

# General Psychiatry **Cancer-related psychosocial challenges**

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## ABSTRACT

Over the past decade, cancer incidence has increased globally while its mortality has decreased. Accordingly, healthcare practitioners aim to provide comprehensive care to cancer patients. The biopsychosocial model suggests medical professionals' understanding of how psychosocial factors influence the entire course of cancer is critical. However, until now, an integrative review summarising the full scope of these psychosocial domains has been lacking. This review substantiates that cancer patients, survivors, their caregivers, and oncology professionals face substantial psychosocial challenges. Cancer patients and survivors may experience deterioration of self-concept, disturbance of body image, sexual problems and difficulties in social relationships while attempting to cope with casual issues. The burdens of care provision and the impact on the health of caregivers of cancer patients are also noteworthy. Improving the quality of patient–doctor communication and overcoming burnout are significant challenges for oncology healthcare professionals.

## INTRODUCTION

Despite decades of combating the illness, cancer remains a malignant problem that is yet to be obliterated completely, and the burden continues to be serious. According to the World Health Organization (WHO) International Agency for Research on Cancer's report, in 2020, the global cancer burden was estimated to have risen to 19.3 million new cases and 10 million deaths. One in five people are expected to develop cancer during their lifetime.<sup>1</sup> Meanwhile, in the past decade, the general cancer mortality rate has decreased, and the 5-year survival rate (often regarded as the criteria for a successful 'survival') has increased.<sup>2</sup> An increasing number of various types of cancer are being acknowledged and treated as chronic diseases rather than life 'terminators'.

Accordingly, improving the overall quality of life for cancer patients and survivors has become an important and comprehensive goal of treatment.<sup>3</sup> Referring to the well-known biopsychosocial model, a reciprocal effect exists between psychosocial factors and biological outcomes.<sup>4 5</sup> Psychosocial factors affect physical and mental well-being<sup>4</sup> and also practical concerns, such as medical

expenditures.<sup>6</sup> The progression or recovery from a disease causes psychological distress and affects the emotions, perceptions and beliefs, as well as the daily lives of patients.<sup>7</sup> Additionally, coping with cancer is not just an individual battle. Patients' caregivers, as well as oncology medical staff, play vital roles throughout the entire journey.<sup>2</sup> Consequently, the demands from caregivers and oncology professionals to understand the psychological and social challenges faced by cancer patients are necessarily significant.

## CHALLENGES ENCOUNTERED BY PATIENTS WITH CANCER

The effects of cancer on patients and survivors are always complex and subtle and can be interpreted from two perspectives: time and function. Patients' and survivors' long interactions with cancer are roughly divided into multiple stages: pre-diagnosis, post-diagnosis before treatment, short-term after treatment, and long-term after treatment.<sup>8</sup> Different stages entail different problems and demands. Regarding the functional domains, cancer results in challenges at the individual level, such as somatic problems, psychological distress, and questioning about spirit and existentialism<sup>3</sup>; and at the interpersonal and social levels, such as the deterioration of social functioning and relationships.<sup>9</sup>

### Deterioration of self-concept

Self-concept is a complex notion that comprises several components. Psycho-oncology research has examined the following subconcepts: self-esteem, body image, self-discontent and self-appraisal.<sup>8</sup>

Self–cancer interaction, which refers to the interaction between an individual's fluctuation of self-concept and the whole process of cancer, is a bidirectional relationship. On the one hand, in the 1990s, researchers stated that cancer not only causes physical pain but may also undermine patients' self-concept. As a chronic disease, some typical aspects of cancer (eg, uncertainty) and cancer treatments (eg, aggressive physical damage) cause patients and survivors to be especially



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vulnerable to changes in their self-perceptions.<sup>10</sup> On the other hand, self-concept was proven to be a dependent and independent variable of the development and progression of cancer, the outcome of cancer treatment, and the adjustment to the illness. For example, low self-esteem is negatively related to social functioning, inducing a reciprocal decrease in self-esteem.<sup>8</sup>

To investigate further, the change in self-discrepancy, which refers to the gap between one's actual self and ideal self,<sup>11</sup> is a critical dimension for understanding self-concept in psycho-oncology. For example, a study found that patients with cancer who exhibited more physical symptoms, had worse health, and perceived their cancer as a chronic rather than an acute disease had higher self-discrepancies. Conversely, low levels of self-discrepancy were correlated with higher life purpose, more positive relationships with others and fewer depressive symptoms.<sup>12</sup>

However, cancer can reconstruct one's self concept in various ways. A qualitative study investigating 26 adolescents and young adult cancer survivors found that 15 regarded cancer as 'part of the past', while another 5 said the 'cancer survivors' identity rarely influenced how they defined themselves in daily life.<sup>13</sup> Therefore, cancer patients' and survivors' self-perceptions should be understood case-by-case in clinical circumstances.

### Body image disturbance

Body image is a direct personal perception and appraisal of one's appearance; thus, body image dissatisfaction may result in severely distorted psychosocial well-being.<sup>14</sup> Cancer may profoundly change a patient's body appearance and function<sup>15</sup> during the different treatment stages because of, for instance, surgical interventions, chemotherapy, radiotherapy and drug use.<sup>16</sup> This could result in scarring, hair loss, body shape alteration, and other temporary or permanent consequences.<sup>17</sup> Fear of change in one's body image begins before surgery or other treatments.<sup>18</sup> Excess concern about this change is detrimental to patients' quality of life and may result in depression, anxiety and overall psychological distress.<sup>18 19</sup>

Although body image issues affect an array of patients with cancer<sup>15</sup>, the most typical and subtle cohorts, such as those with head and neck cancer and female patients with breast cancer, have attracted the most attention in previous research. For example, one study stated that the perceptions of female patients regarding the loss of their breasts were filled with contradictions, tension and uncertainties while negotiating the discrepancy between self, the body, and societal expectations and perceptions of femininity and womanhood.<sup>17</sup>

### Sexual trouble

Sexual dysfunction is one of the most common causes of distress among patients with cancer.<sup>20</sup> It negatively affects the quality of life and, in some instances, is the most difficult aspect for patients with cancer.<sup>21</sup>

Cancer patients and survivors may face sexual problems regardless of the cancer type or treatment.<sup>22</sup> A recent study showed that one-third of adolescent and young cancer patients and survivors reported being dissatisfied with their sexuality, feeling less intimacy and having supportive care needs in this area.<sup>21</sup> Another integrated study using both qualitative and quantitative methods reported that sexual frequency, sexual satisfaction, and engagement in penetrative and non-penetrative sexual activities were reduced after cancer in both men and women.<sup>23</sup> Today, oncologists attribute sexual problems to physical factors, such as the disease and its treatment, as well as other psychological and social factors, such as interpersonal, religious and cultural influences.<sup>22</sup> For example, a Brazilian study of patients with breast cancer reported that in traditional gender cultures where the female body is linked with youth and feminine sexual attractiveness is highly valued, some patients found themselves beautiful but sexually unattractive.<sup>24</sup>

Unfortunately, many cancer patients and survivors are not prepared for potential sexual changes and do not receive the needed information and support.<sup>20 22</sup> A survey of 2657 cancer patients and survivors in the Netherlands indicated that 65% of the respondents needed information about sexuality.<sup>22</sup> Clinical practitioners should note that support for sexual issues needs to be addressed, even when the patients do not have reproduction-related (breast, gynaecological and male reproductive organs) types of cancer.<sup>21</sup>

### Maintaining social relationships

For young, single patients, cancer delayed the initiation of romantic relationships.<sup>25</sup> Moreover, the marriage rate of such patients was lower than that of their siblings and the general population.<sup>26</sup> As for married people, studies showed mixed results of how cancer influences intimate relationships. According to Swensen *et al*,<sup>27</sup> couples affected by cancer expressed more love to each other after the diagnosis than healthy couples. However, marriage problems for both groups did not differ. The couples affected by cancer were found to be less committed to each other after the diagnosis. Other studies indicate that cancer may induce marital distress and decrease the quality of the relationship.<sup>9 28</sup> In a related survey, 13.1% of the respondents complained of facing difficulties in their marriage and sexual lives.<sup>9</sup>

Family relationships, especially those between patients and their caregivers, are significantly influenced by the physical and mental conditions of the patients. A study examining the family types of cancer patients, including the caregivers, found the functioning of the entire family changes because of the illness; most of the families affected by cancer showed a low expressiveness characteristic, followed by supportive and detached family types.<sup>29</sup> In the general dimension of socialising, as cancer patients and survivors encounter challenges such as unemployment, social isolation and rehabilitation,<sup>30</sup> they may experience other related problems, such as social constraints

(avoidance and criticism) and cancer-related loneliness (feeling socially disconnected due to cancer).<sup>31</sup>

### Emotional distress

Being considered a major life stressor, cancer may cause substantial psychological distress as well as mental health disorders.<sup>6</sup> The most common mental health disorders include major depressive disorder, generalised anxiety disorder, adjustment disorder, panic disorder and post-traumatic stress disorder.<sup>32</sup> A poor psychological state is always related to a less satisfying quality of life, decreased psychosocial functioning<sup>33</sup> and a worse prognosis.<sup>34</sup> Survivors with late effects (symptoms caused by advanced cancer) exhibited higher levels of psychological distress, somatisation and anxiety. Higher levels of depression are associated with femininity, not being in an intimate relationship and experiencing late effects.<sup>7</sup>

Many cancers are associated with shame and guilt. Some patients experience disease-related stigma. For example, lung cancer has been proven to be significantly correlated with smoking behaviour; consequently, patients with lung cancer are prone to developing self-stigma and thoughts of self-blame.<sup>34</sup> Due to the nature of the illness, cancer patients and survivors often feel a self-perceived burden.<sup>35</sup>

A study in China found the prevalence of psychological distress accounted for 10.6% and 20.0% in healthy controls and patients with cancer, respectively.<sup>36</sup> Another recently published survey showed that adolescents and young cancer survivors (people diagnosed with cancer when they were young) are more likely to experience psychological distress (11.5% of 1757) than adults with no history of cancer (5.8% of 5227), including 11.2% reporting distress more than 20 years after cancer diagnosis.<sup>6</sup>

### Treatment-related problems

Among the stressors that cause emotional distress, treatment-related problems are exclusive to the medical field, especially in oncology. Based on qualitative and quantitative results, because of fear, individuals may either decide to undergo cancer screening or postpone their hospital visits to seek medical advice.<sup>37,38</sup> Research shows that individuals facing the fear of breast cancer are more hesitant to go for screening. However, social support may be beneficial for making the decision to take screening.<sup>38</sup>

Fear of recurrence (FCR), often defined as 'fear, worry or concern that cancer may recur or progress',<sup>39</sup> is another major challenge faced by patients and survivors. Whereas mild FCR may encourage adaptive health behaviours, severe FCR can result in depression, high levels of anxiety and preoccupation.<sup>40</sup>

### Casual problems

In addition to treatment, problems experienced outside the hospital can be overwhelming. The economic burden of covering the cost of treatment and the maintenance of a satisfactory quality of life is a major problem for cancer patients and survivors.<sup>41</sup> For example, managing related

financial affairs, such as insurance, may present a huge challenge.

In many countries, the distribution of healthcare resources is imbalanced.<sup>30</sup> This means patients may have to travel between cities to acquire the most accurate medical information, higher quality treatment, or specialized surgery conducted by experts. Arranging for transportation and accommodation in a distant city is another casual disturbance.

Prior to their cancer diagnosis, most patients had shouldered some of their families' domestic responsibilities (eg, served as caregivers for elderly members or young children). Following the illness, filling the roles vacated by the patient becomes challenging. Before the illness, the patient may have been part of the workforce, but intense multimodal treatment may prolong the patient's period of unemployment.<sup>42</sup> Many cancer patients who are able to work efficiently choose to return to work. According to a study of oral cavity cancer survivors, 55.2% returned to work after treatment, which positively influenced their post-treatment rehabilitation.<sup>43</sup> However, inadequate support and communication, toxic work environments, discrimination, and negative perceptions of their work performance acted as barriers to the survivors' rehabilitation.<sup>30</sup>

### CHALLENGES ENCOUNTERED BY INFORMAL CAREGIVERS

Based on a systemic perspective, the diagnosis of a life-threatening disease not only affects patients negatively but also carries over to other individuals involved in the patient's recovery, especially those who perform caregiver duties. Informal caregivers are defined as those who typically provide patients with uncompensated home care. Caregiving activities are physically, emotionally, socially and financially demanding.<sup>44</sup> As shortened hospice care has become a trend, outpatient and home care play a vital role in the recovery and rehabilitation of patients. In America, 4.6 million people care for someone with cancer at home.<sup>45</sup>

### Caregiver burden

Caregiver burden is defined as 'the emotional, social, and financial stress that illnesses impose on caregivers'.<sup>46</sup> Although caregivers provide high-value care (estimated at over \$470 billion per year in 2013), their economic burden is severe. Employment is essential to earn income for treatment expenditures and employment-based health insurance coverage.<sup>47</sup> Additionally, one family member's vacancy at least temporarily doubles the duties of other members for addressing the present and future needs of the family.<sup>41</sup>

### Caregivers' health issues

Because caregivers are often intimate family members or friends, it is noteworthy that the disease may also induce psychological distress for them that is similar to that of the patients. According to a systematic review, the prevalence

of depression and anxiety among cancer patient caregivers accounted for 42.3% and 46.6%, respectively.<sup>44</sup> Another meta-analysis revealed that caregiver stress may result in psychological and sleep disturbances and changes in physical health, such as somatic problems, fatigue and insomnia, and in the immune function. These conditions could be ameliorated with proper intervention directed at improving the caregivers' coping skills, knowledge and quality of life.<sup>45</sup>

### CHALLENGES ENCOUNTERED BY HEALTH PROFESSIONALS

In addition to caregivers, oncology professionals, such as doctors, nurses, therapists and other medical staff, also significantly influence cancer patients. They are the main providers of medical information and services and maintain connections with patients and survivors for a prolonged time.<sup>48</sup> Therefore, the communication skills and work performance of this group are critical. However, health-related work is demanding and challenging for these medical professionals, especially with the recent heavier work-related burdens imposed by the coronavirus disease 2019 (COVID-19) pandemic. In Australia, 69.6% (5458 of 7846 participants) of healthcare workers reported they suffer from moderate to severe burnout.<sup>49</sup> A survey of oncology medical staff in Singapore revealed that 49% of the respondents were unable to do their job as well as they did before the pandemic, and 33% were at risk of distress.<sup>50</sup> In another massive survey of oncology professionals across 101 countries, 67% reported changes in their professional duties since the COVID-19 outbreak. Approximately 25% were at risk of distress 38% suffered from burnout, and 66% were unable to perform their jobs compared with the pre-COVID-19 period.<sup>51</sup>

### Patient–doctor communication problem

Patient–doctor communication during a medical consultation involves interaction between doctors, patients and their families regarding the disease, diagnosis, treatment, health restoration and other related factors, such as medical costs and services.<sup>52</sup> Improved communication between healthcare professionals and patients is associated with many positive outcomes, including better objective and subjective health conditions, greater adherence to treatment and medication use, and higher patient satisfaction.<sup>53 54</sup>

Regrettably, doctors may have more optimistic perceptions of their communication skills than their patients.<sup>55</sup> Therefore, a general consensus exists that healthcare professionals should become more empathetic and patient, implement improved communication skills, and be trained to conduct patient-oriented conversations.<sup>54</sup>

Aside from general communication, knowing how to appropriately convey bad news to newly diagnosed patients and their caregivers is another special and challenging issue for oncologists. There are two widely used models: the SPIKES protocol (box 1) established by Buckman in 2001<sup>56</sup> and the SHARE model (box 2) developed by

### Box 1 SPIKES protocol for breaking bad news<sup>56</sup>

- ⇒ **S: setting (setting context and listening skills).**
- ⇒ **P: patient's perception of the condition and seriousness.**
  - ⇒ Ask patients to state what they know or suspect about the current medical problem.
  - ⇒ Pay particular attention to their vocabulary and comprehension of the subject.
- ⇒ **I: invitation from patient to give information.**
  - ⇒ Try to get a clear invitation from the patient to share information.
- ⇒ **K: knowledge explaining the medical facts.**
  - ⇒ Bring the patient towards a comprehension of the medical situation.
  - ⇒ Aligning: use language intelligible to the patient.
  - ⇒ Explain information gradually.
  - ⇒ Check the reception: confirm that the patient understands what you say.
  - ⇒ Respond to the patient's reactions as they occur.
  - ⇒ Explore denial (if present), using empathic responses.
- ⇒ **E: explore emotions and empathise as patient responds.**
- ⇒ **S: strategy and summary.**
  - ⇒ A precise summary of the main topics discussed.
  - ⇒ 'Any important issues or questions that we should be discussing?'
  - ⇒ A clear contract for the next contact.

Japanese researchers Fujimori *et al.*<sup>57</sup> The implementation of these models has been proven to reduce pressure and distress among both patients and medical staff.<sup>57 58</sup>

### Burnout

Burnout is a well-known syndrome comprising three dimensions: emotional exhaustion, depersonalisation and low personal accomplishment.<sup>59</sup> In most cases, burnout occurs as a result of chronic stress.<sup>60</sup>

This syndrome is detrimental to both institutions and individuals. In organisations, long-lasting burnout among staff may result in higher turnover, lower engagement and higher intention to leave, among others.<sup>61</sup> For individuals, it may induce depression, anxiety,<sup>61</sup> anger, interpersonal aggression and poor health conditions.<sup>59</sup> In 2019, the WHO included burnout in its newly revised version of the International

### Box 2 Components and examples of the SHARE model<sup>57</sup>

- ⇒ **S: setting up a supportive environment for the interview.**
  - ⇒ For example, greeting patient cordially, looking at patient's eyes and face.
- ⇒ **H: considering how to deliver bad news.**
  - ⇒ For example, not beginning bad news without a preamble and checking to see whether the rate of talking is too fast.
- ⇒ **A: discussing additional information that the patient would like to know.**
  - ⇒ For example, answering patient's questions fully and explaining second opinion.
- ⇒ **RE: providing reassurance and addressing patient's emotions with empathic response.**
  - ⇒ For example, remaining silent out of concern for the patient's feelings and accepting the patient's expression of emotion.

Classification of Diseases, 11th Revision, stating that it is likely to cause people to contact health services.<sup>62</sup>

Considering the nature of work, people-oriented professionals who support and offer help to others are at higher risk of experiencing job burnout.<sup>48 52 63</sup> Healthcare professionals provide services to recipients and develop therapeutic relationships with them, maintaining ongoing, intense levels of personal and emotional contact. This can be both rewarding and stressful.<sup>60 63</sup> Burnout risk for oncologists is high; a study examining the burnout phenomenon in Chinese early career oncology professionals indicated that this group was at high risk of burnout; 39% of them had already experienced at least one domain of this syndrome.<sup>64</sup> Another systematic review disclosed the incidence of burnout among oncology nurses: they suffered from high-level emotional exhaustion and enhanced feelings of low personal accomplishment.<sup>65</sup>

## CONCLUSION

Cancer patients and survivors may experience detriment to their self-concept, disturbance of body image and sexuality, and deterioration of their social relationships while attempting to cope with daily issues caused by the illness. Furthermore, the burdens of care provision and the health impact on caregivers of cancer patients are noteworthy. Improving patient–doctor communication and overcoming burnout are two major challenges oncology healthcare professionals face. Significantly, if these healthcare professionals were fully aware of the psychosocial obstacles of cancer patients, survivors, and caregivers and reacted appropriately, all involved in the medical care would benefit.

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