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

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

**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.

**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 on a variety of different issues, including 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.

**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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