from 1994 and 1995, they noted that 70% of people caring for disabled persons are in the labour force, but that a third of primary care-givers had left paid employment after assuming their care-giving role. Forty-two percent of those who had left work were women aged between 45 and 64 years and 26% were women aged between 25 and 44 years, but only 3% of men aged between 25 and 44 years had left work due to their care-giving responsibilities (Gelzer & Wolcott, 2000). As retirement income (and in some countries, eligibility for income support) is based on the number of years spent in paid employment, care-giving has a long-term as well as immediate impact on the care-giver's financial well-being.

Participation in the paid labour force has also been found to have some benefits for female care-givers, despite the obvious stresses involved in juggling the demands of both activities. Schofield et al. (1998) found that full-time employment is associated with fewer health problems for both care-givers and non-care-givers. Cain and Wicks (2000) found a lower level of burden in care-givers employed part-time givers than in those not employed outside the home, or those employed full-time. This finding, however, is based on a very small sub-sample of care-givers (n=12), as 68% (n=94) of their sample were not employed outside the home. Arber and Ginn (1990) argued that there is a gender difference here. For women, going to work, especially part-time work, may act as a respite from the demands of care-giving, but for men, taking on the multiple roles of care-giver, father, and employee is more difficult. Conversely, a study by Anastas, Gibeau, and Larson (1990) that examined the competing demands of care-giving and employment from the point of view of employees who also described themselves as care-givers found that women are more likely to report conflicts between work and care-giving than men are. They also found that women spend more time in care-giving than men. However, unlike the previous studies, this study did not compare working care-givers with non-working, but male and female care-giving employees.

Care of an ill or disabled family member or friend is disproportionately done by women in late midlife, which is also the time in the life course when women's labour force participation peaks (Pavalko & Artis, 1997). However, entering employment does not mean that women are forsaking care work. Because of social pressures, gender expectations, and lack of alternatives women are adding to their responsibilities rather than shifting them: women with careers are no less likely to provide care than other women are (Cox & Spalding, 1996; Pavalko & Artis, 1997). There are important differences between men and women who combine work and care-giving. Care-giving women are more likely than their male counterparts to be employed part-time rather than full-time (Robinson, Moen, & Dempster-McClain, 1995). Fredriksen (1996) reported that in comparison with men who both provided care and were employed, women in those two roles have lower household incomes and are assisting care recipients with higher levels of cognitive and behavioral impairments. The women also report higher levels interference of care-giving in their work. Scharlach (2001) suggested that the majority of gender differences in the integration of family care and work are likely to reflect differences in the gender distribution of demands and resources, including pay, rather than gender per se.

Browne (1998) described care-giving as a site of intersecting oppressions for women, that is; gender, race or ethnicity, class, and sexual orientation. She argued that women's lives are characterized by care-giving whether or not they are also engaged in paid employment, no matter what sort of family they come from, and whether single, lesbian, or widowed. Hooyman and Gonyea (1995) examined the impact of care-giving on women across the life span. For many women care-giving is a life-time responsibility although the recipients of care may change from children to older adults. They point out that caring across the life course has severe economic repercussions for women in older age. From the feminist analysis of care-giving discussed above, it can be seen that care-giving is a site where the inequalities of gender and class intersect; where the dual forces of capitalism and patriarchy combine to restrict the opportunities for women's equal participation in society.

The feminist analyses of care-giving to date have been largely restricted to analysis of existing data sources, for example, the UK General Household Surveys (Arber & Ginn, 1990, 1992), policy analyses (for example, Scheyett, 1990), or reviews of the existing literature (for example, Gibsen & Allen, 1993). There has been little feminist analysis of the lived experiences of the women who are in the care-giving role. The exception to this is a study by Ungerson (1987). Ungerson interviewed 19 care-givers and looked at life style issues, reasons for caring, the way that care-givers felt about providing care, and moral issues related to care-giving, and took a gendered perspective throughout. The sample in Ungerson's study broadly reflects the samples in other studies in which most male care-givers were older spouse care-givers as the four male care-givers interviewed were all over 65 years and all caring for their wives. By contrast eleven of the women were caring for someone other than their husband. In her discussion of life cycle factors, Ungerson (1987) concluded that *"no woman is a volunteer*" (p. 83). She argued that women, unlike men, were subject to considerable ideological and material pressure to be the care-givers of last resort. This pressure was not moderated by their personal circumstances, whether or not they are in paid work, or whether they would prefer to spend their time with their children. In fact, many of the care-givers interviewed felt guilty about their neglect of their husbands and children.

Ungerson found that the material explanations of care-giving, that is the material benefits to the state, men, and capital, and the material disadvantages for women in the gendered division of caring labour, are not enough to explain the loving basis of caring. Strong themes of love and compassion were expressed by the care-givers interviewed. Drawing on the work of Graham (1983), Ungerson argued that the reality of care-giving may be dichotomized, with one group of care-givers being happily engaged and finding their identity through care-giving, and another group feeling exploited. In Ungerson's (1987) words, the latter group *"bitterly regret their loss of autonomy and identity because, through the operation of gendered expectations and obligations, their own needs have become subordinate to the more pressing needs of someone else"* (p. 149). However, more recent literature on motivators of care suggests that Ungerson's conclusion may be too simplistic, with many care-givers feeling both love and obligation.

Abel and Nelson (1990) identified two main feminist theoretical approaches to care-giving. One approach emphasizes the instrumental component of care-giving and sees care-giving as oppressive to women. The other emphasizes the emotional aspect of care-giving and sees care-giving as providing meaning and fulfillment for many women. The first approach, which includes the socialist feminist analyses of care-giving, defines women's work within the home as productive labour and emphasizes the importance of women's reproductive labour to the capitalist economy. Care-giving is not seen as a choice, but an obligation resulting from a mix of material and ideological forces. The second approach argues that care-giving is not only fulfilling for many women, but that care-giving makes the care-giver better able to interact with and understand the needs of others.

Abel & Nelson (1990) argued that both the material and psychological approaches to care-giving are inadequate. The first approach ignores the human side of care-giving, that which Ungerson described as the "loving basis" of care-giving. The second approach with its emphasis on women's fulfillment risks becoming a rationale for the maintenance of women in a subordinate position. Abel and Nelson (1990) point out that in both the private and public domains, *"care-givers are members of subordinate groups, who provide care from compulsion and obligation as well as warmth and concern"* (p. 7). They argued that care-giving has to be understood from within the context in which it occurs, suggesting that the three main contexts of care-giving are the household, formal organizations, and unaffiliated providers. Each of these contexts, they argued, is unable to provide the resources that the care-giver needs to provide care. In the household, the care-giver is often isolated and unable to place limits on their work, and the relationship with the care recipient is complicated by their kinship relationship. In formal organizations, care-givers are often prevented from providing what they consider to be good care by the bureaucratic requirements of the organization in which they are employed. Abel and Nelson (1990) gave the example of a hospital nurse who is working with a withdrawn and depressed patient who, after several days of being withdrawn, starts to share her concerns with the nurse just as the evening meals are served. The nurse has to make the choice between attending to the emotional needs of one patient or the physical needs of several other patients. They pointed out that while formal organizations provide some protection from overwork and exploitation through the establishment of set working hours and clear job descriptions, these organisations also interfere with the human connections that are integral to care-giving. The third context of care-giving identified by Abel and Nelson was unaffiliated care-giving. This is paid care-giving that takes place outside the context of a formal organization, for example, paid personal carers who are employed directly by the care recipient or his or her family.

Fisher and Tronto (1990) also argued that care-giving is best understood within the settings where it occurs. They identified three modes of care: the household/community, the marketplace, and the bureaucracy. They described household/community care as a pre-capitalist mode of care-giving in which women have responsibility for, but also power over, care-giving within a community based on equality, justice, and trust. Resources are shared between equal community members and care-giving is a community rather than individual or family concern. In relation to the marketplace, Fisher and Tronto suggested that, with the introduction of capitalism, the household/community mode of care was altered and new forms of care were created outside the household/community. The household mode of care was altered because the dwindling of community resources meant that women became reliant on goods and services purchased in the marketplace in order to undertake their care-giving role. Although women still retained responsibility for care, power over the caring process shifted to men because of their greater earning capacity. Women care-givers became increasingly isolated from community networks, resulting in the problems of household care described by Abel and Nelson above. The bureaucratic mode of caring is where the state became involved. This mode includes the large hierarchical public institutions devoted to caring, as well as those provided through the market. Care-giving within this mode, Fisher and Tronto (1990) argued, has become fragmented and inadequate. Bureaucracies serve the interests of bureaucracies rather than the needs of their clients. Further, bureaucracies separate the process of care-giving from taking care of (or caring about). The actual hands-on care is provided by people at the bottom of the hierarchy who are far removed from the people who make the decisions about the routines and standards that govern the provision of care. In order to provide adequate care, women, who predominate in the actual care-giving roles, may have to break the rules, thereby risking their position within the organisation.

Abel and Nelson (1990) also discussed the interactions between household care-givers and the outside world. They described the intrusion of experts into the relationships between mothers and children. These experts assume that there is a standard of motherhood to which mothers should conform and that mothers are ignorant and need to be informed by experts. The development of education services for care-givers of the elderly may be seen as a similar intrusion. Abel and Nelson also described the increasingly technological and complex activities that care-givers of the frail elderly are expected to perform, pointing out that this type of care is sometimes more complex that that which nurses are expected to perform in hospitals. Care-givers are increasingly involved in mediating between the realms of the household and the outside world.

The theoretical approach used in this study will draw mainly from the feminist work, described above, that has identified material and ideological forces, rather than women's psychological make-up, as most important in explaining the gendered nature of care-giving. It will also draw on the work of Abel and Nelson (1990) and Fisher and Tronto (1990) in that the home as a context of care, and the interactions between the home and hospital contexts will be a major focus of the study. However, there have been some criticisms of the feminist approaches to care-giving described in this section, which will be examined in the next section.

3.3.2 Criticisms of feminist accounts of care-giving

It has been argued that the common assumptions in the feminist analyses of care-giving in Britain and the United States until the late 1980s were that care-givers were primarily middle aged women, providing care for people within their kinship network, for which they were not paid (Graham, 1991, 1993). There was also a focus on care-giving as work (or domestic labour) (Arber & Ginn, 1997), and the effect that engagement in the work of care-giving had on women's ability to participate in the labour market (Morris, 1997). This conception of care-givers has been criticized on several grounds. First, more recent research has revealed that within certain relationship groups, there are almost as many men as women providing care (Arber & Ginn, 1997). Second, the focus on women care-givers can reinforce rather than challenge the perception that it is a woman's role to care. Third, the absence of the perspectives of care recipients themselves has been seen as problematic (Morris, 1997). Fourth, more recently various forms of payment for care have become more common (Ungerson, 1997). Finally, the experiences of Black and lesbian women have been excluded from the above construction of care-giving. Each of these criticisms and the implications that they have for this study will be discussed below.

The perception in the British feminist literature that there may be more male care-givers than previously identified was based on the data collected in the 1985 General Household Survey (Ungerson, 1997). This survey contained some questions that were designed to identify care-givers and find out about the work that they did. Although there were some problems with the way that the questions were worded, making it more likely that men would identify themselves as care-givers than women (Gibsen & Allen, 1993), these data indicated that as many as 11% of men, compared with 15% of women, were care-givers. Arber and Gilbert (1989) concluded that the exclusion of men from the feminist analyses of care-giving was due to the different relationship groups that male care-givers fall into compared with female care-givers. Male care-givers are more likely to be spouses, or sons who have never moved out of home, while female care-givers are more likely to be adult daughters. The focus of the feminist literature to date, they argued, has been on middle-aged daughters and daughters-in-law who have been providing care for an elderly parent. While the experiences of this group are considered important, they are not generalisable to older spouse care-givers or to unmarried male care-givers.

Despite the trend identified in the the UK General Household Survey data, described above, in Australia (and in the UK) there are still more female than male care-givers (ABS, 1999; Schofield et al., 1998). Furthermore male care-givers are more likely to take on the role later in life when they do not have the conflicting demands of paid employment or a young family. The ABS Survey of Disability, Ageing and Carers (1999) revealed that 22% of women in the 34 to 65 age group were carers compared with 15% of men. It found that for men the most likely time that they would be a carer was when they were over 74 years of age and that they were more likely to care for a spouse than another relative. For these reasons the feminist analysis of care-giving still seems to be justified, despite the resultant dilution of focus on male care-givers.

One of the problems, identified by the author, with the gender analysis of care-giving is that gender and age related stereotypes are used to argue the case both for and against the relative contributions of men and women. For example, the study by Gibsen and Allen (1993) discussed above, states that the types of services that men need (that is, delivered meals and home care) are more readily available than the types of services that women need (that is home maintenance and transport). This analysis represents a restricted and stereotypical view of men and women; that men cannot or will not cook or clean and that women are unable or unwilling to engage in home maintenance activities or drive a car. The assumptions underlying this analysis may also be ageist; that older people cannot be flexible and learn new things or that they are more likely than younger people to be restricted by traditional gender roles.

Another view perpetuated in the literature is that caring is a women's role. Whether this is seen as traditional (for example, Allendale, 1998) or due to women's early socialization (Jutras & Vielleux, 1991), it is a view that should be challenged rather than accepted if the gender imbalance in this area is to be addressed. Another portrayal that is of concern is the representation of non-spousal male care-givers as men who have never left home or who have returned home after a divorce (Arber & Gilbert, 1989). The implication here is that male care-givers, unlike women who combine their care-giving with other family responsibilities, are engaging in the role because they have no other relationships to occupy them. These men could be seen as failed husbands and fathers, rather than men who are choosing to make a powerful and valuable contribution to society. Until care-giving is seen as a legitimate and worthwhile activity for both men and women, women will continue to bear the brunt of the burden.

Graham (1991, 1993) identified the focus on the care-giver, neglecting the care recipient, as a problem because it failed to recognize the concerns and contributions of disabled women. Arber and Ginn (1997) also identified this as an issue within the care-giving literature and argued that care-giving has come to be seen as a one-sided activity, with the care recipients objectified as a social burden. Morris (1997) argued that there has been a false dichotomy perpetuated in the feminist literature that has characterized all care recipients as dependent and disabled and all care-givers as non-disabled and non-elderly. This has been problematic for a number of reasons. First, it fails to challenge prevailing attitudes about old age and disability; second, it fails to take into account the social and political construction of disability; third, it fails to recognize the often reciprocal nature of the care-giving relationship and the value of older and disabled people as a resource rather than a social burden; and finally, it fails to address the question of why the care-giving role exists in the first place.

The advantage of taking a structural perspective in this study is that it does not problematise the individual care recipients, any more than it does the care-givers. The disability level of the care recipient is not seen as the problem; it is the structural disadvantages experienced by care-givers that are viewed as the problem. This study is not about the recipients of care in home-based rehabilitation. Their experiences have been studied elsewhere (Dow, 1999; von Koch, Wottrich, & Widén Holmqvist, 1998). However, the contributions made by the care recipients and reciprocity within the care-giving relationship are explored with the individual care-givers interviewed. Furthermore care recipients are made welcome to participate in the interviews with care-givers, should they wish to do so.

The experiences of Black women in the United States and Britain are very different from those of white women providing care within their own families. Many Black care-givers in Britain and the United States work for low wages for white families, effectively limiting their opportunities to care for their own families in the unpaid capacity critiqued by feminist scholars (Graham, 1991, 1993). A study of home-care workers in Ontario, Canada also identified racism as an additional oppressive force (intersecting with gender) for paid home-care workers (Neysmith & Aronson, 1997). However, the exclusion of Black women is not considered to be problematic in this study because in Australia, there has not been an influx of Black or Hispanic migrants as there has been in the United States and Britain. It is acknowledged that in Australia, between 1910 and 1970, an unknown number of "half-caste" Aboriginal children were removed from their families and many of the girls were trained to work as domestics for white families (Manne, 2001), but it is not expected that this or any other racial practice will impact upon this study. It is expected, however, that care-givers from a diverse range of cultural and linguistic backgrounds will be involved in home-based rehabilitation across Victoria. The implications of this cultural diversity for home-based rehabilitation care-giving is examined in the interviews with program staff.

The problem of exclusion of gay men and lesbians is not perpetuated in this study as all care-giving relationships are included. However, the exclusion of and discrimination against lesbians and gay men in society generally may mean that it is more difficult for them to take time off work to provide care for their partner or partner's family. Furthermore, even when lesbians and gay men are included in studies such as this one, the nature of the relationship may not be disclosed to the researcher.

The feminist literature on care-giving to date also assumes that the episode of care-giving is long-term and that the care recipient will not recover. This is because the feminist analysis of care-giving to date has been largely in response to the reduction in nursing home beds and the de-institutionalisation of people with psychiatric and intellectual disability. Further, the analysis of care-giving has concentrated very much on dementia care, in response to the realization that dementia was becoming a significant social and medical issue. Dementia is almost always a long-term care issue. This study extends a feminist analysis to the new wave of health policy, which commenced in Australia in the 1990s, that shifts acute and rehabilitation services from hospital to home.

The assumption that care is long-term may also be linked to the perception that care-givers are now more likely to be paid for their work. There are two payments that care-givers in Australia may be entitled to: the Carer Payment and the Carer Allowance. These benefits are only paid to care-givers where the episode of care is expected to last for at least six months. Furthermore, these payments do not represent a wage for care, or a financial compensation for lost wages or opportunities in the paid labour force. Instead, these payments are simply designed to ensure that the care-giver does not become financially destitute as a result of the care-giving role. The focus of these carer payments is on the alleviation of individual poverty or financial distress, rather than on adequate compensation.

It is expected that the majority of care-givers who are caring for home-based rehabilitation clients will be white women, providing care for people within their kinship group, for which they will not be paid. This study takes the view that the criticisms of feminist analysis described above do not counteract the argument that within white Western society it is still predominantly women who take on the family care-giving roles, and that they do so to their own material disadvantage.

As identified in the previous section, the focus of the bulk of the feminist literature, in contrast to the general care-giving literature, is on structural issues, government policies, ideologies, and trends, and the impact that these have on women's lives. Despite this there is very little research that takes a structural perspective and examines the experiences of individual care-givers. The bulk of the research that directly engages with care-givers does so from a stress-coping perspective. Like Ungerson' study, this study will use a feminist approach to examine the impact of a particular public policy on the lives of individual care-givers. It will also examine the implementation of that policy from the perspectives of program staff. As Orme (2001) noted, in relation to social work, a feminist perspective must include the relationship between the professional helper and the person receiving help. Where the work involves the implementation of government legislation or policy, it represents a relationship between the individual and the state. This study examines the interface between the public sphere and the private experiences of individual care-givers.

3.4 SECTION FOUR: A FEMINIST APPROACH TO CARE-GIVING IN HOME-BASED REHABILITATION

Most of the early feminist work that examined the position of women as care-givers took a socialist perspective, which aimed to raise the profile of the work that women did in the home and to critique the government policies of deinstitutionalisation and community care that confined women to unpaid domestic labour (Finch & Groves, 1983; Ungerson, 1987). Further, these writers argued that care-giving was a collective responsibility that should be addressed through adequate public policies and social supports, rather than relegated to individual women (Dalley, 1996; Ungerson, 1987). The subsequent criticisms of this approach, outlined above, have argued that the diversity in care-givers' experiences and the existence of male care-givers, renders the feminist structural analysis meaningless. The current analysis argues, however, that while the different class, historical position, race, and social circumstances of care-givers make it impossible to speak for all care-givers, there is sufficient universality in the experiences of white female care-givers for a feminist analysis to be meaningful. Further, there is considerable similarity between the community care policies that led to the early feminist critique of deinstitutionalisation and the current early discharge policies. Both are couched in terms of client or patient well-being, both result in considerable savings to the public purse, both come at a time when there is a electoral preference for small government, and an ideological push for the reinstatement of the nuclear family, and both rely on the unpaid labour of women. As long as this reliance on women can be ignored, it can be sustained, to women's considerable disadvantage. If community care was equally shared between men and women, and if care-givers were seen as making an important contribution to the community that could be recompensed both in the short-term and through retirement benefits in later life, it would not require a feminist analysis. However, neither of these conditions have yet been achieved. This study adopts a socialist or dual systems analysis of care-giving, but one that benefits from more recent theorizing about patriarchy (Walby, 1990), and an awareness of the short-comings of the previous work in this area, discussed above.

Walby's (1990) model of patriarchy is used in this thesis to explicate the structural oppression of women as care-givers. At the most abstract level, Walby is a dual systems theorist; that is a feminist theorist who argues that it is the dual forces of patriarchy and capital that maintain women's subordination (Tong, 1989), rather than primarily one or the other. At a less abstract level Walby identified six structures that comprise the system of patriarchy. These are paid work, housework, sexuality, culture, violence, and the state. She argued that the inter-relationships between these structures create different forms of patriarchy; private and public patriarchy. She noted that in private patriarchy, household production is the basis of women's oppression whereas public patriarchy is based primarily on the public structures of employment and the state. Although the household does not cease to be a patriarchal structure in the public form, it is no longer predominant. In each form of patriarchy, all the patriarchal structures are present but there is a shift in those that are dominant.

Walby further argued that the strategies of oppression are different in private and public forms of patriarchy, with exclusion being the primary form of oppression within private patriarchy and segregation and subordination the main strategies in the public form. In private patriarchy, she argued, the expropriation of women's labour occurs through individual patriarchs within the household, while in the public form it is a more collective expropriation. Walby (1990) contended that the gains by the women's movement over the 20th Century have resulted in a shift in the oppression of women from the private patriarchy of the husband and family to the more public patriarchy of the state and the labour market. She stated, *"women are no longer restricted to the domestic hearth, but have the whole society in which to roam, and be exploited"* (p. 201). Figure 3, below, is the author's attempt to present Walby's model diagrammatically. This study argues, taking a dual systems approach, that it is the combined forces of patriarchy and capital that perpetuate the exploitation of women as care-givers, and that these forces continue to affect women's lives within both the private and public spheres. As discussed above, care-giving occurs in both the public and private mode and it is the interface between these modes that is the focus of this study. In particular, this study focuses on the interface between the household and the outside world. The outside world comprises the state, as represented by the formal organisations of the rehabilitation programs and hospitals, culture, in particular the culture of the family, and the market, specifically women's opportunities in the workforce.

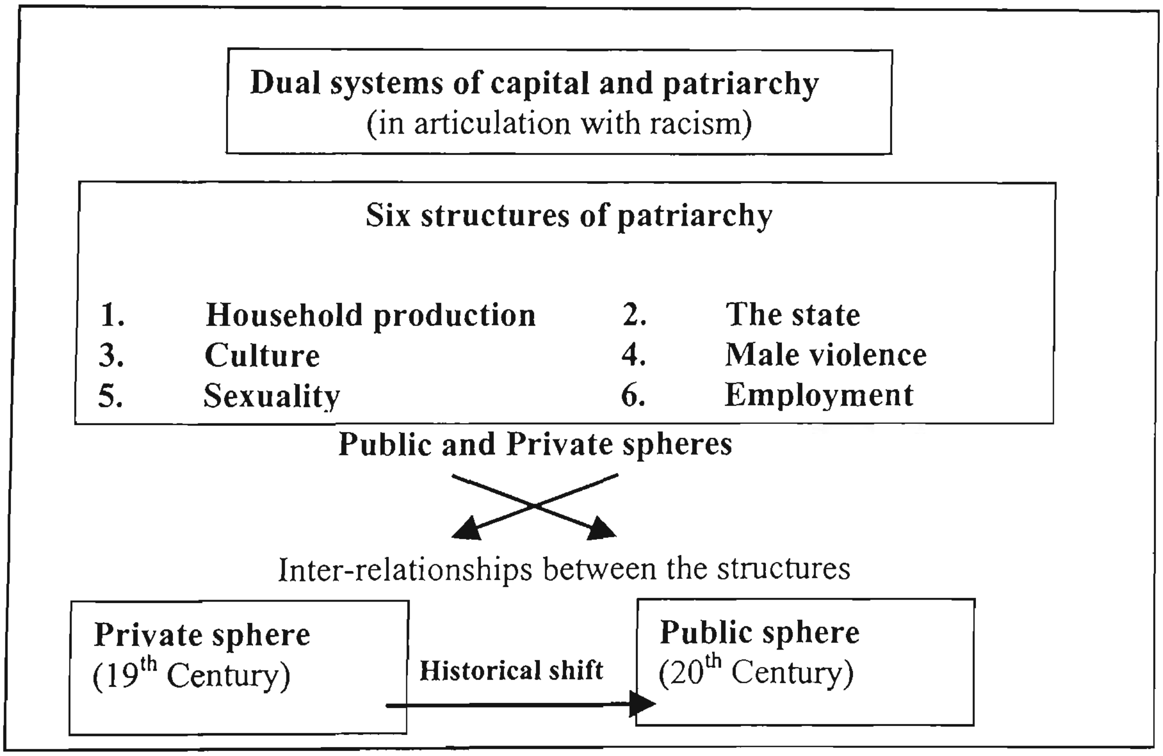


Figure 3 **Diagrammatic representation of Walby's model of patriarchy**

In this thesis the main structures of patriarchy that affect the lives of care-givers are expected to be: the household, with its gendered division of labour; the state, which has a direct role in deciding who is going to provide care for disabled community members; and culture, which provides the ideological force behind the socialisation of women into care-giving roles. The context of care-giving described by Abel and Nelson (1990) as the formal organization, and by Fisher and Tronto (1990) as bureaucracy, is also expected to be important in understanding the interface between individual care-givers and the home-based rehabilitation programs. It is at this interface that the household mode of care, characterized by isolation and lack of protection from overwork, but also with the care-giver largely in control of the process of care-giving, comes into contact with bureaucratic structures and organizational norms. Although there are some potential benefits here for the care-giver, in terms of assistance with the work of care, and access to professional expertise, there is also the potential for the care-giver to lose both confidence in his or her ability and control of the care-giving process. There are also different gender relations operating within the bureaucratic sphere to the household sphere. For example, the medical hierarchy, or medical dominance (Willis, 1989) may start to impact upon the process of care-giving. The next sections will expand on how the patriarchal structures of the state, the household, culture, and employment work together to serve the interests of men at the expense of women in care-giving roles.

3.4.1 The state as a patriarchal structure

There are a number of ways in which the state is involved in constructing and reconstructing gender relationships in Australia. Firstly, the personnel of the state are divided by gender. The state arms men and disarms women (Connell, 1987). The government and police forces are dominated by men, both numerically and in managerial power. The most recent Australian Bureau of Statistics (ABS) figures show that in 1997, less than 20% of state Members of Parliament and 21% of federal parliamentarians were women. Furthermore, women held only six of the 37 ministerial positions and three of the 24 shadow ministry positions in the federal parliament. In 1995, women made up 13% of sworn officers of the Australian police forces but only 2% of inspector to senior executive level positions (ABS, 1997).

Secondly, the state has had a pivotal role in the regulation and reinforcement of social relations that impact upon the position of men and women in the labour force and in the family (Bryson, 1992). It has been argued that Australian history has seen the development of two welfare states, a men's welfare state and a women's welfare state (Bryson, 1992). The men's welfare state was largely initiated through the 'family wage', which was instituted in Australia after the Harvester judgment in 1907. The men's welfare state was a wage earner's welfare state and provided advantage to those who were male, Anglo-Celtic and heterosexual. Men were paid a wage that was considered to be sufficient to cover the costs of supporting a wife and raising a family. In 1919, a minimum wage for women was also set, but this was set at 54% of the male equivalent. This was considered sufficient for single women, as all married women were deemed to be covered by the family wage. Until it was expunged in 1974, all men, whether single or married with dependants, received the family wage. No women were entitled to the family wage even if they were the family breadwinner. Thus the state modified the workings of the capitalist labour market by inserting social conditions into the wage fixing system.

The women's welfare state was characterized by women's position as dependent, their subordinated citizenship, and their economic and social disadvantage (Bryson, 1992). The development of the Australian social security system further entrenched women's position as dependent on men. Each successive pension or benefit had an associated wife's allowance. The War Widow's pension, introduced towards the end of the First World War, saw the state as providing for those women who were left husbandless, even if they had no dependent children. It was the women themselves who were seen as dependent.

For a brief period in history, in the 1970s and early 1980s, there was some movement away from the state's adherence to traditional gender roles. In 1973, the Whitlam government introduced the Supporting Mother's Benefit, which recognized the needs of women with dependent children as separate individuals (that is, without male partners). An even more significant shift came with the extension of this benefit to fathers. In 1978 the Supporting Parent's Benefit was introduced. As Bryson (1995) pointed out, for the first time Australian men were entitled to a benefit based on "caring fatherhood" rather than "breadwinning fatherhood".

More recently there has been a shift towards a more market driven, neo-liberal state in both Labor and conservative governments in Australia (Bryson, 1995; Hancock, 1999). There is a shift away from the idea of the welfare state, in which every citizen is entitled to a basic level of education and health care, to a market state where individuals choose the services they require and pay for them themselves. Linked to this shift to the market state is the concept of mutual obligation, in which individual recipients of state income support are expected to make a contribution in return (Macintyre, 1999). Bryson (1995) argues that this shift to the market state has been legitimized by the state's definition of the market as the major contributor to the nation's wealth and the construction of the public sector as a cost to the nation. As she points out, this position ignores the large contribution made by the state to the private sector of the economy in areas such as education, training and health, and infrastructure costs, such as roads, and overestimates the potential of the private sector to contribute to the common good. Bryson (1995) states that by not counting unpaid domestic and caring labour in the nation's GDP, the cost of the public sector is exaggerated. This has a number of implications for women and, in particular, for women as care-givers.

Women's well-being is dependent upon a healthy public sector because of their longevity relative to men and their care-giving responsibilities; because their employment opportunities are more likely to be found in the public sector; and because their gains towards more equal citizenship have relied on state interventions (Bryson, 1995). Since 1992, the gender gap in wages has been widening again and with the cutbacks in government services, women are again being relied upon to provide care for older and disabled family members as well as young children. It is the contention of this study that the state is currently engaged in promoting the notion that care of dependants is the responsibility of the family, and in particular, of women. The next section discusses the origins and current status of the ideology of the family. It is argued that it is through the perpetuation of a family ideology that the state relegates its care-giving responsibilities to women.

3.4.2 Household and culture – the ideology of the family

Feminists have identified the modern nuclear family as the centre of women's oppression (Eisenstein, 1984; Gittins, 1993). It has been argued that the nuclear family emerged in the early 1880s as a result of the separation between household and market production (Abramovitz, 1992; Dalley, 1996). This separation, to meet the requirements of modern manufacturing, meant that one family member had to go out to work to earn an income and another had to stay home to care for the house and dependent family members. This led to the gendered division of labour whereby masculinity became linked with waged labour, authority, and economic support of the family, and femininity with caring for the home and for dependent family members and servicing and submitting to the man. The family ethic (Abramovitz, 1992) or the ideology of familism (Dalley, 1996) emerged at this time to inform men and women of society's expectations of them and to convince them to adhere to these expectations. This ideology was supported by the prevailing belief that these gender-based roles were biologically determined and enforced by laws that defined women (and children) as the property of men. Adherence to these norms was the only way in which women could be economically secure, ensure the survival of their children, and gain social respectability (Abramovitz, 1992).

Despite the changing composition of the family (in Australia the number of families made up of couples with families has declined from 60% of families in 1976 to 50% in 1996, (ABS, 2001)) conservative political and religious forces still promote the ideal of the traditional nuclear family, particularly for middle class families. What have been seen as gains by the women's movement, such as increased funding for women's education, funding for women's refuges, and increased freedom to choose the type of family that women wish to be part of, including lesbian parented families, have been perceived as causing major problems for society. Phenomena such as increased divorce rates and single parent families have been held responsible for a number of social ills, including juvenile crime, poor discipline in children, and youth homelessness (Dalley, 1996; Hartman, 1995).

Conservative governments such as the Thatcher government in Britain (Dalley, 1992), the Carter government in the US (Hartman, 1995), and the Howard government in

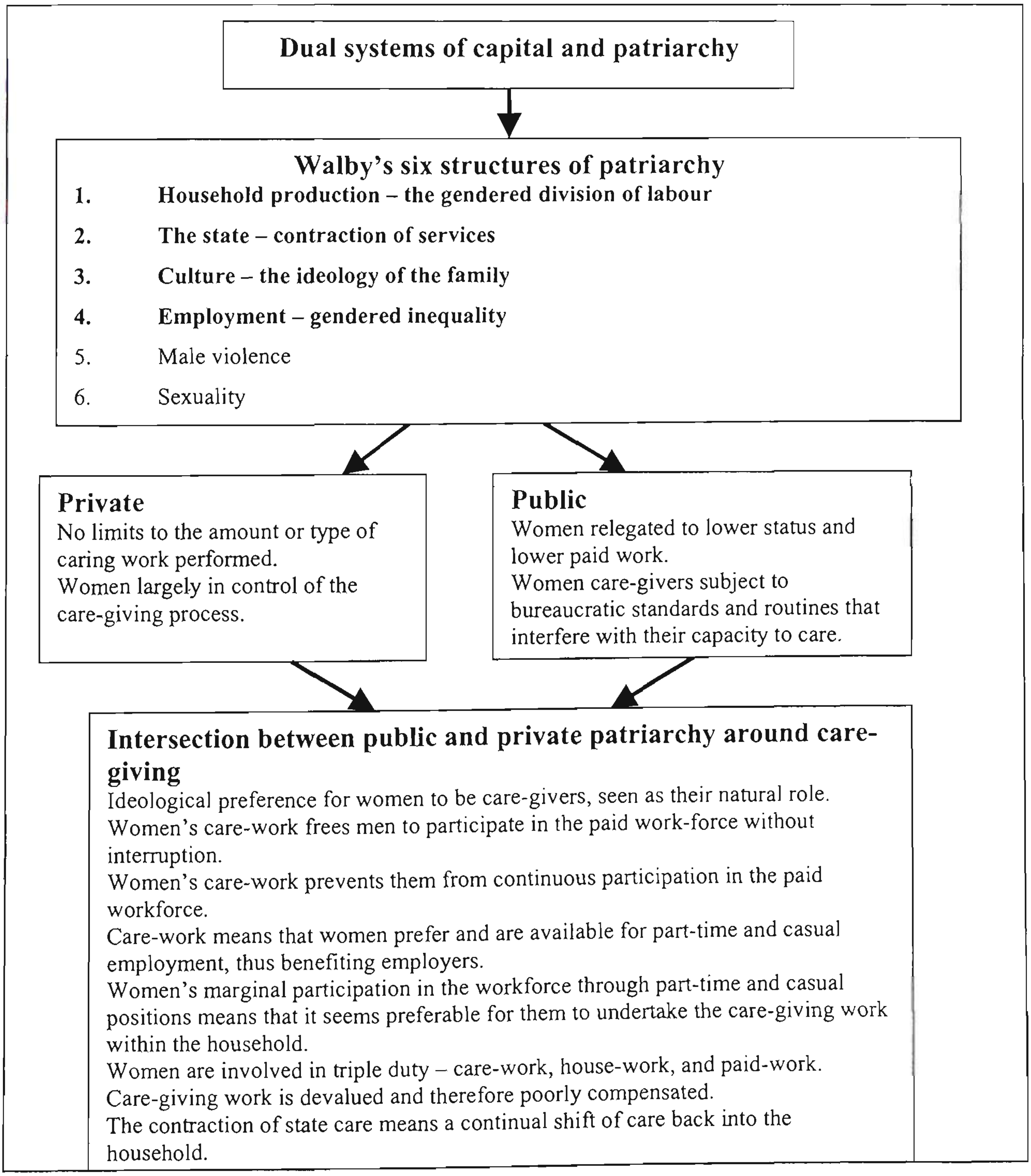
Australia (Bryan, 2000) have been advocating a return to family values to redress this so-called crisis. For example, in a speech to the ACOSS National Congress in 1998, John Howard stated, *"Robust communities, cohesive families and responsible individuals are fundamental for building a strong economy. And without a strong economy a caring community becomes much harder to achieve"* (Howard, 1998, in Bryan, 2000, p. 203).

Cass (1983) argued that in times of labour market recession and contractionist economic policies, such as the late 1970s and early 1980s, there was an ideological push to re-establish the family as the provider of services for the state. Cass (1983) also argued that in the 1980s, the non-indexation of the family allowance, cuts in funding to child care, and incentives to families to purchase private services (such as education and health insurance) were all aspects of an implicit "family policy", which resulted in *"the reinforcement of women's dependency as non-market workers responsible for housework and childcare, and the reinforcement of men's obligation to provide income by waged work"* (p. 184). The assumptions that underlie these policies, she argued, are that the sexual division of labour is natural and must be supported and that the problems which families experience should be solved individually rather than collectively. She argued that by promoting the *"traditional obligations and dependencies of families"*, an " invisible welfare state" is being activated, which relies upon the unpaid domestic labour of women (Cass, 1983). This study takes the view that in the early 2000s, the contraction of health spending and the transfer of care from hospital to home are similar circumstances to those of the early 1980s. Thus, Cass's concept of an invisible welfare state that relies on the unpaid labour of women is still applicable today. However, in the early 2000s the welfare state has been replaced with a market state, in which there is no universal entitlement or right to state care. Services, such as education, health, income support, and even the use of some roads now have to be either paid for or earned. Although there is rhetoric of individual choice and the tailoring of services to meet individual need, the reality is that not everyone is in a position to purchase or earn the services that they require. As Macintyre (1999) states, individuals are now seen to be accountable for their own welfare outcomes. This thesis argues that just as in the 1980s, when women's labour filled the vacuum created by the contraction of the welfare state, in the 2000s women's labour is the unacknowledged resource that fills the gaps created by the shift to the market state. It is the aim of this study to make visible a component of this invisible asset through exposing and exploring the work of women care-givers in rehabilitation in the home.

3.4.3 Employment and the division of labour within the household

Women are participating in the paid workforce in ever increasing numbers. In 1998 54% of women were participating in the paid labour force, compared with 36% in 1966. The move of women into the workforce, however, has not substantially improved their position in relation to men. Women are still paid less than men and are often relegated to lower status positions within the workforce. In 1996, only 4% of employed women were managers and administrators compared with 10% of men. These proportions varied considerably with the type of occupation. For example, 87% of child-care coordinators were women but only 29% of education managers (ABS, 1997). Women are often employed in part-time or casual positions. In 1997, 43% of women compared with 12% of men were employed part-time (Gray, 2000). Women's employment is also subject to many more interruptions due to child bearing and caring for other dependants than is the case for men (Gray, 2000). Furthermore, women's increased participation in the workforce has not meant men's increased participation in domestic duties (Bittman, 1998; Gilding, 1997; Browne, 1998). It has been argued that women are now doing double duty, serving the interests of both capital and patriarchy. It is the expectation of this study that many women are in fact doing triple duty: participating in the paid workforce, often on a part-time or casual basis; doing the bulk of the housework and child rearing; and caring for their older or disabled relatives at the same time.

In summary, this chapter argues for a broadly dual systems approach to understand the position of care-givers in home-based rehabilitation. These two systems are patriarchy and the state. More specifically the theoretical framework adopted in this study focuses on four of the structures of patriarchy proposed by Walby (1990): the household, culture, the state, and employment. It is expected that women's relegation to care-giving roles in home-based rehabilitation will be explained through: the gendered division of labour within the household; the contraction of state health care; the ideology of the family, and the continuing inequities perpetuated in the labour market that make it seem preferable that women rather than men interrupt their paid employment to provide care for family members. Furthermore, it is expected that care-giving in home-based rehabilitation will represent an intersection between the public and private realms, through both the patriarchal structures involved and the intrusion of the state into the lives of care-givers. Figure 4 below represents an extension of Walby's model depicted in Figure 3. The extent to which this theoretical framework adequately explains the experiences of care-givers and the perspectives of the program staff interviewed for this study will be discussed in Chapter Eight.



Dual systems of capital and patriarchy

Walby's six structures of patriarchy

1. **Household production – the gendered division of labour**
2. **The state – contraction of services**
3. **Culture – the ideology of the family**
4. **Employment – gendered inequality**
5. Male violence
6. Sexuality

Private
No limits to the amount or type of caring work performed.
Women largely in control of the care-giving process.

Public
Women relegated to lower status and lower paid work.
Women care-givers subject to bureaucratic standards and routines that interfere with their capacity to care.

Intersection between public and private patriarchy around care-giving
Ideological preference for women to be care-givers, seen as their natural role.
Women's care-work frees men to participate in the paid work-force without interruption.
Women's care-work prevents them from continuous participation in the paid workforce.
Care-work means that women prefer and are available for part-time and casual employment, thus benefiting employers.
Women's marginal participation in the workforce through part-time and casual positions means that it seems preferable for them to undertake the care-giving work within the household.
Women are involved in triple duty – care-work, house-work, and paid-work.
Care-giving work is devalued and therefore poorly compensated.
The contraction of state care means a continual shift of care back into the household.

Figure 4 **Adaptation of Walby's theoretical model to apply to care-givers**

The following chapter will outline the aims and objectives of this study, together with the research hypotheses and questions that have been derived from the literature, the theoretical framework outlined in this chapter, and the research problem identified in the introduction to this study.

Chapter Four - Methodology

4.0 INTRODUCTION

The first section of this chapter outlines the study aim, research objectives, hypotheses, and questions. These have been derived from the unanswered questions about the impact of current health trends identified in Chapter One, the gaps in the literature outlined in Chapter Two, and the theoretical framework discussed in Chapter Three. The next section outlines the study methodology, which is the overall plan of the research. The ethical issues involved in this research are also discussed in this section. The final section shows how each of the study objectives is addressed in the following three results and discussion chapters.

4.1 STUDY AIM, OBJECTIVES, HYPOTHESES, AND QUESTIONS

4.1.1 Study aim

This study aims to employ a feminist theory and methodology to explore the involvement of (family and informal) care-givers in home-based rehabilitation, so the study findings can be used to inform the future development of early discharge policies and programs in Victoria, Australia.

There are nine key objectives in this study. They have been listed below with the related hypotheses, strategies, and questions.

4.1.2 Objective One

To determine whether the State is relying on a predominantly female care-giver labour force in the implementation of home-based rehabilitation programs.

4.1.2.1 Hypotheses - objective one

- Patients are more likely to be discharged early from hospital to undertake rehabilitation in the home if there is an informal caregiver present (either co-resident or locally available).
- There will be more women than men providing informal care in home-based rehabilitation.
- Services such as home care and Meals on Wheels are more likely to be provided when there is no informal caregiver present.
- Services such as home care and Meals on Wheels are more likely to be provided to male than female caregivers.

4.1.2.2 Questions - objective one

- How many clients are there in home-based rehabilitation programs (that replace or reduce hospital admission) in Victoria ?
- How many of these clients have a designated informal care-giver?
- How many of these care-givers are female? or male?
- How many home-based rehabilitation programs (that replace or reduce hospital admission) have admission criteria that specify that the admission of a client is dependent on the presence of a care-giver (either resident or non-resident)?
- What services are organized and provided by the home-based rehabilitation program for clients with designated care-givers, compared with clients without designated care-givers?
- What services are organized or provided by the home-based rehabilitation program for male care-givers compared with female care-givers?

4.1.3 Objective Two

To demonstrate that the work undertaken by female care-givers is qualitatively and quantitatively different from the work undertaken by male care-givers.

4.1.3.1 Hypotheses – objective two

- Female care-givers in home-based rehabilitation will spend more time in care-giving and undertake a greater variety of care-giving tasks than male care-givers.
- Female care-givers will spend more time on hands-on care-giving tasks, such as showering and dressing, than male care-givers.
- Male care-givers will take on more of a case management role than female care-givers.

4.1.3.2 Questions – objective two

- How much time do care-givers spend providing care for clients in home-based rehabilitation?
- What sort of tasks do they engage in?

4.1.4 Objective Three

To demonstrate that care-givers in home-based rehabilitation do not receive fair pay for the work that they do.

4.1.4.1 Hypotheses – objective three

- Most home-based rehabilitation care-givers (>50%) will not receive any payment for their work.
- Even when care-givers do receive a payment, it will not compensate them on an hourly rate for the work that they do.

4.1.4.2 Questions – objective three

- How many care-givers receive financial compensation for their care-giving work?

- For those who do receive financial compensation, what form of compensation do they receive and what are the criteria for eligibility?

4.1.5 Objective Four

From the perspectives of the care-givers themselves, to explore how decisions to become a care-giver in home-based rehabilitation are made and how they differ for male and female care-givers.

4.1.5.1 Hypotheses – objective four

- Both men and women in the care recipient's family and rehabilitation in the home program staff will designate the role of care-giver to women more often than men.
- The identity of care-giver will be attributed to both men and women by hospital staff or the researcher more frequently than by the designated care-giver her or himself.
- The attribution of the care-giver role will be more often applied to women than men by hospital staff.
- Due to gender specific socialization, women will be more likely than men to define themselves as care-givers and to see care-giving as their responsibility.
- The decision to take on the responsibility of care-giving will be more influenced by work and other commitments for men than for women.
- Women will be more likely than men to take on the responsibility of care-giver in addition to their work and other commitments.

4.1.5.2 Questions – objective four

- How are the care-givers included in this study identified as such?
- How and when do people identify themselves as care-givers?
- How is the decision to enter care-giving made?
- What factors influence the decision to enter into care-giving?
  - Employment

  - Health status
  - Availability of alternatives
- Are the answers to the above questions different for men and women?

4.1.6 Objective Five

From the perspective of the care-givers themselves, to show how involvement in the work of care-giving in home-based rehabilitation affects the lives of male and female care-givers differently.

4.1.6.1 Hypotheses – objective five

- There will be fewer disruptions to work and leisure activities for male than female care-givers.
- Male care-givers will receive more help from family and friends than female care-givers.
- The episode of care will have a more definite beginning and ending for men than for women.

4.1.6.1 Questions – objective five

- How are the lives of male and female care-givers affected by taking on the work of care-giving?
- How much help do male and female care-givers receive from family and friends?
- Do they perceive this help to be sufficient?
- Has the episode of care had a definite beginning and end point for the care-giver?

4.1.7 Objective Six

To demonstrate how practices within home-based rehabilitation programs and the hospital system reinforce gender stereotypes about caring.

4.1.7.1 Hypothesis – objective six

- Within home-based rehabilitation programs and the hospital system, the contribution of care-givers will be taken for granted as invisible, unpaid women's work. This will be evidenced by
  - the predominance of female care-givers,
  - care-givers not receiving a payment for their work,
  - care-giver contributions not being included in the economic analysis of home-based rehabilitation, and
  - limited consideration being given to the care-giver's situation, including work commitments, other care-giving responsibilities, and so on, in assessing the client for admission.

4.1.7.2 Questions – objective six

- What is the ratio of female to male care-givers in home-based rehabilitation?
- How do the home-based rehabilitation programs include the care-giver in their assessment and program planning process?
- How is the contribution of care-givers measured and compensated for by the hospital system?

4.1.8 Objective Seven

To explore the experiences of both male and female home-based rehabilitation care-givers and the meanings that they attribute to their experiences.

4.1.8.1 Hypotheses – objective seven

As this is an exploratory objective, there are no related hypotheses.

4.1.8.2 Questions – objective seven

- How do caregivers in home-based rehabilitation feel about providing care?

- Are there any benefits associated with the care-giving role?
- What meanings do they attribute to the care-giving experience?
- How does it affect their relationship with the care recipient?
- Are the meanings and feelings associated with care-giving different for men and women?

4.1.9 Objective Eight

From the perspective of care-givers in rehabilitation in the home, to assess the adequacy of support services provided.

4.1.9.1 Hypotheses – objective eight

- Most care-givers (>90%) will state that they receive adequate support from home-based rehabilitation and community support services.
- Care-givers will have some ideas and suggestions about how these services could be improved.

4.1.9.2 Questions – objective eight

- Do care-givers perceive that they receive adequate support services from home-based rehabilitation and other formal support services?
- How do care-givers perceive the actions of the health service in implementing early discharge for rehabilitation at home?
- What changes would care-givers like to see made in the services provided to themselves and/or the care recipient?
- How could care-givers in home-based rehabilitation be better supported, acknowledged, and compensated?

4.1.10 Objective Nine

To improve the recognition, compensation, inclusion, and support of informal care-givers in home-based rehabilitation in Victoria.

4.1.10.1 Strategies – objective nine

- Through discussion with care-givers and program staff, to generate ideas about how to improve practice in relation to care-givers in home-based rehabilitation.
- To act on the recommendations made by care-givers themselves for improvements to their relationship with rehabilitation in the home and other community support services.
- To communicate with the relevant Federal or State Government Department about any problems with their policies or practices experienced by care-givers.

4.1.10.2 Questions – objective nine

- How can practice in home-based rehabilitation be improved in relation to inclusion, support, and recognition of care-givers?
- What changes would care-givers themselves like to see made in terms of their recognition, support, compensation, and inclusion in home-based rehabilitation?
- Do care-givers have any complaints about current government practices or policies that impact upon them as care-givers?

4.2 STUDY METHODOLOGY

According to Crotty (1998), there are four elements within the research process. They are the epistemology, theoretical perspective, methodology, and method. The epistemology and theoretical perspective informing this study have been outlined in Chapter Three. The methodology, outlined in this section, provides a rationale for the choice of methods and makes links between the theoretical framework, the methods, and the data analysis techniques employed to answer the research questions.

4.2.1 Feminist methodology

Just as there is no single feminist theory, there is no one feminist methodology (Reinharz, 1992). As Dale Spender (1985) stated, *"at the core of feminist ideas is the crucial insight that there is no one truth, no one authority, no one objective method which leads to the production of new knowledge"* (p. 5-6). There are however, some common principles that underlie most feminist research. The following principles have been compiled by the author, and are based on primary sources of feminist critique of the positivist paradigm that has until recently dominated most social science research.

The first principle relates to the inclusion of women in research. Spender (1985) argued that patriarchal knowledge is based on the experiences of only half the population. In feminist research, all human experience is regarded as valid. One of the aims of feminist research is to make visible women's experiences. Related to this is the conscious focus on gender as a fundamental feature of social life (Harding, 1987). Although the gendered nature of care-giving makes this study primarily one about women, the experiences of both male and female care-givers have been explored, and the opinions of both male and female program staff attended to. The study questions and the research process have maintained gender as a central issue in this study. For example, when the researcher briefed the home-based rehabilitation program staff about the research project, gender issues were identified as a key component of the research. In the analysis of the data, all the responses were analysed according to the gender of the respondent.

Secondly, feminist research does not divorce the research problem or the knowledge claims derived from research from the social and political context in which the research takes place (Harding, 1987). The researcher is an active participant in the research rather than an objective observer. Feminist research does not privilege the notion of objectivity in which the researcher tries to be neutral and value free (Mies, 1993). Feminist challenges to positivism have shown that the questions that are asked, the people of whom they are asked, and the questions that are not asked, contribute as much to our understanding of the research problem as the official findings of the research (Harding, 1987). In this study, it was not possible to separate the research about care-givers from the context of program development, economic constraints, and gendered social expectations that have been outlined earlier in this thesis. The researcher's own background in this area of work and her personal experiences as a caregiver meant that she had the triple perspectives of a mother and daughter care-giver, a critical feminist researcher, and an ex-program manager. She could share and relate to the experiences of care-giver and program staff participants as well as critically examine what was happening from a critical feminist perspective. Study participants were made aware of these multiple perspectives during the course of the research project, either in response to questions (for example, when they asked her "do you have children?") or as part of her introduction when meeting them for the first time.

A third principle, which is related to the abdication of the stance of objectivity, discussed above, is the breakdown of the traditional hierarchical relationship between the researcher and the study participants. As Harding (1987) stated, *"locating the researcher on the same critical plane as the overt subject matter*" (p. 9) opens up the process of the research to scrutiny as well as the results of the research. Apart from the attempts at openness described above, the researcher also took her findings and analyses back to the study participants, where possible, to check that they were a true reflection of what they intended to say. In relation to the scrutiny of the research process, this chapter attempts to honestly recount the process. This account of the research process is based on the researcher's recollections and field-notes that she recorded after each interview or meeting with program staff.

Finally, it has been argued that what is essentially feminist about feminist research is its concern with the oppression and subordination of women and its endeavors to change patriarchal society, whether that change be revolutionary or incremental. Harding (1987) observed that the questions that women want answered are not so much searches for pure truth but questions about how to change the conditions that maintain their subordination. Crotty (1997) noted that while feminist researchers share the methods and methodologies of many other types of research, it is the feminist vision, values, and spirit that distinguish feminist research from other approaches. He argues that *"methodologies and methods become channels and instruments of women's historical mission to free themselves from bondage, from the limiting of human possibility through culturally imposed stereotypes, life-styles, roles and relationships"* (Crotty, 1997, p. 182). As argued in Chapter Three, the assumption and expectation that women should undertake care-giving, either in addition to or instead of their other life responsibilities, is a form of women's oppression. This study is concerned with achieving recognition and compensation for women care-givers, and as such is a practical and political study, committed to achieving social justice for women care-givers. The ways in which this was achieved have been outlined in Chapter Eight. This practical intent has also influenced the study design and methodology.

4.2.2 Study Design

This study was essentially exploratory and explanatory rather than descriptive. Its aims were to learn about the current situation for care-givers in home-based rehabilitation, to explore the experiences of care-givers and staff, and to make sense of those experiences using a critical feminist theoretical framework. It was concerned with the relationships between three parties: the state, as evidenced in home rehabilitation program policies and procedures; the experiences of program staff, that is, how they respond to these state directives; and the care-giver situation, both objective (numbers of care-givers, number of support services, and hours per day spent in care-giving tasks) and subjective (their lived experience of caring for someone undergoing rehabilitation at home).

The demonstration of these relationships was done in a non-experimental way as it was not possible to manipulate the variables of gender, social stereotyping, or the presence or absence of a care-giver in home-based rehabilitation, nor to randomly select the study population. Furthermore, the research questions focused on the complex and dynamic relationships and the sometimes competing interests between these forces. It was not expected that relationships would operate in a uni-dimensional or linear way. Figure 5 below, illustrates the inter-relationships between the state, care-givers, and program staff.

The study was retrospective as the research questions were about what had already happened in home-based rehabilitation, rather than the evolution of the program. The treatment of time was cross sectional. Although there are few longitudinal data about care-giving, the short-term nature of the home-based rehabilitation episode made it very difficult to collect longitudinal data. This limited the findings to a particular time rather than mapping the changes over time both for care-givers and for the evolving home-based rehabilitation programs.

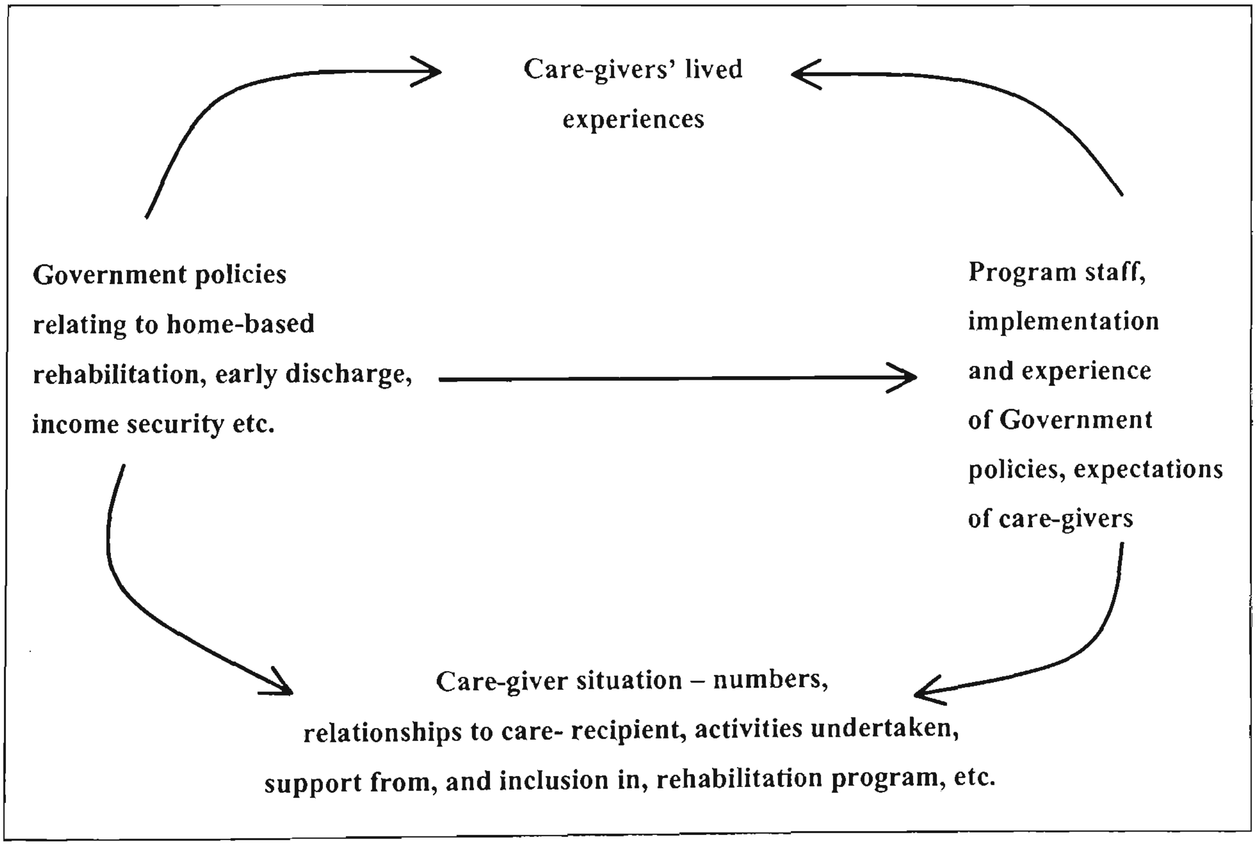


Figure 5 **Relationships between the state, home-based rehabilitation programs, and care-givers**

In accord with the feminist research principles outlined above, the study methodology sought ways to break down the traditional stance of objectivity and the distance between the researcher and the researched. In this study, the participants had some input into the study design, the content of the interviews, and the analysis of the data. The choice of care-giving as the research topic was influenced by the researcher's work in the field and the discussions she held with care-givers, clients, and staff in home-based rehabilitation about the effect that early discharge was having on care-givers. Once her PhD candidature was underway, the researcher met with the program staff prior to commencing the data collection to discuss the aims of the research and the proposed methodology. This process was a two-way exchange in which the researcher became aware of some of the practical constraints that might prevent her from undertaking the proposed research, and the program staff reported that they became aware of the gender and social justice issues relating to care-givers in home-based rehabilitation. Once the research was underway, the questionnaires for care-givers, the data collection sheets, and the points for discussion with program managers and staff were all modified following feedback from the study participants. For example, the researcher included cultural diversity as a discussion point, as it was suggested that this had a significant impact on the way in which care-giving was understood by care-givers and program staff in some programs. Finally, the opinions of study participants regarding the study findings and the recommendations for change were sought and have been included in the results and recommendations sections of this thesis.

4.2.2.2 Level of analysis

As discussed in Chapter Two, most research about care-givers has focused on the individual care-giver as the unit of analysis. There has been some extension of this into the care-giver-care recipient dyad and into the immediate family and service system level. There has also been some policy analysis in the literature. However, there has been little research that focuses on the interface between government policy, as implemented in a particular program or model, and its impact on individual care-givers. This study attempts to redress this gap. This study has examined and critiqued government policy, and its reflection of broader societal inequalities, both at the level of a program that has the responsibility for implementation of that policy, and at the level of a sample of care-givers' lived experiences of that policy. By interviewing program staff as well as care-givers, the researcher has examined the policy shift from hospital to community care at the point at which that shift is occurring. In so doing she has been able to expose the (often unstated) expectations that hospital and program staff have of care-givers. Just by asking questions about these expectations, program staff have become more aware of the pressures that they were placing on care-givers and have talked about ways that they could adjust their practice to take into account the care-giver's rights and needs. These changes have been further discussed in the Chapters Seven and Eight. Thus the two main levels of analysis in this study were the individual care-giver level and the program staff level.

4.2.2.3 Rigour

Lincoln and Guba (1985, p. 290) posed four questions that must be answered in any research into human activity. These questions were about "truth value", or the truth or credibility of the findings; "applicability", the generalisability of the findings or the extent to which they can be applied in other settings; "consistency", the replicability or reliability of the study findings; and "neutrality", the extent that the findings apply to the respondents and the phenomena under scrutiny, rather than the researcher's own biases or interests. Some of the strategies that they suggested for ensuring that these standards are met in qualitative enquiry are triangulation, participant checking, and keeping an audit trail. The following section describes how these strategies have been applied in this study.

Triangulation refers to the use of multiple strategies for *"mutual confirmation of data to ensure that all aspects of a phenomenon have been investigated"* (Knafl & Breitmayer, 1989, in Krefling, 1992, p. 219). Triangulation may involve the use of different sources of evidence, and/or different methods, and/or different researchers in a process of checking and verifying the findings (Miles & Huberman, 1994). In this study all three types of triangulation were employed. Two different data sources were used to answer some of the study questions. For example, in trying to ascertain what care-givers in home-based rehabilitation do for the care-recipients, both program staff and care-givers were asked questions about this. The care-givers referred to by the program staff were not the same group as those interviewed individually, so the triangulation was not for the purpose of verification but to gain two different perspectives on the same phenomenon. Different methods were used within each program to gain information about care-giver involvement within that program. The program manager and/or the program staff were asked general questions about how they treat care-givers in an interview, and the case managers were asked more specific questions about individual care-givers that were recorded on a data sheet. In this way, the answers to the interview questions could be verified with reference to the data sheet responses. For example, in relation to service brokerage, there was some discrepancy between the availability of services, as described by the staff, and the actual provision, as recorded on the data sheets.

The study findings were further verified through the process of participant checking. After each visit to a program, the researcher forwarded a summary of her findings back to the program staff to ask them to check the accuracy of the information. The findings of this study were reported back to program staff at two forums. The program from which the care-giver sample was drawn was consulted about the findings of the whole study and provided some input into the recommendations for change and the care-giver interview findings were reported on at a state-wide meeting of all home-based rehabilitation programs. A further presentation and report was made to this meeting in February, 2003. The care-giver participants were also sent a copy of the study findings and recommendations. A stamped envelope was included with the report and participants were invited to send their comments to the researcher. Eight responses were received from care-givers. These are discussed in Chapter Six and the care-givers' recommendations are included in Chapter Eight.

In order that the research project could be subject to auditing and the findings verified, the researcher kept all the raw data and records in such a way that they could be easily made accessible to another person. Although an audit was not actually conducted, the researcher consulted with a post-graduate student peer to make sure that all the information needed for an audit was accessible. Robson (1993, p. 406) has produced a list of information required for audit, which was used as a guide. The following documents have been kept and could be made available by the researcher should an external audit be conducted: the de-identified raw data (tapes, transcripts, and fieldnotes), the write ups and summaries, the data reconstruction and synthesis products (tables and matrices), the original proposal and documents relating to the development of ideas about the project, and first and subsequent drafts of data collection tools. Furthermore, in the writing up of the findings for this thesis, the interviews referred to were documented and the program numbers or participant pseudonyms for quotes were included.

4.2.3 Methods

A combination of qualitative and quantitative data collection strategies was used to achieve the study objectives. Qualitative data were sought where the focus was on experiential or process issues, and in order to capture the perspectives of the participants themselves, such as the care-giver's feelings about providing care or the processes of including the care-giver in the rehabilitation program. Quantitative data were collected where it was possible to answer the study questions with numerical data; for example, the number and percentage of clients in home-based rehabilitation who have a designated care-giver. There were three main methods employed in this study: care-giver interviews, staff interviews, and data collection from program staff about program clients and care-givers. These methods were chosen for their suitability in meeting the study objectives. For example, to achieve objective seven, it was necessary to interview care-givers to explore their experiences in the care-giving role. The methods chosen and their relationship to the study objectives have been outlined below in Table 8, Study Design.

4.2.3.1 Care-giver interviews

The care-giver interviews were of between 30 and 90 minutes duration. With one exception (a care-giver who was also a student at the University of Ballarat and preferred to be interviewed there) the interviews took place in the care-giver's home. The interviews were conducted between May and December 2001. An interview schedule was used in the interviews with care-givers. The schedule was designed to address the study objectives, from the point of view of the care-givers themselves. The objectives that the schedule was designed to address were: to establish the nature and extent of the work that care-givers did during the home-based rehabilitation admission (Objectives Two and Three); to investigate how their involvement in care-giving affected other aspects of their lives (Objective Five); to show how gender stereotypes about caring are reinforced in decisions that are made about who provides the care, the type of work performed, and the supports received by care-givers (Objectives Four and Six); to explore the subjective experiences of a sample of care-

givers in home-based rehabilitation (Objective Seven); and to assess the adequacy of support services to care-givers (Objective Eight).
The interview schedule consisted of both open and closed questions about the care-giver's existential experience of care-giving, as well as questions about the practical implications of care-giving for their lives. The following areas were covered in the interview: basic demographic data, such as the age and gender of the care-giver and care recipient and the diagnosis of the care recipient; the care-giving activities that the care-giver had engaged in immediately after the care recipient's admission to the home-based rehabilitation program and the amount of time these had taken; the impact that care-giving had on various aspects of their lives; how they felt about providing care; the type and adequacy of support services they had received; the extent of their involvement in the admission process; the extent of recovery of the care recipient; the cost and benefits of care-giving; and the meanings of care-giving in their lives. Finally, they were asked whether they would be interested in coming to a function to hear and comment on the study findings. The full interview schedule can be seen in Appendix A.

Individual, rather than group, interviews were selected for several reasons. First, the content of the discussion was sensitive and individual interviews ensured that the participant's confidentiality and privacy could be protected. Second, while it would have been difficult for most care-givers to come to a group meeting, individual interviews could be conducted at a time and place that suited the care-giver. Third, not all care-givers would have felt comfortable engaging in a group discussion, so it was anticipated that individual interviews would achieve a higher participation rate. Finally, given the slow rate at which care-giver participants became available for the study, a group interview would have occurred too long after the home-based rehabilitation care-giving episode for the care-giver to be reasonably expected to remember the details required for the interview.

4.2.3.2 Program data collection

The program data collection process was designed to answer questions about the extent to which the State was relying on care-givers in the implementation of home-based rehabilitation (Objective One); the payment that home-based rehabilitation care-givers receive (Objective Three); and the process of designation or acceptance of the care-giver role (Objectives Four and Six).

Information was gathered on: the number of clients in home-based rehabilitation who had designated care-givers; some information about these care-givers, such as their age and relationship to the care recipient; the extent of their contribution to client care; whether they received financial compensation for their work; and the services provided to them and/or the client by the home-based program or other community services (see Appendix B). This was done through completing a data sheet for each client currently admitted to each of the home-based rehabilitation programs included in the study. The researcher completed these sheets with the program's case management staff or another designated staff person who was able to answer the questions posed about the clients. This process was conducted on-site at the program, on a day arranged to suit the program staff, and the information collected related to that day only.

The researcher would have preferred to obtain this information over a longer data collection period to increase the generalisability of the findings, but this would have meant asking the program staff to collect the data on the researcher's behalf, an option that was not practicable for the program staff.

4.2.3.3 Staff interviews and review of program documentation

In addition to the data collection about clients and their care-givers described above, program staff were interviewed to find out whether their program required that a care-giver be present before they agreed to admit the client (Objective One); to explore with them their processes for inclusion of the care-giver in program decision making, and the provision of support services to care-givers by their program (Objectives One and Eight); and the ways in which they, as agents of the hospital system, might reinforce gender stereotypes about caring in their treatment of care-givers in home-based rehabilitation (Objective Six).

Table 8 Study Design

Objective	Data type	Method	Sample	Timing	Analysis
1. To show how the State is relying on a predominantly female "care-giver" labour force in the implementation of home-based rehabilitation programs	Quantitative	Data collection frequency of admissions	23 staff and 102 clients from 8 home-based rehabilitation programs	Cross sectional – Program data collection Collected once in Nov 2001 – Jan 2002	Statistical – descriptive and bi-variate non-parametric analysis
	Qualitative	Review of program documentation Program staff interviews		Staff interviews Single interviews conducted in Nov 2001 – Jan 2002	Content analysis – responsive to study questions – subject to participant checking
2. To demonstrate that there is a gender difference in the work undertaken by care-givers in home-based rehabilitation.	Qualitative	Care-giver interviews	24 care-givers	Cross-sectional Care-giver interviews Single semi-structured interview conducted between April and December, 2001	Content analysis
3. To demonstrate that care-givers in home-based rehabilitation do not receive fair pay for the work that they do.	Qualitative and Quantitative	Care-giver interviews	24 care-givers	As for care-giver interviews above.	Content analysis and Descriptive statistics
		Program data collection	102 client data sheets	As for program data collection above	
4. To discover how decisions to become a care-giver in home-based rehabilitation are made and to demonstrate how the decisions are different for women and men.	Qualitative	Care-giver interviews	24 care-givers	As for care-giver interviews above.	Content analysis
	Quantitative	Program data Collection	102 client data sheets	As for program data collection above	Descriptive statistics
5. To show how involvement in the work of care-giving in home-based rehabilitation affects the lives of men and women differently.	Qualitative	Care-giver interviews	24 care-givers	As for care-giver interviews above	Content analysis
6. To demonstrate how relationships within the families of the care recipients and within the hospital system reinforce gender stereotypes about caring.	Qualitative and Quantitative	Care-giver interviews	24 care-givers	As for care-giver interviews above	Content analysis
		Program staff interviews	23 staff	As for staff interviews above	Content analysis Descriptive statistics
		Program data collection	102 client data sheets	As for program data collection above	Descriptive statistics
7. To explore the experiences of a sample of RHP care-givers and the meanings that they attribute to their experiences.	Qualitative	Care-giver interviews	24 care-givers	As for care-giver interviews above	Interpretive-phenomenological analysis
8. To assess the adequacy of support services provided to care-givers in home-based rehabilitation and make recommendations for improvements if required.	Quantitative and Qualitative	Care-giver interviews	24 care-giver	As for care-giver interviews above	Content analysis and descriptive statistics
		Staff interviews	23 staff	As for staff interviews above	Content analysis

Where possible these interviews were conducted with the staff as a group in order to gain a wide range of views and to give participants the opportunity to discuss their views with their colleagues. Group, rather than individual interviews, also helped to raise the consciousness of staff about the possibility of their participation in gender stereotyping, or in ignoring and devaluing the work of care-givers in home-based rehabilitation. However, sometimes it was not possible to speak with the staff as a group and in these cases the researcher met with the program manager or a staff member designated by the program manager to discuss these issues. A list of questions and points for discussion that was sent to the program staff prior to the researcher's visit is attached in Appendix C.

4.2.4 Population and sampling

4.2.4.1 Care-giver process

The care-giver participants were recruited from one home-based rehabilitation program only. There were a several reasons for restricting the care-giver sample to one program. Firstly, one of the aims of the study was to examine the interface between a sample of home rehabilitation care-givers and a home rehabilitation service. Restricting the sample of care-givers to one particular program made this aim achievable. This part of the study was not intended to make generalisations about home rehabilitation care-givers in general. (In contrast, because the findings from the sample selected for the program level research were intended to be generalised to the whole population of home rehabilitation care-givers, data were collected about a much larger group of care-givers.) Further, restricting the data collection to one program meant that a more in-depth data collection process could be achieved in the time available. The researcher aimed for both breadth and depth in the interview sample selection process. It was hoped that a broad range of care-giver situations would be included, encompassing a range of both relationship types and levels of care, and ensuring the inclusion of some male care-givers. At the same time, it was considered important to spend sufficient time with each care-giver to ensure that their situation could be properly described and observed. However, restricting the interview participants to one program resulted in some unexpected limitations. As will be described in Chapter Seven, some significant differences emerged between the two models of home-based rehabilitation that were included in this study as well as differences between regional and metropolitan programs. The experiences of care-givers in a regional program that adopted a Continuum of Care model (described in Chapter Seven) may therefore have been different from those involved in a metropolitan or Alternative to Inpatient model.

All care-givers recruited from the designated program who agreed to participate over a nine month period were included. The care-giver recruitment period was initially intended to be six months, but after a six month period insufficient care-givers had been interviewed (17) to achieve the breadth required in the sample. For example, only two men had been interviewed during the initial six months and the relationship types were restricted to spouse and daughter or grand-daughter care-givers.

The researcher met with the program staff to explain the purpose of the research, to answer any questions and to provide them with copies of the interview schedule. The program staff were asked to pass on information about the research project to any care-givers with whom they came in contact. They were asked to find out if the care-giver or care-givers did not wish to participate in the research and, where this was the case, to ensure that their names and contact details were not passed on to the researcher. If the care-giver agreed, after the client's discharge from the program, the staff member provided the researcher with essential details on the client and care-giver. These details included: the care-giver's name, phone number, and relationship to the client and the client's discharge date. The researcher then telephoned the care-givers, explained the purpose of the research and the sorts of questions she would be asking them, and, if they agreed, made an appointment to visit them in their home to conduct the interview. The Plain Language Statement and consent form for care-giver participants are included in Appendices D and E.

4.2.4.2 Program staff process

As an ex-program manager of a home-based rehabilitation program, the researcher had been involved in initiating a state-wide meeting of staff from home-based rehabilitation programs, which commenced in 1997. This group had been meeting quarterly, but at the start of this research process, the group had not met for over 12 months. The researcher, with two colleagues from two home-based rehabilitation programs, initiated the resumption of these meetings. Staff from all the programs known to the researcher and her two colleagues were invited to attend a meeting in Melbourne at which, among other agenda items, the researcher described her research and requested the participation of the programs represented at the meeting.

After obtaining verbal agreement from the program staff, the researcher contacted each program to see whether it met the inclusion criteria for her study. The main inclusion criterion was that the programs had either replaced all or part of a previously existing inpatient rehabilitation program or had achieved early discharge from an acute inpatient facility. Nine programs met this criterion and all agreed to participate. The researcher then applied to the relevant ethics committee or manager of each facility for ethical approval to conduct the study. Ethical consent for the project was obtained for eight of the nine sites. One committee refused consent because it believed that the clients and care-givers about whom de-identified information was sought should give informed consent for the project. This would have meant asking the program staff to obtain this consent and it was decided that this task would be too onerous for them, so the site was excluded from the project. Once ethical consent was gained, the researcher arranged to meet with the program staff at their place of work, at a time that suited them.

4.2.5 Ethical Issues

4.2.5.1 Ethics Approval

Ethics approval for this study was sought and obtained from the following ethics committees and Hospital Managers (see Appendices F to M for copies of letters of approval and Appendix N for an example of the ethics application).

Table 9 **Record of ethical approvals**

Individual or committee responsible for ethical consent	Date received
The University of Ballarat Human Research Ethics Committee	March, 2001
Ballarat Health Services and St John of God Hospital Ethics Committee	March, 2001
Bundoora Extended Care Centre Ethics Committee	August, 2001
Southern Health Human Research Ethics Committee	October, 2001
Royal Melbourne Hospital Clinical Research and Ethics Committee	November, 2001
Peninsula Health Research and Ethics Committee	December, 2001
The Northern Hospital	November, 2001
Wodonga Regional Health Service – Chief Executive Officer	October, 2001

4.2.5.2 Participant consent

All of the study participants, staff, and care-givers, had the aims of the study and the purpose, extent, and expectations of their involvement clearly explained to them by the researcher both verbally and in writing prior to seeking their consent. It was also made clear that participants were free to withdraw their consent at any time and that their involvement (or non-involvement) in the study would not in any way jeopardise their participation or employment in the rehabilitation program. Written consent was sought before commencing the interviews and included consent to tape the interviews.

4.2.5.3 Confidentiality

Confidentiality of the individual participants and the programs involved in the study was protected in the following ways.

Care-giver interviews: The interview schedules did not include any identifying data about the study participants. However, sometimes the first name of the care recipient was mentioned. This and any other identifying information that was inadvertently taped, for example, the names of staff members, was deleted from the transcripts of the tapes before they were printed for analysis.

The list of interviewees and the consent forms were stored separately from the tapes, the completed interview schedule, and the transcripts of interviews. All identifying information was removed from the tapes, the completed interview schedules, and the transcripts. The typists employed to transcribe the tapes were briefed about the requirements of confidentiality and signed a written agreement to comply with these requirements.

Staff interviews: The information collected during the staff interviews about program clients and their care-givers contained no identifying information. Sometimes, during the interview process the researcher would see the names of clients written on a board or on a medical record but she did not retain or record this information. The taped interviews were not transcribed and the tapes were kept separately from the list of programs involved. The tapes did not have any identifying information written on them.

4.2.5.4 Security of data

All of the completed interview schedules, data collection records, and transcripts were kept in a locked filing cabinet in the office of the researcher for the data collection and thesis writing period. The tapes were kept in a separate locked cabinet. When the final draft of the thesis is submitted these tapes will be transferred to the office of the researcher's principal supervisor and stored for five years, after which time they will be destroyed.

4.2.5.5 Participant distress

On two occasions the care-giver interviews caused distress, once to a care-giver interviewee and once to the care recipient who was listening to the interview. In the case of the care-giver, when she became distressed because of the questions asked by the researcher, the researcher turned off the tape and stopped the interview. The interview was interrupted for a few minutes while the researcher listened and responded empathically to the care-giver's distress. The interviewee then asked to continue the interview so the researcher resumed taping and completed the interview. At the end of the interview, the researcher discussed support services that the care-giver could use. After the interview, and with the care-giver's consent, the researcher contacted one of the program staff in the home-based rehabilitation program to ensure that she was aware of the care-giver's concerns.

In the case of the care recipient becoming distressed, the interviewer apologized for discussing her care-giving needs in front of her and offered to discontinue the interview, but the care recipient assured the researcher that she did not mind. However, the researcher was not convinced by this assurance and although she did complete the interview, she believes that the issue of involvement of the care-recipient in the interview process was not satisfactorily resolved in this study. This issue has been discussed below in the section on research shortcomings.

4.2.5.6 Researcher debriefing

The researcher was fortunate to share an office with several supportive post-graduate students during the course of the study. Informal debriefing was offered by these colleagues; for example after an interview with a care-giver who had lost four babies to a congenital illness. More formal debriefing, about how to address the problem of care recipient distress, for example, was offered by the researcher's principal supervisor. In general, however, little distress was caused to the interviewees or the researcher in undertaking this study.

4.2.6 Data analysis

This study used both qualitative and quantitative data to answer the study questions. The process of summarizing, presenting, and interpreting these data is described below. Table 10, below, includes a summary of the data analysis techniques selected for each study question. The data were collected and analysed according to the study objectives and associated questions, outlined under 4.1, above.

Three main approaches to data analysis were employed (see Figure 6, below). The first approach was statistical analysis of the quantitative data. For objectives one, two, and three, objective data were collected to answer the study questions. Most of the study questions were posed directly to the respondents in either the care-giver or staff

Table 10 Analysis of data

Objective	Questions	Analysis
One	Number of admissions	Frequency
	Number of care-givers	Frequency
	Gender of care-givers	Ratio female to male
	Admission criteria – care-giver specified?	Yes/No
	Services provided – for care-giver and non-care-giver groups x gender	T-tests to establish whether there is a significant difference between groups
Two	Care-giver activities	Categorisation of activities T-tests to determine whether there is a significant difference between male and female care-givers
	Time spent	Chi-square tests to establish whether there is a significant difference between male and female care-givers
Three	Financial compensation	Frequency of care-givers who receive payment
	Form and eligibility criteria	Categorisation of types of payment Number in each category Qualitative analysis of eligibility criteria
Four	Designation of care-giver role	Qualitative analysis of care-giver interviews
	Gender attribution of care-giver role	Qualitative analysis of staff and care-giver interviews Frequency in each category on data collection sheet
	Identification of care-giver	Frequency of yes responses in interview
	Identification as care-giver	Qualitative analysis of care-giver interviews
	Decision making factors for care-givers	Qualitative analysis of care-giver interviews
Five	Affect on care-giver's lives	Qualitative analysis affects and gender differences
	Assistance provided	T-tests to determine whether there is a significant difference between groups on service provision
	Continuation in the role	Frequency of yes/no responses X gender
	Beginning and end point	Frequency of first episode and yes/no responses by gender
Six	Ratio of female: male	Frequency and percentage of male: female on program data sheets
	Other commitments	Qualitative analysis of care-giver interview transcripts
	Decision making	Qualitative analysis of care-giver and staff interviews
	Inclusion of care-giver in program admission and planning	Qualitative analysis of staff interviews Qualitative analysis of interviews
	Measurement of and compensation for care-giving	Frequency of yes responses to compensation question on data collection sheet.
Seven	Feelings about the role Benefits associated with the role Meanings Effect on relationship Gender differences in meanings and experiences	Qualitative analysis of care-giver interviews
Eight	Adequacy of support services	Quantitative analysis of rating scale - % > or = 4.
	Requirements for assistance	Qualitative analysis of responses to question about improved support.

interviews (for example, "how much time did you spend caring for (client's name) when he or she was discharged from hospital this time?"). Alternatively, quantitative data were collected that addressed the study questions. An example of the latter type of questions was – "How many services were received by clients with care-givers, compared with clients without care-givers?" To answer this question, data were collected about the number of services received by all clients included in the study. The clients were separated into two groups, those with care-givers, and those without care-givers. The mean number of services for each group was calculated, and a T-test was performed on the data to see if there was a significant difference between the groups. This finding was then applied to the study hypotheses to see whether or not they were supported.

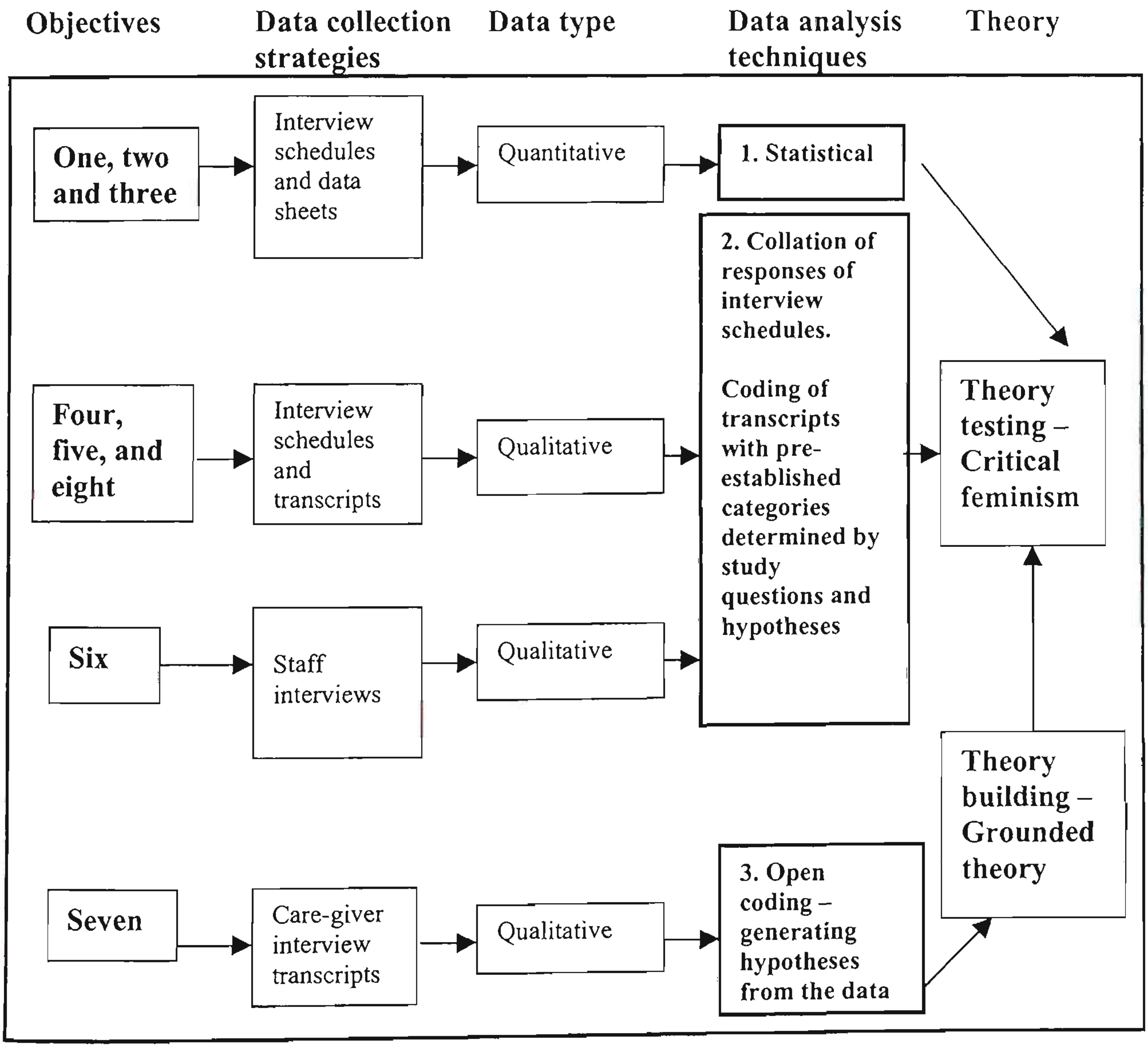


Figure 6 Data analysis framework

The second approach was content analysis of qualitative data. The data relating to objectives four, five, and eight were collected from the perspectives of the care-givers themselves. Where the questions were asked directly, for example, "Were there any other supports that would have been useful to you?" the responses were collated and grouped into categories according to their similarities; for example, recommendations about home-based rehabilitation. These were then applied to the study hypotheses and reported in the results and recommendations sections of this thesis. Where there was no direct question, for example the author was interested in how care-givers entered into the role but this was not asked about directly in the interview, the data were analysed according to the concepts or codes that emerged from the transcripts. Any reference to entry into the role was noted and coded according to its similarity in meaning with other comments. These codes included: conscious decision, taken for granted, or lack of alternative. However, the decision to group these comments according to the category of "entry into care-giving" was made before the data were collected and was determined by the study hypotheses. For objective six, which aimed to demonstrate how practices within home-based rehabilitation programs and the hospital system reinforced gender stereotypes about care-giving, the transcripts of the staff interviews were coded as above. For example, the staff were asked directly about their expectations of care-givers. Their responses to this question were collated according to the concepts that emerged from the data but the category of "expectation of care-givers" was pre-set by the researcher.

The third approach to data analysis was to build a theoretical explanation from the data through open-coding. This approach was taken for objective seven, which was to explore the experiences of care-givers and discover the meanings that they attributed to the role. Although there were pre-determined hypotheses based on a feminist theoretical framework for this objective, as for the others, the aim was to allow the participants' own perspectives to emerge. A grounded theoretical approach to data analysis was judged to be the best way to achieve this aim. The technique used was to examine the transcripts of the care-giver interviews line by line and label the concepts that seemed to synthesize the meanings embedded within the dialogue. These concepts were then compared and grouped into categories that were similar in meaning and had some explanatory power for more than one case. Finally these concepts were grouped into categories that had explanatory power for all the cases.

This process was an iterative one, in which one transcript was examined, concepts were allowed to emerge, and these concepts were applied to the next transcript. At this point additional concepts emerged which were then applied to the next transcript, and so on until there seemed to be concepts for all the information emerging from the transcripts. Then the transcripts were reviewed again to see whether the concepts and categories arising from analysis of subsequent transcripts applied to the earlier ones. The process of grouping concepts into categories was continuous and informed by the emergence of new concepts from the primary data.

This process was adapted from Strauss and Corbin's (1998) data analysis approach for the purpose of developing grounded theory. The final step in analysing the data collected for objective seven was to relate the findings back to the original theoretical framework to test whether the grounded theoretical explanations were consistent with or antithetical to the feminist theoretical explanations.

The major difference between strategies two and three was the way in which the categories were developed. For strategy two, the categories were pre-set. They were based on questions or hypotheses that had emerged from the literature or from a critical feminist understanding of care-giving. For strategy three, these categories and hypotheses were drawn directly from the data.

4.2.7 Methodological Shortcomings

4.2.7.1 Inclusion of care recipient

Although this research was not about the experiences of the care recipients, it was not possible or desirable to exclude them from the data collection process. Most of the time this was not a problem. In 12 of the 24 interviews conducted, care-recipients were present for all or part of the interview. In these cases, the researcher included the care recipients in the interview process and addressed questions on the interview schedule (such as the diagnosis of the care recipient) directly to them where appropriate and asked for their opinions where possible (such as the impact of the care episode on their family life). However, on occasions it seemed that the presence of care recipients constrained the care-givers' responses and on one occasion, mentioned above, the care recipient was distressed by the interview process. The researcher had given the interviewee the option of conducting the interview elsewhere during the telephone contact prior to the interview, and always made it clear that she only needed to speak to the care-giver. However, often it seemed preferable to both the care-giver and care recipient for the care recipient to be present. Often the room in which the interview was conducted was the room in which care recipients spent most of their time so it would not have been appropriate to ask them to go away while the interview was conducted. Furthermore, care recipients were usually aware that the interview was about the care that had been provided for them and so they were interested to hear what was said. On balance, despite the problems mentioned above, it was probably better to include rather than exclude those care recipients who wished to be present at the interview.

4.2.7.2 Duration of program data collection

The restriction of data collection about program clients to one day only was a limitation in this study. It would have been preferable to collect data over a longer period to obtain a more robust sample of home-based rehabilitation clients and their care-givers. However, although it was originally intended that the data be collected over a one-month period to account for fluctuations in care-giver status and service delivery, this was ruled out in the preliminary discussions with program staff.

4.2.7.3 Program Sample

Three problems emerged with the sampling process. The first was that there was no list of all the home-based rehabilitation programs in Victoria. This was due to the different funding sources accessed by the programs and to their rapid growth. There was no one point of oversight of these programs. Although every effort was made to obtain a complete list of the programs (through resuming the network, and asking program staff to identify any additional programs they knew about) it is possible that the eleven programs targeted for inclusion in this study were not a comprehensive sample of home-based rehabilitation programs in Victoria. Some new programs that commenced during the study period were included, but others (for example, those that commenced after November, 2001) were not included as it was not possible to extend the data collection period beyond the end of February, 2002. The second problem was that once a home-based rehabilitation program is established, the service profile of rehabilitation at the hospital or health service where it is located is altered. Patients who once stayed in hospital now go home. In this study program staff were asked about whether their program replaced or reduced hospital length of stay compared with the hospital length of stay prior to the existence of their program. This analysis could only be done where staff were personally aware of or had the information to judge what had been the practice prior to their program being established. The researcher relied upon the staff's assessment of this in deciding who should be included or excluded from the study but she does acknowledge that this assessment could be inaccurate. In the three health services included in the Continuum of Care Funding Model Report (Department of Human Services, 1999), the two sites that established a home-based service recorded a reduction in average length of stay (ALOS) of one and five days respectively. However, this length of stay (LOS) represents the entire stay including the bed days spent in home-based rehabilitation. Although these figures do not specifically show the reduction in hospital LOS, they do show an impact on the overall LOS with the introduction of a home-based rehabilitation component to the service.

4.3 FRAMEWORK FOR PRESENTING AND DISCUSSING THE STUDY FINDINGS

The next three chapters will present and discuss the findings of the care-giver interviews and the interviews and data collection process conducted with the program staff. Each of the three chapters has been constructed around some of the study objectives. Table 11, below provides a guide to where each of the study objectives will be discussed.

Table 11 Framework for discussing the study findings

Chapter	Section	Objective
Five	5.2	Four - Assumption of care
	5.3	Two – Amount and nature of work
	5.4	Five – Impact on care-givers' lives
	5.5	Seven – Experience and meaning
Six	Whole chapter	Eight – Interface with formal services
Seven	7.2.1	One – Reliance on care-givers
	7.2.2	Two – Gender differences in care provision
	7.2.4	Three – Care-giver payments
	7.2.5	Six – Reinforcement of gender stereotypes
Eight	8.5	Nine – Improve the position of care-givers

Chapter Five – Results and Discussion 1: "As You Do"

Family care-giving in home-based rehabilitation

5.0 INTRODUCTION

The findings from the care-giver interviews have been divided into two chapters. The first section of this chapter describes the study recruitment process and characteristics of the twenty-four interview participants. The following four sections document the participants' responses to direct questions and other statements that they made during the interviews. Each of these sections relates to one of the study objectives. The final section includes a discussion of how these findings challenge traditional definitions of physical rehabilitation. The final section also discusses how the impact of care-giving for home-based rehabilitation care-givers is much more complex and long lasting than the stress-coping paradigm would suggest. The next chapter documents the care-givers' perceptions about their interactions with formal supports.

All the questions asked in the interviews were about the time that the client was admitted as a client to the home-based rehabilitation program. Care-givers were asked to reflect back to the time immediately after the client came home from hospital to answer the questions about the type of care they were providing. Thus, all the experiences of care-givers recounted in these chapters concern the time that the care recipients were technically rehabilitation hospital inpatients.

5.1 CHARACTERISTICS OF STUDY PARTICIPANTS

5.1.1 Recruitment process

A total of twenty-four care-givers were interviewed for this study. They were recruited from a regional home-based rehabilitation program that, for the purposes of this study, will be known as (A Rehabilitation in the Home) ARITH. They were recruited over a nine-month period, from April to December, 2001. During this time 147 clients were discharged from ARITH, 79 women and 68 men. Table 12 (below) shows how many of these clients had a designated care-giver. A greater percentage of male clients (50%) than female clients (32%) had a designated care-giver.

Table 12 Care-giver status of ARITH clients.

Gender of client	Number with a care-giver	Number without a care-giver	Care-giver status unknown
Female (N=79)	25	47	7
Male (N=68)	34	25	7

Overall there were 60 designated care-givers, caring for 59 clients. One client had two care-givers. Forty-two of the total care-giver group (70%) were female, 16 (27%) were male, and for two (3%) the care-giver's gender was unknown. The relationship types of the total group of 60 care-givers and the 24 who participated in an interview are shown below in Table 13.

Only 24 (40%) of the total sample of 60 care-givers were interviewed. Thirty-six names and contact numbers were provided to the researcher. These included thirty female and six male care-givers. Of these, twenty-one female and three male care-givers participated in the study. The reasons for not interviewing the other twelve were: refusals – seven; unable to contact – four; and unable to give informed consent – one. Unfortunately, three of the male care-givers who agreed to be interviewed when asked by the program staff were not able to be included in the study (two refused, and one was not contactable). It was not always possible to determine why the names of the other 24 care-givers were not passed on. It is known that five refused and three were not asked because the care coordinator felt it might further complicate or confuse an already complex situation. A further two had very brief admissions so that the care coordinator did not have the opportunity to meet the care-giver and ask him or her to participate, but that only accounts for 10 of the 24 not included. The care coordinators, being very busy with their work, may have just failed to ask the care-givers, or to record their refusals.

Table 13 **Relationship between care-giver and care recipient of all ARITH care-givers**

Relationship to care recipient	Number (% of total)	Number interviewed (% of total interviewed)
Wife	25 (42%)	13 (54%)
Husband	13 (22%)	2 (8%)
Daughter	7 (12%)	3 (13%)
Sister	3 (5%)	0 (0%)
Son	2 (3%)	1 (4%)
Daughter-in-law	2 (3%)	2 (8%)
Friend (female)	2 (3%)	1 (4%)
Friend (male)	1 (2%)	0 (0%)
Niece	1 (2%)	1 (4%)
Mother	1 (2%)	0 (0%)
Grand daughter	1 (2%)	1 (4%)
Unknown	2 (5%)	0 (0%)
Total	60 (100%)	24 (100%)

5.1.2 Study participants

Twenty-one female and three male care-givers were interviewed. They ranged in age from their twenties to their eighties (see Table 14, below). Most of the care-givers (15) were spouses of the care recipient, five were daughters or daughters-in-law, and there was one son, one niece, one grand-daughter, and one friend. Seventeen of the care recipients were male and six were female. They ranged in age from 24 to 95 years. Most of the care-recipients (22) were aged 60 or over, see Table 13 below.

Table 14 **Age of clients and care-givers**

Age range (years)	Number of care-givers	Number of clients
21 – 40	5	1
41 – 60	7	1
61 – 80	8	13
81 – 90	4	5
90 +	0	2

Table 15, below, shows the age and relationship type of the care-givers who participated in the study. They have been allocated a pseudonym (rather than a number) so that the reader can keep track of each individual's story throughout this and the following chapter.

Table 15 Characteristics of care-givers and care recipients

Interview number and pseudonym	Relationship to care recipient	Age of care-giver	Diagnosis of care recipient	Gender of care recipient	Age of care recipient
1 – Amy	Niece	60s	Fractured pelvis	F	84
2 – Paula	Daughter	47	Fractured pelvis	F	84
3 – May	Grand-daughter	29	Hip replacement (THR)	M	78
4 – Frances	Friend	30s	Fractured hip	M	80s
5 – Bea	Daughter	50s	Fractured hip	F	95
6 – Lisa	Wife	50s	Stroke	M	63
7 – Judy	Wife	20s	Amputation	M	24
8 – Bernadette	Daughter-in-law	50s	Surgery for cancer	M	87
9 – Sally	Daughter	30s	Bowel cancer	F	67
10 – Ernie	Husband	74	Parkinson's Disease	F	74
11 – Anna	Wife	60s	Stroke	M	72
12 – Ruby	Wife	74	Bowel cancer	M	77
13 – Rose	Wife	65	Total knee reconstruction (TKR)	M	60
14 – Ivy	Wife	70s	Amputation	M	Unknown
15 – Gwen	Wife	80	Fractured ribs and shoulder	M	82
16 – Julie	Wife	50s	Parkinson's Disease	M	70
17 – Emma	Wife	80s	Stroke	M	84
18 – Heidi	Daughter-in-law	30s	Fractured hip, cancer	M	64
19 – Fred	Husband	78	Stroke	F	78
20 – Carol	Wife	60	Stroke	M	63
21 – Dave	Son	53	Fractured hip	F	91
22 – Jill	Wife	60s	Stroke	M	63
23 – Freda	Wife	50s	Brain tumour	M	62
24 - Ingrid	Wife	88	THR	M	89

5.1.3 Diagnoses of the care recipients

Table 16, below, lists the diagnoses of the care recipients. The discussions below about the frailty of the care recipients and the nature and duration of care further illuminate what these diagnoses meant for the care recipients and the care-givers.

Table 16 Diagnoses of care-recipients

Diagnosis	Number
Stroke	6
Parkinson's Disease	2
Amputee	2
Hip Fracture	4
Cancer	3
Other fracture	2
Hip replacement	2
Knee replacement	1
Other surgery	1

5.2 THE ASSUMPTION OF CARE

The following section includes the interview data that pertain to study objective 4, which was, "From the perspectives of the care-givers themselves, to explore how decisions to become a care-giver in home-based rehabilitation are made, and how they differ for male and female care-givers."

When asked if they saw themselves as a care-giver, only one interviewee did not identify herself as a care-giver. Amy said that she associated care-givers with people who were paid professionals. For most care-givers, taking on the role of care-giver was not a decision upon which they had consciously deliberated. Amy said of taking on the care of her aunt, *"when her health went down a bit I just automatically stepped in to do a little bit to help her out."* Heidi and Emma both said *"It just happened"*, *"...he rings when things go wrong, so he doesn't really ask...it just sort of happens, I think"* (Heidi), and *"It just happened. When my husband got sick and he couldn't walk and some-one had to take over and I was the logical one"* (Emma). Care-giving was something that they saw as their responsibility. For example, Jill said, *"I think it is my duty to do that [provide the care] because there is only the two of us and so I am responsible to do that...."* For some this episode of care was an extension (or continuation) of their role in life. Bea said that she had always cared for elderly people. She said, *"...I suppose we have always had elderly people coming and going and ... we were more or less doing Meals on Wheels on bikes, I was, in my teenage years."* Anna said, *"yeah [I would care for someone again if needed] even if one of my kids got sick I would go down there because you have done it all your life."*

Many care-givers said that there was no-one else who could take on the role. However, the reasons that they gave for others not being able to provide the care did not seem to apply to themselves. For example May said that she had moved in to care for her grandfather *"because there was no-one else"*. Later she said that her father could not help because he ran a pub and so was not available, but she had given up her job and moved house in order to provide the care. Somehow leaving her employment and moving house were seen as acceptable sacrifices for her to make, but not for her father. Providing care was described as *"the right thing to do"* by Amy and Paula, and *"the natural thing to do"* by Amy and Bea.

Some care-givers saw themselves as having a choice, for example, Ruby said, *"Well I could have said no"* but the care recipient was better off at home and *"it was going to save me running every day [in to see him]"* but the choice was about *when* the care would resume, not *if* it would resume. For most care-givers there was no other option. Heidi said, *"it has got to be done, so I just do it... there was never any choice."* Emma said, *"Well I don't think you become a carer by preference... You just have to accept it."* Although they didn't see themselves as having a choice, this did not mean that they did not want to provide the care. As Freda who was caring for her terminally ill husband described it, *"...it didn't really hit me that it was something that you would have to do. You had no choice. You have to do it and you do it because you want to do it... you do it anyway."*

There was a strong theme of familial obligation in the care-giver interviews. Only one of the care-givers was not related to the care recipient by marriage or blood. Frances was a paid care-giver in a Special Accommodation House (SAH[4]) and she identified herself as the care-giver because the care-recipient had no other family, and because she provided care for him above and beyond the care that she was paid to provide in the SAH. Many care-givers commented that they felt responsible for caring for their spouse, parent, or parent-in-law because they were part of their family. For example Paula said, *"You can't leave your mother."* Bernadette commented, *"...plus it is*

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[4] Special Accommodation Houses are accommodation facilities that are usually run privately for profit. Staff in these facilities provide meals and 24-hour care for older and disabled people. Residents usually share a room with at least one other resident and bathroom facilities are generally shared.

family and they have to be looked after." Fred said of caring for his wife, *"Well, I would sooner not have to do it but the thing is we have to look after each other."* Some care recipients also stated that it was the responsibility of the care-giver to care for them. A husband care recipient, who had had both his legs amputated, responding to a question posed to his wife Ivy about how she had become his care-giver, said *"She's my wife, number one and that should be sufficient."*

There was an element of actual or potential reciprocity expressed as part of this familial obligation. For example, Jill said, *"...We have been married 40 years a couple of months ago...I'm sure that if the boot was on the other foot, A would do that for me too."* Anna said, *"...you go with them through the good parts, you go with them through the bad parts and that's life...If the boot had been on the other foot I am sure he would do the same for me."* Sally said of caring for her mother, *"It doesn't bother me. She done it for me when I was little."*

Some care-givers made a distinction between caring for family and caring for others. For example, Dave said, *"I'd only do it for Mum. I'd find it difficult to do it for anyone else."*

5.2.1 Discussion of study questions about the entry into care-giving

1. Do the people identified as care-givers in this study see themselves as care-givers?

Yes, of the 24 care-givers interviewed, 23 said that they saw themselves as a care-giver for the ARITH client. The only person to answer negatively to this question said that she thought of care-givers as people who were paid to provide care.

2. How and when do people identify themselves as care-givers?

Some of the care-givers interviewed saw the entry into care-giving as clearly aligned with the onset of the condition that led to the ARITH episode. For example, Lisa who was caring for her husband who had experienced a stroke named the exact date of the stroke when asked how and when she became a care-giver. Others said that they had always been care-givers. For example Bea told of transporting meals on her bike to a neighbour to illustrate that being a care-giver was just part of her life's experience.

3. How is the decision to enter into care-giving made?

Although there was considerable variation in how and when people identified themselves as care-givers, there was consistency in the absence of a clear decision. The most frequent answer to the question "How did you come to take on the role of care-giver?" was a comment on the health of the care recipient. The fact that the care recipient needed care was cited as the reason. Five interviewees mentioned that there was no-one else. Not one interviewee gave the impression that it was a decision that they had thought about. None said that they had ever entertained the idea of not providing care for the ARITH client.

Although the assumption of care was described as automatic by the study participants, there were some indications that they were responding to both internal and external pressures. These pressures were: the ideological hegemony about women's role as care-givers, the scarcity of offers from other family members, direct pressures from health service staff, the pressure for early discharge from hospital brought about by the state and federal governments' health policies and funding guidelines, and their own compassion and concern for the well-being of the care recipient. These pressures will be discussed in Chapter 8.

4. What factors influence the decision to enter into care-giving?

Some factors were identified that influenced the care-giver's decision. The lack of anyone else was cited by five care-givers as part of the reason for their becoming a care-giver. This was also mentioned in the study of 10 stroke care-givers conducted by Wood (1991). The participants in Wood's study identified the absence of anyone else as the reason that they felt responsible to provide care. The care-givers in this study also talked about their responsibility to care for the ARITH client because he or she was a member of their family. The avoidance of worse alternatives was also discussed during the interviews. In answer to the question "Would you do this again if the care recipient or someone else needed care?" sixteen care-givers replied with an unequivocal "yes"; two said that they would only do it for a close family member; one said it would depend on her health; three said no; and for two no answer was recorded. So, in response to the above question, the availability of acceptable alternatives was the main factor verbalized by care-givers as influencing their decision to enter the care-giving role. The assumption that it was a woman's role may have influenced their decision, but it was not an influence identified by the care-givers themselves.

5. Are the answers to the above questions different for men than for women?

It is difficult to answer this question because of the small sample of male care-givers. All three male care-givers cited the care recipients' illness as the reason that they became care-givers. When asked if they would provide care again, the son care-giver said he would only do it again for his mother; one spouse said yes, if his health permits; and the other gave an unequivocal yes. In this small sample, there did not appear to be any difference in the reasons for taking on care. However, it may be, as discussed above, that there were so few male care-givers in the sample because factors such as work had led to their decision not to provide care.

5.2.2 Discussion of study hypotheses about the entry into care-giving

4a) That it will be assumed by both men and women in the care recipient's family and friendship network that women rather than men will take on the responsibility for care.

The data discussed above indicate that it was assumed that the care-giver, whether male or female, would be the one to take on the care-giving role within the family or friendship network. Although this assumption was generally accepted by the care-giver, it was not always clear to the researcher why this particular family member or friend was designated as the care-giver. For example, Bernadette was caring for her father-in-law whilst he was in the home rehabilitation program at the same time as working full-time and caring for her own parents. There was no apparent reason why Bernadette's husband, the son of the ARITH client, did not take on the care-giving role. Bernadette did express some anger that her husband did not do more for his father, but she did not seem to really question that she would be his care-giver.

The small number of men in the interview sample makes it difficult to substantiate whether for men the assumption of care was less likely to be presumed and more likely to be open to scrutiny or discussion. Two of the male care-givers were spouses, and like most spouse care-givers, they assumed and accepted that they would provide the care for their wives. The only other male care-giver was a son who resided with his mother and whose sisters were living an hour and a half's drive from their mother's residence. He did not accept that he was the person in the family who would necessarily continue to provide care for his mother; however, his proximity to her had meant that he had been the obvious person to provide care in the early stages post-discharge.

4b) That for male care-givers, the decision to take on the role will be more influenced by their work and other commitments than it is for female care-givers.

4c) Female care-givers will be more likely to take on the responsibility of care-giving in addition to their other responsibilities than male care-givers.

As discussed above, the small sample of male care-givers included in the interview sample makes it difficult to substantiate any hypotheses on the behaviour or experiences of male care-givers in home-based rehabilitation. However, the small sample may in itself indicate the influence of patriarchal structures in home-rehabilitation care-giving. The absence of male care-givers in the study sample and the low numbers of male care-givers in the sample from which the interview sample was drawn (27%) may be because, for men, work and other commitments serve as an adequate reason not to become involved as care-givers. For women, however, work or other commitments do not excuse them from their care-giving responsibilities. Many of the women interviewed in this study had other responsibilities that were affected by their decision to take on the care-giving role, but that did not stop them from taking on the role. For example, Judy, Sally, and Heidi had child-care responsibilities; and

Paula, May, Frances, Judy, Bernadette, Carol, Jill, Gwen, and Freda were all either working or studying.

5.3 THE NATURE AND AMOUNT OF CARE

This section will discuss the data derived from the care-giver interviews that pertain to study objective two, which was, "To demonstrate that the work undertaken by female care-givers is qualitatively and quantitatively different from the work undertaken by male care-givers." Although the small sample of male care-givers rendered any meaningful comparison between male and female care-givers impossible, this section will look at the type and amount of care-giving work undertaken by all the care-givers in the interview sample. This objective will also be further discussed in Chapter Seven, using the quantitative data collected from the other home-based rehabilitation programs.

5.3.1 Discussion of questions about the nature and amount of care

1. How much time do care-givers spend providing care for clients in home-based rehabilitation?

2. What sort of tasks do they engage in?

Eighteen of the 24 care-givers were providing 24 hour-a-day care. For eleven care-givers this meant being present 24 hours a day and the other seven not only had to be there, providing supervision and monitoring, but were also actively doing things for the care recipient 24 hours a day. For example, seven care-givers reported having to get up several times every night to attend to the toileting of the care recipient or to move them to prevent bed sores. The other six care-givers provided between one and 21 hours of care per day.

The tasks that the care-givers were engaged in can be divided into five categories: treatment and procedures; hotel-type tasks; personal care services; nursing-type care; and case management. These categories of care have been fully described in Chapter One. Most care-givers provided hotel-type services (23 preparing meals and 22 doing housework) and supervision (22). Slightly fewer were involved in personal care; still, a majority (16) were helping with dressing and 15 with toileting. Fifteen care-givers assisted with rehabilitation activities, but nursing tasks (6) were less likely to be provided by care-givers, who often made the comment that the (ARITH) nurses performed those tasks.

Twelve care-givers reported that their responsibilities had diminished over time, but seven did about the same, and five reported that their care-giving responsibilities had *increased* since the time immediately post-discharge from hospital.

The only other study that examined the tasks undertaken by rehabilitation care-givers in the period immediately post-discharge from hospital found that many care-givers expended more than 20 hours per week in care for their relatives and that many were engaged in a wide variety of care-giving tasks (Kane et al., 1999). The authors concluded that in the two weeks immediately after discharge, care-giving equalled more than a half-time job (28 hours per week). Over the twelve months of their longitudinal study, the number of tasks dropped but some activities, such as shopping, transportation, and supervision, remained high throughout the year. These data on tasks undertaken and time spent by the care-giver interview sample will be compared with the data collected from the program staff and further discussed in Chapter Seven.

Table 17 Nature of care-giving work and time spent

Task	**Number of care-givers engaged in this tasks**	**Time per day (range)**
Dressing	16	10 – 60 minutes
Housework	22	30 minutes to 4 hours
Keeping company	19	50 minutes to 16 hours
Meal preparation	23	30 minutes to 4.5 hours
Medication preparation	17	10 – 60 minutes
Nursing tasks	6	15 – 90 minutes
Personal care	10	10 – 30 minutes
Toileting	15	30 minutes to 3.5 hours
Rehabilitation tasks	15	20 – 90 minutes
Supervision	22	12 – 24 hours
Task	**Number of care-givers**	**Time per week (range)**
Taking to/from appointments	14	1-8 hours
Managing financial affairs	18	30 minutes to 5 hours
Talking to professionals	14	45 minutes to 6 hours
Other	15	1-2 hours

5.4 IMPACT OF CARE-GIVING

The following section will discuss the data derived from the care-giver interviews that pertain to study objective five, which was, "From the perspective of the care-givers themselves, to show how involvement in the work of care-giving affects the lives of male and female care-givers differently."

For the purposes of this study, the impact of care-giving on the life of the care-giver has been conceptualised along two dimensions. The first dimension denotes the impact on the individual's personal, family, leisure, and work life. This dimension moves from the intra-psychic and physical impacts, through interpersonal relationship impacts, to the impacts on the care-giver's ability to pursue outside employment and leisure interests. The second dimension, about which much less was said in the interviews, is the dimension of time. There are immediate consequences for the care-giver on all aspects of the first dimension, discussed above, and these consequences are compounded by the length of time spent caring. Furthermore, some of the consequences of caring are not felt until some time has elapsed, like Bea's superannuation difficulties, discussed in the next chapter. The data taken from the interview transcripts have been categorised according to these dimensions (see Figure 7, below).

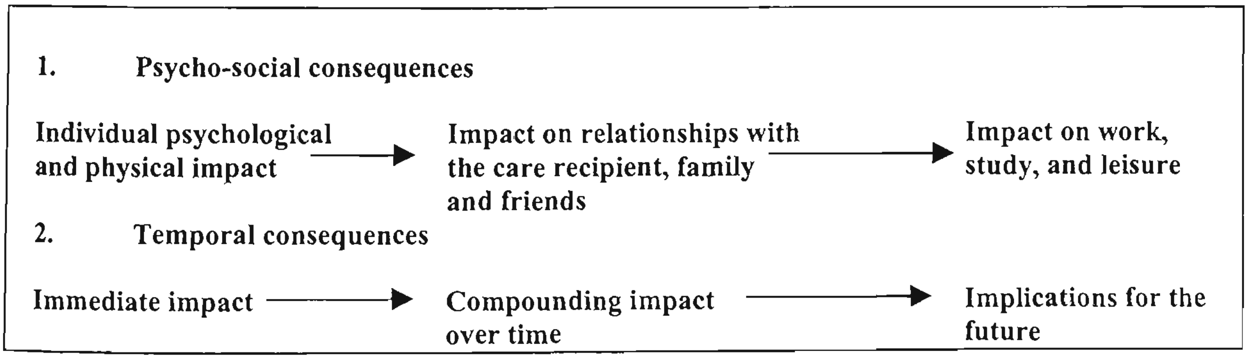

Figure 7 **Impact of care-giving on the care-giver**

The impact of care-giving on the "whole person" has been described before by Schultz and Schultz (1990, p. 10). They identified five aspects of the person on which care-giving had an impact. These were: physical, psychological, social, emotional, and spiritual. This thesis expands the social aspect of their model to include the other aspects of the care-giver's life: that is, work, study, family, and other commitments, and adds the temporal dimension.

5.4.1 Psychological and physical impact

Although stress, strain, and burden were often the foci of previous literature on care-giving, this was not the language used by the care-givers in this study to describe their emotional states. Only one care-giver used the word "stress". Bernadette said, *"I was really stressed out"*, as she was caring for her father-in-law, her own parents, and trying to maintain a full-time job. Care-givers generally described themselves as accepting of their situation and taking it in their stride. For example, Anna said, *"...now I got this, I take it as it comes...I could sit down and say, why me?...you got to take what comes and not growl,"* and Julie said of caring for her husband who had Parkinson's Disease, *"well that's the only way to take it, in your stride. If you think it is no good then I am only making him miserable, myself miserable..."* They seemed to try to avoid letting themselves think (or feel) about their situation. For example *"(I) try not to think about it, otherwise you make your life misery..."* (Bernadette). However, there were some significant exceptions to this where care-givers described themselves as frightened, angry, drained, and "brain dead", and some care-givers experienced a range of feelings about their situation. For example, Heidi said of caring for her father-in-law as well as three small children, *"It's really draining when you are not used to it, it is really draining...the kids you can sort of switch off..."* Jill, who was working during the day said,

> *When I would get home, I've got to shower A, than I've got to mow half the back, then mow the front and I think, I can't do all these things. I'm absolutely brain dead as well. Of course those things don't [just] take all of my brain, they take all of my body.*

Gwen described her frustration with her situation,

> *I was somebody that likes to be on the go all the time and working. You know sometimes you'd feel like you would like to get out and get down to the bargain centre [the opportunity shop where she used to work part-time] and toss the old shoes around and get into the rubbish and get rid of the frustrations, but you have to stay put.*

Freda was both angry and resigned about her situation. She said, *"You do get angry. I get really pissed off at times. I get mad at him – and I get angry at life because it has done him this way."* And, *"my outlook on life is something I learned from the first time [he was diagnosed with cancer]. You don't push things, shit happens...it just happens and you learn to take it..."*

Care-giving also had an impact on the care-givers' perspectives on the world. Some care-givers felt that care-giving had taught them something valuable. For example, Carol said that caring for her husband had made her realise that *"life is precious. Every day is a bonus, it is incredibly short. It [care-giving] makes you feel very humble."* Freda said,

> *...you learn that there are things that are really important in life...Things like I got up this morning, or I can go to bed at night. That's important...money doesn't count...family and friends, that's important, not money.*

Heidi also felt that care-giving had been a good learning experience for the three children in her care. She said, *"...it was great for the kids. They understand more about sick people. They understand that they can't bounce all over his leg because he has a sore leg...its good for them to learn."*

5.4.2 Impact on relationships

Care-giving had an impact on the care-givers' relationships with the care recipients and with other people in their lives. Care-givers often described having to adapt their capacity to meet the needs of other family members due to the needs of the care recipient. Judy had to put her three-year-old son into crèche more often. She said,

> *Oh that was bad, he didn't like it. He cried. He still does now when I take him. He sort of only used to go half a day here and half a day there when I was at uni. (But it's) three full days now, nine to five. He feels a bit shuffled around, I think.*

Heidi said, *"...I found that we [Heidi and the children] couldn't go out for our walks in the morning because there was always someone due and he couldn't get to the door to open the door..."*. Bernadette said, *"...I have just had to cut down on visiting Mum and Dad quite so much, but I can still go and see E as he has no-one else and Mum can fend for herself a bit more now."*

Care-giving also had an impact on the care-givers' friendships. May said she had learnt who her true friends were as she had not been able to spend time with friends but her true friends had stuck by her. Freda said, *"some people can't cope with terminal illness"* so Freda and her family had had to cut down on their social life.

5.4.3 'Til death us do part – impact on the marital relationship

For many married care-givers and care recipients, the assumption of a care-giving relationship changed the nature of their relationship with each other. For four wife care-givers the marital relationship had become more of a mother-child relationship. They said, *"It's like having two children"* (Judy); "I used to say to him *"I've got another baby,"* (Ruby); *"The first time I left him, it was like a mother leaving her new baby"* (Jill); and,

> *...he's still my husband but he is not my husband. There is still closeness but not in a sexual relationship. I am now his mother rather than his wife and that's a hard thing to come to terms with* (Freda).

Another major change in marital relationships was not being able to do the things couples liked to do together. For example, *"...(we) used to go to bingo together...I hope that we can get back to normal. Sit down and have a cuppa together and be alright again"* (Ernie), and *"...we did the garden together and now I sort of do it"* (Julie). For some care-givers and care recipients this had been the time when they were expecting things to get a bit easier. For example, Jill said,

> *I mean this should be the best time in our lives, not the tough time. I thought we'd been through the tough times...This is our time to ...do things and we will do them...It's OK because I am positive that we will and if we don't we will just make the most of what's there.*

In contrast, Carol stated that things had become easier for her since her husband had had the stroke. She said,

> *Prior to the stroke, he was getting on my nerves. He ruled with a rod of iron. Now the worm has turned. I'm in charge and it's working out well. I'm*

> *looking after him and doing a good job. Life is better now than before. He used to be a heavy drinker and gambler.*

Another change in the marital relationship that was often mentioned was the change in the division of labour. In most of the married care-giver dyads, the husband had done the outside jobs prior to becoming ill. The care-givers often described having to take these jobs on as well as everything else. An exchange between the care-giver and care recipient illustrates this point. Gwen said, *"I've always been the one to do things, haven't I?"* Her husband replied, *"I've done all the outside work."* Gwen responded, *"Yeah, really there wasn't much change except there was more of it."* Another wife care-giver, Anna, said, *"... I do all the work inside, he does the work outside...but now he can't mow the lawn anymore so I do that..."* And Freda said, *"I do the lawns now – that takes you outside the house for a few minutes."*

There were also some changes for the male spouse care-givers. Ernie had taken over *"doing things"* when he retired, but these responsibilities had increased *"when she got sick I took over all the cooking and housework."* Fred, the other husband care-giver said (referring to cooking and housework), *"I'm not useless as some men are."* Jill described how her husband who had retired had been doing some household chores but that his stroke had put a stop to that, *"...I didn't realise how much he did do. He'd get the vegetables done and now every job is my job and the dishes as well."*

5.4.4 Moving house

Six care-givers had been forced to move house. Four had moved in with the care recipient in order to provide the care, Heidi had the care recipient move in with her, and Carol and her husband had moved into Ballarat to be closer to health and community support services. These moves had a major impact on some care-givers. Paula had left her house in Melbourne vacant to move in with her mother. May had moved out from sharing accommodation with friends to live with her grandfather. She said that she was reluctant to invite her friends over because, *"apart from the fact there is a photo of me on the wall...there is nothing else of me here."* She also found the environment unpleasant,

> *...when I first walked in here, the stench, like the dog stench was just like, in my face. I thought I can't live here. I can't do this, I might have to back out,*

> *and even now I'm still at the point where I've tried to keep the dogs outside as much as possible. [But] because he is so used to them and them [being] his company, I can't do that either. It's a tough one.*

For Carol, who had to find a place in Ballarat while her husband was in hospital, moving house was one of the most traumatic aspects of the whole experience.

5.4.5 Expenses

Fifteen care-givers reported that there were expenses associated with care-giving. The most common expenses were purchasing equipment (7) and house modifications (2), but care-givers also reported increased household expenses (2), having to pay more rent (1), increased medical costs (1) and increased transport costs (3). The types and amounts of these expenses are shown below in Table 17.

Table 18 **Type and amount of expenses incurred by care-giver and/or care recipient during the ARITH episode**

Expense	Number of clients and/or care-givers	Amount
Equipment	5	$30 to $300
Modifications	2	$7,500
Transport	2	$15/week
Medical expenses	1	$20/week
Food and groceries	1	Not stated
Rent	1	$160/week
Community services	1	$17 /week
Gifts	1	Not stated

For some care-givers (and care recipients) there were considerable costs associated with alterations to their house or the purchase of equipment required due to their altered physical needs. However, few care-givers reported direct expenses as a result of the care-giving role. The one exception to this was May, who had moved from free rental accommodation into accommodation with her grandfather where she was required to pay reant. Having to give up or reduce working hours also had financial implications.

5.4.6 Work/study

Thirteen care-givers reported that providing care had led to disruption of their usual work activities. Four care-givers had given up their paid work altogether. As a result Paula currently had no income. Carol had less money but she was receiving a Carer Allowance[5] ($82 per fortnight). Carol and Sally both said that they missed the social aspect of work as well as the money. As Sally said, *"I just miss the mingling in with people."*

For the three care-givers who continued to work in paid employment, being a care-giver had a significant impact on their work lives. Bernadette reported having to take stress leave from work and she also talked about the ongoing impact of care-giving on her work. She said that she tried not to think about the worries and demands of care-giving at work. She said, *"I work with oncology and medical and I really have to switch off from outside and concentrate and be alert for what I am doing."* Jill reported similar concerns, described above under "Constancy of care". May had had to take on casual work and this affected her eligibility for the Carer Payment. The care-givers' experiences with the carer payments provided through Centrelink are discussed in Chapter Six.

Three care-givers who had been involved in voluntary work had relinquished it. Three were trying to study but found that care-giving had impacted on their ability to attend lectures and to concentrate on their studies. Dave said,

> *...its difficult to re-commence computer studies...I find that it's a disincentive to pursue things...I suppose you could say that it's a cop out but it's a situation where you really have to work your life...around the person you are caring for. It does place a lot of obstacles in pursuing the things you want to do.*

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[5] The Carer Allowance is one of two payments that are provided to eligible care-givers by the Commonwealth Government. The other is the Carer Payment.

5.4.7 Leisure

Care-giving also impacted upon the care-givers' leisure. Sixteen care-givers reported some disruption to their usual leisure activities. Some of the descriptions of these disruptions were, *"well I don't do anything. I'm a golfer but of course...I don't do that now"* (Jill), *"...obviously with the volume of appointments she has got, I find I can't play golf or even go for a walk. It disrupts my general social life and it's all care"* (Dave), and,

> *They [relaxation activities] were on hold. I normally go to the gym once a week at night. I was too exhausted to do anything by the end of the day...that is my main get away from the house time and I just didn't. I couldn't do it. And as I said, walking with the kids in the morning, we didn't get to do that* (Heidi).

5.4.8 Long-term impacts

The interviews were mainly restricted to the current situation and little was said about the long-term impact of caring. However, the effects of care-giving on the care-givers' current situation, especially for those who had had to give up work, would have had long-term ramifications for their financial and employment situation. The following case study has been included here to illustrate the longer-term impacts of care-giving.

5.4.9 Paula's story

Paula was in her late 40s and she usually worked as a nurse. She had taken extended leave from her nursing job because she had to move in with and care for her mother, Alison, who had undergone a total hip replacement after a fall. Alison only had a short hospital length of stay because she had been assessed as suitable for home-based rehabilitation. The fact that Paula could come and stay with Alison had influenced this assessment, but Paula felt that she had been given a choice and that a paid carer could have been made available if Paula had not been able to move in. This could have been arranged through the ARITH for a few days, but as Paula was planning to stay with her mother on a long-term basis, either until Alison regained her realistic alternative. Paula prepared the meals for them both, did all the housework, shopping, and gardening, and helped Alison with bathing. Because Paula was keen to help Alison to regain her independence she encouraged her to do what she could for herself, although she supervised all Alison's activities.

Paula's usual residence and workplace were in a town approximately 120 kilometres away from her mother. As she was not able to continue working at all during the period that her mother needed care, she had left her house unoccupied. She had some paid leave and her plan was to apply for the Carer's Payment when the paid leave ran out. She could not apply for the Carer's Payment straight away because it is means-tested. She was somewhat concerned about her financial situation as the Carer's Payment would not be adequate to maintain her own house in the long term.

Paula did not mind being there for her mother. She saw herself as being the only one (in the family) who could provide care and she imagined that she would stay with her mother until she improved or until she needed nursing home care. Paula was grateful that her employers had dissuaded her from resigning and had said she could return to work when she was available. Paula was not receiving any hospital, community, or income support at the time of the interview.

5.4.10 Immediate and long-term implications for Paula

Paula's story illustrates some of the potential and actual short and long-term impacts of taking up care in home-based rehabilitation. Paula left her home, her work, and her friendship network and moved in to care for her mother. This had the immediate financial impact of complete loss of income. It also affected her leave entitlements as she was using up all her paid leave, and she would not be accruing any more until she returned to work. In the longer-term, her absence from work would affect her long service and sick leave entitlements. It would also reduce her superannuation entitlements, as she was not making any contributions whilst she was not at work. Paula also missed out on any training and professional development that was offered while she was away. Finally and hypothetically, taking time off work to provide care could affect the way that she was viewed at work. As she had taken extended leave, her commitment to the job could be questioned, which could affect the type of work, promotions, and other opportunities that she was offered in the future.

Having to move out and leave her house vacant also had both immediate and long-term ramifications for Paula. In the short term she had the cost and worry of maintaining her house from a distance. In the longer term, her financial situation may have been such that she cannot afford to keep her own home but may have to sell it. This would mean the loss of an important investment, and one that could be very important to her future financial security.

Finally, taking leave from work and moving away from her home also had social implications for Paula. She had moved away from her work colleagues and friends and was not able to keep in touch with them easily. Apart from the immediate loneliness and isolation that this caused, it could also affect her transition back to her usual life once the period of care-giving is over.

5.4.11 Discussion of study questions about the impact of care-giving

1. How are the lives of male and female care-givers affected by taking on the care-giving role?

There was considerable evidence that the lives of both male and female care-givers were substantially affected by taking on the care-giving role. The examples outlined above illustrate both the immediate and long-term effects of care-giving for the care-givers involved in this study. As two of the male care-givers who were interviewed were retired and the other was unemployed, there was no disruption to their paid work schedules, but one said that he had been forced to give up his volunteer work, and they all said that their social lives were affected. The younger male care-giver could not look for work effectively because of his care-giving responsibilities. Thus, the lives of both male and female care-givers in the study were affected, but as only the women in this sample had paid work or other care-giving responsibilities, their lives were arguably more affected.

2. How much help do male and female care-givers receive from family, friends and neighbours?

3. Do they perceive this help to be sufficient?

Twenty one of the twenty four care-givers were receiving some form of family support. As Figure 8, below shows, most (18) care-givers rated the support that they were receiving from family and friends as quite adequate or better. However, five care-givers rated the support that they received from family and friends as inadequate or worse. Further, care-givers were more likely to rate informal support as inadequate than rehabilitation or community support. For example, May commented that her friends were great but her family was a hindrance, and two others reported that they did not receive any family support but would have liked some. Bernadette complained that although there were some other relatives who could be expected to help out, her husband was geographically closest to his father, which meant that she had to provide care. *"He [her husband] is the closest so no-one else does anything."* She later commented that even her husband did very little, *"it always annoys me that he doesn't do enough for his father, even if he mowed the lawns it would be better...."*

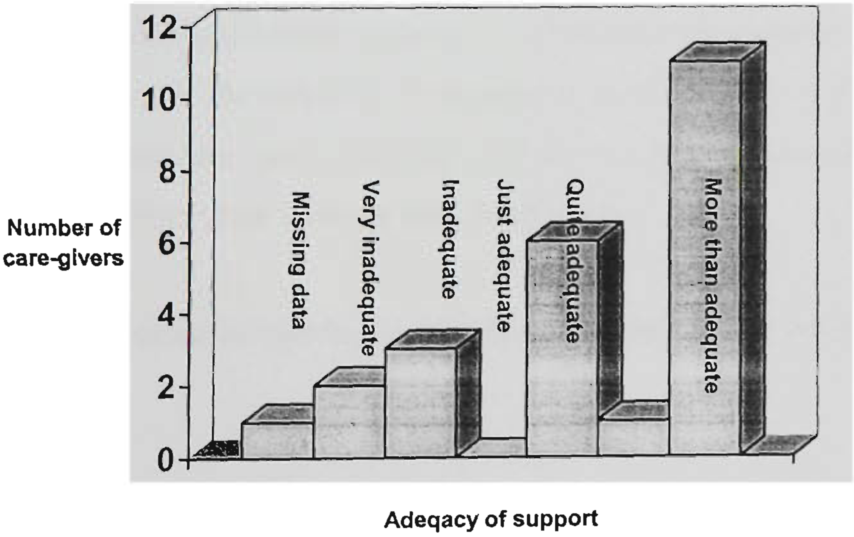

Figure 8 **Adequacy of family supports**

Help from family and friends emerged as very important in the care-giver interviews, both in a positive and negative sense. It was also observed by the researcher to be of significance for the care-giver. Those care-givers who were happy with the support they were receiving seemed to be more positive about providing care. For example Ivy had a friend and neighbour, Y, whom she could rely on for anything she could not do herself. She said, *"Anything that I haven't done, Y takes over and bomp, bomp, it's done"*. She seemed to be quite happy with her situation despite the fact that she had had to move out of home to care for her mother who had a terminal illness. Bea also seemed quite content despite the high level of care she was providing for her mother and she also reported a high level of support from her family and friends. She said,

> *We have had meals given to us and we have had slices and cakes and lots of goodies. We have had people coming in and offering to stop with her, [and] myself if C [the paid carer] hasn't been here.... Someone has helped me to lift Mum up onto the chair, just last week when the transferring wasn't very good and C wasn't here. My brother comes up from Melbourne once a week and he has helped out. He helps C if I'm not here.... He does some gardening for us which has been great. Another cousin has come and swept up leaves for us.*

By contrast, Bernadette was feeling very stressed out, and she was frustrated and angry that her husband and his family didn't do more for their father. Similarly, Dave was angry that his family did not do more, and he felt that unless they were to put in more effort, he would not be able to continue in the role. He said that his family help was,

> *...inadequate and I know it sounds cruel because they would be here if they could but...it's the only way I can judge it, from my point of view...I have told them exactly how I feel. They have just got to...help me more because I just can't continue to do it on my own indefinitely.*

5. Has the episode of care had a definite beginning and end point for the care-giver?

For 13 of the 24 care-givers, the current episode of care was part of an ongoing care-giving relationship. Twelve described it as a continuation of an existing care-giving episode and one as a third episode of care for the same client. Eleven care-givers reported that this was the first episode of care. None of the care-givers reported that they had finished providing care for the care recipient. However, most of the care-givers (16) reported seeing some improvement in the client's health and ability to do things since their discharge from hospital. Five care-givers reported a deterioration in the client's health, and three said that the client was about the same. When asked about their expectations for improvement in the future, twelve care-givers expected further improvement, six expected no improvement, three did not know whether there would be any further improvement, and three said they were hoping for further improvement.

Although there was a discrete episode of rehabilitation for the current disabling condition of the client, in terms of their admission to rehabilitation in the home, this did not coincide with the care-giving episode for the care-giver. The length of care-giving ranged from six weeks to fifty five years (for one woman who had been caring for her husband since his return from the Second World War) (see Table 19, below), whereas the average length of stay in ARITH for the study time period was 18.2 days. One of the assumptions made at the beginning of this study was that the episode of care would be short-term, but it was not as short as the length of stay on the home-based rehabilitation program. None of the care-givers reported that they had finished providing care for the client.

Table 19 Duration of care

Length of care-giving episode	Number of care-givers
Less than 6 months	8
6 – 12 months	4
1-2 years	0
2-3 years	5
4-5 years	3
5-10 years	2
More than 10 years	2

5.4.12 Discussion of study hypotheses relating to the impact of care-giving

5a) That there will be less disruption to work and leisure activities for male than female care-givers.

There was not enough evidence in the interview data, given the small sample of male care-givers, to substantiate or refute this hypothesis.

5b) That male care-givers will receive more help from friends and family than female care-givers.

There was not enough evidence in the interview data to substantiate or refure this hypothesis.

5c) That the episode of care will have a more definite beginning and end point for male than female care-givers.

There was not enough evidence in the interview data to substantiate or refure this hypothesis.

5.5 EXPLORATION OF THE CARE-GIVERS' LIVED EXPERIENCES

This section documents the themes that emerged from the interviews with care-givers that reflected their lived experiences of the role in line with study objective seven, which was, "To explore the experiences of both male and female home-based rehabilitation care-givers and the meanings that they attribute to those experiences."

5.5.1 The emotional side of care

One of the major themes to emerge from the analysis of the care-giver interviews was the emotional side of care. A distinction has been made in the literature between caring *for* and caring *about* the care recipient (Dalley, 1996). Family care-givers are expected to both care for and care about the care recipient. There is no corresponding expectation in professional care, where caring about the care recipient may even be discouraged. The emotional side of care described in this section could also be described as *caring about* the care recipient. Such caring is in addition to the work of care, described below, which could also be described as *caring for* the care recipient.

The main ways in which care-givers described caring about the care recipient were: their concern about the care recipients' health and emotional well-being; their love for the care recipients; and their descriptions of their emotional struggles, especially when dealing with aggression or care recipient demands.

For several care-givers, it was the emotional side of care-giving, that is, dealing with the emotional needs of the care recipient, that was most difficult for them. Dave, who was caring for his mother who had fractured her hip, said, *"...it is easier to look after them physically, than emotionally"*. He went on to elaborate, *"Anxiety levels are the things that really strike me. She becomes confused, she gets confused and anxious and can't do the things she did. That's when she becomes difficult to handle because she gets frustrated."* Heidi stated that, *"...maintaining conversation I find very difficult during the day, and he also needs a lot of reassurance. He tends to get really down when he thinks he's not doing things."*

Care-givers also seemed to put considerable care into looking after the emotional needs of care recipients by respecting their wishes and privacy, and by thinking of ways to lift their spirits. For example, May spent several days cleaning out her grandfather's house before she moved in when he was discharged from hospital after a total hip replacement, but she was careful not to throw anything out until he had given her permission. Ruby, who was caring for her husband who had cancer, described how she respected his wishes about showering; *"if he wants to have a shower, I shower him. If he doesn't, well, I just sponge him."* Care-givers found ways of assisting the care recipient without embarrassing them. Anna, who was caring for her husband after he had experienced a stroke, described how she swapped over the meals that they had ordered in a restaurant so that she could surreptitiously cut up his meal for him. Care-givers also talked about trying to keep the care recipients happy. For example, Sally who was caring for her terminally ill mother, said, *"[I'm] just trying to make her happy."* Bea, who was caring for her 95 year-old mother who had fractured her hip, said that she was just hoping for the day when her mother

> *...will be able to stand up for us, be able to walk. All we want is for her to be able to walk from the lounge room to the kitchen or out into the car. Put her in the car and take her for a little drive...just making life happy for her.*

Having company was seen as very important in keeping the care recipient happy and if there was no-one else around the care-giver saw this as his or her responsibility. Despite having many other demands on her time, Bernadette had lunch with her father-in-law in her lunch break from work because he needed the company. Dave said of his mother, *"...she needs company. [It's] very important for her...that's what* *she is very dependent upon. She is very dependent on people being around."* Jill, who was working during the day as well as caring for her husband who had had a stroke, said she did not like to go out at night because, *"...that's one thing he likes is some good company...I should be here I feel for his sake."*

The care-giver's feelings towards the care recipient were sometimes mixed. May cared for her grand-father despite a prior history of abuse perpetrated by him. Her feelings towards him were very ambivalent. She described her love for him as a grandfather, *"...you're the only one [grandfather] I know, the only one I love, you are my grandfather"* and also her anger and frustration with him for not doing what he could for himself, and for expecting her to be at his beck and call, *"...its almost like to him I'm on demand now – I'm on call and I don't put up with that".* Others talked about enjoying their relationship with the care recipient. *"I enjoy her company anyway"* (Amy). *"They (the children) just loved having him, absolutely loved it and he loves being with the kids..."* (Heidi). One other care-giver, apart from May, spoke about her frustration with having to do so much for the care recipient. Bernadette was annoyed that her father-in-law refused help from community services by saying that *"Bernadette will do it".* She said, *"...he put it all on my shoulders...I don't think they [service providers] realise the time it takes to do things for them really. They don't realise."* Sally saw her mother's demands as a good thing, a sign of recovery. She said,

> *...you know she is getting better because it's like a real bloody Hitler. She does give the orders out, but they are not bad orders, and she still has a sense of humour and we can sit here and have a joke.*

Some care-givers also experienced love and appreciation from the care recipient. The care recipients were present for eight of the interviews and these comments often came from them. For example, a wife who was being cared for by her husband, Ernie, because she had Parkinson's Disease said of her husband, *"he is so good to me."* Sally's mother said, *"...between you [her daughter] and Y, I'm better than when I go to hospital."* The care-givers also reported feeling appreciated. For example, Frances said, *"...it gives them so much joy and pleasure to think that some-one cares about them,"* and Judy, who was caring for her young husband after a motor cycle accident that had resulted in the loss of a leg, said, *"He respects me and appreciates what I have done."*

5.5.2 The work of care

Another major category to emerge from the analysis of the care-giver interviews was the sheer hard work of caring. Included within this category are discussions about the volume of work, the intimate and sometimes unpleasant nature of the work, the double or triple shift that the care-giving work represented and, despite all this, the way in which care-givers described it as "no big deal".

Many of the care-givers interviewed were doing a huge volume of work as care-givers. Ruby described how showering and dressing her husband could take nearly all day. *"(It took) nearly all day because he would wet himself and I would have to change him, nearly all day. It was all I did,"* and at night, *"I'm up four or five times a night rushing to get the bottle for him because he can't reach over and get it...I don't get a lot of rest of a night time."* Bea described how she got up at 7.15 every morning and was on the go until she went to bed at 9.00 at night. She also got up in the night to turn her mother so that she didn't develop bed-sores. She described some of the nursing tasks that she did for her mother. They included mouth washing, eye washing, changing kylies (incontinence pads), swabbing the ulcers in her mouth, massaging her legs, and doing her glucose readings. She also took over an hour to feed her mother every meal time and needed an extra person to assist her every time her mother needed to be transferred from bed to chair, chair to commode, and so on. Dave described some of his daily routine,

> *...I give her breakfast...and I give her meals on Friday, Saturday and Sunday...I do the cleaning in between [the home care service] and I'll make the beds, wash the linen and generally make sure [she is alright], wash her clothes, that sort of thing....*

Fred, who was caring for his wife who had had a stroke, described his night-time care routine

> *...she can't get out of bed at night ...[if] she tries to get up she is so easy going to fall forward or fall back onto the bed. I am there to support her [one to four times every night].*

Taking the care recipient out was often a major undertaking. Dave described how going to the doctor with his mother took up a whole morning and visits to the physiotherapist took up a whole afternoon. Fred described taking his wife out to an appointment,

> *I used to have to get her out of the car, get her into the street, take her in and find a chair for her to sit down on, then go back and shift the car, and then come back again. Oh, it was a nightmare, I can tell you.*

The work of care was often very intimate and sometimes unpleasant. May had to clean the toilet after her grandfather had used it because he used to *"miss"* and tip over his commode when he emptied it. Heidi described how her relationship with her father-in-law had changed because, *"I mean, I have been through all his guts and looking at you know, colostomy bags and all sorts of stuff. You see a person in a different light completely."* There were many more descriptions of cleaning up after incontinence and dealing with colostomy bags. Carol's story, recounted below, illustrates some of the intimate care tasks that ARITH care-givers were involved in. Other intimate personal care tasks included shaving and putting on deodorant (Freda), doing his wife's hair (Fred), and putting cream on her husband's bottom (Julie). Care-givers seemed to generally have done whatever was required. Anna said, " I prepared the meals, cut them up, and put them in front of him. I'd just give him a hand in everything, did just what needed doing. Even put the blankets over him at night." Sally said, "Anything she wants we get. If it means at 10 o'clock at night she wants Chinese [food], we will track down a Chinese shop and go get it."

The work of caring was often being done in addition to other domestic or paid work. For example, Amy, who had moved in to care for her aunt, said she still had to look after her husband – cook his meals and do his washing and so on. In addition to caring for her father-in-law who had undergone surgery for bowel cancer, Bernadette had a full-time job as well as her own parents to care for, and she still took responsibility for all the domestic work for herself and her husband. She said,

> *...even still now I am later home and meal preparation [for herself and her husband] is always later...if I start at 7.00 in the morning...if I see Mum, go and see E [father-in-law] and get all his things done, dishes after he has had*

> *his tea, then go and see Dad [in a nursing home] quite often it's six o'clock before I get home.*

Heidi was looking after her own two children aged two and three, as well as her two-year-old niece during the week as well as caring for her father-in-law and Jill was working 4 days a week. Jill described getting home from her paid work and trying to shower her husband, *"...I shower him at night and he is not too co-operative at 5.30 or quarter to six at night...and I'm not feeling so good after doing eight hours (paid work)..."* She had also had to take over the gardening, *"...I'm the gardener as well. I mean its pretty full-on...all the time I have to think ahead about what I am going to do and how I am going to do it..."*

Despite the descriptions above and below of the nature and volume of the work, many care-givers described it as if it was no great trouble to them. For example, Amy really did not think she had done much at all for her aunt, but as she was prompted in the interview she revealed that she prepared the morning and evening meals, did all the housework, watered the garden, assisted her aunt with getting dressed, emptied her commode, helped her with her walking, and stayed with her all the time for the first week after she was discharged from hospital. A typical comment from Amy was,

> *Well, I got A's breakfast for her which is very easy to get. You just get two pieces of toast and a cup of black tea...Oh, that didn't take long at all. No, it would only have taken what something like 10 minutes, I suppose.*

Rose described caring for her husband who had had a total knee replacement,

> *I bring his four meals to his bedroom and take them away, and then I suppose the bed has to be changed and made. Sheets and everything washed and...the cleaning...say once a week vacuuming and all that. There is not a great deal.*

Sally, who had moved in with her mother to care for her, leaving her own home and teenage children said, *"(It) isn't a hassle. I get to see the kids every day when they come here. I can scoot around and do whatever."* She said that providing care for her mother, *"doesn't bother me at all."* Several other care-givers expressed similar feelings, *"no worries, happy to do it"* (Paula), and *"don't mind at all (providing the care)"* (Ernie).

5.5.3 Carol's story

Carol's story is included here to illustrate the level and intimacy of the work of care in the ARITH. However, it also provides an example of some of the other impacts that care-giving can have on the life of the care-giver. Carol's whole life – her sense of well-being, her home, her work, leisure, and friendships – was disrupted when Pete had a stroke and needed her care. Furthermore, their relationship completely changed. This change, however, in Carol's opinion, was for the better.

Prior to Carol's husband Pete having a stroke, they lived on the outskirts of a country town about 30 minutes drive from Ballarat. Carol was very involved in the local community. She worked in the supermarket and was involved in several social activities in the town. She also loved to read and borrowed books from the visiting library service whenever it came to town. When Pete had a stroke and was admitted to hospital, Carol had to find some accommodation in Ballarat as it soon became clear that he would not regain his previous level of independence and they would need to live close to medical facilities. Carol could drive but was used to driving around the country. Pete had always driven when they visited Ballarat in the past. While Pete was in hospital, Carol had to drive around Ballarat to visit him and to find a house to rent. She also had to arrange to move out of their rented accommodation in the country and into Ballarat. She said that she had never managed their finances and organizing the disconnection and reconnection of all the utilities was completely new to her.

When Pete was discharged from hospital and came home with the support of the ARITH, he was unable to swallow and so had to be fed through a peg that went into his stomach. He also had a colostomy bag to empty his bowel and a catheter for urine. Apart from this, Pete could not speak so he communicated with gestures and grunts. Carol had to help Pete with all activities of daily living. The ARITH supplied a nurse to assist with showering and dressing, and to check Pete's peg, catheter, and colostomy bag for the first few weeks. However, even with this help, Carol still had to feed him through the peg, assist him to get around the house, and change his colostomy bags. All of this was completely unfamiliar to Carol and she found the responsibility quite overwhelming. She said she felt very depressed and often couldn't stop crying. Her general practitioner prescribed anti-depressants but she was reluctant to take them. She found the support of friends critical at this stage and really missed her previous home and community. However, she did have a friend who provided her with a *"waterproof shoulder"* to cry on and she felt that this had helped her get through the worst times. The worst time for Carol was when Pete's peg came out and Carol did not know what to do about it. She did not know whether she should be able to reattach it herself or whether she needed to call for medical assistance. Luckily, this happened just before the ARITH nurse was due to visit and the nurse arranged for Pete to be readmitted to hospital.

By the time of the interview, Pete was able to communicate verbally and he was ambulant with a frame. He no longer required a stomach peg and was taking in some sustenance orally. However, Carol was still helping him with showering and dressing, managing his colostomy, feeding him, doing all the housework, managing the finances, and doing the small amount of gardening that their unit required. She also felt that she couldn't leave him, and so had not been able to get to the library to borrow books for some weeks.

Despite all the work and the disruption to Carol's life that caring for Pete entailed, Carol felt that the changes to their relationship were to her advantage. She said that Pete had been a problem drinker and gambler in the past and that now that she was managing the finances his gambling had been curtailed, and his ill health prevented him from drinking. She also said that he had dominated the relationship in the past, even to the extent of not letting her see her son from a previous marriage. Carol said that, *"the worm has turned"*.

This story illustrates the level and type of care that one ARITH care-giver was providing. It also illustrates some of the life changes that care-givers go through when care recipients become ill. In Carol's case, the life changes would have had to occur regardless of Pete's participation in the ARITH as he and Carol would have needed to move even if he had been retained in hospital for rehabilitation. However, the initial assistance with personal activities of daily living, managing his feeding, and continence, would previously (prior to the establishment of the ARITH) have been done in hospital. The requirement for constant supervision was another aspect of hospital care that had been picked up by Carol and other ARITH care-givers, as the following section illustrates.

5.5.4 The constancy (and worry) of care

As stated above, 18 of the 24 care-givers interviewed reported having to be present 24-hours a day. It was not surprising that the constancy and worry of care emerged as a major category from the care-giver interviews. The constancy of care-giving had three main features. The first was fear of leaving the care recipient and a need to be on call when the care-giver did go out. The second was fear of the care recipient falling, which was mentioned in almost every interview. The third was the impact that this had on the care-giver; the feeling that their own lives had to be put on hold.

Some care-givers could not even leave the care recipient alone in a different room for a few moments. For example, Bea, who was caring for her 95 year-old mother could not leave her alone in a room in case she tried to get up and fell. Heidi had to be there all the time, *"yeah, because he wasn't steady on his frame and you couldn't just leave him. So it was an ongoing thing all the time like getting in and out of bed, getting up and down off chairs, just everything."* Many care-givers couldn't go out of the house at all. For example Emma who was caring for her husband after a stroke, said, *"Yes, I must be here or someone must be here all the time. Normally me."* Fred said, *"All the time, there is no-one else here with me. That was the big thing. I had to be here all of the time...I can't say well I am finished and out the door and home. I'm here."*

Even when they could go out briefly, care-givers' thoughts were with the care recipient. Gwen provided an example of this hyper-awareness. Her husband had fallen from a ladder and been crushed by a chainsaw. This accident had resulted in injuries to his ribs and shoulder. Gwen said, *"...I would be on edge, go down the street and think, Oh, I've got to get home."* Ruby described having to go to the doctor but feeling very uncomfortable leaving her husband,

> *Yes, I had to go to the doctor's but she is only around the corner and that only [meant I] left him for about 40 minutes. I said to him, you stay in your chair and don't get out. Well he didn't need to get out, he had his bottle beside him if he needs to do urine.*

Jill was also anxious about leaving her husband, *"I mean I have a thousand heart attacks when I am not here and I know he is going to do that [get a cab to the hospital]."* Many care-givers had a mobile phone so that the care recipient could contact them at any time. Rose said she was always there *"...except when I have to go and pay the bills and do the grocery shopping...he knows he can ring me. I usually have the mobile ."*

The fear about the care recipient falling was shared by most care-givers. This was one reason that they felt they could not go out. *"Well, I thought I did [need to be there all the time] just in case he fell...you better not leave them alone..."* (Anna). The fear of falling was also a part of the constancy of caring in the home. For example, Jill feared that her husband would fall in the shower, *"...was he going to [fall while I was showering him]? That was always in my mind. I could have done with some more back-up, more assistance..."* Heidi described how she was afraid to have her father-in-law at home because he might fall. She said,

> *...one day we were there [in hospital] and the next morning he fainted and needed two blood transfusions. They said, oh well, that's OK. I was terrified. I said, what if he does this at home? Like are you going to send him home to me and he could collapse on the floor?*

The need for someone to be there all the time had a huge impact on the care-givers' lives. They talked about having to put their own lives on hold (May), about not being able to go out *"...[I] can't just go and have a coffee whenever I like"* (Judy), and about having no time for themselves, *"it just takes all my time"* (Bernadette). The impact of care-giving on the care-givers' lives has been further discussed above.

Finally, most care-givers were very concerned about the care recipient's health. Often they would comment sympathetically about the level of pain that the care recipient was experiencing. For example, Amy, a niece caring for her aunt who had fractured her hip, said, *"...she's in pain all the time."* Frances, who was caring for a friend she had met in the course of her work at a Special Accommodation House who had also fractured his hip, said, *"He's in quite a bit of pain. I just think he is going to die."* Carol, who was caring for her husband who had experienced a severe stroke, said, *"I don't think he's going to get better. Some days he's improving, other days ...He won't* *see old bones."* They also spoke about how hard life was for the care recipient. For example, Heidi talked about how she was glad to be able to be there for her father-in-law who had fractured his hip and who also had cancer because,

> *...his brother died in April, and they were best friends – so it's been a really bad six months really. He was due to go in to have a full week of chemo [therapy] and I got that put off ...because his brother had a car accident and we didn't know if he was going to live or not...losing his brother was really bad, so he sort of had no one to talk to so it [having her care for him] has sort of made a difference.*

5.6 DISCUSSION

The preceding five sections of this chapter outlined some of the findings taken from the questionnaire schedules and interview transcripts of the 24 interviews with ARITH care-givers. These have been presented with very little interpretation so that the voices of the care-givers could, to a large extent, speak for themselves. This section discusses the way in which these findings challenge some assumptions made about rehabilitation, and how these findings pertain to the literature reviewed in Chapters Two and Three.

5.6.1 Assumptions about rehabilitation

In the early phases of this study, it was assumed that the care-giving episode for both the home-based rehabilitation client and his or her care-giver would be short-term. It was also assumed that the care episode would be limited to the home; that is, that when the care recipient was in hospital, care by the informal or family care-giver would not be required. It was also anticipated that the care-giver would feel encouraged by observation of the care recipient's physical improvement and the expectation that the episode of care would be time limited. Although these assumptions and expectations were borne out in the experiences of some care-givers, for the majority they were not. For most (13), the care-giving role did not begin with the admission to the ARITH, and for all 24 it did not end with discharge from the home-based rehabilitation program. Furthermore some care-givers were involved in a long-term care-giving relationship which included care for the care recipient whilst in hospital or residential care. For some, as will be discussed in the next chapter, getting the care recipient home represented a respite from hospital visiting as well as an increase in care-giving tasks at home. Furthermore, although most (16) care-givers were able to witness improvement and increased physical independence in the client, for three clients there was no improvement, and for five clients there was a physical decline.

These findings call into question the way in which rehabilitation is generally defined and the implications that this has had for the way that home-based rehabilitation programs have been established. Intensive rehabilitation of the type that is provided through the ARITH and other home-based rehabilitation programs is usually only provided on a short-term basis, to a maximum of eight weeks. This is based on the notion that rehabilitation is a restorative process rather than a supportive or palliative one. The expectation is that clients will improve, either to a previous level of function or to a level where their care requirements are reduced. Rehabilitation has been defined as a process that aims to:

> *improve function and/or prevent deterioration of function to bring about the highest possible level of independence, physically, psychologically, socially and economically, to maximise quality of life and to minimise long-term health care needs and community support needs of these people* (The Australasian Faculty of Rehabilitation Medicine, Victoria Branch, (AFRMVB)1997, p. v).

In order to be admitted to the ARITH, the client must meet several admission criteria. Included in these are the criteria that, *"the client has been assessed as requiring active rehabilitation and has the potential to improve functional ability; and the client is medically stable* (Dow, 1999, p. 148)".

According to both the above definition and the program criteria, there is a clear expectation of functional improvement among the clients of the service. Further the definition includes the explicit aim of reducing dependence on long-term care and community support. The AFRMVB publication expanded on this aim to include the possibility of cost reductions. It stated that rehabilitation aims *"to minimise the long-term health care needs and community support needs of these people and so bring about considerable cost savings both in acute health care and in long-term social* *security, community care and supported accommodation* (AFRMVB, 1997, p.2)". The ARITH admission criteria also made the economic aim of home-based rehabilitation explicit in the criterion that *"the estimated costs of the ARITH are less than those applying to inpatient care* (Dow, 1999, p. 148)."

One of the features of home-based rehabilitation that is starting to emerge in the literature is that it is more holistic and more conducive to community reintegration than hospital-based rehabilitation (von Koch et al., 1998; Dow, 1999; Mayo et al., 2000). In the home, rehabilitation can include activities that are designed to reintegrate clients into their communities, such as attendance at church or having a cup of coffee at the local shopping centre. These activities may not impact on clients' physical function, but may improve their emotional or spiritual well-being. Furthermore, these activities may not reduce the need for community services or care-giver support. Rehabilitation viewed in this way may also be a very long-term process.

Furthermore, for some home rehabilitation clients, their condition means that despite rehabilitation, their function will continue to decline. For example Freda's husband and Sally's mother, who had terminal cancer (and who have both since died), were unlikely to physically improve as a result of rehabilitation. However, rehabilitation led to a reduction in some of the handicaps associated with their impairments. For example, given environmental aids, such as a shower chair, and a device for putting on socks, Freda's husband was able to dress himself independently for a longer period than he would otherwise have managed. The issue here is not that there is no place for physical rehabilitation in cases where the client is likely to decline, but that care-givers (and service providers) need to understand that restoration of function is not always possible or timely.

For half the participants in this study the work of care had either stayed the same or increased since the care recipient had first come home from hospital. There was also a high level of reliance on the care-giver after the period of rehabilitation had finished. This was not really surprising considering the severity of physical handicaps experienced by the care recipients. What is of concern here is the impact on care-givers of unrealistic expectations about the likelihood of the clients' recovery. Care-givers who expect that the care recipient will be medically stable and likely to gain functional improvement as a result of rehabilitation may have expectations about the episode of care that are not realistic in the light of these findings. They may expect that the care recipient will improve to a previous level of function and that the care relationship will be short-lived. What is clear from these findings is that the care required by the rehabilitation clients in this study was neither of low intensity nor short-lived. One of the few studies that examined care-giving for orthopaedic rehabilitation clients (Williams et al., 1996) found that care-givers had expected that the care recipient would recover more quickly than they did and that the discrepancy between actual and expected recovery time is a concern for care-givers. They recommended that care-givers be given better information about the expected progress of the client.

The other aspect of the above definitions and program admission criteria that is pertinent here is the aim of reducing costs in acute health care, long-term social security, community care, and supported accommodation. The findings of this study indicate that where there is an (unpaid informal) care-giver, this aim is achieved regardless of the improvement in the clients' functional state. The care recipients in this study were not relying on acute health care, long-term social security (only five care-givers received the Carer Payment), or supported accommodation and, as the next chapter will illustrate more fully, there was only limited reliance on community support services.

5.6.2 What is the real impact of care-giving?

As discussed in the literature review, the majority of the literature on care-giving focuses on the constructs of burden, stress, and strain. A range of measures have been developed to measure these constructs and the effectiveness of care-giver support services have been measured according to the extent to which they alleviate care-giver stress, strain, or burden. The findings of this study show that ARITH care-givers do not describe their experiences of care-giving in these terms and raise the question of ownership of these constructs. Do care-givers themselves see what they are doing and the impact of care-giving in terms of stress, strain, or burden, or in other terms? If the care-givers themselves do not identify with these constructs, why do researchers continue to measure them? As discussed in the literature review, these constructs are individualising, and locate the care-giving problems with the care-giver and his or her own coping skills. Furthermore, they steer attention away from the social structures and pressures that place these burdens on care-givers in the first place.

What then is the real impact of care-giving from the perspectives of care-givers themselves? The following is a discussion of the impact of care-giving on the lives of the care-givers as perceived by the 24 care-giver participants in this study.

5.6.2.1 Try not to think about it

Although the care-giving experience was not constructed in terms of burden, stress, or strain, it certainly took its toll on the emotional, social, and financial well-being of the care-givers. Care-givers often described themselves as 'trying not to think about it' when asked how they felt about providing the care. They seemed to think that allowing themselves to think (or feel) would only make the situation worse both for them and the care recipient. Ungerson (1987) described similar responses in her qualitative study of 19 care-givers in the UK. Some of the care-givers in her study said that they could only continue with the care if they cut themselves off from their feelings in order to get on with the immediate caring tasks. In Ungerson's study these responses were restricted to daughter (or daughter-in-law) care-givers who were caring for a parent (or parent-in-law). Ungerson theorised that this was due to the longevity and complexity of the relationship and the fact that (apart from spouse caring) there were no alternative non-professional caring models to the mother-child relationship. As the daughters or daughters-in-law were not comfortable with the feelings associated with mothering their parents or parents-in-law, they divorced themselves from these feelings and acted more like nurses than close relatives. In this study, expression of the sentiment that it was better not to feel or think about things but just to get on with the tasks at hand was not restricted to daughters or daughters-in law but was also expressed by several wife care-givers. It was also the wife care-givers who talked about becoming a mother to their husbands and not feeling comfortable with this role. It may be that Ungerson's interpretation of this distancing response could be extended to wives, who also do not feel comfortable with the mothering role, or it may be that there is some other reason for this response. It seemed to the researcher that these participants were afraid that if they gave vent to their feelings they may be overwhelmed by them, and as they said, only make themselves and the care recipient miserable. This seemed to be more likely to be due to the extent and nature of the work of caring, including the constant worry documented above, than due to avoidance of feelings associated with a mothering role. The main feelings expressed (when they were expressed at all) were of frustration and anger at having to do so much (for example, Jill, Bernadette, and May) and at the restrictions care-giving placed on the rest of their lives (for example, Gwen and Dave).

Care-givers also talked about how care-giving had changed their perspectives on the world (for example, Freda and Carol). As discussed above, Carol said that caring for her husband had made her realize that *"life is precious"* and Freda said that care-giving had made her re-evaluate what was important in life. This finding is consistent with the findings of previous qualitative research in which care-givers have described an appreciation of life in general (Wood, 1991) and *"a new way of being in the world"* as a result of the care-giving experience (Fraser, 1999, p. 9).

5.6.2.2 Doing it alone

One of the problematic aspects of the care-givers' experiences as outlined in this chapter was the constancy of the care required, and the level of worry and responsibility associated with providing this care. The few care-givers who had someone who could relieve them whenever they needed to do something else seemed to be experiencing the whole care-giving episode as less worrying than those who felt the full weight of the responsibility alone. As outlined under 5.2.6 above, there were three features of their experience of the constancy of care. One was the need to be constantly on call, the second was worry about the care recipient's frailty, in particular, fear that they would fall, and the third was the impact that this had on the care-giver's life. The first two aspects illuminate an important feature of the ARITH care-giving experience, which was the high level of responsibility that care-givers assume when they take on the care of someone who has been recently discharged from hospital after a fall (resulting in broken bones), a stroke, surgery (such as an amputation or bowel surgery), or after an exacerbation of an already serious illness, such as Parkinson's Disease. The type of care required is not only often physically arduous but requires a high level of vigilance and monitoring to ensure that the care recipient does not become ill again (through a fall, a further stroke, or grand-children clambering over them).

If this care was provided in a hospital setting, the environment would be set up to minimise accidents and falls, and would include sufficient staff to respond to crises if they emerged. The hospital is also set up with various professional staff, each with their own area of expertise. A domestic worker in a hospital is not expected to identify when a patient is having a stroke, nor is a medical practitioner expected to prepare and serve the meals. In contrast, informal care-givers do it all. Finally, in a hospital or community service setting, there are teamwork and supervisory arrangements that staff can use for consultation and support if they are concerned about a client or patient. Care-givers, especially when they do not feel that they are part of the team (see discussion in the next chapter), do not have this opportunity. The care-givers in this study were managing the physical care, maintaining constant vigilance, and taking responsibility for the well-being of someone recently recovering from a major health problem, and were generally doing it alone.

5.6.2.3 Work and relationships

Care-giving had a complex effect on the relationships between the care-giver and care recipient: sometimes bringing them closer together (Bea and Heidi); sometimes changing the nature of their relationship, especially for three younger wife care-givers (Judy, Jill, and Freda); and sometimes threatening the viability of the relationship (Dave and May). The impact on the care-givers' social and work lives was more straightforward. All those who were working prior to taking on the care-giving role had either left their job (Paula, Carol, Sally, and Bea) or had experienced some disruption to their work. For example, both Jill and Bernadette had to take leave from work when the person they cared for had first come home from hospital. They also both reported having to discipline themselves not to think about their care-giving responsibilities whilst they were at work and to focus on the job at hand. No care-givers reported any employment benefits associated with care-giving.

Care-givers' social lives were also affected. Care-giving restricted what they could do and for many this meant giving up their usual leisure activities. However, four care-givers did say that they enjoyed the company of the care recipient. No care-giver benefited financially from being a care-giver and many were financially disadvantaged through taking on the role. These findings are in general agreement with the findings of the study by Kane et al. (1999) discussed earlier. Their study took an open-ended approach to exploring the experiences of care-givers who were caring for people post stroke or hip fracture (n=307). The study included care recipients who had been admitted to nursing homes as well as those being cared for in the community. Two weeks after discharge, 40 % of care-givers of community-based relatives (and 13% of those caring for nursing home residents) described their care-giving as a full-time job. Like the care-givers in this study, they were also performing a large variety of care tasks. Although there were some sources of satisfaction for the care-giver, for example seeing the care recipient's health improve, only one received any material reward. The effects of care-giving included both positive and negative impacts on the relationship with the care recipient and effects on other relationships, but the most frequently mentioned negative effects were effects on finances and employment. Like this study, the Kane et al. (1999) study illustrated that when care-givers are invited to identify the things that are problematic to them, they are more likely to identify aspects of the experience that are structural or environmental in origin than psychological or interpersonal problems.

5.6.2.4 Benefits of care-giving

In the literature review, this study critiqued much of the previous literature for being overly interested in the negative aspects of care-giving, and thereby potentially obscuring both benefits to the care-giver in providing care and reciprocity in the care-giving relationship. However, in this study, care-givers reported few benefits in taking on the care-giving role. One benefit, which has been described in the next chapter, was that having the care recipient at home meant that the care-giver did not have to visit them in hospital. This benefit has been identified elsewhere (Dow, 1999; Rink et al., 1998). Apart from this, some care-givers did say that they felt closer to the care recipient (Bea and Heidi) as a result of the care-giving role, and some (Freda and Carol) said that it had helped them to appreciate what was important in the world. Although few benefits were identified, the overall impression that the care-givers gave was of strength and resilience. They had taken on a considerable task and felt the weight of the responsibility, but they were not complaining.

5.6.3 Summary and conclusion

The impact of home-based rehabilitation care-giving on the care-giver has been documented in previous literature but with the exception of the Kane et al. (1999) study, described above, the focus has been mainly on care-giver stress and strain. This study has found that the impact of care-giving extends beyond the personal and interpersonal circumstances of the care-giver, described by other authors, into the realms of employment, housing, and the financial circumstances of the care-giver. Furthermore, the unique finding of this study is that these impacts are experienced by care-givers working within a hospital-level health service, where the care-giving episode may have been expected to be straightforward, short-term, and alleviated by the support provided through this service.

The extent to which these impacts were alleviated (or contributed to) by the health and welfare system is discussed in the next chapter, which looks at the care-givers' perceptions of and experiences of rehabilitation and community support services.

Chapter Six – Results and Discussion 2: Interface with formal support services

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6.0 INTRODUCTION

All of the care-givers interviewed for this study were caring for someone who had been recently discharged from the ARITH. With the exception of one care recipient (Emma's husband), all care recipients had been discharged from hospital prior to their admission to the ARITH. This chapter documents the care-givers' perceptions about their interactions with the hospital system, the ARITH, and community and income supports. These perceptions were derived from their responses to interview questions and other statements recorded in the interview transcripts.

The chapter has been divided into six sections. Sections one and two contain data taken directly from the interview schedules as well as categories derived from the interview transcripts. These data all relate to study objective eight, which was, "from the perspectives of care-givers in home-based rehabilitation, to assess the adequacy of support services provided." The study questions under objective eight were –

1. Do care-givers perceive that they receive adequate support services from home-based rehabilitation and other services?
2. How do care-givers perceive the actions of the health service in implementing early discharge for rehabilitation at home?
3. What changes would care-givers like to see made in the services provided to themselves and/or the care recipient?
4. How could care-givers in home-based rehabilitation be better supported, acknowledged, and compensated?

The first section documents the extent of rehabilitation and community service provision to the care-recipients while they were on the ARITH and the care-givers' perceptions of the adequacy of these services. The second section discusses the care-givers' perceptions of their interactions with the hospital system, particularly at the point of transfer from hospital to home. The third section documents the payments received by care-givers, their perceptions about these payments, and other social justice issues. Two case studies have been used to further illustrate the social justice issues associated with care-giving in the ARITH. The fourth section contains two categories that emerged from the interview transcripts, and both categories relate to the care-givers' preference for not having to rely on help from others. These have been labeled "Independence" and "Better off at home". Section Five discusses these findings in relation to the relevant study hypotheses and literature. Finally, a summary of the participants' responses to this analysis of their stories has been included in this chapter.

6.1 REHABILITATION AND COMMUNITY SUPPORT SERVICES

The questions asked in the interviews about rehabilitation and community support services refer to the time that the care recipient was admitted to the ARITH. The ARITH consists of a multi-disciplinary team of staff who visit clients at home to assist them to achieve their rehabilitation goals. The program also brokers (that is, arranges and pays for) community services that are assessed (by the care coordinator) as needed by the client.

6.1.1 Rehabilitation services

The following table shows the number of clients that received services from each of the rehabilitation team disciplines at some time during their admission to the ARITH. This table (and all the information in this chapter) is based on the perceptions of the care-givers. The researcher asked specifically about some disciplines (marked with an asterisk), and then asked if there were any others not already mentioned. Although all clients on the ARITH would have been allocated a care coordinator, only five care-givers identified a care coordinator as someone not already mentioned.

Table 20 **Services provided by the ARITH**

Rehabilitation Service	Number receiving service (N=24)
Allied Health Assistant*	22
Rehabilitation nurse*	21
Occupational Therapist*	21
Physiotherapist*	21
Social work*	7
Care coordinator	5
Speech pathology*	2
Specialist in rehabilitation medicine*	2
Dietician	2
Psychologist	2

* Denotes those disciplines that were asked about by the researcher.

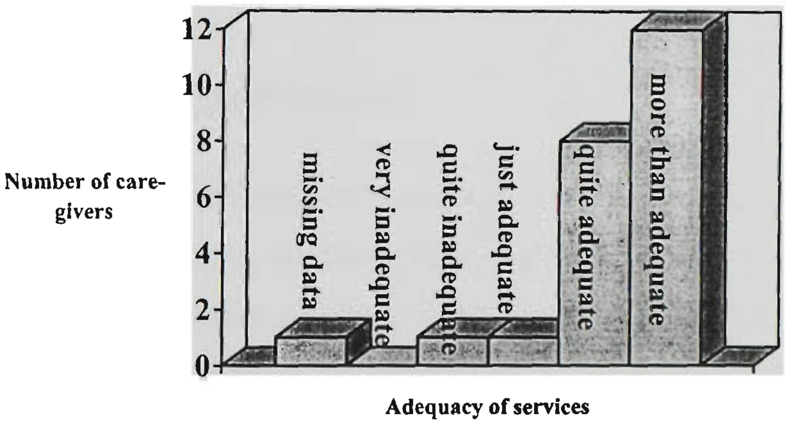

Figure 9 **Adequacy of rehabilitation services**

Figure 9 above shows the extent to which care-givers found the rehabilitation services to be adequate. These responses reflect very positively on the rehabilitation service, as 21 care-givers rated the service as quite adequate (4) or above. However, some of the comments that accompanied these ratings were not so positive. Ten of the care-givers were unambiguously positive about their experience of rehabilitation in the additional comments that they made. For example, Anna who was caring for her husband after a stroke said *"...you couldn't fault it. You know whatever you wanted they looked after you."* Emma, who was also caring for her husband who had experienced a stroke, gave the service *"Top rating."* A further ten were slightly more ambiguous but still generally positive. For example, Bea said, *"...I was going to say more than adequate but it wasn't because we are still waiting on a shower chair, and there is still a wheelchair that we have to get..."*, and for Heidi the service was somewhat marred by its abrupt finish, *"it was sort of good but then all of a sudden it just stopped."* The other four were more critical of the program. Three care-givers commented that although the support to the client was adequate, they did not receive enough support as care-givers. The final negative comment was from May who was asked repeatedly by ARITH staff to shower her grandfather. She did not want to shower him because he had previously sexually assaulted her, but the ARITH staff were not aware of this. She said,

> *...the rehab would have to be put between a 3 and a 4 because there are areas where they were great, but there were other areas like the phone calls, and there were like three in a row in an hour where at the end of it I was like NO. Yeah, I really had to stand my ground....*

May's story has been further elaborated on in Section 6.3.2 below.

6.1.2 Community support services

The number of clients who received each type of community support service is shown below in Table 21. With the exception of the hospice and the care support service, all these services were brokered (paid for) by the home-based rehabilitation program. The services that the researcher asked about have been marked with an asterisk. The others were added by the interviewee.

Table 21 Community Support Services provided to ARITH clients

Community Service	Number of clients receiving service (N=24)
GP – home visit *	15
District Nurse *	13
Meals on Wheels *	11
Home care *	10
Personal Alarm	9
Personal carer	1
Podiatry	1
Hospice	1
Carer support service	1

* Denotes services that were asked about by the researcher

Figure 10 below, shows the care-givers' perceptions of the adequacy of these services. According to the comments made about community services, most care-givers (17) were happy with the adequacy of these services either because the service was good or because they did not require any services. There were four negative comments.

One care-giver felt that the visiting nurses were too quick to accept that the client did not want a shower; another felt it was harder for her to get the help she needed because she was working; a third felt that the services were adequate for the client but inadequate for her; and a fourth was unhappy with the funding of Safetylink (the personal alarm service provider). Three care-givers did not make any additional comment.

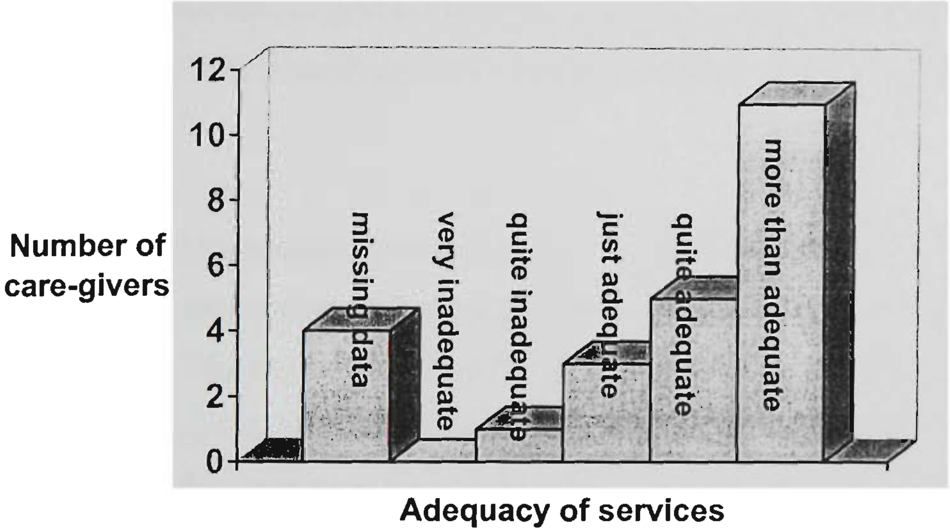

Figure 10 Adequacy of community support services

6.1.3 Care-givers' experiences of rehabilitation and community supports

Many additional comments were interspersed through the interview transcripts about the care-givers' experiences of the help they received from the formal support system. Although many positive descriptions were given of the assistance provided by rehabilitation and community services, a lot of confusion was also expressed about who the health professionals were, where they came from, and how they related to each other. Discharges from hospital and home-based care were often experienced as abrupt. Another problem for care-givers was feeling that they had been excluded from discussions and decisions about the care recipient that affected them as care-givers. There were a few areas in which care-givers would have liked more help but mostly what they wanted was better information about services and inclusion in the planning and decision-making about the care recipients' care.

Some care-givers were amazed at the extent of services provided by the ARITH and other community support services. Freda, who was caring for her terminally ill husband, said that the help from the ARITH had been *"more than adequate...it has been sort of overwhelming."* Ruby and her husband were receiving a range of community support services. The nurses had visited every day for the first week and now, *"they are coming three times a week to check his wound. And the nurses have been coming to shower him...."* Respite care was due to start the next day, *"there is a carer coming tomorrow to give me a few hours out..."*, and Ruby really liked the visit from home help, *"she's really good, she sits down and has a cuppa tea with me before she goes."*

Many care-givers were also impressed with the quality of the care. There were several comments about how excellent, wonderful, and helpful the ARITH team were. Some examples were, *"Wonderful help from the QE"* (Fred), *"It was excellent really"* (Ernie), and *"the OT couldn't have been more helpful"* (Bea). Several care-givers commented that they could not have done without the help from the ARITH. For example, Rose said, *"I wouldn't have been able to cope without it, without them, I don't think."*

One of the most important aspects of the care provided through the ARITH was their perceived capacity to get the care recipient going. For example, Julie who was caring for her husband who had Parkinson's Disease, said that she thought the physiotherapist was, *"excellent, very important...mobility, I put that down to the physio...they just do wonderful things...they just seem to do the impossible, those physios."* The value that was placed upon the independence of both the care recipient and the care-giver has also been discussed in more detail below.

However, some dissatisfaction with the quality of services was also expressed. Frances was not happy with the physiotherapist who did not spend enough time with the care recipient, and she also felt that the district nurses were too quick to accept that the care recipient did not want a shower. However, dissatisfaction with the quality of services was not frequently expressed. A few care-givers felt that the service system was fine for the care recipient but that they could have done with some more help for themselves. May felt that there was *"no compassion within the system* *for the carer"*, and Jill said, *"...probably I needed their encouragement as much as A does because it was a whole new role for me too you know."* One clear gap that identified in the service system was someone to mow the lawns. This was identified by five care-givers as something that would have been helpful had it been available. Anna said, *"I just wanted someone to cut the grass and do you know what they said? "No, we don't do that", and I said "Well that's what he [the care recipient] did."*

The more common themes were confusion and exclusion. At least half the care-givers interviewed expressed some confusion about professional staff. Some examples of confusion were, *"[I] didn't know where the nurses came from but they were very good"* (Gwen), *"I was just so confused, I didn't know who they were"* (Ernie), *"they sent me someone from the town hall, I don't know who he was"* (Anna), and *"are they from the QE...G and them?"* (Rose). Jill suggested drawing up a tree of the service system so that clients and care-givers could know who was visiting them, where they were from, and how the services worked with one another.

Feeling that they were being excluded from information provision and decision making was also frequently expressed. For example Jill said,

> *I didn't understand the program and nobody took me into consideration...I didn't know it was going to run two and a half weeks. I didn't know it was going to run a month. I wasn't sure. I just could have been incorporated a bit more.*

Bernadette was annoyed that she was not consulted by community service providers. When conducting their assessment with her father-in-law, they asked him if he wanted any help and he said *"No, Bernadette will do it"*. They did not check with her that this was the case.

6.1.4 Discussion of study question relating to adequacy of services

The care-givers' perceptions of service adequacy were, as expected, very high. Eighty-eight per cent (88%) of care-givers rated the rehabilitation service as quite adequate or more than adequate, and eighty per cent (80%) rated community support services similarly. Many of the comments made in the interviews reinforced these findings, with care-givers speaking highly of the care provided by both the rehabilitation service and community services' staff. Apart from the absence of a service to cater for lawn mowing and other outside jobs, adequacy of services provided by ARITH was not a problem. However, some issues were identified by care-givers about communication, information provision, and the way in which the rehabilitation service interacted with them (or failed to interact with them) as a key part of the care team. Most of the comments about being left out of the picture refer to the time that the care recipient was in hospital, and some refer to discharge planning, discussed below.

6.2 IMPLEMENTATION OF EARLY DISCHARGE

This section includes a description of the care-givers' perceptions of interactions with staff whilst the care recipient was still in hospital, including the processes of discharge from hospital, and tells the story of one care-giver who felt that she had been excluded from the discharge planning process.

6.2.1 Discharge – planned, pressured or pushed?

In response to questions posed in the interview, thirteen care-givers said that they did not have a choice about discharge and eight perceived that they were given a choice. However, only one believed that the client would have managed without their care. Fourteen said that they were consulted about the discharge, and nine said they were not consulted. They identified the people who consulted with them as someone from the hospital (n = 6), the medical practitioner at the hospital (n = 3), the nurse (n = 2), or the social worker (n = 2) from the hospital. Two were not given any time to prepare but the rest were given between half a day (n = 1) and fourteen days (n = 1) to prepare for the arrival of the client. Most (n = 15) had between one (n = 3) and seven (n = 4) days to prepare. For sixteen care-givers this was adequate time to prepare but for six it was not. Twelve care-givers said they were not offered any alternatives, and nine were offered alternative care for the client. The types of alternative offered were hospital care (n = 3), residential care (n = 3), a paid carer at home (n = 2), or hospice care (n = 1).

In the interview transcripts, there were two descriptions of discharges where the care-givers believed they had been consulted and involved in the decision. Gwen appreciated the medical transfer to her own GP. She said, *"...they notified our doctor, to let her know that we were home and she came round two nights later to check him and make sure that I was managing alright."* Freda appreciated being offered alternatives even though she didn't want them at that stage. She said, *"...they did give me a list of places if I needed more help and if things weren't working. They obviously were [working] but that's a nice thing to know."* Some care-givers were eager for the care recipient to get home. For example Julie said, *"we were both wanting to get home ... all the time. As soon as he was ready, I was ready. He was pushing to get home as soon as he could."* However, discharge was perceived to be problematic for many care-givers.

Some care-givers felt that the discharge had more to do with the hospital's needs than the needs of the care recipient. Paula described her mother's discharge as *"getting rid of her out of hospital."* Judy said that *" they didn't want a staph infection from the Alfred [hospital] in their ward"*, referring to the fact that her husband had contracted a staphylococcus infection while in another hospital. May felt that her grandfather should have stayed in the rehabilitation ward longer, but that he was discharged due to a shortage of beds. She said, *"I didn't feel that he was ready to be out of the care system and my view is that he should have gone to the QE (the inpatient rehabilitation facility) and had a week there for his own emotional security."*

Some care-givers felt that the discharge from hospital was rushed or premature. Dave said, *"The (pre-discharge) home visits were too early...they brought her home the following week and they admitted that it was too early and it caused a fair bit of trauma with her."* Gwen's husband had had to be readmitted to hospital, he said *"...they shouldn't have sent me home... I was in terrific pain...they had to take me back in the middle of the night."*

The other main problem associated with discharge for the care-giver was the lack of consultation with them. As Judy stated, *"no-one told me before-hand or gave me any warning that he was going to be coming home."* In some cases the care recipient was consulted but not the care-giver. Jill, in response to a question about whether she had a choice, said, *"no, certainly not...they told him that he was certainly coming (home)."* Heidi was perplexed by the discharge processes from both the hospital and the ARITH. She said,

> *No, I still didn't know that he was coming home...I don't know if they had a spare bed they would keep him. I don't know. It's really strange how it works...And they will say "he is coming home today" and then they will say, "No, he's not".*

She also found the discharge from the ARITH to be abrupt and poorly explained. She said,

> *...it was sort of really good and then all of a sudden it just stopped...like it was really strange because ...they rang on the Friday and said, "we have done our plan and discharged you from the program" and that was the conversation, that was it. I got off the phone and I thought, well I didn't know if the nurses were still coming. I didn't know if the physio was coming back or anything. It was just really strange. And then everyone kept coming but...she didn't explain what was going to happen.*

Given the level of care that the care-givers were providing, it was critical that they were informed about the discharge plan for the care recipient, but they often reported that they had had little or no warning or time to prepare for the care recipient's home coming. Ernie said that the discharge had been discussed with his daughter but not with him. Judy said that discharge may have been discussed with her husband but, *"no-one told me before-hand or gave me any warning that he was going to be coming home."* Heidi felt that she was being excluded from the information chain because of her relationship with the care recipient, being his daughter-in-law, rather than his wife. She said, *"...they don't tell you much. I think that obviously they must tell wives things but I found it very hard getting information about anything much really...being a public patient, the registrar, they are not always very helpful..."*. She also found it hard to access the registrar because of her child-care responsibilities,

> *The nurses kept saying, "come and see the doctors. They are in the ward between 9 and 11". Yeah well, I come in with my three children between 9 and 11 in the morning. That's fine but you just can't do it. And trying to get a registrar on the phone to ask them anything is hopeless.*

Freda's story has been included below as an example of the consequences to care-givers of not being consulted by the health services that are providing care for the care recipients, and as an example of some of the injustices for care-givers perpetuated by the income security system.

6.2.2 Freda's story

Freda's husband had first been diagnosed with a brain tumour five years prior to this admission to hospital. The tumour had been successfully removed. Since then he had worked part-time and although there were some residual handicaps, he was still able to work, and was independent in all activities of daily living. About two months prior to the interview with Freda, her husband had been diagnosed with another tumour and had undergone further surgery. This time, however, the surgery had not been successful and Freda knew that his prognosis was poor.

Prior to his discharge from hospital in Ballarat with the ARITH, Freda's husband had been in hospital in Melbourne. Freda was very distressed that she had not been notified when her husband was moved from hospital in Melbourne to inpatient rehabilitation in Ballarat. She had discovered the move when she went to Melbourne to visit him. She had at first assumed that he had died because when she went into his ward he was not there, the bed had been made up, and his things removed. When asked about adequacy of services she answered, *"Besides co-operation from the doctors in Melbourne, what would have been adequate was to be notified that they were actually sending him back from the hospital in Melbourne to Ballarat. I'm still waiting for that phone call."*

Freda's husband was one of the ARITH clients whose condition had deteriorated after discharge from the program. At the time of the interview, he required care with all activities of daily living. As he had severe visual impairment, Freda had to guide him around the room, and from room to room within the house. He also needed assistance with showering and dressing as well as all the household management activities mentioned above. He was unable to go out.

Freda was a full-time student but she had been able to do most of her studies at home. Her area of study was fine arts and she was able to do some sculpture when she was not needed by her husband. Freda had been deemed ineligible for the Carer Payment because she did not meet the criteria and was instead, in receipt of Newstart[6]. She told the researcher that she had been advised that she had to participate in the "work for the dole" scheme in order to maintain her eligibility for Newstart and she was to be given work as a carer in a hostel. She asked if she could care for her husband instead but her request was denied. She pointed out that the government would have had to pay for respite residential care or a paid carer to replace her if she had had to go out to work. In the end, because she was a full-time student, she did not have to complete the work assignment.

Freda had to interrupt the interview several times to assist her husband to get dressed and to guide him from room to room. He was terminally ill with cancer and has since died. She was clearly providing full-time care to an adult whose disability was long term and severe, and who would otherwise require full-time professional care, yet she was deemed ineligible for financial support. Moreover, Freda had to wrangle with the authorities from Centrelink to avoid further disruption to her care-giving role. In her response to the summary of findings sent to the participants, described in Section Six below, Freda said she was still fighting with Centrelink to obtain her entitlements.

6.2.3 Discussion of research question about care-givers' perceptions of early discharge

The data derived from the care-giver interviews shows that care-givers were somewhat cynical about the extent to which discharge was in the best interests of the client. They perceived that discharge sometimes had more to do with the needs of the hospital than the patient. They also reported that discharges from hospital to home were not always adequately planned. From the point of view of the care-givers, there was inadequate time for consultation about the care recipient's needs and to prepare themselves to take on the care required. However, as outlined in Section 6.4 below,

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[6] Newstart is the current term for payment to the unemployed in Australia.

despite these difficulties with the transition to home, there were some advantages to care-givers in having the client at home.

In summary, many care-givers expressed appreciation of and satisfaction with rehabilitation and community support services, but they also expressed confusion about these services, and frustration at the lack of consultation and information provided to them about care planning, and discharge decisions. This was despite the fact that they were clearly relied on to provide a significant part of the care required by the ARITH client (see descriptions of the amount and nature of care in the previous chapter). Although care-givers were a critical component of the package of care provided to the ARITH client, they did not see themselves as fully participating members of the ARITH team.

6.3 CARE-GIVER PAYMENTS – TOO LITTLE AND TOO HARD TO GET

This section documents the problems that care-givers had with access to income support and some of the other areas in which they felt that they were not being treated fairly. These issues emerged from the transcript analysis but they were also the focus of some of the study questions. The description of these problems from the point of view of care-givers has been included here as they are part of the interaction between the care-givers and the formal support system. However, the study questions to which this section pertains will be discussed in the next chapter in conjunction with the quantitative data under study objective three.

Twelve care-givers reported that they received a payment. Five received the Carer Allowance, and five received the Carer Payment. One care-giver was paid a wage but that was for the time that she spent as a paid carer in a hostel. She did not receive payment for the additional time she spent with the care recipient, visiting him when he was in hospital, doing his errands, and so on. One care-giver received a Partner's Allowance as her husband was on a Disability Pension. None of the care-givers reported any other financial benefits.

Most care-givers experienced problems associated with carer payments, including lack of information and troubles establishing eligibility. Several care-givers said that they had not been informed about these benefits or that they were unsure about what they were being paid. For example, Anna said in relation to carer payments, *"... I wouldn't have a clue...I haven't asked anyone and nobody has said anything to us",* Julie said that she did get an allowance; she didn't know its name but that it was $82 per fortnight, and *"...we only just not long ago got that...we didn't even know about that...."*

Some care-givers were ineligible for the Carer Payment due to receiving other income and for Bea, whose story has been outlined below, this seemed particularly unfair. She had contributed to her own superannuation fund during her working life because employer-funded superannuation had only been offered to male employees, and the income she now received from this fund made her ineligible for the Carer Payment. This was despite the fact that she spent all her waking hours, and interrupted nights, caring for her mother who would otherwise have had to go into a nursing home. Undertaking paid work created eligibility problems for care-givers receiving the Carer Payment. May, whose story has also been outlined below, found that if she worked one day per week, she had to spend another day rearranging her entitlements for the Carer Payment.

Finally, the Carer Allowance was seen as inadequate. Dave said,

> *I've just applied for and received the Carer's Allowance. It's a pittance...If I had been paying Safety Link, that's $15 a fortnight. Taxis...and everything - $40 a week...there is nothing left. Financial assistance is just totally inadequate...If everyone was in care with the government (it would) cost them $70,000 a year and I am doing it for $2,000. I think they are doing pretty well.*

6.3.1 Injustice

Apart from the problems associated with carer payments, other perceived injustices were reported by care-givers. Two care-givers felt that they were being asked to do too much by the ARITH staff. May did not want any intimate contact with her grandfather, and she felt under considerable pressure to shower him. Jill also felt pressured to shower her husband; *"They were pretty positive I could do it [shower him] saying he hadn't fallen over yet "*. Jill also felt that staff conducting the assessment for home care had different expectations of her as a woman than they would have had if her husband had been providing the care. She said,

> *But I felt to this point, if it had been me who had had the stroke and A was working, would they expect the same of him? Or would they provide some home help if the boot was on the other foot? Sometimes I just felt, "don't do that to me just because I am a woman". I think women do enough.*

Dave also felt that the funding arrangements for Safety Link were illogical and unfair. He said,

> *I just can't bloody follow it. They said if I wasn't here they would automatically fund her for Safety Link...I can't be here all the time, and I can't see the sense in that...I could be out for an hour or two hours, I could be in the back yard. I mean I don't see what bearing me being here has on her being funded for Safety Link. Do you?*

Two case studies taken from the care-giver interviews have been included below to further illustrate the way in which the health and welfare system can compound the difficulties experienced by care-givers.

6.3.2 May's story

May was a woman in her late 20s who had moved in with her grand-father eight weeks before the interview. He had had a fall and broken his hip, and had been discharged from hospital with the ARITH. The hospital staff decided that he would be better off having his rehabilitation at home with the ARITH because his home environment was safe and May was there to care for him. At the time of discharge from hospital he needed 24-hour supervision. This had improved by the time of the interview but he still needed some help morning and evening and couldn't be left for too long on his own for risk of falling. When May wasn't there, she carried a mobile phone.

May did not agree with the decision to discharge him. She thought he would be better off with a longer stay in hospital, but she did not want him to have to go into hostel or nursing home care (even temporarily), so she moved in to care for him. The decision to care for her grandfather was not an easy one for May to make. She perceived that she was the only one who could do it in the family. Her father was occupied running a hotel, and her mother and siblings were interstate. One of the reasons that it was difficult for her to care for her grandfather was that there had been a prior incident of sexual abuse. He had sexually assaulted her whilst she was visiting him in hospital in the year prior to his fall. She had been severely traumatized by the incident and had been unable to work for some months. She had consulted a counselor and had discussed this incident and several other incidents that had occurred in her childhood that had been witnessed but not perpetrated by her grandfather. She decided that she needed to sort out her relationship with her grandfather, and that moving in to care for him might be a good opportunity. However, she refused to shower him and placed a lock on her bedroom door. The ARITH staff were unaware of this history and asked May several times if she would be prepared to shower him. In the end, a nurse from the ARITH assisted May's grandfather with showering during his ARITH admission.

May seemed to have a "new age" philosophical approach to her situation. She saw herself as having unfinished business with her grandfather and that being his care-giver gave them the opportunity to sort things out before he died. However, this was not proving to be very successful. She felt that he could be doing more for himself but was enjoying having her there as his care-giver and preferred her to do things for him. She was distressed about her relationship with him and wondered whether she was getting anywhere in her attempts to sort things out as he seemed reluctant to discuss his previous behaviour with May. She also found the house dirty and smelly, as her grandfather smoked and kept several animals inside.

Apart from the difficult time May was having emotionally being the care-giver for her grandfather, there were financial implications in her decision to be his care-giver. She had been staying with a friend rent-free and she now had to pay half the rent and bills. She was eligible for the Carer's Payment, but did not find this to be sufficient to live on, especially in the longer term as expenses like car repairs could not be put off. This meant that she had to get some work. She did find work at a local factory on a casual, on-call basis but this work had to be organized around both the care needs of her grandfather and the staffing needs of the factory, so the number of shifts that she worked changed every week. Because of the income test associated with the Carer's Payment, the amount that she received had to be adjusted according to the amount that she earned. This was also the case with her rent as her grandfather lived in a publicly funded house and the rent was calculated according to the tenant's ability to pay. May said that for each shift she worked she had to spend a day rearranging her pension and rent entitlements. She had had her income reassessed by the Victorian Government Department of Housing three times in eight weeks.

As she said herself,

> *...there is a lot of running around associated with (the Carer Payment)...any time there are any changes in the situation. Like today I worked one day a week. That's giving me one day of running around ...most carers would be discouraged from working outside of the care environment for that reason.*

6.3.3 Bea's story

Bea was in her late 50s and was the main care-giver for her 95 year-old mother. She had been caring for her mother full-time for four years. Earlier in the year that the interview was conducted, her mother had fallen and fractured her hip. She went into hospital for a hip replacement and was later discharged with the ARITH. As her mother had been confused and disoriented in hospital, the hospital staff, Bea, and her family all considered that her mother would be safer and better off at home. Bea and her sisters were available to care and so they agreed that their mother should be discharged. They wanted her to come home as soon as possible. The hospital kept a bed available for her over Easter in case things did not work out at home.

Bea and her three sisters still lived at home with their mother. They had one other sibling, a brother, who had married and had several children. He and his family lived in a regional centre - about one and a half hours drive from Bea's home. Bea's mother would have been in a nursing home if Bea and her sisters had not cared for her. She required two people to help her every time she was moved from chair to commode, bed to chair, and so on. Bea was her full-time care-giver but one sister worked part-time, three days per week, so she could help out on the other four days, and a paid carer came in for a few hours on the three days that the other sister worked.

Bea was happy with her job as care-giver. She had been retrenched around the time that her mother had started to need full-time care, and it made sense to her and the family that she would be her mother's care-giver. She said that they (she and her sisters) had always been carers in a way. She could recall taking a meal to an elderly lady on her bike when she was a teenager, because the lady had refused to go into residential care but was unable to cook for herself.

The only complaint that Bea had, apart from wishing her mother could recover, was that she was no longer eligible for the Carer's Payment. Bea had worked full-time for most of her adult life. She had been the personal secretary to the manager of a local company, a position from which she was retrenched after 11 years. Prior to this she had had one other clerical job. She had had just two jobs over a period of 33 years. As a single woman, Bea was concerned to provide for her own retirement, and as employer funded superannuation had only been available to her male colleagues, she invested in a private superannuation fund. Superannuation was only extended to women in private enterprise in the late 1980s, so Bea only had eight years of contributions from her employer despite a 33-year working life.

Her superannuation had had an impact on her eligibility for the Carer's Payment. When she first became a full-time care-giver, she had been eligible for the Carer's Payment. However when she turned 55 years and 9 months of age she became eligible for some income from her superannuation investment. As the Carer's Payment is means tested, Bea's superannuation income made her ineligible for it. However, she did still receive the Carer's Allowance, a payment of $82 per fortnight. As a point of comparison, the paid carer, who received about $12 - $14 per hour, would get daily more than the amount that Bea would receive in a week.

6.3.4 Discussion of Bea and May' stories

Both Bea and May had their own reasons for providing care for their relatives. They both gained satisfaction from doing what they saw to be their duty. May believed that there was some potential for personal healing if her grandfather was to acknowledge and regret what he had done to her and Bea relished the opportunity to be close to her much loved mother. However, there were clearly considerable costs to them in providing this care. Furthermore, services that were there to support them were not always experienced as supportive and at times even served to compound the difficulties inherent in their situations.

Both Bea and May had forgone other paid work opportunities in order to provide care. Their social and leisure activities had been severely restricted and May's friendships had been affected. They had both suffered financially. May felt exploited by her grandfather and experienced his refusal to address his past abuse of her as a perpetuation of that abuse. Both care-givers spent their days in an activity that they believed had intrinsic merit, and that represented an important contribution to their families, communities, and society as a whole, but that was not recognised as important or adequately compensated by those beneficiaries.

Because of the care recipients' physical states, if their care-givers had been unwilling to take on care, alternative care would have been required. This care could have been provided in several ways. First, another family member or members could have stepped in. In Bea's case, this would have forced one or more of her siblings to give up their work and/or family commitments. In May's case, her father would have had to find someone to look after his business until her grandfather regained his independence. The second option would be for community support services to be put in place. In both cases this would have entailed employing an overnight carer as well as paid carers during the day. For Bea's mother this would have required more than one paid carer during the day and overnight care for an indefinite period. The third and most likely option would have been for May's grandfather to stay in hospital for the full period of rehabilitation and then move into a hostel[7] for an unknown period of time, and for Bea's mother to go into a nursing home[8]. Each of these options would

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[7] A hostel is a residential care facility that provides medium-level care for older and disabled persons. 24-hour supervision and all meals are provided.

[8] A nursing home provides high level care for older and disabled people. 24-hour nursing care and all meals are provided.

entail considerable costs, either to other family members, or to the state as the provider of hospital and residential care. Bea and May's work as care-givers meant that the other family members and the state (and the whole tax paying society) benefited from not having to incur these costs.

So how were these women supported by the state to provide this care? Both had support from the ARITH (funded by the Victorian State Government) for the period immediately post-discharge from hospital. In Bea's case, a hospital bed (Victorian Government funded) was also kept available for her mother should she require readmission. Both received support from community services (funded through the Health and Community Care[9] scheme and local government). May's grand-father received Meals on Wheels and Bea's mother had the support of a paid carer who was employed by the local council. They both also received income support from the Commonwealth Government.

These rehabilitation and community services were greatly appreciated by Bea and May, and in Bea's case probably meant the difference between her continuing in the role and having to place her mother in a nursing home, an option she did not wish to pursue. Bea was particularly appreciative of the paid carer and the hospital keeping a bed available for her mother in the first few days post-discharge. However, both care-givers experienced problems with carer payments, and May was angry about the direct pressure she experienced from ARITH staff to shower her grand-father, although she did acknowledge that they didn't know about the prior history of abuse. Both care-givers spent some time talking about the problems they were experiencing with the carer payments. In Bea's case, she thought it particularly unfair that she was now being penalized for her foresight and responsibility in contributing to a superannuation fund despite having no employer support to do so. If she had kept the money, rather than investing it, she would have had a better standard of living at the time and now she would be eligible for a Commonwealth Government payment equivalent to a pension. In Bea's own words,

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[9] The Health and Community Care (HACC) program is a joint Federal and State Government funded scheme that provides community support services to older and disabled people with the aim of enabling them to remain at home (rather than in a residential care facility) as long as possible.

> *I didn't get much super off my two employments...women weren't allowed super and I was the only woman...so I put it all in myself, in my own personal super...Now I think to the government, "you pay me back something", but I can't get anything.*

In May's case, although she was eligible for the Carer Payment, it was not sufficient to live on in the longer term and so she had been forced to find some work that she could fit in around her grand-father's care needs. Once she earned some other income, this had to be declared to Centrelink and the amount of her Carer Payment was adjusted, even though this income was temporary, variable, and subject to the care needs of her grandfather. As she said in the interview, the ongoing means testing for the Carer Payment forced her to spend a day running around for each day that she worked, which she thought would discourage most carers from working outside the care environment.

The Carer Payments are obviously not designed to compensate care-givers for the work that they are doing otherwise both these care-givers would receive a wage for the hours that they were working. They are also not designed to compensate care-givers for the contribution that they are making in providing a high quality of care, in giving the care recipients the choice to return home, and in saving the community the cost of caring for these people in institutional settings, otherwise they might be calculated as a percentage of the cost of residential care. They seem to be designed as a way to maintain care-givers in the role with the least possible cost to the rest of the community. Furthermore, because of the administrative requirements in applying for and maintaining eligibility for these payments, they served as an additional workload, and a source of humiliation and worry for the care-givers.

As mentioned above, apart from the pressure experienced by May to shower her grand-father, most services were experienced positively by care-givers. Although the support provided to Bea, of having a bed kept available for her mother and a paid carer to assist her when her sister is at work, was experienced positively by her, it was the minimum assistance that she required in order to continue caring for her mother. It did not allow her to go out and pursue her own interests, or to take a holiday.
Although caring for her mother was Bea's choice, as discussed above, this caring

entailed considerable costs to Bea and considerable benefits to others. The support services that Bea and other care-givers used did not challenge or redress these social justice issues and perhaps contributed to the inequities experienced by care-givers by helping to maintain their current situations.

6.4 PREFERENCE FOR MANAGING WITHOUT HELP

The following themes emerged from the analysis of the interview transcripts. Although most of the findings related to objective seven, which was to explore the care-givers' experiences, have been discussed in Chapter Five, these categories have been included in this chapter because they refer to the interface between care-givers and the formal support system.

6.4.1 Independence

The value of independence was identified by care-givers in two ways. The first was the independence of the care recipient. As discussed above, care-givers valued the work done by professional staff to help the care recipient regain their independence. They also valued the care recipient's own efforts to do things for themselves, as the more the care recipients could do for themselves, the easier it was for the care-giver. Some examples of this were, *"He ...wants to be pretty independent and that makes it easier for me...He's trying all the time...to do what he wants to do"* (Anna), *"she has gotten better because she is starting to try to do a lot of things for herself, which is good"* (Sally), and *"he is gradually doing more for himself ... I don't know (how I'd feel) if I would have to be a carer of someone permanently disabled. That would be a lot I think"* (Rose).

Seeing improvements also made them feel better about providing the care. For example, Judy said, *"If he was constantly...not able to do anything, I would probably have gone crazy by now"*, and Carol said,

> *...he is able to do a lot more, shaving himself and he could feed himself if he had to. It makes a difference to how I feel. As he's improving, I'm improving and we are able to have a life together.*

Independence of the care recipient was also valued for the care recipient's own sake. For example Heidi said when her father-in-law was ready to return home,

> *He could probably do with Meals on Wheels but he doesn't want it. And I don't want to, you know, he hasn't got much dignity left, so he is cooking OK by himself and I just fill his freezer once a week....*

Secondly, care-givers valued their own independence, generally preferring to manage without help. On some occasions, this was in response to not getting the help that was needed. For example, after saying that they didn't get any help from family and friends, Ivy said, *"We don't need them, do we love?"* Anna, in response to not being able to get anyone to help her to mow the lawn said, *"I wasn't sick anyway, I don't need help – I cope pretty well."* More frequently, however, help was offered but declined because the care-giver preferred to manage independently. In response to offers of help from community services Julie said, *"(we) could have had (Meals on Wheels and Home Care) if we'd wanted it but it wasn't necessary...better for someone who needs them"*, and Freda said, *"At this time we don't need it but it has been offered."* Similarly they often preferred to do without help from family and friends. Judy said *"(I) don't want to depend on friends for anything"*, and Rose was annoyed that her husband had asked a passer-by to help saying, *"...no I didn't want (help), like one day he called out to the cleaner over the road to come and get a chair off the back verandah and put it there. I could have done it."* This reluctance to accept help also extended to receiving a payment for some care-givers. Ingrid, who had been caring for her husband for 55 years, refused to be paid for the interview, and she also did not think that she should be paid as a care-giver. Another two care-givers did not want to receive a carer payment. Ruby said, *"Someone said to me about it and I said, "Why should I? We get the pension"*, and Gwen said, *"Some people might require it but I don't see the need for it."*

6.4.2 Better off at home

There were two aspects to the perception that the care recipients were better off at home. The first was a belief that they recover better at home. Ivy said, *"being in your (her) own home has a lot to do with it (recovery) because it's your surroundings."* Rose commented, *"I think that they get better quicker because they are in their home* *environment...he has got confidence in knowing that these people are coming."* This preference for the home environment was associated with the care recipient wanting to be at home. Ivy also said that her mother *"...was up in the wheelchair and off and gone – just wanted to come home."* Bernadette said that her father-in-law *"...was anxious to come home."* However, home care was sometimes seen as better for the care-giver as well. Julie said *"...it made it easier for me when he's home because it saves you going over there (to the hospital) twice a day. I felt I had to be there for pill time."* Gwen thought that,

> *...the hospital visits were the most traumatic part. Since being home (he) has been on the improve...It was very tough going up to the hospital twice a day...by the time you looked for (car) parks...you don't know what you were going to find when you got in there... .*

In contrast two care-givers made comments on the disadvantages of home care. They talked about the problems of the physical environment. Jill said, *"...I would certainly say that homes are difficult to nurse in. There are too many traps, aren't there? Doors aren't wide enough, all those sorts of things."*

The second aspect to the preference for home was the fear of, and avoidance of, alternatives. There were comments about the need to avoid residential care, such as, *"(I) couldn't bear the thought of someone like him not being able to defend himself. A rehab. hostel would kill him"* (Carol). Dave, talking about nursing home care, said *"...the alternative is that she has to go into full-time care and that is why I am prepared to do it."* There were comments about the need to avoid hospital care. Heidi said,

> *I didn't want him to be a patient. I wanted him to be able to go home and still be independent...if he had gone into hospital I think he would have sort of turned into a patient and I didn't want him to.*

Comments about not wanting strangers to care for the care-recipient were also made. For example, Ivy said that she trusted *"...Y (a friend and neighbour) ...with Mum instead of getting someone else in"* and Amy said that she thought, *"...oh no, I can't let a stranger come in. I'd like to stay here, so I did."*

6.5 DISCUSSION

The interactions between the ARITH care-givers and formal supports comprised a complex mix of appreciation and reliance, a preference for independence, and anger at the way in which care-givers were influenced by but excluded from the power relationships within the health and welfare system. The system was clearly gendered in its reliance upon the work of female care-givers without allowing them any recognition, compensation, or power over decision making. It was also gendered in the types of supports offered. These issues and the implications that they have for the ARITH and home rehabilitation in general have been discussed in this section with reference to the relevant literature.

6.5.1 Care-givers' perceptions of formal and informal supports

Consistent with the findings of previous research, the care-givers in this study preferred to manage without support from the formal support system. Previous research has found that care-givers are reluctant to use support services, either because they associate service use with a sense of failure (Heenan, 2000), or because they do not want to entrust the duties of care-giving to others (Ganzer & England, 1994). These findings are supported by the care-givers in this study who preferred to manage alone because they valued their independence, and who wanted to avoid alternative care arrangements where possible. They preferred the care recipient to be at home, rather than in hospital. There was a clear preference for family care as opposed to care in an institution, or care by strangers. This was mainly due to a perception that the care recipient was better off at home but also at times because the care-giver found it easier to care for the care recipient at home rather than visit him or her in hospital. This study provides another explanation for preferring to manage without help. As discussed above in relation to Bea and May's stories, some support services compound an already difficult situation because of the problems in accessing them and maintaining eligibility. People may prefer to manage alone than to undergo the humiliation and worry of trying to establish eligibility for support, particularly income support.

Despite these problems, the care-givers were often very appreciative of the help that they received from rehabilitation and community support services. They were more likely to be critical of hospital care or of injustices in the income support system, than of rehabilitation or community support services.

One theme that applied to all formal services was that of exclusion from decision-making. The issue of exclusion, or lack of consultation, has not emerged from the literature. This may be because the interaction between care-givers and formal supports has not previously been examined in an open-ended way. However, problems with communication and information provision have been identified with home-based rehabilitation care-giving (Slauenwhite & Simpson, 1998), and with Hospital in the Home (Haggard & Benjamin, 1992). Slauenwhite and Simpson (1998) found that there was a need for improved communication between nursing staff and patients and families, especially during the transition from hospital to home. This finding is supported by this study. However, this study also suggests that communication between hospital staff and clients and care-givers needs to go beyond one-way provision of information. Care-givers want to be able to contribute their knowledge and understanding of the client to the client's care plan. They also want to be included in decision-making, especially, as in the case of discharge planning, where the decisions directly affect them.

6.5.2 Gender issues

Gibsen and Allen (1993) argued that it was women's labour and not men's that maintain older couples in their own homes, representing considerable savings to the public purse. This study found that in the ARITH, there were not only more female care-givers than male care-givers (70% of total sample), but that there were more male than female care-recipients. In the total sample 50% of male clients had a care-giver compared with 32% of female clients. In the interview sample there were 17 male care recipients and six female (one with two care-givers).

Gibsen and Allen (1993) further argued that the types of services required by men are more freely available than those required by women. Their study was critiqued in Chapter Three for its acceptance of a stereotypically gendered division of labour, where men are seen as incapable of, or unwilling to participate in traditionally female activities such as cooking and cleaning. Gibsen and Allen argued that services required by men, such as Meals on Wheels and home care, are freely available but those required by women, such as lawn mowing and transport are not available. In this study many care-givers reported that they had relied on a traditionally gendered division of labour prior to the incident that led to the (usually male) care recipient requiring rehabilitation. The only service that was reported as being needed and unavailable was someone to mow the lawns. Gibsen and Allen's (1993) contention that the welfare system is "parasitic" on women and "phallocentric" in responding to the needs of men over women was supported by the findings of this study.

Furthermore, this part of the study shows how women's labour is also being used to shore up the short-falls in government spending that have led to reduced hospital stays and the provision of health services in the home.

6.5.3 Implications for the ARITH

There are two main issues that emerge from these findings that have implications for the ARITH. The first is its position within the health service system. Some care-givers perceived the discharge of the care recipient to home with ARITH support as being due to factors other than the assessed needs of the care recipient. They saw the discharge as serving the needs of the hospital (for beds, or for avoidance of infection) rather than the care recipient. Although in general they preferred the care recipient to be home as soon as possible, they did not want this preference for home to jeopardize the care recipient's health or safety. There were some cases (for example, interviews May, Gwen, and Dave) where, in the opinion of the care-giver, the discharge had been too early and put the care recipient at risk.

The ARITH is under considerable pressure to facilitate discharge from the acute and sub-acute wards of the hospital. Although early discharge can benefit many clients, benefit to clients is not always the main reason for this pressure. The pressure is also due to economic constraints. If the cost of informal care-givers' time is not included, it is much less costly to provide a service at home than in a hospital or residential setting. This is a difficult issue to address as the ARITH is part of a larger health service and has a responsibility to assist that service to meet its targets within its allocated budget, as well as a responsibility to best serve the needs of its clients. This conflict was also experienced by some of the other home-based rehabilitation programs and will be discussed further in Chapter Eight, in conjunction with the findings from the other programs.

The second main issue for the ARITH is the finding that care-givers feel excluded from the decision making process. They are clearly a critical part of the package of care that the ARITH clients need in order to be safe at home, but they do not feel that they are a fully participating member of the care team. In order to be a fully participating member of the care team their comments in the interviews indicate that they would require the following –

1. to be consulted and given a say about the care recipient's discharge from hospital to home;
2. to participate in the assessment of the client's needs and decisions about the support and rehabilitation services that are put in place;
3. to be given a full and complete picture of all the people who will be visiting them at home, who they are, where they come from, and how they interact with each other;
4. to be invited to participate in case planning and discharge planning about the ARITH client whilst he or she is on the ARITH; and
5. to have their contribution acknowledged by the ARITH by being treated with the same concern and respect that they treat their professional colleagues.

It is acknowledged that this could only occur with the permission of the ARITH client and that the same guidelines should apply to the ARITH client as well.

6.5.4 Discussion of study questions about service improvement

The main issues identified by the care-givers themselves that require action were: their inclusion as part of the care team; information flow from hospital to home, especially regarding discharge planning; easier access to income security; and access to a lawn mowing service. These issues will all be taken up in the study recommendations, outlined in Chapter Eight. Three provisional recommendations were sent for appraisal to the care-givers who participated in this study. These included recommendations about the publication and dissemination of the study findings (for example, informing Centrelink of the problems with Carer Payment experienced by care-givers); changes to the ARITH program in line with the suggestions outlined above; and the development of a service map to be provided to all program participants. Care-givers were given the opportunity to respond to these recommendations and to check the study findings as part of the participant checking process, discussed in the next section.

6.5 PARTICIPANT CHECK

This section summarizes the responses of the participants to a summary of these data and the interpretations documented in this and the previous chapter that was sent to them for their comments. Some documents (Appendices O, P, and Q) were sent to 22 of the 24 care-givers interviewed for this study. These included a summary of the interview findings and the researcher's interpretations (Appendix O), a reply form (Appendix P), and a covering letter (Appendix Q). The reply form included questions about whether the findings reflected the care-givers' experiences, and whether they agreed with the interpretations and the recommendations that were included in the document. They were also asked to add additional comments, and whether they would like to be put in touch with the other care-giver participants in the study. A stamped, self-addressed envelope was included with the documents. In the covering letter, they were advised that if they did not wish to comment on the study findings, they did not need to respond to the letter. Two care-givers were not sent this document because, in both cases, their husbands, for whom they had been caring, had died since the interview. Further, one of these care-givers had become distressed during the interview, and the other had been confused and upset when she had received the payment for the interview, confusing it with payment for her husband's organ donation. To ensure that no further distress was caused to these participants, the researcher decided not to correspond with them further.

Eight care-givers replied to the letter. All of them said that the findings reflected their experiences as a care-giver, and all agreed with the way that the findings had been interpreted. Similarly, they all agreed with the recommendations that were included in the report. There were some additional comments and recommendations. These comments served mainly to reinforce the arguments made by the researcher, for example, the constancy and hard work of care, and the problems with Centrelink. Carol noted, *"the medical condition, heaps of medications, catheters, testing urine, feed through peg, on and on...washing machine, on and on"*. Freda commented that she was still having problems with Centrelink. She said that she'd had to, *"FIGHT these last three months to convince Centrelink that (her husband) died in January – I really AM a widow."* The further recommendations will be picked up in the final chapter, Conclusions and Recommendations. Only one care-giver wanted to be put in touch with the other care-givers but as he was the only one who requested this, he was informed by the researcher that it was not possible.

These responses indicated that the findings were trustworthy in two ways. First, these eight respondents indicated that the summary of findings reflected their experiences. Second, these eight respondents indicated that they agreed with the researcher's interpretations of the data. It was also a very rewarding part of the study, as the researcher's aim was to give voice to the study participants, and these eight respondents indicated that she had succeeded in this aim.

The next chapter outlines the findings from the interviews with program staff and provides an analysis of the data collected from the eight home-based rehabilitation programs that participated in this study. These findings are then discussed in conjunction with the findings outlined in this and the previous chapter.

Chapter Seven – Results and Discussion 3: Caring for the state

Informal care in home-based rehabilitation across Victoria.

7.0 INTRODUCTION

This chapter adds another dimension to the care-givers' perspectives outlined in the previous two chapters. The findings reported in the preceding two chapters were derived from the interviews conducted with individual care-givers. This chapter outlines the state of informal care in home-based rehabilitation from the point of view of staff working within eight home-based rehabilitation programs in Victoria. The findings are based on the current status of the programs at the time of the data collection process. This part of the study differs from most previous care-giving research in that the researcher analysed the interface between the care-givers and a health service, from within the health service itself. This provided a unique opportunity for triangulation of the experiences of the care-givers with the perspectives of the program staff.

This chapter has been divided into three sections. The first section of this chapter describes the three main program models of home-based rehabilitation in Victoria, the rationale for their inclusion in the study, and the data collection process. The second section provides an analysis and discussion of the data about clients and care-givers that were collected from the program staff in relation to study objectives one, two, three, and six. In this section, triangulation of the study findings has been conducted where possible, for example, the number of support services recorded on the data sheets is compared with the staff's perceptions of support provided. The third section includes a discussion of some of the issues raised by the program staff that were not addressed by the study objectives or questions.

7.1 SECTION ONE: DESCRIPTION OF PROGRAMS

The information outlined in this section is based on the program descriptions and documentation provided by the program staff, the author's own experience of working in this area, and where acknowledged, Victorian Government documents. The program documentation usually took the form of internal policy documents or brochures that had not been published.

7.1.1 Three models of home-based rehabilitation

The author has identified three main models of home-based rehabilitation in Victoria that were in existence at the time that the study was conducted. As these models had not previously been identified as such, the author has categorised them according to the dimensions listed in Table 22, below, and labeled them the Continuity of Care (CoC) model, the Alternative to Inpatient (Alt) model, and the Community Rehabilitation (CR) model.

Both the CoC and the Alt model aimed to replace and/or reduce hospital LOS. Some programs admitted clients directly from acute hospital, thereby avoiding admission to inpatient rehabilitation altogether. Others only admitted from their own centre's rehabilitation or Geriatric Evaluation and Management (GEM) wards but discharged clients early from these wards. The CoC and Alt models both aimed to give clients the choice between inpatient and home-based rehabilitation, and could provide rehabilitation services at the same level as those provided in hospital. The three models varied in the extent to which community services could be provided. The CoC model aimed to supply all services that the client would have received if they had remained in hospital. The Alt model only supplied those services that the client needed in order to manage their rehabilitation at home that were additional to those that they had in place prior to this admission. The CR model did not generally supply community support services to the client.

Table 22 Key features of the three models of home-based rehabilitation

Feature	CoC model	Alt model	CR model
Aims to reduce or replace hospital LOS	✓	✓	
Aims to reduce admission and re-admission to hospital	✓	✓	✓
Aims to give the client a choice between inpatient and home-based rehabilitation	✓	✓	
Aims to assist in the transition from hospital to home	✓	✓	✓
Rehabilitation services can be provided at the same level and intensity as inpatient rehabilitation	✓	✓	
Client must require multi-disciplinary rehabilitation input	✓	✓	
Rehabilitation services are provided in the client's home	✓	✓	✓
CRAFT[10] or per diem funded	✓	✓	
Funded on the basis of CRC places			✓
Client charged a fee			✓
The same staff work in the hospital and the home-based program	✓		sometimes
Case management model	✓	✓	sometimes
Has the capacity to broker community services	✓	✓	
Community services are brokered on the basis of replacing those services that would be provided in inpatient rehabilitation	✓		
Community services are brokered on the basis that they are required in addition to the client's usual community service needs		✓	

One of the key differences between the CoC and the Alt models was that the CoC staff worked in the inpatient as well as the home settings. This meant that they were able to follow clients through the different phases of their rehabilitation, getting to know them in hospital, and then working with them in their home environment. For the CoC model, this also meant that an occupational therapist employed by the program conducted a home assessment with the client prior to the client's transition to home. One of the programs included under this category did not have an inpatient rehabilitation facility. However, it was still possible for the staff in this program to follow through with clients from the other wards of the hospital in this way. In the Alt

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[10] Clinical Rehabilitation and Funding Tree (CRAFT) is a funding model that categorises patients into 17 groups according to their clinical diagnosis and functional level. These groups attract a set rate of funding based on the expected resource utilisation and length of stay in hospital.

model the occupational therapy home assessment was conducted prior to the client's discharge by hospital staff (who did not work in the home-based program) or by the program staff once the client was already at home. In the CR model this assessment would not have been required. The assessment process for the programs included in the study has been described more fully in the next section of this chapter.

All three models of home-based rehabilitation aimed to assist the client to make the transition to home if they had been in hospital, and all three had the capacity to provide rehabilitation services in the client's home. Many programs provided a mix of centre, community, and home-based services. For example, a client may have come into the rehabilitation centre for hydrotherapy or attended a community-based activity as part of their rehabilitation.

The type of model adopted by the health services in this study had some implications for care-givers. The CoC models were generally able to supply a higher level of community services to the client than the Alt model, which led to less pressure on the care-giver to provide care. The continuity of care from hospital to home also meant that the staff in the CoC programs usually had more opportunity to meet with care-givers and get to know them before the client was discharged to home-based rehabilitation. These differences are discussed further in 7.2.5.1 below.

The home-based rehabilitation programs that existed in Victoria at the time of writing (December, 2002) have been categorised into the three models in Table 23 below.

Table 23 All Victorian home-based rehabilitation programs categorised according to service delivery model

Continuity of care	Alternative to inpatient	Community rehabilitation
Bundoora Extended Care Centre *	Melbourne Extended Care and Rehabilitation Service *	Colac Community Health Service
Ballarat Health Services *	Kingston Centre *	Caulfield General Medical Centre
Wodonga Regional Health Service *	Broadmeadows Hospital *	Barwon Health – Grace McKellar Centre
Angliss Health Service	Sunshine Hospital *	Wonthaggi Hospital
	Mt Eliza Aged Care and Rehabilitation Centre *	St Vincent's Hospital
	Royal Talbot Rehabilitation Centre	Lyndoch Health Service - Warnambool

* denotes programs that participated in the study

7.1.2 Funding of home-based rehabilitation

All three program models were funded by the Victorian Government Department of Human Services. The CR model was funded as a Community Rehabilitation Clinic on the basis of "CRC places". *"A CRC place represents a full day place or a full day of treatment and may be utilised by one or more than one client"* (Department of Human Services, 2001, p. 56). CRC clients were required to pay a fee for each service they received.

The Alt and CoC models were funded either through the Clinical Rehabilitation and Funding Tree (CRAFT) funding model, or through per diem funding. Per diem funding was the funding model that preceded CRAFT and at the time of the study still applied to rehabilitation facilities of less than 20 beds. For the 2001-2002 financial year the per diem rates for rehabilitation were $419 per day for Rehabilitation Level One (for example, spinal injury, amputation and head injury), and $348 per day for Rehabilitation Level Two (for example, stroke, orthopaedic and other neurological conditions; Department of Human Services, 2001).

Thus, although the Alt and CoC services were provided in the client's home, they were seen as equivalent to hospital care and funded as if the patient was in hospital. This was the basis for their inclusion in the study.

7.1.3 Rationale for inclusion in the study

As the aim of the study was to examine the impact of early discharge from hospital on informal care-givers, the study participants were restricted to those programs that reduced or replaced inpatient length of stay. This included the CoC and the Alt models but excluded the CR model on the basis that clients were admitted to the CR home-based rehabilitation program after discharge from hospital or after discharge from one of the inpatient-level home-based rehabilitation programs. CR was an addition to, rather than replacement for, inpatient rehabilitation.

All except one of the CoC and Alt programs listed in Table Twenty-two were asked to participate in the study. Appendix R shows where they are located in Victoria, Australia. The exception was the Royal Talbot program as it was established after the data for this study had been collected. The Angliss Health Service was not included because ethical approval was not granted by their ethics committee.

7.1.4 Process of participation in the study

As outlined in the Chapter Four, the program staff were informed about the study at a state-wide meeting of home-based rehabilitation program staff in May, 2001. All the program managers of the relevant services agreed to participate, and the researcher then approached the relevant service managers and ethics committees for permission to proceed. This was quite a lengthy process and in some cases there had been staff turnover in the intervening period. However, ethics approval and informed consent were gained from all participating services and staff before the data collection process was commenced.

Table 24 Summary of the data collection process conducted at the eight home-based rehabilitation programs included in the study

Program Number	Visits	Data sheets	Staff interviewed
One	3	24	3
Two	1	6	1
Three	1	18	4
Four	2	8	3
Five	1	16	3
Six	1	11	2
Seven	1	14	3
Eight	1	5	4
Total	11	102	23

The researcher visited the program staff at their place of work on one or more occasions depending on the scheduling of the interviews. The researcher met with the program manager and staff designated for inclusion by the program manager to discuss the points outlined in Appendix C. She then met with staff who had a case management role to complete the data sheets (Appendix B). Information about the study, copies of the data sheets, and the discussion points that the researcher wished to discuss in the interview were forwarded to the program manager prior to the researcher's visit. Table 24 above, shows the number of visits to the program, the number of data sheets completed, and the number of staff interviewed for each program. In order to maintain confidentiality, the individual programs will not be identified in the following discussion.

At programs one, four, five, six and seven, the staff were interviewed together about the discussion points in Appendix C. At the other programs, the staff were interviewed separately. Although the researcher expressed a preference for joint or group interviews for the reasons outlined in the Methodology, this did not always suit the staff. At times it was more convenient for them to schedule meetings with the researcher separately. In total, eleven visits were conducted to collect data about 102 home-based rehabilitation clients and their care-givers, and to interview 23 staff members.

7.1.3 Verification of data

Within one month after the data were collected from each program, a report was sent summarising the data collected from each site. This was either altered or verified by the program manager and the following discussion of findings includes only those data that have been verified in this way.

7.2 SECTION TWO: DISCUSSION OF FINDINGS RELATED TO OBJECTIVES ONE, TWO, THREE AND SIX

7.2.1 Objective One - Reliance on care-givers in home-based rehabilitation

This section documents the study findings that address study objective one - to show how the State is relying on a predominantly female care-giver labour force in the implementation of home-based rehabilitation programs. Both the data collected from the 102 completed data sheets and the findings of the staff interviews have been discussed in this section.

7.2.1.1 Client and care-giver characteristics

It was expected that patients would be more likely to be discharged early from hospital to undertake rehabilitation in the home if there was an informal caregiver present (either co-resident or locally available) and that there would be will be more women than men providing informal care in home-based rehabilitation (> 50% women). In order to confirm or refute these hypotheses, questions were asked about the total number of clients in home-based rehabilitation in Victoria; the number of these that relied upon a care-giver; and the gender of the care-givers.

Data were collected on a total of 102 clients (60 female, 42 male) and 99 care-givers. Clients' ages ranged from 19 to 95 years, with a mean age of 68.1 years. Barthel Index scores were collected for 48 clients and these ranged from 27 to 100 (out of a possible maximum of 100), with a mean score of 74.4. Functional Independence Measures (FIM) were recorded for 43 clients and these ranged from 45 to 122 (out of a possible maximum of 126), with a mean of 92.8. With both the BI and the FIM, a low score represents high dependency needs. The primary diagnoses of the clients are listed in Table 25, below. A total of 38 clients (37.3%) had neurological conditions and a total of 37 clients (36.3%) had orthopaedic conditions. The other 25 clients for whom a diagnosis was given had a range of other disabling conditions, including cardiac conditions and cancer.

Table 25 Primary diagnoses of home-based rehabilitation clients

Diagnosis of client	*n*	%
Stroke	26	25.5
Fractured hip	19	18.6
Other neurological	12	11.7
Other fracture	8	7.8
Cardiac	6	5.9
Total knee replacement	5	4.9
Cancer	5	4.9
Total hip replacement	3	2.9
Other orthopaedic	2	2.0
Chronic obstructive airways disease	2	2.0
Other	12	11.8
Missing	2	2.0
Total	102	100.0

In accord with the data collected from the care-giver interviews, discussed in the previous two chapters, there were very few "straightforward" rehabilitation conditions, such as total hip or knee replacements, in this sample. Only eight of the 102 clients had these conditions. There was a prevalence of hip fractures (19), strokes (26), and other neurological conditions (12). These data also concur with the staff interview findings reported below. Program staff noted that the types of conditions experienced by clients in home-based rehabilitation were becoming more complex and that those clients with "straightforward" rehabilitation conditions were no longer being catered for by their programs, perhaps instead going directly to a community rehabilitation centre (CRC).

7.2.1.2 Reliance on care-givers: survey data

A total of 83 clients were being cared for by one or more care-givers (73 had one care-giver, and ten had more than one). Nineteen clients did not have a designated care-giver. Seventy-six care-givers were living with the client, including those who had moved in temporarily to provide care.

The level of care provided by the 99 care-givers is illustrated in Table 26, below. Consistent with the findings from the care-giver interviews, this sample of care-givers were providing a high level of care for the home-based rehabilitation clients. Forty five per cent (45%) were providing more than 12 hours of care per day and a total of 31 care-givers (31.3%) were perceived by program staff to be providing 24 hour a day care. The types of care provided have been discussed in 7.2.2, below.

The provision of this level of care by unpaid family care-givers calls into question the notion that these programs have replaced hospital care. In fact, it seems that in many cases the client's family have replaced the bulk of the care that was provided in hospital, and the rehabilitation team provide the rehabilitation treatment and education about how to follow it through. This issue has been further discussed below in conjunction with the expectations that the staff had of care-givers.

Table 26 Level of care provided by home-based rehabilitation care-givers

Level of care	**All care-givers (n=99)**	
	n	%
<1 to 12 hours per day	49	50
13-23 hours per day	16	14
24 hours per day	31	31
Missing	3	3
Total	99	100

7.2.1.3 Reliance on care-givers: interview data

The following section documents the discussion with program staff about the involvement of care-givers in the decision to admit the client into the home-rehabilitation programs, and the expectations that staff had of care-giver involvement in the program once the client was admitted. In this and other sections of this chapter where the interview data are recorded, the program number from which the information and/or quotes were drawn has been inserted in brackets, and the pronoun 'they', rather than he or she has been used throughout to disguise the gender (and the identity) of the informant.

None of the eight programs included in the study specified that a client had to have a care-giver in order to be admitted. However, in four programs, the staff said that a client was more likely to be admitted if there was a care-giver present (2, 3, 5, & 6). The staff in one program said,

> *... there is a lot of negotiation with the family, at least on the rehab ward...it may be put quite strongly ... what it is seen that this person may be able to do and what kind of care (he or she) needs in order to be home...then the family in a way either say, yes we can do that or no we really can't be held to do that (5).*

and in another,

> *there is certainly a prevalence of clients who have a care-giver at home because that (the presence of a care-giver) has a huge impact on whether they can get home and if they do get home whether they can be managed at home. We don't exclude people because they don't have a care-giver but it's certainly part of the discussion but it is not actually in our paperwork which is interesting looking at what you are doing (2).*

The preference for a care-giver was seen as due to either the safety requirements of discharging the client to home, such as the need to have someone there to supervise the client's movements around the house; the safety requirements of conducting a rehabilitation program with the client at home, that is the need for supervision of the client's exercises and equipment; and/or the need for active assistance. For example one staff member (3) commented that if the client's functional level meant that he or she needed assistance to get into the shower, then he or she would not be admitted unless there was a care-giver available to provide that assistance.

> *If they are requiring assistance of one to walk for instance, or one to shower but there is nobody at home then we couldn't have them on the program (3).*

Table 27 Number of clients with a care-giver in each program

Program number	Care-giver		No care-giver		Total
	n	%	n	%	
1	15	62.5	9	37.5	24
2	5	83.3	1	16.7	6
3	17	94.4	1	5.5	18
4	6	75.0	2	25.0	8
5	15	93.8	1	6.3	16
6	10	90.9	1	9.1	11
7	11	78.6	3	21.4	14
8	4	80.0	1	20.0	5
Total	83	81.4	19	18.6	102

The staff from two programs (1 & 7) said that the presence of a care-giver made no difference in the decision to admit the client because they could provide all the care that the client would need through service brokerage. Staff from another two programs (4 & 8) said that the client was *less* likely to be admitted if he or she had a care-giver. The reason for the latter perception in both the programs was that the staff thought that if the client had a care-giver, he or she was more likely to be discharged home without the support of the home-based rehabilitation program. It was thought that clients without care-givers were more likely to be offered the support provided by the program. Table 27, above shows the number of clients with care-givers in each program. Programs 1 and 7 did have the most clients without a care-giver, supporting the staff's statements that the presence of a care-giver did not influence their decision to admit the client. However, the high level of clients with care-givers overall supports the statements by the other programs that care-givers are relied upon for safe discharge home from hospital and the safe implementation of rehabilitation at home.

The staff from the Alt program models had less say in the decision to discharge the client home, as opposed to admitting the client into their program, than the staff from the CoC programs. As the CoC staff had the opportunity to be involved in case discussions about clients prior to their discharge from hospital, they may have been able to influence the discharge decision as well as the decision about admission to their program.

7.2.1.4 Identification of care-giver

Some programs had a space on the referral form that identified the client's care-giver (3, 5, & 6). The staff from two programs (1 & 6) said that they assumed that the client's spouse was the care-giver unless any other family member identified themselves as such, and program 8's staff said that the care-givers identified themselves, either by ringing in or by being present when the program staff visited the client in hospital. Formal identification of the client's care-giver was seen to be something that could be improved in the future.

7.2.1.5 Expectations of care-givers

Some of the staff interviewed did not consider that they had any expectations of care-givers (5). They felt that they had no right to expect anything of the client's care-givers, that the care-giver just did what he or she was prepared to do irrespective of any expectations of the program.

> *(We) are not in a position to have any expectations of care-givers…it's just something they are doing because they have chosen to do it or they feel they have to do it and we really can't expect that they will do anything at all (5).*

The staff from this program did also note that the decision about whether the client was discharged from hospital was made by hospital staff prior to them having any contact with the client. Thus their own expectations seemed to them to have little to do with the care situation that was already established. Their program was an example of the Alt model, discussed above.

Most of the staff interviewed expected certain things of care-givers. These expectations are divided into three areas. The first area of expectation is about meeting the client's needs, the second is about meeting the needs of the rehabilitation team, and the third is about care-givers meeting their own needs as perceived by the rehabilitation program staff.

In relation to client's needs, care-givers were expected to provide the 'hotel' type services (2, 3, 4, & 7) and personal care needed by the client (6). These included maintenance of the physical environment – housework, laundry, outside jobs, shopping, and running errands; meal preparation and assistance with feeding the client if necessary; transport; running errands, banking, and payment of accounts; and to a lesser extent, personal care, such as assistance with showering and dressing the client. For example the staff in program seven said, "*if they agree to do personal care, to cook for him, then we would have the expectation that that would be ongoing.*" In contrast to hotel type activities, personal care and nursing activities were more often recognised as care-giving tasks by program staff. This recognition meant that these tasks were usually discussed with the care-giver, the care-giver's ability to undertake these tasks was assessed, and if necessary, a paid care-giver was employed to carry them out (3 & 4). Care-givers were sometimes required to undergo training in the use of equipment that was required by the client, such as a walking aid or a hoist (2 & 3). Supervision and monitoring of the client was another care activity that was expected of care-givers by program staff (1, 2, 3, 4, 6, & 7). Monitoring meant that the care-giver had to be around to make sure that the client was all right. Supervision was a more active role where the care-giver was expected to be there during an activity, such as showering, prompt the client if needed, and intervene if the client needed assistance. Supervision could be required for any activities of daily living, personal care activities, and medication, as well as rehabilitation exercises and activities. Care-givers were also expected to assist the client with their rehabilitation activities. Program 3 staff described their expectations of care-givers as,

> *A lot of encouragement and support – their OK [for the client] to come home – [looking after] the physical situation, providing the meals and the hotel type support... Supervision assistance/follow through needs to be tailored to the care-giver's ability, if they can do it safely then sure go for it.*

There were some consistently identified expectations that related to meeting the needs of the rehabilitation team and/or the rehabilitation process. These were expressed as '*that they work as part of the team*" (1), and "*to be compliant, cooperative, amenable and if they're not they are often labeled difficult, resistant, obstructive...*" (2). The staff in program 8 said that they expected that care-givers would be,

> *...customers as well in the patient's rehab. It is not essential – we don't require it but it is very difficult to go into the home [without their co-operation]. [We also expect] them to be ...enthusiastic and encouraging about our presence in their home (8).*

These expectations were also sometimes more clearly spelled out. The staff in one program expected that the care-giver would let them know if anything occurred after their working hours that had implications for the client's health, safety, or rehabilitation progress (1). They also expected the care-giver to make him or herself available once a week to meet with the case manager. The staff in another program expected that the care-giver would assist with the coordination of services coming into the home and also with the scaling down of these services when the client was discharged (2). The most frequent expectation that program staff had of care-givers was to follow-through with the client's rehabilitation program (1, 2, 3, 4, 6, & 8). For example one program's staff said, *"...most rehab is easier if there is some attempt at carry over of the rehab plan, and of the goals. It makes it a lot easier if you are working with the carer"* (8). This meant that when the program staff were not present, it was hoped that the care-giver would encourage the client to practice their rehabilitation tasks. Furthermore, care-givers were expected not to interfere with the rehabilitation of clients by doing things for them that the team was trying to encourage them to do for themselves. It was acknowledged that this was sometimes against the wishes of the client who may prefer to have things done by the care-giver than to struggle to do them independently. The problem of care-givers helping too much has also been identified by Tamm (1999) in her study of the relationship between occupational therapists and care-givers. Tamm identified three types of hindering relatives, including the "emotionally overheated" care-giver who impeded the rehabilitation process by helping too much (Tamm, 1999, p. 40).

The third area of expectation was that the care-giver would look after his or her own needs (1, 2, & 8). The staff from program eight expressed this very clearly. They said,

> *I think that I would also expect that they would be open to dealing with their own issues as well, in terms of carer stress, in terms of carer issues, in terms of the help they need...(8).*

Many program staff talked about their frustrations with getting care-givers to accept help from community services. Several comments were made to the effect that it was more likely that the care-givers would expect too much of themselves than that the program staff would have high expectations. For example the staff in program one said, *"I think that people assume a heavier sort of input sometimes than we expect of them* "(1). The problems associated with care-givers' reluctance to accept community support services, will be discussed in conjunction with the program's capacity to provide services in 7.2.1.7, below.

There were two additional perceptions about expectations of care-givers. Firstly, some staff noted that the expectations of care-givers in home-based rehabilitation were much higher than they would be if the client remained on the rehabilitation ward (6 & 7). The staff from program seven stated that,

> *...there is no doubt that with home rehab. the care-giver has taken on a much greater role than before. There is an expectation I think that they will care for the client at home while we do the therapy as opposed to them sitting in hospital, and it increases their stress.*

Secondly most staff said that all expectations were tailored to the willingness, availability and capacity of the care-giver (3, 4, 7, & 8). For example the staff from program seven described it as "*a case by case scenario really. You walk in the door and see what there is. Because quite often we've set up all the care even though there is a carer*" (7).

Although it seems clear from the preceding section that the staff did have expectations of care-givers, they were reluctant to own these expectations. These expectations seemed to be coming from elsewhere rather than being initiated by the staff. They saw themselves as finding a way to meet the client's requirements for participation in the home rehabilitation program given the constraints of reduced hospital stays, and their own budget constraints. Many program staff (3, 4, 5, & 6) said that they could not provide a level of brokerage that would replace the care-giver in all instances, or for an extended period of time (1). This meant that regardless of their own personal expectations, in order for their programs to continue to operate, someone had to pick up the care. This someone was usually a family care-giver. Unfortunately, this reluctance to acknowledge the expectations of their programs did not make these expectations go away. Instead, it meant that the expectations were not clearly articulated or acknowledged with the care-giver as the following sections on care-giver inclusion in the programs will illustrate. The next section takes up the issue of whether the staff's expectations differed depending on the characteristics of the care-giver.

7.2.1.6 Gender of care-givers

There were 58 female and 41 male care-givers. The relationships of the care-givers to the clients has been outlined in Table 28, below. Although there was a greater number of male care-givers in this sample than in the interview sample, most of them were older (over 65 years of age) spouse care-givers, see Figure 11, below. There was much more diversity among the relationship groups of the female care-givers.

Table 28 Relationship of home-based rehabilitation care-givers to clients

Relationship type	*n*	%
Wife	18	18.2
Husband	22	22.2
Defacto partner (all male)	3	3.0
Daughter	16	16.2
Son	7	7.1
Daughter-in-law	5	5.0
Mother	6	6.1
Father	1	1.0
Other blood relative – female	9	9.1
Other blood relative – male	3	3.0
Friend (five male: four female)	9	9.1
Total	99	100.0

This finding is consistent with the findings of previous literature, for example, Arber and Gilbert (1989), who found that male care-givers were most likely to be older spouse care-givers or sons who had never married or left home. Arber and Ginn (1990) noted that between the ages of 30 and 69 there is a higher proportion of women than men as carers but from age 70 onwards there is a higher proportion of men. In this study, half of the male care-givers were 65 years or older and in this age group male care-givers outnumbered female care-givers 19 to 15. Furthermore, most of the male care-givers were husbands, with 22 of the 38 male care-givers fitting into this relationship group, compared with 18 wives. Unlike their female counterparts, who were more likely to be daughters (16) or daughters-in-law (5), male care-givers were less likely to have the competing demands of work and family commitments when they took on the care-giving role. This study shows that this pattern, previously identified, has continued into the early 21st Century and into home-based rehabilitation programs.

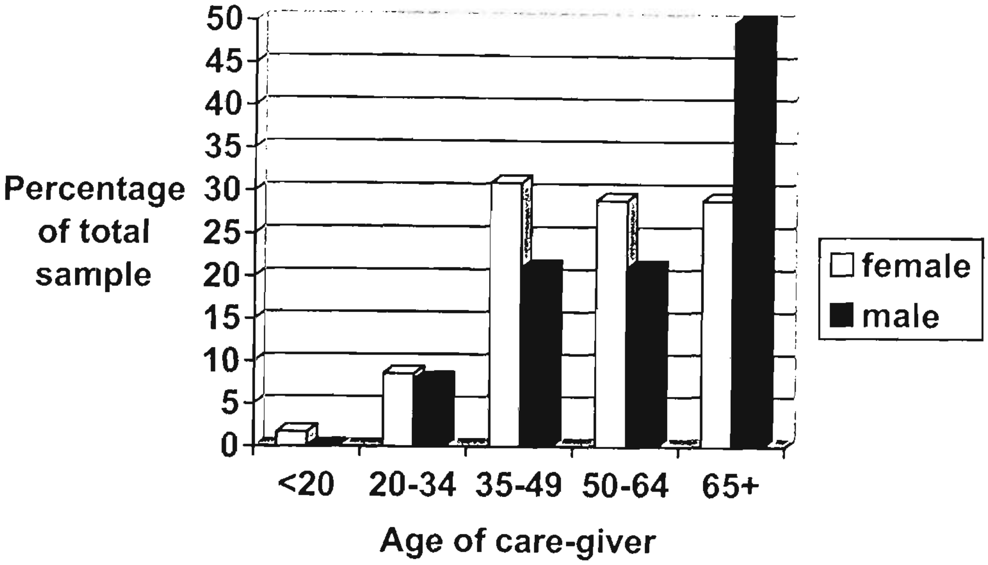

Figure 11 Age of home-based rehabilitation care-givers

7.2.1.7 Rehabilitation and community support service provision to home rehabilitation clients and their care-givers.

It was expected that services such as home Care and Meals on Wheels would be more likely to be provided when there was no informal caregiver present and that these services would be more likely to be provided to male than female caregivers. As the following section will show, these hypotheses were not supported by the study findings.

The rehabilitation services provided to clients were based on the staff's assessment of the clients' rehabilitation needs and goals. Most programs were able to supply a full range of rehabilitation services in the client's own home, with some services, such as hydrotherapy, being provided at the rehabilitation centre. Table 29, below shows the range and average frequency of rehabilitation service provision in home-based rehabilitation.

Table 29 **Range of rehabilitation services and the number of clients receiving each service in home-based rehabilitation programs**

Rehabilitation service	Number of clients receiving service (n=102)
Physiotherapy	97
Occupational therapy	93
Case management	87
Social work	60
Rehabilitation nurse	59
Allied health assistant	47
Medical care	30
Speech pathology	28
Dietician	25
Podiatry	6
Psychology	4

Most services were provided to the client based on the staff's assessment of the client's needs. However, as some of the staff interviews revealed, service provision was also based on what the care-giver could and could not do, and some services were brokered in specifically to support the care-giver. The range and frequency of community service provision has been documented in Table 30, below. The only care-giver support service was respite care which was provided to three clients only.

Table 30 **Number of clients receiving each community service**

Community Service	Number of clients receiving service (n=102)
Delivered meals	22
Personal care	18
Pharmacy	14
Personal alarm system	12
District nursing	11
Day centre	8
GP	8
Respite care	3
Transport	3
Handyman or gardener	2

On average clients were receiving 5.4 rehabilitation services, ranging from 2 to 10, and 1.3 community support services, with a range from 0 to 5. T-tests revealed that there was no significant difference between clients with care-givers and clients without care-givers nor between male and female care-givers in relation to either rehabilitation or community service provision (see Tables 31 and 32, below).

Table 31 **Comparison between clients with and clients without care-givers on service provision**

	Clients with care-givers (n=87)	Clients without care-givers (n=15)	*df*	*t*
Rehabilitation services	5.4	5.2	100	0.43
Community services	1.2	2.0	100	2.54

Table 32 **Comparison between female and male care-givers on service provision**

	Female care-givers (n=58)	Male care-givers (n=41)	*df*	*t*
Rehabilitation services	5.1	5.7	97	1.78
Community services	1.4	1.0	96	0.76

A T-test revealed that there was no significant difference between metropolitan and regional programs in terms of rehabilitation service delivery (see Table 33, below). However, a T-test did reveal a significant difference in the provision of community services between metropolitan and regional services (see Table 33). On average regional clients with care-givers received 2.4 community services, compared with 0.8 for metropolitan clients with care-givers. This may be due to the problems with accessing HACC services in metropolitan areas, discussed in 7.3.5, below. There was also a significant difference found in the amount of community services provided by the CoC compared with the Alt programs (see Table 34, below). On average the Alt programs provided less than one (0.8) community service per client and the CoC programs provided an average of 2.4 services per client. There was also a difference between the two models in terms of rehabilitation service provision, with the CoC programs providing an average of 6.1 rehabilitation services, compared with 5.2 services for Alt programs.

Table 33 **Comparison between metropolitan and regional care-givers on service provision**

	Metropolitan care-givers (n=70)	Regional care-givers (n=29)	*df*	*t*
Community services	0.8	2.4	36	4.49*
Rehabilitation services	5.3	6.0	97	1.86

*$p<.05$

Table 34 **Comparison between CoC and Alt program care-givers on service provision**

	Alt program care-givers (n=71)	**CoC program care-givers (n=28)**	*df*	*t*
Community services	0.8	2.4	33	4.31*
Rehabilitation services	5.2	6.1	72	2.91*

* $p<.05$

The difference in community service provision between the two models of home-based rehabilitation was to be expected given the different philosophies about service provision. The Alt model aimed to top up existing service provision and the CoC aimed to supply services at a level comparable to hospital care. However, as the two models were funded according to the same formula, this is an area that warrants further investigation by the managers of these programs and the Victorian Department of Human Services as the responsible funding body. The reasons why clients receive more community services in one program model than another need to be explored further. The next section documents the findings of the staff interviews in relation to support to care-givers.

7.2.1.8 Staff perceptions about support to care-givers

Staff reported that support to care-givers was provided in a number of ways. These have been listed below in Table 35. The question about support was asked as an open question and staff were not prompted about the types of support that might be offered. The table below reflects the responses that were given in the interview, rather than a comprehensive check of the supports offered by each program. These data were compared with the data collected from all the programs about their clients (n=102). Home care, delivered meals, and personal care services were the three services that were most frequently received by home rehabilitation clients, with 44 clients receiving home care, 22 receiving delivered meals, and 18 receiving personal care services, supporting the staff perception that these supports were offered by all programs. However, the clients in these eight programs were receiving on average only 1.3 community support services, and 39% of metropolitan clients and 15% of regional clients were not receiving any community support services at all.

Furthermore, despite the perception of staff from five programs that they were providing respite care, only three clients were receiving this service. Handyman and gardening services were also rarely provided with only two clients receiving these services, but only one of the programs claimed to be providing these services. Most of the other services listed below were provided by the rehabilitation staff themselves, either by a social worker or the case manager. Sixty of the 102 clients about whom data were collected were receiving social work services and 87 had a case manager.

Table 35 Types of support provided to care-givers by the home rehabilitation programs

Type of support	Programs providing the support
Brokerage of home-care and personal care services	1, 2, 3, 4, 5, 7, 8
Referral to care-giver support agencies	1, 3, 4, 5, 6
In-home respite care	3, 4, 5, 6, 8
Social worker visits at the same time as another therapist so that the social worker can talk to the care-giver while the client is otherwise engaged	1, 2, 4, 7, 8
Assessment of care-giver as well as client needs	2, 5, 7, 8
Education and information about the client's condition	3, 7, 8
Short-term counseling	5, 6, 8
Social work support	4, 5, 6
Support from case manager	1, 2
Assistance to access Centrelink entitlements and other services	4, 5
Brokerage of home handyman and gardening services	2
Future planning	5
Follow-up post discharge	5

There were some differences, noted above, in support provision in the two models of home-based rehabilitation programs, and in the support supplied by regional compared with metropolitan programs. These differences meant that clients and care-givers were receiving different levels of care depending on the location and type of the program that they were in.

Some program staff believed that they were able to provide a higher level of services than care-givers were willing to accept (1, 7, & 8). For example, the staff in program one said, *"I try to put in probably more than they need because I'm really aware of carer stress... "(1).* The staff in program seven said that they sometimes had to resort to *"conning them"* in order to get at least *"some back door case management in...somebody from the council at least" (7).* Program staff were worried about the level of stress that some care-givers were under and felt that if they accepted more help, this stress would be alleviated to some extent. However, staff in one program also postulated that care-givers may be more likely to accept help if they felt that they were part of the team (1).

However, community services were not always available even if the care-giver was prepared to accept them. The staff in program four identified these discrepancies as the most frustrating aspect of their work with care-givers,

> *I think the most frustrating thing is when you can see something that they could benefit from and they'll refuse or alternatively there's a need that you can identify and there's nothing in the community to fill those gaps as well. Yeah it's frustrating.*

The staff from program seven noted that the socio-economic status of the care-giver was critical to their stress levels because people from higher socio-economic groups were more able to purchase services.

> *The biggest single problem that I have is their financial status. Most of our clients are low income. It is completely different for those on a high income. They can buy care. Where people have been in a position to buy services there is no doubt the stress has been less. Every wealthy client we've had there has never been a huge issue. They just purchase the services and they feel comfortable with that....*

This comment is interesting in the context of the perception by staff from other programs that they could provide a higher level of care than the care-givers were willing to accept. Perhaps, given this program was one where the staff were having considerable difficulty accessing Home and Community Care (HACC) services, even with full cost recovery, clients who were able to purchase private services had better access. Or perhaps, given some of the comments above about the invasiveness of services and their lack of cultural sensitivity, discussed below, privately purchased services are more easily tailored to the needs and preferences of the care-givers.

The differences in service provision noted above also call into question the staff arguments about care-giver preferences as a full explanation for the low level of service provision. In those programs where more services were offered, either due to the commitment to replace hospital level care or better availability of services, more services were being accepted by care-givers.

In the few studies that have examined service provision to clients and care-givers in home-based rehabilitation, service use has been found to be low. Holmqvist et al. (2000) found that only 15% of patients in the home rehabilitation service used home help in the six months post-discharge from hospital. There was no difference in service usage for the routine rehabilitation group. However, Mayo et al. (2000) found that the total number of rehabilitation services for the home rehabilitation group was lower than the routine (hospital) rehabilitation group. In Holmqvist et al. (2000), there was a slightly higher usage of family care-giver assistance (85%) in the home rehabilitation group than the routine rehabilitation group (70%) at discharge. By 3 months, however, 63% of both were still receiving assistance from a family care-giver. The results of this study support the findings of low service usage for home-based rehabilitation of previous research. However, in this study no comparison was made with patients being discharged from hospital based care.

This study also supports the findings of previous studies that care-givers are unwilling to accept services (for example, Ganzer & England, 1994). However, it also goes further than previous research in determining why this might be so. The staff interviewed here gave a number of reasons why they thought care-givers did not wish to accept services. These were: that services are perceived as invasive and intrude on the care-giver's privacy; that services are not culturally appropriate; and that cultural and family pressures make care-givers feel that they should provide the care themselves without outside assistance. The care-givers interviewed for this study also gave some reasons why they prefer to manage without services, discussed in Chapter Six. However, although the author accepts all these explanations as partial explanations, another possible reason for care-giver reluctance to accept services that has emerged from this study is that care-givers do not wish to be treated as if they are a client of the system. Rather they wish to be treated as part of the rehabilitation team. The provision of support to care-givers is based on a professional assessment of their needs. The more the care-giver is perceived as stressed and not coping, the more support they are offered. This approach problematises the individual coping of the care-giver, rather than the changes to health policy and service provision that result in more work for care-givers.

This individualising of the problems associated with care-giving may partially explain why care-givers were reluctant to accept services. Care-givers in home-based rehabilitation who have been handed a huge amount of work and responsibility with very little acknowledgment, no opportunity to have a say, and no compensation, are unlikely to see the provision of community support services or counselling as the solution to the problem. Furthermore, they may consider the offering of these services as a further blow to their sense of control and self-esteem and thus be unlikely to accept these services. What the care-givers interviewed for this study said that they wanted (and the staff acknowledged that they were not getting) was to be given more information, to have a say in the decision-making about those aspects of the client's care that affect them, and to be included as part of the team. The only additional support service that they would have liked was someone to mow the lawns.

7.2.2 Findings related to Objective Two – Gender differences in care provision

It was expected that female care-givers in home-based rehabilitation would spend more time in care-giving and undertake a greater variety of care-giving tasks than male care-givers. Specifically female care-givers were expected to spend more time on hands-on care-giving tasks, such as showering and dressing, than men. It was also expected that male care-givers would take on more of a case management role than female care-givers. These hypotheses were not supported by the study findings (see Table 36 below) but there were some gender differences in the tasks undertaken by care-givers (as illustrated in Table 37 below) and the expectations that program staff had of care-givers as discussed in the interviews.

As with the care-giver interview sample, most care-givers were involved in 'hotel type' care-giving tasks. These included maintenance of the physical environment, that is, housework and outside jobs; meal preparation; and transport.

Table 36 **Comparison between female and male home-based rehabilitation care-givers on hours of care provided**

Level of care	Female care-givers		Male care-givers	
	n	%	*n*	%
<1 to 12 hours per day	29	50	20	49
13-23 hours per day	8	14	8	20
24 hours per day	19	33	12	29
Missing	2	3	1	2
Total	58	100	41	100

A Chi – square test revealed that there was no relationship between gender and hours of care, ^{2} (2, n = 96) = .583, p = >.07.

A high percentage (over 70% of both male and female care-givers) were involved in supervising the clients and keeping them company. A lower number (less than 50% of both male and female care-givers) were involved in personal care, case management, monitoring of medication, and rehabilitation tasks. The least often provided activity was nursing care. Male and female care-givers differed significantly in three areas. Significantly more female than male care-givers were engaged in housework, preparation and monitoring of medication, case management, and transport.

Table 37 **Comparison between male and female care-givers on types of care provided**

Care-giving activity	Female (n = 56)		Male (n = 40)		*df*	*t*
	n	%	n	%		
Personal care	25	44.6	15	37.5	94	0.69
Nursing tasks	5	8.9	5	12.5	93	-0.53
Meal preparation	40	71.4	27	67.5	94	0.41
Housework	47	83.9	24	60.0	69	2.58*
Medication	26	46.4	14	35.0	86	1.12*
Supervision	40	71.4	29	72.5	94	-0.11
Keeping company	44	78.6	30	75.0	94	0.41
Outside jobs	16	28.6	26	65.0	93	-3.69
Case management	26	46.4	9	22.5	92	2.52*
Financial management	28	50.0	21	52.5	94	-0.24
Transport	44	78.6	26	65.0	75	1.60*
Rehabilitation tasks	22	39.3	19	47.5	94	-0.80

$^{*}p < .05$

7.2.2.1 Program staff occupation or gender based expectations

Program staff were asked whether they had different expectations of care-givers depending on the gender and/or work status of the care-giver. Only three interviewees identified different expectations for working care-givers. Staff from one program said that they could make themselves available to meet with care-givers after hours on some occasions but that they also expected the care-givers to make themselves available during working hours sometimes (1). The staff from another program said that they try to make sure that working care-givers do not take on too much (2). They also noted that work and other commitments could place constraints on the amount of care that could be provided and stop the care-giver from burning out with care-giving. They said,

> *The high risk carer is the retired spouse who doesn't have the protective mechanisms of a job or a new baby. They're the ones who think they should do everything and if they're not careful they'll end up doing too much (2).*

A third program's staff said that working care-givers were not expected to do as much as non-working care-givers as they had had problems with working care-givers in the past (6). They gave an example of a working care-giver who had taken the client to work which meant that the client was not available to participate in the rehabilitation program. The other staff interviewed did not identify any differences in expectations between care-givers in paid employment and care-givers without employment.

There were some consistent gender differences identified by program staff. Although the program staff's expectations of what the care-giver would do did not alter depending on the gender of the care-giver, there were some differences in their response to care-givers depending on their gender. Staff seemed to notice male care-givers more. They were frequently surprised at what the men were prepared to do,

> *...I was really quite surprised just how much these two gentlemen were doing for their wives...I think that if you're designating that (the great job that the two male care-givers were doing) as something worthy of comment, the assumption is that you're not expecting that...(1).*

They often mentioned the fantastic male care-givers they had met (1,3, 4, & 5).

> *...it's awful to generalise. I mean we get fantastic male carers who roll up their sleeves and do the lot, but I think – you might say, that they are like good*

> *at the organisation...more likely to use personal care services...you can't generalise (3).*

They also noted that they were more likely to acknowledge this with the care-givers themselves and tell male care-givers what a fantastic job they were doing (1 & 4). The staff at two programs (1 & 4) said that they thought male care-givers were more likely to be offered and to accept services, whereas both the staff and the female care-givers assumed that the female care-giver would manage.

The other difference that was noted between male and female care-givers was that it seemed more difficult for men than women to enter into the care-giving role (4, 5, & 7) because becoming a care-giver entailed a greater life-style change for men.

> *If it is a man being a carer it is probably something that is new for him. If the wife is going home and is recovering from a stroke or a fractured hip then it is probably a new concept [for him] (5)* and,
>
> *...[it is] particularly [hard] for a lot of the blokes. They try really hard many of them but we have to get them to understand the washing machine sometimes. You know...if they [have] gone from being cared for to the position of being the carer, for a lot of older blokes it is just an emotional impossibility for them...to make that transition (7).*

Related to this was the observation that male care-givers were more likely to be older, retired husbands (5). Staff in two programs (6 & 7) said that their expectations were not so much gender based as based on what the care-giver had been doing previously. If domestic duties were new to the care-giver then more assistance with cleaning and meal preparation would be offered.

In summary, although most of the staff interviewed did not perceive that they had different expectations of male and female care-givers, there were some differences in their response to, and treatment of, male and female care-givers. There was some evidence of greater acknowledgement for male care-givers. They were also more likely to be offered help, especially if they were seen to be new to the tasks associated with care-giving.

7.2.3 Discussion of objectives one and two - Patterns of care in home-based rehabilitation

These data show that, consistent with the data from the care-giver interviews, care-givers in home-based rehabilitation had taken on a great deal of the care of the home-rehabilitation clients, particularly in the convalescent care or 'hotel type' areas that have been successfully transferred from hospital to home.

Although there is some evidence in these data that the traditional division of labour is present in rehabilitation in the home, there is not the consistent pattern that has been identified in previous literature. Although not all studies have found gender differences in care-giving tasks, where gender differences have been found, they have indicated that men were more likely to take on case management while women were more likely to take on personal care activities (Stommel et al., 1994). However, in this study, women were found to be more likely to take on case management than men, with almost half the female care-givers taking on case management roles (46.4%), compared with 22.5% of the male care-givers. There were also proportionately more women than men engaged in personal care (44.6% compared with 37.5%) but this difference was not found to be statistically significant. This study also found that there were proportionately more men than women engaged in outside jobs (65.0% compared with 28.6%) but this difference was not found to be statistically significant. There were statistically significant gender differences in the amount of housework, medication management, case management and transport undertaken, with women doing more than men in all four areas.

Despite the stated aim of these programs to replace hospital care, it seems that only the rehabilitation aspect of these programs has been replaced by professional or paid staff. There was a very low level of service provision, with clients receiving an average of only 1.3 community services. This may reflect care-giver preference or difficulty in accessing these services, as well as budgetary constraints. These issues will be discussed in conjunction with the findings about the inclusion of the care-giver in the program discussed in 7.2.5, below.

7.2.4 Objective Three - Care-giver payments

It was expected that most home-based rehabilitation care-givers (>50%) would not receive any payment for their work and that even when care-givers did receive a payment, it would not compensate them on an hourly rate for the work that they did. These hypotheses were supported by the study findings. As with the interview sample, very few care-givers in the program sample were receiving any payment for their contribution. Only 13 of the 99 care-givers were known to be receiving a payment. Eight received the Carer Payment and five received the Carer Allowance. None of the care-givers received a wage. Data were not collected about the length of time that the care-givers had been caring for the clients. However, the low numbers receiving a payment may indicate that the care-giving episode was less than six months as one of the criteria for receiving a government carer payment is that the care-giving episode is likely to last longer than 6 months (Centrelink, 2001). The latter eligibility requirement is obviously a problem for care-givers in situations where the episode of care may be intense but short-term. This issue will be discussed in Chapter 8 and is the subject of one of the recommendations of this study.

7.2.5 Discussion of findings related to objective six: gender stereotypes

Most of the findings that relate to objective six have already been presented in this and previous chapters. The two questions that have not yet been discussed are -

- How do the home-based rehabilitation programs include the care-giver in their assessment and program planning process?
- How is the contribution of care-givers measured and compensated for by the hospital system?

The next section discusses the staff perceptions of care-giver involvement in the rehabilitation process. Figure 12, below, illustrates the pathway that home-based rehabilitation clients typically go through. Care-giver involvement at each step along the pathway was discussed in the interviews and has been documented below.

Pre-admission	Admission	Week 1	Weeks 2 – 8	Discharge	Post-discharge
First meeting between client and program staff – aims to explain the program, gain informed consent, initial assessment of needs, goals Home visit assessment	Assessment by medical specialist Home visit assessment Case manager appointed	Discipline assessments Occupational Therapy Physiotherapy Rehabilitation nursing Social Work Speech Pathology Dietician, etc.	Therapy program continues, based on the client and rehabilitation team's goals for the client. Brokered services continue	Based on the maximum length of stay of the program, usually 8 weeks and/or the achievement of the client's rehabilitation goals	Follow up phone call or visit by case manager or designated therapist Client satisfaction survey
	Client pathway				
		First case conference Goals set Discharge set Brokered services commence	Client is given a weekly program on which scheduled visits are documented	Referrals for ongoing rehabilitation or community support	

Figure 12 **Client pathway in home-based rehabilitation**

7.2.5.1 Inclusion of care-givers in pre-admission and admission

The pathway into the home-based rehabilitation program varied from program to program, and within the same program. Clients were admitted from home, via acute hospitals, and from rehabilitation and geriatric evaluation and management (GEM) wards. The CoC programs were able to transfer clients from inpatient to home-based program within the same health service. The Alt programs' clients were discharged from hospital prior to admission to the home-based rehabilitation program. The staff in program one, a CoC program, thought that the inclusion of the care-giver in the pre-admission and admission process was better when the client was transferred from the rehabilitation ward than when they were referred from acute hospitals. They said,

> *I find it much more satisfactory when people have their pathways from inpatient rehabilitation because you get to know the carer and you can actually give them the information on the program (rather than relying on hospital staff to do this) and you can discuss the purpose of it (1).*

A staff member from most programs (1, 2, 3, 6, 7, & 8) would routinely visit prospective clients either in the rehabilitation or acute hospital ward prior to their discharge to home. The purpose of this visit was to provide clients with information about the home-based rehabilitation program, to start to assess what their community service and rehabilitation needs would be, and to gain their consent to participate in the program. Care-givers were always welcome to be present at these visits and were usually notified (1, 3, 6, & 7) but none of the programs had a pre-admission process that required the care-giver's participation. The staff from program one explained the care-giver's involvement in this process.

> *I make sure that if there is a care-giver involved that when I initially speak to the client, I also speak to the care-giver as well...I explain the program to the carer and to the client and then...generally I feel that when I've finished there that we sort of have a mutual understanding of what's expected from the program or what is going to happen (1).*

Staff from programs one and seven noted that when the client was admitted to home-based rehabilitation from the rehabilitation ward, a family conference was sometimes conducted. The aim of this meeting was for the client and family to meet with the entire inpatient treating team to discuss the client's rehabilitation progress and to plan for discharge. As the purpose of this meeting was to involve the client's family in the case planning process, it was usually scheduled at a time that the care-giver and/or other family members could attend. The staff of program seven were very critical of family meetings as they felt that they were intimidating for families and usually served to inform the family of decisions already made rather than include them in decision making.

All programs conducted an initial home visit assessment. The purpose of this visit was to determine the suitability of the program for the client and to ensure that the client and his or her environment were safe to conduct a rehabilitation program. The timing of this visit varied according to the program model. For programs one and two, both CoC programs, this visit was undertaken before the client was discharged from hospital. The client would be taken home from hospital by the program staff and asked to do certain activities, such as, getting on and off the bed, and assessed for safety and/or equipment requirements in order to enhance safety, and then taken back to hospital to await discharge. The other programs would conduct a similar assessment but this was usually done after the client had been discharged from hospital. Most programs took clients from acute and rehabilitation wards of hospitals that discharged patients into their catchment area and, to a lesser extent, clients who had been referred by community services or general practitioners. As with the pre-admission interview, care-givers were always welcome to be present at these home visit assessments and some programs expected them to be there. Care-givers were usually notified of these visits, and in the case of programs one and two, the care-givers often had to be there to ensure access to the client's home.

All programs required that the client be assessed by a geriatrician or a specialist in rehabilitation medicine prior to admission. This assessment was to determine whether the client was medically stable and likely to benefit from rehabilitation. Care-givers were not usually involved in these assessments which often took place before the client left hospital.

The staff from one program talked about how little the care-givers were involved in the decision to discharge the client from hospital.

> *(I don't think) we involve the family and the carers in the actual formulation of the decision about whether the person will go home or not. We make our recommendation then we inform, sometimes. Sometimes I've heard that clients in the ward have a three-week period of time when we're doing our assessment in determining the level of care. At some point of time suddenly the staff start talking to the client about, "Oh it's great, you're going to go home. Now we're going to start doing home visits and we're going to get you mobilised because you've got three steps at home." The family asks, "What has happened? All of a sudden Mum's told me she's going home. I know nothing about this. What's shifted? Something dramatic has happened and I didn't even know about it. I've got to unlock the house, I've got to get the cat back. I have got to be available. When is this happening? I've got to be home for the home visits. When did this shift take place and why didn't I know about it, because this has huge implications for me. My daughter has just had a baby and now they tell me Mum's coming home..." It's very paternalistic still and we get challenged on it when people complain but we don't have a*

> *strategy at the moment for dealing with it proactively as part of standard client, customer service (2).*

Care-givers in this program were involved in the decision making about discharge to the extent that they could set limits on what they could do for the client, for example, *"I can only have her home if she can manage to get from bed to chair independently... "* (2). This would impact on what the therapists would try to achieve in the therapy sessions in the hospital, prior to discharge.

In summary, most programs had some contact with the client prior to his or her discharge from hospital and program staff provided information about the program to prospective clients. In most cases the care-giver was invited to be part of this process. However, care-givers were not generally involved in the decision to discharge the client to home. According to the staff, the care-giver's role pre-admission to home-based rehabilitation was to gain information about the nature of the program and to participate in discussions about what they could and could not do for the client so alternatives could be found for the things that they could not do.

7.2.5.2 Inclusion of care-givers in assessment

Apart from the entry into the program and the opportunities for continuity of care in the pre-admission assessment phase, discussed above, there was little difference between the two program models in terms of inclusion of the care-giver as part of the rehabilitation team. Once the client was at home, the processes of assessment, treatment planning, and implementation were the same for both the CoC and the Alt programs. The differences in service provision, noted in 7.2.1.7 above, were not identified by the program staff.

After the initial home visit assessment, described above, a number of discipline specific assessments were conducted in the client's home, usually within the first week of admission. These visits were based on the needs of the client as determined at the home-visit assessment. For example, a client who had had a stroke would usually be assessed by a speech therapist. Some programs arranged for all clients to be seen by some disciplines; for example, in program eight all clients were seen by the physiotherapist, occupational therapist, and social worker.

Most programs (3, 4, 6, & 7) invited care-givers to be present at these discipline assessments. As the staff in program three noted,

"Without exception our therapy staff would interview both the client and the carer at their initial assessment, get them to participate in whatever was appropriate."

In some programs (7 & 8), the client and care-giver were seen as a unit, that is, it was seen as impossible to separate the needs of one from the other. The staff from program seven said,

> *It is hard to separate the client and the carer. You are treating one and involving the other. In my work they're included in just about every session I have. It is very rare that there is a separation unless there is acute depression or some other issues.*

It was common for a social worker to see the client and care-giver together to assess how they were coping and whether any supports were required (4, 5, & 7). It was less common for the care-giver to be included as an informant about the capacities of the client and this information was sometimes obtained by default. For example,

> *Just last week there was a suggestion that this woman might be educated on how to make her own breakfast whereas the care-giver, his experience was that the woman was really a grave risk even in using a kettle...it had been quite some time, years in fact (since) she could be safely left in the kitchen (1).*

Care-givers were also involved in the assessment of what services were required by the client. This involved determining what the care-giver could and couldn't do for the client and arranging for community services to provide those things that the client needed but the care-giver could not provide (such as Meals on Wheels or home care) (4 & 5). In program three care-givers were involved in the assessment process so that the staff could explain the rehabilitation goals to them and the care-givers could offer the appropriate support and assistance to the clients (3).

7.2.5.3 Inclusion of care-givers in goal setting and the planning of the client's program

None of the eight programs had a formal process for inclusion of the care-giver in the planning of the client's rehabilitation program, although one program did have a formal process of client goal setting (1). The staff from two programs stated that they always encouraged clients and care-givers to participate in the setting of rehabilitation goals (7 & 8) and program seven had a strong culture of inclusion of and listening to the care-giver's expertise. Care-givers in this program were seen as a member of the team and could initiate meetings with the staff working with the care recipient if they had any concerns that they wanted to discuss. An example of the description of care-giver involvement in this program was,

> *Every therapist goes out and sets goals with the client and care-giver and then brings them back to case conference. A very big effort (is made) by everybody to include the client in all the discussion about the rehab. goals that we have. This also includes the carer... we do so many ADL (activities of daily living) types of things – you almost need the carer's permission to do things...you're in their home. Yea, you're in their home and I need to do some things that's mucking up your kitchen, is that OK?*
>
> *There's a lot of negotiation about what their needs are. I guess that is one of the key things that all of us are pretty good at, asking what their expectations are and what they really need. You know, rather than talking about what the client may be needing in isolation...it's just not going to survive. Particularly in the very disabled people...it's a continual renegotiation of goals. (7)*

Client and care-giver involvement in goal setting and case planning was an area targeted for improvement in one program (2).

7.2.5.4 Inclusion of care-givers in treatment

Most of the staff interviewed said that the care-giver was often present when the professional staff visited to treat the client. However, only two programs (1 & 7) said that the therapists took into account the care-giver's knowledge of the client in conducting the therapy. Care-givers were involved in another two programs (2 & 3) to the extent that they were offered education about the use of equipment and instructed about how to prompt and encourage the client to practice his or her rehabilitation program. Care-givers also sometimes chose not to be present when the therapists were there, using the time to go out and get some errands done, or for time out from care-giving. As one staff member put it,

> *I have to say that in not all of the instances carers are keen or interested and quite often in my experience the carer will sometimes say "Look I'll leave you to it I've got other things to do," and be off. In those instances if they were to*

> *indicate that they did not want to participate (it would be) noted and reported in a team meeting if the carer did not want to participate where it was appropriate for them to do so. If the client was independent then it wouldn't be an issue (3).*

Staff described the care-giver's involvement in their program in this way.

> *Certainly I would say that without exception they would leave a program of things to do that the client and the carer could do together if that's necessary. Or if the client can do it by themselves even inform the carer so that they can be the prompt and the reminder and the encourager.(3)*

Staff from two programs (1 & 2) said that they felt that care-givers were not involved as much as they should be in the client's treatment program. The staff in one program identified workload and time constraints as the main reasons for this. They said,

> *I don't feel that I'm practising satisfactorily on a number of levels. It's just having to do a lot in just a few hours and also the client centredness that we seem to have lost sight of sometimes..., and ...most of mine are only on at the moment for about three weeks...and I feel that by the time you try to build up rapport with the care-giver and the client (and they're quite busy at the same time) that...you're just getting to know them and they're off the program...(1).*

Another barrier to participation in the client's care plan that was identified by the staff in program one was the power differential between the staff and the care-giver. They felt that even when the care-giver was consulted he or she may not really say what they thought out of deference to professional staff and their expertise. For example one staff member said that

> *perhaps notionally they're there and they're listening and they're nodding but they're not introducing the topics that they think would be useful...they're the sufferer of the action rather than the ...co-worker (1).*

7.2.5.5 Inclusion of care-givers in program planning and evaluation

Two programs (1 & 4) had a client satisfaction survey that was routinely sent to clients post-discharge. Both of these surveys could be completed by either the care-giver or the client. The staff interviewed did not know what happened to the feedback collected via these surveys. Program three had a client satisfaction survey that was directed at clients rather than care-givers. Staff from a further four programs (2, 5, 6, & 8) were planning to implement some form of post-discharge evaluation measure, with staff from programs eight and five considering the inclusion of a care-giver component. This was identified as an area about which the research had prompted action by program staff.

To summarise the discussion about care-giver involvement in the rehabilitation program, it seemed that care-givers were included as part of the client dyad rather than as part of the rehabilitation team. Care-givers were given information about the program so that they would know what to expect when the client was discharged home, but they were not involved in the decision to discharge the client to home. Care-givers were involved in the assessment of the client's suitability for rehabilitation in as much as they were part of the client's support system upon which the rehabilitation relied. However they were not generally seen as key informants in the assessment process. The extent of community support service and rehabilitation nursing provision depended on the willingness and ability of the care-giver to provide care for the client as well as their inclination to accept services, so they were always consulted about the client's service needs. Staff were also very concerned about care-giver stress and often tried to convince them to accept help from community support services. However, again they were seen as part of the client system rather than part of the team. Finally, as the staff from some programs noted, care-givers were not adequately included in the client's goal setting and care planning process or in the program planning or evaluation, although as discussed below, this was being challenged by some more articulate and assertive care-givers.

In the hypotheses relating to objective six, it was expected that within home-based rehabilitation programs and the hospital system the contribution of care-givers will be taken for granted as invisible, unpaid women's work. This would be evidenced by:

- the predominance of female care-givers,
- care-givers not receiving a payment for their work,
- care-giver contribution not being included in the economic analysis of home-based rehabilitation, and

- the limited consideration given to the care-giver's situation, including work commitments, other care-giving responsibilities and so on, in assessing the client for admission.

There was some evidence for all the above factors in the quantitative data and the interview findings of this study. There were more female than male care-givers in both samples. There were very few care-givers receiving a payment for their work, and only one receiving a wage. The contribution of care-givers was not considered in the economic analyses of home-based rehabilitation either in the literature or in the evaluations conducted by program staff. Finally, although there was some consideration of the care-giver's work responsibilities in the view of the program staff, this was not supported by the care-giver interviews. All the care-givers interviewed who were working had altered or ceased their work commitments and those who had family responsibilities continued to manage these in conjunction with providing care to the home rehabilitation client. However, there were other ways in which both the staff and care-givers in home-based rehabilitation were affected by the prevailing ideologies about care-giving. They were also affected by other patriarchal forces, such as the state, the household, and employment. These issues will be discussed in the next chapter.

7.3 OTHER ISSUES FOR CARE-GIVERS AT THE INTERFACE BETWEEN THE HOSPITAL AND THE HOME

In the process of determining the study questions, the researcher met with home-based rehabilitation staff at a state-wide forum, described in Chapter Four. At this forum, staff indicated that they thought that cross-cultural issues were important in considering care-giving in home-based rehabilitation. For this reason, a question about cultural diversity in care-giving was introduced into the interviews with program staff. The first part of this section will discuss the staff perceptions of cultural diversity in care-giving. During the interviews the staff identified some issues that were not directly surveyed by the researcher but are discussed in the following sections. These were the trend towards greater recognition of consumer rights; the potential invasiveness of home-based rehabilitation for clients and care-givers; the lack of recognition by both care-givers and staff of the care-givers' essential place in the programs; and the impact of pressure from government and funding bodies to avoid or reduce hospital admissions.

7.3.1 Care-giving across cultures

Twenty-three care-givers were known to come from a culturally diverse background. Program staff were asked whether they thought there were any cultural issues that were pertinent to care-giver involvement in their program. Three main issues were identified. The first was a gender issue; that women were clearly expected to be care-givers in families from diverse cultural backgrounds. The second was the perception of and willingness to accept support services, and the third issue was the way that rehabilitation was perceived by clients and care-givers from culturally diverse backgrounds. Discussion of these issues was often prefaced by the comment that the staff were not trying to set themselves up as a norm from which to evaluate difference and that many of the observations that they made could be applied to care-givers from all cultural backgrounds. For example, one staff member said, *"Just on that cultural thing, so many of our clients are from a non-English-speaking background that ... it's hard to pinpoint how we deal with them"* (4).

Comments in relation to gender reinforced some of the broader gender issues in care-giving discussed throughout this thesis. The comments about support and rehabilitation services, however, point to some issues about the cultural sensitivity of these services, and are therefore considered to be worthy of discussion here.

Staff from five of the programs (1, 2, 3, 4, & 5) noted that in families from culturally diverse backgrounds women were expected to be the care-givers.

> *I think that because this is a multi-cultural area the majority [of care-givers] that you work with are female. [When I] look at issues around the caring role I find that I am looking at issues of guilt. If they are not able to fulfil the role, even if the care needed is very high level, they see it as a failure...It is expected in some cultures that the wife cares for someone if they are ill... (3).*

Furthermore there were very high expectations of women as care-givers and these expectations were not mitigated by the women's work, family, or other commitments. *"Women are expected to keep going 'til they drop"* (4). One staff member recounted a story of a male care-giver from Malta who did not want any services because he could not see why his wife couldn't continue to provide them.

> *He still wanted his wife's cooking, yet she was the one who had just come out of hospital. She was the one who was sick and he expected her to do these things because he felt that because she was at home, she was quite capable then of being able to do her duties within the home (1).*

Related to the perception that it was the woman's job to care, was the view that in families from culturally diverse backgrounds, family care was better care (3 & 4), and that clients from culturally diverse backgrounds were more likely to live with their extended family (6).

> *I have to be careful not to generalise here but, often the non-English speaking clients that we have had, have had a very diverse carer support system, usually not just the spouse but other family members are more likely to be involved too...often living with an extended family (6).*

The staff from one program (5) also commented that they had found a feminist perspective to be less than helpful in working with families from culturally diverse backgrounds. An example was given of a male client who was difficult to engage in the rehabilitation process.

> *I think he felt that if he started to do a lot more he would be in a way questioning the quality of the wife's care. I picked up from the way he spoke – I didn't actually have this conversation with the wife herself - that she wasn't prepared for him to do too much. It was almost as if it was her honour, it was an honourable role... I think we often go in with a sort of feminist perspective which is totally irrelevant to many people (5).*

Secondly, there was a common perception that clients and care-givers from culturally diverse backgrounds were less likely to accept assistance from community support services than clients from the dominant cultural group. This was seen as being due to a culturally driven desire to care for one's own family members rather than have them cared for by strangers (1, 2, & 8), to a lack of information or understanding about the nature of these services (1 & 5), or to a perception that these services would be an intrusion into family life and lead to loss of control over decision making (1, 3, & 5).

> *They're used to supporting each other. They're not used to having outside agencies come in and providing...say the Meals on Wheels because generally in those groups, the communities brought in all this food to fill the fridge...so whether it was that or whether it was they just didn't want authority intruding into their space...(1).*

Finally, cultural background was seen as affecting the way in which rehabilitation was perceived. The rehabilitation aim of maximum independence was sometimes seen to be at odds with the family's feelings of obligation to care for the client and to do things for them (3 & 5).

> *We do have a lot of Vietnamese (clients) and the older Vietnamese expect the younger people to look after them and often that can clash with their rehab. goals as we are trying to get them independent with activities. They are quite passive because they expect their daughter to do that for them (5).*

Staff from a number of programs felt that they were pushing services *"almost to the point of rudeness "* (4) onto women from culturally diverse backgrounds (1, 2, 3, 4, 5, & 8) as they felt that these women needed support but were under a strong familial and cultural obligation to provide care with no outside assistance. In program five an example was given of a Vietnamese family who did not want community services,

> *...this situation was very shaky...the family were really polite. I pushed it to a little bit beyond the level of politeness and then I said, well, that's it I've got to stop (pushing them to accept services) (5).*

Two important issues emerged from the discussion about cultural diversity. The first was to what extent staff should advocate for more gender equity in care-giving in families from culturally diverse backgrounds, and the second was the cultural appropriateness of the support services that are routinely offered in home-based rehabilitation. Previous research (Delgado & Tennstedt, 1997; Morse & Messimeri-Kianidis, 1998) has consistently found women are the most frequent care-givers in families from non-English speaking backgrounds. It has been expected, however, that with the trends to greater workforce participation and higher educational levels, women would be less likely to be available to provide this care (Morse & Messimeri-Kianidis, 1998). This study has shown that these trends lead to women taking on care-giving as well as these other responsibilities. Rather than being relieved of the care-giving role, it is added to their other work, study, or family responsibilities. This finding is consistent with the findings of previous research (Cox & Spalding, 1996; Pavalko & Altis, 1997).

However, as one staff member in this study noted, the role of care-giver may be seen by these women as an honourable one, and one that they do not wish to relinquish. Although care-giving is certainly an honourable role, the findings of this and other studies do not support the idea that it is a freely chosen role and one that would not be relinquished by women of any cultural background if they felt that acceptable alternatives were available. In line with the findings of the care-giver interviews in this study, an Australian study of 150 Greek care-givers found that they took on the role because they saw it as their family responsibility, because there was no-one else, or because they wished to avoid residential care for their disabled relative (Morse & Messimeri-Kianidis, 1996). The role of advocate for women care-givers from both Anglo-Australian and non-English speaking backgrounds would thus seem to be an appropriate one for home-based rehabilitation and other community services staff.

It has also been consistently reported that care-givers from diverse cultural backgrounds in Australia receive little support from their families or the wider community (Plunkett & Quine, 1996; Morse & Messimeri-Kianidis, 1998). This challenges the myth, expressed by some of the program staff in this study, *that "they look after their own"* (Morse & Messimeri-Kianidis, 1998, p. 203). Some of the reasons for the under-utilisation of support services by people from a non-English speaking background have been identified as - lack of information, lack of availability of culturally appropriate services, and problems with access to these services, including transport, hours of opening, and availability of interpreters or bi-lingual staff (Plunkett & Quine, 1996). Some of these obstacles are unique to care-givers from culturally diverse backgrounds but some are applicable to all care-givers regardless of cultural background. Although recommendations made previously (Plunkett & Quine, 1996) about the cultural appropriateness of these services may go some way to addressing the problem, a universal, rather than residual, approach to the provision of these services may be a better way of alleviating some of the problems of access for care-givers of all cultural backgrounds.

7.3.2 Consumer rights

Staff from four programs discussed the trend towards greater recognition of client and care-givers' rights, and the implications of this for their programs (2, 3, 7, & 8). Program two staff noted that they were encountering much more articulate and assertive (and younger) family members who understood the health service system and expected to be consulted about, and involved in, the planning of the client's care. They commented that,

> *I'd like to see [us] hearing more, becoming less anxious about ... empowered carers and families [and] to help the health care providers understand more the benefits of understanding where they [the families] are coming from...I find it exceptionally complex and time consuming but very rewarding working with "difficult" families...It's a learning opportunity for us because we'll face this again. Fifty year olds having strokes, it's scary... We'll get more involved with carers whether we like it or not"* (2).

It was noted that discharge to home was often the result of clients and care-givers pushing for the opportunity to manage the client at home (3 & 8). The staff in program seven said that they celebrated seeing clients and care-givers taking more control. They said,

> *...they take control [at home] whereas in the ward [they don't]...they take control of their own lives...we try to make them stand up for themselves. It [the rehabilitation program] is successful when they tell us they've had enough therapy and it's time for us to go (7).*

They also noted a trend towards younger clients and saw this as being problematic for care-givers.

> *Age is the other one. Perhaps the complicating factor is that people have no expectations of being a carer in their 30s, and the ramifications of that are huge. They're the toughest ones for me. I've had three clients, 30, 40 and just on 50, looking at income, caring for children.... Part of our role with them is adjustment, preparing them for that (7).*

This trend towards younger clients was also identified by staff in the context of the impact that it had on the staff (2). The staff could identify with the younger clients, either with the client (for the staff in their 40s and 50s) or with the children of the clients (for the staff in their 20s). This had implications for their interactions with the client, and with the client's family, and was seen as another area in which staff needed training and support.

7.3.3 Invasiveness of home-based rehabilitation

The second issue identified by staff was the invasiveness of the program for care-givers. Staff were concerned about the invasion of people into the care-giver's home and tried to organise their visits around the usual activities of the care-giver (7). It sometimes took a while before the care-giver would feel comfortable enough to request this. They said,

> *...yes it will often take a couple of weeks until they feel comfortable enough with us to say, could you not come until after 10 or can I have that afternoon free?(7).*

This perception of invasiveness was also extended to community support services. Despite program one paying full cost recovery, the assessment worker from the council had conducted an income assessment with one of the home-rehabilitation clients. The staff thought that, *"some people would just rather do without (community support services) than expose themselves to the inquisition"* (1).

This concern on behalf of staff for the invasion of care-givers' privacy has been identified in previous research. Sims et al. (1997) noted that staff were concerned about the invasiveness of the "Going Home Service". In the evaluation of the Ballarat Health Services Rehabilitation in the Home Program conducted by the author (Dow, 1999), staff also expressed concern about invasion of the client and care-giver's home. However, this concern was not expressed by the care-givers in this or the previous study by the author. Rink et al. (1998) reported on the care-giver findings of the Sims et al. (1997) study discussed above and noted that a few care-givers were concerned about the invasion of their homes by program staff. In this study, care-givers were concerned to know who everyone associated with the program was, where they were from, and when they were coming, which may be another way of expressing concern about invasiveness, but they also found both rehabilitation and community services staff to be a source of support and expertise. Further research into the relationship between home-based program staff and clients and care-givers would clarify the problems experienced by all three parties and serve as the basis for improving practice in this area.

7.3.4 Lack of recognition of care-givers

Staff saw it as problematic that they were relying on care-givers to implement the home rehabilitation program but that there was no formal recognition of this (2 & 3). Staff noted that although there has been some increased recognition of client's rights (reflected in the client-centred goal setting processes that had been adopted by their programs), this recognition had not been extended to care-givers (1 & 8). One staff member thought that if care-givers were really included as part of the team, this would have an impact upon their willingness to accept the need for time out. She said,

> *I think if they were really part of the team, it would be easier to persuade them that they need their time out, they need their recreation in order to be a better carer (1).*

The issue of reliance upon care-givers without associated recognition or compensation is discussed in some detail in the next chapter.

7.3.5 Pressures for avoidance of hospital care and their impact on home-based rehabilitation programs

Program staff identified a number of other issues that indirectly affected their relationships with the care-givers who participated in their programs. These were: the increasing "complexity" of clients coming into home-based rehabilitation (1, 2, 3, & 8); the frailty of care-givers (1, 3, 4, & 7); problems with accessing Home and Community Care (HACC) services (1, 2, 3, 4, 5, & 7); and the increased pressure for early discharge and avoidance of hospital admissions (2, 3, & 8).

Program staff in four interviews (1, 2, 3, & 8) said that the clients coming onto their home-based rehabilitation programs during the past two years had increasingly complex needs. For example, *"...the straightforward hips and knees (people who have undergone surgery for hip or knee replacements) are just going onto CRC now. Our clients are more likely to have multiple problems...you get the frail, older old ones and the younger ones with lots of health problems"* (1). This shift represented more work for the program staff and more responsibility being placed on the care-giver. Staff from programs one and eight said that this also meant that the clients with "straightforward" rehabilitation conditions, such as a total knee replacement, were more likely to be sent home from acute care without the benefit of a multi-disciplinary rehabilitation program. These clients may instead have just been given an appointment to see a physiotherapist. The issue of increased acuity of patients being treated in the home was also noted by Santamaria and McKenzie (2000) in their study of the needs of care-givers in Hospital in the Home.

It was also noted that some care-givers themselves were very frail and disabled and that this could impact upon the viability of the client and care-giver dyad's survival at home (1, 3, 4, & 7). The staff in program seven said that they often had to assess the care-giver as well as the client to ensure the client and care-giver's safety at home,

> *There are probably 20% of our clients in their 80s where we are probably doing as much work with the carer, to see whether they are capable because they present OK when they just have to front up at the hospital. You know they are starting to forget about putting meals on, medications and all that sort of stuff. Have to do an assessment.*

Staff in program four said that they would sometimes like to admit the care-giver as well,

> *Sometimes I think we could admit them both...I think we should treat them as a unit not as a separate identity. Often as they get older there's a lot of issues for both the carer and the person that we have identified as the client ...*

The observation that some potential clients are no longer receiving a service at all is of considerable concern. Staff perceptions were that this group of "straightforward rehabilitation" clients used to be admitted to home-based rehabilitation when the programs were first established, but no longer were. Because the home-based rehabilitation programs were established in the context of reduction in health-care expenditure, it was not possible for all clients requiring rehabilitation (who otherwise met the admission criteria) to continue to be admitted to these programs. The "straightforward rehabilitation" clients were not seen as a priority when more complex clients required rehabilitation in the home. Unfortunately, this "straightforward" group of clients and their care-givers were not included in the study, because the study only included those clients and care-givers who were involved in the programs. However, it may be that these clients and care-givers are an even more salient example of the shift from hospital to family care than those included in this study. This issue has been highlighted with the program staff and warrants further investigation.

The second issue identified was access to HACC services, such as home care, delivered meals, and Linkages[11]. For program one, a regional program, the problem with access to HACC services occurred after the client was discharged from the home-based rehabilitation program. Their clients were having difficulties with the transition to Linkages or a Community Aged Care Package[12] post-discharge from their program. However, all five metropolitan programs were having difficulty accessing HACC services during the client's admission to their programs as well as after discharge. Even where the program was able to broker the service and therefore pay at the rate required for full cost recovery, the HACC service could not always be supplied.

> *Even with full cost recovery they cannot do it. The way that brokerage services put demand on HACC services...they can't respond to demand... and with the nursing shortages they can't find them [nurses] for love or money (2).*

Program five said that clients could wait up to six months for home care and program three said their clients waited up to six months for a Linkages assessment. Access to services depended on the municipality in which the client resided, so some programs (2, 3, 4, 5, & 7) that catered for clients across a range of municipalities offered different levels of service depending on the client's location. This was more problematic for the metropolitan programs than the regional and outer metropolitan programs. The latter did not identify any difficulty accessing HACC services (for which they paid full cost recovery) during the client's admission.

The problem of differential access to services depending on the client's geographical location was compounded by the disparity in service provision between the two

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[11] Linkages is a HACC funded service for older and disabled people that provides case management and brokered services to help maintain them in their own homes.

[12] A Community Aged Care Package is one of the funding packages allocated to individual clients managed by Linkages services (see above).

models of home-based rehabilitation, discussed above. It is of concern that service provision was based on model type and geographical location rather than clients' and care-givers' preferences and needs. This has also been discussed with the program staff and recommendations made about further investigation into this issue.

The third issue identified was the increased pressure for early discharge and this was linked to the plethora of new government initiatives (funded by both the State and Federal Governments) that had been established with the aim of reducing or avoiding hospital admission (2, 3, & 8). Some examples of these initiatives were unassigned Geriatric Evaluation and Management (GEM)[13] funds, Transitional Care[14] funds, and Winter Bed strategies, all of which have been initiated since 1999. These were additional to other initiatives such as Post Acute Care (PAC)[15], Hospital in the Home (HITH)[16], Rehabilitation in the Home (RITH)[17], and Aged Care Packages (ACPs)[18] that were established in the mid to late 1990s. As one interviewee put it,

> *...I don't know what HARP[19] stands for. It's just all happening at the moment...It's unbelievable trying to get your head around it. HARP is the next. It was Winter Beds and then it was Hospital Demand Management and next year it will be HARP. It's the sort of annual evolution of this hospital demand management stuff (2).*

Detailed discussion of these funding initiatives is beyond the scope of this thesis, so discussion has been restricted to the home-based rehabilitation staff's perception of the impact of these initiatives on their own work-load and that of care-givers. Some of

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[13] Unassigned GEM funds are funds that are targeted at geriatric evaluation and management activities but that can be used flexibly by the funded agencies, either to provide inpatient services or home-based care.

[14] Transitional Care funds are funds targeted at assisting clients with the transition to home after a hospital admission.

[15] Post acute care is a service that brokers HACC services on behalf of eligible clients on a short-term basis post-discharge from hospital.

[16] Hospital in the Home provides acute medical care in the home in order to reduce the length of inpatient stay in an acute setting.

[17] Rehabilitation in the home (RITH) is the focus of this study (see full definition in Chapter One).

[18] See footnote 12.

the home-based rehabilitation program coordinators were managing the funding for these new service initiatives, such as the unassigned GEM funds, in addition to their home rehabilitation budget. One program coordinator (3) had three different funding sources to manage, with three different target populations and three different through-put targets. Other programs (1, 2, 6, & 7) beds were funded through unassigned GEM and/or Transitional Care funding. These clients were not included in the client population sampled in this study. For the program coordinators, this had meant an increase in the volume and complexity of their work. Program staff, particularly the case managers, had also an increasingly complex role as these funds were directed at maintaining a more frail and disabled target group in the home, and the funds available for brokerage differed according to the funding source that was allocated to each client. In the opinion of program staff, this trend towards maintaining clients with more complex service needs in the community affected care-givers as well as program staff because this group of frail and disabled clients was more reliant upon the assistance of family care-givers than the preceding home rehabilitation clientele.

Program staff were also having difficulty keeping track of the different funding sources, policy, and program initiatives coming from the Victorian Government. This is an area in which there was consistency between the experiences of the care-givers and the staff interviewed for this study. Both expressed confusion about the extent of the aged care service system and the relationships between different aspects of the system. The need for clear and integrated information for staff, clients, and care-givers is also taken up as a recommendation of this study.

Another consequence of these initiatives (and the broader policy objectives of curtailing health spending, reducing hospital waiting lists, and removing so called "bed blockers" – elderly disabled patients awaiting residential care) was that when these clients were admitted to hospital they were more seriously ill and therefore it was more difficult to get them home again (2). Furthermore, there was a much greater unmet demand for HACC services (2, 3, 5, & 7) and medical crises were occurring much more frequently in the home (2).

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[19] Hospital Admission Risk Program

Program staff identified a clear causal chain between government initiatives for reducing or avoiding hospital admissions; the increased frailty of clients and care-givers who are trying to manage at home; and the increased pressure on both their services and community services. This thesis argues that there is also an increased workload for family care-givers who are trying to juggle the geater demand for care with their other work and family commitments without being acknowledged by or included in the health service system which has handed them this additional load.

7.4 SUMMARY OF PROGRAM FINDINGS

The key issues identified by staff in this chapter mirror the findings of the care-giver interviews, reported in the previous two chapters. Both staff and care-givers perceived that care-givers were taking on a high level of work and responsibility in home-based rehabilitation with little financial compensation and overall a low level of service use. Furthermore, both care-givers and staff perceived that there was a problem at the interface between the care-giver and the service system in both the provision of information and the inclusion of the care-giver in the decision-making about client care. This occured despite the high level of reliance upon the contributions of care-givers, which has been identified by both care-givers and staff.

For staff, several issues were raised in this chapter. Staff were somewhat concerned about the position of home-based rehabilitation within the broader service system. They experienced pressure to reduce hospital LOS and, at the same time, the increased throughput achieved through reduction in LOS increased their own workload. This workload pressure made it difficult for them to include and acknowledge the care-giver as part of the rehabilitation team even though many of them recognised the need for a more inclusive approach in their dealings with care-givers. Sims et al. (1997), in their study of staff perceptions of home-based rehabilitation, concluded that the community models of care are less regimented than the hospital models with which staff are more familiar, potentially giving rise to professional anxieties. In this study the location of care has also been found to represent a change in the way in which care is delivered. In the next chapter, the notion of the home-based context of care as a conceptual tool for understanding the experiences of both staff and care-givers working in this area will be introduced.

The next chapter also introduces the idea of the invisible contract to explain the phenomenon described in this study, where care-givers are contracted to provide a certain level of care without any formal specification of the terms or limits of the contract. Chapter Eight also outlines the study recommendations and outcomes.

Chapter Eight – Conclusion: A new context of care

Policy and theoretical implications.

8.0 INTRODUCTION

In this chapter the major conclusions drawn from this study are outlined and discussed. Through taking a different focus to the previous literature on home-based rehabilitation care-giving, this study has revealed some new insights into the place of care-givers in home-based rehabilitation. A qualitative approach to data collection has enabled the stories of care-givers to be told in more detail and depth than has been reported elsewhere. The focus on the interface between a public health service and the care-giving experience has meant that the locus for change has shifted from an individual to a program and policy level, but the recommendations for change remain grounded in the lived experiences of the individuals concerned. Furthermore, the structural feminist approach led to the interpretation of care-givers' experiences as a public issue rather than a private concern. This chapter will outline the advances in knowledge about care-giving that have been derived from this study, as well as the recommendations for change and the outcomes already achieved.

In sections one and two of this chapter, the theoretical and policy implications of this study are discussed. A new context of care that incorporates some of the features of both the household and organisational contexts of care is proposed. The ways in which the theoretical framework outlined in Chapter Three can be applied to both care-givers and staff in home-based rehabilitation are discussed, and the idea of an explicit rather than invisible contract between home-based rehabilitation care-givers and the state is presented. In section three the study recommendations are outlined, and finally this chapter returns to the study aim and discusses the extent to which it has been achieved.

8.1 The home-based substitute for hospital as a new context of care

In the feminist literature on care-giving reviewed in Chapter Three, two authors identified the contexts or settings in which care occurs as important theoretical constructs in understanding care-giving. Fisher and Tronto (1990) argued that there are three modes of care: the household/community, the marketplace, and the bureaucracy. Similarly, Abel and Nelson (1990) suggested that the three main contexts of care-giving are the household, formal organisations, and unaffiliated providers. These context or settings were described in Chapter Three. In examining the interface between these contexts, this study has identified a new context of care, that of the home-based substitute for hospital care, or the home-based health program.

The care-givers involved in home-based rehabilitation were not just operating in the household mode or setting. The clients for whom they were caring were technically inpatients of a hospital, and therefore located within the bureaucratic, or formal, organisational setting. The model of rehabilitation that was implemented in the home was developed in a hospital setting. Although there was some adaptation of this model to suit the home setting, many aspects were not altered.

In rehabilitation hospitals in Victoria, the patient is admitted to a bed. Once admitted the patient is seen and assessed by all the relevant rehabilitation disciplines, for example, the specialist in rehabilitation medicine, the rehabilitation nurse, the physiotherapist, the occupational therapist, and the social worker. At some point within the first week of admission a team meeting is held. At this meeting the staff discuss their assessments of the patient and their treatment plans, and estimate a discharge date for the patient. On the basis of this discussion, goals are set for the patient and a treatment regime is agreed upon. Patients receive a weekly program on which all their treatment activities and times are noted. For example, at 8 a.m. patients might attend a breakfast club, at which they are encouraged to get their own breakfast, at 9 a.m. a physiotherapy session or a trip to the hydrotherapy pool might be scheduled. In the afternoon patients might participate in speech therapy sessions or see their social workers. In short, the patient's hospital stay is largely controlled by decisions made by professional staff.

As discussed in Chapter Seven, and illustrated in Figure 12, the progress of the client through rehabilitation is very similar in the home setting to that described above. Assessment is undertaken by each of the rehabilitation disciplines, goals are set, a discharge date is estimated, and a program of activities is undertaken to meet these goals. However, when the rehabilitation process is transferred to home, a number of important changes take place in the balance of power. Power in this context refers to the extent to which the clients, care-givers, and staff are able to exercise control over decisions that affected them (Mulally, 1997). The setting in which home-based rehabilitation occurs has been shown to have an important impact on clients' motivation (Meeds & Pryor, 1990), and the extent to which they feel that they can participate in planning their own rehabilitation (von Koch et al., 1998; Widen Holmqvist et al., 2000; von Koch et al., 2000; Dow, 1999). At home, clients are more motivated to set and work towards their rehabilitation goals. Some of the care-givers in this study supported this contention through their observations of the client being more in control than they would have been in a hospital setting. Conversely, staff in home-based rehabilitation experience some loss of power (Dow, 2000). As clients in this study began to have more say over the content and direction of the therapy, staff were less able to set the rehabilitation goals and to determine the duration and content of the client's treatment plan. Some of the staff in this study talked about the need to develop new responses to clients and their families as they become more articulate and assertive and better informed about their own health care needs. It seems that when the health service is shifted into the client's home, the unquestioned authority of the health professional no longer holds sway. At home, clients feel empowered to negotiate with staff about their rehabilitation programs. At the same time, however, home-based rehabilitation is located within a hospital setting that continues to be dominated by the medical profession (Carpenter, 1993; Dow, 2000). In this study, this dominance was evidenced by the extent to which the medical practitioners still make critical decisions. For example, decisions about discharge from hospital and therefore the timing of admission into home-based rehabilitation in this study were made by hospital medical staff.

Several critical decisions need to be made as the client moves through the home-based rehabilitation program. These are:

- whether the client is admitted to the program (including decisions about discharge from hospital);
- what the client's case plan comprises (including their rehabilitation goals, the content of therapy, and the timing of discharge from the program);
- who will be responsible for the client's care; and
- what are the tasks and responsibilities of those designated to provide care.

In hospital, all these decisions are made by professional staff, with varying degrees of involvement from the client and care-giver depending on the extent of consumer focus of the rehabilitation team. At home, decisions about the entry into the program and the designation of persons responsible for the client's care are still made by the hospital or program staff. The decisions about the client's case plan, however, require more input from the client because at home the client will only do what they want to. As one staff member commented in the author's previous study, *"...they'll just ask for what they want and bugger the rest..."* (Dow, 1999, p. 102). Finally, decisions about the tasks and responsibilities of those designated to provide care are (or should be) negotiated between the client, the care-giver, and the rest of the rehabilitation team. However, as this study has shown, although the responsibility for the general well-being of the client has shifted from the hospital staff to the care-giver, this has been assumed rather than clearly negotiated between the hospital staff, client, and care-giver.

Thus, in home-based rehabilitation the care-giver is in a central position as far as the work and responsibility for care was concerned but in a peripheral position in decision-making power. This was recognized as a problem by both care-givers and staff in this study. Some of the staff interviewed for this study indicated that they would like to involve the care-giver more as an active participant in the decision-making process than they have been doing to date. The main impediments to this seemed to be time and workload constraints. As noted by Frans (1993), in relation to social work, there is a paradox between the perception of the profession as powerless and the endeavours of social workers to empower others. In this study there is a paradox between the desire of staff to empower care-givers and the limits of their own power to do so. As will be discussed in the next section, staff are under pressure to facilitate early discharge from hospital and to increase throughput in home-based rehabilitation. These pressures constrain their ability to treat care-givers as co-workers.

Abel and Nelson (1990) identified some of the advantages and disadvantages of the household as a context of care. In the traditional household setting, care-givers have control over care but are often isolated and unable to place limits on their work. They are expected to be on call 24 hours a day and there is no externally imposed limit to the number of tasks that they can be expected to perform. Furthermore their relationships with care recipients are often complicated by their kinship relationship. All these issues were identified by the care-givers in this study. Abel and Nelson argued that in the historical shift of care from the household into formal organisations, paid care-givers became more able to set limits, being confined by their professional roles and the limits of their working hours. However, within formal organisations the control over decisions about who will provide care, when the care will be provided, and the tasks and activities undertaken by the care-giver, has shifted from the people providing the care (usually women) to those at the top of the hierarchy (usually men) (Fisher & Tronto, 1990).

It is argued here that although the location of care is in the home, the context of care of home-based rehabilitation shares some of the features of the organisational context, described above. The imposition of organisational control over decisions, especially those made by medical practitioners at the top of the organisational hierarchy who had little involvement in hands-on care, is consistent with Fisher and Tronto's (1990) argument about the influence of the organisational context.

However, the benefits derived from the care-givers' relationship with the formal organisation in this study differed from those identified by Abel and Nelson (1990). Care-givers in this study benefited from the support and company provided by rehabilitation and community services staff, especially where they saw that the staff had expertise in facilitating the client's functional recovery. They also benefited from not having to visit the client in hospital as this was logistically difficult and in some cases traumatic for the care-giver. However, as they were not employees of the formal organisation, they did not experience the benefits identified by Abel and Nelson (1990). They were not able to set limits to the amount or type of care that they would provide. As discussed earlier, many were providing around the clock care, and the tasks undertaken by care-givers were not constrained by the boundaries of professional disciplines or position descriptions. At one time they could be acting as a medical practitioner, monitoring the effects of the client's medication or looking out for signs of a further stroke, and at another time, they could be acting as a domestic, cleaning the client's bedroom or emptying a urinal.

Walby (1990) argued that as women move from the private realm of the household into the public realm of work, the strategies of patriarchal oppression (described in Chapter Three) shift from exclusion to segregation and subordination. In considering the position of the small numbers of home-based care-givers who participated in this study, it seems that all three strategies are relevant. Being presumed to provide care resulted in exclusion from full participation in the workforce and this presumption seemed to be gendered as male care-givers were not generally presumed to provide care until after their workplace participation had ceased. Therefore, for the men who participated in this study, care-giving did not generally result in exclusion from the workforce.

At the same time it can be argued that care-givers were subject to segregation and subordination within the rehabilitation program. Although they contributed as much or more than anyone else on the rehabilitation team, they were seen as different from and subordinate to the paid staff. This was evidenced by the lack of recognition of their contribution and their exclusion from decision-making about the client's case plan, discharge planning, and program planning and evaluation. Although both male and female care-givers experienced frustration at their lack of power over decision-making, the staff interviewed for this study said that male care-givers were more likely to be noticed and appreciated by program staff than female care-givers. Furthermore, for all care-givers, unlike anyone else on the rehabilitation team, there was concern about their emotional health, and the extent to which they were coping or not coping. This was probably due to the predominance of the stress-coping paradigm in care-giving research and practice interventions. However, although this approach provided care-givers with emotional support, it set them apart from the rest of the team and made them seem more vulnerable or weak than the other team members. Thus the context of care, being at the interface between the household and the workplace, brought into play both the public and private strategies of patriarchal oppression for the home-based rehabilitation care-givers.

Based on the experiences of the care-givers and staff interviewed in this study, it would seem that the home-based health program represents a different context of care from those identified in the previous literature. The home-based program context had some advantages for care-givers, described above, but it also had all of the disadvantages identified by Abel and Nelson (1990) and Fisher and Tronto (1990) of both the household and the bureaucratic or organisational modes of care provision. Furthermore, being at the interface between both private and public modes of patriarchy, all three strategies of oppression identified by Walby (1990) were present. Thus, the context of care impacted upon the care-givers' experiences, but in a different way from that identified by the previous literature.

8.2 The shifting modes of patriarchy

In Chapter Three it was argued that three of the modes of patriarchy identified by Walby (1990) could be used to understand the position of care-givers in home-based rehabilitation. On reflection, these modes can be shown to be affecting the staff in home-based rehabilitation as well. The three modes are not fixed or independent but are inter-related and constantly shifting. In this section, the ways in which these shifting modes of patriarchy affected the care-givers and staff who participated in this study are outlined. This represents an extension and adaptation of the work of Walby (1990), described in Chapter Three.

8.2.1 The state – policy

As discussed in Chapter One, until recently there has been very little policy focus on home-based rehabilitation. Home-based rehabilitation programs are funded and governed by the Victorian government department that administers public hospitals (DHS, 2001). There is, however, an explicit and high profile Victorian government policy to reduce the waiting time for surgery (Australian Labor Party, 2002). Many of the home-based alternatives to hospital care that have been developed over the past ten years have had the explicit aim of increasing hospital throughput or preventing hospital admissions in order to reduce the waiting lists for surgery (for example, Hospital in the Home, Gunnel et al., 2000). Although home-based rehabilitation has not been explicitly linked with the government's aim to reduce surgical waiting lists, home-based rehabilitation does result in a reduction in hospital LOS (Anderson et al., 2002) and an increase in hospital throughput (Beech et al., 1999). Furthermore, according to the program staff interviewed for this study, all of the programs that were included in this study were established with the explicit intention of reducing hospital stays for rehabilitation and many were funded by the closure of hospital beds.

In recent years the average length of stay (ALOS) in hospital for conditions usually requiring rehabilitation, such as cerebrovascular disease and fractured neck of femur (NOF) has reduced significantly. In 1993-94, the ALOS for fractured NOF was 16.7 days. This had reduced to 12.0 days in 1997-98. The ALOS for cerebrovascular disease was 14.7 in 1993-94 and 10.2 in 1997-98 (AIHW, 2001). In areas where home-based rehabilitation is available, these patients now often go directly home from the acute hospital or have a much shorter LOS in a rehabilitation ward.

8.2.2 The state - ideology

In conjunction with this shift from hospital to home-based care, there has been an ideological shift in the way that health and welfare services in Australia are regarded and supported by the state. In Chapter Three, the current trend from hospital to home-based care was likened to the deinstitutionalisation policies of the 1970s and 1980s. Care in the home and community was then (Finch, 1990) and is now (Creelman, 2002) seen as a more humanitarian option for care recipients. It is also economically attractive for governments in the context of an ageing population and increasing health care costs. There has also been a re-emergence of conservative political and social ideologies that support the transfer of the responsibility and cost of welfare from the state to individuals (Macintyre, 1999; Taphouse, 2001). However, there are also some important differences between the welfare state of the 1980s and the current service provision environment.

In the 1980s there was still some acceptance of a rights-based welfare state in which *"government-protected minimum standards of income, health, housing and education (were) assured to every citizen as a political right, not a charity"* (Wilensky, 1975, in Mcintyre, 1999, p. 113). In the 2000s, the emphasis has shifted from entitlement to obligation (Mcintyre, 1999). The concept of welfare rights has been replaced by notions of personal responsibility, social contracts, and mutual obligation (Mcintyre, 1999; Mitchell, 2001). Creelman (2002) argued that in Australia there has been a shift from the social justice ideology of the Hawke and Keating Labor Governments of the late 1980s and early 1990s to the family ideology of the Howard Government. It is argued here that in relation to home care, the social justice ideology of the previous Labor governments was limited to the care recipients. Care-givers were seen as a resource through which older people would be given the choice to remain at home, rather than be institutionalised in residential care. The concurrent reduction in residential care options restricted the choices of family care-givers upon whom the responsibility for care fell.

The current Liberal coalition government also relies on care-givers for the implementation of public health policy but its policies are couched in different ideological terms. The family is seen as the preferred provider of care as it is the *"core social unit in our society... [and the] ...most effective provider of assistance and support for people of all ages... "*(Moylan, 1996, in Creelman, 2002, p. 277). Both the social justice and family ideological positions were (and still are) bounded by the broader economic ideology of economic rationalism. This means that health and welfare services are increasingly being privatized and that private sector management practices have been adopted in the public sector (Grant, 1998). The health care industry, like any other industry, must be competitive, efficient, and cost-effective. Care in the home and family is therefore seen as both ideologically preferable and economically rational from the perspective of the state.

As a result of the convergence of the impacts of these ideological positions, there has been little debate about the desirability of care in the home. As Shaver and Fine (1996) noted *"private households have now become the preferred site for the exercise of public responsibility... "* (p. 19). If care can be provided within the family, then it becomes a private concern rather than a public issue. Families are seen as responsible for their own. This study has challenged this view. It has taken an approach that depicts care-giving as a public issue rather than a private concern. The next sections demonstrate how the actions of the state have impacted upon care-givers and staff in home-based rehabilitation.

8.2.3 The example of service brokerage

One example of how the ideological and policy trends, described in the previous section, affect both care-givers and staff in rehabilitation in the home is the use of brokerage. Service brokerage is an extension of the practice of competitive tendering, but on a smaller scale. Rather than directly employ the staff required, programs are funded to purchase services from service providers who operate in a competitive market place. For example, those programs in this study that did not employ a nurse could pay for a nurse from a private nursing agency to visit the home rehabilitation client. The nursing agency would then be paid at the rate of full cost recovery; that is, the full cost of supplying the nursing service, including the nurse's wage and transport and administration costs.

This practice has economic and administrative benefits for the home-rehabilitation program. The program does not have to directly employ a nurse or bear all the associated costs, and needs only to pay for the nursing service that is required. However, there are several problems with this practice that were identified by the study participants. From the point of view of program staff, it was not always possible to access the community services they needed, despite being able to pay full cost recovery. The staff member interviewed from Program Two said this issue had been discussed with service providers who had reported that because of the plethora of services with the capacity to broker their services, it was impossible for them to predict demand. They too did not wish to employ any more staff than they required, but it was difficult for them to find trained staff who were available for casual work, who were available in times of high demand, and who were able not to work when demand was low.

From the point of view of care-givers, service brokerage was one of the reasons that they became confused about who was coming into their home. Apart from the rehabilitation program staff, staff from a several different agencies could be visiting to provide services that had been brokered in by the home rehabilitation service. Again these policies of the state impact more upon women than men. In this case, the mainly female employees of the brokered services are under pressure to accept part-time and casual work. The mainly female program managers have to juggle the needs of clients with the limits of their budgets and the complex market-driven service system that has resulted from the shifting ideology of the state. And the mainly female care-givers shoulder the burden when brokered services cannot be obtained.

Another consequence of the ideology and resultant policies currently promoted by the state, of individual responsibility, mutual obligation, and so-called family and community care, is that the contribution of care-givers is rendered invisible. Care-givers believe that they are doing the right thing, the natural thing, and that there is no alternative. Assumptions are embedded in the implementation of home-based rehabilitation that care-givers will provide the care that the state can no longer provide and that this care is the responsibility of the family and in the best interests of the client. Prior to this study, these assumptions had not been previously questioned by either the care-givers or the program staff who participated in this study.

8.2.4 The household, the gendered division of labour and employment

The actions of the state alone, however, do not explain why in the early 21st Century, it is still women and not men who are taking on the bulk of family care-giving responsibilities. Given the increasing workforce participation of women, one might expect a complementary increase in the home-care responsibilities of men, thereby relieving women of some of their care-giving responsibilities. However, empirical evidence suggests that this is not the case. Although a majority of Australians express an ideological preference for sharing the breadwinning role (Hakim, 1997), in most Australian dual parent families once children are born, men take primary responsibility for being the breadwinner (Glezer & Wolcott, 2000). With the birth of their first child, women's workforce participation is disrupted and they usually move out of the workforce or into part-time and casual employment. Gray (2000) found that although there was some reduction in women's responsibility for housework and child-care according to the hours they worked, they (rather than their spouses) continued to take responsibility for these tasks. Furthermore, Gray (2000) found that couples who have not yet had children are more likely to be sharing housework equally than those who have children under five years of age. She noted that *"as women's responsibility [for childrearing] increased, the level of sharing decreased"* (p. 94). Thus although women are now taking some responsibility for income provision within the family, men are not reciprocating by taking on responsibility for housework or care-giving. Although the ideology of the family has shifted to incorporate the ideal of the dual income family, women are still expected to take responsibility for care-giving within the family in addition to their workforce participation responsibilities. There were several examples among the care-givers interviewed for this study in which a female family member was designated as the home-based rehabilitation care-giver even though there was a closer male blood relative who had equal or fewer demands on his time. May's story outlined in section 6.3.2 illustrates this point.

This study also found that not only was there a gendered division of labour within the families involved in this study, resulting in women being designated and assuming the care-giving roles, but there was also a gendered division of labour among care-givers. Although not statistically significant, there was a difference between the number of men and women engaged in outside jobs, with 65% of male care-givers and 29% of female care-givers taking on these activities. There was, however, a statistically significant difference between the number of female and male care-givers engaged in housework with more female than male care-givers taking on these tasks. A similar division of labour has been identified in previous Australian research into the division of labour within the household (Gray, 2000; Glezer & Wolcott, 2000). Furthermore, as discussed in Chapter Six, this study supports the argument made by Gibsen and Allen (1993) that there is a gender inequity perpetuated by the state in the provision of community services to care-givers. The services required by older women were less readily available than the services required by older men. Interviews with the staff also supported the argument, also made by Gibsen and Allen (1993), that older male care-givers are more likely to be seen as requiring home care type services than older women, as they are seen to be less proficient at housework and cooking than women. The staff acknowledged that they assumed that women had the skills to do the 'hotel type' care-giving tasks, but the same assumption was not made of men.

Polatnick (1973-4) argued that there is a circular relationship between women's status in the workforce and their power within the household. She contended that women's inequality in the workforce results in a reduction of power in the household that in turn leads to inequality in the workforce. Women's relegation to care-giving roles within the family is a good example of this. As men earn more than women, it often makes economic sense for them to continue to work full-time while their female partners juggle part-time or casual employment with care-giving and home-care responsibilities. In turn, having to work part-time further disadvantages women within the work-force. Very few senior positions are part-time and casual employment is tenuous and poorly recompensed.

Thus, a complex inter-relationship between direct state interventions, ideological forces, and economic and employment factors contribute to the continuation of the gendered division of labour within the household, which, in turn, means that women more than men are delegated the roles of care-giver within the family. The example of state funded carer payments will be discussed below to illustrate the ways in which the forces of the state, the workforce, and the ideology of the family intersect around the issue of care-giving.

8.2.5 The example of carer payments

There are two principal cash payments that are paid to care-workers by the state, the Carer Payment and the Carer Allowance. These have been described in Chapter One. As Rosenman and Le Broque (1996) pointed out, these payments are neither clearly income support payments, nor payments designed to recompense care-worker for the cost of their time, out of pocket expenses, or lost opportunities. As argued in the commentary on the National Agenda for Carers (Aged and Community Care Division and Office of Disability, Department of Human Services and Health, 1996) there is a need to clarify the purpose of these payments and then to determine the level at which they should be set.

However, in the six years since the proceedings of the National Agenda for Carers Workshop were published, there has been little progress towards clarifying the purpose of, and setting an adequate rate for, cash payments to care-givers. One advance that has been made is that both payments are now administered by the same government agency, Centrelink, so that care-givers are more likely to discover both payments at once. However, work on clarifying the purpose of these benefits has not progressed.

One of the problems identified by the few care-givers in this study who received the Carer Payment was the impact that earnings from employment or superannuation had on their eligibility. The Carer Payment is means-tested as well as subject to a test of the amount of care provided by the care-giver. Any income earned has to be declared within the fortnight that it is earned and the payment is adjusted accordingly. The problem with this for care-givers who are also working part-time in paid employment is that every time they work a shift, their Carer Payment has to be adjusted. Given that the Carer Payment is not adequate to live on, especially in the long-term, most care-givers need to work to earn extra income, as well as to maintain their employment prospects, skills, and the social and emotional benefits of work.

If the carer payments represented an adequate income for care-givers, and were available as soon as the episode of care commenced, then care-giving could be seen as an alternative to paid employment, at least in economic terms. As it is, however, the level of payment does not enable care-givers to completely separate themselves from the paid workforce. Care-givers need to work, but due to their care-giving responsibilities they are only available for part-time and casual work. Care-givers are therefore economically caught between the interests of the state and those of employers. If they were paid at an adequate rate, it would cost the state more. Also these care-givers (estimated to be 15% of the adult population) could not serve as a pool of part-time and casual employees for prospective employers. As ideological and economic forces still lead to the delegation of care-giving to women rather than men, this is more of a problem for women than men. As the case studies outlined in Chapter Five and Six illustrated, the economic and social impacts of disrupted employment can be both profound and long-lasting.

The next section briefly reiterates the impacts (described in more detail in Chapter Five) that the combined forces of patriarchy had on care-givers in this study and examines some of the implications for the staff participants in this study.

8.2.7 The impact of the forces of patriarchy on care-givers and staff

It has been argued that there are three ways in which the current trends in health care impact more upon women than men (Bryson, 1995; Grant, 1998). First, women are the principal users of health care services; second they are the main employees of health services; and third they are the care-givers upon whom the burden of care falls. This study has focussed upon the third aspect of this impact but it has done so from the perspectives of both the care-givers themselves and the paid staff with whom they interact. The case studies that were derived from the interviews with care-givers in this study have shown that the impacts of current trends in health care on family care-givers go way beyond those described in previous research in this area. Furthermore this study has illuminated some important new issues for staff working in this area.

As discussed in Chapter Five, care-giving can affect the care-giver's whole life, their health, their emotional state, their relationships with others, their work-force participation, and their leisure time. These impacts can also have lasting social and economic consequences for the care-giver. These long-lasting consequences were sometimes due to the length of the care-giving episode that in this study was generally much longer than the rehabilitation condition would suggest, and sometimes due to the ongoing effects of the short-term care-giving episode. For example, in Paula's story outlined in Chapter Five, Section 5.4.9, there were long-term economic and social consequences as a result of having to move house and take extended leave from her work, even though the episode of care was of short duration.

The staff interviewed for this study were also placed in a difficult position by the combined forces of the state, their employers, and ideological or cultural forces. As public employees they were required to implement government policies. As program managers they had targets to meet and budgets to manage as well as the needs of clients, care-givers, and staff to consider. They were working at the interface between the hospital and the home. For staff this interface not only represented a shift in the location of care, but also a shift in who held decision-making power. For professional staff the new context of care, discussed in Section One of this chapter, meant losing some of their power (to make decisions about the client) as the care shifted into the household mode and clients become more involved in their own care. However, staff were still constrained by the rules and practices of the formal organization in which they were employed. For example, as noted earlier, decisions about discharge from hospital and therefore the timing of admission into the home-based rehabilitation program were still made by hospital medical staff despite the fact that medical staff were rarely directly involved in working in the client's home.

Furthermore, home-based rehabilitation is just one of a number of government initiatives aimed at reducing hospital length of stay and increasing throughput in order to reduce the waiting time for surgery. The Victorian Government Public Hospitals and Mental Health Services Policy and Funding Guidelines 2002-2003 identified several initiatives as part of their elective surgery access strategy. The initiatives included Post-Acute Care (PAC), the Hospital Admission Risk Program (HARP), Hospital in the Home (HITH), and the Effective Discharge Strategy. All these initiatives rely on service brokerage, discussed above, to provide the care required by their clients, resulting in competition for access to community support services. The initiatives vary in their eligibility criteria, funding guidelines, and target groups. The program managers responsible for home-based rehabilitation had to work within this complex service delivery system. In several cases they were responsible for the management of one or more of these services in addition to the home-based rehabilitation program. Apart from the administrative difficulties that working in this system represents, the program managers and home-based staff had to manage the human side of these policy and program initiatives. For example, they have had to find ways to manage the increase in occurrence of emergency circumstances in the home due to the increased number of frail and vulnerable clients who are being managed at home.

As discussed above, women are participating in the workforce in ever increasing numbers. However, they are still employed in subordinate positions, are paid less and are more likely to be employed on a casual or part time basis than men. Furthermore, women in the paid workforce are more likely to be engaged in hands-on tasks and men are more likely to be engaged in decision making and planning. The health service sector in which the staff interviewed in this study worked is a good example of this. This sector operates with a clear hierarchy dominated by male medical practitioners and male bureaucrats (Carpenter, 1993). Some parallels can be drawn between the position of the staff responsible for the implementation of home-based rehabilitation and the position of care-givers. Just as the care-givers are responsible for the 'hands-on' care, the staff are responsible for the 'hands-on' implementation of government policy. They have to manage the human side of the budget, service targets, and changing practices. Furthermore, just as the care-givers have limited decision-making power over aspects of client case planning that directly affect them, the staff too have limited decision-making power over the allocation of budgets and program targets that directly affect the programs in which they work. With the emergence of new government initiatives to increase throughput and reduce the waiting time for surgery, discussed above, budgets, throughput targets, and the services available for clients are constantly changing. Just as care-givers are forced to adapt to the changing circumstances of the care recipient, so are staff forced to adapt to changes within the service structure over which they have little control.

8.3 Summary of theoretical implications of this study

In summary, the theoretical framework outlined in Chapter Three of this study was found to be applicable to the experiences of care-givers and staff in home-based rehabilitation in Victoria. The patriarchal structures identified by Walby (1990) can be seen as influencing the position of care-givers and staff in home-based rehabilitation. Furthermore this study has identified a new context of care, that of the home-based health program, that differs from those identified by Abel and Nelson (1990) and Fisher and Tronto (1990). This new context of care is an important theoretical construct in understanding the experiences of care-givers and staff in home-based rehabilitation. It would be useful to test the applicability of this theoretical construct in future research into other home-based programs, such as Hospital in the Home.

However, there are also some shortcomings in the theoretical framework described in this study. Firstly it does not adequately explain the position and experiences of male care-givers other than those who are retired spouse care-givers. Although there were a considerable number of male care-givers (41), half of these were 65 years of age or older, suggesting that they were less likely to have been engaged in the workforce at the same time. Another eight were over 50, so only 11 of the male care-givers (29%)

were under 50 years of age, compared with 24 (42%) of the 58 female care-givers for whom age was known. It is acknowledged that the feminist explanation of care-giving outlined above does not account for the presence of the younger male care-givers unless they have taken on the role due to the absence of any available female family member.

The second shortcoming in this theoretical framework is that the care-givers in this study reported that they did not generally mind providing the care. Although there were some exceptions to this, the majority of the care-givers interviewed did not see care provision as a major concern. Although providing care had a major impact on their lives, they did not protest against providing the care that was needed. It may be that this can be explained by cultural or ideological patriarchy, but it may also be that given a range of alternatives, care-givers would still choose to provide care. The study by Glezer and Wolcott (2000), cited above, also found that despite the negative impact of parenting on women's work force participation, both men and women were satisfied with the current situation with men as the primary breadwinners and women combining part-time work with family caring responsibilities. It could be argued that the care-givers in this study had chosen their roles out of personal preference and that even if there were many other options available for care provision, care-givers would make the same decision. However, given the structural impediments to women's equal participation in the workforce, the ideological preference for the gendered division of labour, and the patriarchal influence of the state, discussed above, it is not possible to separate out the influence of individual agency, personal autonomy, and choice, from the influence of patriarchy in this area.

8.4 POLICY OPTIONS FOR CARE PROVISION: MAKING THE INVISIBLE CONTRACT VISIBLE

Shaver and Fine (1996) identified three ways of approaching care. This study exemplifies the first approach, which argues that family care-givers are taking on a community responsibility and that they should be compensated by the community for taking on that responsibility. The second approach, which this study contends is the current approach of both major political parties in Australia today, argues that care is primarily a family responsibility and that government involvement in care should be limited. The third approach, which is Shaver and Fine's preferred approach, argues for shared responsibility for care; a partnership between the state, community, and family. They do stress, however, that alternatives to informal care should not be neglected, as informal or family care is not always the preferred choice for either families or care recipients.

What then should the state's policy position be in relation to care-givers involved in early discharge programs such as home-based rehabilitation? While the capacity of the hospital system has remained constant over the past five years, there has been a significant increase in throughput (Swerrissen & Duckett, 2002), effectively reducing the availability of hospital care. This reduction in hospital care has to some extent been compensated for by home-based service provision. There is, however, a gap in service provision that is currently being met by unpaid care-givers at considerable economic, social, and health related cost to themselves.

As discussed above, there has been an ideological shift in the way that health and welfare services are regarded and administered by the state. However, there is a lack of consistency in this ideology. If the principles of the market were to be comprehensively applied, then care-givers as private providers of care would be contracted by the state to provide care. However, this approach is being selectively applied. Care-giving in the home is seen as a private, family concern at the same time it is relied upon for the effective implementation of public health programs. Mitchell (2001) argued that the current policy and funding environment relating to the provision of social services does not recognize the economic and social contribution made by carers. With the move to contracting out of services (from the state to the non-government sector), and the emphasis on individual responsibility and mutual obligation, carers have effectively been left off the agenda. This is despite the fact that they are already heavily involved in an implied contract that is based on personal responsibility and obligation. Mitchell (2001) raised questions about the nature of the care-giver – care-recipient contract and the state's and community's investments in that contract. She pointed out that the financial support currently available from the government does not meet the full cost of care but is rather a form of subsidy.

Therefore, the carer has only a limited obligation in relation to the state, but the state has a significant obligation in relation to the carer.

The care-givers who participated in this study were already contracted by the state to provide care. They felt that they were obliged to take on the care required by the care recipient. They had taken considerable responsibility for the well-being of the care recipient, and they had been allocated tasks according to their ability, the needs of the care recipient, and the availability of alternative contracted care providers to the home-based rehabilitation program. However, these contractual obligations were not made explicit; they were presumed. This study will recommend that care-givers be given an explicit contract by the home-based rehabilitation program. The introduction of a contract would mean that the rights and responsibilities of care-givers would be clearly outlined and the reciprocal obligations of the program would also be clearly stated.

The next section of this chapter will further outline the idea of an explicit contract together with the other study recommendations.

8.5 STUDY RECOMMENDATIONS

Most of the recommendations outlined in this section were drawn from the study findings by the author. Some additional recommendations were made by the study participants themselves when the study findings were reported back to them. These recommendations have been included in section 8.5.3 below. There recommendations address four main areas: the dissemination of study findings; changes to program practices; changes in government policy; and further research into care-giving. As considerable progress has already been made towards implementing these recommendations, the study outcomes have been discussed below each recommendation. The final section of this chapter discusses the extent to which the aims of the study have been achieved.

8.5.1 Recommendations on the dissemination of study findings.

In order to draw public attention to the position and experiences of care-givers in home-based rehabilitation, it is recommended that the study findings be disseminated to the study participants, to a broader academic audience, and to the relevant government authorities.

Recommendation 1: That the findings of the study be reported back to the study participants.

It is recommended that the study findings be reported back to both the care-giver and staff participants of this study. The purpose of reporting back to the care-giver participants is to enable them to hear about other care-givers who are in a similar situation to themselves; to check whether they agree with the ways in which the information they have contributed has been analysed; and to determine whether they agree with and/or wish to add to the study recommendations. Reporting back to the staff would give them the opportunity to hear about how other programs interact with care-givers; to hear and discuss the study findings; and to enable them to promote the implementation of the recommendations about changes to program practices.

8.5.1.1 Outcomes already achieved in the dissemination of findings to study participants

The entire study findings have already been reported back to the care-giver participants and the staff in the program from which the care-giver participants were drawn. The findings from the care-giver interviews and the individual program findings have also been reported back to all staff participants. As discussed in Chapter Six, the care-givers generally agreed with the author's interpretation of the study findings and with the recommendations made. They requested that some recommendations be added, see 8.5.3, below. Only one care-giver requested that he be put in touch with the other study participants and he was informed by telephone that he was the only one who had requested this. Some of the care-givers commented about their experience of participating in the study. For example, one care-giver wrote, *"Thank-you for listening to us and more important (sic) for actually* <u>*HEARING*</u>

what we said." Another wrote, *"It's good to know that I wasn't the only one that had problems and concerns."*

The recommendations about specific changes to home-based rehabilitation program practices were discussed with the staff from the program that the care-givers were drawn from at a meeting in July, 2002. They generally agreed that the ideas were good but that it would be difficult to put some of them into practice, due to the short length of stay in home-based rehabilitation and their workload constraints. However, they seemed keen to make some changes in line with the wishes of care-givers and they have since implemented an individualised service map (see Figure 13 below). They have also improved their communication with care-givers about discharge decisions, both into and out of the program, by ensuring that someone is allocated to discuss the outcomes of each case conference with the care-giver and client.

Your home-based rehabilitation program

All these services will be organized and paid for by the home rehabilitation service whilst (*client's name*) is on the program.

The attached program will tell you when these people will be coming to visit you at home

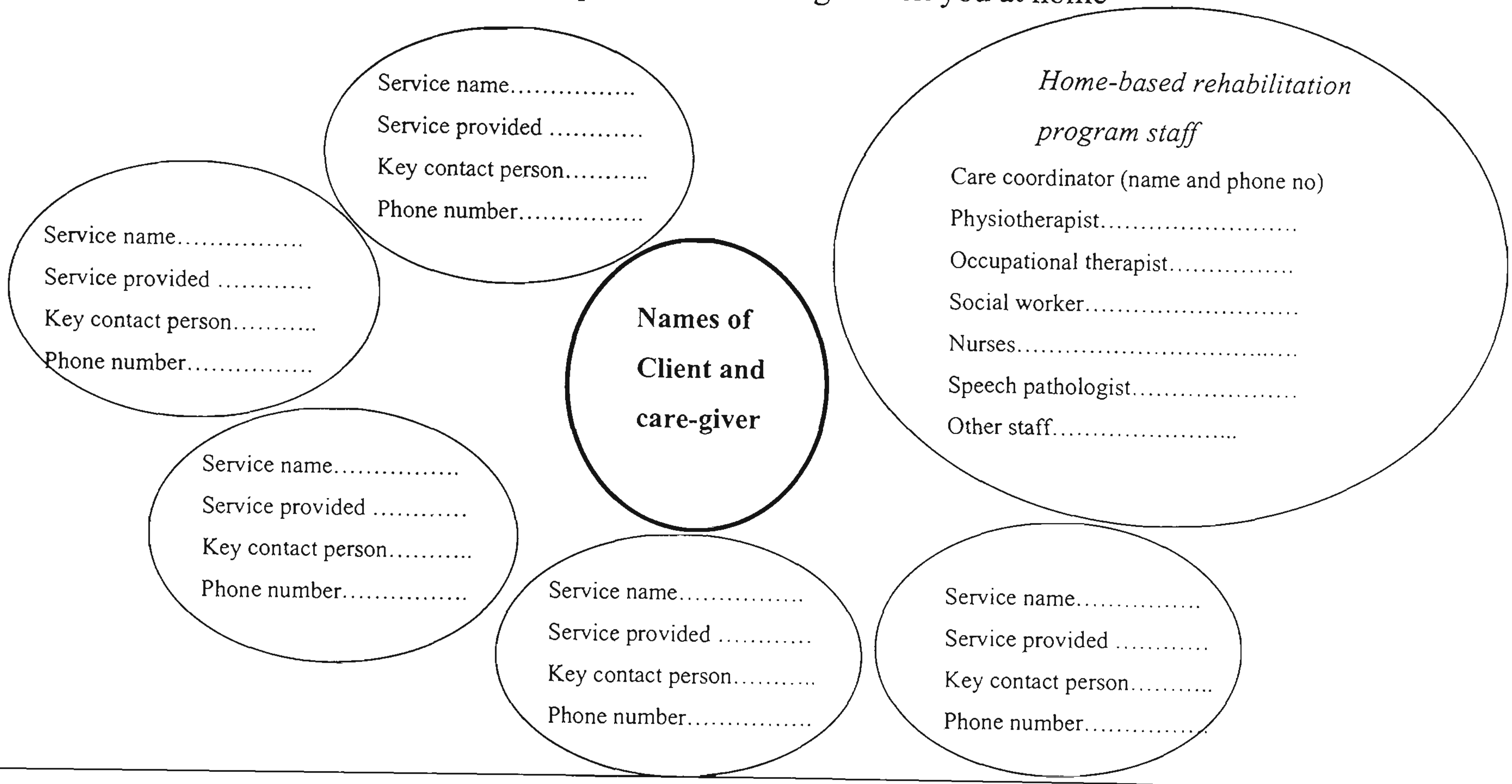

Figure 13 **Service Map**

Recommendation 2: That the findings of the study be reported in academic journals.

Recommendation 3: That the findings of the study be reported at conferences and other gatherings of health professionals.

The purpose of the above two recommendations is to promote public awareness of the contribution made by and the costs to care-givers in implementing the state's policy of early discharge for rehabilitation. It is also hoped that other researchers in this area will adopt the structural rather than individual approach to care-giving issues promoted in these papers.

8.5.1.2 Outcomes of recommendations 2 and 3.

This study has so far been reported on at three conferences and five gatherings of health professionals, and has been the subject of two papers submitted for publication in academic journals. The initial literature review and the problem identification were presented at the University of Ballarat's research conference in 2000. The preliminary findings of the care-giver interviews, reported as case studies, were presented at the "Gender, Work and Organisation Conference" at Keele University, UK in July, 2001. Some other stories derived from the care-giver interviews, together with their policy implications, were submitted for publication by the Australian Journal of Social Issues (AJSI) in August, 2001. A paper on the theoretical analysis of the literature, co-authored with the student's principal supervisor, Associate Professor John McDonald, is to be published by Australian Social Work later in 2003. A paper on the findings and implications of the care-giver interviews was presented at the National Rural Health Conference in Hobart, Australia, in March 2003, and published in the Infront Outback Stream. The findings of this study have also been reported to a gathering of Aged Care Assessment staff in Ballarat, at one psychology and one social sciences symposium at the University of Ballarat, and at the Interest Group on Ageing of the Australian Psychological Society on November 13th 2002.

Recommendation 4: That the findings of the study be reported to the relevant government authorities.

The findings of this study were communicated to the relevant government departments in several ways. Most of them have been discussed under Policy Recommendations, below.

8.5.1.3 Outcomes of Recommendation 4.

Representatives from the Department of Human Services Victoria were present when the findings of the care-giver interviews were presented at the state-wide forum of home-based rehabilitation programs. The staff responsible for the development of home-based rehabilitation in Victoria will also be sent a copy of the final report on the study findings that will be forwarded to the participating programs.

8.5.2 Recommendations on changes to home-based rehabilitation programs

Recommendation 5: That care-givers be recognised and included as part of the home-based rehabilitation team.

Recommendation 6: That care-givers be consulted about decisions relating to client care that directly or indirectly affect care-givers.

Recommendation 7: That care-givers be informed about who will be visiting the client, where they are from, and when they are expected.

Recommendation 8: That further research be conducted into home-based rehabilitation service delivery models with the aim of achieving equity in service delivery across program types and across geographical areas.

The above recommendations were derived from the interviews with care-givers and program staff. As mentioned above, these recommendations have already been passed on to the program from which care-giver interviewees were drawn. These recommendations have been communicated to all the staff participants in the final report on the study that was circulated in February, 2003 and discussed in a verbal presentation also in February, 2003.

The other way in which the researcher will have the opportunity to put these recommendations into practice is as the principal researcher in a longitudinal study of home-based rehabilitation that she commenced in February, 2003. This will be the first project that she will be responsible for in her new position as a Research Fellow at the National Ageing Research Institute (NARI). This new study will aim to evaluate current practice and develop best practice guidelines for implementation in home-based rehabilitation across Victoria.

8.5.3 Recommendations derived from the care-giver feedback

These recommendations were added to those proposed by the author by the care-giver participants when they were given the opportunity to provide feedback on the study findings and recommendations. One care-giver made several recommendations about the training and skills required by nurses and home-care agency staff who were brokered in by the RITH program.

Recommendation 9: That the agency carers and home nurses who are brokered in to assist home-based rehabilitation care-givers and clients receive adequate training in client care.

Recommendation 10:That these paid carers be given adequate information about the needs of the client prior to the commencement of care and adequate information about other services that are involved in the client's care or that may be required by the client.

Another care-giver recommended that the researcher, *"let the public rehabilitation organization know that the 24 hours care (sic) is harder than just their five hour shift work."* This recommendation has already been acted on under recommendation 1, above.

The final recommendation made by a care-giver was to assist care-givers to make the transition back into the *"real world"* after the death of the care recipient. She specifically requested a follow-up visit from a social worker three to six months after the death. This idea has been included in recommendation 11, below.

Recommendation 11:That the RITH program implement long-term follow-up for care-givers especially in cases when the care recipient has died.

8.5.3.1 Outcomes of care-giver recommendations

Apart from the recommendation relating to the dissemination of the study findings, most of the care-giver recommendations concern practices within the RITH programs. These recommendations will be made known to the RITH program staff who participated in this study, and will also be taken into account by the author in the development of best practice standards for RITH programs.

8.5.4 Recommendations on changes to government policy[20]

There are two ways in which government policy could be altered to address the social justice issues identified in this study. The first would be to offer more hospital-based and community care options so that care-givers would have more of a choice about the care they provided. However, previous research has shown that there are benefits to patients in having their rehabilitation at home (Widén Holmqvist et al., 1995; von Koch et al., 2000) and this study has shown that most care-givers want the care recipient to be at home. The second approach would be to recognize and make explicit the impact that government policies have on informal care-givers and work to minimise these impacts in the development of government policy. This study represents a first step in making public the impact of the government policy of early discharge for home-based rehabilitation on family care-givers. It should also be possible for the author to use the findings of this study to influence the development of future government policy in this area. However, a third task needs to be achieved, as discussed under 8.4 above; that of making the invisible contract visible. Recommendation 12, below has been developed to achieve this. If this

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[20] During the time that this study was being conducted, Carers Australia, a national body representing carers in Australia, published a National Carers Policy Framework (Carers Australia, 2003). This framework identifies some key principles that are reinforced by this study. These include - that carers are "recognised for their important contribution to the wellbeing of the Australian community" and that carers are "included in decision-making that relates to their care situation".

recommendation were to be implemented by program staff, it could be used to further influence government policy in this area. As outlined below, it could be used in future research, as a tool in gaining access for carer payments, and it would certainly render the contributions made by home-based rehabilitation care-givers more visible.

Recommendation 12: That staff in home-based rehabilitation programs provide care-givers with a written contract (including the information outlined below) so that care-givers are able to make informed consent about their involvement in home-based rehabilitation.

This explicit contract should include the following information:

- the tasks that the care-giver has agreed to perform;
- the time that these tasks will take;
- the duration for which it is expected that the care-giver will have to continue with these tasks;
- information about the client's care plan, especially any aspects of it that rely on input from the care-giver;
- information about any decision-making forums relating to client care so that the care-giver and/or the client can attend, and have input into, these meetings;
- a description of the extent, timing, and frequency of any community support services that the program has agreed to put in place;
- information about any income security measures and other compensation to which the care-giver is entitled;
- information about the support that will be provided to the care-giver; and
- information about grievance procedures.

This contract would serve a number of purposes. It would make explicit the expectations of the staff and care-givers in home-based rehabilitation and give care-givers written information about the type and frequency of community support services that would come into the client's home. It could also serve as a data collection tool for documenting the expected contribution of care-givers in home-based rehabilitation. This tool could potentially be used in future research to calculate the costs of care provided to home-based rehabilitation clients. The contract could also be used by the care-givers in applying for carer payments provided by Centrelink. Currently, payments can only be made if the episode of care is expected to last for six months or longer. If this criterion could be altered, this contract could be used to apply for the Carer Payment. The study recommendations about carer payments are outlined below.

8.5.4.1 Outcomes in the implementation of a visible contract.

This recommendation was included in the final report that will be sent to the participating programs and discussed at the state-wide meeting of the home-based rehabilitation programs in Victoria held in February, 2003. The author has not yet received any feedback from program staff about this recommendation

Recommendation 13: That the criterion that the care-giving episode be expected to last for more than six months be dropped from the eligibility requirements for carer payments.

As discussed in Chapter Six and earlier in this chapter, the requirement that the episode of care last for six months or more disadvantages care-givers in home-based rehabilitation. The author believes that if they meet the other requirements for the carer payments, they should receive these carer payments.

Recommendation 14: That the income test for Carer Payment be applied on a three-monthly basis rather than on a fortnightly basis.

As the income test now stands, care-givers who work a varying number of shifts per week must have their Carer Payment reassessed even though over a month they would not earn more than the allowed income. If this test were applied less often, the income earned by care-givers could be averaged out over a three month period and they would not be penalised for work whose hours may be outside of their control.

8.5.4.2 Outcomes of carer payment recommendations

The recommendations on carer payments have not yet been forwarded onto Centrelink. The author will write to Centrelink and provide some examples of the difficulties experienced by care-givers in this study.

8.5.5 Recommendations on future research in this area.

Recommendation 15: That future research into care-giving adopt a structural rather than individual approach to exploring the position and experiences of care-givers.

As discussed in several places in this study, most of the previous research into care-giving has taken an individualistic approach, focusing on the stress and coping strategies of the care-giver. This study, through taking a structural approach, has shifted the focus from care-giving as a private concern to care-giving as a public issue, but it has done so by looking at the experiences of care-givers and staff in a broader way than previously accomplished. It is recommended that future care-giving research adopt this approach in areas other than home-based rehabilitation.

Recommendation 16:That future research into the cost effectiveness of home-based rehabilitation take into account the costs of care provided by the client's family and friends.

Previous research into the cost effectiveness of home-based rehabilitation has failed to take into account the cost of the care-giver's time or lost work opportunities. In order to further illuminate and appreciate the work of unpaid care-givers, it is recommended that future research into cost effectiveness include these costs.

Recommendation 17: That future research into home-based care options investigate the applicability of the new context of care identified in this study.

The new context of care identified in this study, that of the home-based health program, may also be a useful way to understand the care provided in other home-based substitutions for hospital care, such as Hospital in the Home. It is recommended that this construct be tested in future research in these areas.

Recommendation 18: That future research investigate the claims made in this study that there is an increasingly frail group of clients who are being denied hospital care and are being treated in their homes. The implications of this trend for clients, care-givers, and staff should also be further investigated.

As discussed in Chapter Seven, there seems to be a trend towards redirection of frail elderly people away from hospital care and into home-based alternatives. Future research could establish whether this is the case and explore the implications of this trend for older people, care-givers, and staff.

8.5.5.1 Outcomes of recommendations about future research

As yet, no outcomes have been achieved in relation to these recommendations. However, as the author is now employed as a researcher in this area, she will have the opportunity to implement these recommendations in her own work.

8.6 DISCUSSION OF THE AIM OF THE STUDY

This study aimed "to employ a feminist theory and methodology to explore the involvement of (family and informal) care-givers in home-based rehabilitation in Victoria so that the study findings can be used to inform the future development of early discharge policies and programs." This final section of the thesis examines the extent to which this aim has been achieved.

The study aim comprised three components. The first was to employ a feminist theory and methodology. This component of the aim was achieved. The study has been driven from the start by the feminist theoretical framework. This influenced the study questions, the way in which the study was carried out, the interpretation of the study findings, and the ways in which the outcomes of the study were followed through. The second component of the aim was to explore the involvement of care-givers in home-based rehabilitation in Victoria. The study focused on the work undertaken by care-givers and also on the impact that home-based rehabilitation care-giving had on their lives. This work was made visible to the care-givers themselves, the program staff, to staff from the Victorian Department of Human Services, and to a wider academic audience through the dissemination of reports, presentation of findings, and the publication of academic papers, discussed under 8.5.1 above. The third component of the aim was to influence the future development of early discharge policies and programs. This part of the study aim has to date only partially been achieved. As mentioned in the Introduction, staff from the Victorian Department of Human Services have recently begun meeting with staff working in home-based rehabilitation in order to develop formal policy guidelines, best practice standards, and reporting guidelines. One of the outcomes of these meetings has been the development of a research proposal with NARI that the author will begin working on in February, 2003. Another outcome is a document that has not yet been published that outlines some of the principles that home-based rehabilitation programs should incorporate. Unfortunately this document is still in draft form so cannot be formally cited here. However, the author believes that there is much more recognition of care-givers than has been evident in any previous documentation on home-based rehabilitation. It is possible that this recognition is an outcome of this study as many of the people on the committee were present when the results of this study were presented. However, as the author was not on the committee that produced the document, it is not possible to draw a direct link between this study and the unpublished document. In any case, the explicit inclusion of the care-giver in the government document represents a step forward.

In summary, this study has achieved an in-depth and faithful depiction of the care-givers' stories; identification of the changes needed in home rehabilitation programs and policies in line with the care-givers' wishes; and an opportunity for the author to further influence government policy in this area. As a result of the research done for this thesis the author has now been employed at NARI in a position where she will be working directly with the Victorian Government employees who are responsible for the development of home-based rehabilitation policy. Thus, although the aim of this study has not yet been fully achieved, the study has enabled the author, together with the study participants, to embark on a course of action through which this component of the study aim can be achieved in the future.

Appendix A Care-giver Interview Schedule

Note: This interview will be conducted face to face with the care-giver. If the care-giver gives permission it will be audio-taped. The questions below cover all the data requirements for the research project and are designed as prompts and reminders to the researcher. The questions will not necessarily all be asked (if the respondent answers a subsequent question in response to an earlier one, the researcher will not cover the same area twice and if a question is clearly not relevant to the interviewee, it will not be asked), however no additional questions will be asked. This schedule includes all possible interview questions and will be made available to the care-giver prior to the interview if requested.

1. Demographic characteristics

1a Age (20-30: 30-40: 40-50: 50-60: 60-70: 70-80: 80-90: 90+) ______

1b Sex ______________

1c Relationship to care recipient ______________

2. Identification of self as a care-giver

2a Do you see yourself as (the main) or a care-giver for (name of care recipient)?

Yes/No ____

2b If not, how do you see care-givers as different from yourself?

____

____

2c How did come to take on the role of care-giver?

____

____

2d How long have you been caring for (name)? In years (decimals)

____

____

2e First episode_______ Continuation of care________ 2+ episode__________

3. Care recipient characteristics

3a Primary diagnosis of the care recipient (see FIM) ______________

3b Age ______________

3c Sex ______________

4. Care-giving responsibilities

I am going to ask you some questions about the sorts of things you do to help (name of care recipient) I would like to cast your mind back to when (name) was first discharged home from hospital after (the stroke, surgery etc) and tell me what you were doing for him/her then. I will go through the tasks I think you might have been doing one by one and then you can add any that I haven't thought of.

4a Did you spend any time doing – **record time in decimal hours/day**

4a1a Meal preparation Yes/No 4a1b Time/day ______

4a2a Housework (cleaning up after (name), making beds etc)4a2b Time/day _____

4a3a Nursing tasks such as dressings Yes/No 4a3b Time/day ______

4a4a Preparing and supervising medication Yes/No 4a4b Time/day ______

4a5a Bathing Yes/No 4a5b Time/day ______

4a6a Toileting Yes/No 4a6b Time/day ______

4a7a Personal care eg shaving, brushing teeth Yes/No 4a7b Time/day ______

4a8a Dressing Yes/No 4a8b Time/day ______

4a9a Rehabilitation tasks, (exercises, walking etc.) Yes/No 4a9b Time/day ______

4a10a Supervision (just being there, making sure (name) is OK) 4a10b Time/day___

4a11a Keeping (name) company Yes/No 4a11b Time/day ______

4a12a Taking (name) out to appointments
(to go to the doctor etc.) 4a12b Yes/No Time/week ____

4a13a Managing (name's) affairs,
(banking, paying bills etc.) 4a13b Yes/No Time/week ____

4a14a Talking to health professional about (name) Yes/No 4a14b Time/week_____

Other care-giving responsibilities, related to the rehab. pt.

List____ 4a15aTime/day_______

List____4a15bTime/week____

4b How much time did you spend with (name) each day (when he/she was first discharged from hospital this time)? ______________________________

4c How much time did you spend doing things for (name) each day? ________

4d Have these responsibilities diminished or increased in the time between (name's) initial discharge to home and the present?

Yes/No ______________________________

4e How do you feel about providing this care for (name)?

4f1 Do you have other care-giving responsibilities, (eg children, other disabled adults?) Yes/No

4f2 Relationship ______________________________

____

5. Disruptions to care-givers usual life

5a1 Did you have to take leave from work, give up work or disrupt your usual work routine to look after (name)? Yes/No

5a2 Can you describe the changes you have made? ______________________________

____

____

5b1 Did you have to make changes to your usual family arrangements to look after (name)? Yes/No

5b2 Describe______________________________

____

____

5c1 Did you have to move house or have (name) move in with you so that you can look after them? Yes/No

5c2 Describe______________________________

____

____

5d1 What about your usual leisure or relaxation activities, did you make any changes there in order to care for (name)? Yes/No

5d2 Describe______________________________

____

____

5e Any other comments on responsibilities and disruptions

____

____

6. Care-giver supports

6.a Did you receive any assistance from rehabilitation staff?

6a1 Nurses (prompt - name of staff member) Yes/No

6a2	Allied health assistants	Yes/No
6a3	Physiotherapists	Yes/No
6a4	Medical staff	Yes/No
6a5	Occupational therapists	Yes/No
6a6	Social workers	Yes/No
6a7	Speech pathologists	Yes/No
6a8	Other Yes/No	
6a9	(List________________)	

6b Has this help been enough for you?

On a scale of 1 to 5 with one representing very inadequate and five representing more than adequate and three representing almost adequate, how would you rate the help you have had from the rehabilitation service?

1	2	3	4	5
very inadequate	**inadequate**	**just adequate**	**quite adequate**	**more than adequate**

6c Did you receive any assistance from community services?

6c1	Meals on wheels	Yes/No
6c2	Home care	Yes/No
6c3	Home handyman	Yes/No
6c4	General practitioner	Yes/No
6c5	District nursing	Yes/No
6c6	Other	Yes/No

6d Was this help enough for you?

On a scale of 1 to 5 with one representing very inadequate and five representing more than adequate and three representing almost adequate, how would you rate the help you have had from community services?

1	2	3	4	5
very inadequate	**inadequate**	**just adequate**	**quite adequate**	**more than adequate**

6e1 Did you receive any help from family or friends? Yes/No

6e2 What sort of help did you receive?____________________

6e3 How often?____________________

6f Was it enough?

On a scale of 1 to 5 with one representing very inadequate and five representing more than adequate and three representing almost adequate, how would you rate the help you have had from family and friends?

1	**2**	**3**	**4**	**5**
very inadequate	**inadequate**	**just adequate**	**quite adequate**	**more than adequate**

6g What sort of supports would have been most helpful to you?

____

____

7. Payment, costs

7a Did you receive any payment for providing care for (name)? Yes/No

7b If yes, What sort of payment did you receive?

Wages____________________
A Government Benefit____________________
Other____________________

7c1 Did you receive any other financial benefit from caring for (name)? (For example, did he/she help to pay the bills or provide child-care that you would otherwise have to pay for?) Yes/No

7c2 List____________________

____

7d1 Were there any other benefits, eg company, moral support? Yes/No

7d2 Describe____________________

____

7e1 Did you have any out of pocket expenses as a result of caring for (name)?

Yes/No

7e2 What sort of expenses did you incur?

Medical costs____________________
Payment for services____________________
Food, power etc____________________

Other____

7e3 Can you estimate how much per week these extra expenses were? ($/week)

____

8. Preparation, choice, benefits

8a1 Do you think (name) would manage at home without you? Yes/No

8a2 Why/ Why not?__________________________________

8b1 Were you consulted about when or whether (name) could be discharged from hospital? Yes/No

8b2 By Whom?__________________________________

8c1 Did you have much time to prepare yourself for looking after (name)? Yes/No

8c2 How much? (days)______________________________

8d Did you feel that you had a choice about looking after (name)? Yes/No

8e1 Were there any other alternatives available to you? Yes/No

8e2
Hospital care
Residential care
Other family members
Other__________________________________

8f1 Were other members of your family involved in deciding who would look after (name)? Yes/No

8f2 Who? __________________________________

8f3 How was the decision made____________________________

8g1 Was anyone else considered as a potential care-giver? Yes/No

8g2 Who? __________________________________

8g3 Why didn't he/she end up doing the care-giving?______________

____

8h How did they/you decide that you would be the main care-giver for (name)? (if not already covered)

____

____

____

8i Have you finished providing care for (name) or does he/she still need your help? Yes/No

8j Would you do it again if (name) or another family member needed your care?

Yes/No____

9. Recovery/expectation of recovery

9a1 Have you noticed any changes in (name's) health and ability to do things since he/she came home? Improved?

Yes/No

9a2 Describe ____

____

9b1 Do you expect to see any improvement in (name's) health/functional ability in the future? Yes/No

9b2 Describe ____

____

10. Meaning, significance of care-giving

Some people find that caring for someone else changes their relationship with that person or even makes them see their whole life differently. What do you think care-giving has meant for you?

____

____

11. Do you have any other comments you'd like to make about the time you've spent caring for (name)?

____

____

Thank you very much for the time you have spent with me today. Your answers to my questions will help us to understand more about the experiences of people like yourself, which will help us to work out the best way to support you and other care-givers.

I will be providing the people I have interviewed with feedback about the results of the interviews. Would you like a copy of the results? _____ or to come to an information night about the study findings?______________________________

Appendix B Client Data Sheet

Please complete one for each client on your caseload.

1. Client Number .... (to be completed by researcher)
Age of client ....Gender ....
Primary diagnosis .... FIM ....BI.............
Care-giver/s (yes or no).........................(if no, proceed to question 3)
If more than one care-giver, give details here..
....

2. Age of primary caregiver .... Gender ....
Relationship to client .... Cohabiting?................
Type of care provided (see list below)
....
Level of care- 24 hour daily hours/day ..... weekly hours/week
Less than weekly
....
Self-identified Client identified Staff identified
Does the care-giver receive any payment? .... If yes, what type of payment?
....

3. Services	Assessed as needed	Provided	Supplied by your program
Rehabilitation nursing	☐	☐	☐
Allied Health Assistant	☐	☐	☐
Occupational Therapy	☐	☐	☐
Social Work	☐	☐	☐
Physiotherapy	☐	☐	☐
Medical care	☐	☐	☐
Case management	☐	☐	☐
Speech Pathology	☐	☐	☐
Other rehab, such as podiatry, dietetics			
Specify....................................	☐	☐	☐

Delivered meals	☐	☐	☐
Home care (housework, shopping etc)	☐	☐	☐
District nursing	☐	☐	☐
Personal care	☐	☐	☐
Respite care (residential, in-home etc)			
Specify..................................	☐	☐	☐
Other services			
Specify.................................	☐	☐	☐

Comments (to clarify above, or any additional comments you would like to make, eg Linkages client, additional diagnoses, NESB)

....

....

....

List of care-giver activities

1. Personal care (showering, dressing, shaving etc)
2. Nursing tasks, dressings
3. Meal preparation
4. Housework, including cleaning, washing, shopping etc
5. Preparation and monitoring of medication.
6. Supervision
7. Keeping company
8. Outside jobs, maintenance, lawns, etc
9. Care management
10. Management of finances
11. Transport to and from appointments etc.
12. Rehabilitation tasks, exercises, supervision of walking etc.
13. Other, specify.

Appendix C Questions/discussion points for program manager/staff team interviews

1. Description of the program - bed replacement, early discharge, types of clients, all rehab or other diagnostic groups as well, how funded, how many staff, composition of team etc.

2. How many people are currently on your program?

3. Is this the usual number or are you quieter or busier than usual?

4. Program admission criteria – any references to caregivers?

5. Do you think it makes any difference to discharge planning from the acute hospital/rehab ward if there is a care-giver present? – More or less likely to be discharged?

6. How do you include care-givers in your admission process, assessment, planning and service provision to the care-giver/client?

7. What about program evaluation and planning?

8. How are care-givers usually identified? Does the client identify them or do you or do they identify themselves?

9. What sort of expectations do you have of care-givers?

10. Do your expectations differ if they are working or if they have other care-giving responsibilities? How do your expectations differ?

11. Do there are any differences between male and female care-givers in the way that you treat them, the expectations that you have of them, the services they receive or in any other ways?

12. Are there any cultural issues that you think are pertinent to the care-givers involved in your program?

13. Are there any other comments that you would like to make about your experiences of care-giving in rehabilitation in the home?

Appendix D Plain Language Statement for care-givers

Are you a caregiver?

If you have received this notice, it is because the staff in the Rehabilitation in the Home Program see you as someone who is caring for a rehabilitation client. You are being asked to join in a study of caregivers who are involved in the Ballarat Health Services Rehabilitation in the Home Program.

What do we want to know?

We are trying to find out what it is like to be a caregiver for a rehabilitation client, and whether you are getting the help that you need from the Ballarat Health Service and other service providers.

Why do we want to know?

This research is part of a study being conducted by the University of Ballarat to find out more about the experiences of caregivers like you. We also want to provide information to Ballarat Health Services about how best to support caregivers in the future.

What would we like you to do?

You will be asked to participate in an approximately one-hour interview that will be taped (with your permission). In the interview you will be asked about all the things that you do for your friend or relative and how much help you receive from other people. **The interview will be completely confidential.** To avoid identification of the respondents pseudonyms will be used and non-essential information will be deleted. Confidentiality will only be breached in rare cases when patient or care-giver welfare is at risk. **PTO**

What next?

Soon after your friend or relative has finished with the Rehabilitation in the Home Program, you will receive a telephone call from Briony Dow, asking you to meet with her for an interview. Briony is a PhD student from the University of Ballarat. If you agree, she make a time to come and talk to you at your home, or wherever is convenient for you. If you do not wish to be involved just let Briony know when she rings.

If you do not wish to be part of this study please inform your care coordinator or another RHP staff member ph: 5320 3851.

NOTE: Whether you decide to be part of this study or not will not influence any other aspect of your or your friend or relative's involvement in the Rehabilitation in the Home Program.

Will you be paid for your time?

Yes, you will be paid a one-off fee of $25 for participation in the study.

Who should you contact if you require any for further information?

You can contact **Briony Dow**, the researcher, on ph: 53279197 or **Michele Pearson**, the Rehabilitation in the Home Program Manager on ph: 53203801 or **Dr John McDonald,** Briony's supervisor at the University of Ballarat on ph: 53279000.

Should you have any concerns about the conduct of this research project, please contact the Executive Officer, Human Research Ethics Committee, Scholarship and Educational Development Services Branch, University of Ballarat, PO Box 663, Mt Helen VIC 3353. Telephone: (03) 5327 9765.

Appendix E Care-giver consent form

I,... (name)

of...

.... (address)

agree to participate in an interview with Briony Dow to discuss my experiences as a care-giver in home-based rehabilitation.

* I do/do not agree to this interview being taped.
(cross out whichever does not apply)

* The research program in which I am being asked to participate has been explained fully to me, verbally and in writing, and any matters on which I have sought information have been answered to my satisfaction.

I understand that:

* all information I provide (including questionnaires) will be treated with the strictest confidence unless my or my friend or relative's (for whom I provide care) well-being is in jeopardy

* the study data will be stored separately from any listing that includes my name and address

* aggregated results will be used for research purposes and may be reported in scientific and academic journals

* I am free to withdraw my consent at any time during the study in which event my participation in the research study will immediately cease and any information obtained from it will not be used.

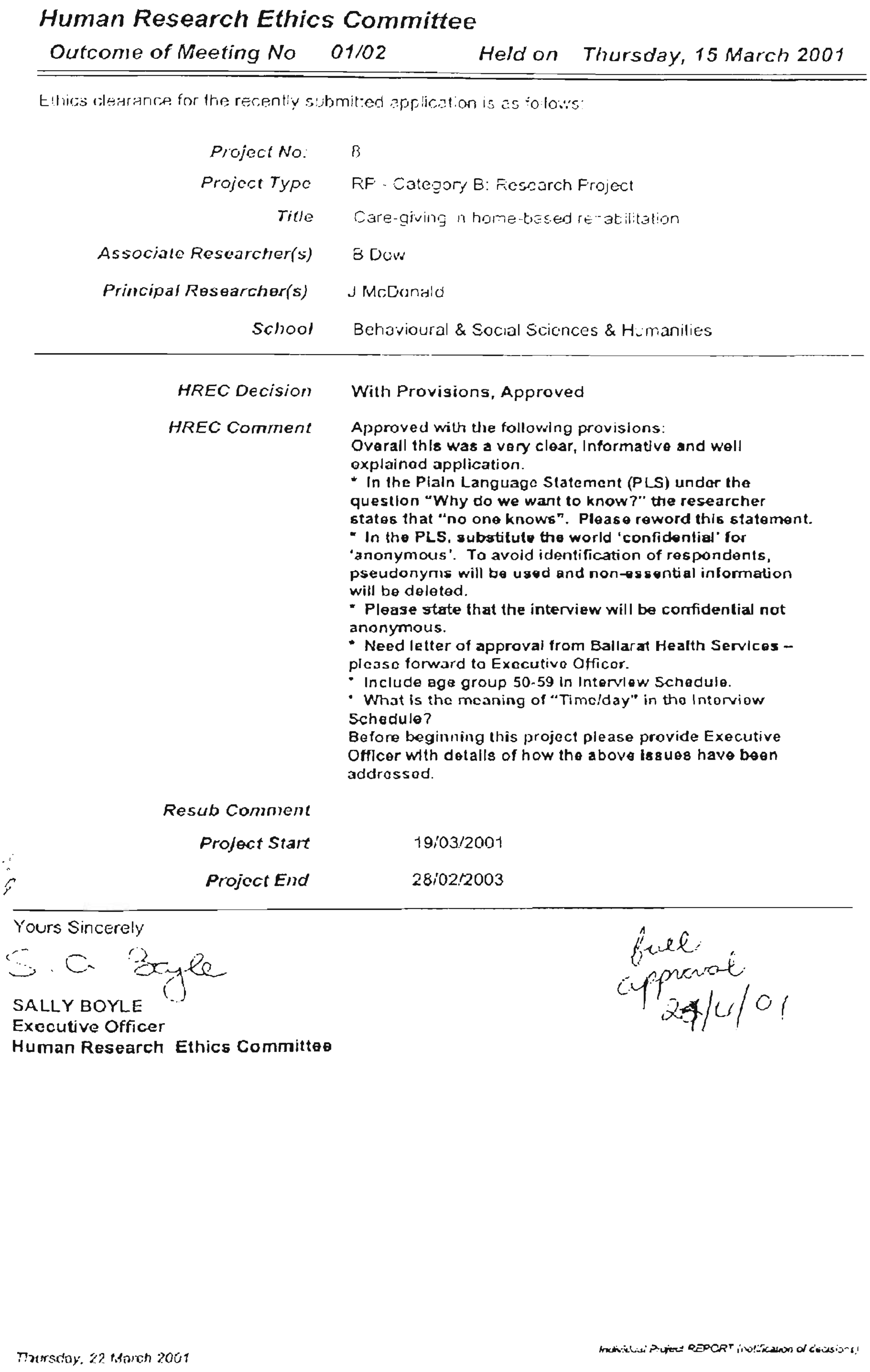
* My participation in this study will have no bearing on my (or my friend or relative's) involvement in the Rehabilitation in the Home program or any other services provided by the Ballarat Health Services.

Name ....

Signed...

Date ....

Appendix F Letter of Approval University of Ballarat



Human Research Ethics Committee

Outcome of Meeting No *01/02* *Held on* *Thursday, 15 March 2001*

Ethics clearance for the recently submitted application is as follows:

Project No: 8

Project Type RP - Category B: Research Project

Title Care-giving in home-based rehabilitation

Associate Researcher(s) B Dow

Principal Researcher(s) J McDonald

School Behavioural & Social Sciences & Humanities

HREC Decision **With Provisions, Approved**

HREC Comment Approved with the following provisions:

Overall this was a very clear, informative and well explained application.

- **In the Plain Language Statement (PLS) under the question "Why do we want to know?" the researcher states that "no one knows". Please reword this statement.**
- **In the PLS, substitute the world 'confidential' for 'anonymous'. To avoid identification of respondents, pseudonyms will be used and non-essential information will be deleted.**
- **Please state that the interview will be confidential not anonymous.**
- **Need letter of approval from Ballarat Health Services – please forward to Executive Officer.**
- **Include age group 50-59 in Interview Schedule.**
- **What is the meaning of "Time/day" in the Interview Schedule?**

Before beginning this project please provide Executive Officer with details of how the above issues have been addressed.

Resub Comment

Project Start 19/03/2001

Project End 28/02/2003

Yours Sincerely

S. C. Boyle

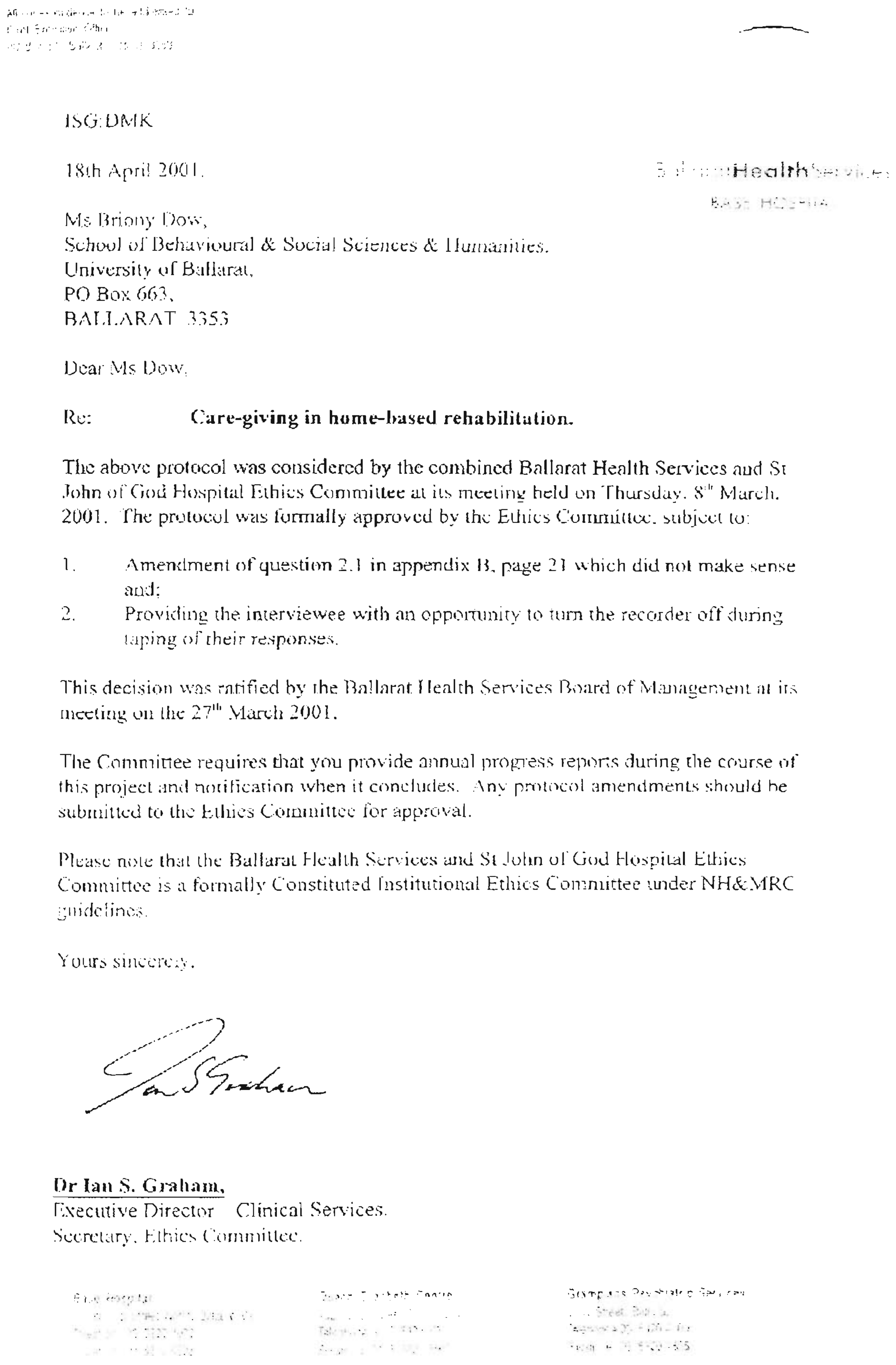
SALLY BOYLE
Executive Officer
Human Research Ethics Committee

full approval 24/4/01

Thursday, 22 March 2001

Individual Project REPORT (notification of decision)

Appendix G Letter of Approval – Ballarat Health Service



ISG:DMK

18th April 2001.

Health

Ms Briony Dow,
School of Behavioural & Social Sciences & Humanities,
University of Ballarat,
PO Box 663,
BALLARAT 3353

Dear Ms Dow,

Re: **Care-giving in home-based rehabilitation.**

The above protocol was considered by the combined Ballarat Health Services and St John of God Hospital Ethics Committee at its meeting held on Thursday, 8th March, 2001. The protocol was formally approved by the Ethics Committee, subject to:

1. Amendment of question 2.1 in appendix B, page 21 which did not make sense and;
2. Providing the interviewee with an opportunity to turn the recorder off during taping of their responses.

This decision was ratified by the Ballarat Health Services Board of Management at its meeting on the 27th March 2001.

The Committee requires that you provide annual progress reports during the course of this project and notification when it concludes. Any protocol amendments should be submitted to the Ethics Committee for approval.

Please note that the Ballarat Health Services and St John of God Hospital Ethics Committee is a formally Constituted Institutional Ethics Committee under NH&MRC guidelines.

Yours sincerely,

Ian S Graham

Dr Ian S. Graham,
Executive Director Clinical Services.
Secretary, Ethics Committee.

Appendix H Letter of Approval – Wodonga Regional Health Service

WODONGA REGIONAL HEALTH SERVICE

29 October 2001

Ms B.Dow
C/- School of Behavioural & Social Sciences
University of Ballarat
Mt Helen Campus
PO Box 663
BALLARAT VIC 3353

Reference: Research Project

Dear Ms Dow,

I acknowledge receipt of your letter dated 16 October 2001 in respect of progressing your research involving the Wodonga Regional Health Service (WRHS) RITH Program.

In response I advise that providing your research uses non-identifiable data and continues to enjoy the support of the Ballarat Base Hospital Ethics Committee, your proposal is accepted. Please liaise directly with Ms Joy Bryant to make necessary arrangements for the visit to Wodonga, etc.

Yours faithfully

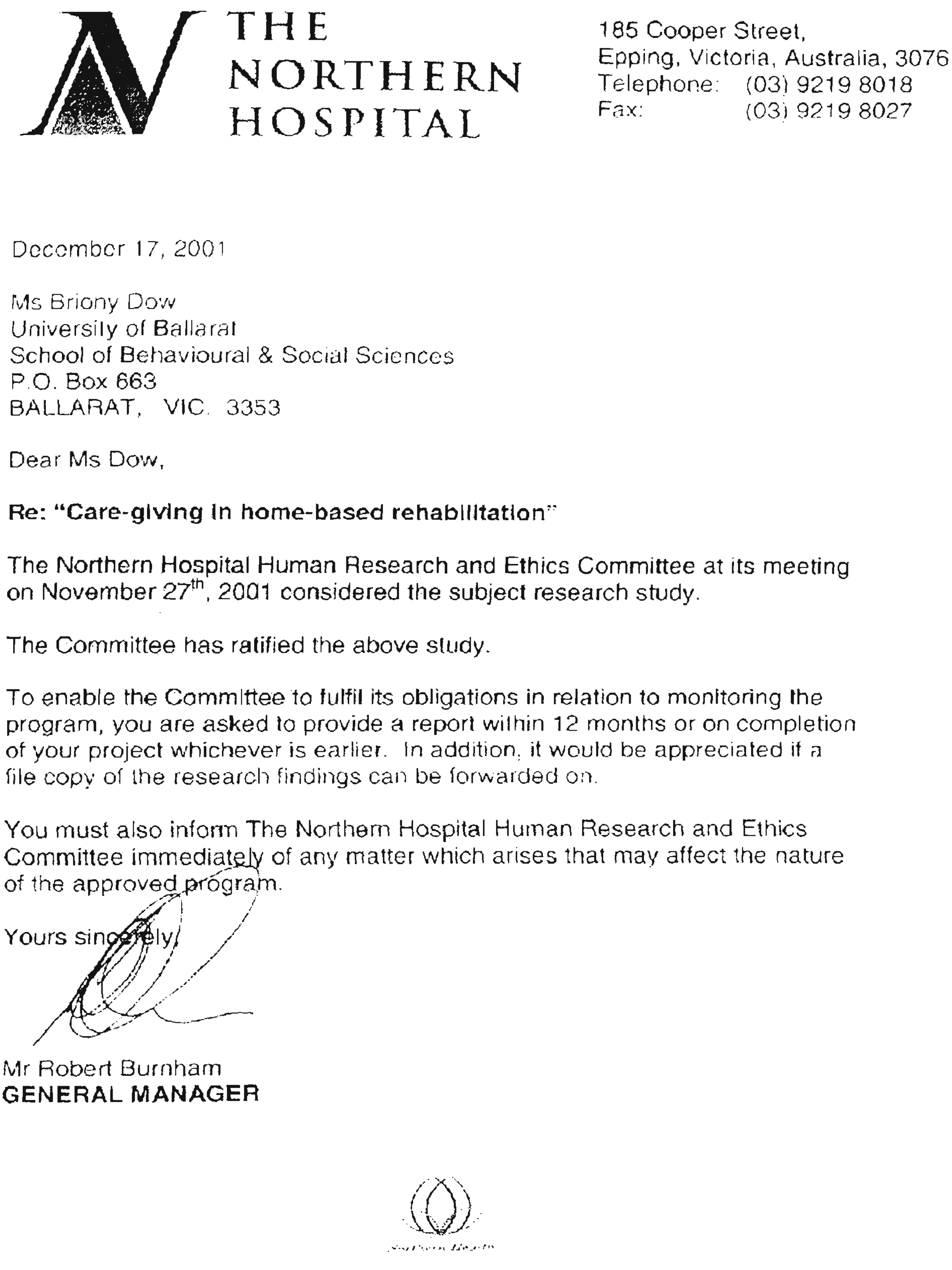
Andrew Watson
Chief Executive Officer and
Executive Director Medical Services

Cc: TL RITH

Vermont Street, PO Box 156 Wodonga VIC 3689 Telephone 02 6051 7111 Facsimile 02 6051 7477

Address all Correspondence to the Chief Executive Officer

Appendix I Letter of Approval – Northern Hospital



THE NORTHERN HOSPITAL

185 Cooper Street,
Epping, Victoria, Australia, 3076
Telephone: (03) 9219 8018
Fax: (03) 9219 8027

December 17, 2001

Ms Briony Dow
University of Ballarat
School of Behavioural & Social Sciences
P.O. Box 663
BALLARAT, VIC 3353

Dear Ms Dow,

Re: "Care-giving in home-based rehabilitation"

The Northern Hospital Human Research and Ethics Committee at its meeting on November 27th, 2001 considered the subject research study.

The Committee has ratified the above study.

To enable the Committee to fulfil its obligations in relation to monitoring the program, you are asked to provide a report within 12 months or on completion of your project whichever is earlier. In addition, it would be appreciated if a file copy of the research findings can be forwarded on.

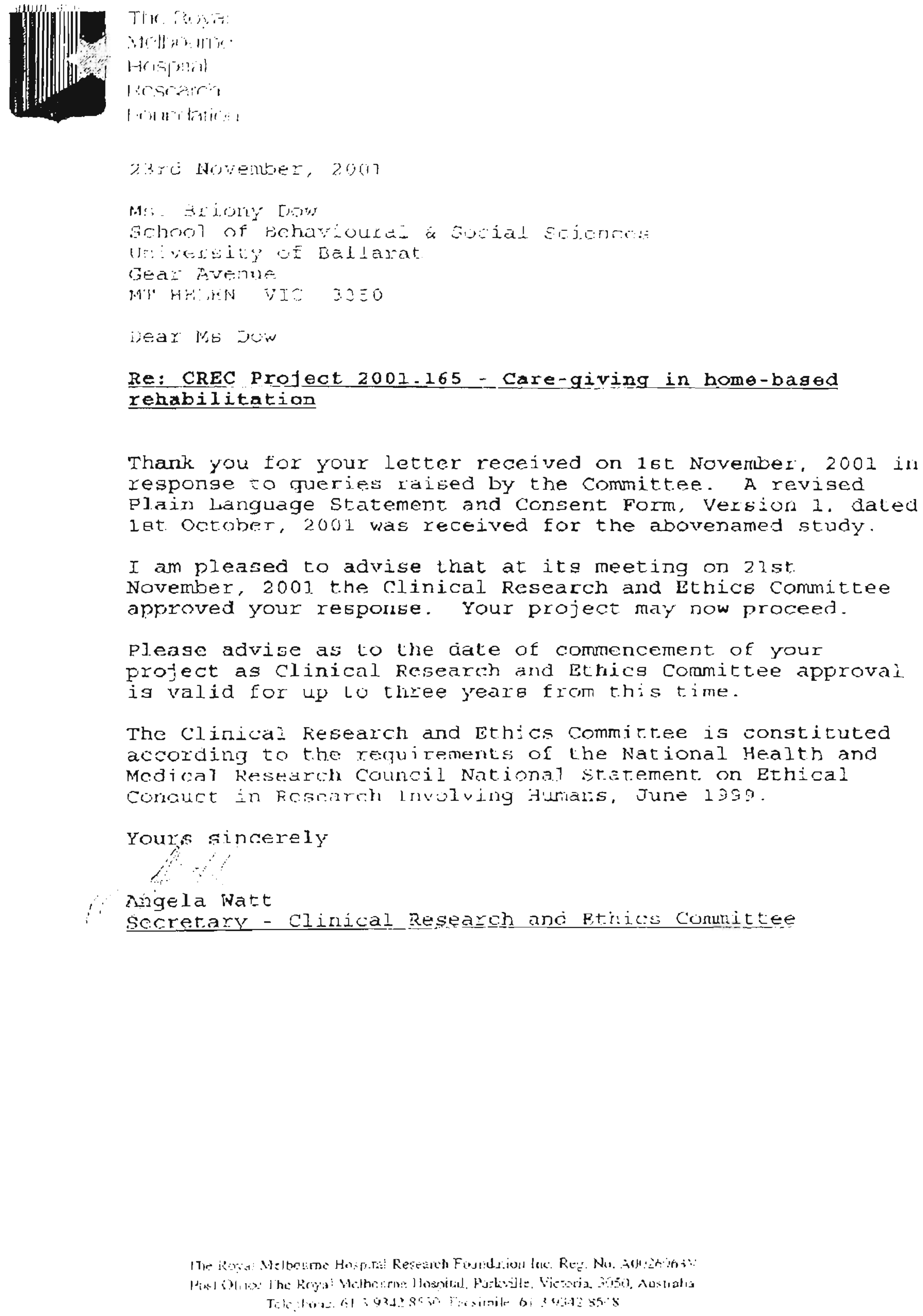
You must also inform The Northern Hospital Human Research and Ethics Committee immediately of any matter which arises that may affect the nature of the approved program.

Yours sincerely,

Mr Robert Burnham
GENERAL MANAGER

The Northern Hospital is a campus of Northern Health

Appendix J Letter of Approval – Royal Melbourne Hospital



The Royal
Melbourne
Hospital
Research
Foundation

23rd November, 2001

Ms. Briony Dow
School of Behavioural & Social Sciences
University of Ballarat
Gear Avenue
MT HELEN VIC 3350

Dear Ms Dow

Re: CREC Project 2001.165 - Care-giving in home-based rehabilitation

Thank you for your letter received on 1st November, 2001 in response to queries raised by the Committee. A revised Plain Language Statement and Consent Form, Version 1, dated 1st October, 2001 was received for the abovenamed study.

I am pleased to advise that at its meeting on 21st November, 2001 the Clinical Research and Ethics Committee approved your response. Your project may now proceed.

Please advise as to the date of commencement of your project as Clinical Research and Ethics Committee approval is valid for up to three years from this time.

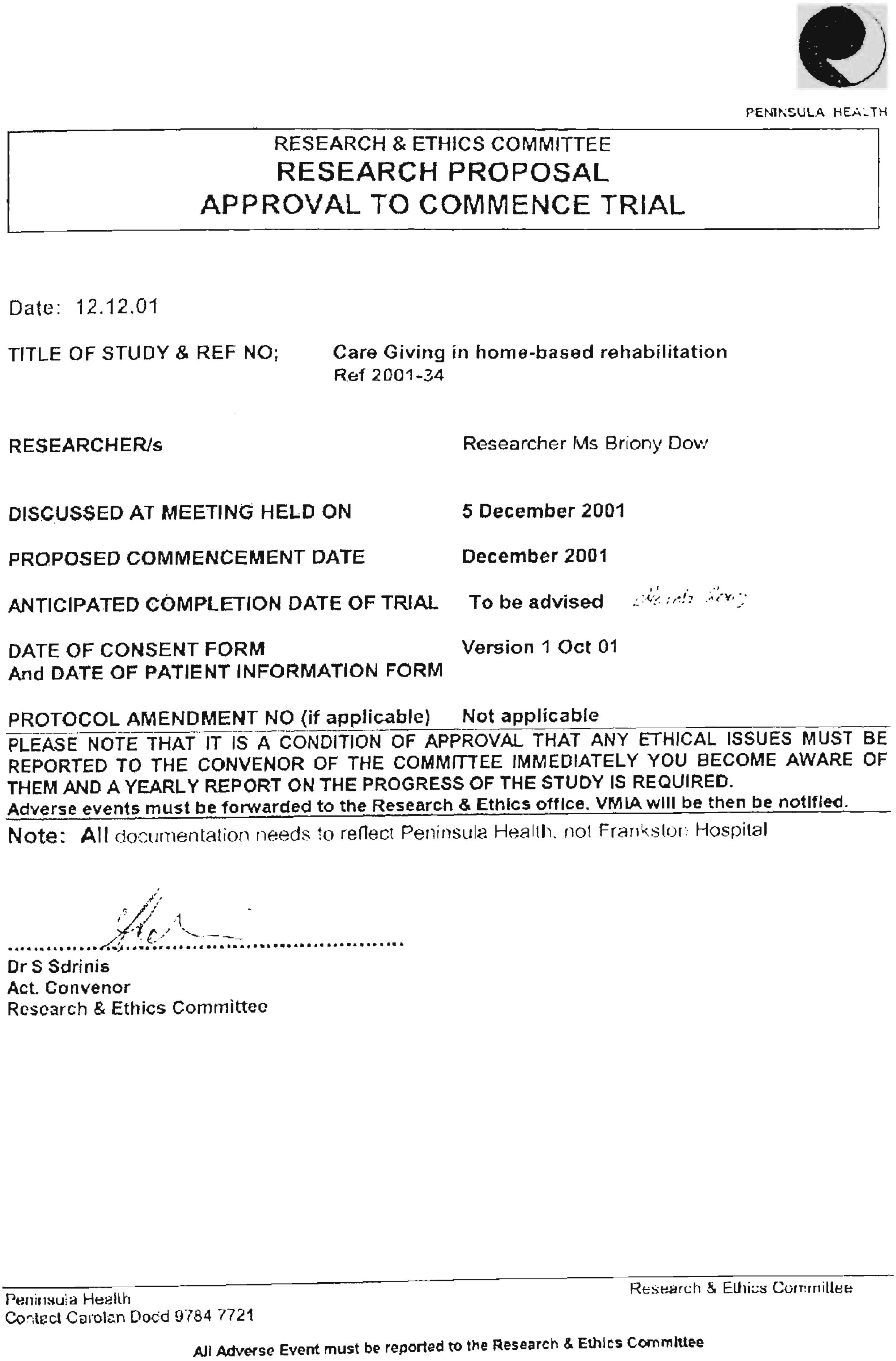
The Clinical Research and Ethics Committee is constituted according to the requirements of the National Health and Medical Research Council National Statement on Ethical Conduct in Research Involving Humans, June 1999.

Yours sincerely

Angela Watt
Secretary - Clinical Research and Ethics Committee

The Royal Melbourne Hospital Research Foundation Inc. Reg. No. A0026263V
Post Office The Royal Melbourne Hospital, Parkville, Victoria, 3050, Australia
Telephone 61 3 9342 8530 Facsimile 61 3 9342 8548

Appendix K Letter of Approval – Peninsula Health



PENINSULA HEALTH

RESEARCH & ETHICS COMMITTEE

RESEARCH PROPOSAL
APPROVAL TO COMMENCE TRIAL

Date: 12.12.01

TITLE OF STUDY & REF NO; Care Giving in home-based rehabilitation
Ref 2001-34

RESEARCHER/s Researcher Ms Briony Dow

DISCUSSED AT MEETING HELD ON **5 December 2001**

PROPOSED COMMENCEMENT DATE **December 2001**

ANTICIPATED COMPLETION DATE OF TRIAL **To be advised** [illegible]

DATE OF CONSENT FORM
And DATE OF PATIENT INFORMATION FORM **Version 1 Oct 01**

PROTOCOL AMENDMENT NO (if applicable) **Not applicable**

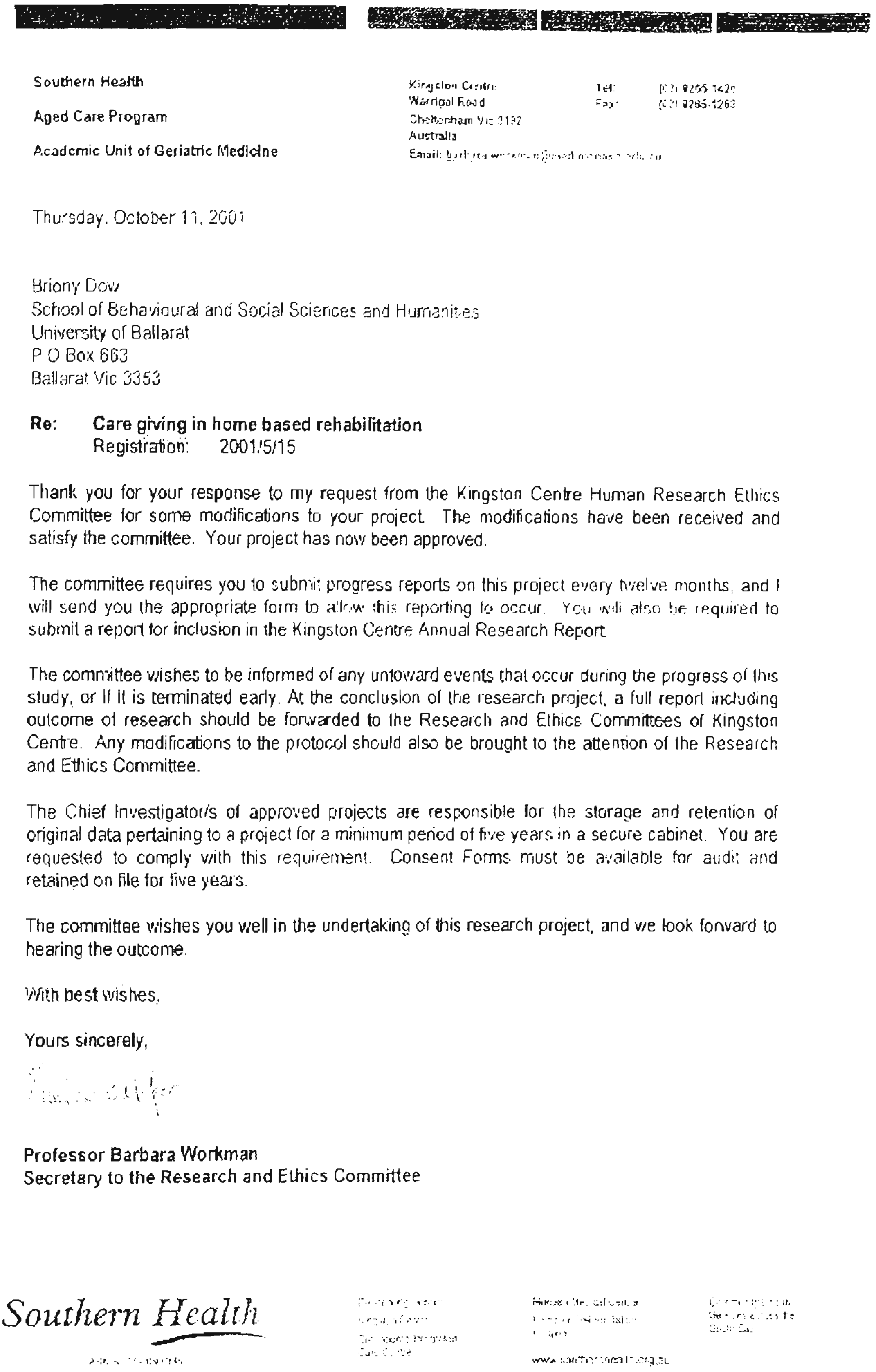
PLEASE NOTE THAT IT IS A CONDITION OF APPROVAL THAT ANY ETHICAL ISSUES MUST BE REPORTED TO THE CONVENOR OF THE COMMITTEE IMMEDIATELY YOU BECOME AWARE OF THEM AND A YEARLY REPORT ON THE PROGRESS OF THE STUDY IS REQUIRED.
Adverse events must be forwarded to the Research & Ethics office. VMIA will be then be notified.

Note: All documentation needs to reflect Peninsula Health, not Frankston Hospital

....

Dr S Sdrinis
Act. Convenor
Research & Ethics Committee

Appendix L Letter of Approval – Southern Health



Southern Health

Aged Care Program

Academic Unit of Geriatric Medicine

Kingston Centre
Warrigal Road
Cheltenham Vic 3192
Australia
Email: [illegible]

Tel: (03) 9265-1420
Fax: (03) 9265-1263

Thursday, October 11, 2001

Briony Dow
School of Behavioural and Social Sciences and Humanities
University of Ballarat
P O Box 663
Ballarat Vic 3353

Re: Care giving in home based rehabilitation
Registration: 2001/5/15

Thank you for your response to my request from the Kingston Centre Human Research Ethics Committee for some modifications to your project. The modifications have been received and satisfy the committee. Your project has now been approved.

The committee requires you to submit progress reports on this project every twelve months, and I will send you the appropriate form to allow this reporting to occur. You will also be required to submit a report for inclusion in the Kingston Centre Annual Research Report.

The committee wishes to be informed of any untoward events that occur during the progress of this study, or if it is terminated early. At the conclusion of the research project, a full report including outcome of research should be forwarded to the Research and Ethics Committees of Kingston Centre. Any modifications to the protocol should also be brought to the attention of the Research and Ethics Committee.

The Chief Investigator/s of approved projects are responsible for the storage and retention of original data pertaining to a project for a minimum period of five years in a secure cabinet. You are requested to comply with this requirement. Consent Forms must be available for audit and retained on file for five years.

The committee wishes you well in the undertaking of this research project, and we look forward to hearing the outcome.

With best wishes,

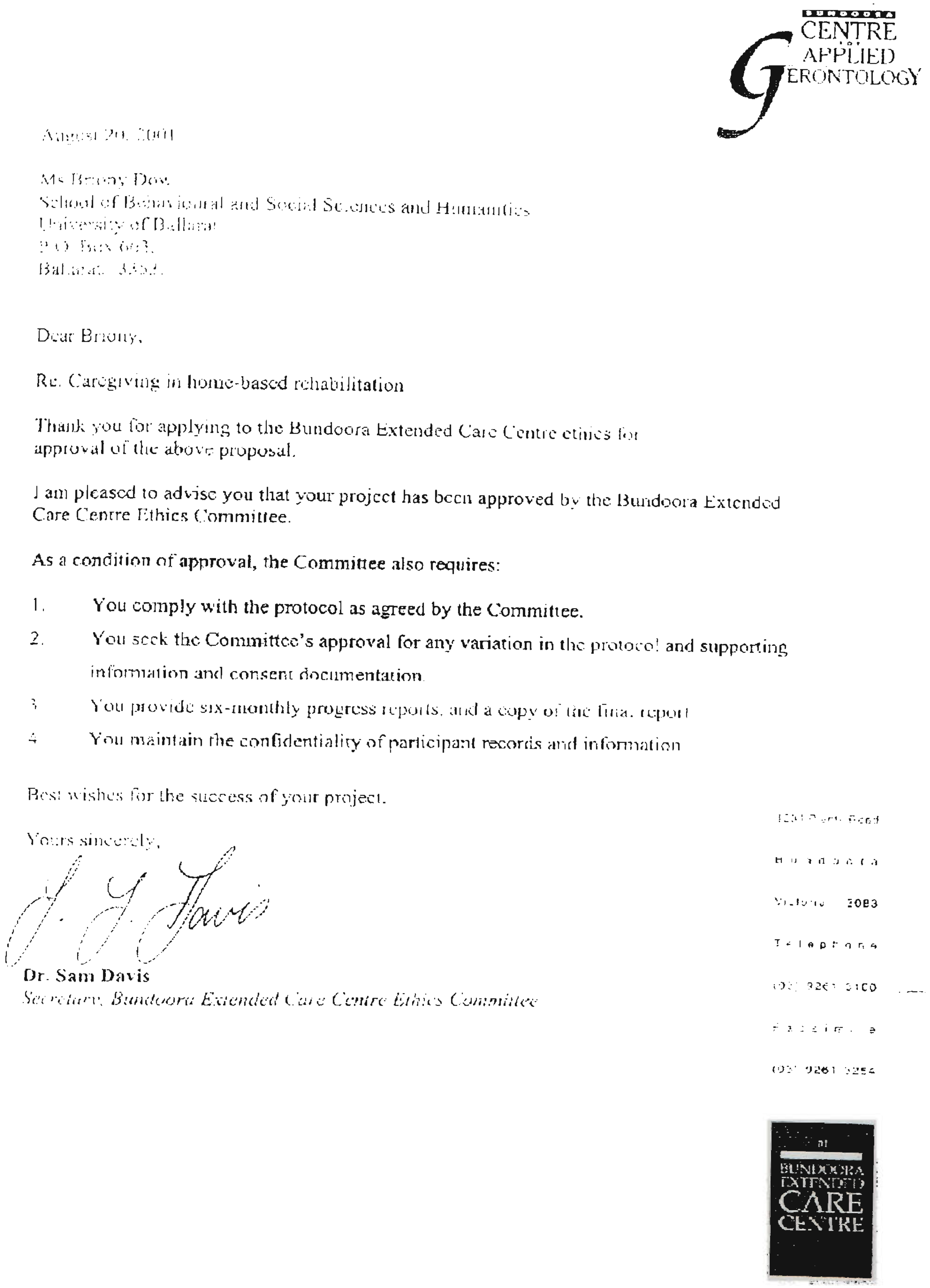
Yours sincerely,

Professor Barbara Workman
Secretary to the Research and Ethics Committee

Southern Health

www.southernhealth.org.au

Appendix M Letter of Approval – Bundoora Extended Care Centre



BUNDOORA
CENTRE
FOR
APPLIED
GERONTOLOGY

August 20, 2001

Ms Briony Dow
School of Behavioural and Social Sciences and Humanities
University of Ballarat
P.O. Box 663,
Ballarat 3353.

Dear Briony,

Re. Caregiving in home-based rehabilitation

Thank you for applying to the Bundoora Extended Care Centre ethics for approval of the above proposal.

I am pleased to advise you that your project has been approved by the Bundoora Extended Care Centre Ethics Committee.

As a condition of approval, the Committee also requires:

1. You comply with the protocol as agreed by the Committee.
2. You seek the Committee's approval for any variation in the protocol and supporting information and consent documentation.
3. You provide six-monthly progress reports, and a copy of the final report
4. You maintain the confidentiality of participant records and information

Best wishes for the success of your project.

Yours sincerely,

S. J. Davis

Dr. Sam Davis
Secretary, Bundoora Extended Care Centre Ethics Committee

1231 Plenty Road
Bundoora
Victoria 3083
Telephone
(03) 9261 5100
Facsimile
(03) 9261 5254

BUNDOORA
EXTENDED
CARE
CENTRE

Appendix N Completed Department of Human Services Ethics Application

MODULE ONE:
CORE APPLICATION FORM AND CHECKLIST

Human
Services

People*first*

ACKNOWLEDGMENT

This Form covers Research Involving Humans. It was developed by a working party of representatives from the Victorian Government Department of Human Services, The Royal Melbourne Hospital Research Foundation, St. Vincent's Hospital (Melbourne), The Alfred Hospital, The Royal Children's Hospital, The Royal Women's Hospital, Peter MacCallum Cancer Institute, Monash University and the University of Melbourne.

BEFORE YOU BEGIN

Please read the **Module One: Core Application Guidelines** before you start this application. The guidelines should be read together with the National Health & Medical Research Council's National Statement on Ethical Conduct in Research Involving Humans (1999).

To complete this **Module One: Core Application Form**, you must complete responses and attach information. To fill out tick boxes, you must:
- Maintain the positioning of the boxes by viewing the document in Page Layout View
- Fill in boxes with an "x", or select a symbol by clicking on the "Insert" option on the toolbar and selecting from the symbol table.

Please leave the form version date in the footer i.e. June 2001.

CORE APPLICATION

1 Full Project Title Application Date:

Care-giving in home-based rehabilitation 14th November, 2001

2 Researchers

Include principal researcher, associate researcher, contact person, student supervisor and student.

Principal Researcher

Title & Name Ms Briony Dow

Appointment PhD Candidate

Department School of Behavioral and Social Sciences

Institution University of Ballarat

Address Gear Ave. Mt Helen, 3350, Victoria

Role in this project: Principal researcher - will conduct the interviews, analyse and report back findings. BSW, MA - extensive interviewing experience as social worker since 1982, completed major research project for MA thesis, MA awarded in 1999.
(Give qualifications and a brief summary of relevant experience for this project)

Will this researcher require extra training to enable him/her to participate in this project? *No*

Work phone 5327 9197 Work pager

Work fax e-mail b.dow@ballarat.edu.au

When filling out this form electronically, copy this box and repeat for each researcher.

Associate Researcher

Title & Name Associate Professor John McDonald

Appointment Director

Department Institute for Rural and Regional Research

Institution University of Ballarat

Address Gear Ave. Mt Helen, 3350

Role in this project: Principal Supervisor - PhD, extensive research and tertiary teaching experience.
(Give qualifications and a brief summary of relevant experience for this project)

Will this researcher require extra training to enable him/her to participate in this project? *No*

Work phone 5327 9000 Work pager

Work fax e-mail j.mcdonald@ballarat.edu.au

Associate Researcher

Title & Name Mr Andrew Day

Appointment Team Leader

Department Home Therapy Service

Institution Broadmeadows Health Service

Address 35 Johnstone St. Broadmeadows

Role in this project: Institutional researcher - Bachelor of Applied Science (Speech Therapy) - experience in management of and working in home-based rehabilitation(Give qualifications and a brief summary of relevant experience for this project)

Will this researcher require extra training to enable him/her to participate in this project? *No*

Work phone 8345 5255 Work pager

Work fax e-mail

For each researcher who requires training to participate in this project, please provide details of training on a **separate page** and include the name of the trainer(s).

Person to whom the HREC secretariat should direct correspondence.

Contact Person

Title & Name Ms Briony Dow

Appointment PhD Candidate

Department School of Behavioural and Social Sciences and Humanities

Institution University of Ballarat

Address Gear Ave. Mt Helen, 3350

Work phone 5327 9197 Work pager

Work fax e-mail b.dow@ballarat.edu.au

3 If Students are Part of Research Team

Are any of the researchers students? *Yes*

If *Yes*, name the degree/course and state any HREC that must also approve this project.

Student Researcher

Name: Ms Briony Dow

Degree/course: PhD

HREC: University of Ballarat

4 Anticipated Duration of Project

15 months

5 Anticipated Commencement Date

......1..../......11....../ ......01......

6 Anticipated Completion Date

......1..../......4....../ ...03.........

7 Broad Category of Research

Please tick the category which best fits the application:

☒ Social Science

☐ Psychological

☐ Public Health

☐ Clinical Research

☐ Clinical Trial

Other (please specify) ....

8 Summary of Protocol in Plain English

The proposed study will be undertaken by Ms Briony Dow, BSW, MA who is currently a PhD candidate at the University of Ballarat. Briony's supervisors are:

Principal Supervisor - Associate Professor John McDonald – University of Ballarat

Associate Supervisors -Ms Wendy Hubbard – Ballarat Health Services
-Dr Yvonne Wells – La Trobe University

The proposed study has two main aims. The first is to determine the extent to which informal family care-givers are relied upon to provide care for clients who have been discharged early from hospitals throughout Victoria for rehabilitation at home. This will be determined by interviewing program staff in all the home-based rehabilitation programs in Victoria about their current caseloads and program admission criteria. This part of the study will determine the number of clients who rely on a family care-giver and the extent to which they are receiving support from the programs at the time that the interviews are conducted.

The second main aim is to explore the experiences of care-givers undertaking the short-term care of rehabilitation in the home clients. This part of the study will be conducted with Ballarat Health Services (BHS) caregivers only. This will involve semi-structured interviews with approximately 30 caregivers from the BHS Rehabilitation in the Home Program.

It is anticipated that this study will provide information to the participating programs about the extent of involvement that care-givers have in home-based rehabilitation and the adequacy of support currently provided to them. The study will make recommendations about ways in which home-based rehabilitation programs can be structured to provide optimal support to caregivers so that they can maintain their important contribution to patient care.

The applicant requests permission to interview the program manager and care coordinators of the Broadmeadows Health Service Home Therapy Service.

9 Literature Search

Give details of literature search strategies used in preparing this project.

Online data bases such as EBSCO host, including CINAHL, Medline, ERIC, PsychINFO and so on, have been used to locate literature on this topic. The reference lists of articles located have been reviewed and many more journal articles and books have been located in this way. Some of the search terms used have been caregiver, caregiving, carer, rehabilitation, home rehabilitation, stroke caregiving and family care.

See Detailed Research Protocol for a summary of the literature.

10 Other Institutions

Name all Australian sites at which this project has been or will be conducted. Disclose any decisions of other HRECs concerning this project.

Name of site	HREC	Review or decision
Ballarat Health Services	Ballarat Health Services and St John of God Hospital Ethics Committee	Approved April, 2001
Bundoora Extended Care Centre	Bundoora Extended Care Ethics Committee	Approved August, 2001
Kingston Centre	Kingston Centre Research and Ethics Committee	Approved October, 2001
Melbourne Extended Care		

and Rehabilitation Service Sunshine Hospital	Royal Melbourne Hospital Human Research Ethics Committee	Suggested changes completed and submitted October 2001.

11 Participants

Number in each project group: 3-5

Number at this site:

Number at each site for which this HREC is responsible:

Number in total project: approximately 35 staff (and 30 care-givers)

Age range: adult - older adult

Competence (for consent): All participants are expected to be competent to make a decision regarding their participation in the study.

Justification: All home-based rehabilitation programs that combine home rehabilitation with early discharge will be asked to participate in the study (11 sites). (The care-giver sample will be a total sample of care-givers in the BHS RHP over a 9 month period.)

Summary of proposed statistical analysis: Both qualitative and quantitative analyses will be used to answer the research questions. See Detailed Research Protocol for more details.

12 Recruitment of Participants

Describe the recruitment procedure, including the source of participants. Attach sample of advertising material

The proposed study was presented to staff of the Braodmeadows Home Therapy Service at a state-wide meeting of home-based rehabilitation programs held at Bundoora Extended Care Centre on 25th May, 2001. Staff from the program indicated a willingness to be involved.

13 Consequences of Participation

Benefits: Information about extent of care-giver involvement in Broadmeadows home-based rehabilitation program compared with all other Victorian programs. Recommendations about best practice relating to care-giver involvement in home-based rehabilitation.

Potential or actual harm etc. (including debriefing/counselling): As staff will be providing non-sensitive and non-identified information about their clients, it is not expected to cause any harm.

Best Care available in ordinary practice:

Alternatives:

14 Payments

What and how will reimbursement, payment or other offers be made to participants?

No reimbursement apart from their usual wages will be offered. The interviews will be conducted during normal working hours.

15 Final Report to Participants

Will a report(s) of the project outcomes (for example, individual or group data) be made available to participants at the end of the project? *Yes*

If *Yes*, give details of the report(s). If *No*, explain why not.

The participating programs will be given a report on their own program within a month of completing the interviews. A complete report, comparing data from all home-based rehabilitation programs across Victoria will be presented at one of the state-wide home-based rehabilitation meetings in 2002.

16 Public Report

Will a report of the project outcomes (for example, group data) be publicly accessible at the end of the project? *Yes*

If *Yes*, give details of the report. If *No*, explain why not. Provide the relevant register/s for this type of research and whether this project will be registered.

Yes, a written report will be made available to all participating programs as well as a verbal presentation, outlined above.

17 Other Ethical Issues concerning Participants

Discuss any other ethical issues relevant to the participants in this project? Give details and explain how they have been addressed.

Participants may be concerned about the confidentiality of the data provided. The researcher will request that no names, UR numbers or other identifying data be passed on to the researcher. Should this occur inadvertently, the researcher will not record this information or use it in the study.

Participants may be concerned that if they refuse to participate (due to time constraints, objection to the research aims or other reasons) this may affect their employment. This is not the intention of the researchers, including the team leader of the service and potential participants will be assured of this.

18 Adverse and Unforeseen Events

What procedures are in place to manage, monitor and report adverse and unforeseen events?

If confidential information is inadvertently disclosed, it will not be recorded.

If the interviewee wishes to terminate the interview for any reason, it will be terminated immediately and if distressed, the interviewee will be referred back to his or her supervisor for debriefing or other support.

19 Data Sources

a) Commonwealth Agency

Does the project involve collection or disclosure of personal information by a Commonwealth Agency? *No*

If *Yes*, give details and specify the type of data to be collected and number of records to be accessed:

(b) Information From Other Sources

Does the project involve collection or disclosure of personal information from sources other than the individuals themselves and without their consent, for example, medical records, state government department or agency, or State-based registers? *Yes*

If *Yes*, name the source(s), specify the type of data to be collected and the number of records to be accessed:

The interviewees may need to refer to clients' medical records to find out whether they have care-givers, the extent of service provision or their Barthel Index score. This information will only be recorded in aggregate form and the client's confidentiality will be protected by the interviewee not passing on any identifying information and/or the interviewer not recording it should it be inadvertently communicated to her.

20 Protection of Privacy

How will you protect the privacy of participants and make anonymous any personal information collected?

During the interview a numbering system will be used to keep track of each case. For example, Client C1 has a daughter care-giver, a Barthel Index score of 87 and receives Meals on Wheels 5 days a week, daily physio-therapy and nursing care, and attends a day centre once a week. The code C1 will not relate to any identifying information, only the data required for this project.

21 Storage & Security of Information

Security of data storage: Hard copy will be stored in a locked filing cabinet. Computer data will be stored on a hard drive which is protected by a user name and password for the duration of the study, then transferred to floppy discs and stored in a locked filing cabinet in the principal supervisor, Associate Professor John McDonald's office.

Location of stored data: For the course of the study, in the researcher's office. After the study has been completed, the data will be stored in the researcher's principal supervisor, Associate Professor John McDonald's office for five years.

Format of stored data: The data will be stored in paper form in a locked filing cabinet. Data that is being analysed on a computer program or tabulated for display will be stored in the researcher's hard disk which is protected by a user name and password.

Duration: Five years post completion of the study

Destruction of data: Hard copy will be shredded and discarded. Computer data will be wiped from the discs.

22 Detailed Research Protocol

Attach a detailed research protocol. Include the scientific description and the experimental procedures. This can be left blank if Module 2 Projects Involving Drugs and Therapeutic Devices is being completed.

Your protocol should include:-

- Summary of previous literature and studies: ☐
- Justification of need for the proposed research: ☐
- Primary hypothesis: ☐
- Project design (include questionnaires and surveys): ☐
- Randomisation: ☐
- Procedures: ☐
- Parameters and outcomes: ☐
- Statistical analysis: ☐

23 Plain Language Statement and Consent Form

Attach a copy of the Plain Language Statement and Consent Form that you intend to use to explain the project to the participant and, if required, their parent or guardian. Make sure it has a version number and date. Attach any third party consent if applicable.

If you do not intend to obtain written consent, explain why.

If the Plain Language Statement and Consent Form are in language(s) other than English, attach a certified, translated version(s).

DECLARATION OF FINANCIAL DETAILS AND POTENTIAL CONFLICT OF INTEREST

Full Project Title: **Care-giving in home-based rehabilitation**

1 Project Budget

Attach a detailed project budget to this application.

Have you included:

- Salaries with on-costs: ☒
- Administration costs ☒

NA

- Research consumables (for example, bed-day costs)

NA

- Participant reimbursement
- Departmental charges (for example, Pharmacy, Pathology, Radiology)

NA

2 Source of Funding

How will this project be funded? For example, grant, commercial sponsorship, departmental funds.

Source	**Amount in $**	**Status of Funds** Available	 Applied for
Australian Post-Graduate Award - covers the costs of the principal researcher.	$17,000 per year	*Yes*	*Yes*
University of Ballarat – covers the cost of supervision, researcher travel, photocopying, stationery etc.	$350	*Yes*	*Yes*
Broadmeadows Home Therapy Service	$75	Yes	Yes

3 Funds Coverage

Do the funds presently available or applied for cover all requirements to conduct the project? *Yes*

If *No,* please explain how the shortfall will be made up.

4 Indirect Costs

Will there be payments over and above the direct costs of this project (for example, travel and conference, recruitment incentives, equipment)? *No*

If *Yes,* please provide details of payments and justification for them.

5 Claims through Medicare

Have any charges been incurred by Medicare as a result of patient participation? *No*

If Yes, has the Health Insurance Commission been notified and given permission? Yes/No

6 Potential Conflict of Interest

Is there any affiliation or financial interest for researchers in this research or its outcomes? *No*

If *Yes,* please give details

DECLARATION BY RESEARCHER(S)

Full Project Title:

I/WE, the researcher(s) agree(s):

- To observe the principles in the National Statement on Ethical Conduct in Research Involving Humans published by the National Health & Medical Research Council (June 1999);
- Only to start this research project after obtaining final approval from the Institution's Human Research Ethics Committee (HREC);
- Only to carry out this research project where adequate funding is available to enable the project to be carried out according to good research practice;
- To provide additional information as requested by HREC;
- To provide an annual progress report to HREC;
- To provide a final report and a copy of any published material at the end of the research project;
- To store information securely as required by law and to maintain the confidentiality of all data collected from or about project participants;
- To notify HREC in writing immediately if any change to the project is proposed or serious adverse event occurs; and
- To agree to an audit if requested by HREC.

Name of principal researcher ....Briony Dow....................................

Signature Date

Name of researcher ....John McDonald...

Signature Date

Name of researcher ....Andrew Day..

Signature Date

CERTIFICATION BY PRINCIPAL RESEARCHER AND HEAD OF DEPARTMENT

Full Project Title: Care-giving in home-based rehabilitation

Certification By Principal Researcher

I accept responsibility for the conduct of this research project according to the principles of the National Statement on Ethical Conduct in Research Involving Humans published by the National Health & Medical Research Council (June 1999).

I certify that all researchers and other personnel involved in this project are appropriately qualified and experienced or will undergo appropriate training to fulfil their role in this project.

Name of principal researcher-.........Briony Dow....................................

Signature Date

Acceptance by Head of Department

I certify that I have read the research project application submitted by the principal researcher.

My signature indicates that I support this research project.

Name of head of Department: -...............Dr Ian Carsen.............................

Signature Date

Plain Language Statement for Program Managers and staff of the Broadmeadows Home Therapy Service

Plain Language Statement
Version 1 Dated 1st October, 2001
Site – Broadmeadows Home Therapy Service

Full Project Title: Care-giving in rehabilitation in the home

Principal Researcher: Ms Briony Dow

Associate Researcher(s): Associate Professor John McDonald

Mr Andrew Day

This Plain Language Statement and Consent Form is 6 pages long (including appendix). Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This research is being undertaken as part of Briony Dow's PhD research at the University of Ballarat.

This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of both the Consent Form and this Plain Language Statement to keep as a record.

2. Description of the Project

The main aim of this project is to determine the extent to which informal family care-givers are relied upon to provide care for clients who have been discharged early from hospitals throughout Victoria for rehabilitation at home.

This will be determined by interviewing program staff in all the home-based rehabilitation programs in Victoria that combine early discharge with the provision of rehabilitation services in the home about their current caseloads and program admission criteria. This part of the study will determine the number of clients who rely on a family care-giver and the extent to which they are receiving support from the programs at the time that the interviews are conducted.

Objective 1

2.2 To determine the extent to which home-based rehabilitation programs in Victoria rely on informal family care-givers for their effective implementation.

Research Questions

2.2.1 How many home-based rehabilitation programs in Victoria specify the availability of a care-giver as a criteria for admission to the program?
2.2.2 How many clients in home-based rehabilitation have a primary care-giver?
2.2.3 Is there a difference in service provision to those clients with and without primary care-givers?
2.3.4 Is there a difference in service provision to clients in home-based rehabilitation according to their ADL status?

Objective 2

2.3 To determine the characteristics of care-givers in home-based rehabilitation.
2.3.1 What are the relationships to the client, gender and ages of the care-givers in home-based rehabilitation?

A total of 10 programs (approximately 35 people) will participate in this project.

Previous experience has shown that clients are satisfied with home-based rehabilitation and that it is at least as effective in achieving rehabilitation outcomes as hospital-based rehabilitation. However, little is known about the impact that home-based rehabilitation has on care-givers. This study aims to address this by finding out about the extent of involvement of care-givers in rehabilitation in the home and their experiences of the role.

You are invited to participate in this research project because your program is one of the 15 programs that have been established in Victoria over the past seven years. As this is a Victoria wide study, the participation of your program is critical to achieving the study aims.

Participation in this project will involve an approximately one hour interview with the program manager and each of the your program staff involved in case management. The proposed content of this interview has been listed in Appendix A, which is attached to this form. Apart from the admission criteria and process of inclusion of care-givers in your program, the researcher will ask about the total number of clients on your caseload, the number with have care-givers, and the service provision to clients with and without care-givers. Some other information, such as the age, gender and relationship between care-givers and clients will be sought.

3. Possible Benefits

The possible benefits of this study include finding out about the impact that home rehabilitation has on care-givers and the adequacy of supports currently available to them. This information may assist in the future planning of home-based rehabilitation services by identifying ways that programs can be structured to best meet the needs of care-givers as well as clients.

4. Possible Risks

The researcher does not believe that there are any risks to the staff participants in the study. However, should the staff participants have any emotional or ethical concerns about the interview they may request it be terminated and the researcher will discontinue the interview immediately.

5. Confidentiality and Disclosure of Information

The information collected from each program will not include any identifying information about the program's clients or care-givers. The data will be collected in aggregate form. In any publication, information will be provided in such a way that your program cannot be identified. The staff who agree to be interviewed will be asked not to name or provide UR numbers for the clients or care-givers discussed. The researcher will give each client a number but these will not be linked to any identifying information. The numbers will only be used to keep track of each case during the interview.

6. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation.

7. Results of Project

The Program Manager of each program will be given a written report of the results collected from his or her program within 4 weeks of completion of the interviews. Comparative data from all participating programs will be reported at a state-wide meeting of home-based rehabilitation programs once the research has been completed. This report will be provided during 2002.

8. Further Information or Any Problems

If you require further information or if you have any problems concerning this project (for example, any side effects), you can contact the principal researcher or her principal or associate supervisors.

Principal researcher	Ms Briony Dow (03) 5327 9197
Principal supervisor	Associate Professor John McDonald (03) 5327 9000
Associate supervisors	Ms Wendy Hubbard (03) 5320 3774
	Dr Yvonne Wells (03) 9479 3700

9. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name:	Dr Ian Carsen
Position:	Executive Officer, Human Research Ethics Committee
	The Northern Hospital
Telephone:	(03) 9219 8018

10. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with the Melbourne Extended Care and Rehabilitation Service or Sunshine Hospital.

Before you make your decision, a member of the research team will be available so that you can ask any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw.

12. Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committees of the following Institutions:

The University of Ballarat

The Northern Hospital Human Research Ethics Committee

Information to be collected from program staff

1. Admission criteria for your program

2. Involvement of care-givers in decision to admit

3. The number of current admissions to your program

4. The number of clients with and without care-givers

5. Care-giver profiles for each client with a care-giver
   Age range
   Relationship to client
   Gender
   Current service provision – provided by the program/other
   BI (Barthel Index) of client

6. For clients without a care-giver
   Service provision – program/other
   BI of client

Consent Form
Version 1 Dated 1st October, 2001
Site – Broadmeadows Home Therapy Service

Care-giving in home-based rehabilitation

I have read, or have had read to me in my first language, and I understand the Plain Language Statement version 1, dated 1st October, 2001 .

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I have a copy of the Plain Language Statement and the Consent Form to keep

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I do/do not agree to this interview being taped (cross out whichever is not applicable).

Participant's Name (printed) ....

Signature Date

Witness to Signature (printed) ....

Signature Date

Researcher's Name (printed) ....

Signature Date

Note: All parties signing the Consent Form must date their own signature.

Appendix O Report to care-giver participants

"Care-giving in home-based rehabilitation"

Briony Dow, May, 2002.

1. Introduction

This report is for the care-givers who were interviewed by Briony Dow about their experiences of caring for someone who had been admitted to the Ballarat Health Services Rehabilitation in the Home Program (RHP). This report presents a summary of the findings of the interviews as well as the conclusions drawn from those findings. You have been sent this report for two reasons. Firstly, just to let you know what the study findings were, and secondly, to give you the opportunity to feed back your views about the study findings and conclusions.

If you fill in and return the enclosed reply form, your views (presented anonymously) will be included in the final report. Once the final report has passed the examiners' requirements, it will be available for you to read in the University of Ballarat library.

2. Participants

Twenty-four care-givers participated in the study (21 women and three men). The person they were caring for had been discharged from the RHP some time between April and December 2001. During this time there were 60 care-givers in total (42 female and 16 male) caring for 59 RHP clients, including 25 women and 34 men. Fifteen of the care-givers interviewed were caring for their spouse (13 wives and two husbands); four were caring for their mother (three daughters and one son); two women were caring for their father-in-law; and there was one care-giver caring for her aunt, one caring for her grandfather, and one caring for a friend.

3. Major Findings

3.1 Most of the people receiving care had a chronic medical condition and so the episode of care was much longer than the episode of rehabilitation.

3.2 Care-givers were providing a high level of care, with 18 of the 24 care-givers interviewed providing 24 hour-a day care.

3.3 Care-givers also provided a high quality of care, looking after the care recipient's emotional needs, and generally doing whatever was required, even if that meant going to get Chinese takeaway at 10 o'clock at night!

3.4 Care-givers generally felt that they did not really have a choice about providing the care, either because they assumed it was their responsibility to provide the care, or because there was no-one else to do it.

3.5 Most care-givers did not want the person they were caring for to have to stay in hospital, go into a home or to be cared for by strangers. So even if they had a choice, they preferred to care for the person themselves rather than subject the care recipient to the possible alternatives.

3.6 Care-giving had a big impact on the care-givers' lives. Those who were working or studying had either given these pursuits up altogether, had put them on hold, or had taken some time off. Most care-givers reported that their social lives had been affected as it was hard to keep up with friends, or sporting activities while the care recipient needed such a high level of care.

3.7 Being a care-giver meant considerable financial disadvantage for some care-givers, and most found that they could not easily access carer payments.

3.8 There were very few benefits to care-givers in being care-givers although some said that they enjoyed the company of the person they were caring for and that care-giving had taught them something important about life in general.

3.9 Care-givers were generally happy with the support they received from rehabilitation and community support services but there were some problems identified. These were – lack of consultation about discharge; not being included in decisions that were made about the client; and confusion about services, including what was available, who the workers were, and how the services related to each other. These issues have been taken up further in the next section of this report.

4. Discussion

Although the care-givers were not themselves generally complaining about their situation, there were some problems identified by the interviewer that she thought needed to be addressed. These were - the pressures put upon care-givers to take up the role; the problems (identified above) with support services; and the problems associated with receiving carer payments.

4.1 Social, family and service pressures

The decision about who was to be the care-giver was usually taken for granted by the care-giver, his or her family, and the hospital staff. There was often little discussion between the care-giver and the discharging hospital staff and/or other members of the family about who would take on the care-giving role when the client was discharged to home. There seemed to be a generally accepted assumption that the client's spouse or another female relative, if available, would take on the role. There were only three male care-givers interviewed in this study, however, there were quite a few men who were conspicuous by their absence. For example, the brothers of the daughter care-givers, and the husbands of the daughter-in-law care-givers were only marginally involved in the care provided for their own parents. There were also many more female than male clients in the total sample (all RHP clients admitted between April and December, 2001) who did not have a care-giver (47 female, compared with 27 male clients).

Although there were some male care-givers involved in this study, the predominance of women in the role suggests that there is still a pervasive view in society that it is a woman's role to provide care. This is despite the fact that many female care-givers, including some in this study, are working or studying full-time, and/or have other family responsibilities, such as child-care. These factors seem to excuse most male relatives from caring but not female relatives.

Where there was a care-giver, he or she was clearly relied upon for the client's discharge to home, to ensure that the client was safe at home, and able to participate in rehabilitation. This reliance constituted a pressure in itself as the care-givers realized that the clients would not be able to be at home (where they wanted to be) if the care-giver did not provide the care. Two female care-givers also experienced direct pressure from the RHP staff to provide intimate care (showering) for the client. Thus there were social, family and service pressures that impacted upon all care-givers' in their decision to take up the role and these pressures acted upon women more than men.

4.2 Interactions with support services

Despite the reliance on the care provided by the care-givers interviewed in this study, they were often not consulted about when the client would be discharged to home and what his or her care needs would be when he or she returned home. Despite the general satisfaction with support services, this was one of the few problems identified by care-givers.

A second problem was the lack of knowledge and subsequent confusion about the support services that care-givers were eligible for, who the people were (employed by these support services) and how they interacted with each other. One care-giver suggested that a service map be drawn up that would outline all the agencies involved, the services they provided, and how they worked together.

4.3 Carer payments

All the care-givers who received a payment identified problems associated with gaining access to this payment. These problems were either associated with finding out about the payments in the first place or with the eligibility requirements. For some care-givers it seemed particularly unfair that they were not eligible for a government payment. In one case, the care-giver had to assist her husband in all activities of daily living but she was not deemed to be providing a high enough level of care. In another case, a care-giver had a small income from self-funded superannuation which meant that she was ineligible for a carer payment, despite a very high level of care provision and associated expenses.

In summary, there were three main issues identified. Firstly, there was a greater expectation on women to provide care yet less likelihood that they will receive care. Secondly, all RHP care-givers were relied upon to provide care so that the client could be discharged from hospital therefore saving the health system considerable funds, but they were not recompensed for their contribution. Finally, the RHP care-givers felt that they were not adequately consulted about this contribution or fully incorporated into the care team. These issues clearly needed to be addressed.

5. Recommendations

5.1 Publication and dissemination of findings

One of the aims of this study was to make public the impact of early discharge for rehabilitation upon the care-givers who were picking up the care. Aspects of this study, including some of these findings, have already been submitted for publication in academic journals. The findings have also been presented to a state-wide organisation representing all Victorian home-based rehabilitation programs, including some representatives from the Victorian State Government.

It is recommended that the researcher continues to make the findings public in order to bring attention to the issues identified above. More specifically she should –

- Present the findings to workers from aged care facilities in Ballarat.
- Provide input, based on the findings from the care-giver interviews, to the Department of Human Services working party on home-based rehabilitation.
- Write to Centrelink and outline the problems associated with accessing carer payments that have been encountered by the care-givers involved in this study.

5.2 Direct recommendations to the RHP

It is further recommended that the RHP team be asked to take note of the feedback from the interviews that indicated that, in order to feel part of the care team, care-givers would require –

- To be consulted and given a say about the care recipient's discharge from hospital to home;
- To participate in the assessment of the client's needs and decisions about the support and rehabilitation services that are put in place;
- To be given a full and complete picture of all the people who will be visiting them at home, who they are, where they come from and how they interact with each other;

- To be invited to participate in case planning and discharge planning about the RHP client whilst he or she is on the RHP; and
- To have their contribution acknowledged by the RHP by treating them with the same concern and respect that they treat their professional colleagues.

It is acknowledged that this could only occur with the permission of the RHP client and that the same guidelines should apply to the RHP client as well.

5.3 Service map

A final recommendation is that a service map be drawn up in line with the suggestion by one of the care-givers. This map should document all the agencies that provide aged care and care-giver supports in Ballarat and outline the services they provide, their current staff names and contact numbers. It should also outline the ways in which these services work together. This map should be updated every 12 months and handed out to all RHP clients.

6. Final comment

The complete findings from these interviews are far more extensive and complex than those included in this summary. If there is something that you said in your interview that you want to make sure is included in the final report, or if you do not agree with the conclusions or recommendations outlined here, please complete the attached form or ring Briony Dow on (03) 5327 9197 and she will be happy to discuss the findings with you in more detail. Thank-you again for participating in this study. Hopefully by implementing the recommendations suggested here, and any others you would like to add, the important contribution of care-givers in home-based rehabilitation will gain the recognition and compensation it deserves.

Appendix P Care-giver reply form

Name……………………………………Phone Number ……………

(If you do not wish to be identified by the researcher, do not complete this section)

Do the findings outlined in this report reflect your experiences as a care-giver?

Yes ☐ No ☐ Comment…………………………………………………………

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Do you agree with the way that the findings have been interpreted in the discussion section of this report?

Yes ☐ No ☐ Comment…………………………………………………………

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Do you agree with the recommendations that are included in this report?

Yes ☐ No ☐ Comment…………………………………………………………

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PTO

Are there any other recommendations or comments that you would like to add?

Yes ☐ No ☐ Comment...

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Are you interested in being put in touch with other care-givers who were involved in this study?

Yes ☐ No ☐ Comment...

....

....

Would you like your name and phone number to be given to other care-givers who were involved in this study?

Yes ☐ No ☐

If yes, please sign ....and date...........here.

Thank-you for taking the time to complete this form. Please place in the enclosed stamped, self-addressed envelope and return to me as soon as convenient for you.

If you have any questions about this form or the enclosed report please contact me on (03) 5327 9197.

Thank-you.
Briony Dow

Appendix Q Letter to care-giver participants

13th May, 2002

Dear ,

I am writing to you about the study that you participated in last year as a care-giver in rehabilitation in the home. You may remember that I came to your house to interview about your experiences as a care-giver. It has taken me a lot longer than I expected to complete the all the interviews and to compile the results but I am now sending you a report on the findings of my study.

I would really like to know your views on the study findings so that I can include them in the final report. I have enclosed a stamped self-addressed envelope and a reply form that I would like you to complete and send back to me if you can spare the time.

If you would like to be put in touch with other care-givers who have been involved in this study and you would be prepared for me to give them your name and phone number, please fill out the relevant section of the reply form. If you do not wish to comment on the findings and you don't wish to be put in touch with other care-givers then there is no need for you to reply to this letter.

Thank-you for being part of my study. I would not have been able to complete my research without your cooperation and generosity in sharing your time and experiences with me. Please feel free to contact me on (03) 5327 9197 or my supervisor, Dr. John McDonald on (03) 5327 9000, if you have any further questions about this study.

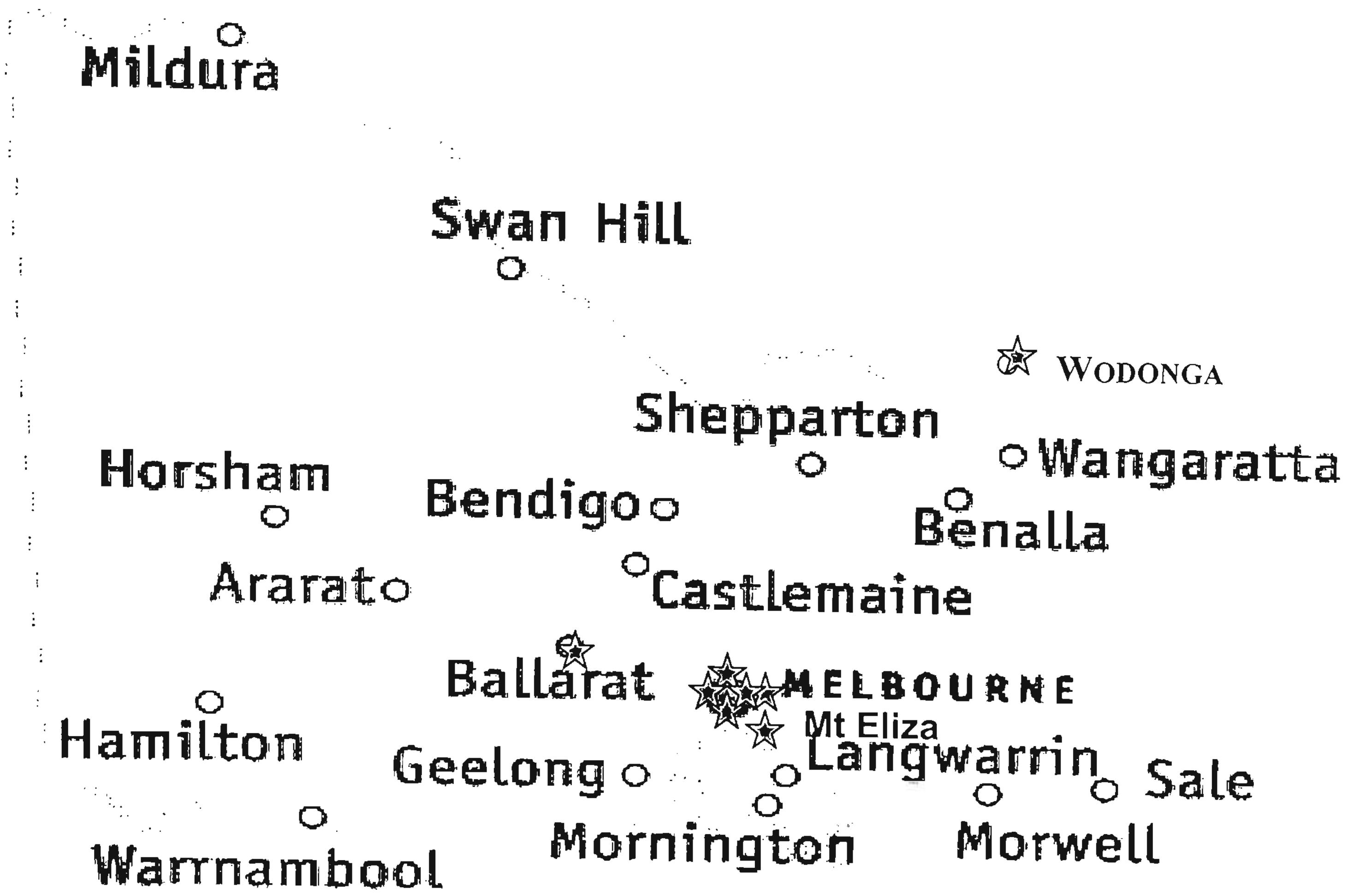
If you have any worries or problems associated with your time as a care-giver that you would like to discuss with someone you could contact your own general practitioner, or Carer's Choice Respite Centre on 1800 351 105, or myself on (03) 5327 9197 and I could help you to work out who would be best for you to talk to.

Thank-you again for being part of this study.

Yours Sincerely,

Briony Dow
PhD Candidate
University of Ballarat

Appendix R Map of Victoria



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