

Mental health status of cancer caregivers, assessment tools, and psychological interventions*

Honghong Xu¹, Ruotong Xue¹, Yi Cheng², Yujie Zhang², Jie Rao², Mei Liu², Shiyong Yu², Lingxiang Liu³, Yiqian Liu³, Yongqian Shu³, Liuqing Yang⁴, Hanping Shi⁴ (✉)

¹ Medical Psychology Department, Peking University Health Science Center, Beijing 100191, China

² Department of Oncology, Tongji Hospital, Tongji Medical College, Huazhong University of Science and Technology, Wuhan 430030, China

³ Department of Oncology, The First Affiliated Hospital of Nanjing Medical University, Nanjing 210029, China

⁴ Department of Gastrointestinal Surgery, Department of Clinical Nutrition, Beijing Shijitan Hospital, Capital Medical University, Beijing 100038, China

Abstract

Many studies pointed out that psychological pain is not limited to the cancer patients themselves, but their caregivers also experience different levels of psychological problems such as depression, anxiety, and stress. This article attempts to review the mental health status, assessment tools, and psychological interventions of the caregivers of cancer patients, and calls on social and medical workers to pay attention to the mental and physical health status of the caregivers of cancer patients.

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Globally, cancer is the second leading cause of death, causing 8.8 million deaths in 2015, and nearly one-sixth of all deaths^[1]. Providing care to patients with cancer can also be overwhelming, and caregivers are at risk for physical and psychological distress that will affect their physical and mental health, and affect their quality of life for a long time. A cancer caregiver is defined by most studies as “the person who spends the most time caring for the patient and does not get paid”^[2–3]; it usually refers to the family members who have the primary responsibility for the patient, such as spouse, children, parents, siblings, etc.

Nowadays, the length of hospital stays has been shortened, and the increase in the shift to outpatient services has placed a heavy burden of responsibility on caregivers, many of whom rarely prepare for it. The rapid development in the field of cancer care has improved our ability to extend lifespan and improve survivability. In many cases, cancer has become a chronic disease rather than a sudden life-limiting disease. These trends have greatly increased the burden on caregivers and,

consequently, their needs.

Many investigations and studies^[4] show that the prevalence of mental illness in the primary caregivers of cancer patients is 20% to 30%, while that of patients with advanced cancer or relatives of palliative care is 30% to 50%. Other studies^[5–6] pointed out that the incidence of psychological problems in cancer patients has reached 100%. In addition, studies in South Korea show that 17.7% of cancer caregivers have been suicidal, and 2.8% of cancer caregivers have attempted suicide^[7]. Therefore, whether it is for the care of cancer patients or for the physical and mental health of cancer caregivers, this group deserves social attention.

Mental symptoms of cancer caregivers

Depression

Depression is a common mood disorder among the caregivers of cancer patients. Grunfeld’s study^[8] showed that 30%–50% of cancer caregivers (here referred to as family caregivers) had different emotional responses, of

✉ Correspondence to: Hanping Shi. Email: shihp@vip.163.com

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which depression was one of the most common emotional responses. In a study of the caregivers of patients with advanced gastric cancer [9], 62.57% of caregivers had depressive symptoms.

Anxiety

Anxiety is also one of the common emotions of cancer caregivers. A study by Park [10] showed a high degree of anxiety in the caregivers of cancer patients, and a study of primary caregivers for breast and prostate cancer by Grov [6] showed that both male and female caregivers had significantly higher levels of anxiety than the normal level. Liu's research [11] also showed that the major caregivers of cancer patients who were hospitalized for chemotherapy had severe anxiety.

Stress

As both the stress level and care requirements for cancer care are higher than for general disease care, research has shown that [12] many cancer caregivers provide care as a result of increased emotional stress. Half of the cancer caregivers report that they experience high levels of emotional stress, while a small number of non-cancer caregivers report that providing care can be very emotionally stressful and that the emotional response of cancer caregivers can have a significant impact on survivor outcomes, including the survivor's own emotional response.

Cancer caregiver mental health assessment tools

A 2016 report on cancer caregivers published in the United States mentioned that pain screening or assessment should be performed for caregivers and that the appropriate resources should be provided [12]. The tools commonly used in clinical work to assess the mental health of caregivers are as follows:

The Burden Scale for Family Caregivers (BSFC)

The Family Carer Burden Scale was developed by Gräsel [13] in 1993 and was originally developed in Germany. As a clinical tool that measures the self-reported burden of home caregivers of relatives. The scale has 28 entries and uses a 4-point scale from 0 (strongly disagree) to 3 (strongly agree). A higher score indicates a greater burden on the caregiver. It provides basic information about the negative effects of care and how care affects the health of caregivers. The advantage of BSFC is that it can be used both as a clinical tool (such as to assess care and identify areas of interest) and for research purposes (such as for observational studies or as a measure of the outcome of intervention studies). Cronbach's α of the scale is 0.91 [14], which has been translated into multiple languages.

The Cronbach's α of the Turkish version of the family caregiver burden scale is 0.89 [15] and the Danish version of the Cronbach's α is 0.91 [16].

The Burden Scale for Family Caregivers-short version (BSFC-s) [17]

The BSFC-s is a short version developed based on the Family Carer Burden Scale. It uses a 4-point scale from 0 (strongly disagree) to 3 (strongly agree). Scores range from 0 to 30, with higher scores indicating a greater burden on caregivers. The Cronbach's α of this scale is 0.92 [18], and it has been widely used in many languages.

Caregiver Burden Scale (CBS) [19]

There are 22 items in the CBS, and a 5-point Likert scale is used. Divided into five dimensions (general strain, isolation, disappointment, emotional involvement, and environment), it covers important areas such as health, mental health, interpersonal relationships, physical burden, social support, economics, and family environment. The scale measures scores and total scores for each dimension, and this helps to understand which specific dimensions have the most impact on caregivers. The questionnaire can be filled-out by the main test subject or by the test subject. A higher score indicates a greater burden on the caregiver. Except for the environment dimension, the Cronbach's α of other dimensions is 0.70–0.87 [20], and the Cronbach's α of the Turkish version of CBS is 0.91 [21].

Caregiver Reaction Assessment (CRA)

The CRA was developed by Given *et al* [22] in 1992 and was originally used to assess the response of elderly caregivers toward long-term care. Divided into four negative dimensions, Impact on Health (IH), Impact on Schedule (IS), Impact on Finances (IF), Lack of Family Support (LFS), and one positive dimension, Caregiver's esteem (CE), for a total of 24 entries, using a 5-point Likert scale. The higher the negative dimension score, the heavier the stress load of the caregiver, and the higher the positive dimension score, the lighter the stress load. The scale is characterized by both positive and negative dimensions and considers the participants' evaluation of positive and negative experiences. Studies evaluating the caregivers of stroke patients have shown that the Cronbach's α of each subscale is 0.62 to 0.83 [23]. CRA is currently widely used to assess the burden of caregivers of patients with various chronic diseases such as cancer, stroke, and Alzheimer's disease [24]. Some domestic scholars have shown that the Cronbach's α is 0.612–0.732 [25] in the reliability and validity test of the Chinese version of the caregiver response assessment scale which has good reliability and validity. However, some scholars have pointed out that the reliability of the

dimension Impact on Finances (IF) in the Chinese version of CRA is not good enough^[26] and needs further revision and testing.

Zarit Caregiver Burden Interview (ZBI)^[27]

The ZBI consists of 22 items rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly always) with the sum of scores ranging between 0–88, and higher scores indicate a greater burden. A score of 17 or more indicates a heavy burden. Dimensions reported include consequences of caregiving, patient's dependence, exhaustion and uncertainty, guilt or self-criticism, embarrassment/anger or frustration, psychological burden and emotional reactions, personal strain, and role strain. The ZBI's psychometric properties have been extensively examined in the caregivers of patients with dementia and demonstrate strong evidence for reliability and validity in that population. The ZBI has also been examined in the caregivers of patients with cancer and brain injury. The reported Cronbach's α for the ZBI in caregivers of patients with cancer and dementia ranged between 0.85 and 0.93.^[28]

Caregiver Strain Index (CSI)

The CSI was developed by Robinson^[29] and used to quickly identify families with potential caregiving concerns. It is a 13-question tool that measures the strain related to care provision. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social, and Time. The scale's answer method is "Yes" (1 point) or "No" (0 point), with a total score of 0 to 13 points. The higher the score, the higher the stress of the caregiver. When the cumulative score is ≥ 7 , it indicates that the stress level is higher^[30]. The Cronbach's α of CSI is 0.86^[29], and the Chinese version of Cronbach's α is 0.828^[31]. As the CSI has only 13 items and the answer method is in the form of "Yes" or "No", it can quickly assess the stress of the participants. It is also widely used in clinical practice, but it also has certain shortcomings. For example, this tool is limited by lack of a corresponding subjective rating of caregiving impact. There is no breakdown of score regarding low, moderate or high caregiver strain. The carer's stress level is qualitatively evaluated.

Caregiver Burden Inventory (CBI)

The CBI is a tool developed by Novak *et al*^[32] for assessing the burden of caregivers and was initially used for caregivers of patients with Alzheimer's disease. The 24-item multi-dimensional questionnaire measures caregiver burden with 5 subscales: (a) Time Dependence; (b) Developmental; (c) Physical Burden; (d) Social

Burden; and (e) Emotional Burden. Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive). The Cronbach's α of the Chinese version of CBI is 0.85, and the Cronbach's α of the physiological, emotional, social, time-dependent, and development-restricted dimensions are 0.83, 0.88, 0.82, 0.90, and 0.87, respectively^[33]. Some scholars have also suggested that although the reliability and validity of the Chinese version of the CBI supports the use of the Chinese version of the CBI as a research tool to measure the burden of Chinese caregivers, further research is needed to distinguish the burden of developmental constraints, the emotional burden, and the social burden^[34].

Caregiver Stress Self-Test

The Caregiver Stress Self-Test^[35] is a self-assessment scale with 14 items that uses a 4-point scale from 0 (never) to 3 (often). A higher score indicates a higher degree of stress. When the score is between 0 and 13 points, the subject is in a good state. When the score is between 14 and 25 points, some signs of stress have begun to appear. When the score is between 26 and 42 points, the burden of stress is greater.

Other scales

Other scales, such as the Distress Management Screening Measure (DMSM), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), Zung's anxiety self-assessment scale (SAS), the Zung depression self-assessment scale (SDS), Profile of Mood States (POMS) Questionnaire, and other scales are also often used in clinical evaluation work.

Existing scales have been tested for their reliability and validity and have been used by many studies to assess the psychological status of caregivers. However, there are still some shortcomings: some assessment tools are simple scales that lack the specific evaluation elements for caregivers, such as BDI, BAI; while some scales are compiled for the group of caregivers, the content of consideration is extremely large. Most of the assessments are the pressure and burden of caregivers, which can only show one aspect of their mental health. The above tools are targeted at all caregivers caring for patients of all diseases; cancer patients are a very special group that needs attention. The specificity of the cancer patients' group causes the psychological distress of their caregivers to be assessed more specifically; some scales have simply been translated and have not been adapted according to China's special cultural background. Pertaining to the application in China, reliability and validity are unknown, and use is limited.

Factors affecting the mental health of cancer caregivers

Related factors for caregivers

General demographic factors of caregivers

Gender The mental health status of caregivers varies. Currently, most studies have shown that women's caregivers have worse mental health. A domestic study^[36] found that the incidence of anxiety and depression of female family members was higher than that of males when family members were the primary caregivers. Studies abroad^[37] show that the incidence of emotional disorders in female family members (23%) is higher than that of male family members (7%) after two years of cancer diagnosis. However, some scholars^[38] believe that the pressure load of male caregivers is higher than that of female caregivers. This is because when men are caregivers, sudden family role changes make it necessary to take care of things that they were not familiar with quickly.

Age In a study of cancer caregivers of patients in hospital chemotherapy^[11], it was found that the anxiety and depression level of the main caregivers of cancer showed significant age differences. Middle-aged and elderly caregivers (aged ≥ 45 years) had higher anxiety and depression scores than younger ones (< 45 years). On the other hand, there are studies that called attention to young caregivers. The research results of He *et al*^[39] show that with the increase of age, the mental resilience of caregivers has gradually increased, which may be more rich due to the social experience of middle-aged and elderly people, greater maturity in handling matters, and their greater ease in obtaining social support.

Relationship with cancer patients The caregiver can be the patient's spouse, children, other relatives, friends, etc. The relationship between the patient and the caregiver is different, and the mental state of the caregiver will also be different. Studies^[11, 40] have shown that the immediate family members' psychological burden during care is higher than that of their other relatives, and the anxiety and depression of parents and spouses are significantly higher than those of their children. Some researchers also believe that the anxiety and depression of patients' spouses and children are significantly higher than other members^[41].

Education level The education level of caregivers can to some extent represent their knowledge of disease, their ability to deal with emergencies, their attitudes towards cancer and death, their ability to actively cooperate with treatment, and their social and family economic status. Fleming *et al*^[42] suggested that the higher the education level of caregivers, the lower the incidence of depression. Research by Cameron *et al*^[43] also found that caregivers with a low educational level have greater psychological

stress.

Economic situation Cancer often requires multiple clinical treatments and has a long course. The family financial status of patients not only affects the treatment and prognosis of patients, but it also affects the physical and mental health of caregivers. Studies^[11, 36, 44] have shown that caregivers with poor financial conditions have more severe anxiety and depression than those with good financial conditions.

Social support

Taking care of patients over a long period of time tends to reduce the social and entertainment activities of the caregiver. The communication with relatives and friends is also reduced, which easily makes the caregiver feel lonely and abandoned. Studies by Kim *et al*^[45] show that the positive feelings of caregivers are positively related to their level of social support, that is, the higher the level of social support of caregivers, the more positive feelings they get. Mosher *et al*^[46] pointed out that reduced social support can lead to reduced quality of life for cancer caregivers. In addition, there are studies^[47] that show that caregivers' anxiety and depression levels are negatively related to their social support.

Attachment types

Attachment is a strong, lasting emotional connection formed between an individual's early years and his or her main caregivers and plays an important role in the individual's life. Some scholars^[48] explored the relationship between the positive feelings of cancer caregivers and attachment and social support, and found that attachment anxiety and social support are the influencing factors of the positive feelings of caregivers; social support plays a mediating role between attachment avoidance and positive feelings.

Hope level

The level of hope is one of the buffering factors that helps caregivers cope with stress, and it is also an important factor that affects the physical and mental health of caregivers^[49]. Studies^[50] have shown that the total score of the hope level of caregivers of patients with advanced cancer is positively correlated with their quality of life, especially with a moderately positive correlation with the score in the dimension of the psychological field.

Coping style

Coping style refers to the way in which individuals handle stressful situations and are generally divided into positive and negative coping styles. The results of many domestic studies^[51-53] showed that positive coping style is an influencing factor of the psychological resilience of cancer caregivers, and the more positive the coping style, the higher the level of psychological resilience. Under the same stress conditions, individuals who took an active response tended to seek outside help and talk to others, which was conducive to alleviating stress and adjusting

their psychological conditions.

Burden

The results of the study^[12] indicate that the burden of cancer caregivers is very high. Most cancer caregivers are in a high-burden situation, and the incidence of high-burden conditions (62%) is significantly higher than that of non-cancer caregivers (38%). Grunflod^[8] pointed out that the burden of care is the main cause of caregiver anxiety and depression.

In addition, the nature of the care tasks undertaken by caregivers can also affect their psychological status. They believe that difficult or unattractive tasks (such as going to the toilet) may lead to higher levels of pain^[54]; research shows that the daily care time^[55-56] will affect the quality of life of the caregiver, reduce their rest and social activities, and lead to the emergence of anxiety, depression, loneliness, and other bad emotions for a long time; the existence of medical insurance can also affect the mental health of the caregiver. Insurance can reduce the financial burden of caregivers and relieve their stress^[36]; length of care and frequency of care have also been shown to affect psychological resilience^[57].

Related factors for cancer patients

Gender and age of patients

Studies^[41] have shown that when patients are male, their caregivers' depression is significantly higher. In addition, Turgeon *et al*^[57] investigated the mental health of caregivers of cancer patients and found that caregivers of young patients were more likely to have psychological problems.

Cancer stage

As patients experience different stages of their disease, the mental state of their caregiver changes accordingly. A number of studies on the caregivers of cancer patients^[8, 57-59] have shown that as the cancer patients' disease progresses, physical function declines, and facing death, the incidence of depression and anxiety of their caregivers will also change. On the other hand, as the patient's condition becomes worse, and the degree of dependence on the caregiver also increases, this increases the caregiving work stress of the caregiver, and then also affects their physical and mental health.

Cancer symptoms

Symptoms of cancer include symptoms caused by the disease itself and the side effects that occur during treatment. The more severe the patient's symptoms, the more time the caregiver needs to spend on care. In a study of cancer patients and their spouse caregivers, Williamson^[60] found that the restriction of the caregivers' daily activities mediates the relationship between stress and resentment, and the limitation of activities is predicted by the severity of the patient's symptoms.

Cancer course

There was a positive correlation between the caregiver's mental health and the patient's disease duration. Studies^[61] have shown that the longer the patient's disease course, the lower the positive emotions and higher negative emotions of the caregiver, and the more likely they are to cause psychological problems. The results of Liu's study^[11] showed that the caregiver's anxiety and depression scores were significantly higher in cancer patients with a course of ≥ 6 months than in those with a course of less than 6 months.

Psychological intervention for cancer caregivers

Caregivers of cancer patients have little preparation, information, or support to perform their care responsibilities. However, their psycho-social needs must be met so that they can maintain their health and provide the best support to their patients. There are meta-analyses^[62] of data from 29 randomized clinical trials published from 1983 to March 2009, which provided three types of interventions: psychological education, skills training, and treatment counseling. Most interventions are provided jointly to patients and caregivers. A meta-analysis shows that although these interventions have small to moderate effects, they significantly reduce the psychological burden on caregivers, improve their ability to respond, increase their sense of self-efficacy, and improve all aspects of their quality of life. Various intervention characteristics are also considered as potential regulators. Clinicians need to provide research-proven interventions to help caregivers and patients respond effectively and maintain their quality of life.

Psychological interventions for cancer caregivers are necessary. First, clinicians need to recognize that patients and their home caregivers respond to cancer as a whole. As such, they have a legitimate need to get help from healthcare professionals. There is a general consensus that when patients and their caregivers are treated at the same time, there will be important synergistic effects that will help everyone's health^[63]. When the needs of caregivers are not met, their mental and physical health is threatened and patients are denied access to the best care from well-prepared home caregivers^[64-65]. Patient-only care plans rarely meet the needs of patients because patient care relies heavily on caregivers. To improve the level of comprehensive cancer care, patients and caregivers should be taken care of when implementing a care plan. Second, there is clear evidence^[63] that interventions provided to caregivers of cancer patients can positively affect many aspects of caregivers. Interventions significantly reduced the burden on caregivers, improved their coping skills,

increased their confidence as caregivers, reduced their anxiety, and improved marriage and family relationships. These interventions appear to prepare caregivers and reduce their suffering, which is likely to have a substantial positive impact on patients.

Different schools have different ways of performing psychological interventions. In clinical work, the common psychological intervention methods are as follows:

Cognitive-behavior therapy (CBT)

CBT is a structured, short-range, current-oriented approach to psychotherapy developed by A. T. Beck. It is an effective measure to improve the quality of life of the caregiver and reduce the degree of psychological distress by changing the mindset and behavior in order to correct irrational cognition, thereby reducing the negative mood and behavior. As a positive psychological treatment method, CBT has been used in psychological interventions for caregivers of cancer patients, and research^[66] shows that CBT can alleviate the depression and improve the quality of life of caregivers of cancer patients. Research by Tang *et al*^[67] showed that cognitive behavioral intervention can effectively reduce the anxiety, depression, and care burden of primary caregivers of patients with chemotherapy for bowel cancer, and can effectively improve their level of positive coping styles. Research by Chen *et al*^[68-69] showed that CBT can effectively reduce the care burden of the primary caregivers of patients with lung cancer undergoing chemotherapy and improve their quality of life. The research by Qin *et al*^[70] showed that the implementation of CBT can effectively improve the post-traumatic growth and quality of life of caregivers of patients with oropharyngeal cancer, allow caregivers to play a more effective role, and improve the quality of care. In addition, CBT can also improve the mental health level for caregivers of patients with dementia^[71], brain surgery^[72], schizophrenia^[73], stroke^[74], and Alzheimer's disease. After interventions, both patients'^[75] and caregivers'^[76] mental health improved.

Mindfulness-based stress reduction (MBSR)

MBSR is a psychological intervention method founded by Jon Kabat-Zinn. The goal of mindfulness is to remain aware at all times to free yourself from a strong attachment to faith, thought, or emotions, thereby developing a greater sense of emotional balance and happiness. One of the purposes of mindfulness practice is to take greater responsibility for your life choices. Therefore, mindfulness can optimize health prevention and disease recovery by participating in and strengthening an individual's internal resources. For refractory diseases, meditation techniques can alter and improve consciousness, regulate the subjective experience of pain, or improve the ability

to manage pain or disability^[77]. Xu's study^[78] showed that MBSR is a safe, simple, and convenient method that can reduce the level of anxiety and depression of caregivers of patients with malignant tumors. Lengacher *et al*^[79] conducted a six-week mindfulness decompression intervention for cancer patients and their caregivers, and the caregivers' psychological condition and quality of life improved, while also reducing the patient's tension and anxiety. In addition, studies have shown that MBSR can improve the negative emotions of the family members of patients with depression and adjust their coping styles^[80]. It can effectively reduce the burden of care of the primary caregivers of patients with severe head injury and improve the psychological flexibility of the primary caregivers, thus increasing their positive coping style and positive experience^[81]. It can also improve the negative mood of caregivers of schizophrenic patients and strengthen their self-esteem^[82].

Music therapy

Music therapy is based on the theory and methods of psychotherapy and uses the unique physiological and psychological effects of music to enable patients to undergo the musical experience through various specially designed musical behaviors, with the participation of music therapists, to eliminate psychological barriers. The purpose of restoring or improving mental and physical health is divided into active music therapy, passive music therapy, and comprehensive therapy. Research by Chen *et al*^[83] showed that music therapy can effectively assist analgesia after finger replantation; Ye's research^[84] showed that music intervention can improve the anxiety and depression of the family's main caregiver in patients with acute myocardial infarction. At the same time, it can also improve the symptoms of the digestive system. Studies abroad have shown that the intervention of Turkish classical music on patients with dementia at home can reduce the nursing burden of the nursing staff and control the blood pressure of patients^[85]. In addition, studies^[86] have shown that music therapy in combination with other psychological interventions improves the mental health of caregivers.

Cancer not only causes physical and psychological pain to patients, but also challenges their caregivers. Compared with patients, the psychological pain of caregivers is often overlooked. However, in recent years, medical professionals and related scholars have gradually realized the need to include care for caregivers as part of the cancer care system. More accurately assessing the psychological pain of caregivers of cancer patients, and conducting scientific, timely, and reasonable psychological interventions can not only improve the mental health of cancer caregivers, but also indirectly

improve their level of care, which is more conducive to the prognosis of cancer patients.

Conflicts of interest

The authors indicated no potential conflicts of interest.

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