

PCAG Weekly Newsletter

Roberta Vadan

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Caregiver Burnout in Palliative Care

The prevalence of terminal-illnesses and cancer within the last decade has skyrocketed. Palliative care has been one of the most widely utilized medical approaches to optimize and provide the best quality of life to those suffering from very complex and debilitating terminal illnesses. The team of health care professionals in palliative homes aim to provide a wide variety of spiritual, psychological, and physical care to their patients. However, many patients endure and feel insecure in palliative care settings due to the lack of a home-felt environment. Thus, they rely heavily on caregiver support in order to make the remaining of their time lively.

Examples of caregivers may be a patient's spouse, child, grandchild, or sometimes include extended relatives such as a cousin, niece, or nephew. Gotze and his colleagues (2014) report from their research investigating distress of caregivers in palliative homes, that spouses particularly experienced the most burnout. This was stated as a spouse's normal household responsibilities were taking place in conjunction with performing duties outside of the home in palliative care environments. The team also iterated that spousal stress has led to progressive difficulty with sleeping at night, abandoning their health, exhaustion, and depression. Most of all, spouses report higher levels of worry and tension claiming that they will never know when their loved one might pass away. Gotze et al. (2014) also showed that there was an association between palliative care patients experiencing an increase in severity of

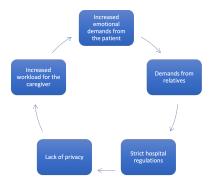


Figure 1: Figure 1: Causes of caregiver burnout (inspired by Johns Hopkins Medicine Community Health article) https://www.hopkinsmedicine.org/about/community_health/ johns-hopkins-bayview/services/called_to_care/

symptoms such as shortness of breath, emotionally instability and depression, and the congruency in family member burnout. The concordance between patient health and caregiver health run hand-in-hand.

According to Johns Hopkins Medicine, there have been many proposed mechanisms towards the causes of caregiver burnout. It has been acknowledged that caregivers providing support to their loved one in palliative care can run into conflicts. One major conflict that caregivers face is emotional demands from their loved one. Being able to be in the moment with them and provide strong emotional and physical support is difficult for some and knowing that there is no exact way to make the patient "better" creates a heavy burden on caregivers. Additionally, the conflicting demands from spouses, health employees, and relatives can arise and being able to handle each situation respectfully can create high levels of tension and anxiety for primary caregivers. Also, depending on specific hospital policies there may be strict restrictions regarding what caregivers may or may not be allowed to do. This may create a lack of privacy and autonomy for the caregivers.

Being able to recognize the signs of burnout as a caregiver is important. Many caregivers are placed in highly sensitive, emotional, and physically aggravating situations that require high levels of attention. Palliative care is a special interdisciplinary approach to provide the best quality of life for patients with chronic and terminal conditions. As a caregiver, it is important to clearly communicate with the health team and other family members to provide the most optimal support during lifelimiting illnesses. Reversing roles, being open about feelings, and discussing ways to provide high quality care with the health team will ensure that each party has time with the patient and can make each visit hopeful and one to remember.

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