

# The Factors Influencing the Development of Psychological Problems in the Caregivers of Palliative Care Patients

Yi Hao<sup>1,\*</sup>

<sup>1</sup> College of Liberal Arts and Social Sciences, City University of Hong Kong, Hong Kong SAR, 999077, China

\* Corresponding author. Email: yihao5-c@my.cityu.edu.hk

## ABSTRACT

Palliative care is a type of active, whole-person care for people who have incurable, deteriorating, or short-lived diseases. It focuses on minimizing pain and other non-painful illnesses while also addressing important mental, interpersonal, and spiritual aspects. This paper reviews previous research into the psychological problems and influencing factors of caregivers of palliative care patients and categorizes the influencing factors into two categories: external and internal to the caregiver. The internal caregiver factors include the caregiver's history of mental illness, perception of the patient's condition, satisfaction with the marriage and gender differences; the external factors include the patient's stage of illness development and symptoms, the patient's attitude and communication, and formal support. In addition, social support for caregivers was not targeted, and future research could build on this paper to target policies and services based on factors influencing patients' caregivers' psychological problems in the expectation of meeting their actual psychological needs.

**Keywords:** *Palliative Care, Terminal Care, Caregivers, Psychological Adjustment, Emotional Disturbance.*

## 1. INTRODUCTION

The World Health Organization (WHO) specifies palliative care as the prevention and relief of physical as well as mental suffering through early detection, active evaluation, effective suffering and other somatic symptom management, and process of implementation, psychosocial, and spiritual distress, thereby maximizing and enhancing the health and wellbeing of people with life-threatening illnesses and their families [1]. Palliative care is for any patient and family member with an incurable disease, regardless of age, condition, diagnosis, or prognosis, including cancer and non-malignant diseases [2]. The goal is to provide the patient and his or her family with the highest possible quality of life. Family members are key supporters of patients receiving palliative care. Most can take on the role of caregiver well, but a minority of caregivers can become very distressed or suffer from emotional disturbances. Whether they live together or not, a caregiver is a person who is primarily responsible for and cares for a relative or friend who need care due to a physical, mental, or cognitive handicap. In general, caregivers include people who are paid to provide care, but this paper will focus on

individuals who are not paid to provide care. The patient's family, also known as the patient's caregiver, is both a surrogate decision maker for the patient and plays an important supportive role for the patient, and to some extent also has an effect on the treatment outcome of the patient in many countries, standards of palliative care practice advocate assessing the patient's family's requirements and providing appropriate psychosocial support [3].

Although it is well established in academic research that palliative care should include the patient, healthcare professionals, family members and social workers, in practice palliative care is often limited to the patient themselves, neglecting the needs of other participants, particularly the patient's family, especially psychological needs. In fact, family members, who are the closest relatives of patients receiving palliative care, must bear the rigid costs of medical care and face the painful reality that their loved ones may pass away soon, which can lead to great mental and psychological stress and easily lead to anxiety or other psychiatric problems and a reduced quality of life.

This paper focuses on the causes of psychological issues in caregivers of palliative care patients. The paper first discusses the current status of the prevalence of psychological problems among caregivers. Then, by reviewing previous research, the causes of psychological problems affecting caregivers are summarized from both internal and external perspectives of caregivers. Finally, the paper summarizes the limitations of the services provided to caregivers and the outlook for future services, exploring the gap between reality and need in the hope of providing better psychological support to caregivers of palliative care patients.

## **2. WHETHER THE CAREGIVER'S PSYCHOLOGICAL PROBLEMS ARE SEVERE**

A small number of caregivers of palliative care patients experience mental illness, while many more experience only emotional distress. According to Nijboer et al., relatives of cancer patients have a prevalence of mental disease that is comparable to or larger than that of people with cancer [4]. According to the findings of a self-statement scale study, up to 20 percent to 30 percent of caregivers of people in the palliative stage of therapy suffer from neighborhood disease [5]. The prevalence of anxiety and depression was found to be 82.35 percent and 40.20 percent, respectively, in a survey of primary caregivers of cancer survivors using the Zung's anxiety test methods [6]. According to Bambauer et al. [7], the diagnostic criteria for a mental disorder as specified by the International Classification of diseases Manual of Mental Disorders were met by 16.1% of patients and 13.1 basis points of their relatives, and the mental disorders of their relatives were mostly anxiety disorders, with a prevalence of 9.53 percent.

Most caregivers of palliative care patients lack professional knowledge and skills, and the time and effort required to care for them can be difficult to obtain positive feedback from others, especially family members, who often complain that they are not taking good care of them. As a result, these caregivers commonly report anxiety, distress, loneliness, panic, and other psychological problems. Due to the high volume of caregiving work and the relatively closed caregiving environment for long periods of time, caregivers tend to become neurotic, lack self-confidence, have a lowered self-identity and lose confidence in their future lives.

## **3. WHAT ARE THE POSSIBLE FACTORS IN PSYCHOLOGICAL PROBLEMS AMONG CAREGIVERS?**

### ***3.1. Factors internal to the caregiver***

#### ***3.1.1. Level of education and occupation***

Cameron et al. [8] discovered that caregivers with limited education were more prone than caregivers with highly educated to suffer negative stress reactions. It has been suggested that a great education enables enhanced career knowledge of the patient's ailment conditions that helps increase the level of power in the profession, resulting in a low prevalence of depression [9]. Depending on the type of employment, the impact of occupation on mental state and psychological health differs in the literature. Spouses of patients with occupations had fewer depressive symptoms than spouses without occupations in Given's study [10], possibly because the occupation acted as a buffering moderator of the career's caring experience, whereas youth with professions were more depressed than youth without occupations. Multiple roles have also been proven to influence the psychological adjustment of patients' occupations, with the more social duties a vocation assumes, the more stress it faces [11].

#### ***3.1.2. Satisfaction with marriage***

Marriage is conceptualized as sexual satisfaction, family support and couple communication. There is currently little research on sexual satisfaction. In terms of family support and couple communication, any palliative care patients' caregivers are their own spouses. Some reports confirm that the character of the patient's connection with their caregiver prior to palliative care can be predictive of subsequent caregiver psychological problems. Williamson and Schulz found that those who had been in an intimate relationship felt less caregiving burden and had fewer depressive symptoms than those who had not been in a mutually supportive relationship [12]. In addition, caregivers in unfair relationships can feel distressed, and one research found that when partners feel that they benefit little from the relationship, they are likely to feel depressed and may become depressed [13].

#### ***3.1.3. Gender differences***

A number of studies have shown gender differences in the psychiatric distress experienced by caregivers. In a study by Li and Zhang et al., it was discovered that caregivers who were women were likelier than male caregivers to suffer from negative psychological stress reactions, which contributed to the development of emotional problems [14]. Some reports revealed that Female patients' partners experienced more depressive symptoms than females in healthy relationships [15]. Although male patients and male partners had the same level of psychological anguish as female patients and female partners, there was really no variation in emotional problems between patients but male partners and their healthy controls. Also, on the Centre for

Epidemiological Studies Depression Scale, 35 percent of female caregivers had greater rates of depression and prevalence than 12 percent of male caregivers (CES-D) [16].

### **3.2. External factors of caregivers**

#### **3.2.1. Patients' stage of disease progression and symptoms**

Caregiver distress increases as the patient experiences more pain and as the patient's physical functioning deteriorates. By studying the mental condition of patients with metastatic breast cancer treated at home, Grunfeld with his team members found that the prevalence of nervousness and depression in the primary caregiver increased significantly as the patient's disease worsened, and the end was near [17]. Kurt et al [18] reported that, as the patient's health worsens, it is necessary to intervene, the caregiver spends more time helping the patient to cope with everyday life, which has a considerable detrimental influence on the health and daily lives of the caregiver, leading to the caregiver experiencing deeper and more frequent symptoms of depression.

In addition, the intensity of the diagnosis has an influence on the caregiver's stress levels. The caregiver's depression increases as the severity of the patient's complaints increases [18]. As the patient's symptoms increase, this can induce depression, increased functional limitations and increased caregiver obligations for symptom management and assisting the patient with his or her limited functional activities. Caregivers need to not only recognize emerging changes but also assist in managing these symptoms [19].

#### **3.2.2. Patients' attitudes and communication**

Patients' attitudes were associated with caregivers' distress. Among other things, patients' avoidant attitudes were associated with caregivers' psychological maladjustment. A study from Rodrigue and Hoffman showed that caregivers who avoided exposing their caregivers to issues in relation to the patient's medical problem or remedy exhibited greater amount of negative emotion [20]. Stress and sadness are on the rise in the wife when the male patient adopt an avoidant coping attitude [21]. When female patients adopt a problem-focused coping style rather than an avoidant attitude, their husbands rarely develop mental illness [22]. Open communication can be helpful for caregivers. Northouse and colleagues discovered that couples who chatted and shared their difficulties together on a regular basis were more aware of the shifting responsibilities related with their sickness, but caregivers who were anxious were less likely to do so [23].

#### **3.2.3. Formal support**

If caregivers feel and receive enough formal support, their mindset will change positively and they will feel more confident in the task of caring, conversely, if they do not receive enough formal support, caregivers will have more negative feelings. The matching hypothesis states that "the effectiveness of social support depends on the match between the social support an individual needs and the support he or she receives from the social network". Caregivers are eager to learn more about the disease process, treatment, adverse drug reactions and prognosis. When caregivers' requirements for medical information aren't addressed, caregivers may become more concerned. Adequate and effective communication requires open discussion between caregivers and the multidisciplinary team about the patient's situation and demands, and the development of a rational treatment and care plan to facilitate the achievement of improved standard of living for the patient and caregiver. Derdarian et al. [24] showed that patients and primary caregivers are more satisfied with the targeted information they need than with standardized information, and that it is more conducive to psychological adjustment. Surveys have shown that patients and those who care for them have elevated expression of satisfaction when caregivers receive information tailored to them [25]. This suggests that information related to the patient's illness can achieve good psychological adjustment for both the patient as well as the caregiver.

### **3.3 Current social support for caregivers' psychological problems**

Current social support for caregivers of palliative care patients falls into two main categories. Many caregivers experience a variety of conflicts with patients and other family members during their long caregiving lives. To help them restore healthy family relationships and reduce negative effects, many family counselling and psychotherapy sessions arise. Most psycho-educational are aimed at providing information about the physical aspects of symptom management and patient-centered care, in addition, some programs that give some attention to the caregiver's spiritual and mental demands, the caregiver's relationship with his or her marriage or family. For example, caregivers are provided with information and skills to resolving home and marriage strife, connection, collaboration, and intimacy. These services are usually provided by day care centers in the community, mental health centers, specialist agencies that provide care services, etc. The help provided through these agencies can reduce family conflicts for the caregiver and will also reduce the psychological stress of the caregiver. Alternatively, knowledge, abilities, and support for caregivers to enhance their performance to care for themselves, maintain their bodily and mental necessities,

improve their trust in their caregivers, keep their social safety net, as well as seek social resources to lessen the pressure of caring. There is also the self-esteem support provided to caregivers. Most caregivers experience a high level of stress because of being in a caring situation for a long period of time, and this stress can cause caregivers to feel a loss of confidence. As this is a common occurrence among caregivers, there are a number of government and institutional programs that provide a range of psychological support services for caregivers, mainly to help them regain their confidence and increase their ability and confidence to face and deal with problems.

The negative emotions of a patient's caregiver can be passed on to the patient, and the caregiver's expressions, attitudes, words, and actions can have some significant impact on the patient. In palliative care, caregivers should identify emotional changes in their caregivers, provide effective psychological support, provide appropriate venues and opportunities for caregivers to express their grief, and listen patiently to their caregivers, understand, and respect their reactions to loss, and provide them with maximum emotional support.

#### **4. CONCLUSION**

This paper reviewed the internal and external factors that contribute to the emotional problems of caregivers and found that caregivers are often under significant mental stress, which is further exacerbated by physical fatigue due to prolonged companionship and internal and external factors that have a detrimental impact on mental health in a big way. Caregivers of patients receiving palliative care are subject to more severe psychological adverse stress. Their psychological well-being is influenced not only by internal factors such as level of education, occupation, marital relationship satisfaction and gender, but also by external factors such as the level and the signs and symptoms of the patient's condition, the patient's attitude, and formal support. This suggests that medical and social workers should take care to assess the mental health of the patient's caregivers and analyze the causes of psychological problems while treating or helping the patient.

The limitations of the previous literature include, but are not limited to, firstly, the fact that previous literature has chosen to focus on the European American region but has not focused on regions with specificities and has neglected the Asian region where palliative care has been slower to develop. Secondly, the depth of research in the previous literature leaves much to be desired and there are other aspects that may have a role in caretakers' mental health that have not been considered, such as: social policies, religious belief factors, etc.

Modern palliative care services are provided by professionals, social workers, and volunteers. Through

this review, the author of this paper hopes to provide some theoretical support to scholars in the fields of social work, psychology, and medicine, and that the formulation of psychological services for caregivers should be based on the actual psychological needs of caregivers and the factors influencing their psychological problems. In the future, scholars and service providers in the relevant fields are expected to provide targeted and diversified psychological services to the families of palliative care patients, with the aim of helping patients to complete their final journey peacefully and relieving the physical and psychological burden of the patients' families.

#### **REFERENCES**

- [1] World Health Organization. National Cancer Control Programmes: Policies and managerial guidelines. World Health Organization. Retrieved April 25, 2022, from <https://apps.who.int/iris/handle/10665/42494>
- [2] N.R. Orford, S.L. Milnes, N. Lambert, et al., Prevalence, goals of care and long-term outcomes of patients with life-limiting illness referred to a tertiary ICU[J]. *Crit Care Resusc*, 18(3), 2016, 181-188.
- [3] R.A. Mularski, Defining and measuring quality palliative and end-of-life care in the intensive care unit[J], *Crit Care Med*, 34(11), 2006, S309-S316.
- [4] C. Nijboer, M. Triemstra, R. Tempelaar, R. Sanderman, & G. A. van den Bos, Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer*, 86(4), 1999, 577-588.
- [5] C. Pitceathly, & P. Maguire, The psychological impact of cancer on patients' partners and other key relatives: a review. *European Journal of cancer*, 39(11), 2003, 1517-1524.
- [6] H. Chen, C. Jiang, Y. G. Sun, & Q. G. Liu, Psychosomatic disorders and factors influencing primary caregivers of patients with advanced cancer, 2002.
- [7] K. Z. Bambauer, B. Zhang, P. K. Maciejewski, N. Sahay, W. F. Pirl, S. D. Block, & H. G. Prigerson, Mutuality and specificity of mental disorders in advanced cancer patients and caregivers. *Social psychiatry and psychiatric epidemiology*, 41(10), 2006, 819-824.
- [8] J. I. Cameron, R. L. Franche, A. M. Cheung, & D. E. Stewart, Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*, 94(2), 2002, 521-527.
- [9] D. A. Fleming, V. B. Sheppard, P. A. Mangan, K. L.

- Taylor, M. Tallarico, I. Adams, & J. Ingham, Caregiving at the end of life: Perceptions of health care quality and quality of life among patients and caregivers. *Journal of pain and symptom management*, 31(5), 2006, 407-420.
- [10] B. Given, G. Wyatt, C. Given, A. Gift, P. Sherwood, D. De Voss, & M. Rahbar, Burden and depression among caregivers of patients with cancer at the end-of-life. In *Oncology nursing forum*, 31(6), 2004, p. 1105
- [11] Y. Kim, F. Baker, R. L. Spillers, & D. K. Wellisch, Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 15(9), 2006, 795-804.
- [12] P. Haddad, *Affective Disorder Amongst Partners of Cancer Patients*. MD Thesis, University of Manchester, UK, 1994.
- [13] M. Kurtz, B. Given, J. Kurtz, C. Given, The interaction of age, symptoms and survival status on physical and mental health of patients with cancer and their families, *Cancer*, 74 (Suppl.) (1994), pp. 2071-2078
- [14] J. Rodrigue, R. Hoffman III, Caregivers of adults with cancer: multidimensional correlates of psychological distress, *J. Clin. Psychol. Med. Settings*, 1 (1994), pp. 231-244
- [15] Y.Q. Li, M.X. Zhang, G.X. Fu, W.Y. Li, L.H. Zhao, Y. Fan, Z.H. Wang, L. Peng, A multifactorial analysis of 89 cases of psychological disorders among relatives of terminally ill patients[J]. *Journal of Liberation Army Nursing*, (05), 2005, 34-35.
- [16] M. Hagedoorn, B.P. Buunk, R. G., Kuijer, T. Wobbes, & R. Sanderman, Couples dealing with cancer: role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 9(3), 2000, 232-242.
- [17] E. Grunfeld, D. Coyle, T. Whelan, J. Clinch, L. Reyno, CC. Earle, ... & R. Glossop, Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Cmaj*, 170 (12), 2004, 1795-1801.
- [18] M. E. Kurtz, J. C. Kurtz, C. W. Given, & B. Given, Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression—a longitudinal view. *Social Science & Medicine*, 40(6), 1995, 837-846.
- [19] S. L. Kozachik, C. W. Given, B. A. Given, S. J. Pierce, F. Azzouz, S. M. Rawl, & V. L. Champion, Improving depressive symptoms among caregivers of patients with cancer: results of a randomized clinical trial. In *Oncology Nursing Forum*, 2001, 28 (7)
- [20] L. Douglass, Reciprocal support in the context of cancer: perspectives of the patient and spouse, *Oncol. Nurs. Forum*, 24 (1997), pp. 1529-1536
- [21] S. Ey, B. E. Compas, J. E. Epping-Jordan, & N. Worsham, Stress responses and psychological adjustment in patients with cancer and their spouses. *Journal of psychosocial oncology*, 16(2), 1998, 59-77.
- [22] J. T. Ptacek, J. J. Ptacek, & K. L. Dodge, Coping with breast cancer from the perspectives of husbands and wives. *Journal of Psychosocial Oncology*, 12(3), 1994, 47-72.
- [23] L.L. Northouse, M.C. Katapodi, L. Song, L. Zhang, & D.W. Mood, Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA: a cancer journal for clinicians*, 60(5), 2010, 317-339.
- [24] A. K. Derdiarian, Effects of information on recently diagnosed cancer patients' and spouses' satisfaction with care. *Cancer nursing*, 12(5), 1989, 285-292.
- [25] L. Pearlin, C. Schooler, The structure of coping. *J Health Soc Behav*, 1978, 19: 2–21.