Interventions to Reduce Burden for Rural Caregivers of Patients with Dementia: A Review
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Citation

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Abstract
Background/Purpose: Caregiving for a person with dementia involves a variety of challenges, mostly physical and psychological, leading to mental health problems. Psychosocial interventions to support caregivers of persons with dementia described in the literature mostly involve urban samples. This study's main objective was to review interventions studied in rural areas of caregivers of persons with dementia and examine their outcomes.

Methods: Pubmed, Psychinfo, Embase and Google were searched to find randomized controlled trials, systematic reviews, and clinical studies, using dementia and rural as initial key words/medical-subject headings. The following terms were then added: dementia caregivers in rural setting and dementia caregiver burden in the rural setting. Studies were limited to those published in English. Titles were initially reviewed to exclude irrelevant articles; then abstracts and full articles were evaluated. Duplicate articles were excluded, as were studies with abstracts that did not fit criteria.

Results: Of 750 articles originally identified, all but 7 were deemed unsuitable for inclusion. Among the 7 selected studies, only 2 were randomized controlled trials. Although their results were mixed, results of the other 5 studies showed improvement with interventions designed to support caregivers.

Conclusions: Future studies would benefit from employing randomized controlled trials methodology and measure outcomes to compare data among caregivers of persons with dementia in the rural population. Possible innovative strategies to reach rural caregivers include therapies delivered through telephone/video or therapies provided in person but in a condensed, brief format.

INTRODUCTION
With an aging population, the numbers of persons with dementia will increase to 63 million by 2030, making the need for informal care even more important than it is now. Most persons with dementia receive ongoing care and support in their home from family members, who confront a variety of challenges in providing emotional support, supervision, assistance with daily activities, and social and financial support. Unfortunately, these challenges are surmounted at high cost and with psychological burden.

Most caregivers need support to address their burden when taking care of their loved ones. There is a consensus that caring for a family member with dementia, who can become agitated, forgetful, repetitive and completely dependent on the caregiver for assistance with activities of daily living as the illness progresses, is associated with unique stressors related to the continuous work and worry of care as well as disruption in the caregiver social activities and sometimes even neglect of their own physical needs. Burden is influenced by duration, dependence, degenerative stage, social isolation, emotional strain, behavioral problems, levels of personal assistance, mobility and medical assistance required. The negative consequences leave caregivers at high risk for mental health problems, especially anxiety and depressive disorder, with some studies suggesting that approximately 43% to 65% of caregivers of persons with dementia meet criteria for clinical depression.

Rural caregivers may have a higher degree of stress than urban caregivers; however, comparative data are scarce. Rural Americans face a unique combination of factors that create an imbalance in health care and social services not found in urban areas, such as lack of physicians, lack of healthcare services, less exposure to education, and cultural and economic factors, all important to deal with chronic
diseases such as dementia. One study suggests that the negative association between caregiving and health outcomes, including mental health, depends upon urban-rural status, finding that rural caregivers may experience more detrimental health-related issues as a consequence of informal caregiving than urban caregivers.

Although several systematic reviews have examined psychosocial interventions to support caregivers of persons with dementia, most involved urban samples. For example, a systematic review in 2002 concluded that interventions with caregivers were successful in alleviating burden and depression and improving well-being, as well as knowledge, with psychoeducational and psychotherapeutic interventions showing the most consistent short-term effects on all outcome measures. A meta-analysis evaluated caregiver intervention strategies, such as a support group, education, counseling, and respite care designed to help caregivers cope with burden, and found that multicomponent interventions significantly reduced it. Another systematic review examining components of interventions found increasing social support and training of problem-solving tasks as the most promising components. Pinquart and Sorenson reported that psychosocial interventions with active participation of the caregivers were most effective. A review of psychosocial interventions for caregivers of persons with dementia also found supportive evidence for use of psychoeducational and multicomponent interventions.

A study from 2003 supports the efficacy of telephone-based cognitive behavioral therapy (CBT) interventions for distressed caregivers of persons with dementia to improve psychosocial functioning. Tele-care interventions (telephone based) led to greater improvements in emotional and psychological outcomes, especially in wives who have anxiety and low caregiving mastery. Nonetheless, translation of CBT interventions to the community has been hindered by both logistical and geographical barriers. This study's main objective was to review interventions studied in rural areas for caregivers of persons with dementia and examine their outcomes related to decrease in burden effect.

SEARCH METHODS

Psychinfo, PubMed, Embase, and Google were searched for randomized controlled trials (RCTs), systematic reviews, and clinical studies of dementia and rural areas. The following key words and medical subject headings were used initially: dementia and rural. After the above terms were combined, dementia caregivers in rural setting and dementia caregiver burden in the rural setting were added; studies were limited to those published in English. Titles were initially reviewed to exclude obviously irrelevant articles. Then abstracts and full articles were evaluated for inclusion that were related to the above-described terms and outcome measures related to interventions used to decrease caregiver burden. No time period was selected so that the review would be as inclusive as possible. Duplicate articles were excluded as part of the search strategy, and studies having abstracts that did not fit the criteria were also excluded. Informal caregiving was defined as unpaid care from family members, and the persons with dementia term was operationalized within the broad term of having had the diagnosis of any type of dementia with impairment that required informal caregiver activity. The reference list of included studies was also screened for potentially relevant studies.

RESULTS

See Figure 1 for a flowchart of articles retrieved through electronic search. Among the 7 selected studies eventually selected for inclusion, 2 were RCTs, 2 were case studies, 1 was a quasi-experimental study, 1 was pre-/post research design, and another was descriptive. See the table for a summary of the 7 studies.

Among the selected articles rurality is defined in different ways. Easom et al. defined it as a population density of 40 people per square mile. The quasi-experimental study defined rural areas as areas having fewer than 2500 people or small cities or towns having fewer than 50,000 residents. One of the RCTs, on the other hand, defined rurality as nonmetro, not adjacent to a large metro area. The remaining articles simply mentioned that the participants belonged to a rural area, without further explanations.

Randomized Controlled Trials

The first RCT compared results with a 12-week, telephone-based CBT intervention (n=14 family caregivers) versus routine education and support (n=5) in a rural Florida. The control group was provided with educational materials, encouraged to contact a research assistant and given the option of taking the CBT intervention after the 12-week assessment. Results suggested that the CBT group showed significant improvement in perceived self-efficacy in caregiving from pre- to post treatment compared with the
control group and had higher levels of satisfaction with the intervention. However, no differences were found in change over time between groups for caregiver burden and depressive symptoms. Explanations for this were that the small size of the sample lowered the statistical power to detect post treatment differences between the 2 groups and that restrictions in the inclusion criteria meant that the caregiver sample was not highly distressed enough to allow detection of a significant change. The CBT intervention included education, relaxation training, caregiving challenges, problem-solving skills, assertiveness and social support.

The second RCT also used a telephone-based intervention and recruited from a large rural region. Caregivers (N=179) were randomized to usual care or active interventions: an 8-week structured counseling intervention (n=42) or a call-in helpline (n=49). The control group (n=39) comprised those who refused either of the interventions. The final sample consisted of 130 caregiver. Information was gathered for all groups upon their first contact with the telehelp line, upon completion of the intervention, after 8 weeks of helpline services and at 6 months later. Caregivers in the intervention conditions reported significantly less stress and improved social functioning, still evident at 6 months. Caregivers in the control group evidenced increased difficulty with interpersonal relations over time. Caregivers in the helpline group showed more distress than the other 2 groups, based on a symptom-distress subscale, and more interpersonal relations related to distress over time. This finding was explained by the low level of intensity of use of the helpline, which averaged only 1 contact per caregiver. Researchers concluded that a telephone-based, structured counseling intervention that encompassed, in this study, 4 components (knowledge, skills, social support and affect) is effective in an overburdened, overwhelmed population in need of service.

Quasi-experimental Study

A quasi-experimental study15 evaluating the Savvy Caregiver Program assessed 54 rural caregivers and 42 urban caregivers at baseline and 6 months. Both groups received 12 hours of in-person training over 1 to 3 days, supplemented with a caregiver manual and educational CD-ROM. The Savvy Caregiver Program16 was designed to improve knowledge of the disease and emotional tolerance and to teach caregivers to take control. Results showed that 88% of the rural participants used the manual and that their depression measures significantly improved, whereas those of the urban group did not. Rural participants also had decreased depression after the intervention.

Case Studies

A study by Sorocco et al. evaluated the benefit of integrating VA care-coordination home telehealth and telemental health within home-based primary care in rural Oklahoma (N=6). This project was led by psychologists to enhance care coordination of health care from medically complex veterans with mental illness. These veterans received the same care other home-based primary care veterans did with the additional home telehealth equipment. The veterans and their caregivers were trained in using the equipment for clinical video technology, with the average number of visits for a 6-month period of 23.75 (SD=7.93) visits. Assessment was at baseline and at 3 and 6 months, with participants providing satisfaction ratings on the benefits. This study not only focused on the caregiver of a person with dementia but also measured caregiver burden over 6 months, with good results, such as improvements in social functioning, decreased caregiver burden and better treatment compliance by the veterans.

Another home-based, in-person study of CBT and spiritual counseling for rural caregivers of persons with dementia who were suffering from depression focused on an analysis of 2 case studies (N=2).4 Initially, community nurses were trained, using a CBT guide book, through a weekend workshop, which included a 12-module program, including topics from basics of dementia care, noting and reflecting feelings, assessing spirituality and counseling skills to caregiver validation and goal settings. Then a pre- and post-clinical trial examined the effects of this training on the severity of identified caregiving problems and depression. Promising results in reducing caregiver depression were identified.

Pre-/Post design Study

Another study, from Easom et al., is a pre-/post research design study exploring the impact of implementing a multicomponent intervention in 11 rural counties in Georgia: GA REACH (Resources Enhancing Alzheimer’s Caregiver Health). Eighty-five caregivers completed the intervention. Researchers concluded all data measurements within 6 months; and results suggested improvement in health self-report, depressive symptoms, self-efficacy to handle difficult
situations and a reported better understanding of the disease. This intervention comprised an intervention manual, a caregiver notebook, and a training manual, as well as the interventionist, who met with the caregiver in his/her home 9 times for, on average, 1.5 hours each visit and a group leader who conducted a telephone-based support group of these caregivers. The interventionists collected demographic information but also addressed and assessed topics, such as safety, behavioral issues, skills and frustration. The group leader conducted 5 telephone-support group sessions (with 5 to 6 caregivers/group) with scripts including topics of concern for the caregiver, such as lifestyle, communication skills, and community resources, as well as financial and legal issues. The study gathered informative data, including burden, depression and frustration; it was based on a previous study model focusing on multi-component interventions that focus on recognizing stressors and changes that could be made, as well as caregiver response to the stressors (REACH).19

Descriptive Study

The study by O’Connell20 described the development of a secure telehealth videoconference support group for rural spouses of individuals with atypical early-onset dementia. The researchers developed a template for a future group, based on key helpful effects observed, which included group composition, structure and process, with the last identifying social contact among group members as crucial because of reduced socialization in the caregivers’ daily lives. The group facilitator provided monthly, 90-minute telephone-based encounters with group members, who could join and leave when ready, and the group members received 1 session of individualized training prior to joining the group to learn how to use the equipment.

DISCUSSION

In our review of the literature from these major databases, only 7 articles were identified that dealt with interventions to assist rural caregivers of persons with dementia and their outcomes regarding burden. Of these, 2 were RCTs, 1 was quasi-experimental, 2 were case studies, 1 was a pre-/post research design study, and 1 was descriptive. Results from the 2 RCTs were mixed: 1 did not show significant differences between the intervention group and controls, and the other showed some improvement with the intervention. Results of the interventions reported in the other articles were positive, suggesting overall improvement.

Most interventions for caregivers of persons with dementia have focused on urban samples, so it is not clear whether they would be as effective in rural settings. Several differences have been identified between rural and urban caregivers of persons with dementia. Rural caregivers are more likely to receive community support and have a deeper sense of satisfaction and growth from their experience than urban caregivers.21 Urban CGs are more likely to use positive cognitive strategies and have more support from family and friends than rural caregivers. Rural white caregivers are less likely to use prayers or religious coping strategies than black caregivers in rural or urban areas;22 and rural and urban caregivers have different motivations for becoming a caregiver, such as self-reward, moral obligation or even lack of alternative, with rural caregivers having a different perception of the disease, evidenced by a deeper sense of independence and uneasiness accepting outside help.

In recent years alternative models of delivering psychotherapies have been proposed to increase access for patients who cannot attend clinical appointments because of geographical, social, medical, economical and stigma barriers.23 Many studies in nonrural samples have found telemental health equivalent to in-person therapies. For example, a recent study24 involving a telehealth intervention, such as videoconferencing, was found to have similar clinical outcomes to the traditional face-to-face psychotherapy when evaluating individuals with mental health problems. Another pilot study from 201425 demonstrated that group CBT could be delivered in a technology-supported environment (on-line video conferencing) and meet the same professional practice standards and outcomes as face-to-face delivery of the intervention program for depression scores. Both studies are good examples of familiar technology that can be applied in rural populations for caregivers of persons with dementia.

Although there are few studies in rural settings, and most are small, there is growing evidence for innovative strategies to reach rural caregivers, particularly therapies delivered through telephone/video or therapies provided in person but in a condensed, briefer format. The 2 RCTs analyzed found telephone-based interventions effective in reducing caregiver burden, with the advantage that in rural areas they eliminate the need for the primary caregiver to leave home to participate, making them better suited for that population.

Among the selected articles only 1 used community nurses to deliver the intervention to reduce the burden. However, existing staff, such as nurses and other healthcare
professionals, in a particular rural area could be used to deliver interventions to reduce caregiver burden; since they already have an established rapport with this population, perhaps they could help to tailor and facilitate the intervention to meet the specific needs of caregivers in a more productive manner.

One study in this review 15 found positive outcomes with a more condensed intervention of a 3-day workshop, raising the question as to whether this should be encouraged in the rural population, since such an intervention is not time consuming and likely to be low cost and still effective in reducing burden. A recent study at Florida State University 26 points out that short, high-impact interventions may be warranted if a client is to attend only a few sessions or show sporadic attendance, for whatever reason.

The conclusions drawn from this review must be considered in the context of many limitations. This review contained a small number of articles, especially RCTs that addressed outcome measures that decrease rural CG burden in persons with dementia. The studies found were mostly inside the Unites States, so the results may not be widely generalizable for other locales outside this country. Although interventions for caregivers to reduce burden were identified, our review was limited to the rural setting, for which the literature is scarce and lacks consistency in terms of the definition of rurality. This review also included 4 databases, and the terms initially were broad to capture all possible studies. An Internet google search using dementia caregiver burden in the rural setting was also used, as well as related articles being used as an important tool, since few articles were found in the database.

In conclusion, although most of the selected studies in this review were small and descriptive or pilot studies, there is already evidence to suggest a necessity to address issues when developing and evaluating interventions that target rural caregivers, such as population peculiarities, training of qualified professionals, and cost effectiveness of interventions, as well as ethical and legal issues. There is growing support for the efficacy of telehealth/web-based interventions as a delivery system for caregivers of persons with dementia, and some projects could serve as prototypes for adaptation for caregiver support programs in rural communities. Obviously, more research is needed to identify interventions that are efficacious for rural communities. Another important point from this review is that, with the mixed methodologies identified, future studies might be able to gain a better sense of what needs to be taken into account to enhance outcomes of interventions aiming to decrease rural caregiver burden in cases of chronic illnesses, such as dementia. It appears that interventions do not necessarily have to be delivered in person or over extended periods and that nurses might be helpful in working with caregivers to increase their knowledge of dementia and decrease their burden.
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Figure 1
Flowchart showing results of search.

Table 1
Summary of Relevant Articles Found in Search.

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