

REVIEW

Caregiver burden among dementia patient caregivers: A review of the literature

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Abstract

Purpose: To identify current evidence of factors influencing dementia-related caregiver burden (CB), describe patient and caregiver characteristics associated with CB, and describe evidence-based interventions designed to lessen the burden of caregiving.

Data sources: Comprehensive literature review of Cumulative Index of Nursing and Allied Health Literature, MEDLINE, and Psych Info was performed for the years 1996–2006 of peer-reviewed journals using keywords CB and dementia.

Conclusion: Dementia caregiving has been associated with negative effects on caregiver health and early nursing home placement for dementia patients. Many factors influence the impact of the caregiving experience such as gender, relationship to the patient, culture, and personal characteristics. Although various interventions have been developed with the goal of alleviating CB, evidence suggests that individually developed multicomponent interventions including a diversity of services will decrease burden, improve quality of life, and enable caregivers to provide at-home care for longer periods prior to institutionalization.

Implications for practice: The ability to properly assess the dementia patient–caregiver dyad related to CB is critical to decreasing its negative physical and psychological health outcomes. Appropriately tailored interventions can improve the health and well-being of both caregiver and patient.

Introduction

Family members caring for individuals with dementia at home often describe the experience as “enduring stress and frustration” (Butcher, Holkup, & Buckwalter, 2001), and the term caregiver burden (CB) is most often used to describe this phenomenon. More than 80% of Alzheimer’s disease (AD) caregivers state that they frequently experience high levels of stress and almost half report that they suffer from depression (Alzheimer’s Association, 2006). CB is associated with poor outcomes for caregivers such as depression, illness, and decreased quality of life (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006) and poor outcomes

for dementia patients such as poor quality of life and early nursing home placement (NHP) (Gaugler, Kane, Kane, & Newcomer, 2005; Yaffe et al., 2002). Families experiencing CB may present in any healthcare setting and thus nurse practitioners (NP) need information on assessment and interventions.

Caregiver burden has been defined as “a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience” (Kasuya, Polgar-Bailey, & Takeuchi, 2000, p. 119). It differs from caregiving, which refers to the “activities and experiences involved in providing help and assistance to relatives who are unable to provide for

themselves" (Pearlin, Mullan, Semple, & Skaff, 1990, p. 583) but does not include the psychological distress that may come from it. CB derives from the caregiver's perception of activities and stressors and thus is influenced by many psychosocial factors such as kinship, social environment, and culture.

Scope of the problem

Caregiving for persons with dementia (PWD) is a global nursing issue, in part because of a worldwide demographic shift to an aging population. An estimated 5.1 million Americans now have AD (Alzheimer's Association, 2007), and globally the number of persons with all forms of dementia is expected to be 63 million by 2010 (Wimo, Winblad, Aquero-Torres, & von Strauss, 2003). Much of the caregiving responsibility will fall on family caregivers, such as a spouse, although other family members (siblings and children) are increasingly assuming this role. In the United States, family members provide up to 80% of the in-home care needed by persons with dementia (Alzheimer's Association, 2006). The amount of time needed for caregiving increases as the severity of dementia increases (Langa et al., 2001). Thus, efforts to identify and reduce CB are an important healthcare issue (Family Caregiver Alliance, 2006).

CB has been associated with earlier NHP for persons with dementia. Caregivers seeking NHP had significantly higher burden scores, more family dysfunction, and decreased social support compared with caregivers who did not seek NHP (Spruytte, Van Audenhove, & Lammertyn, 2001). Other caregiver characteristics associated with NHP were female gender, having greater than 16 h per week away from caregiving, not living in the same household, and those without religious practices. Adult children caregivers tend to initiate early NHP compared to spouse caregivers (Hope, Keene, Gedling, Fairburn, & Jacoby, 1998; Spruytte et al.).

Caregiver characteristics

A wealth of literature has examined caregiver characteristics that influence CB. Kinship ties (spouse, child, and siblings) were an early factor found to influence CB when Zarit, Reever, and Bach-Peterson (1980) originally noted that wives experienced higher levels of CB compared to other family members. Although this finding has been supported (Almberg, Grafström, & Winblad, 1997a; Zarit, Todd, & Zarit, 1986), a study in Ireland found that daughters were overrepresented in the high CB group compared with other kinship groups (Coen, O'Boyle, Coakley, & Lawlor, 2002). More recently, at least one study found no significant differences in CB between adult children and spouses (Chumbler, Grimm, Cody, & Beck, 2003). In general, closer

kinship ties are associated with increased CB (Annerstedt, Elmstahl, Ingvad, & Samuelsson, 2000; de Vugt et al., 2005).

Gender is an influence on kinship roles and perceptions of CB. Several studies have found that female caregivers tend to report more health problems and depressive symptoms than male caregivers (Almberg, Jansson, Grafstrom, & Winblad, 1998; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002), yet other studies have found no gender effect on global measures of CB (Annerstedt et al., 2000; Chumbler et al., 2003). Gender may influence the experience of CB. Almberg et al. (1998) compared male and female caregivers and found differences in their patterns of CB. Male caregivers were found to experience a lack of positive outlook and a need for social support, while females reported increased CB in their relationships with other family members as well as an increase in their own health problems.

Caregivers' coping strategies influence their perceptions of CB. Almberg, Grafström, and Winblad (1997b) describe the relationship between CB and coping strategies. Coping strategies, such as emotion-focused coping, deal with the feelings associated with major strain, whereas problem-focused coping, aims to confront the reality of major strain by dealing with the tangible consequences (Almberg et al., 1997b). Female caregivers tended to report more emotion-focused coping, while males reported problem-focused coping strategies, and problem-focused or mixed coping strategies were found to be most effective (Almberg et al.). Mausbach et al. (2006) found that the use of escape-avoidance coping patterns by elderly spousal caregivers partially mediated the association between patient problem behaviors and depressive symptoms. Self-efficacy behaviors may also influence coping strategies for CB. For example, one study found that the attribute of self-efficacy had a significant independent effect on the caregivers' experience of CB (Gonyea, O'Connor, Carruth, & Boyle, 2005). Caregivers reporting stronger self-efficacy and taking time for themselves had decreased burden and a greater quality of life (Coen et al., 2002; Gonyea et al.). Thus, caregiver self-efficacy and coping strategies are important contributors to perceptions of CB.

Culture shapes one's perceptions of familial responsibilities and thus also influences CB. Distress from caregiving may be expressed differently among people of varying ethnic backgrounds (Adams, Aranda, Kemp, & Takagi, 2002). Studies from various cultures generally find that female caregivers are at greatest risk for CB (Rinaldi et al., 2005; Torti, Gwyther, Reed, Friedman, & Schulman, 2004). In a review of 18 studies, Janevic and Connell (2001) found that Caucasian caregivers tend to report greater depression and appraised caregiving as more stressful than African American (AA) caregivers. Qualitative studies have suggested that AA caregivers experience similar amounts of CB but express it differently than

Caucasian caregivers (Calderon & Tennstedt, 1998; Haley et al., 2004). Among Asian cultures, a greater sense of responsibility to care for elderly family members (Kim, Shin, Jeong, Gormley, & Yoon, 2002; Torti et al., 2004) and a reluctance to discuss family problems leads to less social and emotional support for caregivers. Not surprisingly, Chinese and Korean dementia caregivers scored higher on depression and burden measures compared to dementia caregivers in Western societies (Torti et al.). With increasing diversity in the older population, cultural assessment within CB assessments will be vital.

Patient characteristics

Studies demonstrate that dementia patients' behavioral disturbances are one of the largest factors contributing to CB (Beerli, Werner, Davidson, & Noy, 2002; Sink, Holden, & Yaffe, 2005). Behaviors such as aggression, agitation, and nighttime wandering are strongly associated with CB and depressive symptoms (Gallicchio et al., 2002; Gaugler et al., 2005). Those behaviors that created more physical stress on caregivers such as increased nighttime activity, incontinence, immobility, and difficulty in walking were predictors of NHP (Hope et al., 1998). Miyamoto, Ito, Otsuka, and Kurita (2002) found that caregivers of mobile demented patients reported higher amounts of CB because of behavioral disturbances than nonmobile patients. Savundranayagam, Hummert, and Montgomery's (2005) findings support the existing literature on problem behaviors as predictors of CB and, in addition, provide evidence that problem behaviors mediated the relationship between communication problems and all forms of CB. Behavioral disturbances appear to influence CB and thus recognizing them is an important factor to assess and address in reducing CB.

Surprisingly, the dementia patient's cognitive abilities are not a strong influence on CB. Most studies found either no or weak relationships between CB and the dementia patient's cognitive abilities (Annerstedt et al., 2000; Gonyea et al., 2005; Rinaldi et al., 2005). CB is also influenced by patients' type of dementia. Subjective appraisals of CB were significantly different between caregivers of persons with AD compared with frontotemporal dementia (FTD) (de Vugt et al., 2006). Caregivers of persons with AD experienced more disruptions in their personal life compared to FTD caregivers, while FTD caregivers were less satisfied with themselves as caregivers (de Vugt et al., 2005). Assessment of dementia type but not cognition then may improve CB assessment.

Family conflict

Caregiving for a demented relative has also been associated with family conflict, a decrease in social support, and lim-

itations in social life (Almberg et al., 1997a). Family conflicts can arise because of the caregiving situation itself or when long-standing unresolved family issues continue to spill over into the caregiver's experience, thus increasing demands and interfering with support they might otherwise receive (Neufeld & Harrison, 2003). Li and Sprague (2002) found that caregivers need help and assistance from family members as well as their expressed encouragement and appreciation for the caregivers' work in order to lessen the degree of CB. Deimling, Smerglia, and Schaefer (2001) found aspects of the family environment such as conflict to be an important predictor of caregiver's depression. They also found that as cognitive impairment increases, caregivers view the family as more conflictual and less adaptable. Heru and Ryan (2006) reported caregivers with prior good family functioning had significantly less strain and burden compared with caregivers with poor family functioning. Caregiving can have a strong influence on family relationships; therefore, assessment from a family-centered perspective is important to determine the level of conflict within the family. In addition, the family-centered assessment may help primary caregivers clarify expectations of care, identify potential sources of support, and address conflict resolutions.

Assessment of CB

Screening, assessment, and monitoring of the degree of burden associated with caregiving are essential. Tools such as the Zarit Burden Interview (ZBI) (Zarit et al., 1986), Caregiver Strain Index (CSI) (Sullivan, 2002), and the Screen for Caregiver Burden (SCB) (Hirschman, Shea, Xie, & Karlawish, 2004) along with clinical data can help to predict those caregivers at risk for significant burden.

The ZBI is one of the most commonly used burden scales for assessing dementia CB (Schulze & Rossler, 2005). It is a 22-item questionnaire measuring subjective burden, which has demonstrated high consistency and validity, and a higher score indicates greater burden (Zarit et al., 1986). The CSI is a 13-question tool that quickly identifies those at risk for CB and has demonstrated high internal consistency reliability and construct validity (Sullivan, 2002). Hirschman et al. (2004) developed a shorter version of the SCB with only seven questions that is able to identify caregivers at risk for CB and has shown good internal consistency. The American Medical Association (n.d.) developed a questionnaire caregivers can take to assess their distress level. Such tools can help NPs identify CB and facilitate appropriate interventions.

Interventions

Providing effective interventions to reduce CB is a vital aspect in providing quality care to dementia

patient–caregiver dyads. If a caregiver is supported in their emotional and physical health and has tools to manage the care of their family member with dementia, NHP may be delayed, significantly reducing costs of long-term care. One study found that caregivers who made environmental changes in the home, such as assistive devices in the bathroom and special locks on outside doors, were less likely to institutionalize their family member with dementia (Spruytte et al., 2001). Thus, educating caregivers on environmental changes that can improve care management is one intervention that NPs can provide to caregivers.

Earlier studies focused on single interventions and their effectiveness on reducing CB. For example, Hepburn, Tornatore, Center, and Ostwald (2001) tested a role-training intervention that focused on helping the caregiver assimilate a more clinical belief set about their role as a caregiver and hypothesized that in doing so, the stress and burden of caregiving would be reduced. They found that caregivers in the intervention group reported less depression and burden and were less bothered by behavior problems than the control group 5 months after starting the role-training workshop (Hepburn et al.).

Family intervention programs consisting of education, stress management, and coping skills were also found to significantly reduce depression and stress among caregivers while also reducing behavioral problems (Marriot, Donaldson, Tarrier, & Burns, 2000). Acton and Kang (2001) completed a meta-analysis of 24 published studies that examined effective treatments for dementia caregivers. Interventions were grouped into the following categories: counseling education, psychoeducation, respite care, and multicomponent interventions. Although collectively the interventions did not demonstrate a significant effect on CB, only studies with multicomponent interventions significantly reduced CB. More recent studies have been designed with multiple component interventions and have demonstrated better outcomes than those with single interventions (Callahan et al., 2006; Gitlin et al., 2003).

One of the largest, ethnically diverse, randomized trials investigating effective interventions for caregivers of persons with dementia was the Resources for Enhancing Alzheimer's Caregiver Health (REACH) (Gitlin et al., 2003). At each REACH site, independently developed interventions included such things as individual information, family systems work, psychoeducational and skill-based training, group support, in-home environmental strategies, and enhanced technology systems (Wisniewski et al., 2003). After 6 months of treatment, caregivers in the intervention group scored significantly lower on CB compared to those in the control group, although no single intervention demonstrated significant improvement over another.

Dementia caregivers have different needs; therefore, NPs cannot assume that the same intervention will work among caregivers of various backgrounds and cultures (Gallagher-Thompson et al., 2003). REACH findings demonstrated that certain subgroups of caregivers responded more favorably to interventions than others. For example, female caregivers in the intervention group demonstrated improved CB scores compared to male caregivers. Caregivers with a high school education or less responded more favorably to the interventions than those with higher education. NHP was higher in the control group than in the intervention group (Belle et al., 2006). Thus, interventions must be individualized to caregivers' background.

In a recent clinical trial with over 150-dementia patient–caregiver dyads, researchers investigated if usual care in the primary care setting could be improved through an intervention that provided collaborative care led by geriatric NPs (NP) (Callahan et al., 2006). Geriatric NPs worked along with patients' primary care physicians and followed a comprehensive set of guidelines for the management of AD and dementia-related diseases (Austrom et al., 2004; Callahan et al., 2006). Individualized recommendations based on protocols for symptoms such as sleep disturbances, agitation, repetitive behavior, depression, and delusions were given with regards to managing behavioral symptoms with a focus on nonpharmacological interventions (Callahan et al.). After 12 months, patients in the intervention group showed significant improvements in behavioral and psychological symptoms, and there was a significant reduction in caregiver stress compared to the control group. Additionally, there was no increase in the use of antipsychotics or sedative-hypnotics medications in the intervention group compared to the usual care group.

The above studies have findings similar to Pinquart and Sörensen's (2006) findings from a meta-analysis of effective caregiver interventions. Various interventions were found to have positive immediate effects on caregivers' burden. Psychoeducational interventions that included providing information about dementia and caregiving-related issues as well as active role playing demonstrated the broadest effects, although the interventions did not decrease the risk for institutionalization. However, multicomponent interventions, such as education, support, and respite care were significantly related to delayed institutionalization (Pinquart & Sörensen). These findings suggest that NPs implement multicomponent interventions to reduce CB.

Conclusions

Caregiver burden is a common problem encountered by primary care NPs. NPs need to design and implement multicomponent interventions for caregivers of persons

with dementia because of its associated poor outcomes for caregivers health and dementia patients. Multicomponent interventions targeting the caregiver have demonstrated improvements in CB scores and outcomes such as coping skills, depression, and delayed institutionalization for patients.

Nurse practitioners can address CB through prevention and early detection. Periodic screening of caregivers every 6 months for CB can help to identify those who are at increased risk. When CB has been identified, interventions requiring active participation of the caregiver have shown the greatest improvement (Pinquart & Sörensen, 2006). Interventions that can be offered begin with tailored information about dementia, getting multiple family members involved, assisting the family to identify rewards from caregiving, in-home environmental assessments, and education on safety issues such as doors locks and identification bracelets. As dementia progresses, caregivers need additional in-home assessment and skill-based training to support dementia patients' function (dressing, bathing, and toileting), facilitating formal or informal group support, and offer interventions that promote healthy sleep/wake cycles.

Alleviating CB and delaying institutionalization also has important economic and social implications for reducing the high costs of long-term care (Pinquart & Sörensen, 2006). However, it is important to recognize when placement outside the home is the most appropriate care choice for the health and well-being of caregivers, who are often elderly as well (Buhr, Kuchibhatla, & Clipp, 2006). Choices include adult day services, short-term respite care, assisted living, and nursing home care. By assessing all factors influencing dementia-related CB, NPs can deliver evidence-based interventions to lessen the burden of caregiving and improve care of older adults.

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