

Needs assessment of informal caregivers of people with dementia in Arkansas

Abstract

Objectives: To explore the level of caregiver burden among dementia caregivers and categorize caregiver needs in Arkansas regarding three domains: cognition, behavior, and affect.

Methods: A descriptive design and surveyed $N = 72$ informal caregiver participants. The 104-item survey combined four different scales measuring three domains: The Alzheimer's Disease Knowledge Scale (ADKS), Task Management Strategy Index (TMSI), Caregiver Assessment of Behavioral Skill-Self Report (CABS_SR), and the Caregiver Burden Inventory (CBI).

Results: Findings revealed that most caregivers were knowledgeable (ADKS $M = 23.89$ out of 30) about the care recipient's disease or care. Scores from the TMSI ($M = 59.55$ out of 95) show that caregivers were applying knowledge to their caregiving skills. However, caregivers report a need to improve behavioral skills ($M = 14.34$ out of 34; CBI $M = 35.13$ out of 96), and that they experience high levels of emotional burden ($M = 3.0$ out of 20).

Conclusion: Needs of caregivers in this sample are most prominent in the domains of cognition (skills) and behavior. There is less need in the area of cognition (knowledge) and the affective domain. The domain model was a useful method of performing needs assessment in this population.

Keywords: caregiver burden, dementia, healthcare, Arkansas

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Introduction

There are currently 6.5 million people with Alzheimer's disease in the United States and 58,000 people with Alzheimer's in Arkansas.¹ National numbers are expected to increase by 21.8% by 2025,¹ and it is likely Arkansas will also see a similar increase. As the population of people with dementia increases so does the number of people caring for these individuals. Informal caregivers provide 83% of in-home care to people with dementia in the United States.¹ They are typically unpaid and include relatives, significant others, and neighbors.² Currently, there are approximately 176,000 informal caregivers in Arkansas,¹ which is about three times as many caregivers as care receivers. Unfortunately, informal caregivers often experience caregiver burden. This is defined as the perception that physical, and/or emotional health, social life, or financial status has suffered because of caring for someone.³ Caregiver burden often leads to poor outcomes for caregivers. Dementia caregivers experience higher rates of depression and anxiety compared to caregivers caring for people with other illnesses and the general population.⁴⁻⁷ Moreover, these caregivers are at significant risk for cardiovascular disease,⁸ and have decreased life expectancy.⁹

Because of the prevalence of informal caregivers and the potential ill effects of such care, interventions that address caregiver burden in this population are warranted. We plan to develop and test the effect of an interprofessional caregiver intervention. However, performing preliminary studies is an important prerequisite when developing complex interventions.¹⁰⁻¹¹ Therefore, the purpose of this current study was to describe and categorize needs of informal caregivers of people with dementia in Arkansas in order to optimize the focus of the planned caregiver intervention.

Some studies have investigated caregiver needs; however, the aims of these studies vary widely. For example, Cova I, et al.¹² and Vaingankar JA, et al.,¹³ sought to find relationships of perceived needs

with other variables such as socio-cultural aspects of the caregiver and clinical characteristics of care receivers. Hughes TB, et al.¹⁴ documented the effect of caregiver needs on caregiver burden. Less commonly, other studies examined caregiver needs in order to inform interventions.¹⁵⁻¹⁶ Studies to inform interventions are often performed on specific populations. For example, Hinton L, et al.,¹⁶ examined needs of Latino caregivers and Ducharme F, et al.,¹⁵ examined needs of caregivers of people with early onset dementia. Despite this previous work, no in-depth descriptive studies have evaluated the needs of dementia caregivers in Arkansas. Therefore, obtaining such information was necessary, in order to develop our forthcoming intervention. Definitions of caregiver needs vary across studies as well. For example, Vaingankar JA, et al.,¹³ evaluated caregiver needs in relation to caregiver's involvement in care. Cova I, et al.,¹² described caregiver needs as influenced by predisposing factors (socio-cultural characteristics of individuals) and enabling factors (practical aspects of obtaining care); while Hughes TB, et al.,¹⁴ characterized caregiver needs according to dementia education, availability, emotional support, respite support, and other types of support services. In our study, we evaluated caregiver need based on a conceptual model developed by Schulz R, et al.⁴ Schulz R, et al.,⁴ developed their model specifically to help researchers develop targeted interventions for dementia caregivers. This is the first known study to use this model to describe dementia caregiver needs.

Schulz and colleagues⁴ conceptual model suggest that interventionists consider developing intervention content based on targeted primary learning domains (cognition, behavior, and affect). According to Schulz R, et al.,⁴ the cognitive domain encompasses both knowledge and skills. Concerning knowledge, caregivers experience problems when they have a lack of information about the caregiving process or the role of the caregiver. Whereas problems related to skills arise from the inability of the caregiver to analyze and understand their situation, leading to an inability to function

effectively. Problems associated with the behavioral domain arise from the inability of the caregiver to implement behavioral strategies to regulate their behavior, whether the behavior is in relation to the care recipient or other persons in the environment. Finally, problems arise in the affective domain when the caregiver experiences an excess of negative emotions such as distress, anxiety, or depression and too few positive emotions.⁴ Therefore, it is important to evaluate domains of learning in order to understand content focus for the coaching intervention. The specific aims of this study were to describe level of caregiver burden of informal caregivers of people with dementia in Arkansas and categorize informal dementia caregiver needs regarding three domains: cognition, behavior, and affect.

Methods

We used a descriptive cross-sectional survey study. This design was consistent with the exploratory nature of this study.

Setting and sample

After obtaining approval from the university Institutional Review Board, we sought participants from Alzheimer's Arkansas caregiver support groups and conferences, and an inpatient senior behavioral health unit at a regional hospital. Alzheimer's Arkansas conducts support groups for caregivers of people with dementia across Arkansas and offers dementia caregiver conferences several times a year. The senior behavioral health unit is a regional inpatient psychiatric care unit located in Central Arkansas that serves several surrounding counties. Members of the research team attended and collected data at nine Alzheimer's Arkansas support groups in three Central Arkansas counties and one conference in Central Arkansas. A member of the research team who worked at the senior behavioral health unit distributed and collected surveys to family members of those admitted to the unit on weekends over a 7-month period. Prior to distributing the surveys, members of the research team explained the purpose of the study to potential participants and provided a cover letter with the study's purpose. Inclusion criteria required participants: (1) be 18 years old or older, (2) provide at least five hours of care weekly, (3) have a significant relationship with the care recipient, and (4) have a diagnosis of dementia. Survey participants were eligible for a drawing of one of two gifts valued at \$250.00 each.

Measurement

We compiled a 104-item self-report survey to collect data from study participants. This survey was comprised of four different instruments (*Alzheimer's Disease Knowledge Scale*, *Task Management Strategy Index*, *Caregiver Assessment of Behavioral Skill Report*, and *Caregiver Burden Inventory*), and two stand-alone questions. Each instrument represented either the cognitive (knowledge and skills), behavioral, or affective domains. Prior to conducting the survey and to determine the understandability of the survey, we tested the instrument on five different caregivers, age 55–87 years old. The survey took 15–30 minutes to complete and feedback was favorable on ease of administration. From the survey results, one question was modified, which ranked income on a Likert scale. Feedback from participants in the test group indicated that the question was too intrusive. The questions was changed from having respondents identify their income category to a dichotomous yes or no item, which asked if income was a problem for the caregiver or care recipient.

Knowledge: The *Alzheimer's Disease Knowledge Scale* (ADKS) was used to evaluate caregiver knowledge.¹⁷ The purpose of the 30-item scale is to assess what people know about Alzheimer's disease (AD). The ADK is designed for the public and questions are in True/False

format. Although questions address Alzheimer's disease specifically, they apply to other forms of dementia as well. To alleviate this possible misconception, we replaced the term "dementia" with "Alzheimer's disease" in the instrument. Content of the scale covers knowledge of risk factors, assessment and diagnosis, symptoms, disease course, life impact, caregiving, and treatment management.¹⁷ The scale previously achieved test-retest reliability correlations of $r = .81$; an internal consistency reliability $\alpha = .71$, and was found to have appropriate content, predictive, concurrent, and convergent validity.¹⁷

Skills: We used The *Task Management Strategy Index* (TMSI) to evaluate caregiver skills. The TMSI evaluates caregiver use of specific skills to cope with physical dependency and agitation in people with dementia. Items from the TMSI represent discrete task-simplification strategies such as visual or tactile cueing, simplifying routines, communication techniques, or rearranging objects. The 19-item self-report measure uses a 5-point Likert scale to assess how often the caregiver uses each strategy described in the item (1 = never to 5 = always). The scale demonstrated internal consistency coefficients of .74 and .81 and positive predictive and concurrent validity.¹⁸

Behavior: Behavior of caregivers was assessed using *The Caregiver Assessment of Behavioral Skill-Self Report* (CABS-SR).¹⁹ This 28-item instrument includes two subscales, the *General Approaches to Caregiving* (11 items), and *Behavioral Management of Skill* subscales (17 items). The *General Approaches to Caregiving* subscale evaluates approaches used by the caregiver to understand care recipient needs. Item responses on this scale range from 1-4 (1 = I do not do this very well, 2 = I have some difficulty doing this, 3 = I usually do this well, 4 = I do this very well, 8 = does not apply). The subscale previously demonstrated internal consistency of $\alpha = .94$ and test-retest reliability coefficients of $r = .7$ ($p < 0.01$).²⁰ The *Behavior Management of Skill* subscale evaluates caregiver skill in managing a variety of behavioral symptoms commonly associated with dementia. Four subjects within the *Behavior Management of Skill* subscale include need based, behavior management, pleasurable activities, and confronting/criticizing. These subjects address intervention approaches potentially used by caregivers. Responses range from 0–2 (0 = seldom true or not relevant, 1 = true some of the time, 2 = true most of the time). Scores range from 0 - 34 with more positive scores indicating higher levels of self-perceived skill in using these approaches. This subscale previously demonstrated test-retest reliability coefficients of .60 ($p < 0.01$).²⁰ Convergent validity has also been demonstrated.

Affect: The *Caregiver Burden Inventory* (CBI) was used to evaluate caregiver affect along with overall caregiver burden.²¹ Instead of global scoring, the CBI uses a multidimensional measurement of burden with separate scores for each subscale. The CBI consists of 24 items divided into five subscales that include time-dependence, developmental, physical, social and emotional burden. There are five items in each subscale except for the physical subscale, which consists of four items. Each item is scored using a five-item Likert scale (0 = not at all descriptive to 4 = very descriptive). Higher scores represent higher caregiver burden, whereas lower scores represent lower burden. The Caregiver Burden Inventory has been validated in the United States²¹ and several countries, including Turkey,²² China,²³ and Brazil.²⁴ The CBI consistently demonstrates exceptional internal consistency for the subscales and total scale with Cronbach's alpha values falling between 0.850 - 0.94.^{22,24} Test-retest measures are also high for the total scale and subscales (.867-.98).^{22,24}

Two items on the survey were general questions that addressed perceived knowledge about the disease or disorder of the recipient and perceived knowledge of available caregiver resources. Specifically,

these questions were, “How knowledgeable do you feel about the care recipient’s disease or disorder?” and “How familiar are you with programs and resources available to help you?”. Answers on the Likert scale ranged from (0 = not at all, 1 = a little, 2 = moderately, and 3 = very).²⁵

Data collection

Hard copy surveys were supplied to participants who provided consent to participate in the study and they were asked to complete the survey at the time of survey distribution. If participants were unable to fill out the survey at the point of contact, they were provided with a self-addressed, stamped envelope and instructed to fill out and return the survey at a suitable time. During the survey administration, the researchers were available to answer questions from the participants.

Data analysis

Descriptive statistics (frequencies, range, percentages, means, and standard deviations) were used to describe the survey data. Additionally, a Pearsons R correlation analysis was performed to evaluate the correlation between perceived knowledge and knowledge scores on the ADKS.

Results

Of the 129 surveys distributed, 97 were returned and 25 were excluded because of failure to meet the inclusion criteria that caregivers provide at least five hours of care weekly. Therefore, 72 surveys from participants qualified for analysis. Some surveys had incomplete data on a particular scale (ex. *ADK*, *TMSI*, *CABS*, *CBI*) within the survey. If missing data existed on a particular scale, then that scale was excluded from analysis, but the completed scales were analyzed. Therefore, sample size varies per individual scale.

Demographics

Table 1 displays characteristics of the sample. Participants were predominately white (91.7%) and female (70.8%). Almost half of caregivers (47.9%) had been in the caregiving role for more than 3 years with an average of 53 hours per week. Twenty (28.2%) caregivers were caring for spouses, and fifty (71.8%) were caring for someone other than their spouse. Thirty-seven participants (53.6%) lived with the care receiver. Most caregivers expressed that income was adequate for the caregiver (59.2%), and the care receiver (62%). Most of the sample was either unemployed or retired (60%) and married (78.9%). Almost half of the sample had a college degree or higher (47.9%), compared to 52.1% who had received some college education or less.

Table 1 Demographics of caregivers

Race	N = 72
White	91.70%
African American	6.90%
Gender	N = 72
Male	29.20%
Female	70.80%
Relationship to care receiver	n = 70
Spouse	28.20%
Non-Spouse	71.80%
Living situation	n = 69
Live together	53.60%
Live separately	46.40%

Table 1 Continued....

Caregiver perception of household income adequacy	n = 71
Adequate	59.20%
Inadequate	40.80%
Care receiver’s annual income adequacy	n = 71
Adequate	62%
Inadequate	38%
How long caring for care receiver	n = 71
Less than 3 years	52.10%
3 years or more	47.90%
Employment	n = 70
Employed	40%
Not employed or retired	60%
Education caregiver	n = 71
Some college or less	52.10%
College graduate or more	47.90%
Current marital status caregiver	n = 72
Married	78.90%
Single	21.10%

Results knowledge, skills and behavior (ADKS, TMSI, CABS)

Results of the *ADKS*, *TMSI*, and *CABS* scores are in Figure 1 and Table 2 (see below). The score on the *ADKS* is calculated by adding the correct scores for each of thirty items. Scores can range from 0 – 30. Higher scores represent greater knowledge. The mean score in our sample $n = 72$ was $M = 23.89$ ($SD 4.17$, range 8 – 29). Chronbach’s Alpha in our study was .775.

Table 2 Results ADKS, TMSI, CBS

Scale	N	Mean	Range	Standard deviation	Chronbach’s alpha
<i>ADKS</i>	71	23.89	(8-29)	4.17	0.78
<i>TMSI</i>	65	59.55	(27-91)	13.07	0.9
<i>CABS-SR</i>		30.06		8.54	
<i>General Behavior</i>	69	2.73	(11-44)	0.78	0.9
<i>CABS-SR</i>		14.34	(1-23)	5.23	
<i>Specific Behavior</i>	68	0.84	(.06 – 1.35)	0.31	0.89

The *TMSI* is scored by summing scores on all 19 items. Data was reverse scored for those strategies that should not be used. Possible score range is from 19 – 95. The higher the score achieved, the greater the use of skills. Results of the *TMSI* in our study $n = 60$ was $M = 59.55$ ($SD 13.07$, range 27 – 91). The possible Likert score range for each individual item was 1 - 5, the sample mean was $M = 3.13$ out of five ($SD = .688$, range 1.42 – 4.79). Chronbach’s Alpha was .891. The data from the *TMSI* was reconfigured by recoding each strategy as a 0 (never or rarely used) and 1 (sometimes, often or always used) to determine how often the 19 strategies evaluated by the *TMSI* were being used. A histogram was performed to evaluate the frequency of use of the strategies (See Figure 1). This histogram demonstrates that the average number of strategies used by participants was $M = 12.85$, range 1 - 19. Strategies that were used least often were: 1) I introduce an activity that uses the same motion over and over such as sweeping, raking, or dusting, 2) I use pictures or labels to identify objects in rooms, 3) I use pictures to help my care receiver remember what to do,

- 4) I use bright color or signs to help my care receiver notice an item,
- 5) I use intercom or other monitoring devices to supervise my care receiver when he/she is in another room.

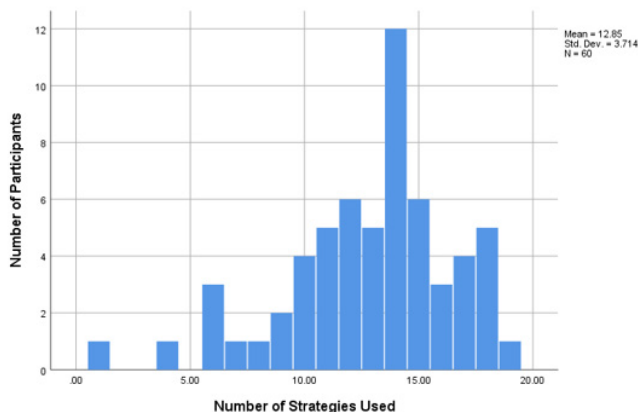


Figure 1 TMSI number of strategies used by caregivers.

Both subscales in the *CABS* (the 11- item *General Approaches to Caregiving* subscale and the 17- item *Behavior Management of Skill Subscale*), are scored by summing the scores on each item, and obtaining the mean Likert score of the summed items. Possible range

of summed scores on the *General Approaches to Caregiving* subscale is 11 – 44. The mean in the sample $n = 69$ was $M = 30.06$ ($SD 8.54$, range 0 – 44). The possible Likert score range was 0 – 4, the sample mean was $M = 2.73$ ($SD .78$, range 0 – 4). Chronbach’s Alpha was 0.882. Possible range of summed scores on the *Behavior Management of Skill* subscale is 0 – 34. The mean in the sample $n = 68$ was $M = 14.34$ ($SD 5.23$, range 1 – 23). The possible Likert score range was 0 – 2. The mean in the sample was $M = .84$ ($SD .31$, range .06 – 1.35). The mean percent of strategies being used in this sample is 58%. Chronbach’s Alpha was 0.724.

Caregiver Burden and Affect (CBI)

The total *CBI* score and the subscale scores (*Time Dependence, Developmental, Physical, Social, and Emotional Burden*) were analyzed and the results are presented in Table 3. Possible scores on overall caregiver burden range from 0 – 125, possible scores on each subscale range from 0 – 20. Mean total *CBI* scores for the sample $n = 68$ were $M = 35.13$ ($SD 17.64$, range 8 – 77). Chronbach’s Alpha was .909. Mean score for the time dependence burden was $M = 11.52$ ($SD 4.69$, range 1 – 20). Mean for developmental burden was $M = 9.54$ ($SD 6.33$, range 0 – 20). Mean for physical burden was $M = 8.18$ ($SD 4.96$, range 0 – 16). Mean for social burden was $M = 5.16$ ($SD 5.25$, range 0 – 20). Finally, the mean for emotional burden which was used to measure the affective domain was $M = 3.0$ ($SD 4.15$, range 0 – 20).

Table 3 Results caregiver burden inventory

N	Mean	Standard deviation	Range	Cronbach's alpha	
<i>CBI</i>	68	35.1324	17.64	8 - 77	0.909
Total Burden					
<i>CBI</i>					
Time	69	11.52	4.69	1 - 20	0.816
Dependence					
<i>CBI</i>	69	9.54	6.33	0 - 20	0.904
Developmental					
<i>CBI</i>	68	8.18	4.96	0 - 16	0.889
Physical					
<i>CBI</i>	69	5.1594	5.25	0 - 20	0.799
Social					
<i>CBIEB</i>	69	3	4.15	0 - 20	0.898
Emotional					

Perceived knowledge of care and services

Over half of participants indicated that they were either moderately (52.8%) or very (25%) knowledgeable about the care recipient’s disease or care. A Pearson’s test between results for this question and knowledge on the *ADKs* demonstrated moderate correlation ($r = .343$, $p = .03$). About half of the sample answered moderate (34.7%) to very (16.7%) for the general question “How familiar are you with programs and resources available to help you?”

Discussion

Sample characteristics demonstrated that participants in this study were disproportionately female. This is consistent with national trends that indicate females are most often caregivers.²⁶ Participants tended

to be well educated, financially stable, not working, and caring for someone other than their spouse. These characteristics differ from national samples, which indicate that most caregivers have a high school education or less, average family income around \$55,000, are employed, and the spouse of the care recipient.²⁶ Finally, the sample was predominately Caucasian (91.7%), which is much higher than the Arkansas Caucasian population (79.1%).²⁷ This lack of ethnic diversity may be due to the fact that our sample was drawn from people who are already receiving services through Alzheimer’s Arkansas and a regional inpatient hospital. It may be that individuals from minority ethnic groups are not accessing services available for caregivers in the state and thus benefiting from them. There is need for further investigation to elucidate the reasons for these disparities.

Cognitive domain (Knowledge and skills)

Cognitive knowledge of participants regarding dementia was high in the sample of this current study. The study revealed higher scores on the ADKS than a student sample ($n = 26$, $M = 20.19$) and a peer sample of dementia caregivers ($n = 40$, $M = 22.70$).¹⁷ Scores in the study were similar to that of a sample of Norwegian psychologists ($n = 946$, $M = 24.10$).²⁶ The high knowledge scores obtained could be a result of the training being delivered in the support groups. These groups routinely provide information regarding dementia to participants. Also, those attending such groups may be more motivated to seek out information, thus impacting knowledge level. Knowledge could also be affected by the higher educational levels of the sample participants.

The results from the present study indicated that cognitive skills were used routinely among the sample. The scores on the TMSI demonstrated that in general caregivers in the sample were applying knowledge to their caregiving skills in the areas of ADL dependence and problem behaviors.¹⁸ The number of strategies being used by caregivers either sometimes, often, or always, was higher than a sample of similar caregivers ($N = 255$), who used 10.5 of the strategies on average.¹⁸ However, the mean score on this tool ($M = 59.55$) was below the total possible score of 95 which indicates room for improvement. Interestingly, several of the strategies that were being used less often involved introducing cues in the environment such as using pictures, bright objects, or monitoring devices. It is unclear why these strategies were being used less often, but there is a need to emphasize these proactive strategies in future caregiver interventions.²⁸

Behavior

The study demonstrated that there was significant room to improve in the behavioral domain. The mean Likert score we obtained on the CABS-SR general approaches ($M = 2.77$) and behavioral management ($M = .77$) scales were lower than the means of a similar group of caregivers $n = 86$ caregivers ($M = 3.25$) & ($M = 1.07$, $SD 0.34$).¹⁹ The summed score on both the general and behavioral scales also fell well below the total possible summed scores. It is not surprising that caregivers, such as those in our sample, may score well on cognitive domains, but do not necessarily translate that knowledge into behavioral change. Behavioral change is a complex process, requiring time and stages.²⁹ Substantial behavior change requires changes in choices, attitudes, thoughts and feelings, values and even core beliefs.³⁰ It also requires that individuals identify and overcome barriers to change.³¹ The caregiving situation may be a particularly difficult environment to change behavior, as caregivers often have entrenched patterns of behaving toward the care receiver over a number of years. Given the complexities of changing behavior and the specific context of caregiving, behavioral change requires that interventions address more than the cognitive aspects of learning but also address psychological aspects of the individual seeking change.²⁹

Interventions seeking behavioral change are often individualized, involve shared decision making, and seek optimum strategies to support individuals to modify behavior over time.³²⁻³³ Psychotherapy, which involves a therapeutic relationship between a caregiver and trained therapist and often uses cognitive behavioral therapy has demonstrated positive outcomes associated with behavioral change.³⁴ Coaching too, is an example of an intervention that is useful in behavioral change. Fielden and colleagues³⁵ described coaching as a relationship that empowers learners to achieve best performance. It involves frequent exchanges between coach and learner over a set period. Meetings between coach and the learner are structured,

scheduled on a regular basis, and focus on a specific, individualized development area or issue.³⁶ Thus, Coaching is outcome oriented, highly individualized, and person-centered. These are precisely the intervention characteristics that Schulz R, et al.,⁴ identified as the most effective in providing support for informal caregivers of people with dementia.

Affective domain

Surprisingly scores on the emotional subscale of the caregiver burden inventory were lower than any of the other subscales of the CBI (time dependence, developmental, social, and physical). Novak and Guest²¹ conceptualize emotional burden as related to negative feelings toward care receivers. Caregivers may resent or feel angry with the care receiver or have feelings of guilt or embarrassment. Characteristics of our sample may have provided clues to the low emotional burden scores.²¹ All caregivers in the study were receiving services of one kind or another that might help to mitigate emotional strain. The demographic factors detailed above (higher socioeconomic status, less spouses, not employed etc.) could also result in decreased emotional burden as some of these factors have been shown to effect caregiver burden scores. For example, spousal caregivers, those who are financially insecure, and who work, tend to have higher caregiver burden scores.⁴ Whereas, in some studies lower educational level is associated with higher perceived positive aspects of caregiving.³⁷ A comparison of scores from the sample with scores from those Arkansans not accessing services could shed light on the usefulness of services in reducing emotional burden.

Time dependence burden ranked highest on the Caregiver Burden inventory subscales. Time burden describes the burden of caregiving that occurs because of restrictions on the caregiver's time.²¹ This burden occurs because of the time and energy devoted to being vigilant and being required to be "responsible" for the care receiver. Time commitments have been associated with increased caregiver burden. The National Alliance for Caregiving and AARP²⁶ noted that the number of hours of care provided are related to increased burden, stating that 92% of providers providing 21 or more hours of care per week are categorized as high burden compared to 16% of lower hour providers. In the population in this study interventions that free up time for the caregiver may be of significant benefit. Respite care, which can be provided in-home through caregivers, or at another site, involves assistance with activities and is designed to give the caregiver time off.³⁴ Adult day care programs also provide both respite and activity programs, while freeing up caregiver time. However, there are limited options for adult daycare in many communities, and they are cost prohibitive.

Limitations

Although the domain model of caregiver interventions proposed by Schulz⁴ proved to be a useful structure for evaluating caregiver needs in the community studied, there were some limitations to implementing the model. A difficulty arose in operationalizing the domains. Differentiating between "cognitive skills" and "behavior" was particularly challenging, as there is a fine line between being able to perform a skill and doing the skill. Given that validity of the instruments was established outside of the model, there might be some issues of conceptual validity related to these domains. A second limitation was achieving a representative sample, as described earlier in this paper. Evaluating the needs of underrepresented caregivers is a future research goal.

Conclusion

This was the first study which assessed needs of caregivers in Arkansas based on the domain model proposed by Schulz.⁴ Information from this needs assessment provided valuable information for intervention development. Based on findings from this needs assessment, the researchers plan to move forward with interventions focusing on the behavioral domain and relieving time burden in our community. This method of assessment could be easily replicated in other venues. Based on the findings from this study, we plan to pursue development of a multicomponent intervention involving coaching and respite care. Sorensen S, et al.,³⁴ have found that these interventions have significant effects on caregiver burden, ability, and well-being.

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Conflicts of interest

The authors declare there is no conflict of interest.

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