



greater or lesser degrees of stress, and therefore how to intervene to alleviate stress. This paper argues however, that the focus on stress and burden has led to an individualistic understanding of caregiver problems and that the resultant supportive interventions have been largely unsuccessful. The studies reviewed for this research indicated that caregivers were often reluctant to use services, associating them with personal failure (Heenan, 2000) and even where services were used, there was very little difference in outcomes for caregivers (Geddes & Chamberlain, 1994; Forster & Young, 1996; Logan, Ahern, Gladman & Lincoln, 1997).

## A feminist perspective

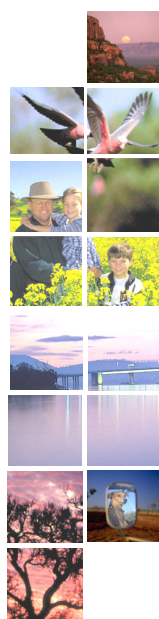
Earlier feminist critiques of the de-institutionalisation policies of the 1970s and 80s, argued that rather than being a shift in care from institutions to the community, de-institutionalisation represented a shift in care from the state to families, and in particular to women (Finch, 1990; Wærness, 1990). This reliance on the unpaid labour of women, rather than on services provided by the state was described by Cass (1983, p.184) as the “invisible welfare state”, as women’s caring labour was not recognised or compensated for in any way. The study presented here took a critical feminist approach to investigating the position and experiences of caregivers in home-based rehabilitation in order to identify whether there had been a shift in care from the state to women, and how this shift was experienced by the caregivers themselves. This paper reports on the second aspect of the study, the experiences of 24 caregivers who had been involved in a home-based rehabilitation program.

## DESCRIPTION OF THE STUDY

### Method

The study consisted of interviews with 24 caregivers (based in a regional centre in Victoria), and 23 staff from eight home-based rehabilitation programs across Victoria, as well as data collection about current clients and caregivers from the eight programs. This paper will mainly focus on the findings of the caregiver interviews. The caregivers were recruited via the home-based rehabilitation program over a nine month period. The 24 caregivers who agreed to participate in the study were interviewed in their own home (with one exception — a student who preferred to be interviewed at university) and the interviews lasted for between 30 and 90 minutes. An interview schedule that included both open and closed questions was used and the interviews were taped. The interview transcripts were coded according to the research questions, for example any comments about entry into the caregiving role were grouped and categorised, and also according to Strauss and Corbin’s (1998) grounded theoretical approach, which was used to allow the participants own perspectives to emerge. The technique used was to examine the transcripts of the caregiver interviews line by line and label the concepts that seemed to synthesise 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, and finally into categories that had explanatory power for all the cases.

Finally, a summary of the study findings, analysis and recommendations was forwarded to the participants to enable them to check and comment on the



All 24 caregivers were caring for someone who had been recently discharged from hospital (with the exception of one client who had avoided hospital admission entirely) to undergo their rehabilitation at home with the support of a home-based rehabilitation program. This meant that the client had been assessed as requiring intensive rehabilitation but had also been considered by hospital staff to be safe to have rehabilitation in their own home. Once discharged from hospital the client was visited by a team of rehabilitation professionals, including occupational therapists, physiotherapists, speech pathologists and rehabilitation nurses, to complete an individualised rehabilitation program based in their own home. Community services, such as Meals on Wheels, Home Care, and District Nursing were brokered (organised and paid for) by the rehabilitation program as required.

As expected, there were more women than men caring for home-based rehabilitation clients, both within the interview sample, and across Victoria. The major themes that emerged from the interviews were associated with the assumption of care, the nature of care, and the caregivers' experience of the formal care system.

It was clear from the interview sample and in the population of caregivers from whence the sample was drawn that caregiving is still a women's issue – at least in rural areas. Of the 24 caregivers interviewed, 21 were women. In the population from which this sample was drawn (all home-based rehabilitation caregivers involved in the program over the nine month period) there was also a far greater proportion of female than male caregivers (70% female). Although in the state-wide data collected there were more female than male caregivers (59% female), the gendered nature of caregiving was more apparent in rural than metropolitan areas, with 66% female caregivers in the two rural programs (n=29) compared with 56% female in the metropolitan and outer metropolitan programs (n=60).

Caregiving was presumed rather than volunteered. It was presumed by the caregivers, their families, and the wider community that they (usually the client's spouse or another female relative) were willing and able to provide the care needed in order to discharge the client to home.

Many caregivers stated that they felt it was “the natural thing to do”, or “the right thing to do”, or that they had no choice but to provide the care. This presumption that the designated caregiver would provide the care was not usually questioned by the caregiver, their family, or the staff in home-based rehabilitation. From the researcher’s perspective, however, it was often not at all clear why the caregiver had been designated to provide care. For example, a daughter-in-law caregiver who was providing care for her father-in-law (the home-rehabilitation client), her own father, who lived in his own home, and her mother who lived in a nursing home, was also holding down a full-time job and doing most of the house-work, gardening and cooking for her own household, consisting of herself and her husband. Apart from her husband, there were other relatives living locally, but she was the one of whom the caregiving role was assumed. Another daughter-in-law caregiver, trying to explain why she had been designated as the caregiver for her father-in-law said, “it just happened...he rings when things go wrong, so he doesn’t really ask...it just sort of happens”.

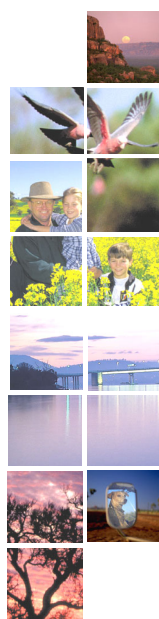
It seemed that this assumption was in part a gendered assumption. Consistent with the previous literature on caregiving (for example, Arber & Ginn, 1990) the male caregivers in both the caregiver interviews and the state-wide data collected for this study were mainly older spouse caregivers. The assumption that spouses will care for each other seemed to be reciprocal across genders. However, in this study, as in most of the caregiving literature, there was a much broader range of relationship groups among the female caregivers. It seems that if there is a spouse available, it is assumed that he or she will provide the care. If not, a female relative becomes the caregiver.

Caregivers were often motivated by the desire to avoid institutional care for their relative. They saw themselves as having no choice but to provide care because care by strangers in a strange environment was not seen as an option. For example, one caregiver said, “I couldn’t bear the thought of someone like him not being able to defend himself. A rehab. hostel would kill him”. Hospital care was also seen as a lesser option for both the client and the caregiver. For the client being at home was seen as a better option because “they get better quicker in their own home”, and because the client often wanted to come home. Another caregiver commented that she didn’t want her father-in-law to “be a patient”, by which she meant she did not want him to become passive and dependent. “If he had gone into hospital I think he would have turned into a patient and I didn’t want him to.” Also having the client at home saved some caregivers from having to go and visit the client in hospital. So although care at home was assumed rather than volunteered it was often seen as the best (or only) option by the caregivers.

## THE NATURE OF CARE: PUTTING LIFE ON HOLD

Home rehabilitation clients were typically frail and chronically disabled. Without the caregiver’s support, they would not have managed at home. All of the 24 caregivers interviewed said that they did not think that the care recipient would manage at home without them.

Many caregivers said that caregiving meant putting life on hold. Eighteen caregivers were providing 24-hour a day care. For seven caregivers this meant working around





## INTERFACE WITH THE FORMAL CARE SYSTEM – CAREGIVERS AS CLIENTS OR PART OF THE CARE TEAM?

However, caregivers were less satisfied with the extent to which they were informed and consulted about aspects of the client's care plan that affected them. For example, consultation about discharge from hospital, and discharge from the home-based rehabilitation program were identified as problem areas for caregivers. One caregiver stated that, "No-one told me beforehand or gave me any warning that he was going to be coming home. " Another caregiver had found both the discharge from hospital and the home-based rehabilitation program to be unexpected and poorly explained. She described the discharge from the home-rehabilitation program,

Given the level of care that caregivers were providing and the extent to which they were relied upon in order to discharge the client safely home, it was critical that they were informed about the discharge plan for the care recipient, but they often reported that they had little or no warning of the client's home-coming. Even in cases where information was actively sought, it was not always possible for the caregiver to gain access. For example, one caregiver was advised to come into the ward between 9 and 11 and wait for the doctors to do their rounds in order to find out when her father-in-law was likely to be discharged. As she was caring for three small children it was not possible for her to come in to the hospital and wait. She said,



Caregivers also encountered problems with the income security system. Only ten of the caregiver sample were receiving any government payment. Five were receiving the Carer Payment, equivalent to a pension, and five were receiving the Carer Allowance, paid at the rate of \$82 per fortnight. Several caregivers said that they had only just found out about the payments and some were having problems with the Carer Payment when they took on part-time work. One caregiver said,

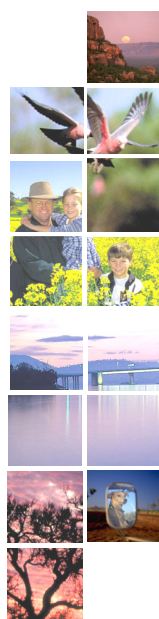
there is a lot of running around with the Carer Payment. Like this week I worked one day and that's given me a day of running around to do...Most carers would be discouraged from working outside the care environment for that reason.

## DISCUSSION

The caregivers interviewed in this study were clearly making an considerable and critical contribution to the successful implementation of the home-based rehabilitation program with which they were involved. The state-wide research conducted for this study confirmed that this was also the case in other home-based rehabilitation programs. The staff interviewed in the second phase of this study were aware of the important role played by caregivers and usually offered social work support and counselling to caregivers as well as services brokered in for the client that served to relieve some of the caregiver's workload. However, in line with most of the literature on caregiving to date, the staff were concerned about caregiver stress and strain so caregivers in these programs were seen as clients or service consumers, rather than part of the service provision or rehabilitation team.

While the caregivers often appreciated these supportive interventions, they preferred to manage without them. The problems that caregivers identified were more associated with information provision and consultation than service provision. What caregivers said that they wanted was

- to be consulted and given a say about the care recipient's discharge from hospital to home
- to participate in the assessment of 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 home-based rehabilitation client, whilst he or she is participating in home-based rehabilitation
- to have their contribution acknowledged by the home-based rehabilitation and hospital staff by treating them with the same concern and respect that they treat their professional colleagues
- to be provided with information about and stress free access to their income security entitlements.



These ideas have already been discussed with the home-based rehabilitation team that participated in this part of the study and various measures have been put in place to address these caregiver concerns. For example, each caregiver is now given a personalised map of the services and personnel who will be involved in the client's rehabilitation program. It is important to acknowledge, however, that the staff are also subject to structural constraints that impact upon their work with caregivers. The interviews with program staff revealed that they too felt that caregivers should be more involved in discharge planning, and program planning and evaluation, but they were impeded from doing what they felt needed to be done by workload pressures.

The staff working in these home-based rehabilitation programs experience considerable pressure to facilitate early discharge from the acute and sub-acute wards of the hospitals with which they are associated. They are also expected to limit the client's length of stay in the home-based rehabilitation program. Most programs are funded through the Classification of Rehabilitation and Funding Tree (CRAFT) funding model, and this is contingent upon the achievement of throughput targets. One of the economic benefits that has been associated with these types of programs is that they increase the capacity to expand case-loads through increased throughput (Beech, Rudd, Tilling, Charles, Wolfe, 1999). This increased case-load means that the work associated with admission and discharge increases, often without increased staffing resources to manage the change. This in turn impacts on clients and caregivers as they tend to be the ones left out of the information and decision-making loop in times of high client turnover.

## RECOMMENDATIONS

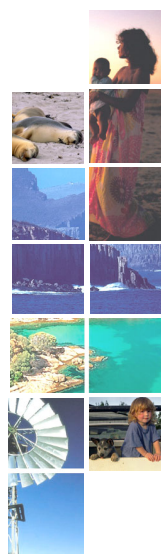
These findings should be presented to staff from all home-based rehabilitation programs in Victoria and Australia so that program can implement changes in line with those requested by caregivers.

A caregiver representative should be included on any future state or national government policy or program development in this area.

The specific problems identified regarding income security payments should be made known to Centrelink, the Australian Government Department responsible for income security, with recommendations for changes to eligibility requirements for Carer Payment.

## Concluding comment

The caregivers experiences described in this paper show that early discharge from hospital in a rural setting is not cost neutral. It comes at considerable cost to the lives of family caregivers. The paper recommends that the contribution of these careworkers be acknowledged. This acknowledgment should not take the traditional form of treating caregivers as part of the client system and therefore seen as "stressed", "coping", or "not coping". Rather caregivers 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.

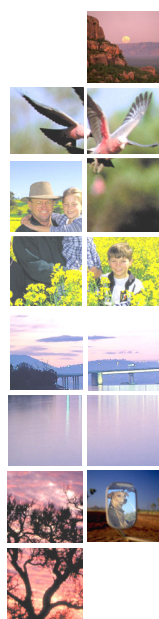


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## PRESENTER

**Briony Dow** has just completed her PhD by research at the University of Ballarat. She is a social worker with practice and research interests in aged care, consumer participation in decision making, and rural and regional health. She also teaches part time in the Rural Social Welfare course at the University of Ballarat.

The study that Briony will be reporting on today investigated the impact of early discharge from rehabilitation hospital on family caregivers. The study consisted of two phases. The first phase involved interviews with 24 caregivers who were involved in a home-based rehabilitation program in a regional centre. The second phase involved data collection and interviews with staff from eight Victorian home-based rehabilitation programs, including two in rural and regional centres. The paper that Briony will present today focuses mainly on the first phase of the study, the caregiver interviews.

