Caregiver Fatigue of Patients With Lower Extremity Amputation

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Abstract

Background: The shift in health care services from hospital-based to community- and home-based care, often provided by family members, exacts a significant emotional and physical toll on both patients and caregivers, an experience known as caregiver fatigue, caregiver strain, or caregiver burden. **Methods:** The Zarit Burden Interview (ZBI) and the Short Form Zarit Burden Interview (ZBI-12) were used to assess caregiver burden in 10 patients with lower extremity amputation who presented with a caretaker over a 3-month period. **Results:** A total of 10 patients (7 men and 3 women; mean age, 61.5 years; age range, 42-73 years) with a medical history of peripheral arterial disease (7 [70%]), hypertension (9 [90%]), diabetes mellitus (8 [80%], coronary artery disease (4 [40%]), and end-stage renal disease (3 [30%]) were included. Two patients had contralateral amputations, 3 had undergone prior vascular interventions, and 4 had received conservative management for atherosclerotic disease. Caregivers included wives (6), a husband (1), daughters (2), and a son (1). On the ZBI, the patients reported a mean caregiver burden score of 32.1 (range, 22-53), while caregivers reported a mean score of 43 (range, 19-58). On the ZBI-12, patients reported a mean caregiver burden score of 15 (range, 0-26), whereas caregivers reported a mean score of 21.6 (range, 12-31). **Conclusion:** Caregivers of patients with lower extremity amputation experience moderate to high levels of burden. While patients recognize some degree of caregiver strain, they underestimate the extent of the burden reported by their caregivers.

J CRIT LIMB ISCHEM 2025;5(1):E3-E9. doi:10.25270/jcli/CLIG25-00006

Key words: caregiver, lower extremity amputation, quality of life, caregiver burden

With increasing health care costs and decreasing availability of in-home care services nationwide, the health care landscape is shifting from hospital-based to community-based care, which is often provided by family members who frequently report significant burden and decreased quality of life.[1] In the United States, an estimated 65 million unpaid family caregivers provide care for patients with chronic diseases, with an estimated economic value of $470 billion.[2] Caregiver burden, also known as caregiver strain or fatigue, is the physical, emotional, and financial strain experienced by individuals who care for chronically ill, disabled, or elderly family members. These informal caregivers often provide unpaid assistance and support to patients.[3] Evidence suggests that higher caregiver burden is associated with poorer caregiver well-being, which may negatively impact patient outcomes.[4,5]

Lower extremity amputations, which include the surgical removal of a toe, foot, or leg, are increasing in the United States and result in permanent disability as well as significant changes in a person's life and daily functioning.[6] Approximately 185,000 amputations occur in the United States each year, and an estimated 3.6 million people will be living with limb loss by 2050.[7] Limb amputation is a life-altering event with social, psychological, and spiritual consequences.[8] After an amputation, the individual often becomes dependent on a family member who may not be prepared for this new role, potentially leading to physical, emotional, social, and financial distress for caregivers.[9]

Caring for a loved one who has undergone amputation is a multidimensional experience that includes both positive and negative aspects of providing care. It can contribute to psychological and physical health challenges, financial and social strain, impaired family relationships, a sense of hopelessness, and other adverse outcomes.[10] As the population in the United States continues to grow, so does the number of people living with chronic disease, with more than half (51.5%) of adults diagnosed with at least 1 chronic condition.[11] Patients with chronic diseases such as peripheral arterial disease, diabetes mellitus, and end-stage renal disease who progress to requiring lower extremity amputations represent a particularly vulnerable population with extensive care and support needs.[8]

TABLE. PATIENT DEMOGRAPHICS.

Caretaker role	N = 10 (%)
Wife	6 (60)
Husband	1 (10)
Daughter	2 (20)
Son	1 (10)

Purpose

In a large, urban, academic vascular outpatient clinic, it was observed that caregivers of patients who underwent amputation may require additional support to optimize outcomes for both themselves and the patients. Utilizing 2 validated surveys, we aimed to assess the burden of caretakers after lower extremity amputation.

Methods

A convenience sample of 10 patients who underwent lower extremity amputation and presented with a caregiver over a 3-month period in 2023 was recruited from a large academic vascular surgery outpatient clinic. Written informed consent was obtained from all participants, including both patients and caregivers, following a thorough explanation of the study's purpose, procedures, potential risks and benefits, and the voluntary nature of participation.

Two validated instruments were used to assess caregiver burden: the Zarit Burden Interview (ZBI)[12] and its shortened version, the ZBI-12. The ZBI, developed by Zarit et al in 1980, is a 22-item instrument widely regarded as the gold standard for measuring caregiver burden. The tool has demonstrated excellent internal consistency (Cronbach α = 0.88-0.92) and test-retest reliability (r = 0.71-0.91) across various caregiver populations. Each item is scored on a 5-point scale ranging from 0 (Never) to 4 (Nearly Always). Total scores are categorized as follows: 0 to 21, little burden; 22 to 40, mild to moderate burden; 41 to 60, moderate to severe burden; and greater than 60, severe burden. The questionnaire assesses various aspects of caregiver burden, including psychological well-being, finances, social life, and the caregiver-patient relationship (**Appendix A**).

The ZBI-12, developed by Bédard et al in 2001,[13] was designed to provide a more time-efficient assessment tool for clinical settings. This shortened version has shown strong correlation with the original ZBI (r = 0.92-0.97) and comparable internal consistency (Cronbach α = 0.85-0.89). Using the same 5-point scale as the ZBI, a score of 17 or higher indicates a high level of caregiver burden. The ZBI-12 has been validated across multiple languages and cultural contexts, demonstrating its utility as a screening tool for caregiver burden (**Appendix B**).

The questionnaires were administered separately to patients and caregivers in private rooms to ensure confidentiality and prevent mutual influence on responses. A research coordinator provided each participant with the paper-based questionnaire and remained available nearby to answer any questions while maintaining an appropriate distance to ensure privacy. Participants were explicitly informed that their responses would remain confidential and would not be shared with their caregiver or patient counterpart. They were assured that the data were accessible only to the research team and would be de-identified for analysis and publication.

Given the potentially sensitive nature of the questions, particularly for patients reading about caregiver burden, a social worker was available throughout the study period to provide support if needed. Participants were informed that they could pause or stop the questionnaire at any time if they felt uncomfortable. Initially, both instruments were administered to caregivers and patients to compare perceptions of burden. Because neither tool has been validated for use by patients assessing their caregivers' experiences, we acknowledge that this represents a methodological limitation, and therefore our primary analysis focuses on the caregiver responses and the comparative performance of the 2 instruments in this population.

In addition to survey data, demographic information was collected for both patients and caregivers. Institutional Review Board approval was obtained from the University of Maryland, Baltimore (HP-00085462) before study initiation. Although this was a process improvement study with minimal risk to participants, careful attention was given to protecting human rights, particularly with regard to maintaining confidentiality, anonymity, and data security. All study data were stored in password-protected electronic files accessible only to authorized research team members.

Results

On the ZBI, caregivers reported a mean score of 46 (range, 19-58), indicating moderate to severe burden. On the ZBI-12, caregivers reported a mean score of 24 (range, 12-31), indicating a high level of burden.

Of the 10 patients assessed, 7 identified as male and 3 as female. The age range was 42 to 73 years (mean, 61.5 years). Two patients had prior contralateral limb amputation, and 3 had undergone previous vascular intervention for atherosclerotic disease. Among caregivers, 7 identified as spouses (6 wives, 1 husband) while 3 were children (2 identified as daughters and 1 as a son) (**Table**).

Comparison of ZBI and ZBI-12 Performance

Among caregivers, there was strong correlation between scores on the full ZBI and the ZBI-12 (r = 0.89, *P*<0.001). The ZBI-12 demonstrated a comparable ability to identify high-burden cases,

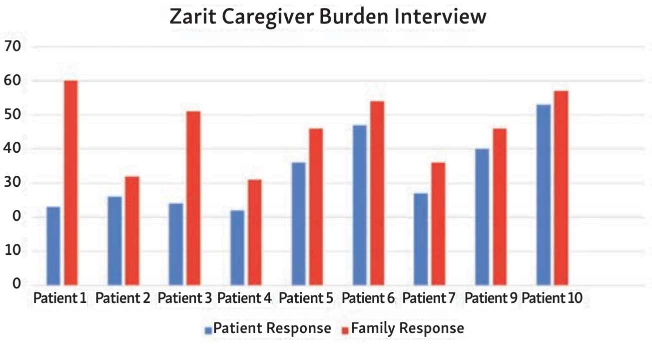

FIGURE 1. Zarit Caregiver Burden Interview Responses. Zarit Scale: 0-21, little; 21-40, mild to moderate; 41-60, moderate to severe; over 60, severe burden.

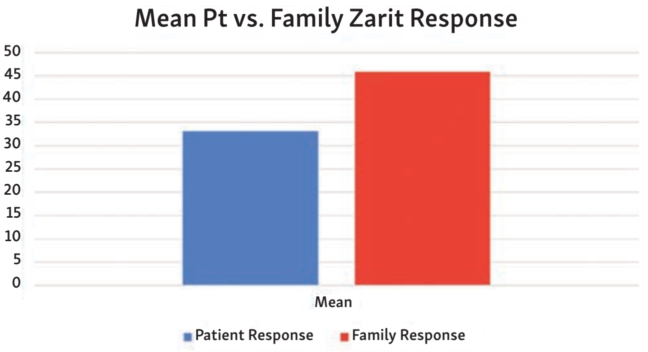

FIGURE 2. Mean Zarit Caregiver Burden Interview responses.

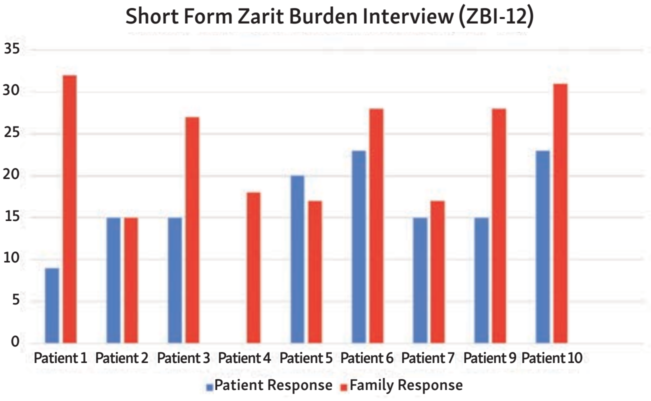

FIGURE 3. Short Form Zarit Burden Interview (ZBI-12) responses.

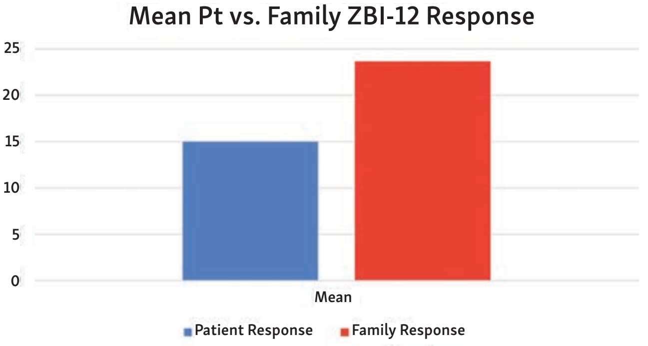

FIGURE 4. Mean Short Form Zarit Burden Interview (ZBI-12).

with 8 of 10 caregivers classified as experiencing high burden on both instruments. The administration time for the ZBI-12 averaged 8 minutes, compared with 15 minutes for the full ZBI.

Caregiver vs Patient Perception of Burden

The ZBI was administered to both caregivers and patients to assess their perception of caregiver burden. The patients perceived that their caretakers experienced mild to moderate burden, with a mean score of 33 (range, 22-53). In contrast, caretakers reported a higher burden, with a mean score of 46 (range, 19-58), indicating moderate to severe burden (**Figures 1** and **2**).

Similarly, the ZBI-12 was administered to both caregivers and patients. Patients perceived their caregivers' burden as mild to moderate, with a mean score of 15 (range, 0-26). However, caretakers reported a higher burden, with a mean score of 24 (range, 12-31), indicating a high level of burden (**Figures 3** and **4**).

Discussion

This study demonstrates that caregivers experience significant burden when providing care for patients with major lower extremity amputations. Caregiver burden is commonly experienced by individuals who provide long-term care, and as shown by our data and prior research, most caregivers are spouses, children, or relatives who assume multiple roles.[1] Furthermore, while patients with lower extremity amputation recognize that their caregivers experience burden, they tend to underestimate its severity.

Caregiving encompasses many responsibilities, including direct care, assistance with daily activities, emotional support, bathing, toileting, dressing, transportation, shopping, and medication management, in addition to psychological and spiritual support.[3] Previous studies, including those by Sekeroglou et al, have reported that caregivers of patients with lower extremity amputation experience moderate to high levels of burden.[8] While patients with lower extremity amputation acknowledge the strain their caregivers endure, they do not accurately assess the level of burden.[8]

Impact of Amputation Level on Caregiver Burden

A prospective study by Çamur et al utilized the ZBI to assess caregivers of patients with various levels of lower extremity amputation. The study found that higher levels of amputation correlated with greater medical and psychological needs in patients, leading to higher levels caregiver burden.[10]

Predictors of Better Caregiver Mental Quality of Life

Costa et al identified several predictors of better caregiver mental quality of life (QOL), including physical activity, lower burden, better family functioning, less traumatic symptoms, and receiving assistance with caregiving tasks.[11] Caregivers who engaged in physical activity at least once per week reported better mental QOL, as exercise serves as a stress reliever and fosters socialization. Additionally, caregivers who had no chronic disease and fewer physical symptoms reported better physical QOL; younger, higher-educated caretakers who slept more than 6 hours a night also showed better QOL. Prolonged caregiving, however, moderated the negative relationship between traumatic symptoms and mental QOL, with prolonged exposure to caregiving challenges interfering with QOL.

Key Attributes of Caregiver Burden

Three primary attributes of caregiver burden identified in the literature include self-perception, multifaceted strain, and the impact over time.

Self-perception: This reflects how caregivers personally experience and internalize their burden.[14] Both subjective and objective perceptions contribute to self-perception. Bhattacharjee describes caregiver burden as "the positive or negative feelings and perceptions of the caregiver associated with providing caregiving functions".[15] This suggests that caregivers within similar caregiving contexts may perceive their burden differently. A mixed approach study by De Korte-Verhoef et al on caregiver burden found that while more than half of family caregivers experienced a high level of burden, only one-quarter reported a negative impact on their daily life.[16]

Multifaceted strain: Caregiver burden is a multidimensional phenomenon extensively described in the literature. Caregivers of patients with end-stage cancer, for example, often pay limited attention to their own health, resulting in various health problems such as weight loss, fatigue, and sleep disturbances.[17] Emotional distress is also prevalent, with caregivers reporting psychological stress, family alienation, and deterioration of family relationships. Providing long-term care can interrupt the caregiver's schedule and overall lifestyle, limiting social activities and resulting in social isolation.[14] Furthermore, economic difficulties are frequently cited as a contributing factor to caregiver burden.

Impact over time: Caregiver burden is not static. Weitzner noted that the effect of caregiver burden on QOL varies depending on the different phases of illness the recipient experiences.[18] The literature suggests that caregiving duration, social/family support, and disease trajectory all influence the caregiver's experience.[19-21] A longitudinal study indicated that burden levels change dynamically based on the number of family members needing care, and how many family members could assist with care tasks changed the perception of the caregiver burden.[20] A separate cross-sectional investigation of caregivers of chemotherapy patients found that burden on caregivers decreased over time, possibly due to adaptation to caregiving responsibilities.[17] According to stress adaptation theory, caregivers can master various health care skills over time and adapt to caregiving demands. Additionally, a quantitative study of caregivers for breast cancer patients demonstrated that external support systems can reduce the overall burden felt by caregivers.[21]

Study Limitations

This study has several important limitations:

1. *Small sample size.* Our cohort of 10 caregiver-patient pairs limits the generalizability of our findings.
2. *Cognitive status of patients.* Many patients in this study had comorbidities such as peripheral arterial disease (70%), diabetes mellitus (80%), and cardiovascular disease (40%), all of which are risk factors for vascular dementia. However, cognitive function was not formally assessed, which may have influenced patients' self-assessment of caregiver burden. Future studies should incorporate formal cognitive screening tools and consider excluding patients with cognitive impairment from self-assessment portions.
3. *Methodological concerns with the Zarit instruments.* While patients were asked to evaluate their caregiver's burden using the ZBI and ZBI-12, their psychometric properties have not been established for patient assessment of caregiver burden. The disparities we observed between patient and caregiver burden scores (mean scores of 33 vs 46 on the full ZBI, and 15 vs 24 on the ZBI-12) could potentially be attributed to cognitive impairment affecting patient insight, rather than purely reflecting differences in burden perception. Our use of both the full ZBI and ZBI-12 provided valuable insights into their relative utility in this population. While both instruments identified similar burden levels, the ZBI-12's shorter administration time may make it more practical for routine clinical screening. However, the full ZBI provided richer detail about specific aspects of burden, which could be valuable for intervention planning. Future research with larger samples could help establish whether the ZBI-12's brevity outweighs the comprehensive assessment provided by the full ZBI in this specific population.
4. *Lack of longitudinal follow-up.* This study did not assess how caregiver burden evolves over time, nor did it collect comprehensive data on available support systems, resources, or interventions that might affect caregiver burden. Future research should consider incorporating QOL assessments, measures of caregiver physical and mental health, and tracking of patient outcomes to better understand the relationship between caregiver burden and patient care.

Implications for Future Research

A larger, more comprehensive study is needed to better understand caregiver burden in patients with lower extremity amputation to develop effective interventions to support caregivers. Future research should include appropriate power analysis, multiple study sites, diverse demographic representation, cognitive screening, longitudinal follow-up, and potentially a randomized controlled trial testing various support mechanisms for caregivers.

Consequences of Caregiver Burden

Unaddressed caregiver burden can lead to:

Decreased quality of care: Both the care recipient and caregiver can be negatively impacted by the consequences of caregiver burden through decreased care provision, decrease in QOL, and both physical and psychological health deterioration.[22] Caregivers with high burden and no support or resources may provide lower quality of care, impacting patient outcomes.[22] Given et al reported that caregiver burden is associated with reduced quality of care,[23] likely due to a decrease in overall coping ability and lack of emotional support. It is known, for example, that a child's state of health (including physical and mental) is directly influenced by the physical and mental state of the parent or caregiver, and their perception of the child's overall condition.[24]

Decrease in caregiver QOL: The literature suggests that caregiver burden negatively affects QOL and that reducing burden improves overall well-being.[25,26] Caregivers often sacrifice personal needs, leading to declining physical and mental health.

Physical and psychological deterioration: Caregivers give copious amounts of time and energy to caring for their loved ones while seldom prioritizing their own needs. Due to time constraints, caregivers may neglect to take care of themselves, even when ill, and may defer seeking medical assistance.[27] Caregivers report chronic health issues such as heart problems and hypertension, in addition to varying degrees of physical fatigue and decreased health after long-term care.[28,29] Caregivers often experience psychological distress, including depression, anxiety, and emotional exhaustion.[27] Family caregivers assisting during the late stages of chronic illness had significantly more anxiety/depression than the general population.[27]

Conclusion

The physical and emotional demands of caring for a family member with lower extremity amputation can lead to caregiver burden and fatigue. Family, community, and social support play a crucial role in alleviating caregiver burden, yet such resources may not be equally accessible to all caregivers. Organizations that provide emotional support, counseling, and community-based respite services can help reduce caregiver burden by allowing caregivers adequate rest and recovery. Expanding access to these resources may improve both caregiver well-being and patient outcomes.

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Manuscript accepted February 10, 2025.

The authors report no financial relationships or conflicts of interest regarding the content herein.

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APPENDICES

Appendix A. The Zarit Burden Interview.

Question	Score
Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
Do you feel that because of the time you spend with your relative that you don't have enough for yourself?	0 1 2 3 4
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
Do you feel embarrassed over your relative's behavior?	0 1 2 3 4
Do you feel angry when you are around your relative?	0 1 2 3 4
Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0 1 2 3 4
Are you afraid what the future holds for your relative?	0 1 2 3 4
Do you feel your relative is dependent on you?	0 1 2 3 4
Do you feel strained when you are around your relative?	0 1 2 3 4
Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

Respondents and subjects are encouraged to circle that which best describes how they feel: 0, Never; 1, Rarely; 2, Sometimes; 3, Quite frequently; 4, Nearly always.

Appendix B. Short Form Zarit Burden Interview (ZBI-12).

Do you feel...?	Never (0)	Rarely (1)	Sometimes (2)	Quite frequently (3)	Nearly always (4)
That because of the time you spend with your relative that you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					