



# Frailty and Caregiver Challenges

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Review Article

Volume 3 Issue 1

Received Date: November 28, 2024

Published Date: January 03, 2025

DOI: 10.23880/oajfs-16000114

## Abstract

Frailty affects the quality of life of older adults by increasing their susceptibility to medical events like falls or illnesses. The caregiver (carer) of a frail older adult (the “caree”) often deals with challenging changes in the care they provide, e.g., additional physical demands, expansion in the number of daily tasks, and an increase in anxiety about the care situation [1-4]. By understanding how caregiving to frail older adults impacts caregivers, adequate resources can be identified and extended to help caregivers as well as care recipients, to establish better ways to expand the caregiver’s access to resources, and to provide health and safety tips to mitigate or manage frailty [3,5-7]. This paper aims to discuss frailty associated with aging, caregiver types, and impact of care for frail individuals on caregivers.

**Keywords:** Caregivers; Caree; Frailty; Caregiver Challenges; Aging; Social Isolation

## Abbreviations

CDC: Centers for Disease Control and Prevention; CRA: Caregiver Reaction Assessment; HADS: Hospital Anxiety and Depression Scale; CSI: Caregiver Strain Index; NSOC: National Study of Caregiving.

## Introduction

Frailty, which is the decline of multiple body systems and an increase in susceptibility to stressors, is commonly seen among older adults and impacts their quality of life [3,8]. Frailty also involves an increase in vulnerability due to age-related declines in health that affect a person’s capacity to function normally and cope with everyday challenges [1-4]. Older adults that need assistance may choose to have a caregiver who provides services, like dressing, toileting, and feeding, as well as maintaining medical appointment schedules and lining up activities or daily chores. Continual engagement of caregivers for frail older adults tends to

result in significant physical, emotional, and financial burden, e.g., burnout, increased levels of stress, financial challenges, social isolation, and chronic physical and mental health issues [3].

## Aging and Frailty

Aging can impact the mental health of many older adults, often causing physical, neurological, and social changes. Aging, a lifelong process and changes during one’s life, can affect how an individual ages. Personal and historical events, experiences, and perceptions help shape people, how they interact with the world, and how they view themselves and the concept of aging [3,9]. Fortunately, medical advances, health initiatives, and social, political, and economic changes are aiding people live [10,11]. A deeper understanding of aging not only helps frailty among older individuals but also those who care for them. While each aging journey is unique, there are some common changes that older adults can experience [3,9].

Physical changes with age occur due to the impact of structural and functional changes that occur over time in an individual and can affect many aspects of life for older adults in terms of their movement, memory, and independence. Some age-related changes are more superficial than hindering, e.g., wrinkles, age spots, senile purpura, and greying of the hair. These changes can affect an older adult's perception of themselves and how they feel of being perceived by others [3]. Self-perception can be based on the aging stigmas and stereotypes that are pervasive in many cultures, which often cause older adults to view aging in a negative light [3,12]. Changing these perceptions of aging and providing older adults with tools and education on self-care and health management can help them age more successfully and have a positive outlook on normal age-related changes everyone is likely to experience.

Normal physical changes with aging can affect an individual's ability to perform instrumental activities of daily living like managing a budget, doing housework, meal preparation, shopping, and extracurricular activities as well as basic living functions, such as bathing, eating, dressing, getting in and out of bed, and toileting [3]. Physical changes

in the skeletal system to the bones, muscles, and connective tissue can result in low bone density, strength, and flexibility, all of which can impact an older adult's gate, general movement, and overall health [2,3]. Inability to accomplish simple tasks can trigger feelings of inadequacy and frustration [9]. Seeking assistance from others is also something that older adults may struggle with as they perceive themselves to be less self-reliant and less resilient [2,3]. While natural physical changes may seldom lead directly to death, they have potential to increase frailty and susceptibility to further decline. Loss of independence can also increase feelings of loneliness and depression as well as self-restrained patterns of behavioral and social interactions [1,3]. This is where a caregiver can aid the caree by organizing social events or providing transportation to a standing activity [3].

### Caregiver

A caregiver is a person who assists the caree with routine tasks like cooking, eating, bathing, dressing, taking medicine, transportation, and moving around the environment [3]. Caregivers of frail older adults can be categorized into informal and formal types and subtypes as shown in Table 1.

Caregiver Type	Subtype	Description
Informal Caregivers	Family Caregivers	They can be spouses (e.g., Gehr TJ, et al. [13], adult children (e.g., Wolff JL, et al. [14], or other relatives, e.g., siblings, grandchildren, and other extended family members (e.g., Johnson RW, et al. Targan A, et al. [15,16].
	Non-Family Caregivers	They can be friends and neighbors, who often provide support out of a sense of their friendship and community (e.g., Targan A, et al. [16].
Formal/Professional Caregivers	n.a.	These include paid caregivers, e.g., home health aides, nurses, and other trained professionals who provide physical and medical care to frail older adults as part of their job (e.g., Johnson RW, et al. [15].

**Table 1:** Caregiver Types and Subtypes.

In addition, Gehr TJ, et al. [13] identified three subcategories among caregiving spouses based on caregiving style and coping strategies:

**The Caring Partner:** Sees caring for spouse is not a burden and does not feel stressful. Wishes that things continue to stay they have been and that they stay together. Avoids thoughts of death and suppresses feeling of separation. Coping styles involve acceptance, preserving composure, relativizing, self-validation, humor, optimism, and suppression—all relating primarily to the 'diverting' coping dimension.

**The Worried Manager:** Manages routine care (personal hygiene, dressing, walking with the wheeled walker, medication, etc.), takes charge of organizational and household tasks, but often worries about caree's condition, caree's transportation, doctors' cost, asking others for

support, reduced social contacts, and other changing life circumstances. Coping style primarily involves 'seeking attention and care' for emotional release, giving meaning, finding consolation and reassurance. Occasionally undergoes social withdrawal and negative emotional coping styles in the form of active avoidance, self-pity, or release anger. Uses relativizing and valorizing their situation as a 'diverting' coping dimension.

**The Desperate Overburdened:** Feels excessively burdened by the care and support for spouse. Feels extremely stressful to stay alert and be available on a regular basis fearing how long the situation would last. Feels sigh of relief and grateful when others pitch in. Regrets missed opportunities due to caregiving responsibilities. Appears to be resigned from social activities by doing everything for caree. Complains caree's lack of engagement in therapeutic exercises. Worries

about future. Coping styles involve 'negative emotional,' e.g., rumination, self-pity, resignation, and release of anger. No recognizable 'diverting' coping dimension due to inability to integrate the current situation into caregiver's life.

## Methodology

For this literature-based paper, the authors selected the support studies using the keywords caregiver experiences, caregiver burden, frailty in older adults, frailty, frailty tests, personal accounts of frailty, and experiences with frailty. The search timeframe was between the years 2017 and 2024, with a few exceptional seminal sources. The search engines used were ProQuest, EBSCOHost, APA PsycInfo, and Sage databases to search peer-reviewed literature.

These search engines resulted in peer-reviewed articles from ScienceDirect, APA Psych Articles, ERIC, Directory of Open Access Journals, Psychology and Behavioral Sciences Collection, HeinOnline, Gale Academic OneFile, PMC PubMed Central, and Medline Complete, which were used to analyze and synthesize material to support the literature review and framework for the present study.

The exclusion criteria for the sources included information on populations 60 years and younger, articles not pertinent to caregiving or frailty, studies looking at specific disease issues or involving certain medications. The inclusion criteria for the sources included information on populations 60 years and older, any gender, any ethnicity, any account of caregivers, articles pertaining to frailty or issues with activities of daily living.

The search resulted in 41 articles relating to the topic of caregivers and frailty. The articles were then appraised for quality in that the relevance, study design, sampling methods, data collection methods were all assessed and determined peer-reviewed and in good standing with IRB approved research practice. The researchers then looked at bias, method of analysis, and the results interpretation to review and assess the information provided for quality. Once deemed a quality article it was then further reviewed and incorporated in the current literature review. To create this literature review, the researchers mixed the results of the various studies into the review in order to align with the topic under study.

## Impact on Caregivers

Frailty not only affects those who are frail but also has significant implications for their caregivers. Extant research employed such instruments like Caregiver Reaction Assessment (CRA), Hospital Anxiety and Depression Scale (HADS), Caregiver Strain Index (CSI), and Relative Stress

Scale to assess care giver burden [17].

## Increased Burden

Several studies found an increased burden on caregivers of frail older adults [17]. Chan CY, et al. [18] found based on their study of 188 participants that: (1) nearly 72 percent reported caregiver burden; (2) that caregivers who perceived burden tend to have significantly lower levels of caregiving competency, positive aspects of caregiving, and social support. Others found the influence of demographic and clinical factors on caregivers' burden: (1) female caregivers tend to experience higher levels of stress; (2) longer durations of illness tend to increase stress levels; (3) caregivers of those suffering from dementia and stroke tend to experience higher levels of stress than other frailty conditions; and (4) spouses and children tend to experience more caregiver stress in term of their relationship with caree than other types of caregivers [19,20].

The 'Worried Manager,' according to Gehr TJ, et al. [13], attributes burden, less to the caree than to the changed living situation. The situation becomes burdensome when it cannot be managed alone, and outside help is difficult to accept. The increase in duties often leads to more time spent caregiving and removes time for other things like personal time, work, or socializing, depending on the situation and the number of caregivers involved [3].

## Emotional Stress

Caregiving takes a toll on a person's mental status because they may constantly be thinking of the needs of the caree and foregoing their own needs [21]. Feelings of frustration, anxiety, depression, stress, and guilt may be present as the caregiver provides care and as a caregiver's role changes alongside the needs of the caree [21]. This can be especially challenging if the caregiver must balance multiple roles like being a parent, employee, and caregiver [2,3]. Mental health issues affect 60 percent of caregivers, often causing disruptions in their ability to perform their caregiving tasks as well as manage their daily needs [3,21].

The 'negative emotional' dimension may also stem from a perceived low level of control over the situation [13]. In the process of coping with increased emotional stress, some caregivers may resort to substance abuse or alcohol use and tend to become more hostile than those who are not caregivers [3,21].

Encouraging caregivers to ask for help and seek solutions to alleviate the care burden is often the first step to help reduce their emotional strain and to reduce the feeling of having to do everything alone [3,21].

## Financial Issues

Caring for frail older adults can place a significant financial burden on caregivers. According to Skufca L, et al. [22], nearly eight in ten caregivers face regular out-of-pocket costs, averaging around \$7,242 annually or 26 percent of the caregiver's income, that goes directly to housing expenses like rent or mortgage payments, home modifications, and assisted living fees. In their findings based on an AARP survey, about one-half of caregivers reported that they used their own money for the caree's household-related expenses; 30 percent covered rent or mortgage payments; and 21 percent financed home modifications. Medical expenses (e.g., paying for health care, therapists, in-home care, or medical equipment) totaled up to 17 percent of caregiver spending. Additionally, caregivers frequently experience indirect financial impacts, such as reduced work hours or even leaving the workforce, which can lead to lost income and benefits [23]. This strain is particularly pronounced among younger caregivers and those from Hispanic/Latino or African American communities. The caregiver can also experience an increase in personal health expenses due to caregiving's toll on their health and well-being [3,23]. Effective policy measures, such as the proposed Credit for Caring Act, which provides a tax credit of up to \$5,000 to eligible working caregivers help mitigate caregiver's financial stress at least to some extent. However, the economic impact of caregiving extends beyond individual finances, affecting employers and the broader economy as well [24].

## Social Isolation

Primary family caregivers of frail older adults are highly vulnerable to social isolation. Liang J, et al. [25] studied a sample of 881 primary caregivers of older adults from the 2015 and 2017 National Study of Caregiving (NSOC) by measuring social isolation that included objective social disconnectedness and subjective loneliness. The study found that both objective social disconnectedness and subjective loneliness have direct effects on depression among primary caregivers; and that social isolation mediates the relationship between objective stress and depression. Other studies also found that social isolation and loneliness result in negative health outcomes, such as rapid decline in cognitive skills, increased depression, decreased sleep quality, and strained family relationships [26,27]. Caregivers may find it challenging to maintain social connections and participate in activities they once enjoyed. This reduction in social interaction can exacerbate feelings of isolation [3,25,28]. Access to support systems, such as caregiver support groups and respite care, can help mitigate the effects of social isolation. These resources provide opportunities for caregivers to connect with others in similar situations and take breaks from their caregiving duties [29,30].

## Conclusion

Frailty is commonly considered "a syndrome that affects biological, physical, psychological, and social process of a person's life and leads to increased vulnerability and adverse outcomes in old age" [30].

Older adults encounter a variety of changes and challenges to aspects of their daily life and mental, emotional, and physical well-being as they age and subsequently have needs that require resources, unique care approaches, and assistance [3,31]. Caregivers—informal and/or formal—come in to assist frail older adults [1,3].

Although informal caregivers experience some positive aspects, like a sense of giving back or reciprocity and continued part of a loving relationship, there can be some detrimental effects. In the process of caregiving, caregivers tend to neglect their own health and well-being and encounter various challenges—physical, emotional, and financial—that manifest in such forms as burnout, emotional stress, financial issues, physical strain, exhaustion, loneliness or social isolation, sleep disturbance, depression, anxiety, loss of self-esteem, and so on [1,3,30]. Such adverse caregiver experiences can negatively impact their ability to discharge their duties to carees. They may also be prone to risky behaviors like smoking, use of alcohol and drugs, etc. [32-34]. Kilmer G, et al. [35] observed that age-adjusted estimates for caregivers were unfavorable for 13 of the 19 health indicators when compare with non-caregivers during 2021-22. Therefore, it is essential to provide sustainable care for caregivers and reduce burden. Those efforts include extending cash benefits to caregivers and providing them with much needed respite care and preventive health care. In Hoffman F, et al. [36] words:

Informal caregiving remains the backbone of care provision in Europe and for many dependent older people it is their preferred care option. Complete replacement of informal care by formal care services is neither financially feasible nor socially desirable. Policymakers should therefore ensure that the carers' own needs as much as those of the care recipients are taken into consideration and met. Some countries have already taken steps in this direction, namely by providing carers with a statutory right to receive an assessment of their needs for services in addition to services for older people (as is the case of the UK).

Finally, as Kilmer G, et al. [35] suggested, those interventions that are already available at community organizations can be tailored for caregivers to relieve their strain, including skills training, support groups, and care coordination. Furthermore, health care professionals may identify patients who are engaged in a caregiving role and

encourage them to seek and utilize necessary help on a timely basis to maintain their own health and wellbeing.

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