# Aging, Disability, and Caregiving





## INTRODUCTION

IMPACT OF DISABILITIES AND RESULTING CAREGIVING ON THE CAREGIVER AND RECIPIENT

Worldwide, mental and physical disabilities impact many individuals' daily lives. The afflicted individual's limitations can include not only measurable deficits, but perceived deficits that can affect recovery and desire to grow (Li & Moore, 1998). Understandably so these daily challenges limit the patient's independence and ability to participate in activities of daily living, often inducing a stress response (Kasepalu, Laidmae, & Tulva, 2014).

These disabilities and changes of daily life not only affect the patient, but also their close friends and family. Loved ones can quickly become caregivers, leaving little time for their own healing (Xiong, Biscardi, Nadler, & Colanonio, 2018). Some caregiving occurs in the safety of their own home, while others can occur in hospitals or institutions. Regardless of the location, caregiving can cause significant mental stress in both the caregiver and the receiver (Buchanen, Radin, & Huang, 2011).

#### **ADDITIONAL RESOURCES**





MedStar National
Rehabilitation
Network
https://www.medstarnrh

https://www.medstarnrh. org/our-network/location American Parkinson
Disease Association
https://www.apdaparkinso
n.org/resources-support/re
hab-resource-center/

# **Caregiving Without Sacrificing Quality of Life**

Understanding that caregiver burden is a state of emotional, physical, or mental fatigue and knowing both parties boundaries is the first step to maintaining a sustainable relationship between the caregiver and patient. Balance is essential for any relationship thus any shift in power dynamics takes time and patience from both sides (Forducey, Bergquist, Maheu, & Yutis, 2012).

Research, from a study with 104 dementia caregivers known as the Koyama Experiment, shows that caregivers who utilize professional help such as respite care had fewer sleep problems and an overall better health-related quality of life (QOL). Nurses who monitored the caregivers' frequency of headaches, migraines, chest pain/ rapid heartbeat, and cortisol levels found that without the aid of outside resources the caregivers' health declines with time (Koyama et al., 2016).

30%

of people with MS require assistance at home (Buchanen et al., 2011).

80%

of assistance provided by unpaid, unequipped caregiver (Buchanen et al., 2011).

### **Burdens of Caregiving at Home**

While in-home care in comparison to institutionalization and hospitalization is beneficial for the patient, the consequences for the caregiver are inevitably burdensome (Xiong, Biscardi, Nadler, & Colantonio, 2018).

These negative consequences resulting from the burden of caregiving have been linked to high levels of cortisol and blunted cortisol awakening responses (Mortensen et al., 2018). These irregular stress responses result in depression, low mental health, and increased risk of mortality and serious illness (Geng et al., 2018).

When caregiving occurs at home, health care professionals during appointments can treat symptoms of the patient in addition to being cognizant of the mental and physical health of the caregiver (Buchanen et al., 2011). Friends, family, and health care providers must be aware of their loved ones acting as informal caregivers and know when to step in to encourage the step towards more professional care.

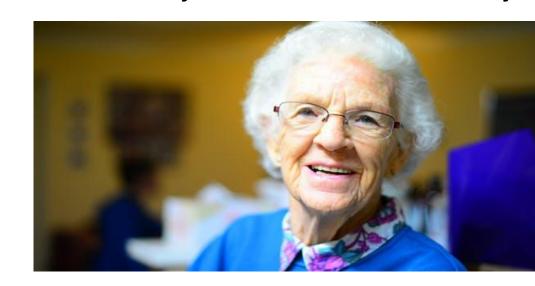
## **Benefits and Drawbacks of Home Healthcare**

Home health care is professional care provided to an individual in their own home. Professionals such as nurses, physical therapists, and social workers provide individual care for patients (Landers et al., 2016).

Individuals receiving home health care actually benefit from living at home because it provides them with a feeling of familiarity and independence, allowing them to heal and prosper despite the stress of decline. Most individuals also feel less burdensome on their loved ones, resulting in the ability for them to rest and reach homeostasis (Kadowaki, Wister, & Chappell, 2015).

Some research shows that living at home while receiving home health care can result in loneliness due to isolation which can induce the stress response in the individual. Some symptoms of stress related to loneliness include, anxiety and depression which can lead to further decline of the individual (Kasepalu, Laidmae, & Tulva, 2014).

An increased amount of homecare, can reduce the cost of the American healthcare system (Kok, Berden, & Sadiraj, 2013).



#### Rehabilitation and its Correlates

The attitude of the recipient and the caregiver can affect rehabilitation and its effectiveness.

For the recipient, there is a significant need for social acceptance. Although gender is not a significant factor (Saban, Smith, Collins, & Pape, 2011), other factors such as emotional support, a personal desire to grow and succeed, and even perceived discrimination can impact the effectiveness of recovery (Li & Moore, 1998).

On the side of the caregiver, common issues in treatment would be stereotypes of certain disabilities, which lead to less effective treatment as a whole. More complex interactions are required to better suit an individual patient's needs, and provide the highest quality care to reduce the possibility of regression (Parker, Schaller, & Hansmann, 2003). Another factor is the aging patient base, as the baby boomers create a larger amount of older patients, which generates new caretaking issues with their own needed solutions (Cichy, Leslie, Rumrill and Koch, 2017).

### **SUMMARY**

The benefits and drawbacks of home health care should be taken into consideration based on the individual. Health care providers should be aware of the impact on the caregiving and know when to step in to suggest options beyond home health care (Buchanen et al., 2011). Additionally, caregivers must incorporate self-care into their daily routine and utilize all resources. Social influences as well as common norms among both society and rehabilitation can change the rate and effectiveness of recovery in a patient.

#### **DISCUSSION**

TAKE HOME POINTS FOR CAREGIVERS, HOME HEALTH CARE PROVIDERS, AND THE RECIPIENTS OF CARE

Societal goals should include eliminating stigmas and reducing social stress for people with disabilities.

Caregivers and individuals should make home health care decisions based on the both the needs of the individual and their loved ones (Geng et al., 2018).

Rehabilitation goals of the therapist should align with the goals of the patient and caregiver. Therapists should have access to more literature that encourages transactional approaches to disability, and pushes for an individual-based treatment (Parker et. al., 2003).

Caregivers should not work alone; reaching out and receiving professional help is the first step towards alleviating caregiver burden (Caron, Griffith, & Arcand, 2005).

