

What price early discharge? Informal caregiving in home-based rehabilitation

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INTRODUCTION

The trend to early discharge

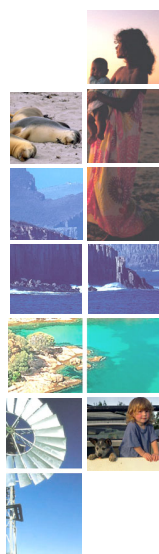
Over recent years there has been an international trend towards shorter hospital stays, and the provision of alternative health services in the home (Philp, 1996). This paper focuses on one example of this trend, home-based rehabilitation. Other examples are hospital in the home programs (Gunnel, Coast, Richards, Peters, Pounsford & Darlow, 2000) and domiciliary midwife services offered to women discharged early from maternity hospital (Thompson, Roberts, Currie & Ellwood, 2000). In Victoria, home-based rehabilitation has been available as an alternative to hospital-based care since 1995 when the first home-based rehabilitation program was established at the Greenvale campus of the North-West Hospital. Since then another ten programs have been established in Victoria as alternatives to in-patient care. Similar programs have also been established in other Australian states and overseas (for example, in Western Australia, Bairstow, Asche, Heavens & Lithgo, 1997; and in Sweden, Widén Holmqvist, de Pedro Cuesta, Holm & Kostulas, 1995).

Whose interests are served by early discharge?

It could be argued that home-based rehabilitation serves the interests of both the service users and the service providers. Being able to be at home, among familiar surroundings, family and friends is important to rehabilitation clients (Dow, 1999). At the same time home-based care is much cheaper than hospital-based care, representing considerable savings to the public purse. The literature on home-based rehabilitation would certainly support this view, with many studies indicating that home-rehabilitation is at least as effective, if not more effective than in-patient rehabilitation in terms of functional outcomes for clients (Widén Holmqvist et al., 1995), as well as being cost-effective when compared with in-patient care (Anderson, Mhurchu, Brown & Carter, 2002). However, there has to date been very little focus on the impact that these programs have on family caregivers. There has been no calculation of the cost of caregiver time or the cost of their lost earnings or production in the studies of cost effectiveness (Moffa-Trotter & Anemaet, 1999).

Caregiver research

Over the past 20 years there has been considerable research into family or informal care, leading one academic to ask, "Is there anything left to say about family caregiving?" (Miller, 1997). However, most of the research has focused on the stress and burden associated with caregiving (Han & Haley, 1999; Low, Payne & Roderick, 1999). This research has been important in identifying the main factors associated with



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

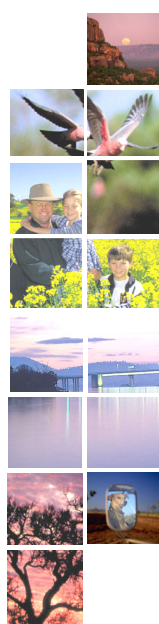
Earlier feminist critiques of the de-institutionalisation policies of the 1970s and 80s, argued that rather than being a shift in care from institutions to the community, de-institutionalisation represented a shift in care from the state to families, and in particular to women (Finch, 1990; Wærness, 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.

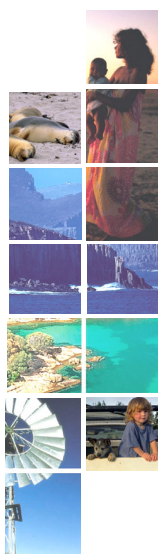
Finally, a summary of the study findings, analysis and recommendations was forwarded to the participants to enable them to check and comment on the



researcher's interpretation of the findings. They were asked to respond if they had anything they would like to add or if they wished to disagree with the interpretations or recommendations. All eight respondents indicated that they agreed with the analysis and the recommendations although some made additional comments regarding their own circumstances and/or the study recommendations, which were included in the final report.

Participants and program description

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.



MAJOR FINDINGS

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.

The gendered nature of caregiving

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).

The presumption of care

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.



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,

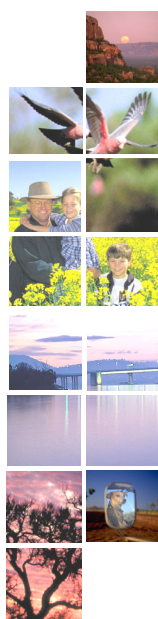
there is a lot of running around with the Carer Payment. Like this week I worked one day and that's given me a day of running around to do...Most carers would be discouraged from working outside the care environment for that reason.

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.

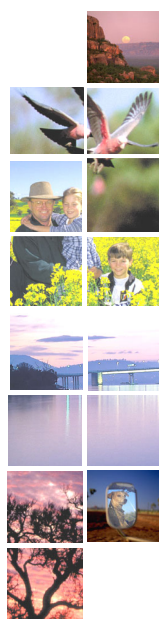


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REFERENCES

- Anderson, C., Mhurchu, C. N., Rubenach, S., Clark, M., Spencer, C., & Winsor, A. (2000). Home or hospital for stroke rehabilitation? Results of a randomized control trial. II: cost minimization analysis at 6 months. *Stroke*, 31(5), 1032-1037.
- Arber, S., & Ginn, J. (1990). The meaning of informal care: Gender and the contribution of elderly people. *Ageing and Society*, 10, 429-454.
- Bairstow, P. J., Ashe, S., Heavens, M., & Lithgo, P. S. (1997). The Home Based Rehabilitation Service: Rationale, operation and outcomes. *Australian Health Review*, 20(2), 55-67.
- Beech, R., Rudd, A. G., Tilling, K., & Wolfe, C. D. A. (1999). Economic consequences of early inpatient discharge to community-based rehabilitation for stroke in an inner-London teaching hospital. *Stroke*, 30(4), 729-735.
- Cass, B. (1983). Population policies and family policies: State construction of domestic life. In C. Baldock & B. Cass (Eds.), *Women, social welfare and the state*. Sydney: Allen & Unwin.
- Dow, B. (1999). *An evaluation of rehabilitation in the home: Client, carer and staff perspectives*. Unpublished Masters, University of Ballarat, Ballarat.
- Finch, J. (1990). The politics of community care in Britain. In C. Ungerson (Ed.), *Gender and Caring: Work and welfare in Britain and Scandinavia*. Hemel Hempstead: Harvester Wheatsheaf.
- Forster, A., & Young, J. (1996). Specialist nurse support for patients with stroke in the community; a randomised controlled trial. *British Medical Journal*, 312, 1642-1646.
- Ganzer, C., & England, S. E. (1994). Alzheimer's care and service utilization. *Health and Social Work*, 19(3), 174-181.
- Geddes, J. M. L., & Chamberlain, M. A. (1994). Improving social outcome after stroke; an evaluation of the volunteer stroke scheme. *Clinical Rehabilitation*, 8, 116-126.
- Gunnell, D., Coast, J., Richards, S. H., Peters, T. J., Pounsford, T. J., & Darlow, M. (2000). How great a burden does early discharge to hospital at home impose on carers? A randomised controlled trial. *Age and Ageing*, 29(2), 137-142.
- Han, B., & Haley, W., E. (1999). Family caregiving for patients with stroke; review and analysis. *Stroke*, 30(1), 1478-1485.
- Heenan, D. (2000). Informal care in farming families in Northern Ireland: Some considerations for social work. *British Journal of Social Work*, 30(6), 855-866.



- Logan, P. A., Ahern, J., Gladman, J. R. F., & Lincoln, N. B. (1997). A randomized controlled trial of enhanced Social Service occupational therapy for stroke patients. *Clinical Rehabilitation*, 11, 107-113.
- Low, J. T. S., Payne, S., & Roderick, P. (1999). The impact of stroke on informal carers: A Literature review. *Social Science and Medicine*, 49, 711-725.
- Miller, B. (1997). Is there anything left to say about family care-giving? *Family Relations*, 46(4). 451-453.
- Moffa-Trotter, M. E. & Anemaet, W. K. (1999). Cost effectiveness of home rehabilitation: A literature review. *Topics in Geriatric Rehabilitation*, 14(4). 1-22.
- Philp, I. (1996). Comment: Community alternatives to hospital care. *Reviews in Clinical Gerontology*, 6, 195-196.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research* (Second Edition). Thousand Oaks: Sage.
- Thompson, J., Roberts, C., Currie, M. A., & Ellwood, D. A. (2000). Early discharge and postnatal depression: A prospective cohort study. *Medical Journal of Australia*, 172, 532-536.
- Wærness, K. (1990). Informal and formal care in old age: What is wrong with new ideas in Scandinavia today? In C. Ungerson (Ed.), *Gender and caring: Work and Welfare in Britain and Scandinavia*. (pp. 110-132). Hemel Hempstead: Harvester Wheatsheaf.
- Widén Holmqvist, L., de Pedro Cuesta, J., Holm, M., & Kostulas, V. (1995). Intervention design for rehabilitation at home after stroke: A pilot feasibility study. *Scandinavian Journal of Rehabilitation Medicine*, 27, 43-50.

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.

