

Qualitative

Many factors make family members caring for an elderly relative with dementia reluctant to use support services

Morgan D, Semchuk K, Stewart N, D'Arcy C. *Rural families caring for a relative with dementia: barriers to use of formal services*. *Soc Sci and Med* 2002 Oct;55:1129–42.

QUESTION: What are the barriers to formal support service use among the family carers of elderly people with dementia?

Design and participants

Focus groups were conducted using a semi-structured interview schedule with 13 family members of people with dementia and service providers from 3 divisional offices of a homecare programme, 7 nursing homes and 4 hospitals.

Setting

Rural areas of Saskatchewan, Canada.

Main results

Barriers to service use identified by family members and service providers included stigma associated with having a family member with dementia; need for privacy; family members' attitudes; need for self reliance; lack of awareness about services; financial constraints; acceptability of services; accessibility of services, and ability of services to offer useful support. Family members focused on a variety of different issues, including

problems in assessment, waiting for nursing home placement and stress. Some family members suggested that accepting help from formal support services was an admission that they could not cope alone. Some service providers suggested that family members may feel guilty for seeking assistance. Homecare staff suggested that service use could be improved by increasing regular contact between service providers and family members and providing more information about the range of support services available.

Conclusions

Caregivers supporting a relative with dementia at home experienced a great deal of stress. Family members and homecare staff both suggested that caregivers were reluctant to use services that might help relieve their stress. The reasons for this reluctance included both caregiver attitudes and perceived deficiencies with support services.

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COMMENTARY

This study corroborates what is known about low service use by family caregivers of dementia patients. Service providers were well represented. In contrast, participation by family caregivers was low, with only 4 family members caring for a demented relative in the community and 9 family members whose relatives lived in nursing homes included. The authors do not report the overall number of community-dwelling dementia patients cared for by family members, but 4 participants are unlikely to represent the total cohort. The results therefore focus largely on formal caregivers' perceptions of the reasons for underutilisation of services by community-based families who care for demented relatives. As Morgan *et al* point out, the degree to which service providers' impressions match those of family caregivers is unknown. Consequently, the results need to be interpreted with caution and cannot be readily used to propose changes in the types of homecare services provided, or changes in the ways in which these services are delivered.

Perhaps Morgan *et al*'s most important contribution is suggesting that the main barrier to service use involves developing supportive, empathic and caring relationships with clients who are initially suspicious, resistive and possibly hostile. For instance, one homecare provider suggested that it took months or years before trust was established, due to resistance from clients. Thus the primary barrier in service use may be unresolved communication and relationship issues at the interface between what the elderly client or family caregiver needs and what services are offered.

The barriers to service use that Morgan *et al* identify apply to urban dwelling caregivers as well as rural families. Two additional issues that may be important in a rural environment are: (1) insufficient availability of clinicians with expert knowledge of dementia, and (2) lack of anonymity since care providers live in the same small community as the families needing their services.

It is well documented that care of someone with dementia is either compromised or enhanced by the mental health status of the caregiver. This study focuses mostly on the "perceived challenges and opportunities of rural dementia care." Family caregivers' emotional responses to their care-giving functions are covered to a lesser extent. There is not a strong focus on how caregivers managed negative emotions or how they engaged in mourning the "loss" of the demented family member due to changes in cognitive and physical function. A possible reason for this gap may be that although the providers included nursing services, personal care, homemaking, respite, Meals-on-Wheels and palliative care by nurses and home health aides, mental health services provided by trained clinicians were not available. The formal caregivers who did participate, although not mental health experts, did suggest that family caregivers were faced with numerous mental health issues such as stress, feelings of uncertainty and helplessness and being overwhelmed.

The study may have benefited from examining caregivers' subjective responses to their care-giving roles, because anger, guilt and depression act as barriers to accessing services. The authors may also have been more successful in recruiting family participants had they offered one-to-one, in home interviews.

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Author's response

The focus groups in this study allowed participants to describe issues of concern to them. Consequently, both family caregivers and service providers played a large role in shaping which topics were covered. The stigma associated with dementia, a major theme in the study, made recruitment of family members difficult. Given the paucity of research in this area, the article focused on general issues in rural dementia care rather than more specific issues such as how caregivers managed negative emotions or how they coped with the "loss" of the demented family member (all important questions but not the *a priori* focus of this study).

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