



## Research article

## Exploring the problems faced by patients living with advanced cancer in Bengaluru, India

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## ABSTRACT

**Purpose:** Cancer is a key influence on psychosocial and emotional distress among patients. Problems that advanced cancer patients in the western world face have been widely explored, but these findings may not be applicable in the non-western world due to the cultural differences. Exploring the problems of advanced cancer patients will help professionals plan appropriate therapeutic interventions to take care of the patients' physical, emotional, social and practical needs. Hence, this study aims to explore the psychosocial and emotional problems of advanced cancer patients in India.

**Methods:** Data were collected from 10 advanced cancer patients from Bengaluru, using purposive sampling and semi-structured interviews. The interviews were audio-recorded and transcribed. Themes were generated using thematic analysis.

**Results:** The prevalent themes were financial instability, hopelessness, family anguish, self-blame, helplessness, anger, stress, and suicidal thoughts.

**Conclusion:** This research has highlighted that advanced cancer patients have several issues, indicating the importance of using a holistic approach while handling this vulnerable population by focusing more on the patient rather than the disease.

## 1. Introduction

Cancer is a major concern as a leading cause of death worldwide. It is a group of diseases that is characterised by uncontrolled cell growth, which affects healthy body functioning, leading to fatal outcomes for the individual (National Commission on Macroeconomics and Health, 2005).

The International Agency of Research Centre (2018) states that the global cancer burden has risen to a total of 18.1 million patients and 9.6 million deaths due to cancer in 2018. Approximately, 1 out of 5 men and 1 out of 6 women develop cancer during their lifetime; out of these, 1 in 8 men and 1 in 11 women face death. The global cancer burden is intensifying at a breath-taking rate, expected to double by 2030 (Are et al., 2012; Torre et al., 2015; Bray et al., 2012). The global pattern observed shows that nearly half the new cases being registered and the number of deaths are due to cancer; more than half the global deaths occur in Asia alone because about 60% of the world's population resides there (Saranath and Khanna, 2014). India alone contributes 7.8% to the global cancer load and 8.33% of deaths due to cancer (Saranath and Khanna, 2014). India has registered 1.1 million cases of cancer, most of which are

registered in the terminal stage, directly leading to a higher death ratio of precisely 0.78 million (Sahoo et al., 2018). According to the World Health Organization (WHO), India is projected to attain a death toll of 13.1 million deaths due to cancer by the next decade (Rath and Gandhi, 2014).

Cancer causes great psychosocial distress among patients (Sivesind and Baile, 2001; Parker et al., 2003). Distress affects an individual depending on their culture and how the illness is perceived by the patient. During the illness, many common psychological problems such as depression, anxiety and an increased risk of suicidal behaviour arise (Chochinov, 2001; Filiberti and Ripamonti, 2002; Breitbart et al., 1998), leading to intense emotions (Slevin et al., 1996) and troubling thoughts that affect the individual in multiple ways (McClement & Chochinov, 2008) leading to poor quality of life.

Quality of life is an essential factor that needs improvement. To lift the status to a remarkable stage, we must first dive into the problems that the population faces, after which the appropriate steps for a contingent plan can be taken. Patients' quality of life can be improved by working on psychosocial factors that bring distress to the patients. Moreover, adapting to the nature of illness and utilizing the health care facility

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promptly will help. Additionally, medical care can be reshaped to fit a patient's needs better (Jevne et al., 1998).

Distress is reflected in the illness of the patients. Data pointing to the psychiatric disorders in cancer patients is negligible, with limited research in the area (Chaturvedi, 2012). The problems faced by advanced cancer patients in the western world is widely explored, but the findings are not applicable in non-western countries due to cultural differences. Despite India being the second-most populous country housing a large number of terminal cancer patients, little has been explored in this field (Mehrotra, 2008). Applying the findings from western studies to treat patients is a daunting task for Indian scholars (Weng et al., 2011). Furthermore, conflict and disapproval from society may arise (Asch et al., 1995). Exploring the problems of advanced cancer patients will help professionals plan appropriate therapeutic interventions that take care of the patient's physical, emotional, social, and practical needs (Davies et al., 1995; Doka, 1997; Parkes et al., 2001; Rando, 1984, 2000). Therefore, this study aims to provide insight into the emotional and psychological problems advanced cancer patients face in non-western settings, such as India, because cultural influence plays a vital role in the behaviour and attitude of patients at the end of their life (Weng et al., 2008).

## 2. Methodology

### 2.1. Study design

Explorative research design was used in this study with the aim of exploring the problems of advanced cancer patients. According to National Cancer Institute "Advance Cancer that is unlikely to be cured or controlled with treatment. The cancer may have spread from where it first started to nearby tissue, lymph nodes, or distant parts of the body. Treatment may be given to help shrink the tumor, slow the growth of cancer cells, or relieve symptoms."

The study was conducted in December 2018 and January 2020 by interviewing the patients in the Karnataka Cancer hospital and Karunashraya hospice in Bengaluru, a metropolitan city in India. According to City population website, Bangalore has a population of more than 8 million and a metropolitan population of around 11 million, making it the third most populous city and fifth most populous urban agglomeration in India. Bangalore is called as the Silicon Valley of India in light of the large number of information technology companies located in the city because of which people from all over the country come to Bangalore in search of employment. Every year more than 10 000 new cases of cancer are diagnosed in the city; 80% of them seek palliative care, both physical and emotional, in the very late stages (Shanmugasundaram et al., 2006).

Thematic analysis was considered a relevant research approach and was hence used to systematically identify, organize, and offer insight into patterns of meaning (themes) across a data set (Braun and Clarke, 2012).

### 2.2. Recruitment and participants

Purposive sampling was used as the researcher had to carefully choose and approach eligible participants based on inclusion and exclusion criteria. Using purposive sampling, two participants were chosen from the hospital and eight from the hospice, i.e., 10 advanced cancer patients (3 males and 7 females) were recruited (see Table 1). The eligibility factors are as follows:

- a) Being well-informed about their illness
- b) Able to communicate without impairment
- c) Being proficient in Hindi, English or Kannada for the interview process as only these languages were known to the researcher.
- d) Aged 18 or above

The patients excluded were those who were on ventilators and/or those were suffering from psychological disorders such as schizophrenia, autism, dementia, etc. The study was explained in detail to the selected participants. They were allowed to make clarifications. The participants' convenience was considered when scheduling and conducting the interviews. Each patient was interviewed once, during which demographic information such as age, gender, religion, education and occupation were also collected.

### 2.3. Data collection tool and procedure

Enrolment in a 6-month palliative care internship program at the Karunashraya hospice was a beginning of research for the investigator. The medical director of the institute helped the researcher develop communicative and questioning skills and understand how to handle interviews and tackle situations arising during interviews. The overall training involved a combination of roleplays, rehearsals and lectures. The researcher selected the participants with help from in-house counsellors using purposive sampling. Before each interview, written consent was obtained from the patients. The study and their rights, such as choosing not to answer any question, withdraw from the study at any point, full confidentiality and privacy and the freedom to uninhibitedly express their views, were explained in detail. Semi-structured interviews were conducted. The interview guide was drafted with the help of a literature review and considering the local ethnicity, it was also translated into Kannada language by employing a professional translator. Participants were probed in a way that threw light on their cancer journey. Questions such as views on life, difficulties they faced due to the illness, goals, and expectations in future etc were asked. Each interview lasted 34 min on average.

### 2.4. Data processing and analysis

The interviews collected were transcribed by the researcher. Qualitative thematic analysis was used to analyse the data by following the principles of thematic analysis using the six-stage approach recommended by Braun and Clarke (2012). The data set was scrutinized multiple times and the audio was listened to keenly until it became familiar, then data were analysed through coding and each code was recognizable by its own features related to the research objective after which codes were used to identify the predominant themes and sub-themes. Each identified theme and sub-theme was reviewed such that they represented data then the themes were named and defined so they ideally summed up the essence of the data and addressed the research question directly. Finally, the report was produced (Braun and Clarke, 2012).

### 2.5. Ethical approval

The study had been approved by the Ethics Research Committee of the Karunashraya hospice. Respect was given to the patient's condition and the interview was discontinued when the participant was unable to continue. Afterwards, ward nurses were asked to observe the patients for any changes and the counsellors held a session with them to gauge if the interview negatively impacted them in any way.

## 3. Results

Ten advanced cancer patients participated in this study. Pseudonyms were used to ensure anonymity.

Five themes emerged from the thematic analysis of the interviews:

- 1) Financial instability
- 2) Debilitating efforts
- 3) Distress

**Table 1.** Socio-demographic characteristics.

Pseudonyms Names	Age	Gender	Cancer	Religion
BA	39	Male	Leukemia	Hindu
BG	38	Female	Carcinoma Breast	Christian
TJ	69	Male	Carcinoma Thyroid	Hindu
CT	34	Female	Carcinoma Breast	Hindu
NR	50	Female	Carcinoma Breast	Hindu
RC	45	Male	Oral cancer	Hindu
LK	44	Male	Oral cancer	Christian
RK	59	Female	Carcinoma Stomach	Hindu
AF	60	Female	Carcinoma Stomach	Islam
CD	64	Female	Carcinoma Stomach	Converted Christian

Ten participants were enrolled in this study. The standard deviation in age is 12.10 and the mean age of the patients was 50.2 years (38–69 years); 60% were females, while 40% were male. Regarding religion, 60% were Hindu, 30% were Christian and 10% were Muslim. One patient did not complete the interview due to an unstable health condition.

- 4) Anger
- 5) Family anguish

Within some themes, there were specific sub-themes that have been explained below using direct quotes from the participants (see Table 2).

*3.1. The woes of financial instability*

Financial instability was a common problem for every participant as they belonged to either the lower income class since they were daily wage workers and could not afford medical expenses or middle class who had a secure job but sadly had to support their family.

a) Insufficient funds

Participants were mentally disturbed by the fact that treatment could cost them a fortune. Most participants were their families’ breadwinners; the thought of arranging large sums of money for treatment produced feelings of distress. BG shared,

Initially, I noticed a small lump in my breast, but after a few days it became big. I went for a consultation at Dr R. He said that it may be cancer and recommended that we get tested in Kidwai. We went to Kidwai, where they made a card for 550 (\$7.51) rupees and got me checked. The test confirmed cancer. They said that the treatment would cost us 5 lakh rupees (\$6830.50). We did not have so much money nor could we adjust by asking someone. The thought of 5 lakh rupees (\$6830.50) was constantly running in our minds.

Lack of money led to the patients suffering mentally and physically. BG mentioning the cost of a hospital card indicates the insufficient funds and how much each penny matters to them. Likewise, participants also could not visit the doctor as they could not gather money for follow up tests. NR mentioned,

A PET scan costs ₹24,000 (\$327.86). We are poor people. We have to work hard and eat. We have to earn our daily bread. To gain financial help, I enquired with the doctor if I could avail health insurance of my brother, to which he said the insurance will not cover sisters and only

**Table 2.** Summary of findings with direct quotes.

Themes	Sub-Themes	Quotes
The Woes of Financial Instability	Insufficient funds	“Initially, I noticed a small lump in my breast, but after a few days it became big.... The thought of 5 lakh rupees was constantly running in our minds.” “A PET scan costs ₹24,000 (\$327.86). We are poor people. ... only holds good for mothers, fathers, wives, and children. I couldn't even get insurance...” “I just imagined myself suffering like this only and eventually dying because I cannot arrange so much money.”
	The Burden of Debt	“Maa, my aunt died because of ovarian cancer. ... I belong to a poor family and my father is old to work and earn us a living.”
	Responsibility Towards Family	“I was born in a poor family. ...I chose to spend the savings on my family rather than on my treatment.”
Debilitating Efforts	Hopelessness	“I did as much as I could because I wished to live, but now, ...What is the point of holding on to hope when God doesn't want me to live?” “We all have to die when it is time. .... I feel very lonely and helpless as I have no control over anything anymore.”
	Helplessness	“I feel I am left with nothing. ... so I'm bearing it. No matter how much it hurts.”
	Suicidal ideation and attempts	“I felt very sorrowful because of my situation and illness....I tried to commit suicide by drinking Baygon (insecticide spray).” “Because of the pain, ...There was nobody to help me.”
Distress	Worry About the Family	“If my daughter was grown up, I wouldn't have worried. But she is only 4 years old, still so small. She needs a mother. It worries me.”
	Worry About the Illness	“I don't want to think about death and my illness as well. It worries me a lot and I am unable to handle worries.”
Anger	Anger with Self	“I was addicted to alcohol and smoking. I am suffering today because of these unhealthy behaviours. I hold myself responsible for my illness and present condition.” “I hold nobody but myself responsible for my illness. .... I also hold myself responsible for delaying treatment which landed me in this situation.”
	Anger towards God	“I was very angry at god. ... but I can't even do even that.” “I love my Creator a lot but after ... Who will take care of her now?”
Family Anguish		“My daughters were worried about my health. ...We ended up in Vaidhevi hospital for treatment.” “At home, my children are broken-hearted that this has happened to their mother. .... They don't allow me to do any work and feed me too.”

holds good for mothers, fathers, wives, and children. I could not even get insurance...

As participants did not get financial help and could not arrange such huge amounts, they felt helpless. When BG was asked about this situation, she responded, "I just imagined myself suffering like this only and eventually dying because I cannot arrange so much money."

Participants were surrounded by financial hardships and, finally, had nothing to do but avoid treatment. This choice had a mental impact on them as they advanced through further stages of a terminal disease.

#### b) The Burden of Debt

While the participants were undergoing their share of financial anxiety and helplessness, their family members were concerned with the well-being of the participant so much that they were not hesitant in taking loans to overcome the initial hurdle, despite having low income to repay the debt. BG mentioned that her daughter was worried and would sob, "Maa, my aunt died because of ovarian cancer. Please get yourself operated. We'll take a loan or make some other arrangements. We will manage somehow, but please get the operation done, maa!"

Participants resorted to loans even in the absence of a primary and/or auxiliary source of income for surgery. However, the worry does not cease even at this point. CT mentioned,

I was operated after availing a loan of ₹2,00,000(\$2740.68). So far, I have covered 1.5 lakhs (\$2049.15) and will pay the remaining 50 thousand (\$683.05) at the time of discharge. But what about the future? We did not have any money left after this! I belong to a poor family and my father is old to work and earn us a living.

Debt and worry loomed, as their families would not function normally because the participants themselves were the providers.

#### c) Responsibility Towards Family

When participants were the primary earner in the family, responsibility towards family took precedence over their treatment. BA shared,

I was born in a poor family. I'm the only son, so I need to take care of the responsibilities of the family. Getting my sister married was one such task and I chose to spend the savings on my family rather than on my treatment.

Hard choices were needed to fight the financial inadequacy. When participants had savings, they chose to spend it on their families. In some cases, to ensure that their families had enough after the individual's death, doing nothing about the illness was the only option.

### 3.2. Debilitating efforts

#### (a) Hopelessness

The participants expressed that they felt despair because of the troubles faced due to cancer. They had initially put effort into winning the battle, but as they had reached an advanced stage and efforts did not pay off, hopelessness overtook hope. For instance, BG expressed,

I did as much as I could because I wished to live, but now, I have given up all hope and I am not willing to try anymore (cries). I no longer have the strength in me to face this situation. What is the point of holding on to hope when God does not want me to live?

Additionally, patients' physical immunity had weakened as they cited incidents of increased pain, extra doses of medication, etc. Participants experienced loneliness and loss of control due to their advanced illness and were simply waiting for death. TJ states,

We all have to die when it is time. My time is very close. Now I cannot do anything or even hope to avoid death. I feel very lonely and helpless as I have no control over anything anymore.

A sense of hopelessness broke the participants completely. It showed during the interview. Participants had lost hope and surrendered as they could not control the situation, leaving them with little expectations of a positive outcome.

#### b. Helplessness

Participants at the last stage of illness faced many difficulties, whether mentally, physically and/or financially. Feelings of helplessness crept into the patients after their attempts to fight cancer had failed, thus leaving them emotionally vulnerable. BA shared that, "I feel I am left with nothing. I have put in all my efforts and now that death is approaching, there is nothing I can do about it."

The participants endured immense trauma. The tolerance that was seen in the early stages vanished with the increase in pain and suffering. When the participants reached a point of saturation, the willingness to manage the pain and illness faded and they succumbed to the illness. For example, NR said, "The illness has brought me pain that I can do nothing about the pain or illness. Feels like I have to bear it, so I'm bearing it. No matter how much it hurts."

Helplessness may lead to feelings of anxiety and fear of death at the end of life. It negatively impacts the mental health of the patients because they feel powerless, feeble and in no control of their lives, both mentally and physically.

#### c. Suicidal ideation and attempts

Suicide can be attributed to psychological suffering and unattended psychological needs, arising from disturbed mental health. Feelings of helplessness, hopelessness and sadness may result in suicidal thoughts in some; it seems like an easy option to get rid of their pain and mental suffering. When BA was questioned about the situation, he said,

I felt very sorrowful because of my situation and illness. It was very difficult for me to accept the pain and suffering and also see my family go through pain along with me. I tried to commit suicide by drinking Baygon (insecticide spray).

BG said,

Because of the pain, I tried to commit suicide. The cancer had developed maggots that I had to remove myself. Maggots that should have been on my dead body were on me while I was still alive. The pain and suffering were intolerable. There was nobody to help me.

The attempt to gain relief from uncertainty in using the unconventional method of suicide seemed right to the participants as their psychological needs were unaddressed and physical suffering unattended. Participants were found to be unable to cope with these feelings when they could not receive timely medical help.

### 3.3. Distress

Some informants experienced stress during the entire illness as they could not manage it effectively, reaching a point where they felt suicide was the only way to put an end to the stress.

#### a. Worry About the Family

The patients were concerned about their families' futures, especially after their death. This could be due to the realization that their chance of survival is less and because they felt helpless and hopeless. For example, CT expressed, "If my daughter was grown up, I would not have worried.

But she is only 4 years old, still so small. She needs a mother. It worries me.”

CT's worries regarding her daughter were compounded by the fact that she is separated from her husband and her father is too old to take care of her. Worry about families and their well-being were topics of concern. Unfinished business, such as being unable to secure the family's future made them more anxious and helpless.

#### b. Worry About the Illness

Some participants were under tremendous stress and suppressed their emotions about their illness and imminent death. When asked about their illness, participants refused to revisit the related memories or thoughts. TJ said, “I do not want to think about death and my illness as well. It worries me a lot and I am unable to handle worries.”

Participants showed that the stress and tension was no longer tolerable, avoiding the thoughts that would again land them in more stress.

### 3.4. Anger

#### a. Anger with Self

Participants showed severe emotional responses due to psychological disturbance; anger was one such response. Notably, the patients directed the anger toward themselves. For instance, TJ stated, “I was addicted to alcohol and smoking. I am suffering today because of these unhealthy behaviours. I hold myself responsible for my illness and present condition.”

BG said,

I hold nobody but myself responsible for my illness. It happened because of the mistakes that I have made in life. Karma gave me this disease. I also hold myself responsible for delaying treatment which landed me in this situation.

For TJ, the anger towards himself was an indication that he regretted the life he lived. He kept repeating that his actions had led to his suffering today. Similar anger was seen in BG's case as well. This anger towards the self-caused mental disturbance in the participants.

#### b. Anger towards God

Some participants expressed their anger towards God, raising questions about their illness. Participants felt they were chosen to suffer by God and were not happy about it. BA shared,

I was very angry at god. I asked, why did He give me this illness? If the illness was my fate, why was I born in poverty? The rich can afford treatment at least, but I cannot even do that.

CT expressed,

I love my Creator a lot but after I was diagnosed with this illness, I was furious with Him. I asked Him, why did you do this to me? If He had chosen to give me this condition, why had He blessed me with a daughter? Who will take care of her now?

The terminal illness causes anger in patients. BA shared his annoyance by questioning God about his poverty. He believed that if he had sufficient income, he could have received treatment on time. CT continued to worship her god, but cancer made her angry at god for putting her in a situation where she cannot help herself or her daughter.

### 3.5. Family anguish

Some of the participants relayed the pain of their family members because of their illness. BG said,

My daughters were worried about my health. They told me several times to get treatment, but I denied their requests. Finally, as the deterioration of my health bothered my family, they forced me to get treatment, including my brother-in-law. We ended up in Vaidhevi hospital for treatment.”

NR explained,

At home, my children are broken-hearted that this has happened to their mother. They did their best to arrange help for me. My daughters-in-law are very concerned about my health. They do not allow me to do any work and feed me too.

When a family member faces a life-threatening disease, only the individual is not affected; the entire family endures agony. BG and NR's family felt stress because several problems loomed over them, such as the illness itself, the suffering it caused, and inadequate financial resources and treatment. The caregivers take extra care of the patients, to give them a sense of mental comfort as their illness is accepted by the family.

## 4. Discussion

The highlights of the interviews pointed to various difficulties that the participants experienced. A common concern was financial instability, which seemed like a great barrier to overcoming their illness in time. Relevant research has proven that besides the physical and psychological concerns, advanced cancer patients face numerous other problems such as lack of funds, state-sponsored social welfare schemes and anxiety about family welfare (Doherty et al., 2019; Sunanda et al., 2018). All the patients in this study were very poor. CT and NR were charged nominally by Karnataka Cancer Hospital, while the rest received free care from Karunashraya.

The participants stated that their family members had mental pain; they highlighted the despair among their family members due to their illness. The entire family is impacted when a single member is diagnosed. It is observed that the relatives taking care of the patients become distressed and depressed because of financial, personal and social problems (Brodaty and Donkin, 2009).

Emotional reactions to cancer include anger and anxiety, which were seen in 20% of the cancer patients (Baskin and Enright 2004). Anger is also correlated with pain. The participants mentioned experiencing physical pain associated with their terminal illness, affecting their mental health. From the literature review, it was seen that around 60–90% of patients with advanced cancer experience excruciating pain (Rumsey et al., 2003). In recent studies, anger towards oneself was connected to the intensity of the pain (Christensen and Ehlers, 2002). Other aspects of anger include blaming oneself for past behaviours (Enright, 1996) and also exhibiting rage on God.

How an individual views a circumstance is key to their adjustment to stressful events (Kim et al., 2007; Scharloo et al., 2005; Servaes et al., 2002; Li and Lambert, 2007; Servaes et al., 2002, 2002; Costanzo et al., 2005; Janoff-Bulman, 2010). In this study, the participants expressed being stressed about illness, and they notably attempted to evade thoughts surrounding the torment they underwent. Block (2000) stated that the distress and disruption during the last weeks of a patient's life leads to a deprivation of different facets of life, including loss of meaning in life and disconnection with others, which directly impacts quality of life.

Cancer itself is a very stressful matter, leading to psychiatric disorders and impacting the physical health of patients (Saunders, 1959; Rosenfeld et al., 2000). Extreme cases have been recorded of treatment being compromised by the psychiatric symptoms of stress (Saunders, 1959), giving way to more health issues than anticipated during the end of life. Higher stress levels lead to suicidal thoughts and attempts, seeking assisted suicide and/or wanting faster death (Daneker, 2006). The participants of this study were so stressed and worried about their illness that they expressed and justified their suicidal thoughts. When a patient

is emotionally disturbed or has unfulfilled psychological needs, suicide seems like an answer to end the pain and trauma which have arisen due to the illness (Minagawa et al., 1996).

Patients with suicidal ideation also have higher rates of depression, distress, helplessness, and poor pain management (Massie and Holland, 1992). The thought of loss of control affects patients emotionally and, consequently, increases helplessness and hopelessness. During the interviews, helplessness was observed to have emerged among the participants because of the extreme torment they had undergone. Snyder (1994) reported that patients are bound to undergo physical and emotional changes, which may have a direct and adverse effect on the body and its ability to function as expected. When seeing their illness through a negative lens (Flemming, 1997), patients viewed their lives as hopeless and meaningless (Morita et al., 2000; Shanmugasundaram et al., 2006). Hopelessness among the participants seeped through various factors that took a toll on their mental and physical ability to manage the illness, like being financially unstable, unable to manage pain, feeling helpless, not having a direction of thoughts and being worried about their family's future.

Statistics show that about 20–70% of terminal patients are unaware of pain management, 30% are emotionally unsatisfied and one-third are depressed (American Psychological Association, 2017). Most cancer centres do not approach mental health professionals, such as psychiatrists or psychologists to tackle patients' mental health problems (Shankar et al., 2016). The results of this study show that the patients are mentally, physically and emotionally drained. This is true for the patients and their families. This is bound to happen with advanced cancer patients, as it includes the variations of feelings such as hopelessness, depression, anxiety and fear of death. Major concerns like these go unnoticed and unaddressed (Sunanda et al., 2018). This latency could result from a lack of knowledge about the psychosocial and emotional problems faced by advanced cancer patients from non-western societies, which hinders attempts to provide interventions to tackle these issues.

To overcome such shortcomings, health professionals could work and build on mental health of patients. A good mental health supports a better physical condition, as strides are made into understanding the patients mental condition, it is equally important to make way for their betterment. This major role can be taken up by the psycho-oncologist to gauge and effectively manage emotional, psychological and social aspects of oncology care of the patient (Mathew et al., 2019). The greater the management and understanding of such problems will help the patients as they are given the opportunity and ample support to be verbal about the effects of illness, change in self-image, management of their roles with family, friends, loved ones and healthcare professionals relating to the treatment of their illness. They can be allowed to discuss the life altering nature of the illness and ways to cope with it along with being able to communicate the same (Given et al., 2001). Group psychotherapy is another such great addition due to its supportive expressive nature that helps to confront existing issues, promote emotional expressions and imbibe social support (Akechi et al., 2005).

More intensive research can be done to investigate and bring out newer problems faced due to advanced cancer among patients in countries such as India. Defining the problems is the first step needed for a positive change. Solutions for the improvement of patients' situation have to be discovered following their traditions and culture (Elsner et al., 2012); including full-time mental health professionals while providing care will then help a great deal (Shankar et al., 2016).

## 5. Limitations

One limitation is that this study was conducted in just two institutes and on a few participants. Second, the findings cannot be generalised, which is characteristic of qualitative research. A larger number of participants would further strengthen the outcome of the study. There is also scope to include family members or caregivers to understand the phenomenon better.

## 6. Conclusion

The findings of this study elucidated the problems of advanced cancer patients in Bengaluru, India. This research has highlighted that advanced cancer patients face several issues such as financial instability, hopelessness, family anguish, suicidal ideation, anger and stress, advocating the importance of using a holistic approach by healthcare professionals while handling this vulnerable population by focusing more on the patient than the disease. This can help patients to see themselves through the illness with comfort, dignity and acceptance of death while leading a quality end of life.

## Declarations

### Author contribution statement

Maria Wajid: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Eslavath Rajkumar: Conceived and designed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Romate John, Allen Joshua George, R. Lakshmi: Contributed reagents, materials, analysis tools or data; Wrote the paper.

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### Data availability statement

The data that has been used is confidential.

### Declaration of interests statement

The authors declare no conflict of interest.

### Additional information

No additional information is available for this paper.

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## References

- Akechi, T., Onishi, J., Morita, T., Furukawa, T., 2005. Psychotherapy for depression among incurable cancer patients. *Cochrane Database Syst. Rev.*
- American Psychological Association, 2017. Brochure on End of Life Issues and Care. <http://www.apa.org/topics/death/end-of-life.aspx>.
- Are, C., Rajaram, S., Are, M., Raj, H., Anderson, B.O., Swamy, R.C., Cazap, E.L., 2012. A review of global cancer burden: trends, challenges, strategies, and a role for surgeons. *J. Surg. Oncol.* 107 (2), 221–226.
- Asch, D.A., Hansen-Flaschen, J., Lanken, P.N., 1995. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. *Am. J. Respir. Crit. Care Med.* 151 (2), 288–292.
- Baskin, T.W., Enright, R.D., 2004. Intervention studies on forgiveness: a meta-analysis. *J. Counsel. Dev.* 82 (1), 79–90.
- Block, S.D., 2000. Assessing and managing depression in the terminally ill patient. *Ann. Intern. Med.* 132 (3), 209.
- Braun, V., Clarke, V., 2012. Thematic analysis. In: *APA Handbook of Research Methods in Psychology*, 2.
- Bray, F., Ren, J.-S., Masuyer, E., Ferlay, J., 2012. Global estimates of cancer prevalence for 27 sites in the adult population in 2008. *Int. J. Canc.* 132 (5), 1133–1145.

- Breitbart, W., Chochinov, H.M., Passik, S., 1998. Psychiatric aspects of palliative care. In: Doyle, D., Hanks, G.E.C., McDonald, N. (Eds.), *Oxford Textbook of Palliative Medicine*. Oxford University Press, New York, pp. 933–954.
- Brodsky, H., Donkin, M., 2009. Family caregivers of people with dementia. *Dialogues Clin. Neurosci.* 11 (2), 217–228.
- Chaturvedi, S., 2012. Psychiatric oncology: cancer in mind. *Indian J. Psychiatr.* 54 (2), 111.
- Chochinov, H.M., 2001. Depression in cancer patients. *Lancet Oncol.* 2 (8), 599–606.
- Christensen, A.J., Ehlers, S.L., 2002. Psychological factors in end-stage renal disease: an emerging context for behavioral medicine research. *J. Consult. Clin. Psychol.* 70 (3), 712–724.
- Costanzo, E.S., Lutgendorf, S.K., Bradley, S.L., Rose, S.L., Anderson, B., 2005. Cancer attributions, distress, and health practices among gynecologic cancer survivors. *Psychosom. Med.* 67 (6), 972–980.
- Daneker, D., 2006. *Counselors Working with the Terminally Ill. VISTAS*. [https://www.counseling.org/Resources/Library/VISTAS/vistas06\\_online-only/Daneker.pdf](https://www.counseling.org/Resources/Library/VISTAS/vistas06_online-only/Daneker.pdf).
- Davies, B., Reimer, J.C., Brown, P., Martens, N., 1995. *Fading Away: the Experience of Transition for Families with Terminal Illness*. Pediatric Palliative Care Library. <https://pedpalascnetlibrary.omeka.net/items/show/11370>. (Accessed 14 October 2020).
- Doherty, M., Power, L., Rahman, R., Ferdous, L., Akter, K., Quadri, S., Khan, F., 2019. The psychosocial and spiritual experiences of patients with advanced incurable illness in Bangladesh: a cross-sectional observational study. *Indian J. Palliat. Care* 25 (4), 487.
- Doka, K.J., 1997. *Living with Grief: when Illness Is Prolonged*. Taylor & Francis.
- Elsner, F., Schmidt, J., Rajagopal, M., Radbruch, L., Pestinger, M., 2012. Psychosocial and spiritual problems of terminally ill patients in Kerala, India. *Future Oncol.* 8 (9), 1183–1191.
- Enright, R.D., 1996. Counseling within the forgiveness triad: on forgiving, receiving forgiveness, and self-forgiveness. *Counsel. Val.* 40 (2), 107–126.
- Filiberti, A., Ripamonti, C., 2002. Suicide and suicidal thoughts in cancer patients. *Tumori* 88 (3), 193–199.
- Flemming, K., 1997. The meaning of hope to palliative care cancer patients. *Int. J. Palliat. Nurs.* 3 (1), 14–18.
- Given, B.A., Given, C.W., Kozachik, S., 2001. Family support in advanced cancer. *CA A Cancer J. Clin.* 51 (4), 213–231.
- Janoff-Bulman, R., 2010. *Shattered Assumptions: towards a New Psychology of Trauma*. Simon and Schuster.
- Jevne, R., Nikolaichuk, C., Williamon, H., 1998. A model for counselling cancer patients. *Can. J. Counsell.* 32 (3), 213–229.
- Kim, Y., Schulz, R., Carver, C.S., 2007. Benefit finding in the cancer caregiving experience. *Psychosom. Med.* 69 (3), 283–291.
- Li, J., Lambert, V.A., 2007. Coping strategies and predictors of general well-being in women with breast cancer in the People's Republic of China. *Nurs. Health Sci.* 9 (3), 199–204.
- Massie, M.J., Holland, J.C., 1992. The cancer patient with pain: psychiatric complications and their management. *J. Pain Symptom Manag.* 7, 99–109.
- Mathew, A., Jagan, S., Abraham, J., 2019. Mental health care as part of cancer care: a call for action. *Canc. Res. Stat. Treat.* 2 (2), 244.
- McClement, S.E., Chochinov, H.M., 2008. Hope in advanced cancer patients. *Eur. J. Canc.* 44 (8), 1169–1174.
- Mehrotra, S., 2008. Psycho-oncology research in India: current status and future directions. *Ann. Indian Acad. Neurol.* 34 (1), 7–18.
- Minagawa, H., Uchitomi, Y., Yamawaki, S., Ishitani, K., 1996. Psychiatric morbidity in terminally ill cancer patients: a prospective study. *Cancer* 78 (5), 1131–1137.
- Morita, T., Tsunoda, J., Inoue, S., Chihara, S., 2000. An exploratory factor analysis of existential suffering in Japanese terminally ill cancer patients. *Psycho Oncol.* 9 (2), 164–168.
- National Commission on Macroeconomics and Health, 2005. *Burden of Disease in India, Burden of Disease in India*. Ministry of Health & Family Welfare, Indian Government. [https://www.who.int/macrohealth/action/NCMH\\_Burden%20of%20disease\\_%2829%20Sep%202005%29.pdf](https://www.who.int/macrohealth/action/NCMH_Burden%20of%20disease_%2829%20Sep%202005%29.pdf).
- Parker, P.A., Baile, W.F., Moor, C.D., Cohen, L., 2003. Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho Oncol.* 12 (2), 183–193.
- Parke, C.M., Relf, M., Couldrick, A., 2001. *Counselling in Terminal Care and Bereavement*. British Psychological Society.
- Rando, T.A., 1984. *Grief, Dying, and Death: Clinical Interventions for Caregivers*. Research Press.
- Rando, T.A., 2000. *Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones, and Their Caregivers*. Research Press.
- Rath, G., Gandhi, A., 2014. National cancer control and registration program in India. *Indian J. Med. Paediatr. Oncol.* 35 (4), 288.
- Rosenfeld, B., Breitbart, W., Krivo, S., Chochinov, H.M., 2000. Suicide, assisted suicide, and euthanasia in the terminally ill. In: Chochinov, H.M., Breitbart, W. (Eds.), *Handbook of Psychiatry in Palliative Medicine*. Oxford University Press, pp. 51–62.
- Rumsey, S., Hurford, D., Cole, A., 2003. Influence of knowledge and religiousness on attitudes toward organ donation. *Transplant. Proc.* 35 (8), 2845–2850.
- Sahoo, S., Verma, M., Parija, P., 2018. An overview of cancer registration in India: present status and future challenges. *Oncol. J. India* 2 (4), 86.
- Saranath, D., Khanna, A., 2014. Current status of cancer burden: global and Indian scenario. *Biomed. Res. J.* 1 (1), 1.
- Saunders, C.M., 1959. *Care of the Dying: Euthanasia, Control of Pain in Terminal Cancer, and Mental Distress in the Dying*. Macmillan Publishers.
- Scharloo, M., Jong, R.J.B.D., Langeveld, T.P.M., Velzen-Verkaik, E.V., Akker, M.M.D.-O.D., Kaptein, A.A., 2005. Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer. *Head Neck* 27 (10), 857–863.
- Servaes, P., Verhagen, S., Bleijenberg, G., 2002. Determinants of chronic fatigue in disease-free breast cancer patients: a cross-sectional study. *Ann. Oncol.* 13 (4), 589–598.
- Shankar, A., Dracham, C., Ghoshal, S., Grover, S., 2016. Prevalence of depression and anxiety disorder in cancer patients: an institutional experience. *Indian J. Canc.* 53 (3), 432–434.
- Shanmugasundaram, S., Chapman, Y., Oconnor, M., 2006. Development of palliative care in India: an overview. *Int. J. Nurs. Pract.* 12 (4), 241–246.
- Sivesind, D., Baile, W.F., 2001. The psychologic distress in patients with cancer. *Nurs. Clin.* 36 (4), 809–825.
- Slevin, M., Nichols, S., Downer, S., Wilson, P., Lister, T., Arnott, S., Cody, M., 1996. Emotional support for cancer patients: what do patients really want? *Br. J. Canc.* 74 (8), 1275–1279.
- Snyder, C.R., 1994. *The Psychology of Hope: You Can Get There from Here*. Free Press.
- Sunanda, V.N., Priyanka, M., Archith, J., Shravan, M., Rao, A.S., Hadi, M.A., 2018. Quality of life assessment in cancer patients of regional centre of Hyderabad city. *J. Appl. Pharmaceut. Sci.*
- The International Agency of Research Centre, 2018 [Press Release]. (2018, September 12). [https://www.iarc.fr/wp-content/uploads/2018/09/pr263\\_E.pdf](https://www.iarc.fr/wp-content/uploads/2018/09/pr263_E.pdf).
- Torre, L.A., Bray, F., Siegel, R.L., Ferlay, J., Lortet-Tieulent, J., Jemal, A., 2015. Global cancer statistics, 2012. *CA A Cancer J. Clin.* 65 (2), 87–108.
- Weng, L., Joynt, G.M., Lee, A., Du, B., Leung, P., Peng, J., Yap, H.Y., 2011. Attitudes towards ethical problems in critical care medicine: the Chinese perspective. *Intensive Care Med.* 37 (4), 655–664.
- Weng, H., Chen, H., Chen, H.K., Hung, S., 2008. Doctors' emotional intelligence and the patient–doctor relationship. *Med. Educ.* 42 (7), 703–711.