

Perceptions of People with Advanced Cancer on Quality of Death and Dying

Thesis submitted in partial fulfillment of the requirements for the Degree of
Doctor of Philosophy in Psychology

By

MARIA WAJID



CENTRAL UNIVERSITY OF KARNATAKA

Department of Psychology
School of Social and Behavioural Sciences
Central University of Karnataka
Kalaburagi, India - 585367

August 2021

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MARIA WAJID

(PHDPSY1806)

Under the Supervision of

Prof. ROMATE JOHN & Dr. ESLAVATH RAJKUMAR



CENTRAL UNIVERSITY OF KARNATAKA

Department of Psychology
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CENTRAL UNIVERSITY OF KARNATAKA

(Established by an Act of the Parliament in 2009)

Romate John PhD

**Professor & Head, Dept. of Psychology
Dean, School of Social & Behavioural Sciences**



Kadaganchi P.O, Aland Road,
Kalaburgi Dist, Karnataka-585367,
India

Phone: (08477) –22740

Phone no.: 9448936115

www.cuk.ac.in

romatejohn@cuk.ac.in

deanssbs@cuk.ac.in

No: CUK/SSBS/

/ 2021-22

Date: 16-08-2021

CERTIFICATE

This is to certify that this thesis entitled “**Perceptions of People with Advanced Cancer on Quality of Death and Dying**” is a bonafide record of research work carried out by **Miss Maria Wajid**, under my supervision and guidance, and that no part of this has been presented before for the award of any degree, diploma, associateship or fellowship of other similar title or recognition.

Place: Kalaburagi

Supervisor

Date:

Prof. ROMATE JOHN

CENTRAL UNIVERSITY OF KARNATAKA

(Established by an Act of the Parliament in 2009)

Rajkumar Eslavath PhD

Assistant Professor

Department of Psychology

School of Social & Behavioural Sciences



CENTRAL UNIVERSITY OF KARNATAKA

Kadaganchi P.O, Aland Road, Kalaburgi

Dist, Karnataka-585367, India

Phone: (O) (08477) –22740

Phone no.: 7259209285

www.cuk.ac.in

rajkumare@cuk.ac.in

Date: 16-08-2021

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Place: Kalaburagi

Co-Supervisor

Date:

Dr. ESLAVATH RAJKUMAR

DECLARATION

I, Maria Wajid, hereby declare that this PhD thesis titled “Perceptions of people with advanced cancer on quality of death and dying” is an original research work done by me under the supervision of Prof. Romate John, Professor, Department of Psychology, Central University of Karnataka and co-supervision of Dr Rajkumar Eslavath, Assistant Professor, Department of Psychology, Central University of Karnataka. This thesis is submitted to the Central University of Karnataka for the award of the degree of Doctor of Philosophy in Psychology. I also declare that this thesis or any part of it has not been submitted to any other University for the award of any degree or diploma previously.

This thesis is being submitted for the award of PhD Degree in Psychology. References borrowed from the other sources have been duly acknowledged. I also declare that this thesis is free from plagiarism and it is within an acceptable limit.

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Date:

Signature of the Researcher

ACKNOWLEDGMENT

I want to thank the Almighty for providing me with the strength, capacity and the opportunity to undertake and continue my education. It would not have been achieved without his blessings.

I'd like to express my heartfelt gratitude and appreciation for Prof (Dr.) Romate John, my academic supervisor, for guiding and supporting me during this project. Thank you for your constant support and advice, Sir. Without your inspiration, encouragement, and assistance, this research would not have been possible. I'd also like to thank my co-supervisor, Dr. Rajkumar Eslavath, for his kindness, support, and advice throughout the current study. He was continually inspiring me and encouraging me throughout the work. It would have been extremely tough for me to produce this work without his great help. I simply cannot put into words the significance of his role in my research. I'd also like to thank all of the non-teaching staff members at the Central University of Karnataka's Department of Psychology for their assistance and cooperation.

Aside from that, I'd like to thank Dr Srinagesh Simha, Medical Director of Karunashraya, for his attention and support throughout the study period, as well as for providing me with required research facilities. I'd also like to thank Mrs Sarada Lingaraju, Hospice Administrator, Sparsh for her support, collaboration and encouragement. A special thank you to the team at Karunashraya and Sparsh for being very welcoming and cooperative. I would also like to thank the interviewees who volunteered to take part in the interviews to share their experiences and stories.

Next, I'd want to express my gratitude to my parents (Dr Fouzia Choudary Begum and Mr Abdul Wajid) for their unending love and care. They have always encouraged me to pursue my aspirations and explore my potential, believing in me and providing me with the flexibility and space to grow. I'd like to express my gratitude to my brother-in-law, Mr Abdul Majid Maniyar, for his kind assistance and guidance throughout the course. I'd also like to express my gratitude to my father-in-law and mother-in-law (Mr M. A. Nazeer and Mrs Naseemunissa) for their unwavering support and understanding. I'd like to convey my heartfelt gratitude to my husband, Mr Aleem Pasha, for his unending love, understanding, moral support, and assistance.

I am fortunate to have good friends who are always supportive, motivating, and cheering me up in all circumstances. I like to thank my friends Mrs Deepthi D.P, Mr Suhail Samad, and Mr Allen Joshua George, who assisted me in several different ways throughout my PhD.

Finally, I would like to convey my heartfelt gratitude to those whom I may have forgotten to mention by name, but who assisted me greatly in completing this PhD research work, either directly or indirectly.

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ABSTRACT

Introduction: The thought of dying causes constant nervousness and fear of death. Patients are unable to confront their emotional anguish, and death terror is alarmingly high. When death is viewed as a mark of failure rather than as an integral part of life, people are diverted from preparing for it. An overhaul of the standard notions of death is required, which is critical to developing standard procedures of empathetic care for the dying. In the final stages of a dying person, healthcare professionals should facilitate individualized care because caring for the dying patient and depressed family demands specialized skill-sets. More research is needed to examine the concept of a good death from the perspective of terminally ill patients to provide quality treatment that is personalized to patient needs. To generate fresh insights on this important concern, this study seeks to investigate the perspectives of patients with advanced cancer on the quality of death and dying.

Aim: To explore the views of patients with advanced cancer on the quality of dying and death

Methodology: The current study adopted the explorative research method. Twenty-one participants who lived in South India were selected and semi-structured interviews with patients were conducted to collect data. The data was put to a thematic analysis. Subsequently, patterns were established to identify common themes emerging from the data.

Results & Findings: 7 themes emerged from the thematic analysis. They are Goals and ambitions in life, Current priorities in life, Views about life, Views on approaching death, Good death, Needs at end of life and Preparation for death. In several themes, a specific sub-theme was demonstrated with direct citations from the interviewees.

Conclusion: The study gave a thorough overview of death due to advanced cancer at the end of life and the quality of dying. In the light of existing literature, it generated fresh insights directly from the affected population on what factors go into a good death and how it could be attained. Learning about patient experiences provided insights into the formulation of a better strategy and action plan to improve the quality of death in the context of the Indian population. This qualitative research has also generated fresh insights into the integral values, beliefs, apprehensions, and vulnerabilities of terminally ill patients in the twilight of their lives, which can help to establish refined and standard procedures for a good death.

Keywords: Quality of death and dying, advanced cancer patients, desired death, palliative care needs.

Chapter I

INTRODUCTION

An illness or disease directly affects the functioning of the human body. It may be possible that disease can occur due to pathogens and internal dysfunctions. Every disease has its specific symptoms and markers through which the medical condition can be gauged (Bentley, 2017).

Communicable Diseases

Communicable Diseases (CD) spread from one person to another primarily through contact via body fluids, blood, and breathing virus-infected air or through an insect bite. The world has witnessed a range of communicable diseases, and for a long time, communicable diseases have contributed to numerous deaths around the world. As a result of advances in medicine as manifested in the development of antibiotics, vaccines, and improved health and hygiene, communicable diseases have become controllable to a considerable extent but with certain precautions (Jones et al., 2003).

It is observed that despite having developed vaccinations, communicable diseases have gone beyond manageable limits in many countries which are on the road to development (Jones et al., 2003). While developing countries are battling communicable diseases, Non-communicable Diseases (NCD) have been on a steady rise in industrial countries, so much so that NCDs pose a major public health challenge to the developed world (Boutayeb, 2010).

Non-communicable Diseases

41 million people die annually from Non-Communicable Diseases (NCDs), which amounts to 71% of deaths worldwide. NCDs take away 15 million people every year between the ages of 30 and 69, of which 85% occur in low and middle income countries. Every year, 17.9 million people are affected by cardiovascular diseases, cancer (9.3 million), respiratory

diseases (4.1 million), and diabetes (1.5 million) (World Health Organization [WHO], n.d.-a). According to forecasts by the WHO, the annual overall deaths from NCDs will climb to 55 million by 2030 if prompt measures for NCD prevention and management are not implemented (n.d.-a).

Most NCD-related deaths occur in poor and middle-income nations, such as India, which are undergoing an epidemiological transition as a result of growing urbanisation and has resulted in overall economic growth, but with certain accompanying drawbacks (Chakma & Gupta, 2014).

India, with a population of around 1.3 billion people, accounts for more than two-third of all NCD fatalities in WHO's South-East Asia Region (SEAR) (WHO, n.d.-e). According to the 2011 report on NCD status in SEAR, high blood pressure, high blood glucose, and cigarette use were the three leading risk factors responsible for the majority of deaths in this region every year (Nethan et al., 2017).

In India, NCD mortality accounted for 65 percent of total deaths in 2019 and the illness burden shifted from communicable to non-communicable diseases over 26 years (1990-2016). Total disability-adjusted life years from NCDs were 30.5 percent in 1990 and 55.4 percent in 2016 (Public Health Foundation of India, n.d.). The population attributable fraction (PAF) for smoking-related cardiovascular disease and cancer was 15.5 percent and 39.8 percent, respectively (Choudhury & Roy, 2016).

The chief behavioural risk factors for NCDs include physical inactivity, poor diet (low in fruits, vegetables, and whole grains but rich in salt and fat), tobacco use (smoking, second-hand smoke, and smokeless tobacco), and hazardous levels of alcohol consumption. They lead to high blood pressure (hypertension), diabetes, high and abnormal blood lipids (dyslipidaemia), and obesity. Air pollution is also a major cause of NCDs, both outdoor and

household air pollution. Solid fuels for cooking or heating has been the primary source of household air pollution. While the majority of NCD morbidity and mortality occur in adulthood, susceptibility to risk factors begins in childhood. NCDs are rapidly spreading around the world and have reached epidemic proportions in several countries, shaped by the forces of globalisation, industrialisation, and fast urbanisation, as well as demographic changes (National Health Portal of India, n.d). As a result, understanding NCDs and their risk factors in the context of young people are extremely important.

The governments and health professionals need to keep up with the growing need for policies, services, and infrastructural systems to avert a surge in NCDs (Alwan, 2010). The WHO urges policymakers to develop effective and competent policies to battle chronic NCDs (Beaglehole et al., 2011). The world needs a concentrated, planned, and multi-sectoral framework to halt the negative trends of NCDs as evidenced in the growing incidence of cancer (Yach et al., 2004).

Cancer: Incidence and Prevalence

Cancer affects the lives of millions of people the world over. The term cancer was coined by Hippocrates in the fifth century BC to describe a type of tissue dysfunction that spreads uncontrollably throughout the body (C Vanlalhruii, 2018). Cancer is a condition that causes abnormal cells to proliferate uncontrollably and spread throughout the body. Cancer cells can develop from a variety of tissues and organs (Kliensmith, 2014). Cancer comprises of a range of diseases characterized by uncontrolled cell growth that destabilizes a fully functioning body, and with fatal outcomes. There are over a hundred different forms of cancer documented (C Vanlalhruii, 2018).

One out of every 5 people will acquire cancer throughout their lives, and one out of every eight men and one out of every eleven women will die of cancer, according to the

International Agency for Cancer Research (IARC, 2020). Currently, more than 50 million people are leading their lives within five years of a cancer diagnosis. An ageing global population and socioeconomic factors continue to be major drivers of the occurrence of cancer (Union for International Cancer Control, 2021).

Cancer diagnoses have almost doubled in the past decade, from 10 million in 2000 to 19.3 million in 2020. The International Agency for Research on Cancer estimates the global cancer burden at 19.3 million in 2020, with 10 million fatalities. The number of diagnosed cancer patients is projected to rise in the next few years and would be almost 50% higher in 2040 than in 2020. By 2040, the number of cases is projected to reach 30.2 million (WHO, n.d.-b).

The most prevalent causes of global cancer mortality in 2020 were lung (1.80 million deaths); colon and rectum (935 000 deaths); liver (830 000 deaths); stomach (769 000 deaths); and breast (685 000 deaths) (WHO, n.d.-a). India alone has contributed to 1.32 million cases and 8,52,000 deaths; by 2040, India is expected to have 2.09 million cases and 1.38 million deaths (Saranath & Khanna, 2014). Data from GLOBOCAN 2018 suggest that the most pervasive forms of cancer in the Indian context for both sexes are breast cancer (14%), oral cancer (10%), cervix uteri (8.4%), lung (5%) and stomach (5%). The most prevalent cancers in the male population are oral cavity (16.1%), lung (8.5%), stomach (6.8%) and colorectum (6.4%) and among females are breast (27.7%), cervix uteri (16.5%), ovary (6.2%) and oral cavity (4.8%) (Globocan, 2018). Since the risk of cancer develops with age, it impacts longevity as well (WHO, n.d-e).

The burden of cancer is growing internationally, and families, communities and health systems are under immense strain. The burden is disproportional for health systems in developing societies weakened by poverty and unstable incomes, and many cancer patients

have no access to quick detection and treatment. With early detection and quality treatment, the survival rate can improve in countries where many malignancies are robust (WHO, n.d.-a).

Averaging or avoiding important risk variables and applying current, evidence-based prevention methods can prevent 30 to 50% of cancer deaths. Early detection and the management of cancer patients can minimise the burden of disease. Prevention is the most cost-effective long-term cancer management option (WHO, n.d.-a).

Given the advancements in cancer research, it is certain that a third of cancers are preventable, and the other one-third possibly cured with early diagnosis (Nair et al., 2015). If the cancer is diagnosed at a later stage it progresses to terminal cancer. Terminally ill cancer refers to cancer that is not curable or treated medically. At this point, no cure or treatment is effective and is referred to as end-stage cancer (Holland, 2018).

Regretfully, in India, cancers are mostly diagnosed at later stages post which the treatment becomes expensive causing an increase in morbidity and mortality rate (Nair et al., 2015). However, there are many ways to make the experience of the disease less painful, which involves downsizing the effects of cancer through medication and palliative care. While a section of the doctors still administers radiation and chemotherapy, this cannot be a feasible option overall, although it might help in many cases depending upon the degree of illness (Holland, 2018).

Association of Psychological Factors in Terminal Cancer

Psychological factors are made up of an individual's ideas, feelings, and other cognitive traits that influence their attitudes, behaviour, and functions.

Diagnosed from a terminal illness like cancer leaves an unsuspecting individual shattered, turning the person's whole life upside down. At the break of the bad news, the

patients find themselves stunned and shocked, mired in a state of overwhelming emotions and breakdowns (Zanni & Wick, 2010). Not only does cancer disrupt the physical functioning of a human being, but it also hampers mental functioning. Having both physiological and psychological consequences on patients, cancer-related adverse effects are more pronounced compared to other common terminal illnesses. According to research, 35-45 percent of all cancer patients, regardless of the stage or kind of cancer, will endure psychological anguish during the disease (Kissane et al., 2004). Research done by Yun et al. (2010) stated that patients experienced misery (44.2%), depression (39.2%), frustration (28.0%), and feeling of loss (24.3%) at the time of receiving the bad news.

Patients with advanced cancer suffer from emotional anguish and cognitive disorder (Grabsch et al., 2006). Mental impairment is most seen during the time of diagnosis. At least 44% of the patients experience cognitive impairment and about 62.1% develop the same before death (Bruera, 1992).

An oncologist needs to look for mental and emotional distress in cancer patients so that the treatment is more effective (Miovic & Block, 2007). If emotional and mental disturbances are not addressed at the right time, then they may disturb the quality of life of the affected (Grabsch et al., 2006). Unfortunately, most of the time, doctors do not acknowledge emotional pain and depression in patients (Sollner et al., 2001). Patients undergoing the effects of the illness also experience bodily transformation besides mental challenges that may surface as anxiety, depression, and fear of unbearable pain (Classen et al., 2001).

A study shows that 48% of cancer patients meet the criteria of clinical depression, and 25% suffer from persistent anxiety, which is a treatable condition (Block, 2000). Among the aged, the psychological responses in dealing with pain are linked to suicidal thoughts (Zanni

& Wick, 2010). Conventionally, the interpretation and assessment of psychological distress are seen as psychological disorders or psychological morbidity, especially for depression and anxiety. The prevalence ratio of anxiety disorders ranges from 1% to 49% among all cancer patients (Zabora et al., 2001).

Various studies have gone deeper into understanding the mental make-up of cancer patients that show that for almost half of the oncological population, anxiety, depression and adjustment disorders may trigger an extreme psychiatric form of mood disorders, and this can climax in suicide if not adequately treated. Depression among cancer patients ranges from 4.5 to 58% and it is observed that depression leads to cognitive deficits in the patients (Levine et al., 1995). Depression shortens the survival span (Stommel et al., 2002) and reduces the commitment to treatment protocols, which invariably extends hospitalization (Pelletier et al., 2002).

Cognitive failure is exceptionally common before death in patients with advanced cancer, therefore, psychological capacity ought to be consistently observed (Pereira et al 1996). People with advanced cancer become very negative, tend to view life from a disapproving lens, (Mahon & Casperson, 1997) and regard life situations as devoid of all meaning and hope (Morita et al., 2000). In this context, the existentialist idea that death can be dealt with by conquering psychosocial problems can enable a more peaceful process of dying (Flemming, 1997).

Patients struggle not knowing how to confront mental discomfort, and death anxiety is amazingly high (Walker et al., 2011). A growing sense of uneasiness with death at the centre stage influences the joy and well-being of the individual. Persistent thoughts of death bring in acute nervousness and anticipation of death with dread, also known as fear of death/death

phobia. Despite being a shared concern among terminally ill patients, individuals tend to have a distinct response to it (Sherman et al., 2010).

Hopelessness is defined operationally as negative expectations. Hopelessness exerts a stronger influence on suicidal intent than depression (Beck, 1975). Oncological patients could have suicidal intent at any point of their illness. Self-retraction, poor confidence, inability to manage with feelings, and social disconnection and dissatisfaction are five more variables that are related with suicidal trends (Nabipour et al., 2018).

The extent to which suicidal ideations and death anxiety overwhelms the patients depend upon the mental and physical state of the patients. This leads to psychological imbalance and physical uneasiness. Hence, it is of utmost importance to evolve effective methods that can resolve these tendencies in a patient. The latest research suggests that cognitive therapy which is grounded in mindfulness can play an integral role in lowering death anxiety and suicidal thoughts among patients with cancer (Nabipour et al., 2018).

Morita et al. looked at patients from a Japanese hospice to comprehend the nature of their distress. The thoughts that governed such patients include distress over being dependent on others and the feeling of being a burden on family and friends. The sense of being socially non-functional push them to count themselves as irrelevant (Morita et al., 2000). Likewise, Flemming (1997) found that the patient's concerns over having lost control over the present illness were directly linked to their foregone conclusion of not having any kind of future ahead. Therefore, it is vital to create the necessary conditions for oncological patients to develop a sense of control and hope.

Associations of Positive Psychological Virtues in Terminal Cancer

According to Lin & Bauer-Wu (2003), the sense of hope and finding meaning in life are essential to feeling the experience of patients with terminal cancer. The study showed that

patients who find meaning and hope experienced high psychosocial well-being. This is encouraged by different components such as optimistic associations with near and dear ones and keeping up a normal routine in everyday life. Greisinger and colleagues (1997) reported that it is essential for terminally ill individuals to be hopeful, knowing that life has a meaning and purpose and believing that it has been meaningful. Some studies reveal that the meaning of life and hope in patients help them adapt to cancer (Taylor, 1993), reduce mental pain and improve psychosocial well-being and quality of life and build a sense of a good death (Morita et al., 2000).

Benzein et al. (2001) explored what hope means to patients in palliative care. Patients who were deeply aware of the situation they are in and their revised timeline attempted to fully live in the present. They concentrated on achieving small milestones daily instead of planning for longer periods. Their awareness of being terminally ill awakened integral inner aspects such as wanting to be a spiritual, philosophical exploration into the meaning of life, and for some the possibility of life after death. These factors may drive many patients to face their terminal illness by streamlining their presence holistically and with the hope of life in the hereafter.

Different studies demonstrate that keeping up control and maintaining normalcy in day-to-day-life shifts one's point-of-view of the present life and future (Benzein et al., 2001). It cultivates belief in the prospect of treatment (Flemming, 1997), and reinforces faith (Ballard et al., 1997), which are all indicators of the patient who has developed a sense of the meaning of life. When a patient regains meaning and hope, it gives birth to a feeling of happiness and internal harmony which results in psychological well-being. Miller et al. (1989) recognize that an optimistic strand can be very influential to a patient's psychological wellbeing; studies have provided evidence to suggest that optimism is fundamentally linked

to high levels of psychological adjustment. It is positively connected to mental well-being and shares a negative relationship to mental misery (Miller et al., 1996). According to Yeung and Ying (1999), being optimistic, having a peaceful mind, joy and being carefree, along with a note of satisfaction and well-being enhance the quality of life. The capacity to feel happy and celebrate every aspect of life was indicative of the individual being alert to deeper meanings of life and the prospect of a contended death (Mahon & Casperson, 1997).

It is found that self-assurance and being confident are strong suits while battling terminal cancer. The cultivation of these qualities requires financial stability, feeling of independence, self-confidence, happiness, peace of mind, self-respect, completing unfinished businesses and hope of survival (Lin & Bauer-Wu, 2003). Studies conducted on advanced cancer patients by Morassa and colleagues (1999) showed that emotional help and connections with others played a vital role in enhancing well-being. The hope to live and conduct life's affairs appeared to relatively improve prosperity and decrease mental distress (Thomas & Retsas, 1999).

Providing physical solace, relieving emotional stress, managing anxiety and depression, and helping patients to lead harmonious lives are the main objectives of palliative care (Clayton et al., 2005). Upon interviewing 20 patients in a state of recurrent cancer, Mahon and Casperson (1997) noted that patients who possess comprehensive awareness of the illness and its effects retained appreciation of their lives during a recurrence. Also, by accepting the fact that they are ill and continuing to work on themselves physically and mentally to have a peaceful coexistence with cancer, they learn to live with it.

The studies by Payne et al. (1996) observe that the patient's knowledge of their impending death generates both comfort and discomfort. Bishara et al. (1997) used a triangulation approach to generate a path-breaking insight that when a patient's body and

psychological state are synchronized, things tend to work in tandem, which helps patients to enhance their mental wellbeing. If truthful doctor-patient communication is in place, the patient could feel hopeless and shattered at the outset, especially following a diagnosis. As the patient's level of hope, positivity, sense of life's meaning and unfulfilled duties or accomplishments come into the picture, then the psychological aspect of knowing the truth kicks in. The patient being positive thinks that there is nothing worse that can happen and may seek out certain unfulfilled accomplishments from what little is left of life. This kind of positivity stirs the drive within oneself to stay focused to achieve as much as the patient can within a limited time. This factor helps the patients to grow mentally sound and also helps to better the projected time left, not perhaps by an astounding number but yet to a considerable extent. Studies have found that knowing and appreciating reality can contribute to social and psychological well-being (Aoki et al., 1997).

The state of being connected to people can enhance the patient's sense of hope (Benzein et al., 2001; Flemming, 1997). Studies reveal that maintaining a close relationship with the family and receiving familial support was fundamental in regaining meaning and hope among advanced cancer patients (Ballard et al., 1997; Benzein et al., 2001). Good family support was a fundamental indicator of the quality of life in critically ill cancer patients. Several patients who maintained healthy relationships and connections with others around them also enjoyed a good measure of the quality of life, helping them to cope with psychological distress, depression and stirring emotional reboots to cope with terminal cancer (Giese-Davis et al., 2000).

Terminal illnesses and their diagnosis are very stressful for patients and also to their families, thereby generating diverse emotions such as depression, anger, anxiety, and helplessness (Slevin et al., 1996). One of the most influential factors that can curb negative

responses to terminal diagnosis is hope (Chi, 2007). The importance of hope is established during the treatment given during therapy (Miller, 1989).

Difficult and unpleasant situations are a part and parcel of a cancer diagnosis, but during this phase, hope is said to be the most significant factor needed to move on with life. It is an essential element in coping with illness in general, and for the terminally ill in particular. Though definitions of hope are varied, the following definition encapsulates the sense in which it is used in this study: “the expectation of achieving a future good that seems realistically possible and is personally significant” (O’Connor et al., 1990). The concept can be further broken down into overall hope and specific hope that is directed towards achieving a definite goal (Clayton et al., 2005). A sensible approach would be to recognize that hope itself yields to multiple connotations, ensuring to underscore the patient’s understanding of hope rather than force-feed them to external notions (Elliott & Olver, 2002).

Hope is fundamental to moving forward in any stage of life, which helps individuals deal with the vicissitudes of life. Among the terminally ill, hope serves as a boon to ensure the mental stability of the patients. It acts as an integral layer of the spiritual dimension for some and has direct relevance to the end of life (Kernohan et al., 2007). Patients with cancer who are mired in hopelessness may seek hastened death and exhibit suicidal tendencies (Breitbart, 2000). Hopefulness is a way through which the terminally ill can help themselves cope with the pain and at the same time can have a sense of meaning, goals, and self-worth (Duggleby, 2000).

Quality of Dying and Death

Terms like “good death,” “dying well,” “peaceful death,” “suitable death,” “desired death,” and “dignified death” are often used synonymously in the medical literature (Kehl, 2006), in articles, essays, and letters from the 1960s onwards. These included literature on

nursing, medicine, conduct and psychiatry. The expression "good death" was at the time applied to euthanasia, interchangeably with references to situations of active or passive termination of life (Kehl, 2006).

The concept of "good death" became increasingly used in common parlance from the 1980s. While euthanasia was still used (Slater, 1987), others had begun to address what constituted a good death. The discussion on good death was initiated by the writers in oncology (McCorkle, 1981; O'Neil 1983), who regarded death to be good when the timing of death was acceptable when the death process allowed a person to maintain control and stakeholders of the death process observed fundamental moral principles and the person's death style did not defy standard logic. This was also the first attempt to describe a good death. O'Neil was primarily reflecting on the necessary conditions to administer euthanasia, but his formulation of a good death had potentially greater implications. His definition foreshadows later theorizations and is integral to the current understandings of good death, particularly with reference to the issues surrounding the timing of death being appropriate and the dying person retaining necessary control. The Institute of Medicine defines good death as a death free of preventable suffering for the patients, their family members and different caregivers; it attends to the patients' and families' wishes and retains clinical, cultural, and ethical standards (Field & Cassel, 1997).

When dealing with the subject of "good death," terminal palliative care authors are consistent in characterising the broad characteristics of an ideal dying trajectory. They involve knowledge, autonomy, an independent approach and open and honest communication (Goldsteen et al., 2006). The quality of dying requires care for pain and symptoms, clear decisions, preparation to die, feeling of completeness and a person's participation in others.

The above six topics include process, biological, mental, social and spiritual (Steinhauser et al., 2000).

In the light of substantial reviews of existing studies and through a string of qualitative studies, Patrick and Curtis came up with a calculation of the “quality of dying and death” to assess how a person’s inclinations for dying and timing of death correspond to the actual death based on observations by those took part in the dying process (Patrick et al., 2001).

When death is considered as a mark of failure and a point of mourning instead of a significant aspect of life, people distance themselves from embracing it and medicines can do nothing much at that point to assist people to have a good death. There is a need to revisit the idea of death and evolve fresh attitudes to dying. Studies have underlined the need to reclaim death from extreme medicalization, professionalization and sanitisation, which distances it from routine human existence (Henwood, 1999).

More than a third of patients with end-stage conditions may be sad and more than one half of patients with advanced carcinoma feel uncomfortable, anxious. Furthermore, the rates of suicide for terminally ill people are higher than in the normal population and are partly linked to increased depression, psychological suffering and poor pain management (Kutner, 1969).

Spiritual and existential concerns in the context of illness and death refer to how people in their lives find meaning, purpose and worth. They can be specifically religious, but even those without religious beliefs per se share moral and ethical convictions with which they ascribe meaning and purpose to life. This has been recognised over the years by the healthcare profession (Emanuel & Emanuel, 1998).

A valid assessment tool including the main features of death, while being easy enough to use in clinical practise, must be built. The most effective screening techniques and treatments for dead individuals are important to discover (Breitbart et al., 1995). The quality of the experience and even the timing of their death should be shaped by important milestones such as personal and family events. Clinicians are aware of the relevance for patients who die of future milestones or "the unfinished family business" which affect decisions and experiences and can even postpone death. Studies have indicated that after important family occasions such as birthdays or holidays, death tends to occur (Emanuel & Emanuel, 1998).

Denial of prognosis may obstruct communication and preparedness for death, as well as lead to unreasonable requests for treatment. The physicians do not randomly acquire proficiency in dying care through chance meetings with mentors and patients but it should be an intrinsic component of a methodical educational programme (Emanuel & Emanuel, 1998). Clinicians must obtain communication training, specific communication strategies tailored to the needs of terminally ill patients. Clinicians must be at ease discussing the dying process with patients. This training must include systematic procedures, commonly referred to as steps or talking points, for physicians to employ when giving bad news and discussing advance-care planning (Emanuel & Emanuel, 1998).

The physicians should be sensitive to the dying patient's need for making plans, addressing spiritual concerns, and expressing sympathy. Training programmes must also teach physicians how to use standardised assessment methods for physical and mental symptoms in dying patients, as well as how to institute suitable treatments for such symptoms (Emanuel et al., 1995).

Developed nations can make a good death the standard of care. Clinicians recognise the multiple nature of care and the need to deal with concerns besides pain; the hospices are readily available and are increasingly used; advance-care planning has been a priority and medical schools are becoming increasingly aware of health problems. Peaceful death is not an unattainable prospect in the modern era but it is not a promise for all terminally ill patients at this point. The existing framework can help with applying different criteria for a decent death and lead to further study, training, design and refurbishing of health systems so that the promise becomes a reality (Emanuel & Emanuel, 1998).

Until the 1970s, death was hardly a topic of conversation in health care. Physicians largely avoided directly confronting terminally sick patients with the news of their impending death but rather focussed on giving them hope of a genuine chance of recovery. Physicians felt that crushing someone's hope for recovery suggested an overburdening of the emotional life, which would result in a painful death (Wouters, 1990). However, Weisman (1978) opposes the quiet that surrounds the dead in his book *On Dying and Denying*. He contends that ignoring death and being silent may heighten dread. Instead, caregivers and relatives should assist patients in accepting death in a balanced and tranquil manner.

Role of Psychologist

Several key insights into the psychosocial challenges facing chronic patients have shaped end-of-life psychological practice. Psychologists are already involved in treating chronic diseases, such as cardiovascular diseases and cancer, which are currently the major cause of mortality (Federal Interagency Forum on Ageing-Related Statistics, 2000). The treatment of heart disease, cardiac diseases, cerebrospinal disease, cancer, AIDS, dementia,

diabetes, breathing difficulties and multiple sclerosis, among others, contributes significantly to patient and family therapy (Carnic, 2004).

Group interventions were made up of psychotherapy to train in adjustment responses, anxiety, and depression, neuropsychological and other assessments, stress and pain management, and family and group psychotherapy (Carnic, 2004). The active participation of psychologists in the treatment of chronic diseases has been reinforced by a second major development: the advent of the biopsychosocial model in medicine and clinical health psychology. The biopsychosocial model, with its emphasis on psychological and behavioural variables, underpins and directs the innovative and crucial role played by psychologists in disease prevention, improving health and nurturing care closer to death (Sulmasy, 2002).

Psychologists can help patients and families at four points in their lives: (a) before sickness occurs, (b) once disease is identified and therapies commence, (c) throughout terminal illnesses and the dying process and (d) devastated near and dear ones following the death of the patient. These interventions take place in the community, in private practice, general outpatient clinics, hospitals, palliative care and hospice programmes, and nursing homes (Haley et al., 2003).

Some psychological difficulties pertinent to end-of-life care could be encompassed under established diagnostic modalities, such as depression or cognitive impairment; others, while equally significant, are more abstract and elusive. Existential concerns in patients include the patient's outlook towards his or her imminent death, which include the individual's notions of the meaning of death and accompanying emotional reactions to its immediacy. Based on the work on death attitudes and death anxiety, psychologists can be instrumental in delineating factors that generate existential pain and anxieties as death approaches, as well as creating and assessing intervention options (Haley et al., 2003).

To enable a moment of reprieve before death, psychologists can increase care for dying patients and family members. The conceptual framework for "a good mortality" is set by E. J. Emanuel and Emanuel (1998) which presents six major modifications to the patient's experience consisting of bodily markers such as fatigue and pain, mental health and cognitive symptoms such as anxiety, depression and uncertainty, social relations and support, economic demands and care needs, hopes and expectations, and spiritual needs. Patient interviews have highlighted their priorities, with patients mostly seeking a sense of control (Singer et al., 1999) and retaining personal worth. Unfortunately, many of these needs are not attended to. 20-70% of patients nearing death do not have the luxury of relieving their pain, one-third of patients nearing death turn out depressed, and 35% have unfulfilled emotional needs (Bradley et al., 2000). The greater prevalence of unattended yearnings and preventable suffering is distressing as many of the situations discussed by E. J. Emanuel and Emanuel (1998), which are seconded by patient observations, yields to assessment and intervention.

Research Gap

The notions of good dying and a good death are ambivalent. Neither mortality theories nor past studies seem to provide sufficient answers to what the patients who die think and how they deal with imminent death. More investigations into the concerns of dying patients are essential if psychological care is to be optimised (Moestrup, 2014). The strong consensus is that the idea of a decent death is relative and shifting, based on perspective and experience (Kehl, 2006).

The review argues that more research is needed to look at the idea of a good death from the perspective of patients to provide high-quality care that is customised to fit the requirements of every patient. Well-designed studies that study the idea of successful death by enumerating and assessing patients themselves both qualitatively and quantitatively could

influence mental health professional practices and aid members of the family to satisfy the demands of their dying loved ones (Meier et al., 2016).

The thought of dying causes constant nervousness and fear of death. Patients are unable to confront their emotional anguish, and the dread of facing death is quite acute. If death is viewed as a matter of failure rather than an integral aspect of life, people will never prepare for it. It is, however, critical to developing good care for the dying. In the final period, healthcare professionals should arrange suitable care for each patient because coping with the dying patient and depressed relatives' demand a holistic skillset. More research is needed to examine the concept of a decent death from the perspective of patients to provide high-quality treatment that is personalised to meet the requirements of each patient.

This study investigates the perspectives of dying patients with advanced cancer on the quality of death and dying. The study attempts to uncover how the illness altered the patients' perspective of life, their aspirations, what they consider to be necessary conditions for a decent death, and how they wished to be cared for and supported at the end of life.

Chapter II

REVIEW OF LITERATURE

This chapter describes the available studies on this topic, summarises, assesses and clarifies them. It also provides a theoretical basis, crucial data, and supportive ideas. In the current study, the researcher has examined reviews of research papers available in the field of psychology in palliative care. Publications have been selected from research databases including Research Gate, Google Scholar, JSTOR, EBSCO and PsychInfo. The study combined several datasets using keywords such as death and dying, palliative care, hospice and quality of life at end-of-life care.

The aim is to critically analyse and examine prior conceptual and empirical investigations on the current topic. The current study examines the main methodological limitations and conclusions for prospective studies, which previous research has indicated, to identify and define the research gap.

This chapter covers a range of research from the domains of mental health, death and dying, and palliative care. It will allow the reader to gain a thorough overview of the past studies on the topic. The principal objective of this chapter is to investigate the characteristics of the sample from both past and present research. The empirical investigations and how they are related to the variables used have been highlighted in this chapter.

Cancer can be looked at as a life-changing disease and more often than not it upsets the status quo, challenges one's view of the world, influences the way one looks at oneself and to the future. The wide-ranging challenges posed by the occurrence of cancer are portrayed by various common factors that have been documented through patients living with cancer that includes hopelessness, fear, isolation, depression, shock, anger, vulnerability, and the search and uncertainty over the meaning of life (Halldorsdottir & Hamrin, 1996).

Human beings are constantly aware of the forces of societal morality shaping them in different ways (Langner, 2013), while patients who are terminally ill are forced to confront the moral aspects of life in no uncertain terms. As a patient is diagnosed with a terminal illness, which seems a crisis to both patient and her family, life for the patient immediately boils down to unfulfilled commitments or aspirations, especially with the revised projection of time at one's disposal (Emanuel et al., 1996).

Mental suffering is a standout feature amongst the most critical and possibly remediable obstructions in the dying procedure of patients in advanced stages of their disease and their relatives (Pessin et al., 2002). Common mental issues during dying involve depression, anxiety, suicidal ideation and delirium, all of which might develop in the course of a terminal sickness. Various medical and psychosocial problems can prompt these issues, including side effects of medicines, the impedance of the physical body, patient dependency on others, mourning, and family impairment. All these and more factors co-occur most of the time amid an advanced ailment and can accrue different forms of mental distress (Jacobsen & Breitbart, 1996). However, despite the significance of distinguishing and treating end-of-life challenges of the mind, mental clinicians frequently get less instruction or preparation in the assessment or treatment of the psychological issues in individuals nearing death (Pessin et al., 2002). Those people with terminal illnesses very often experience anxiety because of shortness of breath, medicines, fear of death, and vulnerability for the remainder of their lives (Holland & Chertkov, 2001). Persistent nervousness may emerge because of disease-related stressors like adjustment disorder (Payne & Massie, 2000). Spurred by the fear of the deadly disease, problems concerning inability, defacement, and dependency, are worsened by the fact of impending death (Pessin et al. 2002). Anxiety is usual in patients receiving palliative care and may diminish a patient's resilience for physical tension, significant pain, and may

considerably hinder optimal performance in different aspects of life and routines (Craske, 1999).

About half of the terminally unwell patients are anxious, irritated, and nurse a tragic feeling. Whereas, a third of the patients may be depressed. To add up to these woes, data suggest that the suicide rate is high among advanced cancer patients when compared to normal people. These patients might be unable to control pain, psychological distress, and depression (Donnelly et al., 1995). A difficult part of end-of-life care includes the patient's wish for a hastened death. Under unbearable pain, considerations of suicide recur and may fill in as a way of dealing with stress for some patients, enabling patients to articulate the level of suffering they are experiencing.

Investigations on patients having advanced cancer and AIDS have shown a longing for a hastened death. Suicidal tendencies in such patients correlate to an extreme form of depression (Breitbart, 2000 & Rosenfeld, 2000). Some studies locate depression to be a significant driver steering a desire for death (Breitbart, 2000). Understanding what causes patients with advanced illnesses to yearn for death has important ramifications for palliative care professionals and also legal and healthcare policymakers. Despite legitimate restrictions against assisted suicide, a significant number of patients consider and talk about the likelihood of assisted death (Breitbart & Sparrow, 1998). Numerous doctors recognize that many patients who convey considerations of suicide or even plea for assisted suicide do not have intentions of dying (Foley, 1995), but are seeking relief and help.

As a person is diagnosed with terminal cancer, sharing the news with that person is a vital cog in the future course of his existence, and influences the way the person views hope, well-being, spirituality, depression and mental distress. Classen et al. (2001) reported that suppressing emotions can lead to oscillating moods in female patients who have terminal

breast cancer, and this despite their tendency to fail at reporting their level of anguish. Clark and Watson (1991) found that repression of adverse feelings leads to depression and anxiety. On the other hand, endeavours at enthusiastic articulation were identified with better quality of life, much less disturbance in mood, and high hopes. These findings prove that regulation of emotions promotes better adjustment to life-threatening diseases (Stanton et al., 2000). The mood disturbance is prevalent among patients, and to repress or regulate negative influences may contribute to emotional distress in various ways. However, a suppressive emotional regulation strategy might work in certain exceptional situations (Valliant, 2000). Articulation of essential negative feelings, for example, fear, sorrow, or rage, may give rise to catharsis (Greenberg & Malcolm, 2002).

The existence of mental misery, even at a moderate level, can significantly affect the person in the twilight of life. Numerous individuals report a decline in joy, gratification, personal worth, and capacity to build associations with people and refer to these challenges as negatively affecting their general personal satisfaction (Breitbart, 1995). For instance, a patient's attempt at an emotional goodbye may end up in emotional misery. Mental trouble appears to enhance pain as well (Massie & Holland, 1992). In extraordinary cases, the sufferer's capacity to adopt logical treatment choices might be undermined by mental symptoms, causing specific issues amid advanced phases of the disease because several crucial medical decisions come up during the end of life. Psychiatric issues likewise prompt elevated pressure and stress among loved ones, and, this, in turn, leads to distress in the patients (Block, 2000). It has to be noted that acute mental trouble is a crucial driver of suicidal ideation, appeals for assisted suicide, and a desire for early death (Rosenfeld, 2000).

In 2006, Sand and Strang employed a qualitative method to inspect the perceptions, experiences, and emotions of terminally ill patients and also to incorporate the experience of

the family who relied on palliative care centres. When their experiences were studied as a whole, the participants appeared to be mired in intense loneliness and with an elevated level of anxiety. An investigation by the researchers concluded that palliative care was a medium to address these issues concerning fear, loneliness, and anxiety. All these factors were addressed and also reduced. The study makes it clear that the feeling of not having accomplished life's goals leads to unsatisfactory death. Nevertheless, only very few studies have investigated the components of a decent death (Miyashita et al., 2008). A good death is one in which the person is mindful about his death, acknowledges it without hostility, organizes one's will appropriately, and times the death fittingly (Weisman, 1988).

In the Western world, extensive measures were adopted to conceptualizing what constituted a good death (Patrick et al., 2001; Teno et al., 2001). Quantitatively, Steinhauser et al. (2002) have explained significant variables that impact end of life care. Furthermore, they have estimated the accomplishment of a desirable death by terminally ill patients (Steinhauser et al., 2004). For patients approaching death, some of the significant palliative goals include guaranteeing professionally informed end-of-life care and a decent death, time to time assessments and management of death uneasiness (Lehto & Stein, 2009).

Denial

Some patients use denial as a method for treatment, and although denial is not conducive at all times, it enables patients to live today and overlook unfavourable results (Block, 2006). While they are diagnosed to be incurable, they aggressively reject the conventional notion of accepting the state of dying. It is tempting to view this reaction as a form of denial and inadequate management of medical facts in psychological terms. But such a reaction should equally be understood as a question of will rather than a lack of understanding (Goldsteen et al., 2006). There are two ways of looking at this: denial as a

means of psychological coping and denial as a barrier to palliative treatment. In conventional terms (Zimmermann, 2004), negation is portrayed as an unconscious and healthy psychological condition at the onset of a terminal disease, but when it lasts beyond a specific period it becomes 'maladaptive' and 'pathologic' (Zimmermann, 2012). Elizabeth Kubler-Ross's stage model of dying influences psychological knowledge on the process of death from terminal sickness. It entails moving from early denial and numbness, via negotiation and sadness, to the acceptance of the reality that one dies (Kubler-Ross & Ronald, 2013).

Death Anxiety

As patients with advanced illness near death, naturally, the fear of death rises. Assisting those patients to alleviate their fear is an essential objective of palliative care (Tsai et al., 2005). Factors like age, sex, and religious faith have a bearing on the degree of death anxiety (Gesser et al., 1988) and it is found that older people exhibit a moderate outlook towards death when compared to younger people (Kalish, 2019). Maddi (1980) states that the level of anxiety created by death is not just out of a confrontation with it but is also due to the situation of unwanted and unexpected ending, as the time frame of life shrinks, sapped out of exuberant energy and meaning and purpose of life. In this state, supportive relationships can help in many ways like creating meaning, self-worth, and beliefs that provide a sense of accomplishment and prepare the individual to confront death without any fear.

Humankind finds itself in a difficult situation in confronting anxiety and death caused by illness. Death anxiety automatically relates to constant awareness of one's mortality (Solomon et al., 2000). Death anxiety can be defined as negative emotional reactions caused by grave anticipation of a situation that does not account for the existence of the self (Tomer & Eliason, 1996). Death anxiety that helps to formulate the worries and tensions produced by

being aware of one's death (Abdel-Khalek, 2005). According to some scholars, it stems from the fear of annihilation (Klein, 1968), the struggle of living with comparison to non-existing (Kierkegaard, 1966), and separation and castration anxiety (Freud, 1961). Death anxiety has inflicted fear of punishment, pain, and loss of self-control (Feifel, 1973); an event of death sparks more fear as above and over the uncertainty of what lies ahead is the fear of unknown suffering (Conte et al., 1982).

The literature points towards death anxiety as the key to behavioural and emotional outcomes. A study conducted by Feifel, Freilich, and Hermann in 1973 claimed that patients nearing death are afraid of it at an unconscious level when compared to healthy individuals. A survey on terminally ill patients showed that the concerns which bother the patients are loss of control and independence, the probability of being a burden on others, and physical and psychological deterioration (Back et al., 1996).

Palliative care is primarily intended to improve the quality of life and lower the suffering of terminally ill people and their families (National Coalition for Hospice and Palliative Care, 2018). The terminally ill are the most vulnerable population and there has been a worry that sharing views about death might aggravate death anxiety (Emanuel & Emanuel, 2005). But still, palliative care incubates open conversations with various patients and their families about the ideas and worries related to death with the hope of decreasing death anxiety and improving the quality of life even though death is getting closer by the day. Healthcare professionals look into death as a reality that cannot be denied. Since people with death anxiety exhibit behaviour that subdues the issue, the significance of evaluating death anxiety among people having mental distress and behavioural issues are central (Yalom, 1980). Decreased fear of death may enable a good death (Tsai et al., 2005).

Unfinished Business

Unfinished business is described as a cognitive process involving the evaluation of your relationship with a loved one who dies as an unfulfilled and unresolved individual without any closure (Holland et al., 2013). In turn, unfinished business-related anxiety has various negative results, such as regret, wrath, culpability and grief (Klingspon et al., 2015). Unfinished business is referred to as "unfinished or open-ended," but unresolved business is described as "unresolved issue or disagreement" (Masterson et al., 2018).

Several studies have claimed that the top priorities for patients with advanced cancer were the ability to spend enjoyable time with friends and family, to meet unfinished business, and to resolve concerns arising out of legacy and inheritance (Khandelwal et al., 2017). Sense of closure encompassed the notions of goodbye, completion of unfinished business, and preparation for death (Tong et al., 2003). The sort of business undone could be organizing family gatherings and familial ceremonies, ordering financial affairs, and dealing with wills and similar legal concerns (Kehl, 2006).

Quality of Life

Poor quality of life is caused by hopelessness, sadness, lack of social support, lack of capacity, high intensity of pain and other physiological limitations (Rosenfeld, 2000; Breitbart, 2000; Coyle & Sculco, 2004). In other research, sadness and hopelessness are linked to suicidal thoughts and a wish to die sooner (Breitbart & Heller, 2003). One of the most contentious elements of end-of-life care is the patient's claim that he wants to die quickly. If there are no signs of disorientation, palliative care practitioners as well as legal and healthcare policymakers, need to comprehend why a patient with a terminal disease may choose to accelerate his or her death. A large number of patients are considering and discussing the idea of accelerated death, despite the legal bans on assisted suicides (Breitbart

& Sparrow, 1998). In addition, statements of interest in quickened death frequently lead to an assessment of mental health. In these situations, however, diverse ideas want and intents are key aspects of mental health intervention (Pessin et al., 2002).

The integrals of the quality of life of a patient nearing death include psychological pain such as depression and anxiety and physical disturbances like pain and related symptoms (Ferris & Cummings, 1995). Terminally ill patients mostly fear the loss of control, pain, loneliness, and suffering (Grady et al., 2001). Depression usually downsizes the quality of life and wrecks regulation of the symptoms, which results in frequent admissions to inpatient care settings. For advanced cancer patients, being sad and depressed is common. It applies to patients with progressive illness as well, whose finality is medically determined to be death (Pessin et al., 2002).

The goal of palliative care and hospices is to facilitate a good quality of life for the terminally ill and their families. The success of the goal can be recorded when one can overcome issues such as pain, suffering, psychological distress, distressing symptoms and regain autonomy and effective usage of functional efficiency along with the support of family and surrogates, who perform their nurturing roles, respectively. According to Ryndes et al. (1997), hospice patients will have to let go of the curative or aggressive treatment methods for palliative care where some of the curative methods can be selectively included. Hospice goals are rather specific like, comfortable dying, a sense of accomplishment or closure that is determined through self and grieving. The quality of life of dying patients can be transformed into a memorable experience through the accomplishment of personal milestones and family events (Emanuel & Emanuel, 1998).

Spiritual, Religious and Existential Beliefs

The significance of spirituality as a focal area of mental well-being is progressively perceived by health professionals and psychologists (Musick et al., 2004). Patients who have religious beliefs are bound to have higher psycho-existential prosperity than those who don't subscribe to religious instruction. Having religious beliefs may assist a patient to cope with approaching death. Hence, attending to religious issues in palliative care may be useful for those patients who are religious to deal effectively with a terminal illness and related stressors (Balboni et al., 2007). During the end of life, some patients tend to struggle with doubts over mortality, meaning, and purpose of life, and regardless of religious instruction or questions over divine existence, encouraging them to consider thinking about spiritual and philosophical questions may be useful. Kearney and Mount expressed that spiritual concerns "lie at the very centre of the existential crisis that is a terminal illness" (Hummer et al., 1999). Anandarajah and Hight (2001) noted that spiritual anguish happens after an individual faces a situation in which all pathways for attaining meaning, hope, love, peace, strength, and connection in life dry up or when conflict occurs between their beliefs and the realities of life." Research shows that spiritual well-being may cushion healthy psychological functioning and better adaptation to illness (Koenig et al., 1998; Bray et al., 2012; Zhang et al., 2012). It has been also observed that end-of-life individuals who engage in religious/spiritual affairs privately or in the hospital environment tend to have a greater quality of life than those who do not.

Well-received books like *Dying Well* by Ira Byock and *Peaceful Dying* by Tobin T. R. and Lyndsey K. engage with concerns around hospice development, where death is imagined as something to gain from; it is an experience with the potential to bring about emotional and spiritual growth (1999). Spiritual and existential issues play a vital part in the patient's life as

they help in finding value, meaning, and purpose in life. These issues stand out for those who are nearing death and seeking answers about the purpose of life (Quill, 1996).

In terminal-ill patients, spirituality provides confidence in the higher power, the significance of one's existence (Benito et al., 2014), the idea of love, atonement and compassion (Karasu, 1999). Spiritually-driven patients show more tolerance, less dependency, and moderate levels of depression, despite being in advanced stages of the disease, than those who do not (Breitbart, 2000).

Life Satisfaction

Life satisfaction is a significant feature of one's personality. Life satisfaction is a personal attribute that incorporates different aspects of life and is a useful driver of a contented notion of life. It comprises individual thoughts and feelings, various methods of coping with stress, state of health, and social support. Insights on ways to exert reasonable control over future intentions, understanding, planning and systematically implementing a plan of action might be an effective way to attain improvements in life satisfaction (Dubey & Agarwal, 2004). Research shows that life satisfaction serves as a total of human experience. It can be a general assessment of emotions and attitudes about one's life at a specific point in time extending from negative to positive. It is regarded by some scholars to be one of the three noteworthy pointers of well-being: life satisfaction, positive impact, and negative impact (Diener et al., 1985).

It is critical for the respondents of this study to help others to feel more fulfilled in life. When individuals have something to contribute, they tend to be acknowledged or rewarded in return. The possibility of feeling useful by helping others in the same circumstances is vital. Feeling important could also imply that the respondents are preparing themselves and others for any eventualities, e.g. through the preparation of logistics for the

burial, financial arrangements, and other practical concerns (Gourdji et al., 2009). This was done to facilitate support for each other and to ensure the stability of the family (Carlander et al., 2011). In addition, numerous participants in the study of Nissim et al. (2012) opted to volunteer for social causes, based on their wish to contribute to society. The respondents were encouraged to create pleasant memories with the family and to order procedures concerning legacy. Some patients feared that they would be simply branded as unhealthy. It was not only a desire for a prolonged life that motivated the participants to order their legacy, but also a desire to feel justified in terms of how they lived their lives and what they had accomplished (Wrubel et al., 2009).

Some patients have utilised Karma as a framework to make sense of their current state and then suffering becomes more meaningful. Thus, the application of karma by the patients emphasises a special feature of religious convictions in the context of pain and palliative care centres for patients and their families. The idea that cleansing for past actions can lead to moksha after death wasn't completely lacking in the discussions by such patients. Karma is the aggregate outcome and consequence of a person's deeds. It involves the belief that all actions performed by a living being will lead to good or negative karma, have good or bad effects. Excellent deeds will lead to good, happy or good results, whereas negative deeds will have painful repercussions. These repercussions can be felt in the present, in the future or the afterlife. In this sense, belief in Karma automatically requires the acceptance of reincarnation, as the consequences of past deeds are not necessarily experienced in the current life (Gielen & Kashyap, 2019).

Life satisfaction can be derived from involving in difficult jobs when one could no longer work (Svidén et al., 2010). It proved to be of significant value to self-esteem as it provided a sense of achievement from being able to do what the patient wanted (Nissim et al.,

2012). If the health condition drains the capacity to undertake previous jobs, doing some part of it becomes crucial (Cour & Hansen, 2011). Individuals with advanced cancer can continue to live a wholesome life despite a terrible disease (Carter et al., 2004), by actively dealing with their situation. In other words, they could continue to participate, socialise and make decisions based on their priorities (Carlander et al., 2011) and their dear ones (Lavoie et al., 2011). According to Goldsteen et al. (2006), taking responsibility for the continuation of active life involvement and striving towards normalcy are important markers of higher life satisfaction.

Acknowledging Reality

A study has shown strong links between acceptance and both diagnostic adaptability and enhanced psychosocial results (Stanton, 2006). This is the case when the end is in sight as almost one-half of all patients find themselves totally "accepting," thereby experiencing reduced levels of distress (Hinton, 1999). Acceptance is an active condition that allows a person to live with experiences of possible discomfort (Hulbert-Williams et al., 2014). The need to know about one's approaching death is one of the most prevalent normative notions in palliative care. Indeed this notion of knowledge and acceptance is often dealt with by terminally ill individuals in this study. Some highlight that people must deal with the facts and recognise mortality. The acceptance of death here is connected to the personal traits of an individual who is sensitive to the facts and who recognises the fate of impending death. But not all people represent themselves as sensitive people. Some patients appear determined to follow any therapy that promises a cure. While they are classified as incurable and have been diagnosed, they reject the conventional expectation of accepting their (almost) dying state aggressively. In psychological terms, this may be branded as a sign of denial or inadequate acknowledgement of the medical fact. One way of looking at it is to understand the rejection

of acceptance as a deliberate choice by the individual rather than as a sign of inept understanding (Goldsteen et al., 2006).

The acceptance of the patient's terminally-ill condition by the relatives is of pivotal importance (Morris & Christie, 1995). The professionals in the healthcare sector maintain that a "good death" "controls and prepares the patients for their bodily symptoms." Conversely, "not coping with worries of patients" and "not accepting the death of a patient" were linked to an "awful death" (Low & Payne, 1996).

Good Death (Quality of Death)

A primary objective, amongst the other significant objectives of palliative care, is accomplishing a 'good death' or a 'good dying procedure.' Terms such as "good death", "dying well", "peaceful death", "appropriate death", "desired death", and "dignified death" are used synonymously in the domain literature (Kehl 2006). The literature from the 1970s uses the term "good death" as a synonym for "euthanasia". This implies an intentional termination of life by the patient or another person at the patient's request (Kehl 2006). Authors in oncology (McCorkle, 1981) from different parts of the globe started debating about good death and by the 1980s the term became loaded. The first attempt at defining 'good death' was by O'Neil (1983). According to him, "good death is one in which the timing of death is suitable and proper, the person is in control of the dying process, those associated with the dying circumstance observe essential moral standards and the death style of the individual is logical." Researchers diverge on the question as to whether "good death" is a process or an event. Some authors (Mak & Clinton, 1999; Bosek, 2003) regard "good death" as a process and that the quality of dying may improve or reduce overtime, where closure and active decision making play an important role. Whereas, there are other studies which perceive "good death" as an event (Kittel, 2003).

According to the Institute of Medicine, a good death is defined as “a death which has no association with distress and suffering for both the patients and caregivers.” Also, the death should align with ‘cultural, ethical and clinical standards’ (Institute of Medicine, 1997). But the problem arises when such definitions fail to translate into practical guidance. Simply put, good death can be achieved by creating the necessary conditions which enable the patient to look forward to a few weeks of meaningful life rather than making it look like only minutes are left at the disposal of the patient (Emanuel & Emanuel, 1998).

According to literature, a good death is associated with being comfortable where the patients experience no distress and feel content (Field & Cassel 1997; Leichtentritt & Rettig, 2000), and have a sense of closure. This includes being able to say goodbye, complete unfinished business and prepare for death. Acknowledging nearing death implies being aware and accepting the possibility of imminent death (Hopkinson & Hallett, 2002). Authors highlight the significance of honouring beliefs, values, and practices of a personal, cultural, and spiritual nature (Low & Payne, 1996; Field & Cassel, 1997; Mak & Clinton, 1999; Leichtentritt & Rettig, 2000; Steinhauser et al., 2000; Hopkinson & Hallett, 2002; Pierson et al., 2002; Tong et al., 2003). Thoughts of compromise and pardoning are important components of mending broken relationships (Patrick et al., 2001). The role of adequate social support for the dying individual from family, companions, and community was also observed as signs of optimizing meaningful relationships (Neuberger, 2003). The idea of leaving a legacy refers to being remembered by value-adding to the lives of others around (Steinhouse, 2000; Leichtentritt & Rettig, 2000). The issue of being remembered was observed as significant, and how one was remembered by others was equally important (Kehl, 2006).

Kubler-Ross's work on different phases of death and dying has been seminal, especially with regards to the acknowledgement of impending death (Kibler-Ross, 2002). According to Weisman (1988), a good death is attained when an individual's agony is lessened and death is attained with dignity. Research reveals that most of the symptoms of terminal patients can be reduced and can elevate the patient's quality of dying under the holistic framework of palliative care (Cheng et al., 1996). Helping patients to have a decent passing involves alleviating physical agonies in addition to tending to the psychosocial and spiritual needs of patients (Tsai et al., 2005). Chao (1997) researched advanced cancer patients in Taiwan and reported that good death meant harmony and peace of body, mind, and thoughts.

Medical research and infrastructural advancements have evolved so much so in the developed world to standardize care to facilitate a good death. The society also helps as it seeks to ensure good death for the terminally ill. Medical breakthroughs have made medicines and interventions available in the hands of physicians to diminish pain. Clinicians acknowledge the need to attend to the psychological and emotional needs of the terminally ill in addition to alleviating physical pain. Advanced-care, hospices, credible medical institutions, organizations, and schools have joined hands for this cause by including training to the physicians to bring about radical changes in the care of dying. With such tremendous advancements, the world has made good death well within the reach of terminally ill patients but is an unfulfilled promise for most of humanity (Emanuel & Emanuel, 1998). A significant conceptual departure is in the notion that death should be meaningful for a patient and his relatives. Subsequently, it is viewed as significant that the individual knows that death is approaching (Seale et al., 1997; Field & Copp 1990).

Death could be seen with various individual perspectives but if it is seen as a marker of doom and defeat, instead of looking at it as a part and parcel of everyone's life in the world, then people are side-tracked from preparing for it and medicine does not help as much to attain a good death. A new approach is needed in this context (Walker, 2015). The question that should be asked is how good death can become a necessary standard of end-of-life care. Progressively, societal attitudes are gradually moving towards guaranteeing a good death for the terminally ill; doctors have begun to use different interventions to lighten the pain and agony than at any other time; clinicians are perceiving the multidimensional aspects of dying and the significance of taking care of concerns other than pain; hospices are generally accessible and progressively utilized; advance-care planning is supported. In the developed world, a good death is not inaccessible, yet it is not guaranteed to all dying patients (Emanuel & Emanuel, 1998).

Chapter III

METHODS

The preceding chapter presented the details of the research that shaped the methodology plan and discusses different steps taken to conduct this study. This chapter presents a detailed conceptual examination of the quality of dying and death from the perspective of patients who suffer from advanced cancer. It covers various aspects such as research design, participants, measurements, the data collection processes and the methods used for data analysis. The methodology offers thorough information as to how the subjects were studied, how the participants were described and the measures employed by the study.

The research methodology is divided into two major phases: a pilot study and the main study. The details of each step are addressed in the relevant stages, including participant profiles and designs, measurements utilized, methods and analytical methodologies employed.

Pilot Phase

Before the major phase of the investigation, a pilot phase was carried out. The pilot phase aimed to prepare for the main phase of the investigation. The pilot phase began with the identification of common psychological factors in the quality of dying and death. A thorough analysis of existing studies was carried out. The details of the hospitals and hospices in South India were collected. The authorities of these hospitals were then contacted and approval was secured to research one hospital and two hospice centres. An interview schedule for a semi-structured interview was drawn up based on literature review and expert opinion. The pilot study helped to identify practical issues around the interview guide since the population was very sensitive. It uncovered drawbacks and limits of the interview guide

that aided in making required modifications for the main study. During the pilot phase, the researcher conducted two in-depth interviews with advanced cancer patients.

Main Phase

Research question

What is the perception of patients with terminal cancer on the quality of dying and death?

Aim

To explore the views of patients with terminal cancer on the quality of dying and death

Objectives

The following objectives are framed based on the aim of the research:

1. To explore patients' perspectives of end of life
2. To explore patients' perspectives on the quality of dying and death
3. To explore patients' perspectives on the nature of care and support at end of life
4. To develop intervention strategies for quality of death and dying

Operational definition

An operational definition underlines the procedures the researcher would use to measure a specific variable. S.S. Stevens (1935) observes that "an operation is a performance which we execute to make known a concept." "Operational definitions consist of the specification of procedures and expected outcomes (procedures used for producing and measuring a phenomenon) as the necessary criteria for establishing that the terms defined are empirically meaningful" (Ribes-Iñesta, 2003).

Quality of Death and Dying: According to Carr (2003), "A good death is characterized by physical comfort, social support, acceptance, and appropriate medical care, and it should minimize psychological distress for dying."

End of Life: Referred to a period of one or two years when the patient or the patient's family and medical professionals become aware of the life-threatening character of their illness (Cherny & Radbruch, 2009).

Care: The term supportive care needs is an umbrella term that covers the physical, informational, emotional, practical, social, and spiritual needs of an individual with cancer (Fitch, 2000).

Research Design

The term "research design" refers to the complete research process, from conceiving an idea to drafting the narrative, rather than just the methods of data gathering, analysis, and report writing (Taylor et al., 2016). Yin (2014) defined research design as, "The design is the logical sequence that connects the empirical data to a study's initial research questions and, ultimately, to its conclusions."

The current research is qualitative. This qualitative study was designed to elicit replies to specific unidentified research questions. Thematic analysis was used in this investigation to explore the views of patients with advanced cancer on the quality of dying and death. Thematic analysis is a process that begins with raw data and progresses to more meaningful data. This process entails organising data, finding codes, identifying, reviewing, defining, and reporting themes and subthemes (Braun & Clarke, 2006). The patterns are established by applying thematic analysis to identify the obvious themes that emerge from the data.

Population & Sample

A sample of the population is collected. To make an observation that leads to a conclusion, sampling is crucial. The sample is carefully selected to best represent the larger population with the least possible error from the target population. For this study, 21 patients with advanced cancer from 2 hospices (Karunashraya and Sparsh) and 1 hospital (Karnataka

Cancer Hospital) had been chosen using a purposive sampling technique. Purposive sampling is a technique extensively used in qualitative research to identify and pick subjects, who are rich in information for the most efficient use of limited resources (Cresswell, 2015).

Method of Data Collection

An in-depth semi-structured interview method is used to collect data. In-depth semi-structured interviews are widely used in qualitative analyses. In-depth semi-structured interviews are verbal interactions in which the interviewer tries to gather information by posing specific questions to an interviewee. Although the interviewer makes a list of default questions, thorough, semi-structured interviews tend to develop in the form of a conversation (Longhurst, 2009) so that interviewees can convey their views in an extended manner instead of following a linear structure. The participants can reflect on topics they feel are important. The interviewer, by using open-ended questions, allows the interviewees to examine the issue in detail.

Inclusion Criteria

Inclusion criteria are made up of important characteristics of the target group that the researcher will utilise to answer her research question (Hulley, 2013). The patients included are those diagnosed with advanced cancer, aware of the nature of their terminal condition, who can communicate without any inherent difficulties and are conversant either in English or Kannada, who are above 18 years, and signed the consent form.

Exclusion criteria

Exclusion criteria are characteristics of potential participants of the study who meet the inclusion criteria but have additional traits that may interfere with the study's success or contribute to the likelihood of an undesirable outcome (Hulley, 2013). The excluded patients

were also those who suffered from psychiatric conditions such as schizophrenia, autism, dementia, etc. or were on ventilators.

The selected participants were briefed on the study in detail, and all doubts raised by the participants were clarified. When scheduling and conducting interviews, the convenience of the participants was considered. Each patient was interviewed once and demographic information was sought and collected, such as age, gender, religion, education and occupation.

Tools

According to Goode and Hatt (2006), an interview schedule is “a set of questions which are asked by an interviewer and filled in on the spot in a face to face interaction with another person.” A semi-structured interview schedule was utilized for collecting data from the participants. The interview schedule was prepared following an in-depth analysis of the literature and after consulting experts in the field of qualitative research. The reason to go for a semi-structured interview was chiefly that the researcher was looking for precise and vivid information from participants, that reflected a lucid articulation of death and dying. The interview guide was later translated into the Kannada language by a professional translator because of the ethnicity of the participants.

Data Collection Procedure

The researcher sought hospitals and hospices to procure authorization to research their facilities. After obtaining permission, the researcher met with each patient for debriefing and rapport building. Before beginning the interview, the participant's background information was obtained. The researcher made certain that the participants had enough time to open up and express themselves freely. The researcher was only a facilitator, allowing participants to describe their experiences in-depth while directing them back to the topic of conversation if

they strayed too far from it. The researcher urged the participants to provide instances from their own experiences to obtain a more comprehensive picture. The researcher confirmed their answers by rephrasing what they stated. Although not strictly followed, the interview schedule was adopted and was used as a guide. Before wrapping up, the interview schedule was double-checked to ensure that all-important topics were addressed. Each interview lasted 45-90 minutes and was audio recorded with the interviewees' consent.

Data Analysis

Data analysis is a process to analyse the data collected from the participants. Initial data have been transmitted to TextSTAT, a rudimentary text analysis programmer, and the frequency lists of the text were then generated (Huning, 2002). The data analysis was thereafter performed manually. The recordings had been transcribed into Microsoft word format. After all, data were transcribed, each factor was determined by specified factors and separate codes. Thematic analysis was performed to discover data themes. Thematic analysis is a well-known and extensively utilised approach in psychology, as well as in the social and health sciences. It is regarded as a comprehensive approach for analysing the principles that underlie the creation of scientific knowledge (Holton, 1973).

In qualitative research, thematic analysis is commonly used for examining the data and for identifying patterns from the data. The factors were divided into several themes by reading and evaluating them. Subthemes based on the primary themes were spelt out. Each theme and subthemes are briefly explained in the fifth chapter that focuses on the results of the study (Taylor & Gibbs, 2010).

Two specialists were asked to provide their opinions and ideas on theme coding done by the researcher. The researchers then adjusted the categories or themes based on their inputs and recommendations.

Ethical Consideration

The study was carried out after the approval of the Ethics Research Committee of the Karunashraya Hospice. Before enrolment, written informed consent was obtained from the institution. The counsellors at the institute obtained initial consent from the patients and briefed them on the research. Patients were assured that their privacy would be respected and that they could opt out of the study at any point. The participant's health condition was respected, and the interview would be terminated if the individual was unable to continue. If the patient became uneasy at any point during the interview, counsellors were summoned quickly to assist and address the problem. Following the interview, the counsellors met with the patients to see if the interview had any negative effects on them, and the ward nurses were notified to keep an eye on the patients. The patient was given a copy of the interview transcript only upon request for verification of the information. The researcher did not know the participants personally and was not a part of their treatment at any point.

Chapter IV

ANALYSIS AND DISCUSSION

Table 1.

Socio-demographic Characteristics

Pseudonym	Age	Gender	CA	Occupation	Religion
CT	34	F	Uterus	Beautician	Hindu
NR	50	F	Breast	Tailor	Hindu
BA	39	M	Leukemia	School Teacher	Hindu
BG	38	F	Breast	Petty Business	Hindu
TJ	69	M	Thyroid	Coffee Planter	Christian
RL/RC	45	F	Breast	Call Centre	Christian
LK	44	M	Mouth	Driver	Hindu
RK	59	F	Stomach	Home Maker	Hindu
AF	60	F	Stomach	Home Maker	Islam
CD	64	F	Stomach	Baby Sitter	Converted Christian
RT	34	F	Stomach	Nurse	Hindu

RR	62	F	Stomach	Bank Manager	Hindu
ZR	25	F	Stomach	Home Maker	Islam
LM	55	F	Stomach	Home Maker	Hindu
NG	70	F	Sarcum	Home Maker	Hindu
MR	74	M	Stomach	College Principal	Hindu
FM	69	M	Oesophagus	Spoken English Trainer	Christian
TV	44	F	Ovary Cancer	Telangana State Government	Hindu
NS	69	M	Mouth	Auto Driver	Hindu
SD	52	M	Rectum	Medical Distributor	Hindu
SR	42	M	Oral	Car Driver	Hindu

This research had twenty-one participants. The mean age of the patients was 51.45 years (25-74 years); 61.90% were females, whereas 38.10% were males. In terms of religion, 71.43% identified as Hindu, 19.04% as Christian, and 9.05% as Muslim.

Table 2*Themes and Sub-themes*

Themes	Sub-themes
Goals and Ambitions in life	Unsatisfied professional life
	Fulfilling family responsibilities.
	Desire to live and continue to work
Current Priorities in life	Completing unresolved tasks
	Getting closer to supreme power (strong belief in praying to god)
	Waiting for last breath
Views about life	Creating a living legacy: gestures of altruism as a patient
	Death is inevitable
	Experience of adversities in life
	Role of Karma to meaning in life
	Acceptance of death
Views on approaching closer to death	Feeling helpless in life
	Experiencing death anxiety
	Denial of acceptance
	No concerns of death
	Preparing for death
Good death	Acceptance of death
	Painless death
	Dying in a peaceful place
	Dying without troubling others
	Dying in the presence of loved ones
Needs at end of life	Recognition of dying
	Moral and emotional support
	Need for medical care
Preparation for Death	Need for empathy
	Engaging in spiritual and religious activities
	Providing an opportunity of emotional ventilation
	Equipping oneself to accept death
	Breaking the silence about the disease condition

Analysis and Discussion

The analysis and discussion chapter includes information gathered through in-depth interviews from advanced cancer patients. The results provide a clear picture of the patients' perspectives on the quality of dying and death. The information gathered was transcribed and a thematic analysis was carried out. Patterns were established to identify common themes emerging from the data. Seven main themes emerged and several sub-themes have been explained using quotations from the participants. The results are presented under the following headings:

Objective 1

THEME 1: Goals and Ambitions in life

Sub-theme 1: Unsatisfied professional life

Sub-theme 2: Fulfilling family responsibilities

Sub-theme 3: Desire to live and continue to work

THEME 2: Current Priorities in Life

Sub-theme 1: Completing unresolved tasks

Sub-theme 2: Getting closer to supreme power (strong belief in praying to god)

Sub-theme 3: Waiting for last breath

THEME 3: Views about Life

Sub-theme 1: Creating a living legacy: gestures of altruism as a patient

Sub-theme 2: Death is inevitable

Sub-theme 3: Experience of adversities in life

Sub-theme 4: Role of Karma in the meaning of life

Sub-theme 5: Acceptance of death

Sub-theme 6: Experience helplessness in life

Objective 2

THEME 4: Views on Approaching Closer to Death

Sub-theme 1: Experiencing death anxiety

Sub-theme 2: Denial of acceptance

Sub-theme 3: No concerns of death

Sub-theme 4: Preparing for death

Sub-theme 5: Acceptance of death

THEME 5: Good Death

Sub-theme 1: Painless death

Sub-theme 2: Dying in a peaceful place

Sub-theme 3: Dying without troubling others

Sub-theme 4: Dying in the presence of loved ones

Sub-theme 5: Recognition of dying

Objective 3

THEME 6: Needs at End of Life

Sub-theme 1: Moral and emotional support

Sub-theme 2: Need for medical care

Sub-theme 3: Need for empathy

THEME 7: Preparation for Death

Sub-theme 1: Engaging in spiritual and religious activities

Sub-theme 2: Providing an opportunity for emotional ventilation

Sub-theme 3: Equipping oneself to accept death

Sub-theme 4: Breaking the silence about the disease condition

Objective 1

THEME 1

Goals and Ambitions in Life

The life-review process can help a person conclude the final chapter of his or her life with a few options of their own. It allows for self-examination. By looking back at past relationships and events, the dying person can maintain some control over her own life. The person is allowed to get things right or to get things done. The process can also create or reinforce the much-needed good feeling at the end of "success". This makes it easier to deal with the impending loss of human life (Pickrel, 1989). The past becomes part of our conscious present during a revision of life. One reconsiders positive and negative experiences and events, including failures and successes, in past and present lifetimes. Life review may also recall the need to engage in conversations or activities before death, unresolved conflicts requiring assessment, redemption and reconciliation.

The results of the study show that the majority of the patients had goals with respect to different aspects of life. This theme tried to unravel the unfinished business of the participants. It explains what the participants of the study hoped that they could achieve. Under the theme of goals and ambitions in life, there are a total of 4 sub-themes that emerged. They are:

Sub-theme 1: Unsatisfied professional life

Sub-theme 2: Fulfilling family responsibilities.

Sub-theme 3: Desire to live and continue to work

Sub-theme 1: Unsatisfied Professional Life

In the twilight of life, most patients start reviewing their past life. Existing research suggests that it is vital to lament overvalued and yet unattainable goals (Snyder et al., 1996).

This grieving process is likely to be different for each person, and it eventually engenders the acceptance of unattainable goals as they are or current blockage and enables the person to begin pursuing other important and realistic goals because of the shrunk remainder of the time (Gum & Snyder, 2002). Career goals were one of the profound losses the participants felt they missed. One of the respondents, RL, expressed that she felt incomplete as she couldn't pursue her dream of becoming a nurse because of which she found her current job unsatisfactory. RL shared:

I aspired to be a military nurse. That was my goal. But my parents did not give it to me. My father was in the military, and I used to tell them that. But they wanted my second sister to go. My second sister did not want that since she had other goals, but they all pushed us into shorthand typing, forcing us to become secretaries. But my goal is (inaudible)... I was really disappointed that they did not help me... I dislike working in call centres and such settings.

Another participant shared her wish to restart working. She expressed how she had to leave her work because of cancer, and also shared that she would like to start working again:

I used to be a beautician. My uterus had grown weak after the birth of my second child. As a result, physicians advised me not to work. I've been out of work for 5 years. My daughter is four years old and I am into one year of pregnancy. I've been out of work for 5 years. If God grants me the strength, I intend to resume my work.

(Participant CT)

Respondent CT addresses her desire to restart work if possible, cancer had taken its toll on her because of which she had to give up work. Terminally ill people with high hopes can develop and achieve other objectives (Snyder, 1996). This situation must lead to better emotions, individual agency, and greater overall hope, and open up new ways for the

attainment of fresh objectives. Personal interests are important because they create more positive feelings. Dying people need to communicate with healthcare professionals and others about his or her aims for the future and they should be helped to achieve these objectives (Gum & Snyder, 2002).

Sub-theme 2: Fulfilling family responsibilities

Another important concern of patients was the need to take care of their families. As the participants were aware of their limited lease of life, they were concerned about their families and wished well for the future of their near and dear ones. SD shared: “Worried about my child's financial future and how I would care for him after I am gone. This idea occurs for around 15-20 minutes after that typical things.”

Likewise participants BA, NG and SR conveyed that the aim was only to have a successful family as the family for them was a priority. Participant BA states: “Family family family family.” Participant NG states: “My goal was to have a successful family. My spouse had a total of five brothers. And my sister does not work; she is a stay-at-home. Educating them was a priority.” Participant SR states: “My child. I simply want him to be taken care of. My wife, too. I plan on taking some medication, recover, return to work, and see my wife and child happy and content.”

This act of prioritizing family and relationships over everything else has been highlighted by many studies. At this stage, the patients try to engage and optimise time with family and friends (Bosek et al, 2003). Good social support from family, friends and society to the dying person is regarded as part of optimizing relationships (Neuberger, 2003). The participants' relationship with their near and dear ones, at the optimal level, provides essential social support, when in need.

Sub-theme 3: Desire to Live and Continue to Work

Talking about individual goals, a few participants expressed the will to get back to their lives before the onset of disease. However, this did not seem to arise from being in denial, but more out of a wish to live like the olden days.

When asked about what they want to achieve, a 70-year-old participant expressed her wish to cook and feed her husband in the same way she used to do before her diagnosis. She explained how she missed cooking for her husband and that if this was not an option, then she would like to join god.

Yes. I want to be able to make food for both him and myself. That's all I'm looking for. If you (God) wish to take me, please do so. But if not, grant me strength in both legs and the capacity to walk. (Participant NG)

Likewise, the desire to be independent was also seen in a 34-year-old patient, RT. She wanted to go back to work to support herself. She says, "I want to overcome this and go back to my job."

Keeping a sense of normalcy played an integral part in seeking meaning in life. Studies have shown that maintaining control and having a normal daily life will change attitudes towards life (Benzein et al., 2001).

From the statements given by NG and RT, it can be concluded that they would like to be independent like how they were before. The major debates about a good death emphasised the necessity of reducing the load on the family, in particular when the families looked after the dead (Bosek et al., 2003; Tong et al., 2003). Other facets of this quality include freeing the dying person from financial strain or financial assistance (Patrick et al., 2001) and ensuring the patient's independence (Vig et al., 2002). Patients emphasised the importance of physical and financial independence for a decent death (Kehl, 2006).

THEME 2

Current Priorities in Life

Findings from other studies suggest a positive effect of 30% to 90% on patients who report life-threatening diseases. The benefits of the disease include a better understanding of life, changes in priorities, and better interpersonal relationships, among other gains (Zanni, 2010). Priorities are seen shifting from success in finance and work to family and friendship. Many patients take on commitments before the disabling effects of the disease (Classen et al., 2001). When one is faced with death, the central focus of life gradually shifts to other things and priorities change. Participants expressed the things they valued at the moment. This theme has 3 sub-themes. They are:

Sub-theme 1: Completing unresolved tasks

Sub-theme 2: Getting closer to supreme power (strong belief in praying to god)

Sub-theme 3: Waiting for last breath

Sub-theme 1: Completing unresolved tasks

The rewards of being aware of mortality could be a chance to revisit relationships, settle hostilities of the past, getting close to people who one valued as a dying person. Many hitherto unresolved conflicts may settle once and for all driven by practical concerns and emotional clarity (Seale, 1998). On a similar note, this sub-theme comprises incomplete tasks that the participant needs to finalize. Nearing the end of life, patients share their immediate commitments that need to be completed. They participate and delegate the unfinished business that they hope to fulfil before it's too late. For instance, a respondent reported that it was important for him to register the land under his wife's name before anything happened to him. This must be the final thing he wishes to settle for good, which would give him a sense of closure.

Now that the property is there, it must be disposed of or my brother will be granted the power of attorney. I need to have that taken care of. I considered it because my brother is now granting power of attorney. I have to go work on the property and dispose of the land in my wife's name. (Participant FM)

Another participant MR explains how he is continuously thinking of saving something for his grandchildren, he passes his time by thinking of how he can do something for his grandchildren so that he would be fondly remembered by them:

I think about my grandchildren. Will I be able to give anything to them? What can I do for them? If I don't give them something, I won't be at peace. Maybe a small property somewhere. How should I go about it?

Another patient shared that she worries about her child. She is constantly thinking of how she can secure something for her child's future. She expressed how so many things are still left undone and how she wishes to complete them before it's too late. She says, "Till now I have not done anything for my daughter. I want her to enrol in a school and get an education. I have not done anything to secure the future of my daughter" (Participant CT).

Another participant NS expressed his worry for his son:

My son has both mental and physical impairments. My top priority is to get him settled. The government provides pensions to the poor. I'll have to apply for it on his behalf. My need is to have my kid married while also ensuring that his mind develops and that he is physically well. I want him to be able to live on his own. I want him to be able to survive on his own, just like I was able to do after my mother and father died. (Participant NS)

Clinicians are aware of the importance of future milestones or "unfinished family enterprises" for dying patients that can influence their decisions and experiences and can even

postpone death. Studies have shown that major family events such as birthdays or major holidays are followed by deaths (Emanuel & Emanuel, 1998). The idea was to say goodbye, to finish unfinished business, and to prepare for death (Pierson, 2002). The type of unfinished business includes finishing commitments, participation in future family events, financial arrangements, funeral arrangements, bringing legal matters to a logical conclusion, like for the participant FM, who wanted to transfer his property in his wife's name before he died. Fulfilling unfinished business is like saying good-bye, having a sense of closure, and even preparing for death (Pierson, 2002).

For respondents like MR, doing something for the grandchildren and securing her child is of such compelling personal relevance that they do not want to leave it incomplete.

Sub-theme 2: Getting closer to supreme power (strong belief in praying to god)

It is observed that spirituality or religion encourages the adaptation of the experience of illnesses and hardship through its capacity to give meaning and hope (Musick et al., 2004). Many patients rely on faith to answer these complex questions, but others find support outside the framework of religious faith through their spiritual beliefs (McClain et al., 2003). For some participants, they turned to the Almighty. Patient ZR for instance shared that:

I love Allah. I only speak to Allah. I believe that whatever I have to share I speak to Allah. Whether I am troubled or even when I'm happy, whatever sharing I have to do, I do with Allah. I connect with Allah and I speak with him. I am most connected to Allah. Being close to Allah is very important to me I feel.

This statement by a 25-year-old respondent shows how religion was helping her in her difficult times. She expressed how she speaks about her problems, shares her joys and sorrows with God. Turning religious is helping her overcome her problems and through this, she keeps up her mental health. The fact that the participant prioritized God also shows that

when medical aid was inadequate, she found no other option but to seek help from God. This was important to her now. Likewise, another participant's statement shows how much she wished to build her spiritual awareness:

My goal now is to reach *brahman*. It is all about exploration. So whenever I get some extra time and energy, I look on the internet or read books on self-realisation, God realisation and all. That's my goal now. And I don't have any other goal. My daughter is well settled. (Participant RR)

On the contrary, it is also said that advanced cancer patients may struggle with spirituality and religion; according to one study, 44% of patients experience spiritual distress (Winkelman et al., 2011). Spiritual discomfort, suicidal ideation, and poor quality of life are linked to spiritual struggle and poor religious coping (e.g., feeling punished or abandoned by God) (Trevino et al., 2014). A similar spiritual struggle was expressed by participant CD. She expressed how following one's faith was of no help because of which she converted to another religion. This act helped to strengthen her faith and has given her some comfort:

Another thing I'd like to add is...I became agitated...God is causing me so much suffering. This has only happened only to me... That is why I became a Christian. I'll tell God... I should live well... peacefully... (Participant CD)

Another informant shared that at this juncture, praying to God was his priority: "At present, I pray to god. That's the only thing I have in my mind." (Participant MR). "Now, at this moment nothing ma'am. Only reaching my... god, father" (Participant FM).

Many people are afraid of death and dying, especially as they approach the conclusion of their life (Ardelt & Koenig, 2006). Finding meaning and purpose in life becomes a key focal point when one is facing death (Sulmasy, 2006); in terminally ill patients, these concerns are often more prevalent than mere grievances about physical problems (Portenoy et

al., 1994). Many people rely on faith for serenity and a feeling of purpose in the larger context, even in the face of bodily decline, social losses, suffering, and impending death. Religion offers existential meaning that provides a sense of serenity and a sense of place in the larger cosmic context (Ardelt & Koenig, 2006). Patients who practice a religion are more likely to experience a higher level of psycho-existential well-being. A patient's religion may aid in coping with impending death (Balboni et al., 2007). As a result, addressing religious issues as part of palliative care may be beneficial for a patient who relies on religion to cope with the pressures of a terminal disease (Choi et al., 2013). Although there has been little empirical research on religion's effect toward the end of life, the consensus is that religious belief is good and brings increased consolation as death approaches (Idler et al., 2001). However, some people have severe religious struggles as they approach death, and this conflict intensifies anxiety, depression, and functional disability (Burker et al., 2004).

Sub-theme 3: Waiting for last breath

Patients' concern that their lives aren't worth living if they have to live in pain may trigger a sense of hopelessness as a result of cancer discomfort interfering with daily life (Ferrell et al., 1995). Unrelieved cancer pain has been shown to heighten the patients' apprehensions of the future, contributing to existential distress and potentially jeopardising their degree of hope (Strang, 1997). According to recent research, hopelessness is an even stronger motivator for wanting to die (Breitbart et al., 2000). Some of these comments could be interpreted as a plea for help wherein the individual is attempting to communicate the severity of her suffering. Despair, which is described as "being in an untenable situation in which no objective achievement is expected" (Farran et al., 1995), is linked to depression and a wish to die sooner (Chochinov et al., 1998). Unavoidable circumstances related to terminal illness and the feeling of pain, loss of control in life, being left out and the overall turmoil

faced by some of the participants have left them in a state of numbness and ignorance. One of the participants expressed that he lost everything completely, that he is just waiting to join god.

Everything went away completely. If I could just join god, that would do. I'm waiting. Nothing is there. Whatever is there I tell my family. It's like this... they are looking after me... there is not even slight pain. There is no pain only. (Participant BA)

The same view was expressed by other respondents. Participant MR states: "So it happened like that. Because of the disease, I have become very lean. Very thin. I don't know where it goes from here. It will lead to death. I'm waiting for that." Participant NG states: "Nothing. I am ready for God to take me away." And Participant AF states: "It all depends on God... If he takes me, I'll go. I don't have a problem... Until I live, God should keep me... That's enough."

The participants expressed that they felt despair because of the troubles faced due to cancer. They had initially invested effort in winning the battle against cancer, but as they had reached an advanced stage and all efforts went in vain, hopelessness overwhelmed hope. This leads them to give up hope in life as ZR's reply suggests: "I have been ready from before itself. I do not have any fear about that. I am telling you truthfully right from my heart. Death brings a kind of peace."

Participants in the last stages of disease encounter numerous challenges, both physically and psychologically. After their attempts to battle, cancer goes unsuccessful, the patients develop a feeling of helplessness, which makes them emotionally vulnerable, especially participants who were ill-prepared to deal with a great deal of suffering and stress. With no other desires left, waiting for death seemed to be the only option. The urge to die is frequent but is not always associated with clinically relevant mental discomfort. Qualitative

research has demonstrated that diverse routes may lead to a wish for death in different people. Individuals who have lived a self-sufficient life may experience considerable distress if they lose control over their sense of mortality (Wilson et al, 2007).

THEME 3

Views about Life

When faced with a serious illness, patients and their families apply various forms of coping and management through a dynamic process that is influenced by and at the same time affected by the environment, resources, and emotional well-being of the person. After the initial diagnosis of cancer, key concerns for patients include loss of a functional regime, the possibility of disease progression, persistent insecurity, and undergoing treatment for life-limiting diseases (Liao et al., 2017). In response to these stressors, patients often turn to their coping strategies to deal with stress (Walshe et al., 2017). These strategies will evolve as patients evolve effective ways to live with the disease and may include a combination of factors such as staying positive, avoiding thoughts related to the disease, seeking social support, continuing normal life routines, changing life expectations, finding acceptance and participating in religious activities and/or spiritual coping (Alcorn et al., 2010). For some patients, the experience of cancer at an advanced stage can also be an incentive to find deeper meaning and individual growth at the end of life (Moreno & Stanton, 2013). Reviewing life provides some individuals with an opportunity to reflect on topics that matter the most to them or talk about things they would like to remember when death approaches. Life review is a spontaneous, vivid, and inevitable process that takes place in the lives of people who know they are dying. The view changes in different stages of life. Here the researcher showcases the views of life of patients with terminal cancer, to generate insights on what perspectives

they have of life even after being diagnosed with the illness. The meaning of life at the end of life has been captured in the theme.

There are a total of 5 sub-themes that emerged.

Sub-theme 1: Creating a living legacy: gestures of altruism as a patient

Sub-theme 2: Death is inevitable

Sub-theme 3: Experience of adversities in life

Sub-theme 4: Role of Karma to meaning in life

Sub-theme 5: Acceptance of death

Sub-theme 6: Feeling helpless in life

Sub-theme 1: Creating a living legacy: gestures of altruism as a patient

Acknowledgements of past achievements, contributions to the lives of others and leaving behind something of value to others played a prime role in the participants. One aspect of life that was accorded importance was a feeling to take care of family or those in need. It is observed that patients developed altruistic feelings owing to the help that they had received from others. BA remarked: “Besides my personal goals, I had always wished to give back to society. After enrolling in the hospice and seeing how much they are doing, this wish was reinforced further.”

Moreover, because the patients had been through agony and depression, they wished to be able to alleviate these feelings in others. BG expressed: “If God gives me a healthy life, then I want to help orphans and the needy. I have endured a lot of pain in my life. Nobody should experience similar hardships. That’s why we need to help each other.” Similarly, participant NS expresses:

I think like this and so I am actively contributing to reviving that temple. They will remember me as that sick man who came to us, collected 50,100,150 rupees, and

revived this temple. That is what I think. I think that because of this temple some 50,100, or 500 people will remember me. I want my family to remember me like this.

In a research study by Johnson (2007), patients' propensity for hope was found to increase through the legacy and life review activities. Such activities may help people in dealing with terminal illnesses and confer a feeling that their lives have meaning and structure, alleviating to an extent some of the existential issues that come with a terminal diagnosis (Lee, 2008). It is important to note what participant BG says: "If we wish to lead a good life, we need to help orphans and all. Whatever is possible from our end we should do and serve people who are in need." Participant FM also has a similar view:

See, I wanted to build an Ashram for elders. The elderly or for those not having anything or for orphans who need support. And I would have named it after my father and mother. Also, I require some land, somewhere, which could be utilized for a burial ground. Irrespective of cast, where people can go and get buried or cremated free of cost. But God's will is not there, then we can't do much (Participant FM)

From this unequivocal statement, it can be surmised that her socially committed behaviour gives meaning in life. According to them, the aim of life is about being unselfish. This desire to help others is because of the agony and depression they have endured. Altruism gives individuals a feeling of purpose and meaning. It helps them regain self-esteem that had been lost in the course of the sickness. This kindness in their last days will provide them with a sense of self-respect and fulfilment. Some respondents also said that individuals need to be good and should care for the health of the environment as well. This sub-theme focuses more on moral values and good deeds.

When one looks back at one's life, it's common to feel that one led an inconsequential existence. It also allows people to select what they want to do with the time left and, in many

cases, plan a legacy. Being remembered and contributing to others are two aspects of leaving a legacy (Steinhauser et al., 2002; Vig et al., 2002). This quality was particularly essential in the eyes of elders when it came to a good death (Vig et al., 2002). It also entailed leaving an emotional, physical, financial, or social legacy (Kehl, 2006). The importance of being remembered was also emphasised, and how one was remembered by others was deemed to be a significant component of this trait (Steinhauser et al., 2002).

Sub-theme 2: Death is Inevitable

Death is an inseparable part of life. Death should not force people to live in terror but instead inspire people to live their lives to the fullest. A few participants felt that they didn't have any specific outlook towards life as death was inevitable. According to them, life was a mere fleeting experience, nothing unusual about it. This could also be because they didn't pay much attention to think about the purpose of life itself. For example participant, BG expressed: "There is no meaning. Being born is normal. When it's already not there in our hands, why should we think over it?" Another participant (RT) shared the same view on life. According to RT, everyone has to die. People are born with an expiry date and nothing is shocking about it. Hence, we should lead a normal and simple life for whatever is in store. "Everyone is going to die one day or the other. What is there in that? We should just lead a simple life" (Participant RT).

On a similar note, one more participant (FM) shared that life is given by God and he is entitled to take it back as well. Human beings should not worry so much about life as everything is decided by God.

Life is something that is given to us by god. And we will go one day or another. The thing is... human beings... or even bacteria will live up to a certain time allotted by God. After that, it has to end its life. (Participant FM)

Patients with terminal illnesses have a variety of approaches to normative expectations, ranging from "negative" to "positive." One patient accepts his impending mortality to the point where he fully internalises the limitation of his lifespan. He has lost all excitement in the events and problems of everyday life that were once the foundation of conversations as he approaches the horizon of his existence (Goldsteen et al., 2006). Individuals have to find a way to deal with the realities of life, death, and mortality. All of this elicited thoughts of self-awareness and forgiveness, as well as overwhelming feelings of failure and loss (Syrén et al., 2006).

The terms "knowledge of imminent death" and "acceptance of death" are used to describe the process of recognising impending mortality. In many individuals, a lack of awareness was thought to be a substantial barrier to a decent death (Kehl, 2006).

Sub-theme 3: Experience of Adversities in Life

Each individual has a different take on life depending upon what they have experienced, how they took to life events and interpreted the situation as a whole. For some participants, life was all about helping others, whereas for others they viewed life from a pessimistic lens. For example, participant CD expressed how unsatisfactory her life was because all her close relatives passed away, and the ones that are alive were not of much help while she was suffering from advanced cancer.

I have not lived a satisfying good life because I didn't have parents. Everybody died. My siblings died. Only 3 are left now. My mother had 17 children. Now only 3 are left. In those 3, nobody is close to one another... I don't go asking. Despite suffering so much, I can't bring myself to ask for help. (Participant CD)

Likewise, participant RT clearly expressed her dissatisfaction with life because of all the pain she had gone through: “My life has never been happy. I am not happy with my life, that's it” (Participant RT).

Another participant RL shared that she has stopped visiting her relatives. If someone expired, she wouldn't visit them as she would get visions of herself in a coffin. This could be because of how bitter she had become with all the negative experiences in life. But she felt she retained a sense of care because of which she would pray for the departed souls.

I have lost meaning in life...I don't want anything to do with life anymore. I have started doing something in the past 2 years or 3 years... if anyone from our family or anyone for that matter dies I will not go, I can pray for them. The reason being if I go, I get visions of myself in the coffin. I can pray but will not go. (Participant RL)

People suffering from serious illnesses frequently endure physical and psychological discomfort, loss of meaning, direction, and dignity (McClement & Chochinov, 2008). Life's happiness may be the result of conscious and pleasant inner sensations that inspire people to achieve their objectives (Frisch, 2006). The concept of life satisfaction as a crucial indicator of happiness can be developed. Individuals tend to adopt very specific criteria for measuring life's pleasure that they believe is appropriate for their circumstances (Diener et al, 1985).

It is possible that a person is content with practically all aspects of his life, but is not satisfied with a particular domain that he or she considers being the most important, then that discontent with this domain may have a negative impact on his or her overall assessment of life satisfaction. One of the most important characteristics associated with life satisfaction has been identified as one's health (Dubey & Agarwal, 2004). Although life satisfaction as a whole refers to consistency, a large body of research to the tune of Pavot et al. (1998) suggests that judgments based on temporal elements are more trustworthy and accurate.

When assessing life satisfaction, temporality focuses on past, present, and future levels of life satisfaction. Positive thinking about the future has significant ramifications on a person's ability to cope with his or her current circumstances. A positive orientation of the future would shape the present and future life's propensity for happiness in a big way (Dubey & Agarwal, 2004).

Sub-theme 4: Role of Karma to meaning in life

While attributing meaning in life, some participants brought up the role of Karma. According to them their purpose in life had to do with their actions in the previous life. Participant NG expressed her belief that she wasn't a good human being in the previous life and hence she is being punished in this life. She says, "I must have done something bad in my previous life and that is why I am suffering now. Right now, I just want God to take me away as soon as possible without any difficulty and pain." Likewise, participant BA shares that he believes God must be testing him for the kind of human that he is. He also believes that his condition (advanced cancer) is an outcome of his defeat in life's test: "God is testing me. Maybe I will fail, I feel. I feel like that. If you see my health now God is surely testing me and I have failed the test." Participant RR states:

I feel that it is my karma, but I have a clear conscience. I have given my best and I have not done a mistake in this life, but in the past life, I don't know... I must have done something wrong, so I deserve this. Who knows why God is giving me so much pain. I don't know. Once you know that this pain is because of your karma, you will stop blaming others. You face cancer easily. Patients should also remember that they cannot change anything that is willed. (Participant RR)

Illness and agony are seen to be the quickest manner of repaying debt from previous lifetimes; Karmas or deeds must be repaid in this birth, the next, or future rebirths (Firth,

2005). Good karma results in a good birth, while poor karma results in a bad birth. Misery can be traced back to past karma. A dying person can resist drugs to die with a clear and unclouded mind, and pain can be viewed as a means of expunging sin. There is a difference between a spiritually enlightened person's willed death and someone in pain who wishes to end an awful life (Firth, 2005). The conflict between the body and the soul, in comparison to past lives' conduct, and the necessity for more suffering to 'burn' away the karma accrued over several lifetimes implies that providers must be sensitive to the idea of pain alleviation at the end of life (Loiselle & Sterling, 2012)

Sub-theme 5: Accept the death/reality/situation and enjoy life at the moment

Acceptance has been linked to both adaptabilities to diagnosis and improved psychosocial outcomes, according to research (Stanton et al., 2002). This is especially true at the end of life when almost half of all patients are found to be fully 'accepting' of the realities, and this is linked to decreased levels of distress (Hinton, 1999). Death anxiety was comparatively low in terminally ill patients, indicating realistic acceptance and coming to grips with the reality of death (Smith, 2000). New learning and growth, acceptance, increased life meaning, and the quest for an authentic existence is all positive outcomes of death anxiety (Firestone, 1993). Acceptance is an active condition that allows a person to live with potentially distressing situations in this scenario.

While participants shared a pessimistic view, some, on the other hand, shared that the meaning in life was to enjoy and have fun. For example participant, TJ shared that:

Of course, to enjoy life, you know. I want to enjoy life. It (death) comes when the time comes. You are getting old now... time is getting close. As long as he gives life, make the best of it. Now just don't think of the future. Be a little careful and take care of yourself as much as possible and enjoy life.

Similarly, participant NS states:

I want to go to God. What is there for me to do here, instead of giving trouble to others? There are a lot of unfulfilled wishes but unfortunately, I can't do anything for my grandchildren. So it's better to go. I cannot take care of anyone, I cannot make anyone happy. I also do not have money. So it's better if I go. They will say, poor guy, what we can ask of him. (Participant NS)

Here, the outlook of life shifts to enjoying and relaxing for the remainder of time without burdening oneself with the practicalities of life.

The need of being aware of and embracing one's impending death is one of the most significant normative principles in palliative care. Some emphasise expressly that one must confront the truth and embrace mortality; one cannot escape aggressive illness and should better realise and accept this rather than clutch at unhelpful straws. Acceptance of death is linked to personal attributes in this case; a wise person can confront the realities and accept the inevitable fate of death. It's easy to read such an attitude as denial, or an inability to cope appropriately with the medical knowledge provided. However, rather than a question of defeat, this resistance could be read as one of will rather than a matter of deteriorating cognition (Goldsteen et al., 2006). Both understanding and acknowledgement of imminent death are included in the acceptance of death (Schwartz et al., 2003). In many individuals, a lack of awareness was found to be a substantial barrier to a decent death (Bosek et al., 2003).

Sub-theme 6: Feeling helpless in life

Existential distress can be understood as distress “characterized by hopelessness and helplessness due to a loss of purpose and meaning.” (Robinson et al., 2014). People with the advanced disease face an unknown future and a finite amount of time to accomplish their goals, organise their affairs, restore damaged relationships, and spend time with family and

friends. The realisation that time is short may cause a patient to reflect on his or her life, focusing especially on past mistakes, unfinished commitments, and future goals (Steinhauser et al., 2009). Some participants feel that in this situation it was impossible to do anything, let alone have a wish or desire for something. One of the participants, aged 38, shared that now that her time is coming to an end, she feels that there is no point in doing anything and also expressed that she has no strength left in her to even wish for something. She expressed the frustration of living with an untreatable disease. The respondent articulated that cancer had succumbed her into a hapless state:

No nothing like that. Now nothing can be done, then what can we do. I have no strength left in me to even make a wish to live. That's all I'm saying. Nobody should be in my state. Nobody should suffer like me. When they have suffered enough, God should take them away, enough! People like you should help. Cancer is a non-treatable disease. No matter how many lakhs we spend, this is a non-treatable illness. Correct, no? If we get that... it won't listen to you nor it will listen to God. Dying is the only tension that will remain. (Participant BG)

The same view was shared by a 59-year-old participant who made it clear that nothing is important in life now as she had lost everything, including the desires and strength which she had earlier.

Important things, nothing much, madam... everything is lost in life, madam. All desires are lost, madam... I have no desires now. No time now to fulfil my wishes. If there is strength and age left, I could have fulfilled those. Now all that is gone. Nothing is left now. Life means that... if God takes me, then my life is fulfilled I feel. That's all, madam." (Participant RK)

In the last phase, emotions are extremely essential. When patients know that death is approaching, they may be overwhelmed by their emotions. They may experience feelings of worry, despair, or dread of being abandoned or dying in pain. It is considered important from a psychological standpoint to express and share negative emotions with others. Patients can talk about how they deal with things. It seems that patients' perceptions about how to manage emotions effectively differ from others in their surroundings (Goldsteen, 2006). Feelings of inadequacy, powerlessness, and helplessness too were felt by the families who believed that there would be nothing they could do (Sand & Strang, 2006). Others claimed to have made peace with life, death, and mortality. Patients carry all these sentiments of self-awareness and reconciliation, as well as overwhelming feelings of failures and losses (Syrén et al., 2006).

Objective 2

THEME 4

Views on approaching closer to death

In the light of nearing the end of life, patients expressed their views with regards to experiences of death and after death. This theme has five sub-themes. They are:

Sub-theme 1: Experiencing death anxiety

Sub-theme 2: Denial of acceptance

Sub-theme 3: No concerns about death

Sub-theme 4: Preparing for death

Sub-theme 5: Acceptance of the death

Sub-theme 1: Experiencing death anxiety

Death fear, according to Maddi (1980), emerges not just from real encounters with death, but also from experiences of unwelcome ends, constraints on time or energy, or discredited beliefs that undermine the meaning of life. A positive philosophy of life or a

cohesive collection of life beliefs develops as supportive connections increase self-worth and generate meaning, allowing for confronting death without fear (Kallish, 2019). A major concern of the participants was the fear of death. Since this was something that each individual had to face alone, the fear of the unknown induced more death anxiety. This was shared by a 45-years-old participant, RL:

I don't know, I mean I can't see myself dying. I don't know where I will go. Yes, I have the fear of death, that's why I don't see myself dying... but sometimes I get angry with God... why have you done this to me?

In the statement above, the respondent expresses how she fears death and where she will be taken to. Despite reading the Bible and praying, she carries apprehensions about the unknown. However, a sense of anger arises because she was chosen to suffer and accept the fact of being a cancer patient. But there is nothing that can be done except complaining to God about the condition. The fear of annihilation (Klein, 1968), the struggle of the living being against non-being (Kierkegaard, 1966), castration and separation anxiety (Freud, 1961), a view of death as bodily mutilation (Walton, 1979), or as a learned or conditioned response of existential origins have all been proposed as origins of death anxiety (Gordon, 1972).

Although there is a distinction that can be made because "fear is felt in response to specific environmental occurrences or things, whereas anxiety is a negative emotional state without a specific object" (Schulz, 1978). Anxiety and fear of death are identical for practical and empirical reasons as they are part of a continuum and are reliant on the degree to which the emotion is specific to an event or situation (Hoelter & Hoelter, 1981).

Another patient shared that he doesn't like to think about death as it is difficult for him to anticipate it. Both acceptance of death and denial arise in a person's mind, but the fear of

death always haunts. “I don’t want to think about it (giggles). I don’t want to think about death. It's difficult. When the time comes you have to face it” (participant TJ).

The continuous, unnatural, and morbid fear of death is known as death anxiety. The term "death phobia" refers to a fear of dying (fear of death). Although fear of death is a popular topic, people’s emotional responses to death are diverse. Death is a fact of life that has always remained, despite advances in medical care (Nabipour et al., 2018). The fear of pain, punishment, loneliness, and loss of control (Feifel, 1973); dread of the occurrence of death, what happens after death, and fear of ceasing to be (Choron, 1973); and fear of the unknown and fear of suffering (Conte et al., 1982). The fear is felt by all patients. The fear of dying alone, not being able to say goodbye, leaving family members without a provider, losing independence, and being a burden to their families and friends, as well as the regret of things they will never be able to do, are among them. Concerns regarding family members are very prevalent. Death, disfigurement, dependency, handicap, and role disruption further contribute to a patient's level of psychological distress (Massie, 1992).

Sub-theme 2: Denial of Acceptance

Some patients use denial as a coping strategy, and while denial is not always advisable, it enables them to enjoy the present and reject all diversions (Block, 2006). Denial, a psychological coping mechanism, maybe a barrier to receiving palliative care. When a fatal illness is originally discovered, denial is presumed to be an unconscious psychological condition that is natural and healthy, but becomes "maladaptive" and "pathological" after a certain amount of time had passed (Zimmermann, 2004). Denial is a coping method used by certain patients, and though it is not ideal, it allows them to live in the present and disregard difficulties (Block, 2006). For respondent RL it was difficult to accept her failing health. RL expressed:

I am still not in the state. Because everyone says that you need to accept it. And accept death. You need to accept that you have got it. I am not able to accept the fact that... I don't want to live like this in a wheelchair. I keep telling my son when I die, I don't want them to keep ice under me. They keep ice under the body like a soft pillow. I don't want ice to be kept there. I don't like anything cold kept under me. He says maa leave me alone, maa don't talk all rubbish. Don't cover me don't try to cover me... If u want, burn me... If you throw sand on me and cover me, I won't be able to breathe, all those things are coming... I keep thinking a lot of things.

Reasons for her denial of reality could have emerged from fear of what lies ahead following death and thoughts of the afterlife. These feelings could be related to the level of faith and spirituality that one develops over a lifetime; they were thinking about what they might be doing after death, puzzled and unaware of the things that could happen after death, how would it feel if death comes.

Sub-theme 3: No concerns about death

Cicely Saunders coined the term complete pain to underline the importance of patients' existential concerns in end-of-life care in the 1960s. Some participants considered it easier to fully live out the time left as death approached them, rather than thinking about it and making things more complicated: I don't want to think about it (giggles). I don't want to think about death" (participant TJ). Similarly, participant LK states: "I don't think anything, madam... like this or that, nothing like that... that's what, madam. First, I was well, now I am not... I don't think about it only...

Two others shared that they had no fear or any other concerns. This could be the result of the helplessness that they felt. Now when they are at the fag end of life, what can

they possibly do to save themselves? They had overcome the fear of dying by going through the problems in life. The respondents also use humour to make light of the situation

I don't fear death. I can understand very well. Madam, the moment they draw the screen (curtains) or if a senior nurse enters the ward at night I know someone died.

I'm not scared. I laugh about it saying ``I am next. (Participant BA)

Participant BA had seen multiple deaths and has lost the fear of dying. His mind-set is such that he anticipates a day when he has to go away from this world. Another participant expressed: "No, I do not feel scared. I have no sadness, no fear. I keep smiling. Even during these days, I keep laughing. I make jokes about my leg pain. What can I do?" (Participant NG) Similar fearlessness was shown by a 24-year-old participant, ZR: "I was never scared of death even when the disease was not there. I know a lot of stories, Islamic, that you are not supposed to be scared of death that is going to come for everyone."

The young participant developed fearlessness by following her religion and the stories about accepting death. These stories gave her strength and taught her that death is going to come for everyone.

Making the last weeks, not minutes, of life valuable and meaningful is what a good dying entails (Emanuel & Emanuel, 1998). This requires that the patients are aware of their bad prognosis or approaching death and express it freely. This setting allows them to openly discuss the prognosis, which may aid the patient in coping with and accepting his circumstance. This situation is also preferable for caregivers because they do not have to be cautious about speaking about prognosis as they would do otherwise, nor do they have to lie to the patient if they ask directly about their status (Nolan & Mock, 2004).

Sub-theme 4: Preparing for death

Individuals are misdirected from preparation for death if death is viewed as a failure rather than an integral part of life, and medicine does not devote the attention it should to assisting people in dying well. We need a new approach to death, “We believe it is time to break the taboo and to take back control of an area [death] which has been medicalised, professionalized, and sanitized to such an extent that it is now alien to most people's daily lives.” (Henwood, 1999).

This sub-theme depicts how practical the participant had become in life. This showed how they started viewing life with a pragmatic lens. The patients have realized their medical condition and are at peace with the fact that they are at the end of life. The troubles have taught them so much that they want to be relieved from daily affairs.

A participant, FM, said that he is happy and made a cutting retort as to what was there to worry about? He said: “Preparing myself. Why should I worry? Somehow inside I feel happy, sister.” Another respondent expressed how religious stories have helped her in accepting and preparing herself for the inevitable future. She expressed:

I know a lot of stories which say that you are not supposed to be scared of death that is going to come for everyone. That is because I love Allah. I just want to get close to him when he gives me death. I am ready... beyond doubt that I am ready. I have been ready from before itself. I do not have any fear about it. I am telling you truthfully right from my heart. Death gives a kind of peace, there is a pleasure from death that you do not find anywhere else. (Participant ZR)

Patients in the last stages of a terminal illness encounter numerous physical and psychological challenges. After their attempts to battle cancer fail, the patients develop feelings of helplessness, leaving them emotionally vulnerable. Some participants who are ill-prepared to experience great deal of suffering and trauma struggle hard. With no desires left,

waiting for death appeared to be the only option for many. A "decent death," according to medical practitioners, is "controlling the patients' physical symptoms and psychologically preparing them." "Not dealing with patients' fears" and "a patient's refusal to accept death" were found as factors connected to a "bad death" on the other hand (Low & Payne, 1996).

Sub-theme 5: Acceptance of the death

When there is no way out of a situation, human beings tend to adapt to that situation. Likewise, when the participants were told that the disease was untreatable, it was easier for them to accept the reality. Death acceptance has long been regarded as a sign of wisdom. In Erikson's psychosocial theory "Eighth stage" (Erikson, 1963), the wise person believes that he or she has lived a meaningful life (compatible with the ideal of self-actualization) and embraces death. For the unwise, no thoughtful preparations of a future existed and were clueless when death approached. Erikson's viewpoint can be summarised as follows: "Past-related regret manifests itself as despair and fear of death." Furthermore, in the Eriksonian model, the wise person is not only at peace with himself and the life beyond, but also without many significant projects remaining to be completed (Tomer & Eliason, 1996).

According to research, positive thinking structures cancer in a way that enables patients to draw on personal qualities like optimism, ingenuity, and resilience while preventing manifestations of anger or grief. As a result, this discourse presents death acceptance as a form of defeat, and it associates patients who choose to recognize their mortality with undesirable traits to individuals with the moral courage to battle it out. As a result, the patient who wishes to accept the inevitability of death will have a hard time finding a conducive social context to do so. During a time when emotional support is most required, people with terminal cancer may be excluded from the dominant narrative. For example, participant CD said, "Many people in my house died. What is there? I have seen everything.

From big to small, everyone dies. When we are born, death is also guaranteed.” In the same tone, participant NG recounted:

Not today, not tomorrow, our timelines were determined long back. So we will live for that long, and on that day, we will pass away. But that day we do not know.

Patients like me, we tolerate everything for that day. We ask God to give us that day.

And he does not give it. For how many years one would have to go on like this... I do not want all the work to fall on my husband. That is why I want to walk.

These examples imply that the patient has accepted the reality. According to them, once born, death is a certainty. Hence, there is nothing overly frightening about it. It’s a fact of life. This is how the world goes on: “Anything good comes to an end. That’s why I keep laughing (Participant FM).” Participant MR says: “I am 76 years old, what more do I want?”

The need of being aware of and embracing one's impending death is one of the most significant normative principles in palliative care. The terminally sick patients in this study do talk about awareness and acceptance extensively. Some emphasise that one must confront the truth and embrace mortality; one cannot escape incurable cancer and should better realise and accept this rather than nurturing unrealistic expectations around it.

Acceptance of death is linked to personal attributes in this case; a wise person can confront the facts and accept the inevitability of death (Erikson, 1963). However, not everyone lives the life of a rational individual. Some patients appear to be adamant about pursuing any treatment that promises a cure.

New learning and growth, acceptance, having a sense of meaning in life, and the quest for an authentic lifestyle are all potential positive outcomes of death anxiety (Firestone, 1993). Even though terminally ill patients have been told that their condition is incurable, they actively oppose the normative expectation that calls upon them to embrace their status as

a dying person. It's convenient to label such an attitude as denial, or an inability adapt to the weight of medical insights. However, this defiance could also be perceived as a manifestation of will rather than a sign of declining cognition (Goldsteen et al., 2006).

THEME 5

Good death

It is critical to develop effective care for those who are dying. This issue is intricately linked to normative expectations about what constitutes a good death (Goldsteen et al., 2006). Helping people have a good death includes attending to their psychological and spiritual demands as well as their bodily complications (Tsai et al., 2005). A study argues that further research is needed to study the concept of a decent death from the perspective of patients to provide quality care that is tailored to each patient's and the needs of their families (Meier et al., 2016). To provide good death, one needs to understand what constitutes a good death. The patient's side of the story can be accessed through the thoughts shared by patients regarding death and pain. It captures their beliefs as to how they wished to die and what goes into a good death. This theme highlights the factors that participants consider necessary for appropriate dying. This theme has 4 sub-themes. They are:

Sub-theme 1: Painless death

Sub-theme 2: Dying in a peaceful place

Sub-theme 3: Dying without troubling others

Sub-theme 4: Dying in the presence of loved ones

Sub-theme 5: Recognition of dying

Sub-theme 1: Painless death

Pain has the power to alter one's physical and psychological well-being. While some persons living with a fatal disease lead pain-free lives, this is not the case for the majority:

For most, pain is indeed a permanent reality; for many others, it is periodic; and for some others, they worry over the prospect of chronic pain returning. Most participants expressed the wish to die without any pain, meaning that death should be quick and painless within a blink of an eye.

Death should come to me without pain. I want to die without knowing it, just close my eyes and without any suffering. I wish it happens when I am least expecting it, maybe while I am just sitting. (Participant BA)

Respondents were observed being considerate about other's feelings; death that does not cause distress to others, quick and painless death without suffering for long. BG also noted:

I want to die with absolutely no pain. No crying. Should go without pain (crying). I dislike all this Ayyo appa amma kind of wining. It shouldn't be like I'm gone. As I close my eyes, I should die. I have experienced my pain, Ma'am. I cannot take it anymore. But after coming here, there isn't any pain. There is nothing, I am totally fine. If God gave me only this much life, then it's enough. That's all, nothing else, madam.

Similar views were expressed by other participants such as CD: "Good death means... death in sleep, painless. I should go without knowing." Participant SD also holds this view:

"Painless death. I want painless death. I want a painless death."

Affluent countries can move towards making good death the standard of care. The society is increasingly alert to the need of ensuring a good death; a good death is within human grasp, but still, all dying patients will not have the good fortune of availing such services. The framework presented here can aid in the implementation of our thoughts about a decent death, as well as additional research, training, health-system design, and reimbursement required to make the promise a reality. Doctors now have more strong drugs

and other pain-relieving interventions than ever before. Hospice is widely available and increasingly used; advance-care planning is firmly encouraged; professionals are acknowledging the multifaceted dimensions of dying and the importance of attention to problems other than pain. Many medical schools, hospitals, and professional organisations are pledging to teach physicians to improve end-of-life care (Emanuel & Emanuel, 1998).

Psychologists can make a significant contribution to providing improved care for dying patients and their families by enabling a good death for patients. Emanuel and Emanuel (1998) propose a conceptual framework for "a good death" that includes six major modifiable dimensions of the patient's experience: physical symptoms, such as pain and fatigue, psychological and cognitive symptoms, such as depression, anxiety, and confusion, social relationships and support, economic demands and caregiving needs, hopes and expectations, and spiritual and existential beliefs.

Patients with life-threatening illnesses have comparable objectives, with a higher priority placed on gaining a sense of control and personal identity (Singer et al., 1999). Unfortunately, these requirements are frequently ignored. It is believed that 20-70% of dying patients go through insufficient pain management, that more than one-third of dying patients are depressed, and that 35% have unmet emotional requirements (Bradley et al., 2000).

Sub-theme 2: Dying in a Peaceful Place

For both the patient and the family, the location of death and the quality of final treatment are critical aspects of terminal cancer care (Townsend et al., 1990). It is critical to understand the perceptions of terminally ill patients and their families about the place of care at the end of life to enable demand-based palliative care (Luijkx & Schols, 2010). The location of death, according to BA, was a significant determinant. The value of the location where they desire to die reflects their attachment to it. Certain sensations linked with the

location have been observed to provide a sense of comfort at the time of death. A person may have spent their entire life in an area where peace could be found, such as their home. BA comments: “A good place is also important for me to die. A peaceful place like Karunashraya (hospice) is preferable.”

As a result, he preferred to die at the hospice rather than at home because of the sense of security and comfort he had felt at Karunashraya. The respondent believed that the hospice would take good care of him by putting him at ease throughout his final days.

The place of death was important to another participant ZR. She expressed that she wished to die in her holy place. This association could be because of religious instruction she had received throughout her life and also the solace she gets by being spiritual. She says she would like to die “in that place where there is Allah’s house.” Participant RR shares a related view:

I do desire to stay and die at home. But it is not possible for me. I do feel bad staying in a hospital. I do feel. Not that the people here are not good. They are very good in fact. But the hospital atmosphere is claustrophobic. I do feel that here. I want a more airy place. I have a beautiful house. It’s not a big house, but a nice and beautiful house. And I have plants. I hope to sit at the swing, look at the plants and the birds and all. I would like that.

There were also instances in the study by Steinhauer et al. (2000), where patients' priorities differed from that of the respondents of this study. The location of care at the time of death was not a high priority for patients, which may reflect the complexities of decisions surrounding this issue, particularly if tensions exist between patients and their family members. The location of death and the quality of final care are critical aspects of terminal cancer care for both the patient and the family (Townsend et al., 1990).

Health professionals who offer care in the final days of life must constantly re-evaluate the patient's desired location of care, as well as the caregivers' willingness and capacity to offer that care, especially if symptoms worsen or physical functions deteriorate.

Sub-theme 3: Dying without troubling others

Most discussions of a decent death emphasise the necessity of easing the load on the family, particularly if the family was caring for the dying person. Other aspects of this quality include financial freedom or financial support for the dying individual and his or her family, as well as patient independence (Schwartz et al., 2003). The patients highlighted the need of being physically and financially self-sufficient to have a decent death. Some participants find themselves facing adversity while dealing with tension, suffering, and worry. The caregiver, their family, and everyone around them begin to feel that they are a burden owing to the unending anxieties of cancer. The respondents' image of themselves as a burden originated from a desire to die without bothering others, as they thought they were becoming a physical and emotional burden to their loved ones. BG asserted:

The person next to me shouldn't feel annoyed by me. They shouldn't think, "Ayyo, why is she crying so much or why is she cribbing so much? She disturbs me at night with her whining." No one should ever feel like this about me. I shouldn't be a burden to others.

The participants have also seen in the past how people are sometimes mistreated during their last days. RL says:

I am a person who never likes to hurt anybody because I have gone through a lot since I was a child and I know how people feel when they are disturbed or hurt. So, I don't want to be a burden on others or trouble them.

Participant FM says: “That’s all my ambition. I may go away without any problem to others.” Participant MG feels that:

Good death means I do not want to die in a way wherein I will have to rely on someone just for a glass of water. I am unable to bring myself to the thought of being so helpless.. In my heart, I feel like God should take me away before my people start feeling like I am a burden and start thinking when I will go away.

Participant MR states that “I look forward to a silent death. Not giving any trouble to others. Not fighting for life. Simply die.”

The respondents were aware that their disease had progressed to the point where they would have to die soon. Apart from dying without giving anyone around them an opportunity to complain about them being a burden or even a bother, their purpose was to retain self-sufficiency to the last extent feasible. They wanted to leave a positive impression on the people around them. The self-perceived burden is a significant issue for many patients towards the end of their lives. For example, a study of advanced cancer patients indicated that up to 39% of patients expressed minor or no anxiety over burdening others, while another 38% expressed moderate to severe distress (Wilson et al, 2005). Cancer patients receiving palliative care have also identified self-perceived load as the most major social stressor (McPherson et al., 2007).

The carer’s perception of self-perceived load are weighed against their other tasks and duties. Participants discussed the additional burden that caring imposed on already-stressed family members, who were already dealing with difficulties like childcare and professional commitments. Caregiving sometimes necessitated family members to taking time off from work, which added to the strain (McPherson et al., 2007). Receiving care is not just about benefiting from the efforts of others, it may also lead to the feeling that one is causing

difficulties for loved ones (McPherson et al., 2007). The participants were troubled by the physical, social, and emotional burdens that they were causing or those that might sprung up in the future. However, it was observed that self-sufficient participants felt they had become a burden to others. Perceiving oneself as a burden elicited a slew of unpleasant feelings and had a detrimental impact on participants' self-worth. Their primary caregiving demands frequently resulted in feelings of shame, remorse, irritation, and fear about the consequences for others. Worry, remorse, and irritation were identified as defining aspects of the self-perceived burden by Cousineau et al. (2003). Other research has discovered a relation between self-perceived burden and major mental health issues including depression (Wilson et al., 2005).

Sub-theme 4: Dying in the presence of loved ones

For the Indian community, family is a vital part of society, and it is the most important institution in their lives. Family and loved ones play an important role in the patient's life. According to 76-year-old MR, he expressed that the presence of his son being around them was an important factor. He shares:

At least my 2 sons can be with me at the time of death. Also, because I may feel comfortable having them around. I have told them clearly that wherever they are when they hear about my death, they should stop everything and come to me.

Having his dear ones by his side seems to give him a sense of closure. Another respondent shared similar views: “Definitely, I want to die when my daughter is there with me. I do love my son-in-law also” (Participant RR).

Trust in caregivers is instrumental when it comes to a good death. A good relationship between the care provider with the patient and the patient's family can be beneficial. The caregivers should be strong patient advocates and non-judgmental confidantes (Kehl, 2006).

The quality of optimal relationships is discussed in several studies and in a variety of ways. The concept of spending adequate time with family and friends was one of the most important part of this trait. Another consideration was maintaining effective communication with these influential stakeholders. As part of optimising relationships, the concept of reconciliation and forgiveness was also emphasised. The role of good social support for the dying person from family, friends, and the community was also seen as integral to optimizing relationships (Bosek, 2003).

Sub-theme 5: Recognition of dying

Cicely Saunders, an Englishwoman who was worried about the plight of dying people, founded the current hospice organisation (Doyle, 2005). Kubler-Ross, an American psychiatrist, proposed a model with several terminal phases that should provide better insight into how terminally ill patients experience death. She stressed the relevance of death acceptance in her psychological investigations. Both women were pioneers in the field of palliative care (Kubler-Ross, 2002). Both awareness and acceptance of imminent death were included in the recognition of impending death (Schwartz et al, 2003). In many individuals, a lack of awareness was thought to be a substantial barrier to a decent death (Bosek et al, 2003). Having a high acceptance level to death makes it better for the process to endure. A 59-year-old-participant shared that:

We are humans. If we are born, we should die. Birth and death are like night and day. The day is followed by night that leads to a new day and the cycle continues. In life, after we die, someone else will be born. (Participant RK)

Another respondent said: “Whenever Allah says so. I have no right to time my death. I am ready but I just want to be in Allah’s house” (Participant ZR). Participant BA shares this

view: “No. Let’s receive death positively, Madam, like how we receive birth. Nothing can be done when the end is near.”

Being more accepting of death, the fear is reduced. Participant BA explained beautifully that one needs to accept death more positively like how birth is welcomed. The respondent here feels that everything is in God's hands.

Patients with terminal illnesses are seen using a variety of approaches to normative expectations, ranging from "negative" to "positive." Some patients are vehemently opposed to concepts such as open communication. Their initial response is to fight it. Some argue that recognising death is a significant issue in itself. They highlight a normative expectation here, but they believe it is not yet applicable to their current circumstances. There are also countless interview sequences in which patients appear to be ardent defenders of a normative expectation. One patient, for example, accepts his impending mortality to the point that he entirely internalises the limitations imposed by his revised lifespan. He has lost interest in the occurrences and problems of everyday life that used to occupy much of his conversations as he now approaches the horizon of his existence (Goldsteen et al., 2006). Patients are better-placed if they bring themselves up to accepting life, mortality, and death as essential facts of life. All of this elicited thoughts of realisation and acceptance of their current status, as well as overwhelming feelings of failures and losses (Syrén et al, 2006).

Objective 3

THEME 6

Needs at End of Life

A study by Hughes et al. (2008) proposes an apparent need for more research to understand the concept of a good death from the patients themselves. This will help in providing better quality care to suit the needs of the patients. Sanson-Fisher et al. (2000)

observes that need can be defined as “the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being”. Carlson and Bultz (2004) concludes that “a significant proportion of cancer patients at all stages of the disease trajectory will suffer social, emotional, and psychological morbidity as a result of their diagnosis and treatment”. Psychosocial needs are related to the level of emotional and psychological distress or poor emotional functioning. From a psycho-oncology perspective, patients have a psychosocial need when they develop a “clinically defined problematic psychological response to cancer” (McIllmurray et al., 2001).

With the approaching end of life, patients expressed their expectations as to how they want to be cared for and what according to them would be helpful. This theme has 3 sub-themes. They are.

Sub-theme 1: Moral and emotional support

Sub-theme 2: Need for medical care

Sub-theme 3: Need for empathy

Sub-theme 1: Moral and emotional support

Participants voiced their expectations of moral and emotional support from the people around them. Through counselling, patients can achieve deeper insights about themselves and the world, accept reality and express their emotions in a receptive environment. For example, BA shared: “More than my disease, I need moral support. As I told you before, I’m at the climax now.” This patient is aware of the approaching end and hence recognizes the primary need to be supported mentally and emotionally over physical support after a certain point. Similarly, RR said:

I feel there should be a lot of love and care for a cancer patient. When it is not there, the struggle is harder. However, despite meditation and everything else, I do feel a desire for love and affection, someone caring for me, being with me.

Participant TV says, “The most important this is psychological strength.” The participant was looking for somebody to help her get through the terminal phase by being available as a source of mental support.

Research revealed the importance of emotional support and communication with others in the well-being of patients. When the physical and mental demands on patients increase, so do the need for emotional support (Utne et al., 2013). Emotional support leads to positive thinking, which frames cancer in such a way that it helps patients to draw on personal strengths like optimism, ingenuity, and resilience while preventing manifestations of anger or grief (Willig, 2011).

Sub-theme 2: Need for Medical Care

Participants had liberal praise for the attention they were receiving at the medical facility and were extremely satisfied. And they expected the same treatment in future as well. “They have helped me right from the time I came here (hospice). I hope good care will continue in the future also” (Participant BA). Participant BG also held this view:

They are looking after me so well and there is no hint of pain. I would say they are doing more to me than God. Karunashraya is like Vaikunta (God Vishnu’s abode) to me. Even my daughter or mother didn’t look after me so well.

The purpose of hospice and palliative care is to provide patients and family members with the highest possible quality of life. Ease of misery, pain and symptom management, psychosocial support, functional capacity enhancement, regard for independence, and proper participation of family and legal surrogates to attain this goal. While aggressive or curative

therapy must be avoided in palliative care, hospice patients usually consent to forego such treatments. Self-determined life closure, as well as a secure and comfortable death, are all goals of hospice (Connor et al., 2004). When a patient's disease has advanced, the focus shifts from curative treatment to disease and symptom management. Patients and family members must make considerable adjustments throughout this journey to assist with an anticipatory grievance, adjustments, mental disorders, existential and spiritual problems, advance care planning, life assessment, and problems that can surface as important issues. Psychologists can ensure providing support and psycho-social interventions (Haley et al., 2003). Being comfortable is a multi-dimensional idea (1) lack of discomfort; (2) management of physical symptoms, including pain management and dyspnoeal management, (3) management of emotional/psychosocial signs such as fear or worry, cognitive symptoms such as mental alertness remain, and symptoms of spiritual anguish. Patients and experts of healthcare generally indicated that they were comfortable, and this was more agreed than challenged (Ayers et al., 1997).

Sub-theme 3: Need for Empathy

To belong — to seek attachment or connect with others — is a fundamental human emotion. An important factor that one of the respondents brought up was that she wanted to be treated with empathy. Participant ZR expressed her sadness whenever she was treated like an outsider. She said:

You have to speak to them very slowly, very gently and you should speak to them in a very understanding manner. You should not speak dominantly and not out of anger because it could have side effects. It affects their body a lot. Their body takes in such words very quickly. Now, if you want to speak about this topic, please go ahead. Speak to them about this topic. No problem. This is not something to be afraid of. But

they should be able to understand what cancer is. The first thing is that these people do not know. Even if they are advising from their point of view it should be the right advice and it is important that they speak with understanding, be sensitive to my problem and speak to me.

The feeling of making her feel like an outsider did prick at her heart. She explains how everyone needs to be educated about cancer. The lack of knowledge about the illness among people makes it hard to live in a joint family. She feels that if they knew what cancer is and how much pain a cancer patient goes through then they would treat such patients with respect.

The results of Yeung et al. (1999) found positive results of psychological care for patients when health professionals used empathy, understanding and reassurance. Active listening techniques include the use of open-ended questions, follow-up of emotionally charged commentaries, exploring associations, expressing worries and reflecting on patient impacts. It can also help with understanding and allows considered decisions. Non-verbal behaviour transmits warmth and empathy.

The burnout of doctors is often linked to poor communication skills. The training programmes for psychological care improves skills and doctor satisfaction. Any health care professional should be able to show key end-of-life skills including the recognition of being at the end of the road, the understanding of symptom control and interdisciplinary care principles, shared decision making and the practical application of communication that is patient-centric. Effective communication includes active listening, responses to emotion, communication of difficult information and assessment of the values and preferences of the person (especially for advance-care planning). This enables health professionals to assist patients and their families in planning, managing and promoting end-of-life care. Hospice

care has not been a part of the training for the current generation of health workers and a special commitment needs to be made to improve knowledge and skills (Currow et al., 2020)

THEME 7

Preparation for Death

Counsellors work to help the dying person prepare themselves for the reality of death. This is done through education and therapeutic support. Health practitioners feel that "good death" "controls the physical symptoms of patients and prepares them mentally and emotionally." On the contrary, "no treatment of patient fears" and "no acceptance of death for a patient" are identified as "bad death" factors (Low & Payne, 1996). Using strategies to help them accept the reality will make them successful in going through bad times, attaining meaning in life and also even help manage unresolved goals. These achievements will improve their well-being and also improve their strength. To enhance the effectiveness of this process, the information given by patients and family are helpful. This theme has 3 sub-themes. They are:

Sub-theme 1: Engaging in spiritual and religious activities

Sub-theme 2: Providing an opportunity for emotional ventilation

Sub-theme 3: Equipping oneself to accept death

Sub-theme 4: Breaking the silence about the disease condition

Sub-theme 1: Engaging in spiritual and religious activities

Successful treatment has a strong support system; religion/spirituality, adequate financial resources, including understanding the disease and its associated side effects, and disease pathways. Some patients use negation as a strategy of coping, and although denial is not optimal, it enables them to live in the present and ignore the negatives. It has been

observed that spirituality or religion promotes the adjustment of the experience of sickness and suffering through its capacity to give meaning and hope (Musick et al., 2004).

A common observation made by many respondents was that most of them had turned to God for help. The spiritual zeal was seen in the participants, it played an important role in the patient's life to help them cope with the realities of death. Many people turn to religion because religious instruction provides a sense of order and peace, a recognition of individual existence within the broader cosmic context in the face of physical decline, social loss, suffering and imminent death.

It was observed by a 25-year-old participant ZR that her love for the almighty had only increased in suffering. This could be because she placed her complete trust in God and feels that she is ready to accept the divine design.

Like I don't know what will happen. I don't know, I am here today, but will I be here tomorrow? I can't say anything about the future. There is no hope. I have no hope from life and death because Allah has given me life and one day he will take it away. But ever since I have got this disease, I feel like my time has come. I have only a few more days to live and that I wish to be happy and smiling during this period.

Whatever Allah gives me, I am ready to accept. If you give me life, I am ready. If you give me death, I am ready because whatever Allah does he does for the good. I just want Allah's house to be there whenever Allah says so. I have no right to wish a convenient time for my death. I just want to go close to him when he gives me death. I am ready beyond doubt. I know a lot of stories from Islam that urges people to not be scared of death and that he is going to come for everyone.

Here, her religious orientation has helped her to be more accepting of the facts. Her only will is to meet god. She said that she is ready to die as everything is in Allah's hands.

Similarly, another participant FM shared: “We have to believe in God. That is ultimate. Wherever your turn or whatever you do. It may come late, it may come early. So, we have to ask God to give us a good death.” Participant RR also shares this view: “I had lost confidence and I would go to Bramakumari sister. She used to teach me how to be strong and a source of great emotional support.”

Religious beliefs and practices have positive effects on health prevention, recovery from surgery, mental illness and physical illness (Peterman et al., 2002). Spiritual and existential issues in this context would mean how people in their lives find significance, purpose and value; they may be especially religious, but persons with no religious belief or members of organised religion have belief systems that give meaning and purpose to their lives."

In the face of death and the related questions about the purpose of life, spiritual and existential problems become especially urgent. This has long been recognised by the medical profession, or for instance, in having spiritual sermons and pastoral services in many hospitals. In the same way, spiritual affairs has been central to the philosophy of the hospices and the clergy regularly joined the multidisciplinary hospice teams. Research demonstrates that those patients who are more actively involved in religious activities experience high psycho-existential well-being than those individuals who are not religiously or spiritually involved (Balboni et al., 2007). This proves that the need to address religious and spiritual questions in palliative care is important so that religion and spirituality can be used to cope with health and existential-related stressors.

Sub-theme 2: Providing an opportunity for emotional ventilation

Expressing fully and freely is an important aspect for some respondents. This provides a way out of their emotional struggle and helps them to be satisfied and peaceful.

The act of expressing one's inner feelings was a way of sharing the troubles and emotional burden. One of the respondents repeated that she finds comfort in talking. She says:

A little bit of comfort comes from speaking. Others should also know this and it should be explained to them. Maybe not once or twice, but the third time they will understand. By making them understand, there is a chance for their fears to reduce.

(Participant NG)

The act of communicating is therapeutic to many people. The emotional expression acts as a relief from ongoing troubles and provides a sense of belonging.

Counsellors listening to and reflecting on such issues in the company of the patient can be a major source of strength. It establishes a bond of understanding with patients on whom emotional and social isolation are frequently imposed (Gibbs & Achterberg-Lawlis, 1978).

Emotions are viewed as a vital aspect in the final stage of life. When a patient is faced with imminent death, there is a greater chance that negativities can be surpassed, so that they are mentally healthy. They need to share emotions and feelings of anxiety. Sharing helps patients effectively manage these emotions and overcome tension, fear, stress, etc. Research shows patients' desire to smooth out their emotions as the perfect way of coping with the disease (Goldsteen et al., 2006). In the terminal phase, emotions play an important role. If they realise that death is near, patients could be conquered by their emotions. They can develop feelings of being left alone or dying in pain, of anxiety, despair and fear. It is important to express these negative emotions from a psychological perspective and share them with others. Patients talk about how they handle their emotions. It appears that patients' ideas about emotions may differ from the environment around them (Goldsteen et al., 2006).

Morasso and colleagues (1999) studied emotional support and communication on 89 terminally ill cancer patients and found that emotional support and communication with others were critical to developing a sense of well-being. Empathic listening is an essential communication ability to help patients cope with advanced diseases. Listening allows the patient to hear and be understood, to explore concerns and fears, to grieve losses, to voice hopes and deep yearnings. Listening can ensure that the patient is not too frightened, too tired or too restless and conveys that the patient who may be weakened by disease is still appreciated. Techniques for active listening include open questions, monitoring of emotional commentary, the exploration of associations and expressed worries and reflections on the patient's disposition (Block, 2006). It can also help to monitor understanding, encourage questioning, and improve decision-making abilities with time, when needed (Brown et al., 2000).

Sub-theme 3: Equipping oneself to accept death

Apart from all the help they can receive, helping oneself could be the most effective strategy. A few respondents expressed that one needs to build their strength by themselves:

We should do it on our own. We say that you will get better, by saying that, the patients will think like they are going to die, that God will take them away etc. but that fear should not be there. By making yourself strong, you will get better. By becoming strong, the pain also reduces. (Participant NG)

Participant ZR says, "We will have to make ourselves ready on our own, today or tomorrow."

Participant FM says, "You have to prepare yourself, Madam. Prepare yourself for death."

And participant RR says, "We should know we are just leaving this body and going to another body and another fresh life awaits us. This body is just another clothing. Life is a never-ending game."

Patients were looking up to each other for help. They felt that one needs to build strength by oneself and prepare themselves for the upcoming situation. By helping themselves, they can overcome any situation by not being overly dependent on others.

Sub-theme 4: Breaking the silence about the disease condition

Sharing the facts about the health condition with the patient acts as a device for the patient to gradually live life to the fullest. Knowing the reality of the illness makes the patient value life more and helps him to prepare for what lies ahead. This helps patients to cope with the reality of dying and achieve a quality of death. Participant FM says, “If you keep lying to him, okay, he won’t be prepared, he wants to live more and more, and in effect you are killing him.” Respondent FM explains how giving false hope is akin to killing a person and notes how important it is to tell the truth, and make the transition easy for the patient.

Another respondent RR says:

If they fear for death, you might not want to reveal that it is cancer initially but in the course of time you must tell them. Assure them that even if you die, nothing is going to happen and that you have another life. The caregivers should convey this. They should not hide this from the patient and instead should tell them that they will be getting a fresh life and that they will be greatly missed. Some patients might think that if their death do not matter much to their dear ones. People who love the patient should receive counselling because they feel miserable at the loss of their loved ones. They should prepare for the loss of the person and try and finish their responsibilities to the best of their abilities. (Participant RR)

A study by Bishara et al. (1997) discovered a positive relationship between open and honest communication and mental well-being. If patients are honestly informed of their condition, they are better prepared for death. Advancements include assisting patients to

redefine their current lives, facilitating communication of their burden, supporting individuals in their attempt to transform themselves, enabling them to find a purpose and empowering the patient to live daily (Davies et al., 1995; Davies et al., 2020). Open communication in the family during this traumatic period should be endorsed (Rando, 2000). 12 Japanese patients who died in 18 months were retrospectively analysed by Aoki et al. (1997). They found that the reality about their diagnosis, pathology and prognosis was found to be more complete at the end of life for terminally ill people who were informed of cancer. Some stress the importance and satisfaction of open communication within the family. It is a great advantage to speak clearly about death to kids, organise things together and find common areas to agree and converge. Patients appear to be different in their approach when talking about death and death issues. Some people need to talk about death; it provides satisfaction and rest. Others want to talk to everyone, though not too much, or at least not too much about death alone. However, recent studies on patient preferences for communication in cancer and end-stage diseases suggest that patients value a clear approach, which includes doctor recommendations (Wright, 2008).

Chapter V

SUMMARY AND CONCLUSION

The latest global cancer projections by the International Agency for Research on Cancer (IARC) estimates 19.3 million new cancer cases worldwide and 10 million fatalities in 2020. Going by the current rate of increase, 30.2 million new cases are anticipated by the year 2040. The number of new cases in India alone has increased to 1.32 million in 2020 with 8.5 lakh fatalities (Global Cancer Observatory, 2020). Death is a natural and inevitable life event. The physical, psychological, social and spiritual problems can cause the patient much sorrow (Chaturvedi, 2007). This includes physical discomfort, breathing troubles (dyspnoea), dependency on life-long and intrusive devices, decreased mental acuity, and existential issues over life goals and legacy (Warraich, 2018). A larger degree of discomfort with mortality tends to impact individual happiness and well-being. The idea of death leads to continuous anxiety and a fear of dying. It refers to the dread or phobia of death (Sherman et al., 2010). With terminally sick individuals approaching death, there might be increased fear of death. Helping to decrease dread in dying patients is one of the essential goals of palliative treatment (Tsai et al., 2004). If death is regarded as some form of failure rather than as an essential stage of life, people get distracted from preparing themselves to have a decent death (Smith, 2000), which is why it is vital to develop appropriate care for the dying. Drawing on their domain expertise in dealing with dying patients and distressed families, the clinicians should arrange suitable treatment for every patient throughout their terminal phase (Ellershaw, 2003). More research is needed to examine the concept of a decent death from the perspective of patients to provide quality treatment that is personalised to meet the specific needs of each patient (Meier et al., 2016). Hence, this study sought to investigate the perspectives of patients with advanced cancer on the quality of death and dying. A total of 21

patients with advanced cancer from two hospices (Karunashraya and Sparsh) and one hospital (Karnataka Cancer Hospital) were recruited for the study using the purposive sampling technique. The researcher approached two hospice centres and a hospital to obtain necessary authorization. Following permission, the patients were given a debriefing and a report. The researcher then met with each patient for in-depth interviews. For gathering data from participants, a semi-structured interview schedule was used. Thematic analyses have been conducted to detect data themes. Theme analysis is widely employed in qualitative research for identifying data patterns. Having assessed them, the factors were split into different themes. Primary themes have been divided into sub-themes. Respondents included those who spoke English or Kannada without any impairments and who knew about their disease condition. The patients excluded were those who were on ventilators and/or those who were suffering from psychological disorders such as schizophrenia, autism, dementia, etc. Participants had provided informed consent before data collection and confidentiality was maintained. The study attempted to uncover how the illness altered the patients' perspective of life, their aspirations, notions of a decent death, and how they wished to be cared for and supported at the end of life. The study examined many themes such as life goals and ambitions, current priorities in life, views about life, views on approaching death, a good death, needs at end of life, and preparation for death. The study was able to provide in-depth insights into end-of-life care, good death, how it might be attained as well as the quality of dying and death in advanced cancer.

Limitations of the Study

There is no such thing as a flawless study. There is always scepticism in research, which suggests that some drawback cannot be ruled out.

Limitation of this study are that the data were not examined for gender disparities and the research sample was uneven in terms of gender (men and women) due to respondent unavailability, poor physical health, and unwillingness to participate in the study by many respondents.

Implications

This qualitative study has added to the current body of knowledge on the quality of dying and death. It has contributed to a deeper understanding of the values and beliefs that are most important to patients at the end of their lives, which will assist in the development of assessment tools for successful dying. The study was able to give an in-depth understanding of end-of-life care, good death, how it may be reached, and the quality of dying and death in advanced cancer. Learning about patients' experiences will aid in the development of a better intervention plan and action to improve the quality of dying and death in India. This study has significant implications for policy, intervention, tool development, and in therapy. This research can help administrators and policymakers in a variety of domains, including in the service sector, public sector, commercial sector/corporations, hospitals, non-governmental organisations (NGOs), and so on, to better manage the impediments to a good death.

Suggestions

Based on the findings of the study, as discussed in Chapter 4 of the thesis, the following recommendations might be made:

- Because this data was gathered from only three facilities in South India, there is a scope for more studies by gathering data from other health establishments and with diverse demographic characteristics.
- More multicultural studies may be undertaken to examine similarities and differences across communities.

- It is suggested that a longitudinal study can be carried out in the future to determine new trends and changes over time on the basis of current results.
- There may also be more studies based on socio-economic disparities (lower class, middle class & upper class) to know if there are class differences in perceptions of successful dying.
- The same research might be extended to various age groups to generate more relevant information and insights.
- The same research may be conducted throughout India with a larger sample so that the results are made available to a wider population.
- Studies based on intervention might be carried out in future to improve the quality of death in terminally ill people

Conclusion

The study attempted to uncover how the illness altered the terminally ill patient's perspectives of life, their aspirations, what they consider to be a decent death, and how they wished to be cared for and supported at the end of life. The study examined many themes such as life goals and ambitions, current priorities in life, views about life and approaching death, a good death, needs at the end of life, and preparation for death. The study was able to provide an in-depth insight into end-of-life care, what constitutes a good death, how it might be attained as well as the quality of dying and death in advanced cancer. Learning about the experiences of patients provided insights into the formulation of a better intervention strategy and action to improve the quality of dying and death in the Indian community.

Renowned pioneers of palliative care such as Cicely Saunders, Kubler-Ross and others have expressed the need for special care for the dying (Saunders, 1981 & Kubler-Ross, 2013). Health professionals may identify hopelessness, despair, depression, fear, and anxiety

as distressing and preventable factors. Patients have complained that these factors are much more painful to them than the pain due to cancer. As palliative care experts become progressively conscious of the significance of psychological problems close to the end of life, mental health professionals should refine their skills to effectively engage in settings like these. A focal part of end-of-life mental health care includes precise diagnosis and evaluation of the numerous mental issues that are probably going to rise (Pessin et al., 2002).

Palliative care should be focused on working with physical symptoms and also distressing psychological symptoms (Breitbart & Heller., 2003). The identification and treatment of mental distress towards the end of life is of primary importance. To get there, several obstructions have to be surpassed to make this a complex task (Shuster, 1999). The counselling is a path to/of disclosure with the patient, a co-seeking or 'co-examining' (Morgan, 2000) with the individual of what is critical to her or him with regards to the ailment and the social setting. Therapists can offer help and psychosocial intervention to help with misery and anguish, mental disorder, existential and spiritual distress, advance care, life evaluation, and unsettled issues that might be meaningful concerns for the patient (Haley et al., 2003). Concentrating on positive results of therapy, regardless of outcomes per se, may enable patients to cope with their ailment and empower them to discover beneficial goals regardless of whether their sickness advances or not.

Individual or group counselling are said to be effective and helpful for patients having advanced cancer and adjustment disorders. Supportive-expressive therapy that is evidence-based helps in making the patient talk about their experience and helps the patient to focus on the present problems, relationships, coping, and expressing their emotions in an open environment. Given various accessible interventions that reduce the intensity of the symptoms and improve a sense of control, they should be employed to enable patients and

relatives to acknowledge their fear and nervousness so that they can discuss it with the health professionals. They additionally can employ cognitive coping skills such as relaxation techniques, meditation, imagery, and breathing techniques (Turk & Feldman, 2000).

Along with counselling, clinicians should be trained accordingly to communicate with the patients about their concerns, to make themselves comfortable in speaking to patients and recording their experiences (Quill, 1996). A structural approach must be followed by the clinician in caring for the patients and it is important to be empathetic in sharing bad news and progressing towards advanced care (Emanuel & Emanuel, 1998).

The evolution and the need of psychological methods for end-of-life care is being widely acknowledged now as a means to improve the final passage of life for the terminally ill (The SUPPORT Principal Investigators, JAMA, 1995). According to Henwood (1999), good death encompasses patients being aware of approaching death, having control in life, maintaining dignity and privacy, attaining emotional and spiritual support, and being able to bid goodbye to near and dear ones. These essential points should be kept in mind while planning an intervention for death and dying.

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The thesis may be considered for the award of degree. (Relevant documents attached).

Signature of the Researcher

Supervisor/Guide

Appendix 1: Informed Consent Form

Good morning/afternoon/evening. I, Maria Wajid, am a research scholar from the Department of Psychology, Central University of Karnataka. Very little research has been conducted to explore the experiences of Quality of dying and death in patients suffering from advanced cancer so, in this study, I am trying to discover what are the important factors that will help patients ease death and make their life fulfilling.

Please consider the following points before signing:

- I voluntarily agree to participate in this research study.
- I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without consequences of any kind.
- I understand that I can withdraw permission to use data from my interview, in which case the material will be deleted.
- I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.
- I understand that I will not benefit directly from participating in this research.
- I agree to my interview being audio-recorded.
- I understand that a copy of the transcript my interview will be given to me.
- I understand that all information I provide for this study will be treated confidentially.
- I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.
- I understand that disguised extracts from my interview may be quoted in the thesis and articles.
- I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.
- I understand that signed consent forms and original audio recordings will be retained in Karunashraya
- I understand that I am free to contact the researcher to seek further clarification and information.

- By signing this form I am stating that I am over 18 years of age and that I understand the above information and consent to participate in the study.

Statement of Consent:

I have read the above information. I have asked any questions I had regarding the study procedure and these have been answered to my satisfaction.

I, Mr./Ms. _____, consent myself to participate in this study.

Signature of the participant with date -----

Demographic Information

Name:

Age:

Gender:

Educational Qualification:

Income:

Residence:

Occupation:

Religion:

Appendix 2: Interview Guide

1. What are your views on life? (not death)
2. People set goals in life. Do you feel you have achieved most of your goals? (Bucket list)
3. What are the most important things in your life right now?
4. Please describe the concerns you have about death.
5. What would you consider a good death? A bad death? Why?
6. How do you think your death could be made easy?
7. What would you like in your future care?

Perceptions of People with Advanced Cancer on Quality of Death and Dying

Thesis submitted in partial fulfillment of the requirements for the Degree of
Doctor of Philosophy in Psychology

By

MARIA WAJID



CENTRAL UNIVERSITY OF KARNATAKA

Department of Psychology
School of Social and Behavioural Sciences
Central University of Karnataka
Kalaburagi, India - 585367

August 2021

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Chapter V

SUMMARY AND CONCLUSION

The latest global cancer projections by the International Agency for Research on Cancer (IARC) estimates 19.3 million new cancer cases worldwide and 10 million fatalities in 2020. Going by the current rate of increase, 30.2 million new cases are anticipated by the year 2040. The number of new cases in India alone has increased to 1.32 million in 2020 with 8.5 lakh fatalities (Global Cancer Observatory, 2020). Death is a natural and inevitable life event. The physical, psychological, social and spiritual problems can cause the patient much sorrow (Chaturvedi, 2007). This includes physical discomfort, breathing troubles (dyspnoea), dependency on life-long and intrusive devices, decreased mental acuity, and existential issues over life goals and legacy (Warraich, 2018). A larger degree of discomfort with mortality tends to impact individual happiness and well-being. The idea of death leads to continuous anxiety and a fear of dying. It refers to the dread or phobia of death (Sherman et al., 2010). With terminally sick individuals approaching death, there might be increased fear of death. Helping to decrease dread in dying patients is one of the essential goals of palliative treatment (Tsai et al., 2004). If death is regarded as some form of failure rather than as an essential stage of life, people get distracted from preparing themselves to have a decent death (Smith, 2000), which is why it is vital to develop appropriate care for the dying. Drawing on their domain expertise in dealing with dying patients and distressed families, the clinicians should arrange suitable treatment for every patient throughout their terminal phase (Ellershaw, 2003). More research is needed to examine the concept of a decent death from the perspective of patients to provide quality treatment that is personalised to meet the specific needs of each patient (Meier et al., 2016). Hence, this study sought to investigate the perspectives of patients with advanced cancer on the quality of death and dying. A total of 21

patients with advanced cancer from two hospices (Karunashraya and Sparsh) and one hospital (Karnataka Cancer Hospital) were recruited for the study using the purposive sampling technique. The researcher approached two hospice centres and a hospital to obtain necessary authorization. Following permission, the patients were given a debriefing and a report. The researcher then met with each patient for in-depth interviews. For gathering data from participants, a semi-structured interview schedule was used. Thematic analyses have been conducted to detect data themes. Theme analysis is widely employed in qualitative research for identifying data patterns. Having assessed them, the factors were split into different themes. Primary themes have been divided into sub-themes. Respondents included those who spoke English or Kannada without any impairments and who knew about their disease condition. The patients excluded were those who were on ventilators and/or those who were suffering from psychological disorders such as schizophrenia, autism, dementia, etc. Participants had provided informed consent before data collection and confidentiality was maintained. The study attempted to uncover how the illness altered the patients' perspective of life, their aspirations, notions of a decent death, and how they wished to be cared for and supported at the end of life. The study examined many themes such as life goals and ambitions, current priorities in life, views about life, views on approaching death, a good death, needs at end of life, and preparation for death. The study was able to provide in-depth insights into end-of-life care, good death, how it might be attained as well as the quality of dying and death in advanced cancer.

Limitations of the Study

There is no such thing as a flawless study. There is always scepticism in research, which suggests that some drawback cannot be ruled out.

Limitation of this study are that the data were not examined for gender disparities and the research sample was uneven in terms of gender (men and women) due to respondent unavailability, poor physical health, and unwillingness to participate in the study by many respondents.

Implications

This qualitative study has added to the current body of knowledge on the quality of dying and death. It has contributed to a deeper understanding of the values and beliefs that are most important to patients at the end of their lives, which will assist in the development of assessment tools for successful dying. The study was able to give an in-depth understanding of end-of-life care, good death, how it may be reached, and the quality of dying and death in advanced cancer. Learning about patients' experiences will aid in the development of a better intervention plan and action to improve the quality of dying and death in India. This study has significant implications for policy, intervention, tool development, and in therapy. This research can help administrators and policymakers in a variety of domains, including in the service sector, public sector, commercial sector/corporations, hospitals, non-governmental organisations (NGOs), and so on, to better manage the impediments to a good death.

Suggestions

Based on the findings of the study, as discussed in Chapter 4 of the thesis, the following recommendations might be made:

- Because this data was gathered from only three facilities in South India, there is a scope for more studies by gathering data from other health establishments and with diverse demographic characteristics.
- More multicultural studies may be undertaken to examine similarities and differences across communities.

- It is suggested that a longitudinal study can be carried out in the future to determine new trends and changes over time on the basis of current results.
- There may also be more studies based on socio-economic disparities (lower class, middle class & upper class) to know if there are class differences in perceptions of successful dying.
- The same research might be extended to various age groups to generate more relevant information and insights.
- The same research may be conducted throughout India with a larger sample so that the results are made available to a wider population.
- Studies based on intervention might be carried out in future to improve the quality of death in terminally ill people

Conclusion

The study attempted to uncover how the illness altered the terminally ill patient's perspectives of life, their aspirations, what they consider to be a decent death, and how they wished to be cared for and supported at the end of life. The study examined many themes such as life goals and ambitions, current priorities in life, views about life and approaching death, a good death, needs at the end of life, and preparation for death. The study was able to provide an in-depth insight into end-of-life care, what constitutes a good death, how it might be attained as well as the quality of dying and death in advanced cancer. Learning about the experiences of patients provided insights into the formulation of a better intervention strategy and action to improve the quality of dying and death in the Indian community.

Renowned pioneers of palliative care such as Cicely Saunders, Kubler-Ross and others have expressed the need for special care for the dying (Saunders, 1981 & Kubler-Ross, 2013). Health professionals may identify hopelessness, despair, depression, fear, and anxiety

as distressing and preventable factors. Patients have complained that these factors are much more painful to them than the pain due to cancer. As palliative care experts become progressively conscious of the significance of psychological problems close to the end of life, mental health professionals should refine their skills to effectively engage in settings like these. A focal part of end-of-life mental health care includes precise diagnosis and evaluation of the numerous mental issues that are probably going to rise (Pessin et al., 2002).

Palliative care should be focused on working with physical symptoms and also distressing psychological symptoms (Breitbart & Heller., 2003). The identification and treatment of mental distress towards the end of life is of primary importance. To get there, several obstructions have to be surpassed to make this a complex task (Shuster, 1999). The counselling is a path to/of disclosure with the patient, a co-seeking or 'co-examining' (Morgan, 2000) with the individual of what is critical to her or him with regards to the ailment and the social setting. Therapists can offer help and psychosocial intervention to help with misery and anguish, mental disorder, existential and spiritual distress, advance care, life evaluation, and unsettled issues that might be meaningful concerns for the patient (Haley et al., 2003). Concentrating on positive results of therapy, regardless of outcomes per se, may enable patients to cope with their ailment and empower them to discover beneficial goals regardless of whether their sickness advances or not.

Individual or group counselling are said to be effective and helpful for patients having advanced cancer and adjustment disorders. Supportive-expressive therapy that is evidence-based helps in making the patient talk about their experience and helps the patient to focus on the present problems, relationships, coping, and expressing their emotions in an open environment. Given various accessible interventions that reduce the intensity of the symptoms and improve a sense of control, they should be employed to enable patients and

relatives to acknowledge their fear and nervousness so that they can discuss it with the health professionals. They additionally can employ cognitive coping skills such as relaxation techniques, meditation, imagery, and breathing techniques (Turk & Feldman, 2000).

Along with counselling, clinicians should be trained accordingly to communicate with the patients about their concerns, to make themselves comfortable in speaking to patients and recording their experiences (Quill, 1996). A structural approach must be followed by the clinician in caring for the patients and it is important to be empathetic in sharing bad news and progressing towards advanced care (Emanuel & Emanuel, 1998).

The evolution and the need of psychological methods for end-of-life care is being widely acknowledged now as a means to improve the final passage of life for the terminally ill (The SUPPORT Principal Investigators, JAMA, 1995). According to Henwood (1999), good death encompasses patients being aware of approaching death, having control in life, maintaining dignity and privacy, attaining emotional and spiritual support, and being able to bid goodbye to near and dear ones. These essential points should be kept in mind while planning an intervention for death and dying.