
Psychosocial Impact of Cancer

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Abstract

Diagnosis and treatment of malignant diseases affect in many ways the lives of patients, relatives and friends. Common reactions immediately after the diagnosis are shock and denial, frequently followed by depression, anxiety and/or anger. About a third of all cancer patients suffer from a co-morbid mental health condition, requiring professional support by the entire medical team, including psycho-oncologists. Often overlooked issues are financial and social problems due to inability to work or due to out-of-pocket costs for the medical treatment.

Keywords

Distress · Co-morbidity · Burden · Psychosocial aspects · Coping · Financial problems · Return to work

1 Psychological Impact

1.1 Psychological Reaction to the Cancer Diagnosis

After a person hears he or she is diagnosed with cancer, the first reaction frequently is a sort of shock: “It can not be me; they must have mixed up the test results with another person”. For many patients, receiving such a diagnosis is associated with

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the fear of intense pain, loss of control, stigmatisation and death (Holland and Rowland 1989). Getting such a diagnosis therefore feels like a nightmare. Complex processes of denial and subsequent realisation of the truth, often followed by denial again, are seen in those patients.

After a while, depending on the psychosocial resources a patient has, the truth can be faced more fully by the patient. In this phase of coping with disease, people often start fighting and arguing—with their doctors, their relatives, their fate. It is as if they try to overcome the disease by fighting. When they realise this is not possible, it often results in intense feelings of hope- and helplessness which can turn into depression. Not everybody is able to finally accept the malignant disease as part of his or her life.

These phases of coping described above were conceptualised by Elisabeth Kübler-Ross after she had interviewed numerous dying patients (Kübler-Ross 2008). Her concept has been adapted by many authors, and at the same time criticised for not being empirically valid. Indeed, these “phases” can be seen in many patients (and their relatives). There is, however, no certain order of the “phases” which is why we prefer to call them emotional reactions which can occur consecutively or simultaneously.

1.2 Denial

Denial allows the patient to keep reality away from the consciousness until he or she is able to deal with it. Clinicians should be aware of the fact that this is a natural process of the psyche to keep ones psychological structure alive. At least in the beginning of the cancer trajectory, patients and relatives should get enough time from the medical team until they can refrain from denial. It is not advisable to push them into the truth too fast.

However, continuing denial can be a challenge in oncology, as patients often need to be treated within a short period of time. One should avoid “breaking the denial” by aggressive instructions about the disease and its treatment. This will only result in aggression and anger, be it openly expressed or more silent. Patients may also be in danger of mental decompensation.

Example:

A 58 year old man suffered from a brief reactive psychosis while he was at the intensive care unit. He had a vision of being at a space ship. He was the captain and responsible for the ship, but the cockpit was not functioning, he could neither steer it nor slow it down, it was a nightmare. It turned out that he had been informed about his diagnosis of pancreas carcinoma quite forcefully, and his coping abilities were obviously not strong enough to deal with it at this moment.

A better way of supporting the patient in getting over his denial is to (a) strengthen his psychosocial resources and (b) avoid denial in ones own perspective. Healthcare providers should try to be neutral and not joining the patient in his or her denial. It is often challenging to not do this because it is seductive,

especially when treating young patients, to just avoid the idea of pain and potential death. However, if the patient feels that his carers deny his situation he will be even more convinced that his fate is horrible and that he cannot deal with it (if not even the “professionals” can deal with it!). This can also make the patient feel alone with his fears. So, if the healthcare provider can accept the patient in his denial and at the same time be prepared to also talk about distressing topics such as the danger of functional impairment, losses and death, it will support the patient to overcome his denial.

Example:

My patient is a 40 year old single mother. She received the diagnosis ovarian cancer 5 years ago and I had been seeing her since then. While she first wanted to see a psychologist to identify psychological causes of her disease with the aim of then changing her life accordingly to be cured from cancer, she was faced with multiple metastases in her entire body. Still, she thought that psychotherapy can cure her and she asked me to help her visualize her blood and cancer cells because that is what she had read in a book.

I saw her emotional suffering and wanted to support her, at the same time I knew that she had a tumour with a poor prognosis, she had multiple metastases, and she was admitted to the palliative medicine ward at our hospital. Her daughter was 15 years old, the patient described her ex-husband as being alcohol dependent, so she did not want her daughter to live with him.

The patient seemed torn between the hope of cure and the realisation of nearby death, but the truth was too hard to bear so she denied it and seemed to force all others to share this denial with her. Her physician told me about her refusal to find a solution for her daughter, which needed to be resolved since she was facing death.

During our next session, the patient told me in tears that her parents said to her: “Girl, make sure you get better soon”. When she wanted to talk with them about her fears, they both said: “Don’t say this, you will get better!” This obviously did not help her, as she felt utterly alone. In this situation, I decided to openly ask the patient about her feelings regarding death and dying. No one from the team had done this before, because of feeling sorry for the patient and because she seemed to refuse any conversation about it. However, the patient now reacted relieved. We talked about dying, her experiences with death, her ideas about what happens thereafter, and finally about her daughter living without her.

The patient deceased two weeks later.

This example shows that, although patients often deny, they can at the same time talk about distressing topics if they experience a supporting relationship with someone they trust and who is not in denial himself.

1.3 Co-morbid Mental Health Conditions

At times, psychological distress can be severe for cancer patients, resulting in clinically relevant mental health conditions. Numerous studies have investigated the frequency of these conditions in cancer patients over the past years.

Several meta-analyses and large multicentre studies have shown that, during the time of cancer diagnosis, about 30% of the patients suffer from a mental health

condition (Singer et al. 2010; Mitchell et al. 2011; Vehling et al. 2012; Mehnert et al. 2014; Kuhnt et al. 2016). Less is known however about the course of those conditions during the cancer trajectory. Available evidence suggests that their frequency does not decrease considerably over time (Bringmann et al. 2008; Singer et al. 2016).

Known risk factors for mental disorders in cancer patients are pain, high symptom burden, fatigue, mental health problems in the past and disability (Akechi et al. 2004; Rooney et al. 2011; Banks et al. 2010; Agarwal et al. 2010). There are no consistent correlates of depression in cancer patients (Mitchell et al. 2011).

In some studies, alcohol dependence was more common in men (Matheson et al. 2012; Dawson 1996; Kessler et al. 1994; Bronisch and Wittchen 1992; Krauß et al. 2007) and in patients with malignancies in the head and neck, oesophagus and liver (Shimazu et al. 2012; Freedman et al. 2007; Hashibe et al. 2007; Kugaya et al. 2000).

Not only does psychiatric co-morbidity represent enhanced distress of the patients calling for specific support from the medical team, it also increases the length of hospital stay (Wancata et al. 2001) and negatively affects survival, if not treated adequately (Kissane 2009; Pinquart and Duberstein 2010). It is, therefore, highly important to identify patients suffering from mental health disorders as soon as possible. Unfortunately, healthcare providers often fail in identifying these patients (Singer et al. 2011a; Absolom et al. 2011; Fallowfield et al. 2001; Söllner et al. 2001), resulting in severe under-treatment (Singer et al. 2005, 2011b; Schwarz et al. 2006; Oliffe and Phillips 2008; Stoppe et al. 1999; Werrbach and Gilbert 1987; Wilhelm 2009).

In a large prospective study with cancer patients, we found that of those with mental health conditions, 9% saw a psychotherapist within three months of the diagnosis, 19% after nine months and 11% after 15 months. Mental health care use was higher in patients with children ≤ 18 years (odds ratio 3.3) and somatic co-morbidity (odds ratio 2.6) (Singer et al. 2013a). Interestingly, in this study, uptake of mental health care was equal between men and women, in contrast to findings from studies in the general population (Oliffe and Phillips 2008; Stoppe et al. 1999; Werrbach and Gilbert 1987; Wilhelm 2009). The admission to mental health care did not differ in patients with different educational attainments.

1.4 Potential Positive Impact

During the last decade, increasing interest has been given to potential benefits of the experience of cancer despite it being challenging and often highly distressing, i.e. whether traumatic experiences can lead to emotional growth in patients and relatives (Hungerbuehler et al. 2011; Kahana et al. 2011; Kim et al. 2011; Love and Sabiston 2011; Demirtepe-Saygili and Bozo 2011; Fromm et al. 1996). Such posttraumatic growth has been defined as positive psychological change experienced as a result of the struggle with highly challenging life circumstances (Calhoun et al. 2000; Calhoun and Tedeschi 2001). It describes the experience of individuals whose development has surpassed what was present before the struggle

with the crises occurred, i.e. people feel that they did not simply “go back to life as usual” but that they feel enriched, wiser, grown, etc. after the crisis.

According to Tedeschi and Calhoun (2004), positive changes can be found in five dimensions, representing different types of posttraumatic growth: greater appreciation of life and changed sense of priorities; warmer, more intimate relationships with others; a greater sense of personal strength; recognition of new possibilities of paths for one’s life; and spiritual development (Tedeschi and Calhoun 2004).

Individuals’ experience of posttraumatic growth depends on several predictors. Many facilitating factors have been reported: younger age, female gender, low consumption of alcohol, low levels of pessimism and depression, high life satisfaction, high levels of extraversion, having an active sexual life and receiving counselling (Cormio et al. 2010; Milam 2004; Mols et al. 2009; Paul et al. 2010; Sheikh 2004; Jansen et al. 2011; Barskova and Oesterreich 2009). Benefit finding, a concept similar to posttraumatic growth, depends on the amount of time that has passed since stressor onset, the instrument used and the racial composition of the sample (Helgeson et al. 2006).

To date, only a few studies have investigated whether or not psychosocial interventions can help to increase posttraumatic growth after traumatic events or serious illness. Especially in cancer patients, evidence is scarce. Own research has shown that art therapy once weekly over a period of 22 weeks in the outpatient setting did not increase posttraumatic growth (Singer et al. 2013b). This finding is in accordance with scepticism towards the concept of growth in the context of adversity, including serious illness, and towards positive psychology in general (Coyne and Tennen 2010).

2 Social Impact

Human beings are social beings. We all share our lives with others and are closely related to others, willingly or unwillingly. This implies that a malignant disease not only affects the psychological aspects of one’s life but also social relations. Both dimensions are closely intertwined.

Being a part of a society implies a certain status within that society. That status shapes the image one has and increases or decreases the possibilities to exchange goods. In high income countries, social status usually is defined by income, educational attainment and employment, which is why the term preferred by sociologists is “socio-economic position”. Each of these three factors defining this position can be changed by a malignant disease.

2.1 Socio-economic Position

Low socio-economic position is known to be associated with poor health on the one hand and with less access to health care on the other (Williams 2012; Garrido-Cumbrera et al. 2010; Korda et al. 2009; Habicht and Kunst 2005; Celik and Hotchkiss 2000; Jenkins et al. 2008; Lorant et al. 2007; Weich et al. 2001; Weich and Lewis 1998; Singer et al. 2012). The socio-economic position may even decrease after a cancer diagnosis, especially in younger patients if they lose their jobs due to cancer-caused disability (Banks et al. 2010). On the other hand, it is also possible that social problems may decrease or even disappear after a cancer diagnosis, for example, if a previously unemployed person receives a pension due to disability.

Vocational rehabilitation of cancer patients differs remarkably between countries. For example, while in Scandinavia about 63% of all patients returned to work after a total laryngectomy (Natvig 1983) and 50% did so in France (Schraub et al. 1995) only 11% could return in Spain (Herranz and Gavilan 1999). Predictors of successful return to work are flexible working arrangements, counselling, training and rehabilitation services, younger age, educational attainment, male gender, less physical symptoms and continuity of care (Mehnert 2011).

Similarly, patients' financial burden depends largely on the country's social system and healthcare insurances. Specific problems are the so called "out-of-pocket-health payments". These are expenses the patient has because of the disease and/or its treatment that are not reimbursed by insurance. In the US, breast cancer patients ($n = 156$) who were insured (either by Medicare, Medicaid, or privately) reported that they spent 597 dollars per month for direct medical costs (e.g. stay at a hospital) without reimbursement, 131 dollars for direct non-medical costs (e.g. transport to the hospital, salary for baby sitters etc.) and 727 dollars for indirect costs (e.g. loss of money to do reduced income) (Arozullah et al. 2004).

Regarding the course of financial problems, findings are mixed. In a group of German cancer patients at the time of cancer diagnosis ($n = 799$), 41% reported having financial difficulties due to the disease while this was increased to 52% half a year after diagnosis (Schwarz and Singer 2008). Similar trends were seen in the US (Arozullah et al. 2004) while others found decreasing (Tsunoda et al. 2007; Arndt et al. 2005) or persisting problems (Sullivan et al. 2007).

Financial difficulties can occur not only in the patients but also in the supporters. There are findings showing that especially male support persons and support persons of survivors in active treatment experience increased expenses (Carey et al. 2012).

2.2 Social Relations

Social relations can be a source of great joy and happiness, but also of heavy conflicts and despair. Most patients experience very good social support, especially at the beginning of the cancer treatment trajectory. Family and friends often spend a

lot of time and energy to support the patient. If social support is lacking though, it often leads to increased distress (Mehnert et al. 2010).

At times, social support is experienced negatively, especially if relatives or friends are overprotective implying that the patient is not able to care for himself anymore (Bottomley and Jones 1997). This should be kept in mind in clinical practice. For example, if a breast cancer patient has a husband this does not necessarily mean that she receives more support than a single patient. Clinicians should ask patients how they perceive their support and whether they need help with their social life or not.

Another aspect of social relations should be mentioned here: the desire to have children. In younger patients, family planning can be a challenge, especially in patients receiving chemotherapy or anti-hormonal therapy. Doctors should inform them about future possibilities of getting children and about potential alternatives. If patients cannot have children any more although they wished to, this is often experienced as a great loss and the psychosocial and medical team should treat that accordingly.

In conclusion, the impact of malignant diseases on social and psychological aspects of patients' and relatives' daily living can be tremendous. Healthcare professionals should be equipped with the willingness and competence to address these issues and approach patients actively, offering help and support. If patients do not want that help at a given time, it may be wise to offer it later again. Of course, patients should have the freedom to decline psychosocial support from the professionals, however, it might be that they decline out of denial or because it is the only thing they can decline during the time of their cancer treatment. For these reasons, it is good to offer support more than once during the illness trajectory.

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