

An Exploration of Perceptions of Possible Depression Prevention Services for Caregivers of Elderly or Chronically Ill Adults in Rural Georgia

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Abstract Caregiving for elderly or chronically ill adults can be stressful, contributing to a high rate of depression in caregivers. Rural caregivers are at particularly high risk due to reduced access to mental health care services. This study explored the acceptability among rural caregivers of introducing a program to prevent or alleviate depression. Focus groups with caregivers and community members were conducted in four rural counties of Georgia. Caregivers reported high levels of stress and depression and recommended the following interventions: support groups, respite care, a centralized source of information, training for caregivers and other community members, financial support, and a telephone hotline. There were more commonalities than differences across the locations, but some programmatic preferences and acceptability varied.

Keywords Caregiver · Depression · Intervention · Qualitative · Rural

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Introduction

Recent attention has been given to the psychosocial burden experienced by caregivers of elderly or chronically ill adults in the United States (Pinquart and Sörensen 2003), though more research is needed on caregivers' desire for programmatic efforts to meet their needs, particularly in rural areas. Caregivers are defined as individuals who routinely help others who are limited by chronic conditions (Nerenberg 2002). In this report, the term *caregiver* refers to a person who provides care to an elderly or chronically ill adult, typically a family member or friend, and is not paid for these services. In the 1990s, an estimated 15 million people in the United States were caregivers (Schulz and Quittner 1998). The number is likely higher today, as the population of older adults is increasing (Centers for Disease Control and Prevention 2003).

Multiple studies have shown that caregiving can be burdensome and stressful and that caregivers have high rates of depression. The prevalence of depression in caregiver samples ranges from 40% to 43% among those caring for persons with dementia, and is reported to be about 33% in caregivers of those without dementia (Nerenberg 2002). The numerous consequences of caregiver depression include increased mortality (Schulz and Beach 1999) and elder abuse (Dyer et al. 2000). In addition to causing poor functioning, depression is associated with poorer health, increased use of medical services, and higher health care costs (Cole 2005).

The elevated risk of depression in caregivers is likely due to many factors. In the general population, depression is associated with female gender, poverty (Hasin et al. 2005; Mulder et al. 2001), older age (Heun and Hein 2005), and chronic illnesses (Whooley 2006). Of note, a meta-analysis of 229 caregiver studies found the majority of

participants were female, and the average caregiver age was 59.5 years (Pinquart and Sörensen 2006). Psychosocial factors, such as low self-esteem and poor social support are known to be predictors of depression (Taylor 2001) and may be especially common among people who face challenging caregiving situations and are unable to leave their loved one to participate in social activities. Some studies suggest that the premorbid relationship between the caregiver and receiver of care, and changes in the receiver's personality associated with illness, may impact depressive symptoms in the caregiver (Boss et al. 1990; Hamel et al. 1990).

Living in a rural area might aggravate the stresses of caregiving and reduce the likelihood that a caregiver will seek treatment for depression. Individuals in rural areas are more likely to be isolated and have limited employment, social, and treatment opportunities (Hauenstein and Boyd 1994). Mental illnesses that occur in rural areas are poorly recognized, highly stigmatized, and understood through spiritual and cultural lenses that may not be aligned with biomedical models or current treatment options (Badger et al. 1999; Browning et al. 2000; Hauenstein 2003; Hill and Fraser 1995; Surgeon General 1999). Geographic isolation, travel time, weather, and road conditions can become significant barriers to those who would otherwise seek health care and social services (Sullivan et al. 2003).

Given the many barriers to treatment and the oftentimes chronic nature of depressive disorders, prevention of the first or subsequent depressive episodes is an appealing public health strategy. Several researchers have proposed using cognitive-behavioral techniques to prevent depression among high risk groups (Cole 2005; Gilham et al. 2000). A meta-analysis of seven interventions to prevent clinical depression in different populations found that those receiving an intervention had a relative risk of 0.72 (95% CI, 0.54–0.96) of developing depression as compared to a control group (Cuijpers et al. 2005). Multiple interventions based on cognitive-behavioral therapy have been designed and tested in caregiver populations, including self-instructional therapy, systematic desensitization, muscular relaxation, negative thought reduction (Cary and Dua 1999), and training programs to help participants clarify their own role as a caregiver and develop strategies and realistic beliefs about their care receiver's abilities (Hepburn et al. 2001). A meta-analysis of 78 studies found that caregiver interventions reduced depressive symptoms and improved other outcomes, such as caregiver ability and knowledge (Sörensen et al. 2002).

In order to design effective interventions for rural caregivers, it is important to consider the unique needs of this population. Any efforts to prevent or reduce caregiver depression in the rural South must take into account the poor recognition, stigmatization, and unique cultural

framework surrounding stress and depression in these areas (Hauenstein 2003; Mulder et al. 2001). Interventions that are not sensitive to rural caregivers' needs and preferences are not only unlikely to be utilized by this group, but could be harmful. This is underscored by Eisdorfer et al. (2003), who showed that a given intervention may be useful for a subset of caregivers, but ineffective or harmful for others (e.g., structural family therapy produced decreased levels of depression among a sample of wife caregivers after six months, but increased depression levels among husband caregivers).

Searches of Medline and PsycInfo databases identified no depression prevention intervention designed and tested specifically for caregivers in the rural South. Before such an intervention can be developed, research is needed to determine how this specific population would receive such a program, what resources are already available in their communities, and how much variability of opinion regarding mental health issues exists among caregivers in different rural locations within this region. Rural caregivers tend to rely on kinship networks for support, rather than formal institutions, due to limited availability of and access to formal support systems (Dilworth-Anderson et al. 2002; Hofferth and Iceland 1998). Research has shown that higher levels of community trust, mutual support, and social participation are associated with better self-rated health (Kawachi et al. 1999). Along these lines, caregivers' existing support systems and needs may be influenced by social characteristics of their community. Individuals living in rural communities with population decline and higher poverty rates may have less access to community resources and support, which could influence their perceived need for a program, or the type of program that would best serve them. Differences in caregiving experiences between Caucasians and African Americans may also need to be considered when designing an intervention. African American and Caucasian caregivers often report differences in caregiving burden and coping styles (Dilworth-Anderson et al. 2002; Kosberg et al. 2007; Roth et al. 2008).

The present study sought to identify the felt needs, desired attributes, and acceptability of a stress and depression prevention program for caregivers in four rural areas of Georgia. The Diffusion of Innovations theory (Rogers 2004) was used to guide this study. This theory serves as a useful framework for understanding why some interventions are adopted more quickly than others, and some are not adopted at all. Five characteristics determine an innovation's rate of adoption: relative advantage, compatibility, complexity, trialability, and observability (Rogers 2004). Furthermore, to design an intervention that is likely to be used, one should consider several aspects of the prior conditions, including the felt needs or perceived problems, the degree to which the population is innovative,

and the norms of the social system. Likewise, the socioeconomic and environmental characteristics of the decision makers, as well as their personality and communication behavior, should be taken into account (Rogers 1995). The following six questions were addressed: Is there a felt need for an intervention to protect rural caregivers from depression? Would a depression prevention intervention be acceptable in rural communities? What would be the best/most trusted source for dissemination of such a program? Should the program be administered in person, through telephone, or via the internet? Are there regional differences within Georgia in the felt needs and attitudes regarding depression and the prevention of it? What kind of depression prevention program would best serve rural caregivers?

Methods

A qualitative approach was selected for this study because this method is considered particularly appropriate for exploratory inquiries. In lieu of testing hypotheses, qualitative analysis can be used to uncover phenomena whose importance may have been previously unknown to researchers or to better understand how various factors relate to one another, which lays the foundation for theories that can be tested in later inquiries (Pope et al. 2000; Sandelowski 2000). Twelve focus groups were deemed sufficient to determine commonalities and meaningful differences among the four counties included in this study. Three focus groups were conducted in each county for two reasons: 1. this allowed for comparisons between groups within each area, and 2. emergent differences between the four areas would be more likely due to regional variation than to differences between the individuals of a given group. The four counties were chosen because they are in four different quadrants of the state (north, southwest, southeast, and east); they are all non-metropolitan; and they have varied racial compositions, median incomes, and rates of population growth or decline. The key

demographic characteristics of the counties in which focus groups were conducted are described in Table 1. The populations in the north and southeast counties are primarily Caucasian whereas the other two counties have large African American populations. Two of the counties had experienced significant population growth in the decade prior to the period of research, whereas in the other two counties, the population had declined.

The study was approved by the Emory University Institutional Review Board and all participants provided written informed consent. In each county, current or former caregivers were recruited for two focus groups and other community members who knew or worked with caregivers were recruited for a third. Participants were recruited primarily through word of mouth and snowball sampling, initiated through contacts in churches, cold calls to health care organizations, as well as through advertising in a local newspaper. Attempts to recruit both African American and Caucasian participants were made. Also, in those counties where participants were recruited primarily within church communities, efforts were made to recruit individuals outside of churches as well. The initial description of the research topic given to participants did not include the words “depression prevention” so as not to influence individuals’ likelihood of participating. Instead, it was presented as an exploratory study of “whether there is a need for emotional support or related services for caregivers in your area.”

Current or former caregivers were defined by four criteria. One was that they regularly performed tasks for or took care of an elderly or a chronically ill adult, or that they had done so in the past. Tasks include preparing meals, driving, shopping, cleaning or maintaining the house, bathing, and attending medical appointments. A second criterion was that they saw this adult two or more times in a typical week. A third was that they had performed regular care for this or another adult during six consecutive months. The final criterion was that they were not paid for the caregiving tasks. Adults who did not meet these criteria but who knew other caregivers in the community were

Table 1 Key demographic characteristics in the four Georgia counties

Geographic location	Population growth, 2000–2007 (%)	Racial composition	Median household income (2007)
North	23.5	African American: 1.6% Caucasian: 97.2%	\$42,302
Southwest	–11.3	African American: 59.0% Caucasian: 39.5%	\$27,687
Southeast	5.2	African American: 28.6% Caucasian: 69.9%	\$33,003
East	–3.8	African American: 41.7% Caucasian: 56.7%	\$32,461

Data are from the United States Census Bureau State & County QuickFacts, available at <http://quickfacts.census.gov/qfd/states/13/13267.html>, accessed on 5/19/2007

eligible to participate in the non-caregiver groups. The participants in these community-member groups included nurses, community care coordinators, social workers, and friends of caregivers. Two clergy members participated in the focus groups, one as a caregiver and one as a community member. In addition, the participants of all focus groups were 18 years of age or older and had lived in a rural part of Georgia for at least three years immediately prior to the study.

A total of 77 individuals participated in one of twelve focus groups, three of which convened in each of four counties. The number of participants in each focus group ranged from 2 (in a non-caregiver group) to 11 (in a caregiver group), with a mean of 6.4. Basic sample characteristics and distribution across counties are presented in Table 2. Although individuals' ages were not elicited, participants were estimated to be between 40 and 85 years of age. Of those who were contacted for participation, two of 39 declined to participate in the north county, one of 26 in the southeast county, and seven of 27 in the southwest county. Potential participants self-referred in the east county, so no record was made of those choosing not to participate. Of those who initially agreed to participate, 12 were unable to attend, seven of whom reported that this was because of a family or work problem, such as a funeral, a sick family member, or a work emergency.

The first author moderated the focus groups and was accompanied by a note taker for most focus groups. The focus group sessions were 1.5–2 h in length and were held in public places, including four churches, a library, and the back office of a local newspaper. Data were collected using a semi-structured focus group guide developed by the first

and last authors. The focus groups were audio-taped, transcribed verbatim, and entered into TAMS Analyzer software for coding. A codebook was developed by the first and third authors using a deductive and inductive approach. In this methodology, a few salient categories for organizing and interpreting the data were predetermined, but most were gradually built in an iterative process (Pope et al. 2000). As such, both authors coded four transcripts separately, adding codes for emerging themes and arranging these into categories based on Diffusion of Innovation constructs and recurrent themes. The first two transcripts were recoded for accuracy. The first author coded all remaining transcripts and then reviewed the codes while entering them into TAMS Analyzer. Four additional transcripts (one from each county) were independently coded by the third author to verify the accuracy of the coding. The majority of the focus groups were coded identically. All discrepancies were discussed until consensus was reached.

Results

The results are presented for each of the six questions guiding the present analysis (Table 3) and representative quotes are included below. Program models that were proposed and discussed by participants are displayed in Table 4.

Is There a Felt Need for an Intervention to Protect Rural Caregivers from Depression?

Caregivers and community members in every focus group reported dealing with considerable stress and depression. Feelings of distress were an integral and problematic part of their caregiver experience. Caregivers' stress levels and feelings of depression increased over time as the caregiver burden increased, sometimes reaching crisis levels that resulted in suicidal actions, panic attacks, or medical crises.

Whereas stress and depression were perceived as prominent problems for caregivers, they were not considered preventable; rather emotional distress was thought to be a normal response to a stressful situation. Participants commented that it is important to cope with feelings of depression, (e.g. "You're going to get depressed. But it's just how do you deal with it?"). In every county, caregivers indicated that they needed help coping with the stresses of caring for a chronically ill or dying family member. However, there were many different opinions on what kind of services would help them most, whether or not programs or services would relieve emotional distress in caregivers, and whether or not the programs would even be used by those caregivers most in need.

Table 2 Study sample composition ($n = 77$)

Caregiver participation (two focus groups per county) ($n = 62$)	
North	17
Southwest	17
Southeast	13
East	15
Community member participation (one focus group per county) ($n = 15$)	
North	3
Southwest	5
Southeast	5
East	2
Gender	
Female	69
Male	8
Race	
African American	27
Caucasian	50

Table 3 Discussion of felt needs, desired attributes, and acceptability of a caregiver program

Guiding question	Common themes
Is there a felt need for an intervention to protect rural caregivers from depression?	Participants experience high levels of stress and depression Feelings of stress and depression are seen as part of the caregiving experience Participants expressed a need for help, support, and services
Would a depression prevention intervention be acceptable in rural communities?	Some caregivers are too proud to ask for help or do not believe in the sincerity of help offers Some do not want to share their situation or have someone else tell them how to take care of their loved one Some are in denial of their need for help
What would be the best or most trusted source for dissemination of a program?	Former caregivers, medical professionals, church leaders, or a combination of these Some may not trust a government program, others believe it is the only entity that could maintain a program in a rural environment
Should the program be administered in person, through telephone, or through Internet?	Internet was considered expensive and impersonal; it had limited appeal, but could be used to augment programs Telephone preferred over internet Seen as confidential, good for those who are home-bound, and less time restricted; phone networks are a possibility Lacks assurance of trust or interest; some find talking on the phone to be stressful In person Removes caregivers from stress in the home Takes up valuable free time
Are there regional differences within Georgia in the felt needs and attitudes regarding depression and depression prevention?	Commonalities more evident than differences Differences in appeal of phone usage, utility of support groups, and need for financial support Members of communities with growing populations reported more instances of support from friends and family than those in diminishing or stable populations

Would a Depression Prevention Intervention be Acceptable in Rural Communities?

Whereas participants readily admitted that caregivers in their communities experienced a considerable amount of stress and depression and that a variety of programs could potentially help them cope with the caregiving burden, there were mixed opinions about whether caregivers would participate in a program. Participants frequently stated that caregivers do not want to ask for help or accept offers of help because they are proud or because they believe these offers are insincere.

Another major concern was that caregivers did not want to share their situation with others in the community:

When you're in a rural area, your business is your business. And you might not want to have So-and-So tell you how to take care of Mama.

Denial is another barrier to potential help-seeking in this group. For instance, a former caregiver commented that, although she did previously need help coping, she did not realize it at the time and would not have taken advantage

of available care. Therefore, although a number of programs were identified as potentially helpful, not all caregivers indicated that they or their peers would participate.

What Would be the Best/Most Trusted Source for Dissemination of Such a Program?

Participants identified a number of potential organizations that could house or lead a caregiver program in their communities. Former caregivers, medical professionals, and church leaders were most frequently identified as appropriate leaders. Some caregivers suggested a combination of two or more of these leaders. Others asserted that, in rural areas, it takes a great deal of determination to maintain programs, as there are fewer people to participate in a given locale. There was considerable disagreement between participants about whether the government should play a role in establishing programs, with some caregivers expressing distrust for anything government-led and other caregivers stating that the government is the best entity to take action across communities.

Table 4 Characteristics, benefits, and disadvantages of programs for caregivers in the rural South

Proposed program	Common themes
Support groups	Benefits: connect with others, share stories, reduce isolation, and relieve stress Could be modeled after existing support groups Disadvantages: lack of time, interest, and anonymity
Respite care	Benefits: provides rest, personal time Different lengths of time needed Disadvantages: poor quality of care, far away, unavailable due to income level or affordability, and uncomfortable for the care recipient
Centralized source of information	Benefits: makes resources known, especially for new caregivers Could be delivered through flyers, 1–800 number, doctors offices, or internet site
Training for the caregiver	Benefits: instructs caregivers on different aspects of their responsibilities Disadvantages: skepticism about the effectiveness of training, each person needs training on different skill sets, and some tasks are too technical or difficult
Financial or material support	Benefits: a relief to caregivers who are unable to keep a job and also care for their loved one Disadvantages: current programs have many eligibility requirements, caregivers are unaware of available aid, policy changes are needed
Training for other people in the community	Medical professionals, community leaders, and hired caregivers should be trained to improve the quality of their care and their relationships with caregivers Some skills are needed by everyone in the community
Other programmatic suggestions	Individual counseling: over the phone or in person to alleviate acute feelings of stress and depression Story telling: positive cathartic experience, expressed both explicitly in focus groups and implicitly Home visits: alleviate isolation and reduce transportation costs for caregivers

Should the Program be Administered in Person, Through Telephone, or Via the Internet?

The internet had only a limited appeal for caregivers in the rural south in 2007 when the study was conducted. Participants indicated that, although some people use the internet, many do not use it or are not sufficiently internet-savvy, particularly if they are older or have limited financial resources. Furthermore, the internet was perceived as impersonal. A few caregivers suggested that an internet component could serve as an optional supplement to a caregiver program, and some said that they seek out medical information through the internet.

Many participants indicated that the telephone is preferable to the internet. They noted, however, that the telephone is not as personal as most caregivers would prefer. For some, talking on the phone in general can be stressful. Caregivers may not be able to fully pay attention during a phone call and one group worried that the person on the other end may not be interested or even listening. Nonetheless, participants commented that the telephone is accessible to caregivers who are partially or fully homebound. Furthermore, a service via telephone could potentially have the added advantages of confidentiality and availability whenever the caregiver has questions or concerns, as opposed to a program with a more rigid time

schedule. Some participants suggested that a 1-800 confidential hotline through which caregivers could get information or emotional support would be useful. They also suggested that telephone networks could be used to supplement a traditional support group.

Focus group participants agreed that caregivers would benefit more from meeting each other in public places than they would from any intervention that is conducted at home. Indeed, for some, the very purpose of a support group would be to give the caregiver time and space away from their loved one receiving care. Nonetheless, participants from all four communities noted that it can be difficult for caregivers to leave their loved one alone. A couple of caregivers remarked that, because it was so difficult to get away, they would choose free time over participation in a program.

Are There Regional Differences Within Georgia in the Felt Needs and Attitudes Regarding Depression and the Prevention Thereof?

Although some differences across the four communities were evident in levels of support and the perceived needs and program preferences of caregivers, these were far outweighed by the commonalities of their experiences. The main differences in the focus groups concerned financial

needs, phone usage, and the utility of a support group. In the county with the highest median household income, none of the participants proposed a program offering financial or material support to caregivers as a method of reducing stress, though they did discuss financial strains. Participants in one county were much less interested in using the phone for getting information or support than those in the other three counties. Furthermore, the communities differed in their level of interest in a support group. Participants in two of the communities were skeptical of caregivers' interest in a support group, whereas no participants in the other two areas voiced similar concerns.

On a similar note, there appeared to be varying levels of informal support already available to caregivers in the four communities. Caregivers in all four communities mentioned needing support from their families, friends, and neighbors. However, caregivers in some counties named more instances of supportive actions from their friends and families, compared to caregivers in other communities. Whereas caregivers in the counties with positive population growth recounted instances when their friends or neighbors sent them cards, came by their houses, or stayed with their loved ones, caregivers in the county with a small population decrease commented on the community's diminished willingness to do so. Caregivers in the county with a more marked population decline did not mention these types of community members' gestures at all.

What Kind of Depression Prevention Program Would Best Serve Rural Caregivers?

Multiple services were proposed for directly or indirectly helping caregivers with stress and depression (Table 4). The programs that were suggested by multiple individuals were, in order of frequency: support groups; respite care; a centralized source of information; training for the caregiver; financial or material support; training for other people in the community; and other ideas, such as individual counseling, the opportunity to tell their story and be heard, and home visits.

Support Groups

Support groups were the most frequently mentioned model for a program that might help caregivers cope with feelings of stress and depression. The perceived advantages of support groups are that they would allow caregivers to unburden themselves, realize that they are not the only ones dealing with challenging situations, and speak to people who understand their problems and empathize with them. This would reduce their perceived isolation and give them an outlet for relieving their stress.

I think a caregiver group might be good, just to let people blow off steam... You might not know there are five other people going through the exact same thing. So, even though you might not be able to reach a solution to the problem you have, you might be able to share, to communicate.

Participants suggested that a caregiver support network could follow the model of existing support group networks for persons or families affected by alcohol abuse, Alzheimer's disease, or cancer. Caregivers and community members were aware of existing support groups, many of which serve specific types of caregivers in their communities, such as family members of an individual with Alzheimer's. None of the existing support groups were relevant to all caregivers in the county, leaving an unmet need.

Participants frequently commented that a support group could engender one-on-one support amongst caregivers. In several instances, they recommended that this could be formalized and encouraged by creating phone trees, or by pairing caregivers with other caregivers in a similar situation or with a former caregiver who could act as their 'sponsor.' Throughout the focus groups, caregivers debated whether it would be preferable to have a support group that was disease-specific or for caregivers in general, and whether or not the person receiving care should be included in the support group. A number of participants commented that the focus group discussion (a guided conversation about their common experiences) was, itself, a good model for a support group.

Most participants indicated an interest in a support group, but several were ambivalent about the idea and a few caregivers did not think that a support group would be useful:

I ain't up for just a whole lot of talking. If you want my stress to be gone, help me where I need help at and I'll take care of getting rid of it.

Others indicated that they would not, themselves, participate or that they doubted others would. Reasons for this included a lack of time, interest, anonymity, or trust. A few caregivers commented that their loved ones might not appreciate caregivers talking about them with others. Several participants commented that there may not be a large enough community of caregivers in rural areas to sustain a support group. Participants identified other potential barriers to caregivers' participation in a support group, including that they would not want to add something extra to their busy schedules, that they would not want to leave their comfort zones, or that they were already overburdened and would not want to give their time to support one another. Although these concerns were acknowledged,

the majority of participants indicated that support groups would be helpful for many caregivers.

Respite Care

A desire for respite care, or providing short-term supervision of the loved one so the caregiver could have a break from their caregiving responsibilities, was discussed in all but one of the focus groups. The need for respite was not exclusive to caregivers with a loved one in their home; caregivers whose loved one lived in a nursing home expressed a need for a person to give them respite from attending to their loved one's needs there. The overwhelming majority of caregivers and community members agreed that caregivers need to spend some time away from their loved ones to seek rest, do errands, or take care of their own health:

Because you actually do need to get away from your loved one, whether it be a husband or a mother or anyone. You get tired. Because if somebody's watching them then you can get that much-needed rest.

The proposed optimum length of time for respite varied. Most often, participants mentioned needing short, regular breaks of a few hours to allow them to take care of day-to-day needs or to attend church services. Other caregivers wanted a longer period of time, such as a full day or several days. Some commented that a few hours were not sufficient to attend to their own needs, particularly when stores are long distances away.

Available respite services were discussed in the four counties, but they often did not fulfill the needs of caregivers. Reasons for this included that they were far away, available only to those who meet certain income criteria, perceived as delivering poor service, or were simply unaffordable. Also, some caregivers estimated that their loved one would only be comfortable with an outsider after meeting him or her several times. Others had loved ones who they feared would never be comfortable with someone else.

Centralized Source of Information

Caregivers indicated that a centralized source of information would be very useful to help them access services in their communities:

I think there are some resources available. It's not always easy to find them and know that they are out there. Some sort of list of what is around and how you go about qualifying for it and how you go about applying for it would be helpful.

This service would be particularly useful to people who are new to caregiving or to caregivers who are new to an area.

The information could be delivered to caregivers via a list, a 1-800 number, flyers in doctors' offices or pharmacies, or an internet site. The potential utility of such a service was underscored by the fact that participants were often unaware of services that others mentioned during focus groups.

Training for the Caregiver

In all four communities, participants commented that caregivers needed training, but on varied aspects of the caregiver role, including how to: deliver good care; help their loved one accept limitations such as not driving; dress their loved one or assist with mobility; handle irritability, aggressiveness, or noncompliance in their loved one; be considerate of a loved one's handicaps; gather information about medicines; cope with the stress of caregiving; and maneuver through the paperwork and finances regarding healthcare services. Some participants were concerned that caregivers were not adequately prepared to deliver optimal care to their loved ones, contributing to their stress:

A lot of times, if you're going to take on the role as a caregiver in the home then you need to position yourself to where you can get the training needed, you can get the emotional support needed, because it's taking on a responsibility.

Although the potential benefits of various types of training were frequently discussed, this topic was also met with skepticism. Some caregivers questioned whether training would adequately prepare them and others wondered whether they would have the time or interest to participate. A few participants disputed the appropriateness of family caregivers being asked to fill new and increasingly technical tasks, such as changing catheter bags.

Financial or Material Support

In three of the four counties, participants indicated a need for financial or material support to help pay for medicines, supplies such as diapers, general bills, and meals. Although caregivers identified some services that helped with these needs, they voiced frustrations with stringent eligibility criteria and wait-listing.

Participants noted that they could not work if they were unable to leave a loved one alone, but without an income they could not pay for services that would allow them to leave their loved one to work. In addition to recommending more sources of aid, caregivers said that they would like help in getting linked to existing aid. Several participants indicated that policy changes were necessary to better provide for caregivers. For example, one participant noted:

Eventually, the government is going to have to acknowledge that “Hey – why are we funneling all this money into long-term care? Why don’t we funnel some of this into the community? And keep these folks in the community and save ourselves a whole bunch of money?”

Participants voiced frustrations that caregivers’ services were not formally valued by government or health care systems.

Training for Other People in the Community

In three of the four counties, focus group participants suggested that training programs for other people in the community would help caregivers. For instance, one caregiver argued that medical professionals need to be taught to value caregivers’ knowledge:

They need to train them to know that, yeah, it’s good to know the clinical side of things, but you need to recognize that the primary caregiver is going to know some things too.

Their suggestions also included initiatives to improve the quality of care delivered by medical professionals, to formally train people to act as hired caregivers, to train senior center directors on engaging the community, and to deliver cardiopulmonary resuscitation and preventive health trainings to the community at large.

Other Programmatic Suggestions

While the above suggestions (summarized in Table 4) were discussed at length in multiple focus groups, other ideas were brought forth less frequently. Some participants in every county saw a need for individual counseling, or simply having someone to talk to. Participants stated that someone who is available over the phone would be helpful for alleviating acute feelings of stress and depression. Participants occasionally commented that caregivers simply need to tell their stories. The desire for collective storytelling was stated directly, but also evidenced throughout the focus groups, in which caregivers exchanged stories and ideas, and stated that participating was a positive experience. A few participants suggested that home visits, either by professionals, or by friends, could alleviate the caregiver’s isolation. Other suggestions for ways to reduce caregiver stress and isolation included assistance with running errands, individualized help, and a tracking system to help families locate loved ones with Alzheimer’s disease if they get lost.

A need for transportation services was discussed by community members in several counties. Community

members stated that transportation to and from doctors’ offices and clinics was expensive and sometimes unavailable to caregivers. Of note, this was the only suggestion that community members offered that was not discussed in any caregiver focus group. It was a theme in three of the community member groups, and thus appeared to be a consistent difference in community members’ perceptions of what would aid caregivers.

In many cases, participants stated that a combination of the services discussed above would be useful. For instance, they recommended a training program that would also give caregivers the opportunity to support one another, or a support group or training program combined with respite services so that caregivers could leave their loved ones to participate.

Discussion

Rural caregivers in Georgia reported intense feelings of stress and depression and wanted help coping with the challenges of caring for their loved ones. Participants agreed that an intervention outside of the home would be most beneficial to caregivers, though they were open to telephone-based services. Although the internet is a tool that some caregivers in rural communities use, it was generally considered too impersonal for a support network. Participants identified a number of potential barriers to being involved in a program, such as not wanting to ask for help, concerns about privacy, denial, and a lack of time or an inability to leave their loved one. Former caregivers, health care professionals, and clergy were identified as the most appropriate individuals to lead a program. Caregivers suggested that support groups, respite care, a centralized source of information, training for the caregiver, financial or material support, and training for other people in the community would be most helpful to them.

Through focus group discussions with several rural Georgia caregivers and community members, this study shows that caregiving can be very burdensome and stressful, that depression is met with stigma and denial in rural communities, and that there is a desire in rural communities to be self-sufficient and not to seek out help from others. The data from some focus groups supported Hauenstien and Boyd’s (1994) concerns about the utility of talk therapy, the acceptance of the disease explanatory model for depression, and confidentiality in the medical community of rural areas. Interestingly, these concerns were not discussed in all of the communities. In particular, participants in the county with the most population growth did not focus on these points. This may indicate that therapy is becoming more accepted in rural communities. Or, those who move to rural areas (particularly from urban

areas) may bring different attitudes and beliefs, resulting in a gradual change across the community over time. If this is the case, mental health treatment or prevention programs may be better received in some rural areas now than they had been in the past.

Caregivers and community members largely agreed about the stresses that caregivers experience and generated similar suggestions to alleviate this stress. One exception was that the community member groups in three of the four communities spoke about the lack of transportation available in rural areas for care recipients to travel to and from medical facilities. In these groups, participants suggested that simply expanding the transportation services and making these less expensive would be beneficial to caregivers, decrease their stress levels, and ultimately reduce their vulnerability to depression. While a few caregivers acknowledged the time burden of transportation, none made this same suggestion. It is likely that those caregivers who found transportation to be most burdensome would not have attended the focus groups. It may also be that caregivers perceive transportation to medical care as a service to ill individual, but not to themselves. Or, because many caregivers would accompany their loved one to and from treatment facilities anyway, transportation options could be a financial relief to caregivers but not result in a reduction of the time burden associated with caregiving.

An intriguing finding of this study was that the acceptability of a psychosocial program for caregivers varied across communities, whereas the desired attributes and felt needs remained relatively constant. The variation across communities in the type of stress and depression prevention program desired was primarily attributable to whether or not the participants in these communities considered financial or material support to be necessary and whether or not they would be interested in this instead of, or in addition to, a psychosocial program. Participants in the county with the highest median income and greatest population growth expressed greater interest in a psychosocial program, whereas participants in the county with the lowest median income and greatest population decline identified more barriers to participation in such a program. This appears to be consistent with Maslow's (1970) hierarchy of needs; physiological needs and the need for safety and security must be met before one can begin to address issues such as belongingness, esteem, and self-actualization. Thus, financial or material needs may take priority over addressing psychosocial needs. Another possible explanation is that population decline may disrupt social ties, leading to a lessened desire or ability to connect with others in the community. Rural caregivers often rely on family for support (Dilworth-Anderson et al. 2002) and the relocation of relatives may be especially detrimental and not readily replaced by other supports. Therefore they may be wary of

a psychosocial program, regardless of their distress level. Future research should investigate whether the acceptability of an intervention to meet psychosocial needs is impacted by the presence or absence of other needs and supports, as well as trust and perceived social connectedness within the community.

Past studies have found differences in the levels of caregiving-related stress, depression, and burden between African Americans and Caucasians. Several studies have suggested that African American caregivers experience more rewards and less stress than Caucasian caregivers, and either less or similar levels of depression (Farran et al. 1997; Picot et al. 1997; White et al. 2000). Caregivers in the predominantly African American focus groups (in the southwest and east counties) did not, however, indicate less stress or more rewards than other caregivers. They did speak about the role of denial, saying that they often did not realize the extent of their stress or depression until after the most stressful time had passed, and only later recognized that they would have benefited from additional support during this period. Racial/ethnic differences in caregivers' coping styles and experiences of depression are not fully understood and merit further investigation. While the present study deliberately attempted to sample two racial groups, the design also included other significant population differences, in domains such as population growth and median household income. Additional research is needed to elucidate the nuanced community dynamics and characteristics that directly affect the needs of different populations.

The focus group data provide some clear guidelines for building a successful stress and depression prevention program for rural caregivers in the South. Common themes, as well as differences, emerged from one focus group to another. Interventions for rural caregivers should be tailored to the preferences within specific communities. Caregivers' needs in these rural communities are both complex and varied. In every focus group multiple programmatic suggestions were made, frequently with the notion to build a program that incorporates more than one of the options discussed. This finding suggests that an ideal program would be multi-faceted. Specifically, a program could combine an evidence-based, cognitive-behavioral approach with practical information and training for caregivers and discussion time in a support-group-like environment. To recruit those caregivers who are most home-bound, and for logistical and therapeutic purposes, a program would ideally provide respite to those caregivers who could not otherwise leave their loved ones. It would gain even greater appeal and usefulness to caregivers if the respite service could be extended to allow caregivers to run errands after participating in programmatic activities. Finally, a phone network or a buddy system that would be

available to caregivers on an ongoing basis may appeal to some. Several programs operate in various rural areas of Georgia, including respite care, training programs, and financial aid. However, most of the caregivers who participated in the focus groups were either unaware of or not eligible for the programs.

The ideal leadership of a program may be a combination of former caregivers, medical professionals, and one or more church leaders. All three of these types of program leaders lend credibility to a program and they could fill complementary roles in addressing caregivers' psychosocial needs. A medical professional could offer training and tips on relevant topics, such as administering medicines, assisting with mobility, and performing cardiopulmonary resuscitation. A church leader could provide space for sessions to take place and spiritual support or informal counseling. Former caregivers could provide social support, either by attending sessions, making themselves available to caregivers over the phone, or providing respite while the caregiver attends sessions.

A limitation of this study is that the sample was not random; it was restricted to caregivers with both the ability and desire to meet with a group of their peers in a central location to take part in the study. By including former caregivers and community members, this bias may have been reduced, because those caregivers who were previously confined to the home were able to speak about their past experiences. A second limitation is that very few data were collected on the study sample's demographic characteristics or number of years of caregiving experience, which would be helpful in describing the sample and comparing the present findings to those of others. However, focus group data are traditionally used to elicit attitudes and beliefs within a community, more so than those associated with specific individuals (Pope et al. 2000). This study, like others based on focus groups, is susceptible to biases introduced by social desirability, but provides a unique opportunity to make observations about the social dynamics among caregivers across the four communities. As in all qualitative studies, the findings cannot be generalized to a population level. A strength of the study is that it was possible to identify potentially important differences between the counties, though these differences cannot be attributed to any specific demographic characteristic, as the communities varied in multiple ways. The extent and nature of caregivers' programmatic needs and preferences should be investigated in further research, as the focus group data indicated that at least some programmatic needs and preferences differ between rural communities, particularly regarding financial needs and the desire for psychosocial services. Further research should also explore the willingness of health care professionals, former caregivers, and church leaders to facilitate a caregiver support program.

This study contributes to the body of literature on caregivers, rural mental health, and stress and depression prevention by examining the perceived needs of rural caregivers. Future studies should take into account the literature on the psychosocial needs of older adults. Additional research should also examine why there is variability in the communities' readiness for a psychosocial intervention and if this variability is explained by differences in income, race/ethnicity, or social capital. As the aging population with chronic diseases increases, there will be an increase in the number of caregivers and in the burden placed on them. A continued increase in the longevity and quality of life of the population cannot be sustained without the involvement of physically and mentally healthy caregivers.

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