

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

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ABSTRACT

Cancer, being a life-threatening disease, gives rise to mental tension, anxiety, and sometimes even depression. Most of the research regarding this topic is focused on patients so I have incorporated caregivers and survivors into my study. While research shows that mental concerns around cancer exist, the practice of seeking professional mental help is not very widespread. This paper explains the problems, ways to diagnose, tools used as well as general fears and worries. As a part of my study, I not only provide data for the prevalence of psychological problems but also include the patients' and caregivers' experiences at various stages. Dr. Rakesh, an oncologist, has also provided his expertise and experience for this study.

Keywords: *Cancer, Caregiver, Survivor, Patient, Behaviour, Illness*

Cancer can be dangerous, both physiologically and psychologically. While the physiological effects are known to all, not much attention has been given to the impact cancer can have on well-being. The APA defines well-being as a state of happiness and contentment, with low levels of distress, overall good physical and mental health and outlook, or good quality of life. The general understanding, for several years, was that cancer did not affect family members as they were not diagnosed with the disease. Years of studies dedicated to this proved that cancer did, in fact, have an impact on caregivers as well as the patients. The factors that affect psychological distress include the type of cancer, time since diagnosis, degree of physical and role impairment, amount of pain, prognosis, and other variables. (National Academies Press (US), 2008.) Gender also plays a key role in the psychological distress of patients and caregivers. Female patients and female caregivers report more distress than their male counterparts. (Northouse, 2012) Female caregivers, however, have the highest distress of all (Northouse, 2012). While many do not classify cancer as trauma (i.e., to say that it does not develop into PTSD except in a few cases). However, cancer does impact one's mental health. The mood and anxiety disorders associated with cancer are 1) Depression 2) Delirium. Depression (major depressive disorder) is a common and serious medical illness that, to put it in simple words, negatively affects how one feels, thinks, and acts. Depression may result in significant weight loss or gain, insomnia or excessive sleeping, lack of energy, inability to concentrate,

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Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

feelings of worthlessness or excessive guilt, and recurrent thoughts of death or suicide. A recent systematic review noted the prevalence of depression as 5% to 16% in outpatients, 4% to 14% in inpatients, 4% to 11% in mixed populations, and 7% to 49% in palliative care (Yuppa, Braun, Meyer, 2014). Delirium is a serious disturbance in mental abilities that results in confused thinking and reduced awareness of the environment. Rates of major depressive disorder are thought to be up to three times higher than in the general population. (Park, E. M., & Rosenstein, D. L. ,2015). However, the impact of cancer on well-being is not limited to disorders. Cancer brings along with itself several fears and worries that also affect the patients and caregivers. The most prominent among these are the fear of recurrence and the fear of death. To assess the existence and prevalence of anxiety, various psychological tools are used. For e.g., Distress Thermometer, Problem list. Patients may have to undergo treatment for their psychological distress as well. These treatments range from support groups to psychotherapy and pharmacotherapy. Many survivors and caregivers show positive growth post-cancer, popularly referred to as post-traumatic growth. It refers to the positive life changes that develop due to a frightening or threatening phase. This positive change is mostly a result of coping strategies. A coping strategy, according to APA, is an action, a series of actions, or a thought process used in meeting a stressful or unpleasant situation or in modifying one's reaction to such a situation. Coping strategies typically involve a conscious and direct approach to problems. The most prevalent coping strategies among cancer patients are religion/spirituality and acceptance of the situation.

Through this paper, I would explain the effect of cancer on both, the survivors, and the informal caregivers (family members, partners, loved ones). This paper also explores why anxiety and mood disorders develop and why post-traumatic growth occurs.

Mood And Anxiety Disorders

Introduction

The impact of cancer on a person's psychological well-being can translate into mood and anxiety disorders. The most common disorders prevalent among cancer patients are depression and delirium. Depression is a mood disorder that causes a persistent feeling of sadness and loss of interest. Delirium is a serious disturbance in mental abilities that results in confused thinking and reduced awareness of the environment. The start of delirium is usually rapid — within hours or a few days. Delirium can often be traced to one or more contributing factors, such as a severe or chronic illness, changes in metabolic balance (such as low sodium), medication, infection, surgery, or alcohol or drug intoxication or withdrawal.

Symptoms

- A few common symptoms for anxiety and depression include (Trill,2013)
- irritability
- difficulty falling asleep (leads to fatigue and low tolerance to frustration)
- recurring, intrusive thoughts and images of cancer
- helplessness and a sense of loss of control over one's own feelings
- Symptoms for delirium include:
 - agitation
 - change in behaviour and mood
 - Difficulty paying attention

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

Factors

Older patients show a higher prevalence of anxiety and depression which suggests that there is a significant relationship between anxiety, depression, and the age of the patient. (Nikbakhsh N, Moudi S, Abbasian S, Khafri S.,2014) Another factor that influences depression among patients is the severity of cancer and symptoms, including pain and fatigue. (Spiegel Giese-Davis, 2003) The prevalence of depression associated with cancer differs according to the type of cancer as well. Breast cancer patients are frequently diagnosed with anxiety and depression and are often undertreated. (Montel, 2010) However, the following are not found to have any consistent effect on anxiety among cancer patients: gender, marital status, social class, and education (Remes, Brayne, Linde, Lafortune, 2016)

Despite the physical burden, caregivers experience more disruptions to their mental health than their physical health. (Kent EE, Rowland JH, Northouse L, et al.,2016) For caregivers, the presence of cancer itself is a dominant source of depression and anxiety while other factors may exaggerate the symptoms. A few of these factors are relationship and communication between caregiver and patient, caregivers' social, economic, and psychological attributes, caregiver's health, and caregiving duration. (Geng, H. M., Chuang, D. M., Yang, F., Yang, Y., Liu, W. M., Liu, L. H., & Tian, H. M. ,2018).

Prevalence

In a study by Pasquini and Biondi, 45 patients were administered SCID-I, (the Structured Clinical Interview for DSM-IV). 20 out of these 45 patients showed adjustment disorders. Depressive disorders were observed in 14 and anxiety disorders in 3 patients. (Pasquini, M., Biondi, Costantini, Cairoli, Ferrarese, Picardi, Sternberg ,2006). Another study (2014) by Moudi, Khafri, and others showed that 29.3% of patients had mild anxiety, 16.7% had symptomatic anxiety. While 26.7% of patients had mild depression, 21.3% of patients had symptomatic depression. (Nikbakhsh, N., Moudi, S., Abbasian, S., & Khafri ,2014).

5-85% of cancer patients develop delirium which varies according to age, level of physical disability, and stage of disease (Lesko & Holland, 1988). Delirium is present in 26%–44% of advanced cancer patients at the time of admission to an acute care hospital or palliative care unit. It is seen that during the last hours and days before death, 80% of patients (in advanced cancer) develop delirium. (Northouse, Katapodi, Schafenacker, Weiss,2012) (Pereira J, Hanson J, Bruera E.,1997) (Bush, Bruera, 2009)

The prevalence of anxiety and depression in cancer patient caregivers, as measured with validated instruments, is approximately 47% and 42%, respectively. (Geng, H. M., Chuang, D. M., Yang, F., Yang, Y., Liu, W. M., Liu, L. H., & Tian, H. M. ,2018). A study of anxiety and depression among caregivers in Korea showed the following results: Mild anxiety - 20.3%, Moderate Anxiety - 13.3%, and Severe Anxiety - 4.6%. The prevalence of depression was 82.2%. (Park, B., Kim, S.Y., Shin, JY. et al., 2012)

The results of these studies prove that anxiety and depression is common in the cancer community, among both, the patients, and the caregivers. Delirium is mostly seen in cancer patients.

Impact

Depression also impacts immunological function, which may have an impact on cancer surveillance. This gives evidence of a bidirectional association between cancer and depression, which opens new therapeutic possibilities.

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

Delirium affects a patient's judgment. Unusual behaviour is often observed, for instance, mood changes. Agitated delirium increases the frequency of conflict between the palliative care team and the patient's family (Breitbart W, Gibson C, Tremblay A., 2002)

Caregivers also have a high prevalence of anxiety and depression that impacts the overall quality of their life. Quality of life is related to overall mental health. (Geng, H. M., Chuang, D. M., Yang, F., Yang, Y., Liu, W. M., Liu, L. H., & Tian, H. M. ,2018). Poor quality of life for caregivers is marked by more emotional distress and low improvement of patients' performance. (Weitzner MA, Jacobsen PB, Wagner H, Jr, et al.,1999)

Tools

- Cancer patients are screened for anxiety and depression using various tools that include Distress Thermometer, Hospital Anxiety and Depression Scale, Problem List, and Patient Health Questionnaire. Systematic screening of cancer patients has two advantages:
 1. Promotion of equal access to psychological
 2. Mental health staff can easily forecast their workload

Distress Thermometer

The distress thermometer is an effective screening tool to identify symptoms of distress. Mostly, a distress thermometer is administered to cancer patients. It can be administered orally or can be printed. It consists of a line with a scale ranging from 0 to 10. The scale is labelled with 'no distress' at the 0 mark and with 'Extreme distress' at the 10 marks. The words 'moderate distress' and 'severe distress' are also present as anchors at specific sites between the 0 and 10 marks. The distress thermometer is a self-reported scale wherein the person taking it must rate how distressed they felt in the past week. A score of 4 or above is treated as significant. 4 or 5 indicates mild distress, 6 to 7 indicates moderate and a score of 8 or higher is severe distress. It is advised to not use the distress thermometer as a standalone tool. This is why it is usually accompanied by the Problem List to determine the source of distress. When a patient rate their distress a 4 or above, a further screening should be added. (Recklitis, C.J., Blackmon, J.E. and Chang, G. ,2016) (Alex J. Mitchell,2007). Hence, a score of 4 or above is treated as a cut-off score. (Donovan KA, Grassi L, McGinty HL, Jacobsen PB,2014). However, a recent study suggests that the cut-off score is 3 or above. (Cutillo, A., O'Hea, E., Person, S., Lessard, D., Harralson, T., & Boudreaux, E. ,2017). The Distress Thermometer is easily administered, requiring only 2 minutes and 20 seconds for a nurse to help a patient complete the tool (Musiello, Dixon, O'Connor, Cook, Miller, Petterson, Saunders, Joske, Johnson,2007). The distress thermometer has significant reliability. It can be easily translated into other languages. It can be used to determine if a patient requires further screening. However, a disadvantage of this tool is that it lacks sensitivity. It is less specific as compared to structured clinical interviews. The DT has shown a large number of false positives which is why it is not suggested to use DT as a standalone tool.

Problem List

The Problem List is usually administered to cancer patients along with the DT. While the DT identifies 'how much' distress a person experience, the Problem List identifies 'what' distress a person experience. The purpose of the Problem list is to identify the sources and causes of distress for the patient. It consists of 39 items which include potential sources of distress. This list is highly organized and comprehensive. Its categories include practical, family, physical, emotional problems, and spiritual/religious concerns. It is seen that

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

patients with distress usually identify the source of their distress under the category of emotional problems. Within this category, 'worry' is the most frequently selected item. Other prevalent sources include trouble with sleep(physical) and nervousness (emotional) (VanHoose, L., Black, L.L., Doty, K. et al.,2014). There is a trend observed where patients who report a score of 4 or more on the distress thermometer usually choose a large number of items on the Problem list.(Clover, K.A., Oldmeadow, C., Nelson, L. et al.,2016)

HADS

HADS or the Hospital Anxiety and Depression Scale is a scale that is usually administered in a 'hospital' setting. However, a few studies show that they can also be used in community settings and primary medical practice. HADS is also very easy to administer, taking around 2 to 5 minutes. The HADS also aims to know how a patient has felt in the past week, so it is administered at not less than weekly intervals. It consists of 14 items, 7 for anxiety and 7 for depression. It essentially contains two parts: HADS-A for anxiety and HADS-D for depression. The items of anxiety and depression are mixed in the questionnaire, but they are separated while the scores are being assessed. A key feature of HADS is its focus on non-physical symptoms which allows us to diagnose depression in people who have significant physical ill-health. Cut-off scores are available for quantification, for example, a score of 8 or more for anxiety has a specificity of 0.78 and a sensitivity of 0.9, and for depression, a specificity of 0.79 and a sensitivity of 0.83 HADS is especially beneficial for initial diagnosis and then to track the growth of psychological symptoms.

PHQ

Patient Health Questionnaire or PHQ-4 is a tool used to diagnose depression and anxiety. PHQ-4 has 4 items, two for anxiety and two for depression, and uses the 4-point Likert scale for scoring. The main purpose of PHQ is to accurately identify the core symptoms/signs of depression and anxiety. It does so by combining the two-item measure. The PHQ uses a cut-off point of 3 for optimal sensitivity and specificity. Like the Distress Thermometer, PHQ can also not be administered as a stand-alone test.

Treatment

Cancer is usually treated with the help of psychotherapy or pharmacotherapy or psychotherapy and pharmacotherapy together. Another technique called relaxation techniques has been especially helpful for cancer patients who are already undergoing cancer treatment. Even support groups can have a positive effect on a cancer patient undergoing a mental illness.

Psychotherapy

Psychotherapy is also known as talk therapy, which suggests that its foundations lie in dialogue. Psychotherapy requires psychologists to apply scientific procedures to help people. The purpose of psychotherapy is to assist people who are going through a mental illness or any other emotional problem. Psychotherapy focuses on the symptoms. Through psychotherapy, mental illness or disturbance-causing symptoms are eliminated or controlled. A few approaches to psychotherapy are Cognitive-behavioral Therapy or CBT, Integrative Therapy, Humanistic Therapy, and Psychoanalysis. Psychotherapy is extremely beneficial. Around 75 % of people who take to psychotherapy benefit from it. The relationship between the psychologist and an individual is of utmost importance. It is essential for a psychologist to be objective and non-judgemental so that they can establish a safe and supportive environment for the individual. It is a collaborative treatment, wherein

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

both the psychologist and the individual together identify and try to change thought and behavior patterns.

In Cancer

Psychotherapy for cancer patients is a little more specific. It includes the illness-related issues in the initial stages, a combination of supportive and interpretive therapy, and special issues pertaining to transference and countertransference field. (Postone,1998) A study showed that psychotherapy did have a positive effect on the quality of life and in the coping process of cancer patients. It also showed that psychotherapy led to reduction in distress, anxiety and depression. (Chong Guan N, Mohamed S, Kian Tiah L, Kar Mun T, Sulaiman AH, Zainal,2016)

Caregivers also undergo stress, and this may result in a mental illness. This is why even they require treatment. Caregivers can benefit from Interpersonal therapy, Supportive therapy, cognitive behavioural therapy, and psychoeducation. (Applebaum, A. J., & Breitbart, W., 2013). Meaning-Centred Psychotherapy (MCP) is a structured psychotherapeutic intervention. It was originally developed for patients but now it is being developed for caregivers as well. It will be called Meaning-Centred Psychotherapy for Cancer Caregivers (MCP-C). (Applebaum, A. J., Kulikowski, J. R., & Breitbart, W. ,2015). It includes new therapeutic approaches designed to enhance meaning, spiritual well-being, and quality of life. (Thomas, L. P., Meier, E. A., & Irwin, S. A. ,2014). A number of studies have showed that psychotherapy increases cancer survival and improves overall quality of life. (Spiegel D.,2013)

Pharmacotherapy

Pharmacotherapy is the treatment of a disorder by the administration of drugs. It uses antidepressants to treat the patients. It deals with the chemical and biological aspect of the brain. Studies show that cancer related depression is treated best when psychotherapy and pharmacotherapy are combined. (Keller MB, McCullough JP, Klein DN, Arnow B, Dunner DL, Gelenberg AJ et al.,2000) (Thase ME. ,1997)

Relaxation Technique

Relaxation techniques are techniques taught to patients to reduce the stress that accompanies cancer, also known as the cancer burden. Relaxation techniques include:

- **Meditation:** There is no one particular way to meditate. While some practise mantra meditation, others use prayers. The purpose of meditation is to help the mind relax.
- **Mental Imagery:** This stress-reduction technique combines breathing and meditation. The individual is asked to imagine a scene or landscape that brings them happiness or joy.
- **Muscle Relaxation:** Muscle relaxation techniques help ease the physiological side-effects of cancer that leads to nausea and vomiting. Relaxation techniques require very little time to teach. Relaxation therapy has evidently helped patients with anxiety symptoms. Although these techniques reduced tension, depression and anxiety, very few cancer treatment programs include these as a part of their programs.

Fears And Worries

Cancer brings with itself several fears and worries, for both the patients and the caregivers. These fears and worries are often the cause of the distress seen in the cancer population.

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

When assessed, 25% to 60% of cancer patients show distress. (Zabora J, Brintzenhofe Szoc K, Curbow B, Hooker C, Piantadosi S.,2001) The most prevalent reasons or causes of this distress are financial burden (Khera Nandita, Holland Jimmie C, Griffin Joan,2017) (van der Geest I M, van Dorp W, Pluijm, van den Heuvel-Eibrink M M,2018) fear of recurrence, fear of death. Many patients and caregivers report more specific worries such as loss of body image, fear of loss of relationships, and loss of control. (M.Gorman,2013) Perceived lack of a personal support system, having a more advanced illness, and viewing the physician as being unsupportive were a few factors that led to the fears. (M. Gorman,2013)

Fear Of Recurrence

Fear of recurrence is a fear that develops both, in survivors and caregivers, wherein they anticipate that they will get diagnosed with cancer another time. It is defined as fear, worry, or concern relating to the possibility that cancer will come back or progress. (Lebel S, Ozakinci G, Humphris G, et al. ,2016).Recurrence of cancer can happen at the same site, near the site, or metastasize to a distant site. (M. Gorman,2013). Fear of recurrence is especially seen in long-term survivors (Gill et al., 2004). Studies show that 31-52% of cancer patients experience FCR. These studies also showed that 24-40% of them have expressed moderate to high levels of need for help with coping with fear. (M. Gorman,2013) (Pasacreta, Minarik, and Nield-Anderson ,2001). Another study (Frost et al, 2000) noted that recurrence was associated with less hope, more uncertainty and constant symptom distress.

Factors affecting the fear of recurrence are

- **Age:** Younger people tend to have a greater FCR. (K. Härtl, Janni, Kästner, et al 2003)
- **Gender:** Females show a greater fear of recurrence (Simard, S., Thewes, B., Humphris, G. et al.,2012)
- **Treatment:** Studies revealed that patients who have undergone treatments such as mastectomy, radiation or chemotherapy resulted in the patients experiencing more FRC. (Koch, L., Jansen, L., Brenner, H. and Arndt, V. ,2013) Yang, Y, Cameron, J, Humphris, G., 2017) (Yuan Yang, Yunhong Wen, Carolyn Bedi, Gerry Humphris,2017)

Fear Of Death

Fear of death is often termed as the fear of the unknown. This fear takes the form of concerns about family's well-being, person's personal career, body image issues. This fear is also seen in caregivers. The fear in caregivers arises due to the patient's own concerns as well as their concern for the patient. Caregivers' fear arises from the thought of losing their loved one. Doctors, who break the news, also have a troublesome time with the thought of death, though this is not necessarily the fear of death. A study shows that 21.7% of cancer patients experience fear of death. (Ali, Shahid, Osmany, Khan, Waheeda; Mishra, Deepti,2014)

The word 'cancer' itself arouses anxiety in people so it is very common for a patient to think of it. A study examined the fear of death in children who are diagnosed with cancer. It showed that children with cancer must be in contact with their parents to have social support. Otherwise, they may develop separation anxiety that could translate into fear of death.

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

To help patients experiencing the fear of death, the existence of an active support system is essential. Some people do feel comfortable if they are given realistic evidence and information about their condition. Spirituality and faith can play a major role in helping with the fear of death. A study showed that questioning patients with advanced diseases about spirituality had a calming effect on the patients. They concluded that such questions were both safe and important.

Fear Of Loss of Relationship

Fear of loss of relationship is seen among caregivers. It also stems from the fear of death. This fear is especially seen in the first two stages of the Kubler-Ross Grief cycle where one thinks of the death of the patient and experiences sadness or anger or both. The fear is higher for caregivers who live with the patient like children or spouse (M. Gorman, 2013). The caregivers start experiencing this loss when the patient is in the early stages itself. They experience life without the patient as many times the patient is confined to their room, resting to reduce weakness etc. As the caregiver sees and experiences less of the patient, they start developing more of the fear by thinking of life without them. In the initial time after diagnosis, they may also feel detached from the person. Loss of relationship also means that the caregiver is afraid of losing the relationship between them and the patient. The relationship could be one of protection or affection. This is to say that the person is scared of losing their role as a friend, a husband, a wife, a parent, etc. On the other hand, patients too fear the loss of their relationships, subsequently leading to loneliness (Worden, 2000). Another fear that stems from this is the fear of abandonment experienced by the patient. They fear that as their cancer is progressing, their loved ones would abandon them. This would lead to them losing their relationships as well as feeling lonely.

Body Image Issues

The treatment for various cancers can affect the patient's physical traits. Chemotherapy, as we all know, results in loss of hair. Treatments for breast cancer and oral cancer also have effects on physical features. Breast cancer patients express concerns with weight. Body image issues are highly prevalent in head and neck cancer patients as well due to visible disfigurement. A study showed that 75% expressed concerns over their bodily changes. (Fingeret, M.C., Yuan, Y., Urbauer, D., Weston, J., Nipomnick, S. and Weber, R., 2012). This very study also highlighted that the patients were not satisfied with the care they received for their body image issues. The psycho-oncology community needs to do more with respect to resources and training to handle body image issues. This modification in one's body may lead to a fear or anxiousness in the patient about their body image. They may feel like they are 'worthless' or 'unlovable' or they might not feel like themselves in their body. This may make them less confident and embarrassed. Body image issues are linked with loss of identity as well. Patients sometimes do not feel comfortable in their own body which makes them question their identity. Loss of identity can also be more subjective when it is related to one's interest, skills, dependency, or dignity.

Fear Of Loss of Control

Loss of control is experienced by both the patients and caregivers in a variety of ways. Due to the weakness and fatigue associated with the disease and its treatment, patients are not as able to carry out daily routine tasks. This might cause loss of control over their life and routine. Another loss of control is experienced with respect to the disease itself. When the disease keeps progressing and the patient is not able to fight it as well, they might experience loss of control of the cancer. Feelings of guilt and worthlessness dominate this experience of loss. The caregivers face a similar loss of control when the disease is

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

progressing and they are not able to stop it. Anger is an emotion that is generally seen in caregivers experiencing this emotion. They might also experience loss of control in their personal lives when they find themselves not able to have a strict control on their routine, sleep and other interpersonal relationships.

Coping Strategies

By now, we all know that cancer causes distress among both, the patients, and the caregivers. To overcome or manage this stress, they all use various coping strategies or mechanisms. Coping strategies are divided into two broad categories: problem-focused strategies and emotion-focused strategies. A study shows that the most commonly used strategy by patients (or survivors) were fatalism and fighting spirit. (Boyes AW, Girgis A, Zucca AC, Lecathelinais C.,2009) Among caregivers, the most common strategies were (a) planful problem-solving; (b) seeking social support, and (c) self-controlling. (Evriliki Papastavrou, Andreas Charalambous, Haritini Tsangari,2012). A lot of people also use physical exercise such as yoga, jogging, etc as a mechanism. Another prevalent strategy is belief in religion and spirituality. With the use of effective coping strategies, people can experience PTG or Post-traumatic growth. The coping strategies do not remain the same throughout. They vary with time, situation, and stage of cancer.

Spirituality makes people connect with themselves and gives them a greater sense of peace and inner strength. Hence, spirituality works as a great effective coping strategy for cancer patients. When people are diagnosed with cancer, they often have a question- “Why me?”. They directly relate their illness to their life deeds and frequently they feel that they must have ‘deserved’ it. Faith and religion are especially beneficial in these scenarios. Using the Spiritual well-being state and the State-Anxiety Trait Inventory, a study proved the long-existing theory that people with high spirituality show low levels of anxiety. Spirituality is one of the most prevalent coping strategies used, along with music. (Christine Zaza, Scott M. Sellick & Loretta M. Hillier ,2005)

Maintaining hope and optimism also relates to spirituality. Cancer is a life-threatening disease, but it can be cured. This is why it is extremely important to remain optimistic. This particular strategy is also essential for caregivers. However, one should not be overly optimistic, this is to say that one must also face the reality. While the two may sound opposing, they do go hand in hand. The optimism should be as per the reality of the situation. Facing the reality is another coping mechanism. Related to this is coming to terms with mortality. As mentioned before, cancer is a life-threatening disease hence patients need to be prepared for and aware to face mortality. If they are aware of their disease, its development and have a realistic knowledge of it, they also are better prepared for mortality. Even the family caregivers need to bring themselves to terms with the mortality and the reality of their situation. Taking an active participatory stance in the treatment process also helps in coping with distress. Exercise is another great way to help patients with cancer. It helps motivate the patient. Exercise, however, is prescribed according to what the patient will be able to handle. (Kerry S. Courneya, John R. Mackey & Lee W. Jones ,2000)

Religious coping, acceptance of reality, and optimism have helped patients cope with the cancer burden and have also led to post-traumatic growth. (McGregor, Antoni, Boyers, Alferi, Blomberg, Carver,2004). A particular study shows how and when a particular coping mechanism can help the patient. It shows that patients who use coping strategies (that require expression and communication) during the early stages of diagnosis, benefit more in

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

later stages of treatment. (McGregor, Antoni, Boyers, M Alferi, B Blomberg, S Carver,2004)

Many caregivers are found to be using emotion-focused coping strategies. (Papastavrou, Charalambous, Tsangari,2012) However, research shows that problem-focused coping strategies have a more positive effect. What lacks is the training of these problem-focused and cancer-specific coping strategies. (McMillan, S.C., Small, B.J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L. and Haley, W.E.,2006). On the other hand,emotion-focused coping strategies showed higher psychological distress. (Teixeira RJ, Applebaum AJ, Bhatia S, Brandão T. ,2018)

Positive Growth

The process of treatment of cancer and the use of effective coping strategies may result in positive growth for the patients as well as the caregivers. This positive growth is often referred to as post-traumatic growth or PTG. This positive growth can occur in different ways - better or stronger interpersonal relationships, new life or career choices, positive outlook or the 'looking forward to' attitude towards life, greater appreciation of life and the world and stronger mental health. Effective coping strategies like spirituality have shown positive effects over posttraumatic growth. Use of coping mechanisms by cancer patients results in post-traumatic growth. There is a little conflict around the term for this growth. Earlier, it was referred to as post-traumatic growth. However, according to the latest version of the Diagnostic and Statistical Manual of Mental Disorders called DSM-5, cancer is no longer considered a traumatic event. Though it recognises that cancer is extremely stressful, it does not classify it as a trauma. Hence, the term post-traumatic growth is replaced by resilience or positive growth.

Factors affecting positive growth in cancer patients and caregivers are -

- **Biological:** These include genetics, or the gene-environment interactions. (Kalisch R, Muller MB, Tuscher O.,2015)
- **Environmental:** These factors include social support. (Somasundaram RO, Devamani KA. ,2016)
- **Personal:** Personal factors include an individual's ability to cope and keep an optimistic outlook. Self-efficacy is an integral personal factor that leads to PTG. (Hu T, Zhang D, Wang J.,2015)

PTG is a result of an adjustment process. Therefore, before achieving growth, one goes through illusory and constructive PTG as subsequent steps. This adjustment process is adaptive and is often termed as 'meaning Making' as it involves the patients and caregivers making sense out of their situation.

Psychologists use various scales to assess whether someone is experiencing positive growth. One such scale is the Post-Traumatic Growth Inventory (PTGI) (*Journal of Traumatic Stress*, 1996) which looks for positive responses in five areas:

- Appreciation of life.
- Relationships with others.
- New possibilities in life.
- Personal strength.
- Spiritual change.

Revisions are being made to these scales continuously.

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

Initially in the patient's treatment, emotion focused coping does lead to growth. However, that growth is temporary. (Sumalla et al., 2009). Active coping, involving both emotion-focused and problem-focused strategies, does result in positive growth. Studies also show that problem-focused strategies result in greater growth or resilience (Houts et al., 1996). One Korean study shows that even caregivers experience positive growth or resilience and a spiritual nursing program is extremely beneficial for this. (Soon Ock Choi,2014)

Overcoming cancer and the treatment allows for greater resilience. (Ruini C, Vescovelli F, Albiéri E. ,2013)(Danhauer SC, Russell GB, Tedeschi RG, et al,2013) (Lelorain S, Bonnaud-Antignac A, Florin A. ,2010)

However, I feel more detailed and specific studies are required to develop accurate information about caregivers and their growth. Another area that requires more research is patient-caregiver dyad related. There need to be more studies that focus on both patients and caregivers and what strategies can help in that environment

Study Analysis

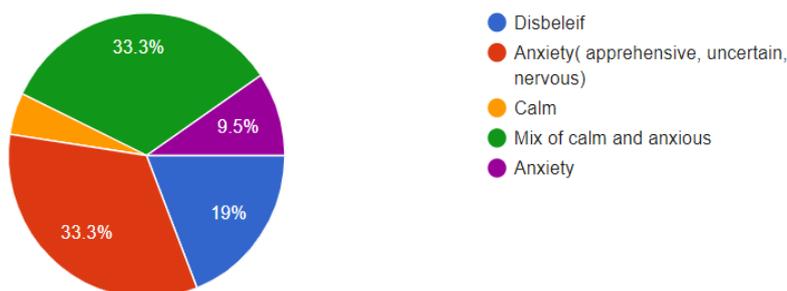
As a part of my study, I approached survivors and caregivers with surveys. I included caregivers as there is a large disparity in the data surrounding caregivers' mental health and the patients'. I also ensured that I take the data from survivors and not patients because comparatively, it is tougher for someone in that process to talk comfortably about this topic. To further the horizons of my study, I also interviewed Dr Rakesh. He brought with himself a doctor's perspective as well as gave me insight into the procedures they follow.

Survivors' Survey Analysis

With cancer, we all must acknowledge that it is extremely subjective especially when observing its emotional aspect. This survey is to bring to light these emotions, experiences, obstacles and solutions to help people unaware about these. The results of the survey show that coping mechanisms have a positive impact on a cancer patient. Even Dr.Rakesh, has observed and concludes that the more positive the patient remains, the more probability that they will recover. However, for those who find it tough to remain positive, which is very frequent and natural, the doctors and psychologists associated with them employ various ways to help them recover. Results also show that spirituality is a very common and effective avenue to maintain hope and retain calmness.

How did you respond when you got diagnosed?

21 responses



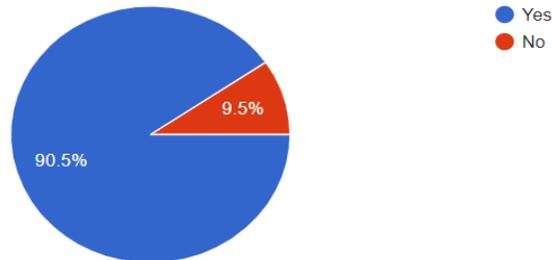
42.8% of the respondents experienced some sort of anxiety when they got diagnosed with cancer. This could be majorly due to the pre-conceived notions surrounding the disease. However, a large proportion of the respondents also experienced a mix of calmness and

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

anxiousness. This could reflect their confused mindset. Few of them also showed disbelief, a comparatively rare but very strong reaction to such news.

Did your physician openly talk about life expectancy or severity of cancer

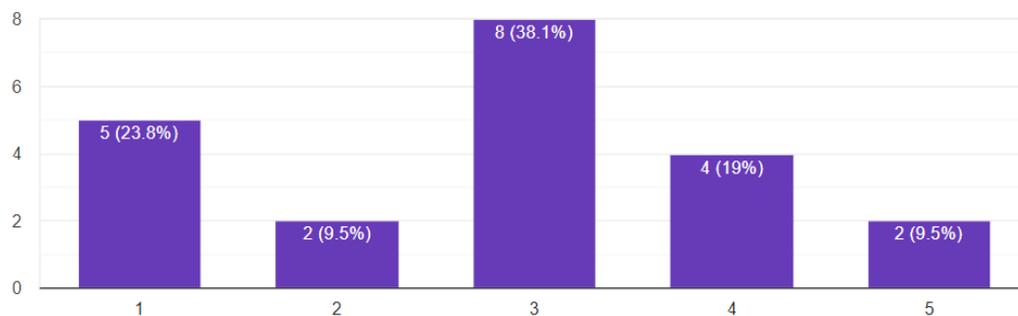
21 responses



More than 90% of the respondents' physicians openly talked about life expectancy and the severity of the cancer. This is essential to give the patient a realistic view so that they may alter their goals and plans accordingly. Of the 9.5% that were not told, the reasons could be varied- maybe the patient is not mentally fit to take such news or age.

If yes, how comfortable did you feel when it happened

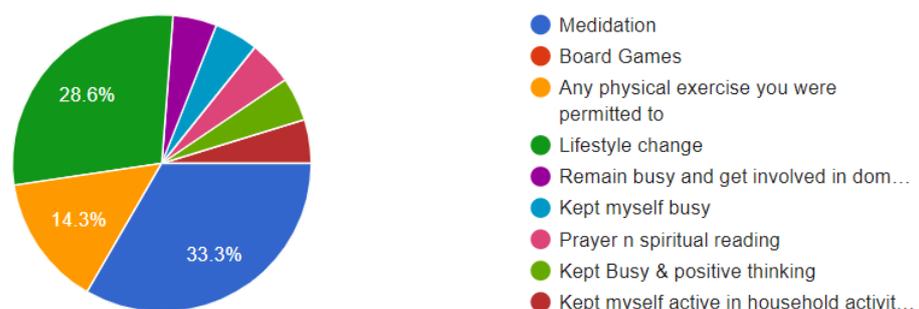
21 responses



The respondents were asked to select from a scale of 1-5 if they felt comfortable while talking about their life expectancy. Most of them responded between 1-3 which shows that they were not very comfortable openly talking about it. As cancer is a matter of life and death, many people who are not used to such conversations, do not find comfort.

Other than medications, what did you personally do to keep morale high?

21 responses



Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

For this particular question, there were varied responses. To sum up, the patients engaged in activities to feel productive and occupied. Many of them took to spirituality in the form of mediation or prayers. Few other activities were playing board games and reading books.

When did you mostly have anxiety(tension/intrusive thoughts)

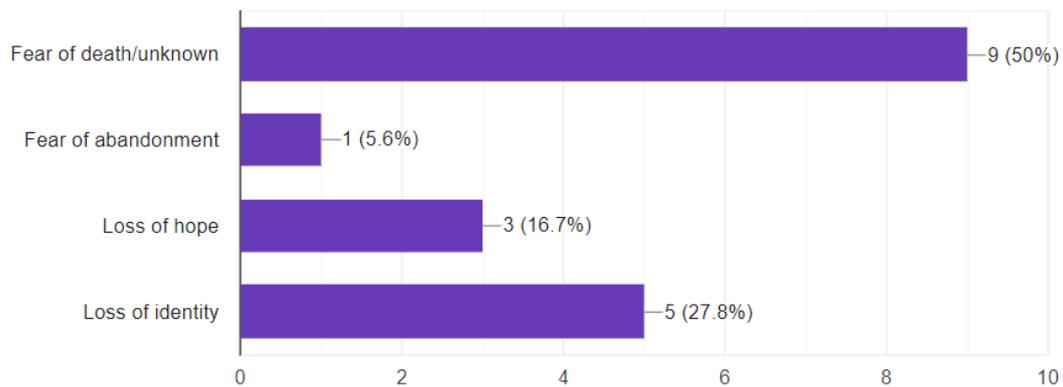
21 responses



According to this data, patients felt most anxious during the period of treatment as compared to diagnosis or when their symptoms started showing. While the statistics are not drastically different, a slight difference is observed. This may be due to the stress for various after effects of treatment or success of treatment.

Which of the following fears/losses have you experienced since diagnosis

18 responses

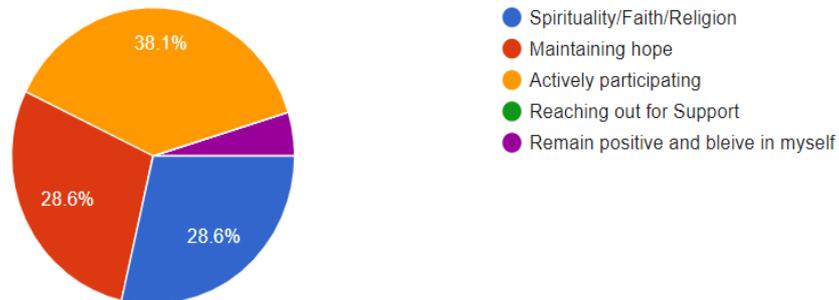


Half of the respondents feared death or the unknown. Fear of unknown is a fear of a force that you do not know of. Simply, it is a euphemism for death. The word cancer itself produces an image of death in one's mind. For someone who is diagnosed with cancer, it is very natural to fear death. Other fears include loss of hope or identity, and fear of abandonment from dear ones.

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

What coping mechanisms/strategies do you use?

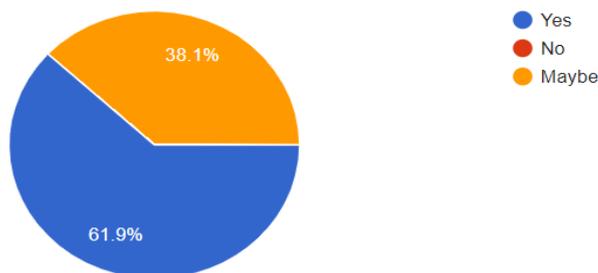
21 responses



Cancer patients routinely use coping mechanisms to manage the various emotions they experience. Almost 40% of the respondents used the mechanism of active participation. The other two common strategies, 28.6% each, are maintaining hope and spirituality.

Has there been any positive change/ growth in you?

21 responses

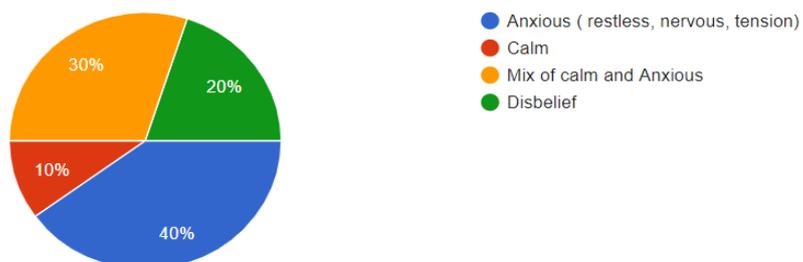


As our respondents were survivors, I was curious to know whether these coping mechanisms benefitted them in actuality. None of the respondents said that they did not experience a positive growth. 61.9% of them claim to have changed for the better and the rest 38.1% are unsure.

Caregivers' Survey Analysis

How did you respond when the patient got diagnosed

10 responses

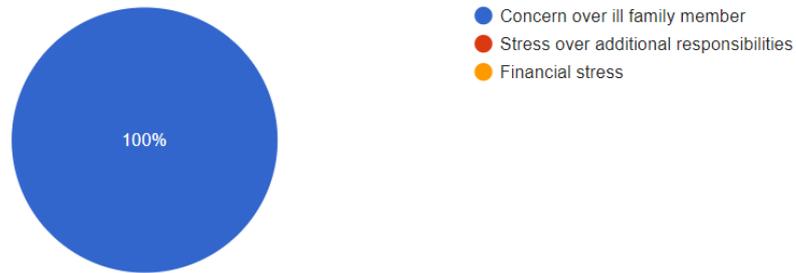


40% of the respondents expressed anxiousness when their near one was diagnosed with cancer. While 30% of them experienced a mixture of calmness and anxiousness, a good 20% also expressed disbelief as they could not imagine that their loved one had been diagnosed with a life-threatening disease.

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

As a caregiver, what kind of stress did you experience

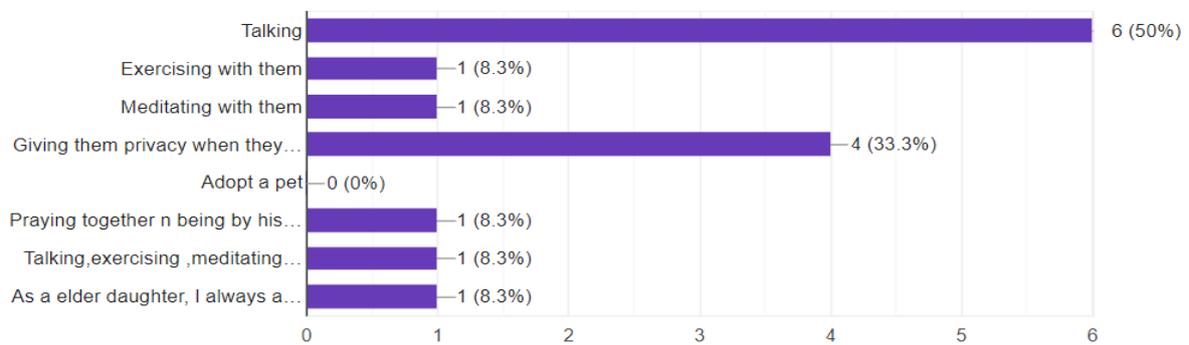
12 responses



The 100% response to this question is testimony for the emotional values and attachment instilled in each of us. All respondents were stressed due to concern for their family member and not over finances or additional responsibilities. However, observing from previous studies, the other two are also major stressors in this situation.

What did you do to help the patient boost their morale?

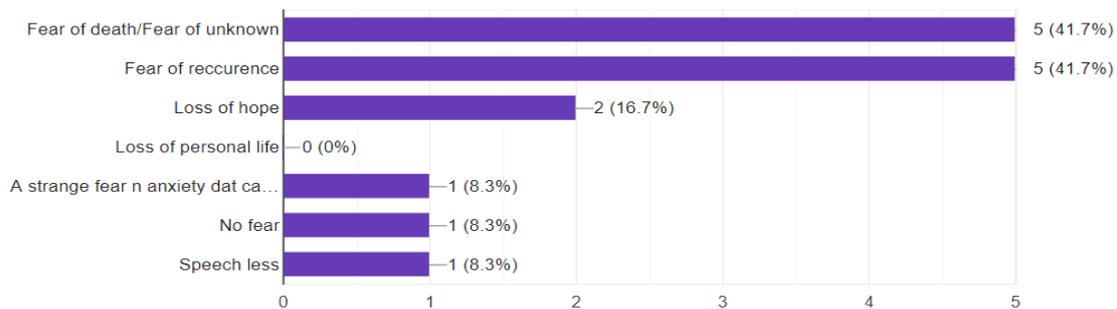
12 responses



The most common strategy to help the patients used by our respondents was engaging in conversations. The second most common, with 33.3%, was giving the patient their required privacy. This is extremely important because as caregivers one must not stick to the patient and allow them to carry out their own tasks as well.

Which of the following fears/worries did you experience?

12 responses

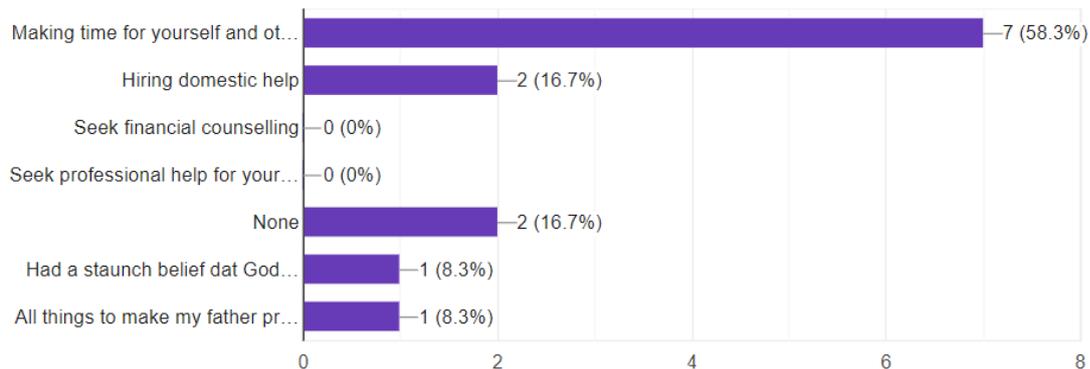


Among caregivers, the two most common fears, 41.7% each was the fear of unknown and the fear of recurrence.

Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

What did you do to take care of your own self?

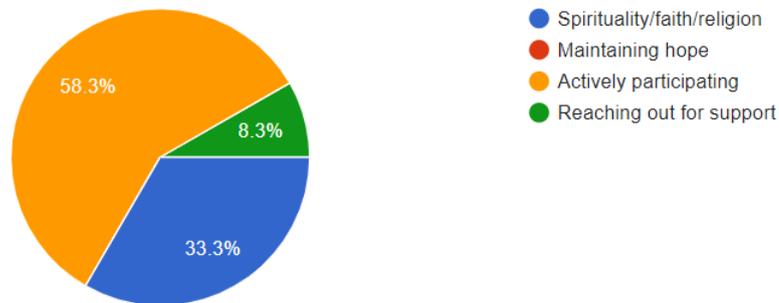
12 responses



Our respondent caregivers did recognise the toll their loved one's disease can take and 58.3% of them took time for themselves, some even hired domestic help to ease their workload. However, none of them resorted to professional mental help which is an indicator of lack of awareness of mental health in an Indian society.

What coping strategies did you use for yourself?

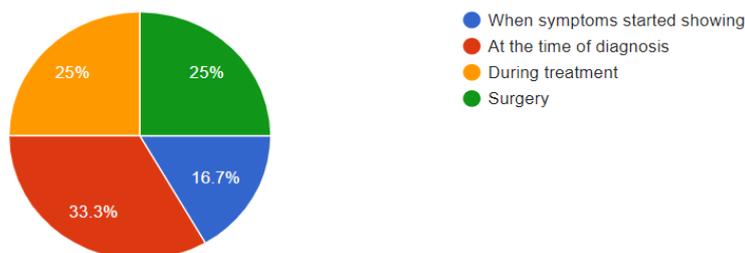
12 responses



58.3% of the caregiver respondents also actively participated in various activities and involved themselves in productive work as a coping mechanism. Spirituality was also a prevalent strategy among these caregivers.

When were you most worried about your patient ?

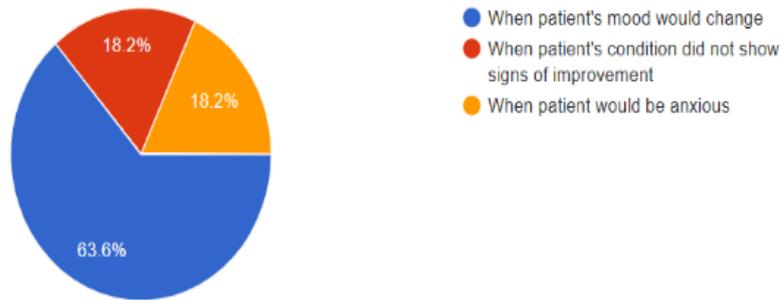
12 responses



Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

When did you mostly have anxiety(tension/intrusive thoughts)?

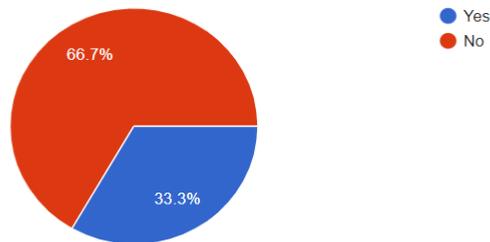
11 responses



Caregivers were most worried about their patient at the time of diagnosis. Caregivers themselves experienced anxiety mostly when the patient's mood would change.

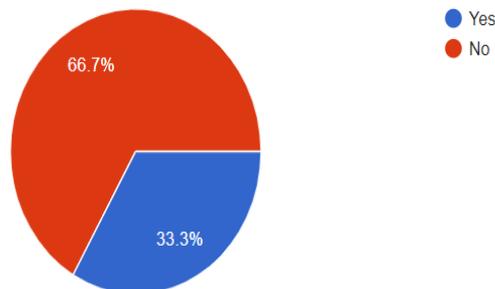
Did you often experience intense moods such as anger or frustration?

12 responses



Did these emotions make you feel guilty?

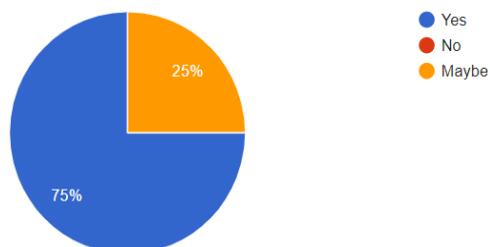
12 responses



More than 60% of the respondents did not experience these emotions. The rest who did experience them, did end up feeling guilty for feeling that way.

Did you experience any positive growth/change during this time?

12 responses



Impact of Cancer on Psychological Well-Being of Cancer Patients and Caregivers

None of the respondents said that they did not experience a positive growth. 75% of them claim to have changed for the better and the rest 25% are unsure. For caregivers, such a period can be a huge learning experience. Along with that, it can also be life-altering, which could be why 25% of the respondents were unsure.

Comparative Analysis

Both, the survivors and the caregivers, experienced anxiety when they or their loved one got diagnosed. While the survivors felt most anxious during the treatment, the caregivers were most worried about the patients at the time of diagnosis. The caregivers themselves experienced anxiety when their loved one's mood would frequently change. For caregivers and survivors both, active participation and spirituality served as excellent coping mechanisms. Positive growth can be taken as a testimony for these coping strategies. 75% of caregivers and 61.8% of survivors did experience positive growth while the rest of them responded with 'maybe'. This is proof that the coping mechanisms employed did have an effect. The fear of death/unknown was more common in survivors than caregivers.

Interview

In my conversation with Dr. Rakesh, I got an insight into the procedures and protocols surrounding cancer. When a patient is diagnosed with cancer, one of the biggest challenges for a doctor is to break the bad news. A protocol doctors follow in this situation is to not use the word cancer. Instead, they call it 'tumour' or 'bad disease'. This is done so that the patient does not get instantly shocked or react impulsively to such news as it shatters their life plans and they do not know what to do. From this moment onwards, the goal of the doctor is to establish trust and a safe environment around the patient. This can be achieved by actively being compassionate and considerate. Dr. Rakesh also says that they provide the patient with facilities to manage their stress. A striking example of this is the financial department which helps patients manage and plan their finances. Dr. Rakesh has also seen that many women who get diagnosed with cancer, are either divorced or left alone by their partner. To handle such situations, external facilities and assistance is essential.

Before the treatment starts, the doctor carefully explains the procedure and its side-effects for the same reasons as stated above for the bad news. In the interview, I hardly noticed any mention of mental health professionals. Dr. Rakesh said that there was no professional involved and the doctors have to themselves play different roles. Another important protocol to follow is to listen and address each and every concern of the patient.

Dr. Rakesh says that cancer can very well be called a 'mind game'. He has observed that patients who are optimistic and have a happy go lucky attitude show more improvement, respond well to treatment and have lived longer than those who are pessimistic.

This interview helps us understand a doctor's perspective when it comes to cancer. It also gives us a look into the real-time working of an oncological environment from the emotions involved to the protocols observed.

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Conflict of Interest

The author(s) declared no conflict of interest.

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