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COMING TO TERMS WITH BURDEN IN HOME CARE*

Valerie Braithwaite

Nursing home care has come to be seen as the least preferred form of care for the frail elderly from two perspectives. From the government's point of view, nursing homes are expensive to run, and with the implementation of the McLeay Report (1982), we have seen a determined effort by policy makers to keep the elderly in the community for as long as possible. While the government's reaction to nursing homes is horror at the expense, the elderly themselves and often their families are afraid of them (Social Welfare Action Group, 1982). Nursing homes, as the community sees them, are institutions which threaten cherished values and basic rights. Institutionalization involves a loss of freedom — schedules and rules restrict choice. Institutionalization also involves a loss of individuality — one's possessions are relinquished and one's privacy is disturbed. Nursing homes also separate the elderly from the community with residents being physically and sometimes psychologically distanced from family, friends, and neighbours.

The alternative, of course, is home care, and this is the sort of care received by most frail elderly. There are hidden costs in this practice, however, costs which are borne largely by those people who find themselves in the role of primary caregiver. For those frail elderly who are only slightly handicapped, assistance is likely to come from a number of sources. A neighbour might pop in with the mail or watch to see that a blind goes up first thing in the morning, Meals on Wheels might provide the midday meal, a daughter might deliver the groceries in the afternoon, and a son might ring to check that all is well. As dependency increases, however, the various sources of assistance diminish in number until the provision of care is concentrated in one person. What is more, there is a pattern in the selection of the caregiver. If a spouse is available and able, he or she will become the carer. If not, a child will step into the caregiving role, most commonly a daughter, but sometimes a daughter-in-law. In other words, when the McLeay Report (1982) refers to the desirability of community and informal support rather than institutionalization, what they are talking about in a significant proportion of cases is care by spouses and care by daughters and daughters-in-law. There is a dangerous tendency to assume that care is dispersed among a group of people. Repeatedly studies have shown in both Australia and overseas, that when the going gets tough, one person takes on the responsibility.

In shouldering caring responsibilities, caregivers confront a number of problems. They experience a number of losses — financial and employment sacrifices are made, friends are contacted less often, and one's social life or leisure activities are restricted, freedom and privacy are reduced, and sleep is often lost. Unwelcome changes are also introduced. The household is disrupted, family life is disturbed, and other household members can feel resentful at the intrusion of their frail elderly relative. And then, of course, there is the actual care that must be provided. Lifting, feeding, bathing and assisting with toileting provide caregivers with a full-time workload, to say nothing of the other responsibilities they must sometimes assume, such as organizing finances, outings, and maintaining the "old house".

These sorts of experiences in the caregiving role have been well documented now. They have led in fact to some new social science terminology. We now talk about the burden of home care. I actually find the term difficult to accept in its current usage. That's not because I underestimate the problems of home care. My reservation is that burden is one of the most guilt inducing terms social scientists could have picked. At times, burden has been equated with the disabilities of the person being cared for and such a usage is widespread in the community. We hear elderly people say "I don't want to be a burden on anyone" and it's obvious that this is a considerable worry for them. I don't accept, however, that dealing with disabilities themselves are burdensome, and, in fact, there is data to support this. A number of studies have failed to find any relationship between level of disability and stress in the caregiver (Cantor, 1983; Gilhooly, 1984; Zarit et al., 1980). Child rearing equips women, if not men, very well for feeding, dressing, bathing and comforting others. That's not to say caregiving is not hard work. Carers acknowledge that it is, but rarely is the work the thing that carers see as a major problem.

The other way we see burden used in the literature is that it is the carer's problem. Burden is the degree to which caregivers are upset by providing care to their elderly relative. Some people have the endurance, the stamina and dedication to care, others do not. I find this usage unacceptable as well. It too is guilt inducing in that it encourages carers to strive for martyrdom and stoicism. Carers have a right to express their upset and distress, without others inferring that they are burdened by caregiving. When the health of a much loved family member deteriorates, distress is a natural reaction for the primary caregiver. In our haste to

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popularize the burden-concept, we have failed to distinguish distress that carers feel on behalf of the person they are caring for from distress they might feel on their own behalf because they must provide the care.

I think if we must use the term burden, we have to think of it not as a characteristic of the receiver of care nor as a characteristic of the provider of care. Instead burden is the mismatch between what the receiver needs and what the carer can or will give. Where caregivers see needs that they are unable or unwilling to satisfy, we have a caregiving situation which is a burden. In this way neither party has to bear total responsibility for home care not working out. An appropriate analogy is the job situation. Some nurses may be excellent with the cognitively impaired, but fall apart in intensive care. We don't blame the patients, we don't blame the nurse. We allow individuals to find what suits them. In the caring situation, neither caregivers nor carereceivers have the chance to shop around. Therefore, chances are that there will be a mismatch between what is needed and what is provided. Our first task is to convince carers and care-receivers that it is not all their fault, that the situation is a difficult one, and it's difficult for everyone. Seeing caregiving in this light paves the way for caregivers to feel able to use external resources to correct the mismatch, or at least lessen the gap between what the carereceiver wants and what the carer can give. Interviews with 144 caregivers in Canberra suggested considerable reluctance to turn to outside support when providing care for a close relative (Braithwaite, 1986).

In considering the specific external resources which can be useful in the caregiving situation, it is helpful to try to tie down the particular aspects of caregiving which are likely to create burden. I have already alluded to the similarities between providing care for children and providing care to disabled elderly adults. The losses are the same — work sacrifices are made, leisure activities are dropped, friends don't call as readily as before, social life becomes non-existent, and sleep is lost. Changes take place — the house is in chaos, chores are not done, and husband and children feel that their place has been usurped. One has to deal with considerable dependency in both cases, and sometimes even anti-social behaviour.

In spite of these parallels we all know that there is a difference. The first factor arises from the importance that our society places on independence and personal growth. Caring for a child results in maturation and independence, leaving parents with pride and a sense of accomplishment. An elderly person on the other hand grows weaker with care, loses independence, a sense of self-worth and sometimes even loses touch with reality, leaving carers with feelings of hopelessness and frustration. The difference is a difference of outcomes. A child's growth is reinforcing. An elderly

person's decline is a point of embarrassment, perhaps even shame, and a constant reminder of the inevitability of the even greater loss to come.

A second factor is the unpredictability of caregiving for the elderly. The course that an illness takes cannot always be predicted. De-development fails to conform to the orderly pattern of development. While parents have some idea of what is ahead of them in child rearing, caregivers of the elderly are often unprepared. In particular, they often have little idea of how long they will be required to provide support.

The third difference between aged care and child care is the quality of the emotional involvement. Caring for a child has overtones of happiness, security and a future. Caring for the frail elderly arouses quite different feelings — anxiety, sometimes the realization that there is no hope, the preparatory grieving process, and often depression.

The fourth factor which differentiates care for the young from care for the aged is time. There is a right time to care for the young. There is no right time to care for older adults. Where parent care is provided, it is likely that the caregiver will have a husband, children, and perhaps even a job. To provide for an elderly person at such a time is a distraction from the caregiver's already time consuming commitments.

Even when care is provided after the children become independent, we have a situation where parent caring is eating into the period when couples are planning to enjoy life to the full — to travel, move to the beach house, retire early, or for some women, pursue a career. This is their time to reap the rewards of their labours and they are asked to sacrifice them.

Where caregiving is experienced at a later stage, often when a spouse is being cared for, a new kind of problem emerges. The carer's own ageing is likely to set limits on just what can and cannot be done. As the caregiver's physical well-being fluctuates, so too does the caregiver's capacity to meet the needs of the carereceiver.

Finally, caregiving to elderly people can be distinguished from care for children by choice. These days children are usually planned at a time which suits parents. When unplanned, there is time for parents to adjust to and prepare for their new role. In contrast, caregivers of the elderly respond to an immediate and often unexpected need in another. Given the strength of family ties, caregivers have little choice but to give and give immediately.

I would therefore argue that burden in home care is largely the result of the difficulties that we as a society experience when we have to deal with falling independence, it has to do with our emotional involvement, more specifically our fears and sadness at losing someone we love, it has to do with the timing being wrong because of other commitments and physical limitations, and it is has to do with uncertainty and

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having little control and choice over the matter. What then can we do about the burden in home care?

I have already mentioned that as dependency increases, caregiving becomes the responsibility of one person. A large part of this is the emotional involvement and the embarrassment we feel about dependency. It is true that outsiders sometimes distance themselves, but just as often, the caregiver and care-receiver distance them. In our Canberra study, 73% of carers acknowledged that friends and relatives offered assistance. Only half the sample had accepted such offers, however, and only half had initiated requests for help. Carers must learn to ask for help — from friends and from family — and they must not be sensitive to having their requests occasionally rejected. The informal network is a valuable network for caregivers to tap.

The second problem that we can do something about is the problem of time — too much to do in 24 hours, and other things that the carer desperately wants to do but can't because of caring responsibilities. On this issue, it is very important to distinguish carers of spouses from carers of parents. Carers of parents have serious role conflict problems. They need to be and want to be in two different places at once. The pressures of work, children, spouse, and parent often conflict. They need someone to care for their elderly dependant while they are at work and while they spend time with their children and spouse. For this group, granny sitting services are vitally important. If they work or want to return to the workforce, day care 5 days a week from 9 to 5 also becomes crucial. If they want a family holiday, respite care for up to 4 weeks is essential. For these families, housekeeping and meal preparation support is far less important.

For spouse carers, particularly those who have health problems themselves, services such as Home Help, Meals on Wheels and home maintenance schemes have an important role to play. Having a minder so that caregivers can do their shopping can also be valuable. Other needs are occasional day care, occasional visits from a minder, and emergency short-term respite care. I say the terms occasional, emergency, and short-term because spouse carers rarely like to be separated for too long. In the spouse situation, caregivers and care-receivers see themselves as a couple, and prolonged separation often causes distress to both. The sorts of needs spouse caregivers are most likely to have are a few days to catch up on sleep, a weekend interstate to celebrate family occasions such as the birth of a grandchild or a brother's golden wedding anniversary. Although, spouse caregivers may be loathe to relinquish their caregiving responsibilities, it is important that they do not withdraw from the com-

munity entirely, severing their informal network as they do so. The network is important, and the spouse caregiver must be encouraged and given the opportunity to maintain it.

So far I have talked about strategies which provide relief from the caregiving role. The other way in which services can ease the burden of care is assisting caregivers come to terms with what has happened to them. Caregivers do not have a Dr Spock to turn to to understand their uncertainties and concerns. There are no handbooks on de-development in the elderly as there are on development in children. Understanding the caregiving experience is provided through self-help groups and through contact with professionals. In our Canberra study, the impact of one particular group of professionals was particularly noteworthy.

Community nurses ostensibly ease the workload by helping with bathing, showering, dressing, administering medication etc. Just as important, however, was the role they played as confidant, adviser, and friend to the caregivers. One of the things that caregivers find most difficult is shouldering the entire responsibility for the well being of another person. The community nurse shared that concern, anguish and responsibility. The community nurse cared for the caregiver.

Conclusion

Providing home care for the frail elderly is not a responsibility for which families are well prepared. The difficulty of assuming this responsibility is exacerbated by constant reminders that one may not be doing enough. So often families must witness degeneration that cannot be reversed, they are taken off guard by changes that they may not be expecting, they experience feelings of helplessness and loss and grief at what lies ahead, and they have other responsibilities which compete with their caregiving commitment and which leave them feeling exhausted and guilty. Few would argue that caregivers should face these problems alone. Too many committed carers, however, suffer silently because of their belief that caregiving is their responsibility and theirs alone. Carers must be helped to realise that they are undertaking a difficult task and that their problems are not unique. Imputations of burden and feelings of guilt must be defused so that caregivers can seek and accept assistance. Finally, the help must be available. The informal network must be promoted and formal services must be ready to meet the needs of the committed caregivers. Unless these steps are taken, caregivers run the risk of becoming prisoners of their own guilt.

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VIDEO

A PROGRAMME SUPPORTING CONFUSED PEOPLE LIVING IN MILPARA HOSTEL

147 ST. BERNARDS ROAD, ROSTREVOR, SOUTH AUSTRALIA

This 40 minute Video follows the lives of 6 confused residents living in Milpara Hostel over a 6 week period. The slides give you an idea of how residents spend their day, their week and their year.

Milpara Hostel is 13 years old and accommodates 76 elderly people unable to be supported in the community. The part of the hostel in which these 6 residents live is partly funded by a special grant from the Department of Community Services. The production of this video was also funded under this grant.

In attempting to explain this particular programme, we felt that it could only be understood by understanding the lives of the individuals who live in it.

We hope that the video demonstrates how a wide variety of needs of each of the six residents has been met but at the same time, clearly indicates where needs are not being met.

The video aims to demonstrate the simplicity of restoring a more typical lifestyle for each resident and some of the benefits of doing so.

The video also aims to demonstrate that while dementia is not reversible, at least some of the confusion and depression in dementing people can be overcome by the restoration of a more typical lifestyle.

We hope the video leaves you with the sense that these are things that could be done for all dementing people, but also with the challenge of how to achieve this in different settings, of how to achieve more, and of when and how to achieve this outside an institution.

The video is made at one point in time. However, the programme had been developing over a number of years and will continue to develop as new needs become apparent or better ways of meeting existing needs are understood.

The video is intended as a training tool for those working in the field, both at a planning or a "hands-on" level. Part or all of it may be used for general education but it was not made with this purpose in mind.

Copies of the video are available from Mrs. Pat Plane, Aged Cottage Homes Inc., 91 Halifax Street, Adelaide, S.A. 5000 — Tel.: (08) 223 3711 — at a cost of \$30.00. There is no copyright and you are welcome to make copies.

Enquiries regarding the programme should be directed to Mrs Thorie Hartland, Milpara Hostel Manager — Tel.: (08) 337 0344.