Mitigating Burden Associated With Informal Caregiving

Dorothea Frederick, DNP, FNP-C, RNFA[1]

Abstract

Informal caregiving is the most common form of long-term care provided in the United States, and with the projected rapid growth of older adults, informal caregiving will be even more critical in the foreseeable future. In the United States, slightly more than 20% of informal caregivers provide care for more than one care recipient, and 10% provide care for three or more care recipients. Caring for a dependent, older adult patient may have negative effects on physical, psychological, psychosocial, social and financial health of caregivers. Careful assessment of the impact of informal caregiving on the caregiver's functioning is imperative, and will enable a practitioner to not only find ways to help caregivers shoulder the effects of caregiving, but also to measure the effectiveness of interventions that seek to mitigate the effects of caregiving.

Keywords

caregiver, chronic disease, burden, measuring/alleviating burden

Introduction and Background

The projected rapid growth of older adults in the United States will result in a critical need for informal caregiving in the foreseeable future. Informal caregivers provide physical, practical, and emotional care and/or support to a relative or a friend without financial reimbursement (1). Informal caregivers may also be referred to as family caregivers or care partners. This informal caregiving may result in a phenomenon identified in the literature as caregiver burden and may lead to adverse effects on emotional, social, financial, physical, and/or spiritual functioning (2). In some instances, perceived caregiver burden predicts anxiety and depression in caregivers and occurs as a result of perceived inability to contend with role demands (3). Therefore, the need exists to measure caregiver burden using psychometrically valid tools so that practitioners can effectively implement and evaluate interventions to reduce caregiver burden.

Problem Statement

The aging population, increased number of people living with chronic disease, and lack of support for informal caregivers have increased the prevalence of caregiver burden (2). There is a need for both effective and sustained clinical engagement by practitioners with families to achieve optimal chronic care management outcomes by identifying caregivers' unmet needs and unidentified health risks (4). Burden among caregivers may be indicated by negative effects on physical, psychological, psychosocial, social, and financial health of the caregiver and may be primarily caused by unrelieved stressors. Caregiver burden may be mitigated by factors such as quality health care, support services, and individual resilience. Caregiver burden is dependent on factors such as family, social, and primary care practitioner (PCP) supports that moderate the causes, in addition to prior existence of predisposing factors, such as an existing healthcare recipient, provider, and vulnerabilities. The problem is that while a patient receives a thorough physical and mental health assessment during a home care visit, the caregiver is not the focus of attention.

Review of the Literature

A comprehensive search of the literature related to caregiver burden included the following databases: PubMed of the

[1] Jefferson College of Nursing (JCN), Thomas Jefferson University, Philadelphia, PA, USA

Corresponding Author:
Dorothea Frederick, Jefferson College of Nursing (JCN), Thomas Jefferson University, 130 South 9th Street Edison Building, Suite 842, Philadelphia, PA 19107, USA.
Email: dorothea.frederick@jefferson.edu

National Library of Medicine, CINAHL, and Ovid SP. The following Medical Subject Headings terms were used for the search: *caregivers*, *chronic disease*, *caregivers and chronic disease*, *caregiver burden*, *measuring caregiver burden*, and *alleviating caregiver burden*. Nineteen studies were retrieved; excluded were 4 studies that duplicated each other and 6 that were descriptive focusing on specific chronic conditions, leaving 9 studies for the review of literature.

The aging population, increased number of people living with chronic disease, and the lack of support for informal caregivers have increased the prevalence of caregiver burden (2). The unmet needs of family caregivers, along with extensive health risk, emphasize the need for both effective and sustained clinical engagement with families to achieve optimal chronic care management outcomes (4). Risk factors for caregiver burden that should trigger assessment include around-the-clock care, high or increasing care needs, and care transitions (2). Effective interventions include providing respite care (1,2,4–6), improving coping skills (1,4,5), improving well-being with psychological programs, such as counseling or psychotherapy (1,4,5), symptom management for patients (2,5), effective communication along with community-based supports (4), and providing interventions at the appropriate time (1,5). Due to the increasing prevalence of caregiver burden, public awareness campaigns have been launched for community members to become aware of the fact that they are caregivers and that help is available; one of these public awareness campaign sites is found at http://www.whatisacaregiver.org/caregiving-for-others.html (4). Addressing caregivers' needs is not a straightforward task; their needs are broad ranging and change over the period of caregiving (1).

Caregiver Burden Quality Improvement Project

Multiple interventions were included in this quality improvement project to facilitate alleviation of caregiver burden; each intervention addressed one of the several factors involved in caregiver burden. These interventions are grouped in Appendix Table A1. Interventions must be adjusted to the specific needs of the caregivers and must result in health gains.

Organizational and Theoretical Frameworks

The fundamental principles for caregiver assessment and intervention include:

(1) Family caregivers are a core part of health care; thus, it is important to recognize, respect, assess, and address their needs.
(2) Caregiver assessment is completed from a family-centered perspective, including the needs/preferences of both care recipient and provider.

(3) Caregiver assessment results in a collaborative care plan with measureable outcomes.
(4) Caregiver assessment encompasses a multidimensional approach and must be periodically updated.
(5) Caregiver assessment reflects culturally competent practice (7).

Stress process theory was first described by Pearlin (8) as a combination of 3 major conceptual domains: exposure to sources of stress, strategies for coping, and outcomes related to stress. In 1995, Aneshensel and associates further noted that "the conceptual framework of the stress process is particularly useful in capturing the dynamic features of problematic life experience, caregiving being an excellent case in point" (9, p 35). Common sources of stress associated with caregiving include changes in role function, additional financial responsibilities, assisting with activities of daily living, and dealing with potential behavioral problems of care recipients (10). Caregiving may create a context in which caregivers experience stress and burden, but methods of coping among caregivers vary considerably. "The meaning a caregiver gives to events, that is, the amount of perceived threat and how disruptive the event is to their lives, impacts how they respond to those events and, ultimately, to the outcomes they experience" (10, p 751). Pearlin (11) has added to his own work, seeing the problem of caregiving increasing as the population ages, noting that becoming a caregiver is not a normal expected life transition, and so one is not prepared for it; some have labeled it the unexpected career (9). The caregiver role can become totally engulfing, displacing one's other roles, reshaping one's life course, and it may adversely affect both health and well-being. In any theoretical framework, PCPs work alongside patients to engage in health-promoting processes and achieve client goals.

Project Design and Methods

Setting and resources. This project took place in a home visit practice that utilized both physicians and nurse practitioners. The PCP, while preserving patient autonomy and privacy, also needs to validate the caregiver role and help resolve potential conflicts between the needs and rights of both the care recipient and the caregiver (12).

Description of the group, population, community. The specific target dyads of this project consisted of homebound patients and their caregivers who were 18 years of age or older. The author saw patients of all ethnicity, race, and socioeconomic status; these demographics were dependent upon the specific areas within the county where visits were scheduled.

Implementation

At each home visit, if there was a caregiver present, they were invited by the author to complete the *ZBI-12 survey*. The ZBI-12 survey includes the following questions:

1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
3) Do you feel angry when you are around the relative?
4) Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?
5) Do you feel strained when you are around your relative?
6) Do you feel that your health has suffered because of your involvement with your relative?
7) Do you feel that you don't have as much privacy as you would like because of your relative?
8) Do you feel that your social life has suffered because you are caring for your relative?
9) Do you feel that you have lost control of your life since your relative's illness?
10) Do you feel uncertain about what to do about your relative?
11) Do you feel you should be doing more for your relative?
12) Do you feel you could do a better job in caring for your relative?

Responses to these questions include never (0), rarely (1), sometimes (2), quite frequently (3), nearly always (4). During project implementation, 51 patients were seen, and 9 surveys were completed by caregivers. The survey score was calculated during the patient visit to determine the *Implementation Plan of Action* that was needed (see Appendix Table A3).

Results

The scores obtained from the 9 ZBI surveys obtained were as follows:

Score	Number of Respondents
0	2
2	2
5	1
9	1
11	1
18	1
20	1

The author analyzed the results of the ZBI-12 surveys as to the level of intervention needed to include (1) universal—providing all caregivers with basic information and skills to assist them in their role (lowest score = 0) (2) selective—caregivers with minimal risk on assessment would be provided with skills training and group support programs (median score = 24) (Table A2), and (3) indicated—caregivers with high levels of risk would be provided with tailored, multicomponent, intensive support programs (highest score = 48) (13).

The author noted that caregivers with low levels of stress, identified by their low scores on the ZBI-12 survey, had caregiving as their sole responsibility. These caregivers did not work outside the home or have other familial responsibilities or financial worries.

Discussion

According to the *Fitzgerald Health Education Associates* (2015) (14), Nurse practitioners encounter caregivers every day in practice. These encounters provide the opportunity to practice preventive care by investigating what caregivers need in order to take care of themselves.

As a direct result of the Affordable Care Act (ACA), the millions of Americans who serve as informal caregivers now have more access to affordable health insurance coverage. This means that caregivers do not have to choose between health care for themselves or their loved ones due to financial constraints. The ACA emphasizes primary care in the home and supplies caregivers with the training and tools they need to fight any adverse effects caregiving may have on their health (15).

The intention was to survey a caregiver at each home; however, only 9 caregiver surveys were completed out of the 51 patient home visits. Several reasons prevented the completion of the surveys by the 35 patient–caregiver dyads.

Husband and wife were both patients, and 1 spouse was the caregiver of the other	2
No caregiver was present	12
The caregiver refused	4
The caregiver had intellectual developmental disorder	3
The patient had no caregiver	16
Survey was left at the request of the caregiver, but not completed	2
Return visit where the survey was already completed	3

The author noted, particularly with caregivers who refused the survey, a high level of stress. These caregivers rushed home from work or rushed around getting ready to leave, with little time to devote to answer questions about their own needs. Of particular interest was the number of patients with no caregiver readily available, or those with family members in distant states. These results illustrate that caregiving can and does result in stress. However, the author was limited in identifying only low levels of stress in those surveyed and unable to measure how well interventions worked or assess outcomes related to those interventions.

Implementation barriers found in this project correspond with the literature, in that burdened caregivers are completely focused on patient needs, not their own experiences, and may not wish to spend time completing even a brief questionnaire. Although this quality improvement project focused on mitigating negative aspects of caregiving, it must be mentioned that some caregivers as well as PCPs note positive aspects of caregiving. Positive aspects of caregiving can be experienced in a variety of areas (16). This positive view of caregiving may make the ZBI-12 survey, as it exists,

difficult for caregivers to identify with and respond to as the survey focuses on the negative aspects of caregiving.

Further study could incorporate phone calls or mailed or online surveys. The author recommends a longer project period to incorporate initial ZBI-12 survey scores, interventions as provided with this project, and then remeasurement of the ZBI-12 survey scores. Perhaps, using information provided by Strouth (16), more positive questions could be asked of the caregivers in addition to the ZBI-12 survey.

Future projects on caregiver burden should be targeted at reaching the caregivers who work outside the home, or live in another state, with telephone calls, mailed surveys, or obtaining e-mail addresses and posting the ZBI-12 survey online, using a tool such as *SurveyMonkey*. This population is important to reach, along with those who declined surveys, since they may be the population most at risk of high caregiver burden.

Conclusion

The project results revealed that caregivers, who had the sole responsibility of caregiving, did not score highly on the burden scale. This project also revealed that a method of reaching caregivers who may have high burden scores must be determined. By reaching out to caregivers and building stronger relationships, practitioners can support both physical and mental health as they build on strengths, facilitate resilience, and bolster areas that need informational, instrumental, emotional, or relational support.

Appendix A

Table A1. Possible Interventions.

Caregiver assessment to identify high levels of burden (*ZBI-12*).

Encouraging caregivers to take a break, take care of their own health, maintain a healthy diet, exercise, and seek their own preventive health care: Caregiver's pledge, https://caregiver.org/caregivers-pledge (Used with permission of Family Caregiver Alliance, (FCA) (8). National Center on Caregiving. For more information, visit www.caregiver.org or call (800) 445-8106.

Helping caregivers learn to set limits and ask for help. When asked "Is there anything you need?", responding "yes"—I need a meal, I need someone to stay here so I can go out, I need some time by myself, I need some groceries. And, learning to say "no" to requests that are draining rather than nurturing is just as, if not more, important (8).

Providing information and encouraging support groups.

Providing information on home modification tools, from comprehensive smart home technology to reachers used to pick up items without bending or stretching.

Encouraging families to seek respite/hospice care when needed.

Helping to identify coping strategies such as praying, talking with friends, and family and obtaining additional information from appropriate web sites. The FCA (8) web site includes several general family caregiving resources, state-by-state resources, online support, caregiver education, and a chance for caregivers to share their stories (6). Another site that offers peer networking, resources, and support is the Caregiver Action Network.

Psychoeducation, skills training, and therapeutic counseling interventions for caregivers of patients with chronic conditions such as dementia, cancer, stroke, and heart failure.

Resource/referrals need to be specific and targeted, so as to not overwhelm the caregiver (8).

Table A2. Possible Resources.

Home modification	http://www.AbleData.com
Caregiver information (general)	https://caregiver.org/state-list-views? field_state_tid=89.
	http://www.caregiveraction.org
	http://n4A.org/about-n4a/? fa=aaa-title-V1
	http://www.caregiver.va.gov (Veteran specific)
	http://www.videocaregiving.org/caregiving.php (Video format)
Disease-specific advocacy organizations offer up-to-date resources and information for family caregivers	http://www.nationalmssociety.org/Resources-support/family-matters
	http://www.theacpa.org (chronic pain)
	http://www.alz.org
	http://www.cancer.org
	http://www.diabetes.org
	http://www.heart.org
	http://lung.org
	http://psychiatry.org
	http://www.strokeassociation.org
Informational resources	http://www.nia.nih.gov
	http://www.aarp.org/home-family/caregiving/

Table A2. (continued)

Decision-making tools	http://decisionaid.ohri.ca
	http://www.caregiving.org
	http://wellspouse.org
Medicare tools	http://nihseniorhealth.gov/medicareandcaregivers
	http://www.medicare.gov/nursinghomecompare/search.html
Medication tracking tool	http://www.safemedication.com/safemed/MyMedicineList/MyMedicineList_1.aspx (Used with permission of ASHP Foundation foundation@ashp.org)
End-of-life planning	http://www.agingwithdignity.org/forms/5wishes.pdf
	http://theconversationproject.org/starter-kit/intro/ (Used with permission of IHI.org)
Apps to assist with caregiving	RxMindMe: provides management and reminder alerts for medications
	Personal caregiver: options include caring for an aging parent, managing medical conditions, losing weight, and questioning a medical bill
	iBioMed: extensive care management tools
	GE MIND (Ipad): interactive modules intended to engage patients and families in creative activities; MIND Facts includes access to learn about the progression of neurologic disorders such as Alzheimer's disease, Parkinson's and stroke. For patients in earlier stages of a disease, the MIND AID section offers helpful tips on organizing finances and labeling cabinets (17)

Table A3. Implementation Plan of Action.

(a) Universal
- Caregiver pledge.
- http://www.whatisacaregiver.org/caregiving-for-others.html.
- information about patient's disease process.
- information about support groups.
- have medications been reviewed and reconciled? Is a medication tracking tool needed?

(b) selective are patient needs identified and symptoms managed to include pain control and pharmacologic interventions as needed for insomnia/dementia?
- are practical supports needed such as domestic/respite care, adult day programs, or food delivery services?
- are there family members/church groups that could be enlisted for help; does the caregiver know how to set limits and ask for help?
- is there technology or home modification tools available to help with patient care?
- are referrals needed for visiting nurses, wound care, physical therapy, speech therapy, occupational therapy, or social work (available funding)?
- is end-of-life planning desired?
- is long-term placement indicated?

(c) indicated
- is the caregiver engaging in health-promoting behaviors that include exercise or other activities that improve quality of life?
- caregiver referral for psychological supports such as counseling, coping skills, problem solving
- immediate mental health intervention as indicated.

References

1. Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochran Database Syst Rev. 2011.
2. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden. A clinical review. JAMA. 2014;311:1052-60.
3. Higginson IJ, Gao W, Jackson D, Murray J, Harding R. Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. J Clin Epidemiol. 2010;36:535-42.
4. Gaugler JE, Potter T, Pruinelli L. Partnering with caregivers. Clin Geriatr Med. 2014;30:493-515.
5. Simonic A, Furlan M, Ravnjak T, Dirkse D. Caring for caregivers: a right way to do it? Curr Opin Support Palliat Care. 2012;6:379-85.
6. Van Durme T, Macq J, Jeanmart C, Gobert M. Tools for measuring the impact of informal caregiving of the elderly: a literature review. Int J Nurs Stud. 2012;49:490-504.
7. Family Caregiver Alliance. Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference (Vol. I). San Francisco, CA: Family Caregiver Alliance; 2006.

8. Pearlin II. The sociological study of stress. J Health Soc Behav. 1989;30:241-56.

9. Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch CJ. Profiles in caregiving: the unexpected career. San Diego, CA: Academic Press; 1995.

10. Sundar V, Fox SW, Phillips KG. Transitions in caregiving: evaluating a person-centered approach to supporting family caregiver in the community. J Gerontol Soc Work. 2014;57: 750-65.

11. Pearlin LI. The life course and the stress process: some conceptual comparisons. J Gerontol Soc Sci. 2010;65B:207-15.

12. Collins LG, Swartz K. Caregiver care. Am Fam Physician. 2011;83:1309-17.

13. Carter R. Institute for Caregiving. Averting the caregiving crisis, an update. 2012. Retrieved January 26, 2015 from: http://www.rosalynncarter.org/UserFiles/File/PositionPaperUpdate3-19-12.pdf.

14. Fitzgerald MA. Maintaining the health of family caregivers. Fitzgerald Health Education Associates, Inc. 2015. Retrieved November 30, 2015 from: http://fhea.epubxp.com/i/607407-november-2015/1.

15. Carbonaro A, Lamont H. The affordable care act and caregivers research brief. 2015. Retrieved August 3, 2015 from: https://aspe.hhs.gov/report/affordable-care-act-and-caregivers-research-brief.

16. Strouth N. Finding meaning in caregiving. 2016. Retrieved April 5, 2016 from: https://elizz.com/caregiver-resources/just-for-caregivers/finding-meaning-in-caregiving.

17. Collier AK. An app to spur creative expression in Alzheimer's patients. Neurology Now. December 2014/January 2015;10(6): 23. doi: 10.1097/01.NNN.0000459058.43822.d1.

Author Biography

Dorothea Frederick is an assistant professor at Jefferson College of Nursing in Philadelphia, PA. She teaches in the Family Nurse Practitioner Program. She also works as a nurse practitioner visiting a home-bound population in Burlington County, NJ.