

THE BURDEN OF HOME CARE: HOW IS IT SHARED?

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Abstract

This paper details the workload of those providing care for the infirm at home. The commitment of these carers and the stresses imposed upon them are documented, as is their reluctance to share their responsibilities with others, particularly those outside the family. For this population, greater professional intervention may be necessary to ensure carers have some relief from caring.

Introduction

Recently, attention has been focussed on the stresses imposed upon families caring for the infirm at home.¹⁻⁶ In response to these findings, a number of community programmes have been urged to assist carers by providing both instrumental and emotional support.⁷⁻¹¹ As yet, however, little data have been forthcoming on the actual willingness of carers to make use of different types of support of either a formal or informal kind. The data presented in this paper shed some light on the types of support that are needed, used and appreciated. In circumstances where care of a loved one is involved, the support that is needed is not necessarily recognized and, even when used, is not necessarily welcomed.

Data base

One hundred and forty-four carers were interviewed through the Woden Valley Hospital Day Care Centres in Canberra and through the ACT Community Nurses. This represented 60 per cent of the carers contacted in the Day Care Centres and an estimated 32 per cent of those contacted through the Community Nurses. The response rates were lower than expected, and in the latter case approximate, because the research staff were unable to seek co-operation from carers directly: professional staff of the organizations acted as "go-betweens" to preserve the confidentiality of their clients.

Interviews with the carers were conducted over two sessions, usually a week apart. In the intervening period, carers were required to answer a self-completion questionnaire. An enormous

range of topics was covered including attitude and commitment to the caring role, personal coping resources, health, both physical and mental, workload, instrumental and moral support from agencies, friends and family, and the past relationship between the carer and the person cared for.

The interviews could best be described as structured but not standardized. Although a structured questionnaire was used, the participants had far more control in the interviewing situation than is usual. Interviewers were prepared to listen to what carers wanted to talk about as well as to their answers to set questions. This was regarded as an essential part of establishing rapport with the carers. The three interviewers involved in the study were trained psychologists with considerable interviewing experience.

The carers ranged in age from 26 to 82, the mean being 58 years. The majority were women though a sizeable 24 per cent were men. The relatively high proportion of men in the study compared to other studies is due to the fact that most were men caring for their wives. The sample comprised 62 people caring for their spouse and 73 cases where the care was provided by a daughter, son, or daughter-in-law. In nine cases the carer was less closely related — a niece, nephew, grandchild or companion.

Those being cared for ranged in age from 23 to 100 (mean = 77) with 96 per cent being 60 years or over. Sixty-one per cent were female.

Assistance provided

The amount of assistance that carers provided varied enormously. In the majority of cases, carers accepted major responsibility for household chores such as shopping (78 per cent), washing (78 per cent), meal preparation (74 per cent), cleaning (53 per cent) and minor household repairs (45 per cent). Fewer than five recipients of care could function independently in the areas of shopping, minor household repairs, heavy cleaning chores, gardening or transportation. These data are consistent with those of Gibson and Rowland who argue that one of the first threats to independent

living is the loss of sufficient mobility and agility to perform tasks such as shopping and changing light bulbs.¹²

The contribution of the carer to personal care ranged from virtually nothing to providing full care. About 17 per cent of patients could function almost independently in terms of dressing, bathing, getting into and out of bed, toileting, eating, moving around the house and taking medication. A similar proportion, 19 per cent were dependent in almost all these areas. The carer again was most likely to be the provider of help when it was needed, the only exceptions being the cutting of toenails, washing hair and bathing. The Community Nurses generally assisted with these activities, though the Day Care Centre's hairdresser and chiropodist also made significant contributions.

Apart from assisting with daily activities, 42 per cent of the carers were involved in day time supervision (apart from the time spent at the Day Care Centre). At night, 73 per cent of carers were not prepared to leave the person they were caring for alone, sometimes for fear that they might fall, other times because of wandering and, in a not inconsequential number of cases, because of the upset it would cause to either the carer or the cared for. In 42 per cent of cases those being cared for had no way of signalling help. Again, supervision was the major responsibility of the carer with assistance from other household members (60 per cent). In only 7 per cent of cases had the carer used private paid help and in only 6 per cent of cases had friends been involved.

Support for the caring role

This study, like those of Kinnear and Graycar, and Jones and Vetter,^{5, 11} demonstrates that caring for a relative or friend at home increases the daily commitments of one person — the carer. What then happens if the carer falls ill? Generally, the family is seen as the short-term backup. Carers were asked what would happen if they were sick for 2-3 days, 2-3 weeks, or 2-3 months. Forty eight per cent of spouses caring thought their children would take over for 2-3 days, though this expectation of support all but vanished when the period was 2-3 weeks or more. In such a situation, paid help at home or hospitalization were seen as more likely alternatives (49 per cent). Where parents, aunts et cetera were being cared for, 39 per cent of carers thought their husband would take over for 2-3 days, and a further 16 per cent thought their children would be their backup. Again this support was short term. For 2-3 weeks carers were most likely to consider paid help at home or

hospitalization (44 per cent). Of particular note is that other family members (for example, brothers, sisters) were not considered viable options; they were mentioned in only 14 per cent of cases. Friends were included by only 2 per cent of the carers interviewed. Thus, in both types of caring situations, providing care was the concern of the carer's own family until formal services had to be called. Neither the extended family nor the carer's informal social network were often considered as alternatives.

When asked about offers of assistance from friends and relatives, 73 per cent of carers acknowledged that they were forthcoming. They were accepted by carers in only 53 per cent of cases, however. Similarly, requests for help had been made by only half the carers (54 per cent). When asked about willingness to seek assistance in the future, 50 per cent gave an unequivocal yes. A further 31 per cent said they would if it were absolutely necessary, and 17 per cent replied, "under no circumstances". In 2 per cent of cases, the carers claimed they had no one to ask.

Overall, carers were extremely committed to their role. Only 16 per cent said they would accept a nursing home or hospital place for the person for whom they cared at that time. Furthermore, the majority saw themselves as competent carers (88 per cent), satisfied with the way they handled problems that arose (78 per cent).

Social-emotional costs

These data describe home care which is family centred, where one person is committed to the role and feels competent in providing care. It sounds ideal, but there are hidden costs.

Twenty-seven per cent of carers had children living at home while they were providing care to an elderly relative. In 26 per cent of cases, carers felt that their spouse or children had moments of feeling resentful about the caring role. Among the most common problems, and the most difficult to deal with for carers, were having less time for the rest of the family and close friends (23 per cent), having less time to oneself (26 per cent), and losing privacy in one's life (22 per cent). These responses suggest that families can suffer as a result of home care.

The carer's mental health, too, appears to be somewhat at risk. Fifty-four per cent complained of anxiety, 36 per cent depression and 61 per cent of irritability, compared with 24 per cent, 21 per cent and 35 per cent respectively in a general population sample.¹³ The vast majority of carers also complained of tiredness (84 per cent).

Formal service use

Having established who is bearing the burden of home care and having raised some concerns about its consequences, the question arises of how to reduce the carer's overload. A number of formal services are available in the ACT to assist carers and Table 1 presents a summary of usage patterns.

Among this sample, the Day Care Centres and the Community Nurses were most widely used—a finding which, to a large extent, reflects the sampling strategy adopted. Among users, however, satisfaction was high as was anticipation of future use. For those not using the Day Care Centres, the major impediment was not the service itself, but rather the patient's unwillingness to co-operate. In 24 per cent of cases, carers said that those being cared for had refused or would refuse to go.

After Community Nursing and Day Care, the most used services were the Mobile Rehabilitation Unit, Shared Care and Home Help. The Mobile Rehabilitation Unit operated from Woden Valley Hospital and advised clients on equipment and household modifications to improve the patient's mobility and independence at home. Little resistance was noted to using the service among those who needed it. Similarly, Home Help was a welcomed service. Its use was restricted by need (54

per cent did not need such assistance) and by eligibility criteria. The percentage of carers using private paid help was 10 per cent.

In contrast, 30 per cent of carers had used Shared Care and a sizeable one-third of them had expressed dissatisfaction with the service. Nevertheless, the need for respite care was reflected in the 33 per cent who saw themselves using it in the future in spite of its problems. Complaints about Shared Care were similar to the reasons given for not using it. Concern was expressed about the suitability of the institutional environment and the need to book ahead (9 per cent) as well as the patients' reactions to being away from home (13 per cent). Respite care has been widely hailed as one of the best ways of temporarily relieving carers of the heavy responsibilities they carry.^{14,15} Our information emphasises, however, that Shared Care falls into the category of a necessary service that is used reluctantly. Perhaps improvements in service quality will increase usage. In some cases, however, concerns about relinquishing the carer role, no matter how temporarily, may give rise to an overly critical appraisal of whatever service is provided. In other words, it may be impossible to provide a service of sufficient quality to enable some carers to freely take advantage of respite care.

TABLE 1

Percentage of carers using services, expressing dissatisfaction and willing to use services in the future.*

	Current use %	Future use %	Dissatisfaction %
Meals on Wheels	17%	14%	4%
Community Nursing	88%	88%	9%
Care at Home (Private agency)	14%	19%	1%
Shared Care (Respite care)	30%	33%	10%
Home Help	27%	26%	4%
Day Centre	58%	53%	6%
Mobile Rehabilitation Unit	52%	54%	3%
Carers' Support Group	8%	8%	1%

* Percentages based on total sample

Among the least used services were Meals on Wheels, Care at Home and the Carers' Support Group. Meals on Wheels was not needed by most patients because their carers were willing and able to take responsibility for food provision (74 per cent). Similarly, Care at Home was not seen to be needed by most carers (54 per cent), though poor knowledge (15 per cent) and the expense (8 per cent) were also reasons given for non-use. For the Carers' Support Group, non-use was attributed to such support being unnecessary (41 per cent), unknown (29 per cent) or not feasible since meeting attendance was impossible (17 per cent).

Conclusions

These data detail the workload and the pattern of service usage by those who care for a relative or friend at home. Before discussing findings further, however, limitations of the sample should be noted. First, carers were service users. Those who are caring without any support from formal agencies either by choice or through lack of information are not represented in this study. Second, the fact that the carers in this study were using services suggests that a conscious decision had been made to try to provide home care. Those not wanting to become involved in home care were probably too preoccupied with finding a nursing home or hospital bed to arrange for services. Third, not all carers contacted agreed to talk with us. It would be foolish not to anticipate a systematic bias here. Those who do not care about home care have undoubtedly escaped our net, as have, possibly, those who care too much.

In this study, the provision of care is heavily concentrated in one person with help coming from the carer's immediate family (spouse, children) and formal services. Even then, use of formal services is

not uniformly high. At the same time, there are clear signs of stress on carers and their families. In other words, carers appear to be a group whose need for outside support exceeds their use of such support.

One explanation for the findings is that "useful assistance" is not available. While this may well be the case, it is the contention of this paper that carers are so committed to providing care, that they find it difficult to take advantage of the support that is available. Why this is so can probably be understood best in terms of some basic social values. Caring was a full-time occupation for those interviewed in this study. Performing well was, therefore, a matter of personal pride. When this value is combined with a sense of family responsibility and independence, powerful motivating factors are operating to guard against reliance on others. Such forces are compounded when those being cared for place their confidence and trust only in their carer.

This is not to suggest that assistance to carers in the form of day care or respite care should not be provided or upgraded in the future. Both services clearly are needed. The point being made is that the emotional involvement of the carers in their role often prevents them from acting on or even acknowledging these needs. In such cases, professionals may have a vital role to play in helping carers and patients not only recognize the necessity for relief from caring, but also find a satisfactory solution. To measure the success of such a solution in terms of enjoyment all round is unrealistic. In many cases, the best that can be hoped for is that carers can recharge their batteries and that those they are caring for can endure their absence.

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