

Caregiver and Palliative Care

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ABSTRACT

Palliative care aims to improve the quality of life of both the palliative care patient and their caregiver. Palliative care caregivers care for palliative care patients who suffer from symptoms and unmet needs. Most reviews and research to date have focused on the palliative patient, also called the care recipient. However, we still have little knowledge about the palliative care caregivers, including the risk factors of these caregivers becoming overburdened leading to caregiver burnout. The objective of this review was to examine the responsibilities of palliative care caregivers and the associated risks of these caregivers developing caregiver burden. We review the caring work of the caregivers, the types of caregivers, the differences between palliative care and general caregivers, the different types and levels of problems they face in caring for their patients and the risk factors of developing palliative care caregiver burden. We hope this review will increase awareness of this problem and help to improve the palliative care system to look after the needs of not only the patients in the system but also the patients' caregivers, who play such an important role.

Keywords: burden; caregivers; palliative care; reviews

INTRODUCTION

At the present in Thailand, we have increasing number of elderly patients diagnosed with non-communicable diseases such as hypertension, diabetes mellitus, stroke, or cancer.¹ Many of these elderly become palliative care patients, requiring a caregiver to help them with their basic Activities of Daily Living (ADLs).²

As defined by the World Health Organization, palliative care is intended to improve the quality of life of both patients and their families. The palliative care team should include family members in their service, and help them learn coping strategies, if required, as part of their caregiving.³ Palliative care patients often have chronic or severe symptoms, requiring a lot of care, especially in

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E-mail: orfp_1187@hotmail.com
doi: 10.31584/psumj.2021247140
<https://he01.tci-thaijo.org/index.php/PSUMJ/>

PSU Med J 2021;1(3):123-129
Received 26 January 2021
Revised 24 April 2021
Accepted 30 April 2021
Published online 2 September 2021

the later stages of their disease. Their caregivers need to learn how to deal with a patient in the last months and days of their lives. During this time they often begin to feel a significant caregiver burden and risk caregiver burnout.⁴ Caregiver burden impacts not only the caregivers through things such as missing doctor appointments or having to stop full-time work, but these burdens can also affect the care recipient, who can be neglected by their caregiver.^{5,6}

In current palliative care practice in many settings, the palliative care team normally focuses on the needs of the patient while paying less attention to the patient's caregiver. This might be because of lack of training, as to date most research has focused on interventions for the patient and paid little attention to their caregivers. Also, the role of family caregiver is still poorly supported by society, health teams and family systems.⁷ If palliative care practitioners give appropriate attention to the needs of the caregivers of their patients, it will help reduce caregivers' burdens and reduce burnout, and inter alia, improve the care for the patient. The purpose of this review is to highlight the potentially overwhelming work of the palliative care caregiver and encourage the palliative care practitioner to pay more attention to the needs of the palliative care caregiver.

CAREGIVING AND THE CAREGIVER

A caregiver is someone who helps someone else who cannot look after themselves properly, who are unable even do the basic ADL by themselves due to some type of debilitating disease, or more commonly older age with some type of debilitating condition such as cancer or other chronic disease. This type of caring is a continuous process which involves 2 parties, the patient and the caregiver.⁸

Caregivers can be separated into formal and informal caregivers. The formal caregiver is a person who has been trained to provide care such as doctors, nurses, or persons who have had special caregiver training, for

example the social worker who has had special training, and who are paid for taking care of their patients.⁸

The informal caregiver is a non-trained caregiver. Mostly they are relatives of the person they care for, such as a husband, wife or child, etc. They are sometimes called family caregivers. These informal caregivers usually have had no formal training, and must learn how to take care of their patients by themselves. And they do not get paid for their caregiving.^{8,9}

The informal caregivers can be divided into two groups, primary caregivers and secondary caregivers. Primary caregivers look after their patients all day, from the time the patient wakes up until they go to bed, and they usually live with their patient. Secondary caregivers are persons who occasionally come to help the primary caregiver with some part of their work, for example, taking the patient to a doctor's appointment. Sometimes the secondary caregiver can be a formal caregiver. In situations where the primary caregiver cannot manage advanced procedures such as checking the medication in a syringe driver by themselves, or if they want a break from their duties for a short time, they will sometimes hire a part-time formal caregiver to help them.^{8,9}

THE CAREGIVER BURDEN AND BURNOUT

More than 40 million adults in the United States act as caregivers, especially caring for patients who are in advanced stages of disease.¹⁰ Caregiver burden means that a caregiver has begun to feel that their care for their patient is having serious detrimental impacts the caregiver themselves physically, mentally, socially and/or spiritually, resulting in fatigue, depression, or general feelings of being unable to cope with their own lives due to the care recipient's needs. A previous study found that caregivers experiencing fatigue from their caregiving often reduced their care, as they had problems with sleep, and were more likely to feel stress, anxiety, depression and even experience suicidal thoughts.⁵ Caregiver burnout may

present in 3 ways: feeling tired, lacking the will power to continue providing care, and/or beginning to step away from their regular care.^{11,12}

A study by Gerain in 2019 examined the relationship between caregiver stress, burden and burnout. This study found 2 types of stressors. The primary stressors were objective elements such as type and intensity of the patient's symptoms, the tasks which needed to be performed and the intensity of care required, while the secondary stressors were consequences of the objective elements such as lack of free time, family conflicts, etc. Both primary and secondary stressors could lead the caregiver to developing unsustainable caregiver burden and the outcome from an extended unsustainable burden is caregiver burnout.¹³

PALLIATIVE CARE CAREGIVERS

The most common conditions requiring a palliative care specialist for adults include cancer, Alzheimer's and other dementias, cardiovascular diseases, cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, Acquired Immune Deficiency Syndrome (AIDS), kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, and drug-resistant tuberculosis (TB).¹⁴ The common symptoms of patients requiring palliative care are pain, anorexia, constipation, weakness and dyspnea.¹⁵ After a period of progressive functional decline, the palliative care patient transits to the end-of life stage. During these later stages, many symptoms such as anorexia-cachexia, dysphagia and delirium can impair oral intake and add to a rapidly decreasing quality of life.¹⁶ The inability to eat/drink and body image changes can also lead to emotional distress for both the patient and their caregiver.¹⁷ The caregiver and their patient have to talk with the professional caregiver team about the natural process of dying, optimization of symptom management, and providing appropriate emotional support to both the patient and the

caregiver, as the last stages can be very stressful for the caregiver as well.¹⁶ One study by Hui¹⁶ in 2015 found that palliative care caregivers felt uncertainty concerning the timing of the final stages and disease prognosis. They experienced frustration and said it was difficult to not know more about what to expect for the immediate future.¹⁷ Palliative care caregivers have to learn how to manage their patient's end-of life symptoms and be prepared to deal with the emotional impact of the patient's distress during their final days.

Many studies have reported a high prevalence of psychological morbidities such as distress, depression, anxiety, and somatization in family caregivers of terminal cancer patients receiving palliative care, indicating a high need for psychological support for palliative care caregivers.¹⁸ Furthermore, the time to death is related to the burden of the caregivers. A study by Korte-Verhoef in 2014 found that palliative care caregivers experienced a fairly heavy or severe burden at 2–3 months before their patient died and the burden increased even more during the last week before death. The same study also found that the severity of the burden was not related to hospitalization.¹⁹

Another study by Perpiñá-Galvañ and team found that in primary family caregivers of palliative care patients, anxiety was a significant problem, and the caregivers had a high average fatigue score (FAS) and signs of intense overload. They found statistically significant correlations between the variables of burden, anxiety, and depression, with the latter two being the main predictive variables of burden. In addition, caregiver burden was associated with a worsening of health. Identifying the factors that influence the development of overburden will allow the specific needs of carers to be assessed in order to offer them appropriate support within the healthcare environment.²⁰

RISK FACTORS FOR PALLIATIVE CARE CAREGIVER BURDEN

The major risk factors for palliative care caregivers developing feelings of being burdened include the caregiver's gender, the relationship to the palliative care

recipient, time spent caregiving, financial support, social support, confidence in their caregiving abilities, the stage of disease of the care recipient, the care recipient's functional status and symptoms, and the number of care recipient visits to the emergency department (Table 1).

Table 1 The risk factors for palliative care caregiver burden

Domain	Risk factor
1. Caregiver's gender	Most family caregivers are female. The female palliative care caregiver has about a 2-fold higher risk for significant caregiver burden than males. ^{17,18} A study by Morgan T and /team/ in 2016 found that women caregivers experienced a greater degree of mental and physical strain than their male counterparts. This was linked to societal expectations that women should provide a greater degree of care at the end-of-life for family members. ^{21,22}
2. The relationship to the palliative care patients	The spouse or partner who acts as a primary caregiver is at higher risk of developing severe mood complications and caregiver burden than other relationships such as sister or daughter. The spouse or partner are more likely to become increasingly aware of death because they continually experience first-hand the extent to which their patient's condition is deteriorating. ²³ Moreover, they are more likely to develop complicated anticipatory grief responses. ^{17,18}
3. Time spent caregiving (hours/day)	The caregiver who looks after their patient more than 8 hours per day will tend to have a greater sense of being burdened than caregivers who are required less than 8 hours per day, especially in caregivers who live together in the same house with the patient. ²⁴
4. Financial support of the caregiver	When becoming a caregiver, some caregivers have to stop or decrease their normal work, resulting in loss of income. If this leads to a situation of inadequate income, they will feel a greater caregiver burden. ²⁵
5. Social support of the caregiver	Social support for palliative care caregivers is an intervention that reduces the risk of caregiver burden. ²⁶ If a caregiver does not receive adequate social support, they are at much greater risk of developing caregiver burden. ²⁵
6. Confidence in caregiving	The palliative care caregiver has to be able to deal with many problems in their caregiving, especially in end-of life care patients. If they are uncertain about their ability to fulfill these duties, they will be more likely to become stressed and develop caregiver burden. ²⁵
7. The stage of disease of the patient	The caregiver who is looking after an end-of life patient will have a higher burden at this time than during other stages. ¹⁷ At the end of life and close to the end of life, in the transitional zone, the caregiver has to change many aspects of their life such as stopping normal working if they had worked prior to this time, dealing with their decreased income and managing the progressive symptoms of the care recipient. Sometimes the transitional zone is a short period of time, but if the caregiver has not prepared for this, it can increase their burden. ²³
8. Patient's functional status	The patient who has a low palliative performance scale (PPS) score will require more care. The caregiver has to increase the amount and intensity of caring. So patients with lower PPS scores will lead to higher level of caregiver burden. ²⁴

Table 1 Continued

Domain	Risk factor
9. Patient's symptoms	Dyspnea, feelings of depression and anxiety are the significant patient factors that impact the caregiver. The caregiver who cares for a patient with dyspnea, especially at the end-of-life stage when the dyspnea becomes severe, or must care for a patient with depressive symptoms and/or anxiety, is more likely to feel a significant burden. ²⁷
10. Number of patient visits to the emergency department	Caregiver burden in palliative care is associated with the number of patient visits to the emergency department. When a patient needs to visit the emergency department, it means their symptoms are worse, which leads to increased caregiver stress and burden. ²⁴

DISCUSSION

This review examined recent research on caregiver burden of palliative care caregivers. Most previous review articles have focused on the patients who need palliative care, and appropriate management of their symptoms.^{3,4,7,14} Recently, however, there has been increased awareness on caring for the caregivers, an area which is no less important than the other aspects of palliative care work. The assessment of caregiving outcomes must recognize the work and potential burden of caregivers, especially those who are likely to end up with burnout, which will affect both the caregiver and the care recipient.^{28,29} The increasing number of publications on this issue reflects the growing awareness of the importance of not only caring for the patient, but also their caregiver.

Most previous studies have failed to adequately address the differences between the palliative care caregiver's responsibilities and those of the general caregiver for chronic diseases.^{2,5,6} This review discusses the many aspects of palliative care caregivers such as specific care in the transition zone to the end-of-life stage and the end-of-life symptoms such as anorexia-cachexia, dysphagia, delirium and impaired oral intake.

This review examines the factors that can lead to caregiver burnout and updates the current information about palliative care caregiver burden, how to recognize it and the warning signs of impending burnout. Our

review discusses the risk factors that increase the risk of caregiver burnout more specifically than previous studies. From the gender perspective, several studies have found that female caregivers showed significantly higher levels of caregiver burden than male caregivers in palliative care caregivers. A study by Washington K and team found that female palliative care caregivers had significantly lower self-esteem and felt more negative impact on their daily schedule, health, and family support than males.³⁰ Our study has also identified a new risk factor for caregiver burnout, the number of care recipient visits at an emergency department.²⁴ The study of Verhoef noted that when a palliative care patient is brought to the emergency room, that means they have more severe symptoms such as severe dyspnea than they experience at home, which can lead to hospitalization and death, which increases the stress level, and contributes to potential burnout, for their caregiver.³¹ Another review concluded that the confidence of a palliative care caregiver is the most important factor associated with caregiver burden.²⁵ The caregiver's confidence can have an impact on the course of the terminal illness. It is also influenced by their needs being met, such as having adequate information about how to care for their end of life patient and their sources and strength of support. If the palliative care caregiver has outside sources of support such as financial or social support, they will have more confidence in doing their work.³² Although some risk

factors may be non-modifiable (e.g. gender, relationship to the recipient or disease-related factors), it is important to increase the health care provider's awareness of and ensure there is early identification of the risk factors. The care-related factors such as time spent, social support or financial support are important for health care providers to manage adequately and create a system for decreasing the burden in palliative care caregivers in the future.

CONCLUSION

This review examines the caregiver burden concept and the risk factors that could lead to a caregiver feeling they are burdened. Healthcare providers should consider the assess each specific situation as well as background, or conditions, assess the level of caregiver burden so they can recognize the signs of developing burnout and take appropriate action to deal with this problem in their palliative care caregivers. The data can also be applied in concept analysis research.

ACKNOWLEDGEMENT

The author would like to thank Mr. David Patterson of the International Affairs Office, Faculty of Medicine, Prince of Songkla University for proof-reading and constructive criticism of the manuscript.

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