

How Do Family Caregivers Describe Their Needs for Professional Help?

Findings from focus group interviews.

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How aligned are the needs of family caregivers with the professional supports available to them? As the first phase of a study of this issue, four focus group interviews were conducted with a total of 40 family caregivers to elicit their views of the kinds of assistance they expect from nurses and social workers.

METHODS

As described in Table 1 (see page 36), most respondents were women and middle to lower middle class. The group was diverse in race and ethnicity. Respondents were experienced caregivers typically caring for recipients with some degree of cognitive impairment. Using standard focus group interview techniques,¹ views were elicited on the central question: In your caregiving role, what has been hard for you that you expected nurses and social workers to help you with? Responses were categorized according to topic, and participants ranked their priorities privately. The interviews were tape-recorded and transcribed. The responses of all 40 participants were included in the categorization of needs; four participants' responses were omitted from the priority rankings because they assigned the same ranking to more than one need. In averaging rankings across the four focus group interviews, topics that weren't mentioned by a particular group and therefore weren't ranked were excluded from the denominator (noted in parentheses in Table 2, on page 37).

FINDINGS

The spectrum of needs included assistance in navigating service systems, learning direct care tasks, understanding disease processes, and managing caregiver stress. Table 2 presents the categories of caregiver needs, their relative priority among all respondents, and the average rankings. Examples of these needs and caregivers' expressions of them are presented below.

Information about available services included daytime activities for care recipients, residential facilities, disease-specific services, and care coordination. Respondents believed that professionals should take the initiative and offer relevant information; one commented:

'If you don't know the question to ask then you can get stuck.'

If you don't know the question to ask then you can get stuck; you don't even know things are possible until two years later because you don't have that kind of training and you don't even know if something is possible.

With regard to **stress management and coping strategies**, respondents sought help with recognizing and addressing burnout, finding support groups, and accessing a crisis hotline.

Assistance with financial issues and insurance coverage included locating sources of aid for various income groups, understanding eligibility rules, making health plan decisions, and long-term financial planning.

Communicating with professionals included assistance with coordinating professional help across care sites, collaborating with professionals in providing care, and finding compassionate providers.

Information on disease included stages of the disease, typical symptoms, and the meaning of particular behaviors.

Recruiting competent help included assistance with checking on qualifications and references and matching available expertise to the needs of the recipient. Typical of the comments was:

TABLE 1. Characteristics of Caregivers in Focus Group Interviews (n = 40)

AVERAGE AGE	63 years
SEX	
Female	95% (38)
Male	5% (2)
EDUCATION	
High school graduate	15% (6)
Some college	22.5% (9)
College graduate	35% (14)
Graduate school	22.5% (9)
MISSING	5% (2)
RACE AND ETHNICITY	
White	67.5% (27)
African American	12.5% (5)
Asian	10% (4)
Latino	5% (2)
Missing	5% (2)
INCOME	
Less than \$20,000	12.5% (5)
\$20,000–39,000	22.5% (9)
\$40,000–59,000	30% (12)
\$60,000–79,000	7.5% (3)
\$80,000–99,000	2.5% (1)
More than \$100,000	5% (2)
Missing	20% (8)
AVERAGE YEARS OF CAREGIVING	3.7
RELATIONSHIP TO RECIPIENT	
Daughter	37.5% (15)
Wife	42.5% (17)
Husband	5% (2)
Sister	5% (2)
Other	10% (4)
PRIMARY CONDITION OF RECIPIENT	
Alzheimer's disease or dementia	50% (20)
Stroke	10% (4)
Parkinson's disease	12.5% (5)
Spinal injury or traumatic brain injury	5% (2)
Multiple sclerosis	7.5% (3)
Other	15% (6)

Note: Totals may not add up to 100% due to rounding.

[It] has been beyond belief trying to hire people and trying to oversee what they do and train them. So I don't know if there is any way for professional nurses and social workers to help people deal with those kinds of issues.

Learning care tasks included training for tasks such as moving or bathing the care recipient, positioning diapers, inserting catheters, using medical equipment, and tailoring care procedures to particular situations.

Respondents believed that professionals should take the initiative and offer relevant information.

Communicating with someone with dementia included strategies for handling problem behaviors, deciding what to say and what not to say, adjusting expectations, and adapting to a new type of relationship. One respondent elaborated:

How to work with a type A male whose brain doesn't work and who still wants to make all the decisions and is very proud. He is all pride, all pride. I don't know how to do it, and it is not written down.

Legal advice focused on topics such as negotiating resuscitation preferences (do-not-resuscitate orders) and advance directives and understanding laws applicable to guardianship.

Information about drugs included adverse events and interactions with other medicines and foods.

Needs related to **addressing end-of-life issues, moving the recipient to a facility, and dealing with family** were ranked lower than the others, but still emerged as important topics. Family issues included involving other family members in care, holding a family meeting, and managing other family problems while caregiving.

DISCUSSION

The focus group interviews delineated 13 categories of needs. Stress management, highly ranked, was also prominent in the review of best practices and evidence-based interventions gener-

TABLE 2. Caregiver Needs in Order of Priority

PRIORITY	CAREGIVER NEED	AVERAGE RANK* (n)
1	Information about available services	5.08 (26)
2	Stress management and coping strategies	5.46 (35)
3	Help with financial issues and insurance coverage	5.71 (14)
4	Help with communicating with professionals	6.06 (26)
5	Information on disease	6.07 (35)
6	Help with recruiting competent help	6.19 (35)
7	Help with learning care tasks	6.37 (35)
8	Help with communicating with person with dementia	7.00 (23)
9	Legal advice	7.86 (26)
10	Information about drugs	7.99 (35)
11	Help with addressing end-of-life issues	10.23 (23)
12	Advice on moving recipient to a facility	10.41 (26)
13	Help with dealing with family	10.46 (35)

*1 = most important; 13 = least important

ated for the state of the science conference (see “Behavioral and Psychosocial Interventions for Family Caregivers,” page 47). Notably, all other reported needs focus on the process of caregiving rather than the well-being of the caregiver, a distinction that may be significant in identifying gaps in the current education of nurses and social workers for supporting caregivers. Giving greater attention to communicating with caregivers, teaching them to perform care tasks while accommodating aspects of their home environment, equipping them with skills for evaluating and recruiting help, and tailoring information to their particular situations might provide an effective response to these needs.

The rankings of needs must be interpreted with caution. The analysis was intended to generate a wide view of the needs that are likely to be considered important by caregivers. Without a probability sample, the methods used are unsuitable for estimating the relative priority of such needs within a larger population. Analysis of focus group data can yield conclusions with high validity for the participants and, by choosing respondents from a variety of backgrounds and circumstances, with broader relevance. Indeed, the range of needs for professional help documented here coincides closely with the unmet needs identified in a 2004 national survey of caregivers.² The process of generating the list of needs to be ranked was iterative, in that new topics were added as the interviews progressed, which meant that early respondents did not have an opportunity to rank the full set. Consequently, the denominators were lower for ratings of those added topics.

In the next phase of this study, the views of social workers and nurses who are directly involved in supporting family caregivers on strategies for addressing these needs will be

elicited. The goal of the larger project is to identify strengths and gaps in professionals’ ability to effectively respond to specific needs of family caregivers and to establish the importance of new research and expertise for supporting professionals in this role. ▼

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