

# The shifting cost of care: early discharge for rehabilitation

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## Abstract

This article tells the stories of two family carers, each of whom is caring for someone who has been discharged early from hospital to have their rehabilitation at home. These stories illustrate the personal impact of early discharge for rehabilitation. The article argues that through its policy of early discharge from hospital, the state has shifted care from hospital to home, resulting in the work of caring and its associated costs being rendered invisible. This is possible because the prevailing ideology on both sides of politics is that individuals — rather than the state — should be responsible for their own and their family's well-being.

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This article tells the stories of two family carers caring for someone discharged early from hospital for rehabilitation at home. A number of issues are raised by these stories. Since governments have moved health care into the home there has been a shift in work and responsibility from the hospital (funded by the state) to home (family). Family carers receive very little support, recognition or compensation. Although support services can be and are, in some cases, provided in a comprehensive way after discharge, they do not cover all of the recipient's care needs and they usually stop after a few weeks, leaving the family to fill the gap. Although family carers describe themselves as willing to undertake this work, they also see themselves as the only ones who can do it. There

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## What is known about the topic?

Throughout Australia there has been a trend to early discharge from hospital for home-based care services.

## What does this paper add?

This article discusses the difficulties carers of home-based rehabilitation patients experience.

## What are the implications for practitioners?

Greater recognition of the role and needs of family carers is required.

is an absence of alternatives that are acceptable to the carer or care recipient. Finally, although the episode of care for rehabilitation can be short term, even short-term care can have long-term consequences for family carers.

The following stories are taken from a series of interviews conducted with family carers in a home-based rehabilitation program in Victoria. Their names and identifying details have been altered to maintain their anonymity. While it is not a new phenomenon for families to provide care during the recuperative phase post-discharge from hospital, they are now taking on the care during the post-acute and rehabilitation phases as well. The rehabilitation care phase was the focus of this study.

## Paula

Paula was in her late 40s and worked as a nurse. She had taken extended leave from her job to care for her mother Amy, who had a total hip replacement after a fall. Amy had a short hospital stay because she was assessed suitable for home-based rehabilitation. Paula's availability influenced this assessment. Paula usually lived and worked in a town about 120 kilometres away from her mother. During the period that her mother

needed care, she left her house unoccupied. She had some paid leave and was planning to apply for the Carer's Payment when that ran out. However, she was concerned about her financial situation as the Carer's Payment would not be enough to maintain her own house in the long term.

During the home rehabilitation episode, Paula prepared the meals, did all the housework, shopping and gardening, and helped Amy with bathing. Paula was keen to help Amy regain her independence, so although she supervised all Amy's activities she encouraged her to do what she could for herself. She didn't mind being there for her mother. She saw herself as the only one who could provide the care, and she planned to stay with her mother until she improved or needed nursing home care. Paula was grateful that her employers had dissuaded her from resigning so 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.

### **Bernadette**

Bernadette was in her fifties with three adult children. She was married and lived with her husband. She worked full-time in a residential care facility and cared for her mother-in-law and her father. Her mother was in a nursing home. About a month before the interview, her mother-in-law and father both underwent surgery on the same day in two different hospitals. Her mother-in-law, Ester, had bowel surgery for suspected cancer, and her father had a total hip replacement. Both were discharged from acute hospital after a short stay. Ester had a brief stay in the rehabilitation ward and was discharged with the home-based rehabilitation program. Although it was possible for Ester to have some support from community services there was a gap between this support and what Bernadette and Ester regarded as an adequate level of care. Ester preferred to have Bernadette look after her so she refused some services, saying, "Bernadette would take care of it". As a result, Bernadette spent 2 to 3 hours every day providing care for her mother-in-law post-discharge from hospital. The district

nurses came in for a few weeks after Ester's discharge to assist her with her stoma and help her in the shower. Meals on Wheels were provided daily and home care once a week, but there was still a lot for Bernadette to do. She visited every day to prepare Ester's breakfast, tidy up afterwards, cook dinner, do her washing, clean the house, make the bed, and once a week she took her to her medical appointment and to shop and pay bills. Bernadette also visited her father every day, took him for regular visits to his wife in the nursing home, and maintained her own house and garden. She described her family caring to her colleagues as her 'geriatric shift'.

When asked how life had changed as a result of her caring role, Bernadette said that she now cooked dinner for herself and her husband later and that her garden had deteriorated, which she found very frustrating. She had taken 2 weeks off paid work when they were both in hospital but had had no respite from home maintenance, cooking and gardening. At the time of the interview, the level of community support that Ester was receiving had decreased and the home-based rehabilitation program had discharged her. However, the level of care Bernadette was providing had only decreased a little.

Bernadette believed that her parents needed care and she was the only one who could provide it. She was angry with her husband as she thought he could do more for his mother and more around the house. She also said that she would love a day off, but that most of the time she tried to "just get on with it". She loved her parents and was fond of her mother-in-law, so she wanted to ensure that they were well cared for and felt loved and included. Bernadette received no community, hospital or income support for this work.

### **The study**

The carers' stories outlined above were part of a study examining family care-giving in home-based rehabilitation in Victoria. The study was a doctoral research project conducted at the University of Ballarat. Its aim was to make visible the work done by family carers in rehabilitation in

the home so that this contribution could be recognised in the development of future early discharge policies and programs. Twenty-four carers and 23 staff from nine home-based rehabilitation programs were interviewed for this study. The interviews with carers were transcribed and analysed by the author for explanatory categories and themes (Strauss & Corbin 1998). A summary of these themes and the study recommendations was sent to the carer participants. Eight respondents made additional comments that were included in the final thesis.

There are two types of home-based rehabilitation funded in Victoria. The 'bed substitution' model aims to replace or reduce the client's stay in hospital and the 'ambulatory' model is an adjunct to hospital rehabilitation. This study included only bed substitution programs.

### **The health service context**

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 reduced to 12 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, patients with these conditions now often go directly home from the acute hospital or have a much reduced length of stay in a rehabilitation ward.

Although advances in medical technology and client choice (Guilleman 1997; Clayton 1995) are partly responsible for this reduction in hospital stay, it has also been prompted by the casemix funding system that was introduced in Victoria in 1993–94 (Swerissen & Duckett 1997). This funding model attaches a dollar amount to each diagnosis, known as DRGs or diagnosis related groups. The dollar amount is based on an expected resource use over an average length of stay for the DRG. This includes the cost of procedures and hotel services. Considering that an overnight stay in a public

hospital ward costs at least \$500, there is 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 the patient and can admit another patient, attracting another DRG-based dollar amount. Rehabilitation in the home is one way of reducing hospital stays and increasing throughput.

### **Rehabilitation in the home**

Since 1995, ten bed-substitution home-based rehabilitation programs have been established in Victoria. Similar programs have been established in other Australian states (Bairstow et al. 1997; Brown 1990). This is part of a broader national and international trend towards early discharge from hospital and the replacement of hospital care with home-based services (Slauenwhite & Simpson 1998; Beech et al. 1999). Other examples of this trend are hospital in the home programs (Gunnell et al. 2000) and domiciliary midwifery services offered to women discharged early from maternity care (Thompson et al. 2000).

Generally (bed substitution) home-based rehabilitation is delivered according to the following program model. The client and their home environment are assessed by an occupational therapist for their safety and suitability for rehabilitation at home, either just before or just after discharge from hospital. Home modifications and equipment are then supplied as required, and a post-discharge program of visits commences. Sometimes several staff members visit each day. Typically, an occupational therapist and physiotherapist visit two or three times a week, an allied health assistant visits daily for exercises and safety routines and a social worker visits weekly to coordinate the care. Rehabilitation nurses may also be involved to supervise showering or for education about aspects of health care such as medication. Home care, Meals on Wheels and pharmaceutical provisions may also be provided by the home-based rehabilitation program.

The client's family carer(s) are generally included in the initial assessment to determine what they can and can not do for the client. Services may be provided for the aspects of care that the carer or client is unable to do. Carers are also expected to assist the client in completing the tasks set by professional staff. Thus, although the assessment and prescription of therapy are conducted by professional staff in the home as they would be in hospital, the day-to-day care of the client and the support and follow through on therapeutic prescription has been largely transferred from professional nursing and allied health staff in hospital to the client and his or her family at home.

### **Evaluation of early discharge programs**

Some evaluative research has been conducted into the effectiveness of early discharge programs in Australia and overseas. Rehabilitation in the home has been evaluated in terms of patient outcomes (Farnworth, Kenny & Shiell 1994; Meeds & Pryor 1990; Widén Holmqvist et al. 1995), participant satisfaction (Dow 1999) and cost effectiveness (Anderson et al. 2000). This research indicates that home-based rehabilitation is at least as effective as hospital-based rehabilitation and has some advantages for the client. As the aim of rehabilitation is to restore the client to his or her optimal level of functioning in their home and community, it makes sense for their rehabilitation to take place in that environment. Home-based rehabilitation has also been found to increase the client's feeling of empowerment (von Koch, Wottrich & Widén Holmqvist 1998).

However, home-based rehabilitation relies on the client's family and friends to be effective. A review of the literature found that the availability of support at home was the main factor that influenced the feasibility of rehabilitation at home (Dow 1999). Despite this, there has been very little research into the impact that early discharge and the provision of services at home has on the client's family and friends. Furthermore, the economic appraisals that have been conducted into

home-based rehabilitation generally fail to include the cost of the family carer's time or the costs incurred by the carer in taking on this role (Anderson et al. 2000; Beech et al. 1999).

### **Care-work as an 'invisible welfare state'**

This lack of recognition and failure to cost care-work is not restricted to home-based rehabilitation or to the current early discharge trend. Cass (1983) argued that in times of labour market recession and contractionist economic policies, such as were seen in the late 1970s and early 1980s, there is an ideological push to re-establish the family as the provider of services for the state. Cass pointed to the non-indexation of the family allowance, cuts in child care and incentives for families to purchase services (such as education and health insurance) privately as aspects of an implicit family policy. She described this policy as "the reinforcement of women's dependency as non-market workers responsible for housework and child-care and the reinforcement of men's obligation to provide income by waged work". Cass argued that by promoting the "traditional obligations and dependencies of families", an "invisible welfare state" was being activated, which relied on the unpaid domestic labour of women (Cass 1983, p. 184).

Feminist authors (for example, Browne 1998) have criticised the way in which women's work in general, and care-work in particular, has been rendered invisible by the prevailing definitions of what constitutes productive activity. Waring (1996) revealed that most domestic activities are excluded from gross domestic product: that is, what has been included and excluded from the United Nations' System of National Accounts definition of 'economic activity'. This exclusion also applies to the work of family carers. In the 1993 System of National Accounts "the care of the sick infirm or old people" when produced and consumed within the same household was specifically excluded from production (United Nations Department of Economic Affairs Statistical Office, 1993, Section 6.20).

The trend towards early discharge in the 1990s and 2000s shares many similarities with the earlier deinstitutionalisation policy. Care in the home and community is seen as a more humanitarian option for care recipients. It is economically attractive for governments in the context of increasing health care costs. There is also a context 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, described by Wilensky in 1975 as a 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 the 2000s the emphasis shifted from entitlement to obligation (Macintyre 1999). The concept of welfare rights has been replaced by notions of personal responsibility, social contracts and mutual obligation (Macintyre 1999; Mitchell 2001). In relation to family carers, however, the concept of mutual obligation is one-dimensional. Despite their obligation, willingly carried out, to take on the care responsibilities discarded by the state, there is no corresponding recognition, compensation or congratulations.

### **The carers’ stories revisited**

The physical and mental consequences of caregiving have been well documented (Han & Haley 1999). The social consequences can be seen in the stories told here. One of the outcomes of individualising social responsibilities is that people become isolated in their roles and feel a strong sense of individual responsibility. Bernadette and Paula felt that if they did complain about their lot the care recipient would suffer further, either by feeling that no one cared about them or by being placed in institutional care. They did not want this to happen. By moving house, Paula moved away from her work, her colleagues and friends

and all her usual social outlets and supports. Through the sheer volume of her work, Bernadette had no time left for social or leisure pursuits. They felt that they couldn’t ask too much of anyone else even though so much was being asked of them.

The care-work also had work and financial consequences for these women. Paula had to take indefinite leave from her work, with the prospect of eventually having to apply for the Carer’s Payment. This would not be financially viable for her in the longer term, and would probably mean selling her house and resigning from her job in order to manage. Even if Amy recovered to the point of independence, Paula had already missed out on a period of pay, superannuation contributions, annual leave accrual, and the other professional development opportunities associated with work. Bernadette had to take some time off but had so far managed to maintain full-time work, housework and care-work. She had out-of-pocket expenses, including the costs associated with travel, washing, purchasing groceries and medications and employing someone to maintain her garden.

Thus, the shift in care-work from hospital to home is not cost neutral. The costs are just not currently recognised or counted. By discharging people early from hospital, and only replacing some aspects of hospital care in the home-based alternatives, there is a gap in service provision that has to be taken up by someone; otherwise the client would not be safe at home. Currently, this gap is being filled by family carers at considerable cost to themselves. If this situation is to continue, it is crucial that the role played by family carers is recognised. They should be supported, compensated and congratulated for the significant contribution they are making, not only to their own families but to the community as a whole.

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## Competing interests

None identified.

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