

Practical Implications of Male Caregivers' Experience of Support and Nonsupport

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Background:

Nearly one-third of family caregivers are men, including spouses and sons, however, they have often been neglected in research about caregiving. As caregivers, men rely on help from family and friends, as well as professionals but may find that these individuals are not always helpful, despite good intentions.

Purpose:

This ongoing research is to develop a better understanding of the types, characteristics, and patterns of nonsupport and support experienced by men who are caring for a relative with Alzheimer disease or other dementia.

Method:

Men who are spouses or sons and who care for a relative with Alzheimer disease or other dementia were interviewed in their homes and asked to complete a brief diary. Focus group discussions with men caregivers and professionals are planned to assist us to identify implications of findings for change in programs and policies. Data are analyzed using a thematic form of content analysis.

Results:

Men described experiences that were unhelpful (nonsupportive) in their interactions with family and friends as well as professionals. Examples of unhelpful interactions with family and friends included: failure to follow through on expected assistance, helpers who lacked essential skills to assist, and supporters who were unavailable, or who withdrew support. In their interactions with professionals men described a lack of needed information about resources or the condition of the care recipient, absence of a sufficiently detailed assessment, or a poor fit between available resources and the assistance that they required. In interactions with family and friends, men experienced support when others affirmed their efforts as caregiver and offered a nonjudgmental, listening ear. Men also described supportive interactions with professionals that included: provision of respite care, a relationship with a professional that offered reliable and consistent assistance, and aid from professional

facilitators and peer caregivers in situations similar to their own.

Conclusions:

The findings of this study will provide information useful to professionals in tailoring support programs and policies to help men as caregivers. Information about nonsupport can also assist family, friends, and professionals to avoid actions that result in unintended nonsupport. These examples of men's experience suggest that comprehensive assessment should document the caregiver's anticipated contribution from others, not just the presence of potential helpers. Additionally in planning interventions it may be useful to tailor interventions to the specific characteristics of caregivers. For example, in support groups men found connections with others in a similar role (e.g. spouse) and stage of caregiving trajectory to be valuable, but participation in groups where others' experience differed (e.g. in role or caregiving trajectory) was not supportive. These implications may also be useful in understanding program evaluation results or in designing evaluations because differences among caregivers may explain differences in response to an intervention such as a support group. It is also useful to recognize that actions intended by family and friends to be helpful may nevertheless be experienced as nonsupportive by caregivers.

Challenges:

Addressing the immediate issues of clients and caregivers may make it difficult to assess support resources comprehensively and tailor interventions accordingly. More research is needed to examine male caregivers' experience of support and nonsupport in-depth.



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