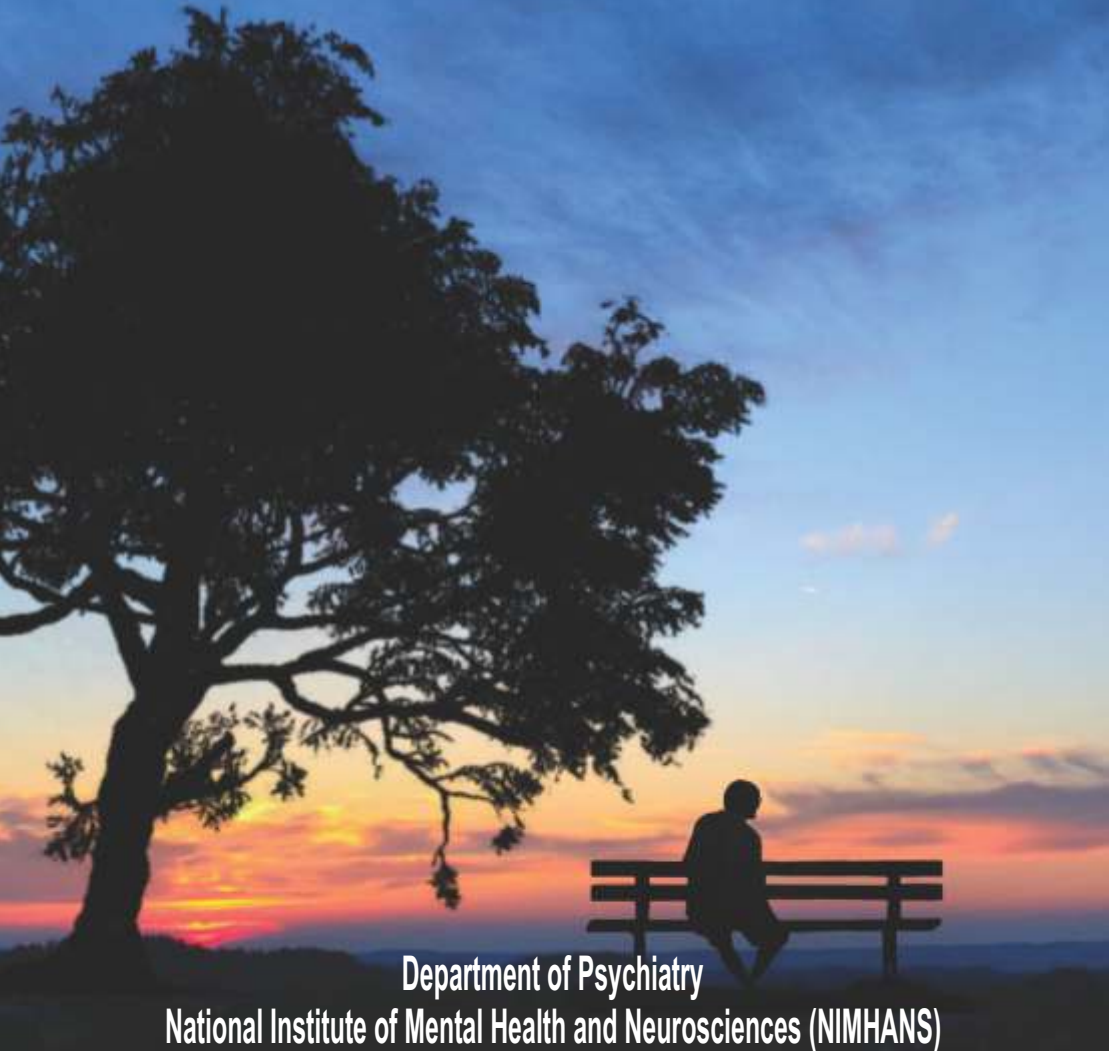




Poignancy to Peace

Identification and Management
of Grief in Palliative Care



Department of Psychiatry
National Institute of Mental Health and Neurosciences (NIMHANS)

POIGNANCY TO PEACE

IDENTIFICATION AND MANAGEMENT OF GRIEF IN PALLIATIVE CARE

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FOREWORD

Birth and death are two sides of the same coin. The former is associated with joy and the latter with sorrow—also called grief. No one can avoid grief. One is struck by it either suddenly or gradually. A dear one being affected by a grievous and potentially fatal illness is an example of the latter. However, all of us are affected by grief differently. The quantum is determined by several factors, many of which can potentially be controlled. Exploiting such potential can mitigate the effects of grief. Interventions are possible for persons affected with or anticipating grief. In this book, edited by Dr V Senthil K Reddi and Dr Shayanth M Gowda, many illustrious authors have written chapters that explain grief, its origins, its dimensions in the family context, special populations like children, interventions to mitigate grief, and a cultural perspective of this distress. In the Indian context, the concept of death is differently understood and this can have an influence on the grief. The belief in rebirth is one such example. Likewise, the belief that the soul is eternal and has no death (it moves on into another new body, just as we change into new clothes), can work during grief and reduce the feelings of guilt. The book addresses issues related to grief in the context of palliative care. Learning that a person close to you will leave your world in a short time (weeks or months), makes one go through that ‘grief’ even while anticipating the departure (death). The authors also discuss interventions that can prepare one to receive this news and overcome the influence of loss.

This book is essential for all professionals involved in palliative care services. The contents equip them to work with those at risk of the effects of grief. These include those receiving palliative care, their close family members, and healthcare staff themselves, thereby enhancing their capacity to provide appropriate and professional help. The presentation style of each chapter has used an approach that ensures

that the content is easy to understand, yet packed with practical tips and very relevant information. The editors have also carefully selected the chapters and their order to help readers grasp the content and build required skills in this area. All contributors merit to be appreciated for this scholarly handbook that will directly benefit the professionals and hence their clients.

Dr B N Gangadhar MD, D Sc

Senior Professor and Director, NIMHANS

PREFACE

Grief is a complex psychological response to the loss of a valued object, person, or health of an individual, that results in a state of emotional turmoil. The experience of grief is unique for each individual—people respond to loss in different ways. Grief in the context of palliative care adds greatly to the existing challenges of the field, and is experienced not by just the individual, but by their family and palliative care staff themselves. Palliative care professionals from varied backgrounds, working in the field of cancer, encounter grief often but may be unable to identify or adequately address the same. This may occur due to a variety of reasons, including but not limited to palliative care professionals tending to normalize the grief reaction, or having a sense of being ill-equipped to manage grief. Being unable to attend to grief in palliative care can significantly impact and limit the quality of palliative care provided. Grief therefore poses significant challenges to palliative care staff and volunteers.

This book provides a practical approach to the identification and management of grief in the context of palliative care. We have tried to focus on multiple aspects of grief in the context of palliative care. The book includes several illustrative case vignettes, which makes it easier to understand and apply to real-life scenarios. The aim is to try and overcome some of the existing challenges, in order to enhance the quality of care individuals are provided.

Chapter one deals with various phases and dimensions of grief and its effects on the family. It also addresses the challenges in differentiating between normal from abnormal grief, and other psychiatric disorders such as depression/demoralization disorders.

Chapter two provides methods of conducting structured assessments of various domains of grief, and identifying predictors as well as risk factors which could influence the development of prolonged or complicated grief.

Chapter three deals with family grief and various factors such as stigma and collusion, often encountered in the Indian setting, which can greatly influence the wellbeing of patients and their family members. Chapter four

focuses on children, a special group in palliative care. Children and adolescents have a unique way of handling death and loss, and pose a unique challenge in identification and management of grief. This chapter deals with identification and management of grief in children. Chapter five provides insights to various psychological models of grief; it also discusses the various psychosocial intervention strategies developed for the management of grief. Chapter six deals with strategies to ensure early identification of “at risk individuals”. This allows for the timely initiation of interventions to provide comprehensive preventive bereavement care, thereby minimizing the likelihood of complications associated with bereavement.

Individuals providing palliative care deal with terminal illnesses and death on an ongoing basis. Despite their best efforts most are affected, thereby impacting their own mental health and psychological wellbeing. The consequences of the same include burnout or a compromise of their caregiving capacity. Hence, the focus of chapter seven is this pertinent area of identification and effective approaches of handling grief amongst healthcare professionals and other individuals providing palliative care.

Last but not the least, chapter eight deals with spirituality in the context of end-of-life care. This chapter empowers palliative care providers to identify the spiritual needs of an individual with terminal illness, and effective ways of addressing these spiritual needs.

This book is a useful guide to attend to the crucial area of grief for those working in the area of palliative care, offering their services to patients and their families, including oncologists, nurses, psychologists, psychiatric social workers, psychiatrists, anesthesiologists, lay counselors or anyone who is involved in end-of-life care.

Dr V Senthil Kumar Reddi

Dr Shayanth Manche Gowda

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CHAPTER 1

Normal and Abnormal Grief: A Current Understanding

Shalini Anji, V Senthil Kumar Reddi

Grief is a diverse and complex response to the loss of someone, or something, with whom there existed a bond or affection. While the terms bereavement, grief and mourning are often used interchangeably, they actually have different meanings. Bereavement refers to the state of loss; grief is the reaction to that loss, such as feeling emotional; and mourning is the process of adapting to the subsequent challenges, i.e. the world without the deceased (Archer, J. 1999). In short, bereavement is the period after a loss during which grief is experienced and mourning occurs.

This chapter will focus on understanding the concept of grief, stages of grief, various kinds of normal and abnormal grief, and the unique grieving experiences of cancer patients and their caregivers.

The experience of grief goes beyond just death and dying

Most people are familiar with the concept of grief associated with death. However, individuals grieve for a variety of losses throughout their lives. These include life events such as unemployment, ill health, loss of social role or status, the end of a relationship, or miscarriage of a pregnancy (Viederman, M. 1995).

Loss can be broadly categorized as either physical or abstract. Physical loss relates to something that the individual can touch or measure, such as the demise of a loved one. Other types of loss are abstract, and are related to aspects of a person's social interactions with the subject, or symbolic losses. For example, grieving in the backdrop of a miscarriage, divorce, loss of a job, etc.

Some people recall grieving the deaths of public figures such as Abdul Kalam, Sri Devi, or Steve Jobs, even though they had never met them. A hundred years ago, when a death occurred, people would hear about it in the town square (*gramina panchayats* in India), and would talk to each other, publicly expressing their sadness and shock in order to facilitate the grieving process (Stroebe, M. 1993). Today, information about such events is readily disseminated using various channels, and social media platforms such as Facebook and Twitter have become our new 'town square'.

Dimensions of grief

Grief has emotional, physical, cognitive, behavioral, social, cultural, and philosophical dimensions. Emotional responses include bitterness, anger, guilt, anxiety, sadness and despair, surprise, fear, disgust, and an urge to blame others; these responses may persist for several months. Physical reactions may include sleep disturbances, fluctuations in appetite, somatic complaints, and illness. The social outcomes range from withdrawal and behavioral changes, to a lack of self-care or care for loved ones and a neglect of social and professional duties. The duration of bereavement depends on the degree of attachment between the bereaved and the deceased, and the amount of time spent anticipating the loss. The grieving process, however, depends not only on the relationship or attachment with the deceased, but also the situation surrounding the death. Cultural customs, rituals and society's rules for coping with loss also exert influence on mourning.

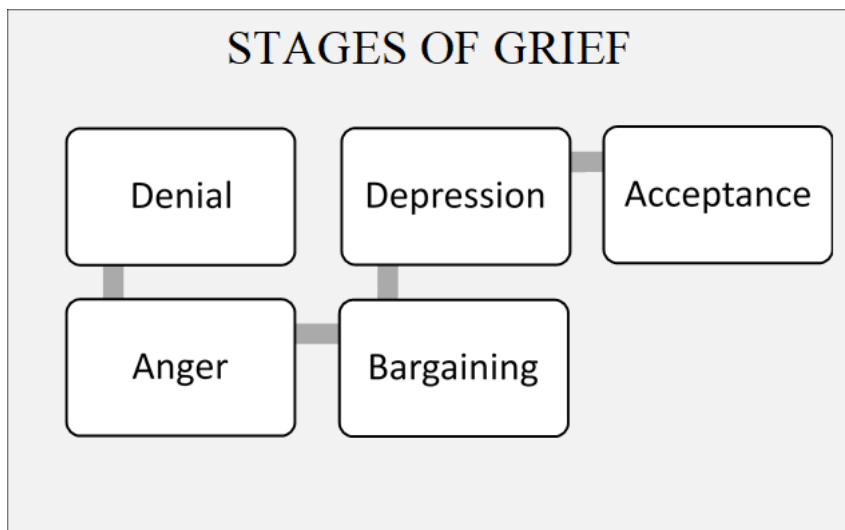
Any memory can be a trigger for the bereaved: the way the bereaved chooses to remember their loved one, and how they integrate the memory of the deceased into their daily lives is unique to each individual (Chaturvedi, SK 2009).

Phases of grief reaction and bereavement

Elisabeth Kubler-Ross first identified the five stages of grief in her groundbreaking book, *On Death and Dying* in 1969. The stages are denial, anger,

bargaining, depression, and acceptance (**Figure 1.1**). Recently there has been an emerging focus on finding meaning in life, in the context of grief. It is also considered as sixth stage by David Kessler. These stages occur naturally in our lives, from day to day, amidst other changes. These stages need not follow the sequence as described. Sometimes one may experience a combination of two or more stages simultaneously.

Figure 1.1: Stages of grief as proposed by Elisabeth Kubler-Ross



The process of bereavement was illustrated to have four phases by John Bowlby and Colin Murray Parkes (Bowlby, J. 1961) (**Figure 1.2**):

- Shock and numbness: The bereaved experiences a sense of shock, and has difficulty in accepting the event of death, sometimes with minimal or no emotional response.
- Yearning and searching: The bereaved person looks for the deceased relentlessly, and feels frustrated and disappointed when these attempts go in vain.
- Disorganization and despair: The person feels depressed, is easily distractible, and has difficulty focusing on their daily life and responsibilities.
- Reorganization: Survivors begin to accept their loss and are able to form new relationships with others. They gradually regain their previous interests and resume their regular activities.

Figure 1.2: Phases of grief as proposed by Bowlby and Parkes



Anticipatory grief

Anticipatory grief is the natural mourning that occurs when a patient or their family awaits imminent death. Many of the symptoms of anticipatory grief are similar to those of conventional grief—the thoughts, emotions, cultural and social reactions are the same as those experienced after a death occurs (Clayton PJ et al., 1973).

Anticipatory grief is different from the grief that follows an accidental death. Accidental loss often causes an imbalance in the coping abilities of a mourner, making it hard for them to function normally. Although they recognize that the loss has occurred, they are unable to come to terms with it psychologically.

Anticipatory grief gives the family time to get used to the reality of the impending loss. People often complete “pending business” with the dying person during this period (for example, expressing gratitude, affection or vocalizing their feelings, to avoid leaving anything unsaid). They tend to show extreme concern for the suffering that the dying person will endure in coming to terms with the impending death, and start to get accustomed to changes that may be caused by the death. The grief experienced prior to a death does not reduce the grief after the death.

To accept a dear one's imminent death while they are still alive, makes one feel as if the person dying is being abandoned. Coming to terms with reality helps strengthen the bond between the bereaved and the person dying. Although anticipatory grief may help the family, the dying person gradually becomes socially withdrawn.

Gradual bereavement

Unlike anticipatory grief, there are instances where people are gradually deprived of something or someone—for example, the gradual loss of a loved one due to cancer. This produces a sense of “gradual grief.”

The blogger of *Mundane Faithfulness*, Kara Tippetts, described her dying due to metastatic breast cancer, as the process of dying ‘by degrees’, her ‘body failing’, and her ‘abilities vanishing’. A person's characteristics and abilities gradually perish during this period.

Cultural diversity in grieving

Each culture specifies a distinct set of practices or rituals which the bereaved are expected to participate in, such as a particular way to dress, adopting a new set of habits or attitudes, etc. Beliefs regarding continuing ties with the deceased vary across different cultures in the world. In India, maintenance of ties with the deceased is accepted and carried out through religious rituals, whereas in the Hopi of Arizona, USA, the deceased are quickly forgotten and life moves on.

Though there are cultural differences in the way a person grieves, they all have a common theme—encouraging the grieving to take up healthy ways of coping with the loss of a loved one and develop a healthy image of oneself and the world over a period of time.

Grief in the context of cancer patients and their caregivers

The diagnosis of cancer is often associated with a profound sense of loss, with varied and complex dimensions. The consequences of a life-threatening illness such as cancer can shatter self-perceptions, life attitudes, individual assumptions and value systems, and can hamper the sense of autobiographical continuity and coherence for an individual as well as their family members and friends.

As a person and their family go through a life-threatening or chronic illness, there are various kinds of losses experienced, and each kind of loss triggers its own grief reaction.

Phases of grief for an individual with cancer

For cancer patients, the period between a diagnosis and death may span many months.

- The acute phase occurs at the time of the diagnosis, given that cancer is associated with “finality”, or the end of life. The paradox of the initial phase is the core of this phase. Individuals are placed in the challenging situation of having to understand the diagnosis, make decisions about their medical care to recover or extend their life, and concurrently come to terms with a perceived sense of an end to various aspects of their being.
- The chronic phase is the time period between the diagnosis and the result of treatment. It is the period of time when a patient tries to cope with the demands of life while also undergoing treatment and coping with the side effects of treatment.
- In the recovery phase, people cope with the mental, social, physical, religious and financial effects of the disease, often through a spiritual and philosophical approach.
- The final (terminal) phase of a life-threatening illness, like cancer, occurs when death is likely to happen and commonly experienced in acute palliative-care settings. The focus shifts from curing the illness or extending the duration of survival, to rendering comfort and relief from pain (Rome et al., 2011). Spiritual, philosophical and religious concerns are often the focus during this time.

Patients report innumerable fears, anxiety, and depression during the terminal phase. A study conducted in India (Chaturvedi SK, 1994) found commonly reported problems to be cancer pain, physical health problems, financial problems, and uncertainty about the future. Other concerns were low mood and sadness, anxiety, being slowed down, and not being able to work (and earn). The emotional distress caused by these concerns needs to be alleviated in order to improve the overall quality of life of the patient, and to help them cope with the pain and other distressing symptoms.

How does the terminal phase of cancer affect families?

People may have a pathway to death that is long and slow, sometimes lasting years, or it may be a rapid fall (a car accident, for instance) during the chronic phase of the illness. The peaks-and-valleys pathway elucidates the life of a patient who has exacerbations and remissions (for example, a patient with leukemia).

Another pathway to death may be described as a long, slow period of failing health followed by a period of stable health at a new, limited level of wellbeing (for example, patients with lung cancer). Patients on this pathway might have to adjust to losses in functional ability (Adler NE and Page AEK 2008). There may be a long period of time between diagnosis of cancer and eventual death, with long-term pain and suffering and/or loss of control over one's body or mind. This phase is likely to drain patients and their families physically as well as emotionally as it extends over many months to few years at times.

Pathological/abnormal variants of grief in patients with cancer and their caregivers

While grief is understood to be a normal process, it is important to know when it becomes abnormal. There are three distinct diagnostic categories which fall under abnormal or pathological variants of grief, namely complicated grief, major depressive disorder and demoralization syndrome.

Complicated grief

Complicated grief is characterized by the persistence of symptoms for long periods, the interference caused by these symptoms, or the intensity of the symptoms (for example, intense suicidal thoughts or acts). It may present as an absence of mourning, an inability to experience aspects of normal grief reactions, delayed onset of grief, conflicted or ambivalent grief responses and chronic or prolonged grief.

Predictors of complicated grief include the abruptness of the death, separation anxiety in childhood, and the nature of relationship with the deceased (for example, an emotionally intense, or intimate, or contradictory/ambivalent relationship) (Keyes et al., 2014).

When a person suffers from post-traumatic stress disorder, they may try to avoid any reminders of, or may panic easily at any reminder of the deceased,

and in some cases, may think excessively or dream about the deceased.

Substance abuse is a fairly common coping strategy employed to avoid experiencing agonizing feelings while tackling with the loss; self-medicating for somatic complaints such as sleeplessness is also common.

The DSM 5 criteria for persistent complex bereavement disorder (PCBD) helps in diagnosing complicated grief effectively in clinical settings. According to this, the duration of intense grieving should last for at least 12 months.

Major depressive disorder

Major depressive disorder is a clinical condition, characterized by at least two weeks of low mood that is present across most situations, is often accompanied by low self-esteem, loss of interest in previously enjoyable activities, and decreased energy levels. If grief reactions progress to major depression, it will have to be treated with both pharmacological and psychological therapies.

Demoralization syndrome

Demoralization syndrome is a diagnostic category recognized in palliative-care settings and is characterized by hopelessness, loss of meaning, and existential distress as its core features, and results from existential conflict (Kissane et al. 2001). It is associated with chronic medical illness, disability, bodily disfigurement, fear of loss of dignity, and social isolation, where there is a subjective sense of incompetence and perceiving oneself to be a burden to others (Sansone and Sansone 2010). The sense of inadequacy predicts worsening in the course of this syndrome leading to a desire to die or to make plans to end one's own life. Depression and demoralization are distinct clinical entities, where the former would have anhedonia and the latter would have helplessness.

Normal grief, complicated grief, major depressive disorder and demoralization syndrome share similar symptoms, but they are distinct subjective experiences and differences among them are illustrated in **Table 1.1**.

Table 1.1: Factors which help in differentiating grief from other related disorders

	Grief Reaction	Complicated Grief / Persistent Complex Bereavement Disorder	Major Depressive Disorder	Demoralization Syndrome
Duration	Normally up to 6 months, rarely up to 1 year	More than 1 year	Minimum period of 2 weeks and up to 2 years, and rarely more than 2 years	Not defined
Onset	Precipitated by the loss	Precipitated by the loss but the onset is often delayed, or there is inadequate experience of grief reaction	May or may not have a precipitating factor	Chronic debilitating medical condition
Course	Decreases over time and occurs in waves that are triggered by thoughts or reminders	Continuous	Continuous	Gradually progressive

	of the deceased loved one.			
Mood	Low mood circumscribed to triggers of the loss	Emotional numbing or intense reactions to memories or reminders of the deceased	Persistent and pervasive low mood	May or may not be present
Anhedonia	Absent	Unable to enjoy good memories about the loved one	Present	Absent
Decreased energy levels	Absent	Absent	Present	May or may not be present
Thoughts	Begins with longing for the deceased and eventually consolidates memories related to the deceased in a meaningful way	Recurrent thoughts that life is meaningless, unfair or empty without the deceased	Constant thoughts of being worthless, hopeless or helpless	Fear of loss of dignity
Ideas of Guilt	Resolves with time	Rumination about the circumstances or	May or may not present	No

		consequences of the death		
Death wishes / Suicidal ideas	No	Frequent urge to join the deceased	Yes	Yes
Perception of being a burden on others	No	No	Yes	Yes
Sleep and appetite disturbances	Adequate	Sometimes affected	Significantly affected; extreme weight loss	Adequate
Psychotic symptoms	Absent	Perceptual disturbances such as pseudo- hallucination of the deceased with a sense of presence	Presents as delusion and/or hallucination	Absent
Impact on social functioning	Adequate	Feeling alone, detached from others, or distrustful of others since the death	Significant dysfunction	
Stages of grief	Passes through all or most of	Persistent feeling of being “stuck”	Depression	Anger and depression

	the stages before reaching the stage of acceptance	in the grieving process		
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Take-home points:

- Death is inevitable for all living creatures. Human beings develop bonds with significant others in their lives, and sustain an emotional attachment through various events.
- The existence of meaningful life is felt through the mere experience of emotions linked with few sets of important memories.
- After the death of a loved one there is a sudden reduction in the interaction and emotional experiences as the loved one is not physically present for such experiences. Hence, a sense of pain and meaninglessness is often perceived following a loss.
- The griever's temperament, the level of attachment with the deceased, and the circumstances around the death, often determine whether the grief reaction will be normal or complicated.
- Grief therapy includes dealing with obstacles in the mourning process, identifying unfinished business with the deceased, and identifying other losses that result from the death.

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CHAPTER 2

Assessment of Grief in the Context of Palliative Care

Shayanth Manche Gowda, Prabha S Chandra

Outline of this chapter

- Need for assessment of grief and the appropriate time for assessments
- Differentiating between normal and abnormal grief
- Unfinished business
- Anticipatory grief and its assessment tools
- Factors which influence the development of prolonged or complicated grief
- Role of coping strategies and its influence on the development of grief

Is there a need to assess grief or bereavement?

Palliative care includes care for the family and caregivers in addition to that of the person with end-stage illness. The loss of a loved one can be a devastating experience and bereavement has been associated with various health outcomes such as weight loss, worsening of existing health problems, higher rates of new-onset medical illness, and an increased risk of development of anxiety and depressive symptoms (Stroebe, Schut, & Stroebe, 2007).

Grief is a process of handling the loss, coming to terms with it, accepting it and then moving on. Most grief trajectories follow the expected path.

However, in some situations people may need help in coping with their grief. At times, it may be difficult to predict who will need extra support or which person may not be coping adequately, and that is where the role of a good assessment comes in.

It is important for palliative care teams to identify two groups of individuals – first, those who may need gentle support to handle the loss, and second, those who are at risk of heightened grief reactions such as blocked grief, complicated grief or prolonged grief.

Assessment is often therapeutic

The assessment itself could be beneficial for many family members as it gives them an opportunity to talk about the deceased person, discuss their distress, and also learn how to effectively manage overwhelming emotions.

The timing of assessment

Grief may begin to manifest much before the actual bereavement. Family members may begin to mourn the loss of the person's role as a parent or spouse, when there are relapses or phases of heightened uncertainty, and when death appears imminent.

Ideally, a person's grief reaction should first be assessed around the time when anticipatory grief is expected, i.e. when the family enters palliative care settings. Following this, it should be assessed when the condition gets worse, in the first few weeks following the death, six months after the death when some relief in the overwhelming symptoms is expected, and then at 12 months post bereavement when you expect anniversary reactions. However, there is no hard-and-fast rule; assess the person's grief when you think they may need it or when the team members point out that a family member is not coping well.

Who can assess for grief?

Anyone who is part of a palliative care team such as nurses, medical and surgical oncologists, psychologists, psychiatrists, psychiatric social workers, anesthesiologists, and NGOs/volunteers can assess for grief.

Normal vs abnormal grief

An example of a brief assessment

A 48-year-old school teacher was evaluated for complicated grief six months after his wife's death. His wife was 42 years old at the time of her death and had carcinoma cervix with secondary metastasis. They had two daughters, aged 16 and 12. The husband reported feeling extremely lonely and overwhelmed with the responsibility of looking after the daughters. He missed his wife dearly and constantly recollected fond memories. He felt betrayed by life and mourned the fact that his wife could not live long enough to see the success of their daughters. He would sometimes cry in situations which reminded him of his wife. However, he felt that he needed to accept the death and focus on securing a good future for his daughters. He goes to work regularly, eats well, and also gets adequate sleep.

Questions that can help in understanding the husband's grief

- Could you describe your thoughts?
- Are you able to talk about the death and the last few days?
- How much time were you able to spend with your wife?
- How was the funeral?
- How have you been handling your work and relationships after the death?
- What kind of emotions do you experience? Are you able to handle them? Do you find them overwhelming?
- Do they come in waves or are they there most of the time?
- Are there any other emotions you feel such as anger, guilt, feelings that you could have done something more, feeling alone or abandoned?
- How do you handle reminders? Do you avoid things that remind you of your wife (photographs, talking about her, activities which you used to do together, or any situations associated with her)?
- How have you handled her belongings, clothes, and books?
- Do you blame yourself for her death?
- How were you able to handle the suffering?
- Was the death traumatic?
- Did you witness her intense suffering before the death?
- Some people feel emotionally numb; is it like that for you?
- Do you feel you don't have an identity without your wife?
- Do you have thoughts of ending your life to be with your wife?
- Are there times where you feel lonely or have difficulty in connecting with others?
- Do you sometimes feel life is meaningless or empty without the deceased?
- How about dreams? Are you able to sleep well?

- Do you get repeated thoughts or images/flashes of the traumatic/painful death of your wife?

Assessing unfinished business

Unfinished business is the feeling of something left undone, such as family members being unable to accomplish something with their loved one while they were still alive (Yamashita et al., 2017). This can be experienced by both patients as well as caregivers. The prevalence of unfinished business is found to be around 26% in palliative care settings (Yamashita et al., 2017). It is particularly important to be aware of unfinished business in the context of palliative care, as higher distress related to unfinished business could lead to more severe, prolonged grief, greater psychiatric symptoms, and more intense continuing bonds with the loved ones after death (Klingspon, Holland, Neimeyer, & Lichtenthal, 2015; Yamashita et al., 2017).

As mentioned earlier, unfinished business is a matter of concern even for patients with terminal illness wherein the terminally ill person feels guilty about not being able to meet their existential responsibility of leading a unique life—one only they could have lived to its fullest potential, finding meaning, purpose, direction, growth in life, and becoming valued members of a culture and the world around them. This existential guilt could manifest in various ways such as fear of death, depression, shame, anger (secondary to fear of loss of love, hope, life), or intense death anxiety in the patients (Becker, 1973; Breitbart, 2017).

A few common scenarios of unfinished business for caregivers in the context of palliative care are: untimely goodbyes, unresolved conflicts with the loved ones, guilt for not spending enough time with the loved ones when they had the opportunity, missing a chance of expressing love or apologizing (Yamashita et al., 2017). A survey conducted on 967 bereaved families of cancer patients admitted to palliative care settings, has reported that in families with unfinished business, the three most important themes expressed were listening to the patient's honest feelings, expressing apologies to the patient, and visiting places that the family and patient had wanted to travel to (Yamashita et al., 2017).

Factors which influence the presence of unfinished business are: death preparedness by the family, information about disease trajectory, patient-family relationships, awareness of how to spend quality time, and appropriate timing to accomplish the family's wishes (Yamashita et al., 2017).

The simplest way to assess unfinished business is to ask the family members if they have such feelings, followed by a description of ‘the most troubling example’ of unfinished business. Distress related to unfinished business can be rated using a ten-point scale ranging from *not at all distressed* (1) to *extremely distressed* (10).

Anticipatory grief

A case scenario involving assessment of anticipatory grief

A 51-year-old man who was diagnosed with hepatic carcinoma stage-IV around six months back, is currently admitted to palliative care after completion of his chemotherapy cycles. The current admission is due to breathlessness and severe pain in the abdomen.

The patient has a son and a daughter, both of whom are married. The son is the primary breadwinner in the family. The patient feels that he has fulfilled his responsibilities as a father and has no apparent unfinished business.

However, the patient’s wife, who has studied up to high school and works at a garment factory, reports a significant fear of separation from her life partner who has always been there for her emotional needs. She worries that she will be all alone after her husband’s death, and becomes fearful and tearful whenever she thinks about the death of her husband. She spends most of her days thinking about her husband’s suffering—the side-effects of chemotherapy, intense pain, decreased sleep and appetite. She has fond memories with her husband and spends a lot of time ruminating; she prays and performs superstitious rituals in the hope of a miracle which may save her husband from imminent death. There is anger towards God, and she constantly ponders over why her husband got this illness even though he has never harmed anyone and has no bad habits such as smoking or drinking—she feels helpless about the situation. She also reports difficulty in concentrating on work, multiple crying spells, and poor sleep.

Examples of assessment in this particular scenario

- What kind of thoughts do you have?
- What kind of emotions do you experience? Are you able to handle them? Do you find them overwhelming?

- Are there any other emotions you feel such as anger, guilt, feelings that you could have done something more, feeling alone or abandoned?
- Have you been able to talk to someone about these difficulties?
- Have you been feeling emotionally numb or had difficulty connecting with others?
- Do you feel that life is empty or meaningless without your husband?
- How have you been handling your daily activities and your role in the family?
- Do these worries about your husband disrupt your daily routine?
- Do you constantly think you will never be the same without him?
- You mentioned that you cry whenever you think of your husband – how often does this happen?
- You also mentioned that you are experiencing sleep difficulties – could you elaborate?
- How is your appetite? Have you lost weight recently?
- What are your thoughts about the future? Do you have any plans?
- How difficult has it been for you to accept the imminent death of your husband?
- Do you regret not having expressed your feelings/emotions towards your husband?
- Have you spoken about the illness with your husband?
- Are there things between you two that you have left unsaid?
- Do you blame yourself for anything?
- Do you avoid thinking or talking about his illness and its consequences?

Anticipatory grief is the process of grieving the loss of loved ones before their inevitable death. Traditionally, anticipatory grief was viewed as a ‘safeguard against the impact of a sudden death notice’, that facilitates adjustment to bereavement (Lindemann, 1944). A family’s anticipatory grief is not just a distressing process of anticipating the death of a loved one, but also a transition to a different reality where the loved one is absent, a process of recognizing the proximity of death, and personal and relational losses following death (Coelho & Barbosa, 2016). Anticipatory grief/pre-death grief is different from anxiety and depression but it may influence these symptoms.

The response to the imminent death of a loved one could manifest at various levels. In the initial stage family members may recognize the imminent death cognitively and still maintain the fantasy that it is avoidable. In most cases, this cognition might progress to emotional distress, which manifests as separation anxiety, worries about the future, fear about the painful death of

the loved one, sadness, apathy, feelings of helplessness while witnessing the painful suffering of the ill person, anger directed towards the disease or towards the ill person because of the sense of abandonment, uncertainty of having made the right decision, or because of failure to prevent death (Coelho & Barbosa, 2016).

Assessment of anticipatory grief

Identification of anticipatory grief requires careful clinical observation of the caregiver and an examination of specific concerns and feelings about the situation. The assessor should keep track of physical and cognitive symptoms such as difficulties in concentration and problem-solving. One must check whether there is avoidance of social interaction or caregiver responsibilities, and assess the caregiver's coping strategy with progressive losses. Combining routine clinical assessment with structured instruments provides additional information towards a better understanding of the anticipatory grief.

There are many different scales which are used to measure anticipatory anxiety. Although most of these scales were initially developed for caregivers of dementia patients, they can be modified according to the need in palliative care settings to assess anticipatory grief. Some of the commonly used scales are:

1. **The Anticipatory Grief Scale** (Theut, Jordan, Ross, & Deutsch, 1991): A 27-item self-report tool; scoring is done on a 5-point Likert scale ranging from 'strongly disagree' to 'strongly agree'.
2. **Caregiver Grief Scale (CGS)** (Meichsner, Schinköthe, & Wilz, 2016): An 11-item scale (5-point Likert scale). This scale assesses four significant aspects of caregiver grief: emotional pain, relational loss, absolute loss (death and the anticipation of the future without the person), and acceptance of loss.
3. **Prolonged Grief disorder (PG-12)** (Coelho, Silva, & Barbosa, 2017): A 12-item scale (5-point Likert scale; and one dichotomous response); it is used for early identification of those at risk of developing post-loss prolonged grief disorder. This scale assesses various domains such as separation anxiety, emotional, cognitive and social symptoms.

High pre-death grief symptoms are generally associated with higher depressive symptoms, caregiver exhaustion, lack of preparation for a loved one's death, excessive information about the prognosis of illness and low communication about death (Nielsen et al., 2017). Coping mechanisms play a

vital role in dealing with anticipatory grief. Acceptance and positive reinterpretation are considered protective, whereas denial is associated with higher grief symptoms (Coelho, de Brito, & Barbosa, 2017). The risk factors for the development of anticipatory grief are mentioned in **Table 2.1**.

Table 2.1: Risk factors for anticipatory grief (Burke et al., 2015)

• Relational dependency with the patient; insecure avoidant attachment style
• Spiritual crisis/distress
• Poor grief-specific social support
• Higher levels of neuroticism
• Lower levels of making meaning of life
• Low levels of education

Factors which can influence development of prolonged grief

Some of the predictors which influence the development of prolonged grief disorders are given in **Figure 2.1** (Thomas, Hudson, Trauer, Remedios, & Clarke, 2014; Tomarken et al., 2008)

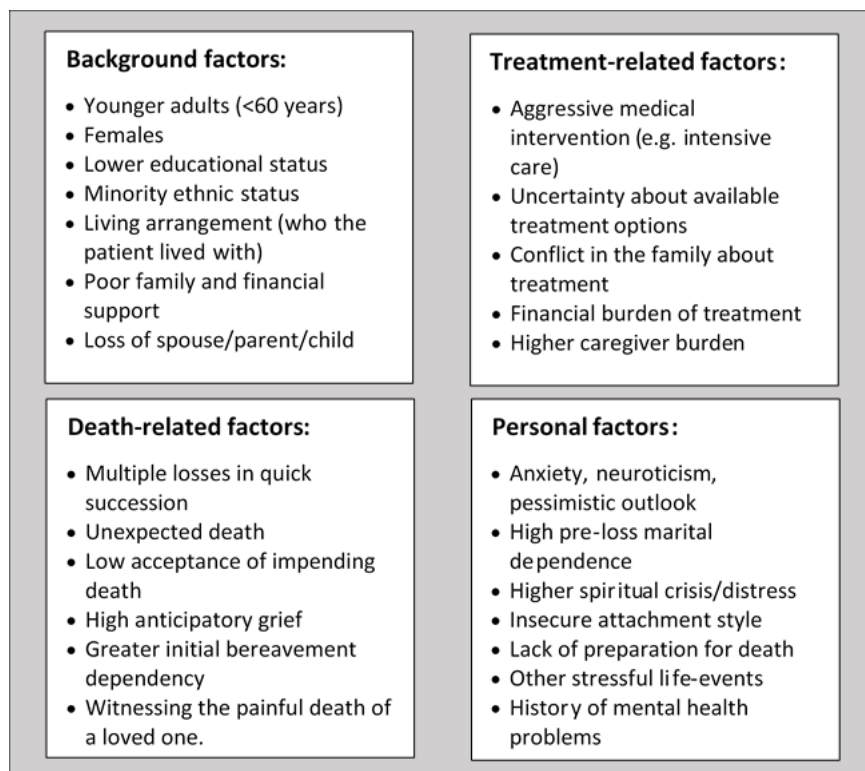
Assessment of anxiety and depression

Screening for anxiety disorders and depression is essential for both, the terminally ill patient as well as their family members/caregivers.

Screening for anxiety disorders

Identifying and delineating syndromal anxiety disorder from normal grief is crucial in order to plan appropriate pharmacological and non-pharmacological treatment. The two most commonly used screening tools for anxiety disorders are: The Generalized Anxiety Disorder 7-item scale (GAD-7) and the GAD-2 two-item scale which is a very short diagnostic instrument.

Figure 2.1: Factors which can influence development of prolonged grief



Questions that may be useful in assessing anxiety disorders

- How often do you feel nervous, anxious, or on edge?
- Do you have difficulty in controlling your worries? How often do you feel this way?
- Do you think that you worry excessively and about too many different things?
- Have you been finding it difficult to relax recently?
- Do you feel restless or find it hard to sit still at one place?
- Have you been irritable or getting easily annoyed recently?
- Have you been feeling afraid as if something awful might happen?

Screening for depression

In terminally ill patients, the main focus is on cognitive symptoms of depression rather than physical or somatic symptoms. However, in the case of caregivers, the usual diagnostic criteria are used to identify depressive disorders.

Questions that may be useful in assessing depression

- How have you been feeling over the past two weeks?
- Describe your mood over the past two weeks.
- Have you been able to enjoy your hobbies or pastimes (food, shopping, watching TV/movies, etc.) lately?
- How is your work going? Are you finding it hard to concentrate on work or any other task?
- Do you have any worries or concerns that I could help you with?
- Do you get tired easily?
- What are your future plans?
- Have there been situations where you have felt hopeless about the future?
- What are your thoughts on your current situation? Do you have feelings of helplessness or worthlessness? How often does this happen?
- Do you ever have thoughts of ending your life or think that you'd rather be dead?
- How confident do you feel making day-to-day decisions?
- Do you have any regrets or guilt?
- How is your sleep?
- How is your appetite? Have you lost weight recently?

Coping abilities

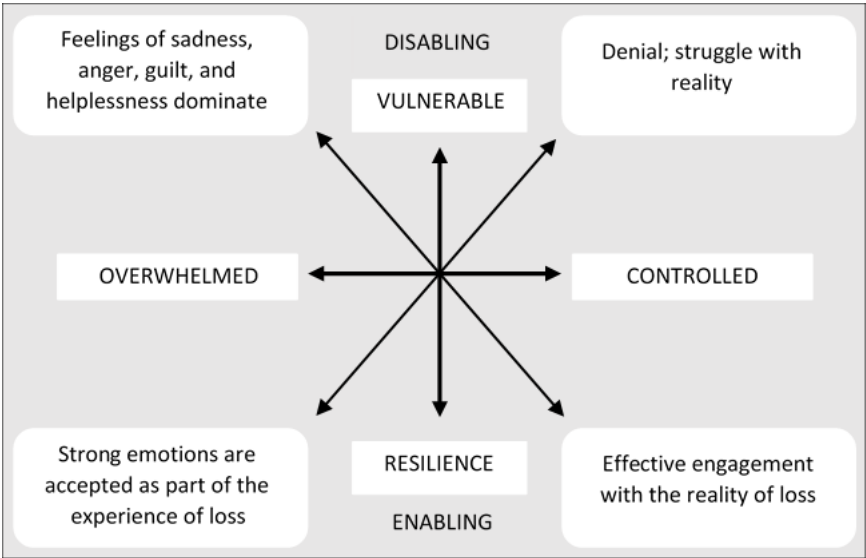
Coping abilities of an individual not only serve as an indicator for the development of complicated grief, but also as a predictor of later health outcomes. There is a need to assess coping abilities while assessing for grief.

As per the Range of Response to Loss (RRL) model, responses to loss are represented on a spectrum of reactions in which, one end of the spectrum signifies distressing increase in overwhelming emotions (sadness, anger, guilt, helplessness, etc.), and at the other end is the control which focuses on the thinking and action (diversion from feelings, attention to thinking, taking action and focusing on the practical elements of caring). This model which

depicts individual coping strategies, and determines whether they are resilient or vulnerable, is pictorially represented in **Figure 2.2**.

Coping and vulnerability to develop complicated grief can be assessed using the Adult Attitude to Grief Scale, a 9-item tool in which scoring is done on a 5-point Likert scale, ranging from strongly disagree to strongly agree (Sim, Machin, & Bartlam, 2014).

Figure 2.2: Range of Response to Loss (RRL) model



Conclusion

Before considering assessments, one should know how to differentiate between normal and abnormal grief, and be aware of the various factors which could influence the development of abnormal/complicated grief. Knowing about these risk factors enables one to be cautious and proactive in looking for complicated grief reactions. Each individual has their own way of coping with and handling negative life events, and this can have a bearing on the development of abnormal grief. Hence, assessment of risk factors and coping abilities is essential. Especially in the context of palliative care, it is crucial to assess for anticipatory grief and unfinished businesses in order to plan an appropriate management plan and to improve the quality of life. The

palliative care team should always screen the patients and their caregivers for anxiety disorders, depressive disorders and phobic disorders, instead of normalizing the grieving process.

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CHAPTER 3

Family Grief

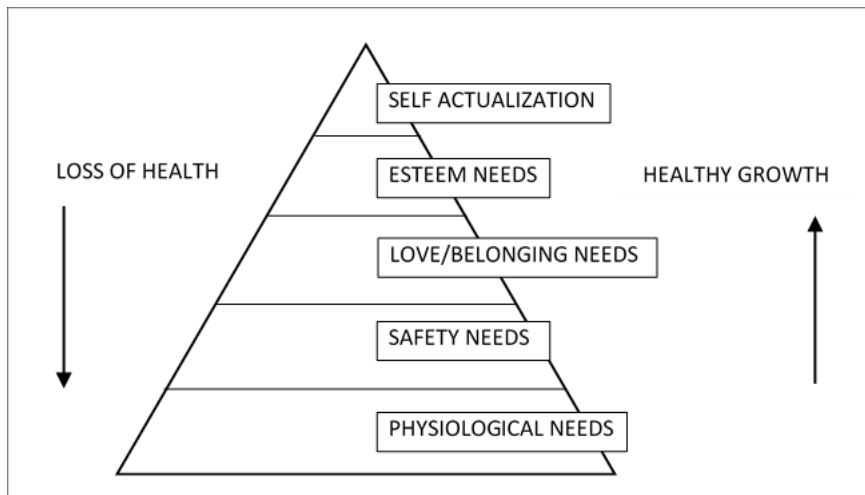
Roshan Sutar, Vikram Rawat

Abraham Maslow described a pyramid depicting the hierarchy of an individual's needs in life, which are essentially rooted in material, psychological and social dimensions that tend to narrow towards its peak to self-actualization (Frame, 1996). These dimensions also involve processes of growth, development and emotional wellbeing. All of them constitute one's quality of life. It can also be summarized as being, belonging and becoming, over a period of time. For patients suffering from cancer, the physical component of health has already been taken over by the psychological perception of a tumor-like visible mass or an ongoing invisible internal pathology (for example, hematological malignancies). Maslow pointed out that the fulfilment of basic needs of a person can spontaneously promote them to upper hierarchy, and any barrier in achieving these keeps the individual in search of satisfying primal needs (Maslow, 1955). Cancer patients tend to drop in this hierarchical pyramid several times through the course of the illness. This is because cancer not only weakens one's physical health but also creates a sense of incompetency, strong denial, rage, and pessimism towards life, the guilt of unfinished business and so-called "sense of bad deeds" of the past. This also spreads to the whole family at various levels of disease progression and its management. The entire family is at risk of falling in the hierarchy (**Figure 3.1**) as cancer progresses through the various stages.

This chapter will focus on various crises and issues that family/caregivers go through while handling a patient with difficult diagnoses. The topics covered in the chapter are as follows:

1. Understanding family grief.
2. Collusion and its extension.
3. Sensitizing counselors and doctors for handling family grief.
4. Role of stigma in family grief.

Figure 3.1: Maslow's Hierarchy



Understanding family grief

The loss of a significant object/person/health of an individual, results in a state of emotional turmoil commonly known as grief. Family grief essentially means the loss of something significant for a family resulting in a state of mourning for the entire family. For example, when the leader of a nation dies, it results in national grief, where people meet in a group to give condolences and share their sorrows with each other. In families, when one member suffers from a life-threatening illness, it evokes a natural grieving reaction resulting in dysfunction in the family. Roles and responsibilities of the individual are transferred to another family member and it creates a sense of deficiency of a functional member in the family unit. In case of acute illnesses, this phenomenon reverses within few weeks, such as when a family member

suffers from an Ischemic heart disease or stroke. But in chronic illnesses such as HIV, cancer, and severe mental disorders, the family experiences different emotional waves. There are different emotional reactions such as shock, denial, and helplessness. This causes them to bargain for emotional support, for example “We feel that he is a fighter and will definitely improve with the care that he is receiving.” Eventually, family members may express anger towards the illness or their misconceived explanations for the illness— “I think the cancer is due to his driving,” or “Maybe the first doctor had given the wrong treatment leading to these complications”—and finally, cursing God or their *karma* for this ill-fated event. A perceived lack of control over the illness may increase the apprehension within the family. These feelings of apprehension can often have concomitant anxiety and depression. When the illness appears to be at an advanced stage, the family may give up on hopes of a cure. They accept the serious and incurable nature of the illness which facilitates the dying process. These stages have been described in detail by Kubler-Ross as given in Chapter 1 (Doughty, Wissel, & Glorfield, 2011).

Collusion and its extension.

An interesting phenomenon that occurs in the family dynamics during cancer progression is the conspiracy of silence or ‘collusion’. By definition, collusion is a secret agreement between two or more parties, sometimes illegal, to limit open competition by deceiving, misleading, or defrauding others of their legal rights (Chaturvedi, Loiselle, & Chandra, 2009). A patient admitted to the cancer hospital claims that they are alright and blames their caregiver for bringing them to the hospital. There appears to be a conscious component which prevents the patient from accepting the illness; this denial transcends to the family level, in an attempt to keep the family defenses ready for the consequences.

Case example 1: A 70-year-old gentleman was angry with his wife when he was admitted to the cancer hospital. He had been shifted there from a general hospital where he was diagnosed with high-grade squamous-cell carcinoma of the lung with pleural effusion. The patient denied that he had any illness, and cursed his first wife and a sister for performing black magic on him to give him such pains.

Families often have an inadequate understanding of the illness, and communicate poorly with the patient about its serious and incurable nature. In low- and middle-income countries, the patient and family often

unconsciously promote silence, and are likely to be affected in terms of psychological quality of life. However, when the atmosphere changes after the diagnosis, prognosis, relapse, recurrence and more such phases of illness, there is an innate component of unconsciousness which warns the patient about the ultimate fate, and sometimes the bell to finish unfinished chores. In Freudian terms, there is always a drive to resolve conflicts through counterbalancing the death instinct with love instinct (Segal, 1993). During the grieving period the loss of autonomy and pain control, could interact with collusion resulting in unwarranted displacement of reactions, as mentioned in the example below

Case example 2: A 55-year-old man was diagnosed with secondary metastasis at the lower end of humerus, and hence underwent resection of bone-metastasis. This was followed by the patient experiencing abdominal pain. Even in that intense agony, he continued to curse the surgeon who had operated on the bone metastasis—he was convinced that the surgeon had done something wrong, leading to this pain now. He was investigated across multiple hospitals before he was brought to us. He broke down when he spoke about the multiple hospital visits while still being unaware of his diagnosis. He was still hopeful of being discharged soon. This gentleman was counseled and relieved over the next week.

Like this man, there are numerous patients who are in search of the right container as described by Wilfred Bion, that would accommodate their symbolic representations of death instincts and establish an optimum object relation that would gratify collective unconsciousness (Steinberg, 2013). Healthcare providers should effectively identify and address the issues related to collusion especially in the context of palliative care.

Sensitizing counselors and doctors towards handling family grief

Since both grief and collusion appear as two sides of the same coin, they need to be handled gently in order to keep a healthy relationship between multiple dyads of doctor-patient, doctor-caregiver, patient-caregiver and between different specialists. Some basic communication skills can help counsellors overcome this problem.

- Assess family understanding in terms of the illness severity and its management.

- Target specific myths that appear to be hindering the family's understanding of the illness, and make them receptive to further processes.
- Use individual interviews rather than the entire family at a time, in order to gauge the illness perspectives and understanding of each family member.
- Identify one key person in the family and encourage them to initiate the process of dissolving collusion and handling the grief.
- Encourage families of different patients to interact, so that they can gain an understanding of each other's difficulties and auto-resourcing.
- Do not overload the family with all the information at once. Check whether the caregivers have understood the information provided before proceeding.
- There is no such thing as a cure for grief; there is a need to facilitate the process of grief. Time needed for each family is variable.

Role of stigma in family grief

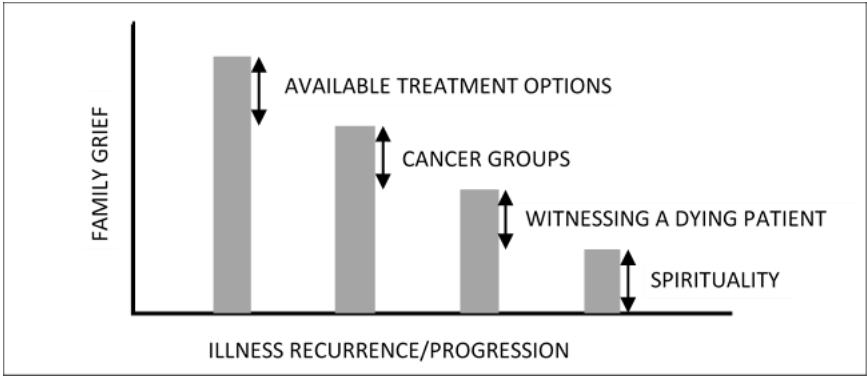
The next important aspect of cancer and collusion is regarding the myths and misconceptions associated with the illness. Communicability of a disease is a common fear in the Indian society, especially in the rural communities. While some of them are unaware of types of diseases that are communicable, there are others who, in spite of being aware, are afraid for unknown reasons. Isolation of children or grandchildren from the patient, avoiding contact with the patient's clothes or belongings, not sharing their food, etc. often breeds a feeling of rejection and increases the suffering. It is commonly reported that healthy spouses of cancer patients avoid physical contact with them, adding to the burden of internal stigmatization and hopelessness in the patient. There is a misconception that severe illnesses have a higher risk of spreading or communicability. The psychosocial intervention required is different for each stage of the illness; the myths vary depending on the burden of disease severity/prognosis—a few comprehensible conversations can help sort out these myths.

The other common myth which forms the basis of collusion is heritability of the illness. Therefore, one has to be particular about the type of concern that a family has rather than providing a generic list of statements about what is correct and incorrect about their beliefs. The implications of addressing the misconceptions of the caregivers/immediate family is of utmost value. If the caregivers are not satisfied with your replies due to the generic use of

interventions instead of individualized interventions, they tend to continue harboring those misconceptions which could further have an impact on the patient. While it may not be possible to solve all the issues contributing to collusion within the family, these interventions can alleviate the stress and provide a therapeutic way for them to deal with problems, thereby improving the quality of life. It is often difficult for a caregiver to discuss the illness with relatives and neighbors due to the stigma attached to HIV, cancer or severe mental illness; at the same time, they need a support system to help them channel their emotional difficulties and cope.

All the above factors significantly influence the hopes of a cure for the illness. Support groups are created for patients as well as caregivers where they can share their feelings in order to ease the process of mourning. There is no single predictor as to the time required by a family to overcome the process of grief, and it often has a dynamic relationship with hope. In most instances in palliative care, a gradual decrease in grief and hope for cure is observed with each subsequent family engagement in group discussions—in addition to exchanging experiences with other families, they are able to get spiritual help for themselves which is an important part of the natural mourning process for the family (**Figure 3.2**). In fact, volunteers who help cancer patients and their families undergoing such emotional turmoil report having related to some of the situations, which had personal significance for them.

Figure 3.2: Self prognostication model of illness by family



Case example 3: A 50-year-old truck driver presented with recurrence of multiple myeloma after five years. He was extremely distressed and in tears. He spoke about a symbolic cure around five years prior, when a specific honey bee sting coincided with an intense agonizing pain in his back, and he was found to have bone metastasis at L5S1 after his admission in hospital. He recovered through chemo-radiotherapy and surgery over the next two years. After five years when he was admitted for relapse of multiple myeloma, the symbolic help and symbolic cure can only be brought back through symbolic (imaginary) repeated honey bee stings and current admission to the cancer hospital. His wife was in denial about his illness and his family members were assuring each other that he will be cured soon.

It is essential for a physician or a counselor working in palliative care to be aware of common therapeutic methods to handle grief at the family level. In fact, there are tools to screen for psychological problems such as depression, anxiety and dissociation. The use of structured screening tools would help identify the psychological problems in patients with terminal illness and their caregivers.

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CHAPTER 4

Handling of Grief in Children

Eesha Sharma, Preeti Jacob

“Does a four-year-old child grieve?”

“What can I tell a child in pre-school about his mother’s sudden death due to a heart attack?”

“Is it okay to tell a child that their Daddy has gone to God?”

“Can I allow my seven-year-old daughter to attend her grandmother’s funeral?”

“My three-year-old son has become very clingy and irritable after his mother’s death. What should I do?”

These questions reflect challenges that arise with handling grief in children. While saying too much may confuse the child, saying too little may hinder a child’s conceptual development of death, and grief resolution. An oft-taken stance is that children should be kept away from any talk about the deceased, and that they will find their own answers as they grow up, or that they can be told when the ‘time is right’. However, the reality is that children as young as 2-3 years old can sense disquiet in a bereaved family, and may grieve (Black, 1998). **Case vignette 1** illustrates the uneasiness and unanswered questions of a five-year-old boy after his mother passed away. Unless the child has overt behavioral problems, adults may not realize the questions/anxieties the child may have. Grief can often be intermittent in children (Schultz, 1999), with return to seemingly normal activity. This makes

it more dubious to identify. Nevertheless, if not handled appropriately, prolonged or pathological grief may result in not only short-term dysfunction, but also long-term developmental consequences.

Case Vignette 1: K is a five-year-old boy whose mother died two months ago in a road accident; the child's father was also grievously injured landing him in the ICU for a month. The child had not gone to school for two months. He was left in the care of his aging grandmother who could not keep up with an energetic five-year-old and would often scold him for behaving badly. K wanted to go back home to his mother and could not understand why no one would tell him why his mother was not coming back. He often waits for his mother at the usual time that she returns from work and becomes irritable and upset when she doesn't arrive.

It is critical to appreciate children's responses to adverse life events in their developmental context. Intellectual ability, temperamental traits, parenting, attachment, prior bereavement experience, and other factors, can influence the expression, and resolution, of grief. For children, working through grief can mean having to reinterpret the loss at each developmental step (Schultz, 1999).

The nature of loss may vary, such as loss (death/separation) of a parent, loss of a limb, loss of a sibling/peer, loss of a pet, or loss of one's home from having to move to a new city. Each situation comes with its own nuances and challenges in terms of meaning for a child and the experience of loss (**Figure 4.1**). Moving to a new home, for instance, may throw up only short-term adjustment difficulties, while loss of a parent may lead to major changes in the child's world (Seshadri & Rao, 2013). **Table 4.1** below depicts the themes that could emerge in different situational contexts of loss.

In the current chapter, we will adhere to a generic approach to handling grief in children by keeping a broad focus, and discussing concepts and approaches that apply across themes. The chapter will first discuss the developmental underpinnings of concepts of life and death in children. Thereafter it will go on to describe assessment and intervention approaches.

Figure 4.1: Factors affecting children’s concepts of death and expression of grief

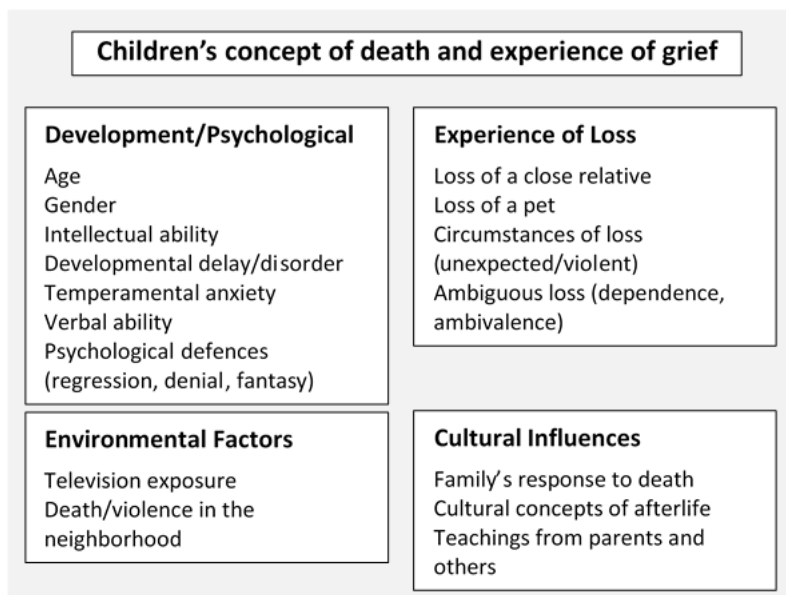


Table 4.1: Themes that emerge in different contexts of loss

Type of Loss	Themes in Grief
Diagnosis of a terminal illness	Desire to know about their illness/treatment. “Will I die?” Secrecy makes matters worse
Amputation	Body-image issues Low self-esteem Diminished social and athletic ability
Death of a parent OR Terminally ill parent OR Parent’s divorce or separation	Self-blame Sense of abandonment/rejection Shame Insecurity about the future Mistrust
Disasters	Loss of control Loss of stability Self-centered reactions

Concepts of life & death in children—a developmental perspective

Researchers have studied the understanding of life and death in young children. For theoretical clarity sub-concepts of death have been studied - universality (all living beings must die), irreversibility (the dead cannot be brought back to life), cessation (all bodily and mental functions stop after death), inevitability (all living beings eventually must die), unpredictability (the timing of one's death cannot be predicted), causality (death is ultimately caused by breakdown of bodily functions), and personal mortality (death applies to oneself) (Kenyon, 2001). In a study conducted on 25 preschoolers (3-5 years old) from Bangalore, India, it was found that 88% had 'spoken about death', to their mothers in most cases (Agarwal, 2006). In this study, play-based methods were used to explore the child's understanding of death. While more than 60% children understood universality, only 35% understood irreversibility, and less than 10% understood cessation. Interestingly, only about 20% children in this sample understood the concept of aging. In an Australian study, researchers wanted to assess not only whether children understood life and death, but also if teaching young children life concepts could change their understanding. Slaughter and Lyons (Slaughter & Lyons, 2003) reported the outcomes of training 60 Australian preschoolers (mean age 4 years 10.45 months) on the functioning of bodily organs. Using a pre- and post-training survey method, they found that 95% of the non-life-theorizers (children who did not initially identify 'life' or 'not dying' as the function of bodily organs) converted to life-theorizers within a week post-training. Life-theorizers were more adept at understanding concepts such as irreversibility, inevitability, and cessation. The gain in conceptual understanding about death occurred in children even without an increase in general intellectual functioning.

The cognitive, social, and emotional development in children is a biologically driven, environmentally mediated, predictable process, with variations in individual sequences. Interpretation of life and death has a developmental trajectory that parallels cognitive developmental stages enunciated by John Piaget (Poltorak & Glazer, 2006; Slaughter, 2005). **Table 4.2** depicts children's concepts of death alongside cognitive developmental stages.

Developmental stages described in **Table 4.2** are not invariant. Life experiences and responses from the family can definitely influence them. One study compared the concept of death among children with and without cancer (Jay, Green, Johnson, Caldwell, & Nitschke, 1987). Children with cancer more

Table 4.2: Developmental stages in children’s concepts about death

Piagetian developmental stage and child’s age	Thinking characteristics	Concepts about death	Understanding of the complexities of death	Possible behaviors/ emotions related to death
Sensorimotor (0-2 years)	Egocentrism prominent; object permanence not developed	No concept about death	None	Separation anxiety; Reaction to the grief of older caregivers
Pre-operational (2-7 years)	Egocentric, magical, animistic, moralistic	Death is reversible, like going to sleep	Universality	Fear that they may have caused the death; May develop magical explanations about death; Anger towards deceased for not returning; Repeatedly ask about the deceased return; Worry about going to sleep; Worry that the deceased may not be getting food to eat/ feeling cold; Fears of abandonment; May react as if nothing has happened and continue with their lives
Concrete operational (7-12 years)	Logical, but concrete; lack future orientation in thought	Death is irreversible, unnatural, caused by concrete elements outside the body	Universality Irreversibility Cessation	Personal safety threatened; Sense of mastery of the world diminished; Faulty connections (hospitals cause death); May display exemplary behavior to ensure that they will not be taken
Formal operational (>12 years)	Abstract thinking; deductive reasoning; feeling of invincibility; similarity to peers very important	Death is irreversible; thoughts of death kept at a distance	Universality Irreversibility Cessation Inevitability Unpredictability Causality <i>May be absent: personal mortality</i>	Fear of personal mortality; Fear of further abandonment; Discomfort about being different from peers; Sense of personal omnipotence

readily appreciated personal mortality, death as justice and that death has complex contributing factors. The closeness of the deceased individual and animate versus inanimate nature of the object could also influence a child's interpretations about death (Sandra, Kay Colby, & Craig, 1985).

Presentation of grief in children

Case Vignette 2: L is a 14-year-old boy who lost his father 11 months ago. He was brought for consultation due to school refusal, angry outbursts, irritability, aggression, suicidal ideation and suicidal attempts. L was very close to his father; he said he did not want to live without his father and wanted to go to him. The child's father died of a sudden myocardial infarction at home. The child felt that sufficient medical help was not given to the father. Parenting styles differed between the parents—the father was indulgent while the mother was the primary disciplinarian. After the father's death, the family went into significant debt. The mother was worried and upset about repaying them; she was also angry with the father with respect to the family's financial situation. This made the child even more upset with her. Due to financial constraints, the family's lifestyle changed. When the mother refused to buy something that the child asked for, he would become upset, angry and, often times, aggressive towards her. He was also experiencing sleep and appetite disturbances.

Case Vignette 2 depicts a child with a lot of anger, aggression, and a significant disturbance in personal-social-occupational functioning after his father's death. To add to the complexities of the loss, there was the disharmony in parental relationship and the family's financial difficulties. The above two case vignettes depict symptoms of grief in two children. Children and adolescents may present with a wide variety of behaviors or responses that signal their distress and anguish, and the circumstances that influence them (Weymont & Rae, 2006). They may experience and manifest different symptoms at different points in time during their grieving process; there is considerable individual variability. It is important for clinicians and caregivers to recognize these behaviors in order to help the child grieve and cope with the loss. **Table 4.3** lists behaviors that could be observed in a grieving child.

Table 4.3: Expression of grief in children

Physical symptoms	Age-inappropriate behavior
Stomach aches and head aches	Acting like a younger child
Disturbed sleep, bad dreams	Acting like an adult
Eating too much or too little	Over-protective about family members
Other behaviors	
Destructive behavior Irritability and angry outbursts Withdrawn behavior School refusal; problems in school work Fear Thinking the deceased person was perfect Clinginess Anxiety about losing another loved one	'Switching off' – appearing as if they didn't understand something that was said Blaming themselves Crying/giggling without an obvious reason Explosive behavior & acting out Unusual auditory, visual or tactile sensations Conduct symptoms – truancy, stealing Difficulty concentrating

Assessment

The assessment must include a thorough understanding of the child's developmental status, the nature and context of the loss experience, individual and contextual predisposing and maintaining factors that could possibly be contributing to the child's grief (Sanders, 1993; Silverman & Worden, 1993; Carr 1999). The first and perhaps the most important step is to understand the symptoms that the child presents with by appreciating what the loss

means to them personally, and allowing them the time and space to verbalize their thoughts and feelings (Faulkner, 1995). Some children may experience significant adjustment problems that amount to a psychiatric disorder (such as depression, anxiety disorders, post-traumatic stress disorder, etc.). This would need professional evaluation and pharmaco- or psychotherapeutic management. Features that indicate the need for professional consultation for the possibility of a psychiatric illness include:

- A child expressing thoughts about death or self-harm
- Prolonged dysfunction with regard to academics and school activities
- A child seemingly depressed, irritable, or frequently crying for several months
- A child not wanting to play with other children or being withdrawn
- Re-experiencing the traumatic event, such as in nightmares
- Persistent avoidance of reminders of the death or the deceased
- Signs of extreme arousal in the child – inability to sleep, restlessness

Intervention

As a caregiver/professional/parent one may not have answers to all the questions of a grieving child. The goal is not to solve everything at once! Rather one must support the child in the grieving process, with an open and honest attitude (Salladay & Royal, 1981; Schultz, 1999). While adults may be in a rush to move on (for instance, changing their residence), it is important for children that too much change does not happen all at once. They need stability to integrate the loss into their lives. Grief reactions can fluctuate and change over time. Anniversaries (one month/one year) may be especially notable. The family could take the opportunity to revisit memories of the deceased, and give children the stability and context to reinterpret the loss. Giving a child the time and space to grieve, heal and healthily incorporate the loss into their life is the overarching principle in grief work.

Most adults have well-formed notions about life and death. They deal with loss in their own personal manner. When there is a young child in the family, however, adults need to be part of the child's grieving process too. Responses from adults in the family help children understand the loss, integrate it into their lives, and move on. Thus, handling grief in children involves family-based as well as individual work.

Individual work with the child

The child has two primary challenges in the grieving process—processing the

actual event, and coping with the loss (Perry & Rubenstein, 2018). Kubler-Ross' stages of grief—denial, anger, bargaining, depression, acceptance (Kubler-Ross, 2005)—may not be as straightforward in children. The primary emotion experienced by children in the first few days after the loss is 'fear' that arises from disturbing thoughts about self-blame, guilt, and uncertainty about the future; over time, sadness takes over (Perry & Rubenstein, 2018).

It is important to use honest and open language with children. For children to adequately process the loss, there may be a need to revisit the topic from time to time, especially as children grow and try to interpret the loss at each developmental step. Listed below are certain key principles that the therapist or parent needs to be mindful of when helping children in grief (Perry & Rubenstein, 2018; Seshadri & Rao, 2013). Not surprisingly, most of them are principles we should always keep in mind during our interactions with children.

- Be available, nurturing, reassuring and predictable.
- Grieving is a complicated process, not an event.
- Working on grief is difficult for adults and children; often they are grieving simultaneously.
- Each person in the family has their own pace of grieving.
- The parent/caregiver needs to be aware of their need to grieve too.
- Individual relationships with the deceased have a bearing on the processes of grieving and healing.
- Do not lie or tell half-truths about a tragic event. It is important to be open, honest and clear.
- Help children, of all ages, to understand loss and death, in a simple yet factual manner.
- Parents should not avoid the topic when a child brings it up again and again.
- One cannot assume that children will always grieve in an orderly or predictable manner.
- Let children know that you really want to understand what they need or how they are feeling.
- It is important to understand that surviving children often feel guilty.
- All available resources—personal, family, or professional—should be made use of, as and when necessary.

Presumptions we make in dealing with grieving children often cause more problems than the harsh, but honest, truth. Children tend to fill 'gaps' in information using their own imagination. This filled-in information may be

nastier and far removed from the simple truth. Adults who try to be secretive about loss ‘to protect the child’ counter-intuitively tend to isolate the child and increase fears (Seshadri & Rao, 2013).

The capacity of children to process information depends on their developmental stage. For example, children 0-3 years old may not understand all facts about the circumstances of death. However, it is important that parents/caregivers not equate death with sleep/travel, as that would reinforce the child’s cognitive distortion. More biological, simple and reality-based explanations may be more reassuring. Since children at this stage do not understand the permanence of death, they may behave as if nothing has happened. They may not seem sad and go on with their usual activities. They may even develop ‘magical’ explanations that overshadow the concept of irreversibility. Simplistic notions about the loss such as, “Daddy can’t come back here”, can replace these unreal, ‘magical’ explanations. Children may have a lot of cross-questions; these should be answered truthfully, in a manner that is simple for them to understand.

In older children, emotional work takes centerstage. Acknowledging, identifying, and naming emotions, or discussing emotions through art or play, may clarify thoughts and feelings in a child’s mind. “How are you feeling about Mummy not being here?”, “Are you feeling sad... angry?”, “What makes you angry?”, “If mummy were here what would you tell her?”. Writing a letter to or role-playing a conversation with the deceased, can help children become more aware about and process their emotions appropriately. Children may be confused about what the right emotion to feel is. It is extremely important to reiterate that sadness and anger are normal. Misperceptions of guilt in a child need to be dealt with gently. By trying to understand the origins of a child’s guilt (i.e. how the child links events that lead to the misperception), corrective suggestions can be made. The child’s strengths, hopes, and future must be discussed; this will help build self-competence about handling the loss and encourage the child to return to functionality. It is also important to address children’s universal fear of further abandonment. Children must know whether surviving parents are healthy. Backup plans of guardianship may also be discussed. If these fears are not expressed spontaneously, it would still be wise to explore them, hypothetically. Encouraging children to reconnect with friends/family, and form new relationships, is another important component of moving on. However, children may need reassurance that establishing new relationships does not replace the one with

the deceased. The deceased can continue to be a meaningful part of the child's life symbolically.

Family-based grief work

The main objective of family-based grief work is to help the child and family acknowledge the loss personally or individually, and together as a family. Psychoeducation regarding the process of grief, in children and in adults, is an important intervention that helps families 'make sense' of the reactions that children might have to loss. Asking for each family member's reflections about the loss helps to understand the events surrounding the loss in a collective manner.

Adults in the family have to handle their own grief as well. Implications of the loss for each member of the family need to be understood through joint discussions. If all family members did not have a cordial relationship with the deceased, these discussions could be done individually. The idea is for the family to appreciate differences in the family environment prior to the loss and after, giving them an opportunity to really comprehend the meaning of the loss for themselves as well as the children. Families should explore ways to accommodate the deceased in their lives, in the future. For example, before the child's next birthday the family can ask the child how they would like to include the deceased person in the celebrations, even though they can no longer be physically present (Walsh and McGoldrick 1991; Webb 1993; Carr 1999). Once the child and family are willing to accept the reality of the loved one's death, reference to the deceased in past tense may be introduced. For example, "Today I've made Daddy's favorite dessert. I am sure he would have loved it!". If the child or family is avoiding reminders of the loved one, then ways to slowly encounter these reminders/events/places must be discussed, as avoidance can hinder grief resolution. Family members need to dwell upon ways to reorganize their lives including roles, rules, routines, responsibilities and their relationships. This helps the family move on, while keeping the memory of the deceased alive. The place given to the loved one must be in keeping with the family's socio-cultural and religious beliefs. New family rituals that incorporate the loved one must also be discussed.

Conclusion

Grief in children and adolescents is a complex process, made especially complicated by the developmental stage of the child. The therapist and caregivers need to be mindful of the nature and context of loss, and work

with the child/adolescent on what is most undoubtedly a difficult period in their young lives. The child has to be allowed to set the pace for any therapeutic work. Emotional and behavioral problems in the child must be handled with appropriate assessments and interventions.

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CHAPTER 5

Grief Interventions

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Grief and bereavement are normal responses which lie on a continuum. The grief response, when prolonged or excessive, gains medical attention. Cancer is a chronic medical illness and brings with it several psychological challenges. In most cases, it is a terminal illness. The word “cancer” itself creates an anxiety, and fear about life, in patients and their loved ones—sometimes to such an extent that they avoid uttering the word altogether. Hence, the need to intervene gains importance.

Palliative care looks at improving the quality of life for patients and their families, by controlling their physical symptoms and reducing psychological, social and spiritual suffering. Palliative care is not considered as a treatment option until all other curative treatments fail to control disease progression. It is often seen as a final measure and hence is termed as terminal or end-of-life care. If palliative care is integrated with curative treatments in the early stages of the illness, it results in better prognosis of the illness and improves the quality of life. Interventions include understanding the meaning of life and self, accepting the illness, existential and spiritual issues, addressing the fear of death or of losing a loved one, and further support for the family during the bereavement period. The aim of palliative care is to provide patients and their families with support throughout the illness. The services are extended by providing continued support to the family after the demise

of the patient as well. An important area that does not receive much focus is grief experienced by health professionals working in palliative care. This chapter will highlight the various interventions available and their respective implications.

The time from diagnosis to death is variable and depends on the type of cancer, stage of cancer, and response to treatment. It may vary from a few weeks to many years. Hence, interventions should be tailored accordingly. A few broad principles to be considered are:

- Time is the most important factor.
- Therapeutic frameworks need to be flexible.
- Involvement of caregivers/significant others is essential.
- Health status of the patient needs to be monitored on a daily basis.
- The patient might not speak about death explicitly.
- There is a possibility of high levels of disengagement, depression and anxiety.

A number of therapies have been tried and found to be effective in people with cancer, for instance meaning-centered therapy (MCT), dignity therapy, cognitive behavioral therapy (CBT), psychodynamic therapy, and humanistic therapy. However, this chapter will discuss MCT, dignity therapy, and CBT in detail.

Demoralization syndrome: Grief in patients

Demoralization sets in with the diagnosis of cancer. Hopelessness, loss of meaning, and existential distress are core features of demoralization syndrome. This syndrome can be distinguished from depression in that it is more commonly seen in palliative care settings. It is characterized by chronic illness, fear of loss of dignity, bodily disfigurement, disability, and social isolation, with a subjective sense of incompetence and feeling of dependency on others. Because of the sense of incapacitation or helplessness, they progress to a desire to die and are more vulnerable to suicide (D W Kissane, Clarke, & Street, 2001). A treatment approach that has the potential to reduce the distress would help in improving the quality of life.

Frank described ‘restoration of morale’ as the key aspect of a successful psychotherapeutic intervention. He conceptualized demoralization as a persistent failure to cope with stress associated with feelings of incapacitation, isolation, and despair (Frank, 1968). In addition to this, an individual’s self-

esteem may be damaged, there may be a loss of significance and meaning of life, and a sense of alienation may arise when the expectations of others are not met. Influenced by Frankl's appreciation of the critical sense of meaning in life, an emphasis was laid on mobilizing hope to induce healing.

Meaning-centered Therapy (MCT)

The basic theory upon which MCT is based was first introduced by Viktor Frankl, a psychiatrist, in his book *Man's Search for Meaning*. Breitbart and his colleagues further expanded these ideas to formulate meaning-centered therapy. MCT comprises of therapeutic approaches designed to enhance quality of life, meaning, and spiritual wellbeing. Some of the key areas that it focuses on are:

- Choice of attitudes even in difficult situations such as end-of-life
- Ability to connect: humor, art, love, nature, and relationships
- Engagement: work, hobbies, or other activities
- An understanding of the present, past and future

Research shows that MCT is associated with better outcomes in people with end-of-life issues (Breitbart et al., 2015).

Dignity therapy

Dignity is the perception of one's own value as a person, and comprises of intrinsic and extrinsic characteristics. The intrinsic factors include living a moral life, having peace of mind, and a sense of existence involving the perception of resignation to God's will. Extrinsic factors that influence a patient's dignity include distress due to illness, care delivery, and the perception of being loved. A dynamic relationship between these elements determines the state of a patients' dignity at any given point of time.

Harvey Chochinov and colleagues worked on dignity, in 'Dignity Conserving Care' and 'Dignity Therapy' - a model to enhance and protect dignity at terminal stages.

It is a brief therapy of 7-8 sessions. Each session focuses on a specific factor affecting the dignity of the patient at the time, with the objective of helping them restore dignity, and move towards a meaningful life and good death. The focus is on: generativity, role preservation, care tenor, maintenance of pride, aftermath concerns, maintaining hope, social support, and continuity of self.

Cognitive Behavioral Therapy (CBT)

CBT is one of the most commonly used forms of psychotherapy. People in palliative care have been observed to have varied cognitive distortions such as catastrophizing, maximization, minimization, an 'all or nothing' manner of thinking, and mind reading, to name a few. The primary working model is the interplay between thoughts, feelings, emotions, and physiological responses. Changing of thought patterns can bring about a change in other domains. This helps in improving the quality of life of people with terminal illness, especially if they have psychiatric comorbidities such as depression or anxiety.

Grief and bereavement in caregivers

Family members and loved ones of patients experience grief from the time of diagnosis until death, and bereavement in the phase after the death of the patient. Grief and bereavement are inevitable; most people adapt to the loss within six months to a year. However, some of them are unable to cope with the loss in an adaptable way.

Family members of patients receiving palliative care services need support, reassurance, education, and information following bereavement. This may be provided by other members of the family, friends, people in similar circumstances, a community support group, or by trained health professionals. Not all bereaved people suffer a significantly noticeable and long-term grief reaction. However, some bereaved caregivers exhibit high distress levels following the death of their loved one. Hansson and Stroebe (2007) proposed a framework which integrated various risk factors that predicated bereavement outcomes, namely, bereavement factors (for example: relationship to deceased, model of death), intrapersonal risk factors (personality, religious beliefs, existing vulnerability), interpersonal factors (social support, family dynamics), appraisal, and coping styles.

Although most people recover premorbid coping abilities and adapt to bereavement, the magnitude, intensity, and result of grief affects various areas of life, such as the practical aspects ("How did my loved one die?"), the relational aspects ("Who am I, now that I am no longer a spouse?"), and the spiritual or existential aspects ("Why did God allow this to happen?"). This has attracted the attention of professionals, and interventions for these aspects have gained significance.

Interventions for grief and bereavement in the family should begin at the time of diagnosis of the patient, in order to improve outcomes and to prevent complicated grief.

The techniques used are family-focused grief therapy and mutual support groups (widow-to-widow model).

Family-focused grief therapy (FFGT)

FFGT is a brief, focused, and time-limited intervention typically comprising 4-8 sessions of 90 minutes duration, scheduled flexibly across 9-18 months.

The intervention predominantly aims at preventing the complications of bereavement by improving the functioning of the family as a system. This is achieved by focusing on communication between family members, cohesion, and helping them handle conflicts. In the process, there is a sharing of the grief related to the patient's illness or death. FFGT has three phases:

1. **Assessment** (one or two weekly sessions) – assess issues and concerns relevant to the family and devise a plan to help deal with them.
2. **Intervention** (typically two to four sessions) – focuses on acting upon the agreed concerns.
3. **Termination** (one or two sessions) – consolidates gains of therapy and confrontation of the end of therapy.

The number of sessions, frequency, and distribution among various phases are modified to cater to the needs of the family. People with terminal cancer are either never referred, or referred very late in their illness phase (Haines, 2011). The result of this is a diminished understanding of the normal bereavement process of the individual, and the effectiveness of interventions other than counseling, i.e. how people in the community support each other and prepare for bereavement.

Mutual support group

Silverman described the principle of mutual support groups as – a bereaved can better understand another bereaved. Mutual support or self-help groups are associations of people who share the same life situation and unite for the purpose of mutual help. The selection criteria for these groups is the element of commonality. All decisions about the content of the discussion and organization are made by the participants.

Mutual support groups provide their members with:

- Person-to-person exchanges based on identification and reciprocity
- Access to a body of specialized information
- Sharing of coping techniques based on realistic expectations for optimal functioning
- An increased sense of personal worth, by focusing on how similar members are to others faced with the same situation
- Reinforcement for positive change and maintenance of efforts toward change through feedback on performance
- An opportunity for education, not only of other persons with similar problems, but also professionals and the public
- An opportunity to help others by giving concrete aid and providing a role model
- Help for the helpers, who themselves are aided by assisting others and by activism towards shared goals.

Mutual help groups in communities have been initiated as an informal alternative caregiving system in addition to formal professional caregiving systems.

Mutual support groups in the post-bereavement phase are for two categories of people:

1. Those facing personal grief, in order to help them deal with personal loss, pull their life back in order, and adjust to the new roles (for example, widow-to-widow programs)
2. People who have suffered loss and grief due to difficult situations, for instance, suicide, homicide, or the death of a child. Intervention focuses primarily on support.

The methods of communication used are one-to-one outreach, group meetings, peer counseling over the telephone or mail, and periodic conferences for members and professionals.

Widow-to-widow model

The initial interviews with widowed women and community agencies were focused on understanding the bereavement process, existing help available during that time, and the perception of widows about themselves. The interviews generated significant findings, which formed the basis for development of the structure of the intervention schedule. Initial services

available were limited to traditional counseling by mental health practitioners. Widows rarely sought out these services because they did not view being upset as a "mental illness". Help was usually sought several years after the bereavement of the spouse, and grief was not a presenting problem they came with. Delayed grief reactions were uncovered during therapy. It was also apparent that the process of bereavement extended from a short duration of a few weeks, to a few years in some cases. The guilt and anger experienced by widows were not thought of as the critical issues needing attention, although these were the common therapeutic foci leading to disparity in the need of the client and professional. Bereavement was best understood not as a 'crisis' but as a 'transition' phase. The death of a spouse initiated a critical life transition, marked by a sudden change in social status (from wife to widow) which required major changes in self-concept, roles, and tasks.

Immediately following the death of the spouse, widows are likely to be numb and may act reflexively. For the first few days, clergymen, funeral directors, family, and friends are there to help with the specific tasks of the funeral and mourning rituals, and are anchors of support. Only later does the phase of 'recoil' set in, and the meaning of the loss begins to dawn on the widow. At this time, the widow is usually left alone, as the family and friends feel she has already overcome the rest, but the widow actually begins to face real-life crises. This recoil period is the ideal time to offer help to widows with practical problems, with management of extreme and exaggerated feelings.

When, who and how?

1. Help should be offered at least 3-6 weeks after the bereavement of the spouse.
2. Initial intervention and discussions by another widow in the neighborhood (who acts as a role model) would be beneficial.
3. Initial sessions should be personalized and on a one-to-one basis, as the widow may not be ready for group interventions. Mutual support groups were found to be useful much later.

It is also interesting to note that there are very few mutual support groups for widowers and bereaved men, the reasons for which are not very clear. However, men who lose a spouse are known to be less vulnerable to complicated grief reactions than women. They do not readily avail themselves of such services and prefer to deal with their problems by themselves. Men are also more likely to be distracted by their work after bereavement.

Grief in health professionals

Health professionals working in palliative care include doctors, nurses, psychologists, social workers, and other allied health professionals. They deal with patients in terminal stages on a daily basis. The ability of healthcare professionals to process both personal and professional responses to a patient's death is very important, but lacking in most cases. Inability to manage the grief associated with loss of patients with a terminal illness might adversely affect their personal and professional life, resulting in less-than-optimal care for other patients and families. The first structured intervention for professionals working with trauma was Critical Incident Stress Debriefing (CISD) sessions. These focused on helping healthcare professionals process the traumatic experience. However, studies have illustrated the need for emotional support and the need to make meaning of traumatic incidents faced by professionals. In view of the same, bereavement debriefing sessions were constructed. The bereavement debriefing sessions aimed at providing emotional support and increasing one's ability to manage grief.

Pereira et al. studied grief in healthcare professionals who had experienced the traumatic event of a child dying (Pereira, Fonseca, & Carvalho, 2011). They explored various experiences which affected their psychological state, namely:

- Loss of relationship with the patient,
- Identification with parents—grief and pain,
- Change in perception of worldview,
- Re-emerging unresolved previous personal losses,
- Grief related to facing personal mortality, and
- Loss of professional expectations (high morals and expectations).

Further details on identification and management of grief in health professionals are discussed in Chapter 7.

Bereavement debriefing sessions should preferably be conducted after the death of every patient, but it is not mandatory. The session is usually initiated and coordinated by the bereavement coordinator. All health professionals involved in the healthcare of the patient, are invited to the session via email and verbal invitations. The session is scheduled at a time convenient for all participants. Although it is rare for multiple units to be involved, occasionally multiple bereavement debriefing sessions may be conducted for the same patient's death.

Structure of the session:

- Welcome and introductions
- Review purpose of the bereavement debriefing sessions
- “How were you involved in the care for this patient and their family?”
- Review the circumstances at the time of death

Case review

- “What was it like taking care of this patient?”
- “What was the most distressing aspect of the case?”
- “What was the most satisfying aspect of the case?”

Grief responses

- “What have you experienced since the death?” (Elicit physical, emotional, behavioral, cognitive, or spiritual responses)
- “What will you remember most about this patient/family?”

Strategies for coping with grief

- “How are you taking care of yourself? How are you making sure that you can continue to provide care for other patients and families?”
- Review the strategies used by them to cope with grief
- Lessons learned: review available resources
- Conclusion: “What lessons did we learn from caring for this patient/family?”
- Acknowledge the care that was provided
- Review bereavement support available for families and staff

CISD and bereavement debriefing sessions differ in the key focus of the intervention and the timing when the intervention is made. The former focuses on the “critical incident” and processing the details, and physical and psychological effects of the event. CISD is preferably done immediately or within a few hours of death (Mitchell et al., 2003). The latter focuses on the emotional response of healthcare professionals to the traumatic incident, with the contextual correspondence of the professionals’ relationship (emotional) with the patient, and not merely the incident of death. Bereavement debriefing sessions are usually held within a week of the patient’s death, often after the funeral. The advantage of this is that professionals have enough time to process the incidents with the patient until death, reflect upon the patient and their experiences, and are able to better express their grief.

The outcome of bereavement debriefing sessions depends on the experience of the facilitator. It is important that the person leading the session is trained in group processes, grief, and loss management, in order to recognize the potential complications of grief and to develop healthy therapeutic relationships.

The opportunity to express grief and discuss the experience of treating a patient and family, provides health professionals with an opportunity to vent and share experiences, resulting in better management of grief. This helps them in maintaining good work environments, an empathetic circle, and to maintain a good psychological state of mind. This in turn, enables them to cater to many more families optimally. Grief is experienced by patients, their families, and healthcare professionals. It is necessary to address these issues so individuals can maintain their mental health. Grief interventions help patients preserve their dignity and gain perspectives of seeing meaning in their life at the time of dire helplessness. This helps family members in accepting the illness of their dear ones, and supports them through the phase of bereavement. Among health professionals, it helps to overcome traumatic experiences of dealing with patients or witnessing deaths of patients, which is a fairly regular occurrence in palliative care.

Take-home points

1. Palliative care involves care for people with terminal illness and their family members.
2. Empathy and sympathy are embedded in the profession unlike any other.
3. The diagnosis of terminal illness affects the patient and family to a great extent.
4. The need to intervene with psychological therapeutic techniques is of utmost importance in order to maintain a good quality of life for the patient, to provide support (by maintaining dignity and meaning of life), and to ensure a peaceful death. The therapeutic techniques found to be helpful in end-of-life cases are: dignity therapy, meaning-centered therapy, CBT and others.
5. The family and dear ones of patients also undergo a lot of stress right from the time of diagnosis, as it creates a need to shift roles and adapt to the stressful situation. The family requires support in the phase of bereavement after death of the patient. Family-focused therapy and mutual support groups are known to be helpful for family members of the terminally ill.

6. Health professionals in palliative care experience high levels of stress and burnout due to the quality of life of the patients they deal with. They face issues of identification, dealing with the death of patients, and seeing the grief of patients and family members in various stages. There is a need to maintain a good work atmosphere, and provide brief interventions for the health professionals at regular intervals to help them maintain their mental health and be able to deliver care adequately to patients in the future.

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CHAPTER 6

Preventive Bereavement Care

Madhuri H Nanjundaswamy, Sundarnag Ganjekar

It is well known that during end-of-life care, bereavement begins even before the death occurs. It is a difficult situation not only for the family and friends, but the patient as well. In most cases, mourning begins at the time of diagnosis of cancer. Physicians who attend to such patients focus on treatment aspects of the diagnosis, and refer the family to counseling. It is important for the counselor to identify the factors that might predict the chances of complex, pathological bereavement and start the intervention early, so that family and friends develop the appropriate skills to cope with the future loss. In this chapter on preventive bereavement care, the authors discuss strategies to identify and help the individual or the family to be able to 'bid farewell' to their loved one in a peaceful and timely manner.

In order to understand why bereavement affects people in different ways, research has tried to identify the situational and personal characteristics which are associated with an increased vulnerability to bereavement outcome variables (Stroebe, Folkman, Hansson, & Schut, 2006). One of the foremost amongst these is emotional loneliness, which has been shown to be very important in the context of bereavement, and it shows a distinctive pattern. Studies have examined factors that might influence feelings of emotional loneliness. Social support does not influence emotional loneliness; however, it does predict grief, depressive symptoms, and positive mood (Stroebe et al., 2006). It has been shown that factors such as good health and high self-esteem, resulted in lower levels of emotional loneliness in a sample of

bereaved older adults (Van Baarsen, Van Duijn, Smit, Snijders, & Knipscheer, 2002). However, knowledge about predictors of emotional loneliness remains scarce. In summary, it is important to look into the risk factors by examining multiple potential variables simultaneously, including grief-specific and general factors, and conducting a longitudinal investigation.

Why do high-risk individuals or their families need support for bereavement?

First there is a need to identify high-risk individuals based on various risk factors, as described in Chapter 2. The rationale for assessing needs in relation to bereavement support may be summarized as follows:

- It aims to reduce the health risks associated with bereavement by proactively offering support to those who may be at risk of developing complicated grief.
- Palliative care includes assessment of the needs of the family—to identify those who have strong social and emotional bonds with the patient, or seek the patient’s active involvement in making decisions.
- The support services should focus on those who are more vulnerable.
- Some of the assessments can aid in creating opportunities to discuss the situation.
- Assessment facilitates objective decision-making about the type of bereavement service that may be needed (Relf, Machin, & Archer, n.d.).

Approach to patients and their families in palliative care settings

- A collective approach in gathering information about the patient’s illness through observation and discussion with the family
- Multi-specialty team of professionals to understand individual ways of coping through formal and informal discussions; structured assessments should be undertaken through a conversational exploration of risk factors and strength/resilience factors
- Palliative care staff usually have more contact with those in a close relationship with the patient, particularly those providing day-to-day care
- Documenting assessments using an assessment form; this documentation is best begun pre-bereavement
- All family members must be assessed

- Any assessment of bereavement must address these frequently co-occurring conditions as well as emotional, behavioral, social, spiritual, and physical domains
- Proactively offering services to those considered to be vulnerable
- Comprehensive holistic assessment and/or referral to a suitably qualified professional if required
- It is important to ensure that information about bereavement services is readily available early in bereavement so that people know how to access help

What is the kind of support that can be provided?

Psychological support:

- Informal: Family, friends, support network
- Formal/organized sources: Self-help groups, professionals

Primary preventive interventions: Programs that are open to all bereaved persons. For primary preventive interventions to be effective, it is necessary for clients to initiate help themselves, instead of help being offered to them (Currier, Neimeyer, & Berman, 2008) (Schut & Stroebe, 2005).

Secondary preventive interventions: Interventions targeted at those who are at risk of developing complications.

Tertiary preventive interventions: Interventions exclusively targeted at grievors displaying complicated grief while trying to adapt to the loss.

The recommended bereavement support includes two types of strategies:

- Universal strategies: Targeted at all carers and bereaved people
- Specialist bereavement support strategies: Targeted at those with an elevated risk of developing prolonged or complicated grief, or with current psychosocial and/or spiritual distress (Hall, Hudson & Boughey, 2012), as shown in **Table 6.1**.

Table 6.1: Bereavement support strategies

Universal strategies	Specialist bereavement support
<ul style="list-style-type: none"> • Screening and risk assessment 	<ul style="list-style-type: none"> • Bereavement counseling and psychotherapy

<ul style="list-style-type: none"> • Best practice symptom management to reduce the impact of traumatic death on carers as well as the patient themselves • Providing structured information and support at various points along the grief trajectory including: <ul style="list-style-type: none"> ▪ At the time of admission ▪ When death is imminent ▪ Immediately following the death ▪ At regular intervals following the death such as three, six and around 12 months (and beyond if required) • Providing access to support strategies such as: <ul style="list-style-type: none"> ▪ Participation in a bereavement information session ▪ Activity-based programs such as walking, meditation, music, and art groups 	<ul style="list-style-type: none"> ▪ Cognitive behavioral therapy (CBT) for complicated grief ▪ Family-focused grief therapy ▪ Complicated grief treatment ▪ Meaning reconstruction approaches to grief therapy ▪ Online support ▪ Bereavement support groups. • Access to in-house or external specialist bereavement services appropriate to their needs • Resource materials on the grief process and support services • Confidential systems for documenting and regularly updating information regarding bereaved people's assessments
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Emotional loneliness

As has been previously discussed, insecure individuals experience higher levels of grief and are more likely to benefit from increasing the importance of other religious and spiritual beliefs (Brown, Nesse, House, & Utz, 2004). People who have high levels of anxious attachment and have lost a partner or someone close, are likely to experience intense feelings of emotional loneliness. On the other hand, early identification of those who are at risk of suffering lasting health consequences makes it possible to intervene and also to possibly prevent negative outcomes. Reviews by Schut, Stroebe, Neimeyer, and Berman (Currier et al., 2008) have emphasized the need for professional help for those who need it and will benefit from it. Studying risk factors will be helpful in gaining some insight on the outcome.

Who can provide preventive bereavement care?

Below are the guidelines from Bereavement Support Standards for Specialist Palliative Care Services, Department of Health, State Government of Victoria, Melbourne.

1. All staff in a palliative care service including administrative staff, volunteers, and non-clinical staff will require minimum training and support in dealing with bereaved people.
2. All clinical staff in the palliative care service should have a qualification in an appropriate clinical discipline, attained minimum competencies for delivering bereavement support services, regular access to academic programs and professional development, professional supervision related to bereavement topics, appropriate training and experience in facilitation and group work.
3. All staff providing specialist bereavement services such as psychologists, psychiatrists, nurses, social workers, counselors with postgraduate qualifications or equivalent in loss and grief, have mandatory access to professional supervision.
4. All staff must be aware of limits of the scope of their practice, and must be aware of internal and external referral systems.

Take-home message

- Early identification of at-risk individuals and their families is essential.
- Collaborative and multi-team approaches are more effective.
- It is crucial to offer bereavement support for the affected families.

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CHAPTER 7

Grief Among Health Professionals

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Case Vignette 1: An experienced surgeon, working in a private hospital, found a large bleeder, while doing a diagnostic laparotomy on a young patient for trauma to the abdomen, and was unable to stop the same. He lost the patient on the table. The patient's relatives, along with persons who'd accompanied him to the hospital, destroyed equipment and damaged property. They were also violent towards his staff. They filed a case of negligence against the surgeon and the story was covered widely in the local news, in both, print and television. He felt that his reputation had been significantly damaged. Now he gets anxious to even go to the hospital and has constant thoughts about the incident.

Case Vignette 2: A patient who had been diagnosed with end-stage pancreatic carcinoma, was told he had a maximum of six months to live, and was referred to a hospice professional. The professional started feeling dejected about the job—he felt that since the patient would die inevitably, whatever he did would be of no value in the end. He also felt that the job was not very satisfactory, as most of the time he would not be able to change the eventual outcome in meaningful ways.

Case Vignette 3: A primary care physician who had been seeing a patient for 30 years, lost his patient due to a sudden myocardial infarction. He was deeply

saddened by the demise of the patient. He would have thoughts about his patient and found it difficult to concentrate while dealing with other patients.

Case Vignette 4: A doctor had a child who was diagnosed with beta thalassemia and required regular blood transfusions. He was the lone doctor in his family and had to educate his wife and family members about the illness, its course, and prognosis. However, he found it difficult to cope with the diagnosis himself, and had questions about why his child got this illness. He found it difficult to cope with the added responsibility of being a healthcare professional and a caregiver. This led to frequent quarrels at home affecting both his personal and familial life.

Case Vignette 5: A nursing staff working in an ICU had 8-hour shifts daily. She had been going through personal difficulties recently, having just broken up with her boyfriend. She began to find it difficult to manage her workload, and found it difficult to concentrate, leading to her being reprimanded for minor errors in her documentation.

Case Vignette 6: A psychiatrist has been seeing a patient with schizophrenia for many years. Although the patient is better, the family is unhappy that he has become more inactive, lazy, put on weight, and doesn't do any activity, in spite the psychological help (in the form of counseling) and other social interventions, which are being done on the advice of the psychiatrist.

The chapter aims to address the following points:

- The need to identify grief in healthcare professionals
- How to identify
 - Signs
 - Symptoms
 - Impact on the profession
- Methods to manage grief
- Coping
- Resilience
- Prevention strategies
- Discussion of case vignettes

The need to identify grief in healthcare professionals

People choose healthcare as a profession to help those who are ill. Although there have been considerable developments in the field of healthcare, there

still exist many conditions for which no cure has been found yet.

Due to this, there are various risk factors which are unique to the profession of medicine which make doctors and healthcare professionals vulnerable to grief. Be it the challenging demands of clinical care, the respect—or lack of it—bestowed upon professionals by society, the exposure to death and the feelings of helplessness in choosing a path in further management of a patient, the limitations of human nature, the exhaustion from working long hours without sleep, and the responsibility to assume the weight of guilt when patients' conditions deteriorate, all contribute to occupational hazards of the profession. Apart from the immediate clinical scenario, complex communication patterns, the perfection demanded by the nature of the work, demanding clientele, as well as cultural and language boundaries, all add to the background stress of healthcare delivery. Other sources of burden afflicting professionals include the increased cost of medical education leading to a high debt burden, limited control over call schedules, and a significant difficulty in managing work-life balance, magnify the impact of stress in a given situation (Gotowiec & Cantor-Graae, 2017).

Even though grief is commonly seen in healthcare providers, systematic studies on this topic have been sparse. The prevalence of grief in this population varies anywhere between 50-65% according to various studies (Sansone & Sansone, 2012). Grief impairs the personal, professional, and social life of the professional leading to faulty judgements that complicate various domains of life. Hence, it is extremely important to identify grief in healthcare professionals and address the issue at the earliest.

How to identify grief in healthcare professionals

Although the individual's resilience, the psychological construct of their mind, and their unique personality factors play a significant role in eliciting the grief reaction, any personally significant stressor could elicit grief.

Overwork: The concept of overwork can be defined as exceeding one's endurance or recuperative capacity to work. This is commonly seen in the private sector where there are no fixed time schedules. As the practice of a healthcare professional begins to pick up, the demands from patients increase as well, which in turn may lead to poor work-life balance.

Burnout: Burnout can be understood as a combination of symptoms of depression which are limited to the hours spent at work, and relief from the

same as one quits the job (Khleber Chapman Attwell, n.d.). The symptoms include:

- Fatigue
- Irritability
- Sleep disturbance
- Difficulty in concentration
- Confusion
- Depressed affect
- Psychosomatic symptoms such as headache, back pain, diarrhea, constipation, tremors, tingling, numbness, dizziness, etc.

Burnout is often observed after a particular event which prompts the person to strive even harder to achieve the target at hand.

There are various factors that drive healthcare professionals to strive harder, to the extent of neglecting basic necessities of life such as eating, sleeping, and socializing. Some of these include:

- religious fervor,
- a belief (perhaps narcissistic) that one is irreplaceable at work,
- identification with family members who were once workaholics,
- sibling rivalry,
- competition with physician-parents, and
- socio-cultural expectations

This cycle can continue, leading eventually to the denial of one's needs, a progressive sense of isolation and sense of inner emptiness, ultimately leading to full-blown depression.

When these early symptoms progress into full-blown depression, it may manifest with anhedonia, anergia, loss of interest, disturbed sleep and appetite, and may be associated with death wishes and suicidal ideations (Ahola & Hakanen, 2007; Rada & Johnson-Leong, 2004). This significantly impacts the professional's quality of life. Along with the personal and familial domains being affected the professional domain of life is also affected; this may manifest in the following ways:

- Forgetting trivial things which are important for patient care
- Poor decision-making and impaired judgement during management of the patient
- Decrease in efficiency of work

- Constant rumination about unnecessary things
- Mismanagement of cases
- Medical negligence

There may be an increase in the background anxiety experienced by the professional, which in turn impairs functioning. All of these symptoms make the professional susceptible to substance abuse, and so substance dependence is a common comorbid problem (Pilling, Konkoly Thege, Demetrovics, & Kopp, 2012; Plante & Cyr, 2011).

Grief in special populations

Students and trainees: Burnout is more commonly seen in resident trainees, although it can affect professionals at any point during their professional life. In this crucial period students and trainees are constantly trying to:

- manage personal and familial challenges
- bear with long hours of work
- deal with unforgiving duty rosters
- tackle a steep curve to master one's craft
- contend with high expectations from patients

It may also require dealing with less respectful behavior from colleagues—both junior and senior—combined with fewer opportunities for relaxation and socialization.

Women healthcare professionals: In addition to dealing with the same stressors of the profession that their colleagues deal with, women carry the extra weight of some unique challenges. The most prominent issue is pregnancy and raising a family while being a healthcare provider. Sexism, from both colleagues and patients, can trigger further conflicts in one's self esteem (Khleber Chapman Attwell, n.d.). While the challenges of parenthood are stressors for any professional, social expectations and traditional gendering of roles may mean that a large part of the burden of parenthood can fall on the mother, in addition to her full-time job. Challenges in terms of social expectations with regards to child-rearing, lack of adequate child-care, and less—or even the lack of—paid leave during pregnancy and early motherhood, can be challenging for women professionals.

Aging professionals: The profession is highly competitive. With newer generations of professionals entering the domain, more conversant with novel skills and techniques, the aging professional has to keep up with the

advances in the field. Occasionally, financial issues which were less important during better times, may begin to haunt the professional when their practice isn't doing as well.

Methods to manage grief in healthcare professionals

Identification of symptoms is the most important step in the management of grief. It is advisable to approach the problem with a bio-psychosocial model. Mild to moderate grief can be managed by improving coping strategies, discussing with friends and family members, and chalking out strategies to tackle the challenges. It's important to consult, or to facilitate consultation of, a professional when things begin to get out of hand.

The basic principles of psychotherapy in managing grief, which have been described in other chapters, apply here as well. Some of the important aspects relevant to this specific situation are described here.

- **Providing a secure base:** Healthcare professionals often provide a secure base for patients dealing with grief. When they experience grief themselves, it may be challenging to find a secure base. A therapist is helpful in most of these situations.
- **Revealing the feelings that block the natural process of grieving:** Denial in relation to grief is commonly seen in healthcare providers. It is worthwhile to probe for the same and help them identify the obstacle in their expression of grief.
- **Addressing social isolation:** Owing to the busy work routine, social isolation is a common phenomenon in healthcare professionals. Self-help groups and professional organizations should plan activities to improve social interaction between professionals and also among their family members.
- **Emphasizing the universality of grief:** Encouraging discussions about grief experiences in professional forums and guest lectures by professionals, to highlight the universality of grief, enhances the coping of individual professionals.
- Maintaining a journal, or symbolic expression through drawing, are some of the strategies which help in managing grief.

Some of the barriers in the management of grief in healthcare professionals include:

- Inability to make free time due to the demands of patient care

- Narcissistic sense of self
- Fear of stigma or diagnosis
- Fear of medication
- Wish for the condition to be purely biochemical: Poor consensus among healthcare professionals about the diagnosis of grief

Preventive strategies: Educating healthcare providers about the condition along with its various stages, is an extremely important component. Regular discussions in professional forums about grief in healthcare professionals and strategies to manage the same, will be a huge step towards managing grief.

Discussion of case vignettes

Case Vignette 1: This is a one-off incident in which a private surgeon is targeted for an unavoidable error in the acute management of a patient. It's better for the doctor to take a break from work, discuss the issue with his colleagues, seek support from professional organizations, medical counsel, and take legal opinion on the same. Once the issue is diffused and he has dealt with his grief, he may resume his practice.

Case Vignette 2: The hospice professional is currently having issues regarding job satisfaction. It is advisable for them to identify the same as early as possible, introspect to find the root of these thoughts, and then deal with them accordingly. The professional also has to constantly remind themselves that their role is extremely important in improving the quality of life of patients suffering from end-stage diseases.

Case Vignette 3: When a physician loses a patient whom they have been treating for a long time, they have to remind themselves that they have chosen a profession with high exposure to death. Discussing with peers on how they have coped with similar losses may be a good strategy. Enhancing awareness of maintaining professional and personal boundaries can help in dealing with the same.

Case Vignette 4: When a healthcare professional is also a primary caregiver in their family, there is an added burden. In addition to helping family members overcome grief, they have to cope with their own grief themselves. In such situations, it is better to seek professional help as it can be difficult to manage both for any person.

Case Vignette 5: Personal issues may affect the efficiency of nursing professionals or other healthcare providers, sometimes leading to mismanagement. The staff should become aware of the same at the earliest and try to resolve the issue. Taking a break from work for a few days and resolving the issue with the concerned stakeholders would be advisable. Once the personal conflict has been resolved, the nurse may return to her normal efficiency.

Case Vignette 6: This is a helpless situation for a psychiatrist—to try and improve the patient’s condition further. However, the psychiatrist must remind themselves of the natural course of the illness and its prognosis in the particular patient, despite the treatment and interventions provided.

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CHAPTER 8

Spirituality and Grief

Lakshmi Shiva, Santosh K Chaturvedi

It is not uncommon to see people experience the loss of a loved one, and each individual is bound to go through various forms of grief at some stage or the other. There are various ways in which individuals try to handle grief and this chapter shall discuss the role of spirituality in bereavement and grief. Spirituality has been studied in patients of palliative care with terminal illnesses such as cancer, as a coping strategy to address their distress with the diagnosis and fear of death.

Religiosity and spirituality: Are they the same?

Although they are often used interchangeably, spirituality is a broader and more abstract term than religiosity. Religion may be an explicit expression of spirituality, wherein an individual chooses to follow a system of faith and a set of rules to guide their life. Therefore, an individual may be spiritual without following a specific religion, or be very religious without having a well-developed sense of spirituality. This chapter talks about spirituality in general and is not restricted to any particular religious faith.

Research shows that spirituality is more commonly positively associated and less commonly negatively associated with grief outcomes. In a systematic review done by Boyle et al., 7 out of 17 studies had found that religious coping was advantageous in terms of reducing distress or increasing illness

adjustment. Religious activities were found to be positively correlated with life satisfaction, happiness, and positive affect, and negatively correlated with pain levels. Four studies in this review had found religious coping to be harmful, while the rest found no effects. Differences were noted among people belonging to different religious affiliations (Thuné-Boyle, Styggall, Keshtgar, & Newman, 2006).

In another systematic review by Gerhild Becker et al., results showed that 22 studies reported positive effects of spiritual beliefs on bereavement, six studies reported limited positive effects, and two studies reported no positive effects of spirituality on bereavement. Only one study reported some negative effects of increase in depression. In qualitative analysis, some of the important themes that emerged as helpful traits were: a belief that loved ones are at peace, traditional aspects of religion as a source of strength, and belief in an afterlife (Becker et al., 2007).

With regard to depression, a study by Thearle et al., investigating 260 families after the loss of a child, reported that bereaved parents who attended church regularly, had less anxiety and depression (Thearle, Vance, Najman, Embelton, & Foster, 1995).

Spiritual concerns are also noted in end-of-life care. In a qualitative study done in palliative care, common spiritual concerns were reported. The benefit of *pooja* (prayer), faith in God, concern about the future, the concept of rebirth, acceptance of one's situation, belief in *karma*, and the question "Why me?", were the seven most common themes that emerged out of the study (Simha, Noble, & Chaturvedi, 2013).

A study by Walsh et al., found that people with relatively low spiritual beliefs resolved their grief more slowly during the first nine months, but by 14 months they were at par with people with strong spiritual beliefs (Walsh, 2002).

We shall now see how spirituality is associated with various aspects of bereavement and grief through a case vignette. The example stated below elaborates the real-life experience of a person in grief, written in his own words, and illustrates how spirituality helped him overcome grief.

Experience of a person in grief:

"I am Mr S and I'm 58 years old. I lost my wife seven years ago. She died due to colon cancer, eight months after its detection, despite the best (!) medical advice and treatment.

Prior to my wife's ailment, my family was bubbling with life in all aspects. I had a satisfying profession, blissful marital life with the one I chose, children who were well-mannered, and service in an educational institution which kept me content. Instead of illusory and short-lived riches, God had showered on me the invaluable treasure of "contentment".

It was in August 2010 that my wife started complaining about her irregular bowel habits. What was thought of as a mild gastrointestinal infection turned out to be monstrous cancer which took her away from me, in the next eight months. When she was first diagnosed, my children and I were shocked, as she was always the healthiest amongst us and did all her work with ease. Though I kept asking God "Why choose her?" I was brave and thought about what could be done next, instead of brooding over the diagnosis. We arranged for the treatment as quickly as possible despite financial constraints. The treatment was completed in six months, and just as I started to believe that we have triumphed over the deadly disease, she had a recurrence of the tumor all over her abdomen. My wife, unlike me, was not overtly spiritual, but she had strong seeds of philosophy, which perhaps helped her endure all the pain and suffering without a

murmur, and with colossal courage and utmost dignity. While we were crying helplessly near her deathbed, she did not shed a tear but smiled in pain. She passed away two months later.

I was then stricken by the deadliest darkness—a state of mind and body beyond my perception. I felt like a punctured balloon falling on a roaring sea, with no shape or hope, no cause or purpose; I was blank and empty.

After her death, my children were shattered and I did not have time for myself, to think about what had happened. I was pressured into following the last rites and rituals. I began making arrangements for the funeral and started consoling all my close relatives, helping them overcome the loss. I could not cry my heart out for the first two days, I did not feel as if she was gone. Being a very spiritual person and coming from a cultural background, I strongly believed that the departed soul has to reach heaven, and a path to heaven will open only if the last rites are performed properly and with utmost faith. During the rituals, I was told the meaning of the ‘mantras’ being recited and told stories about how the soul goes through various stages before it finally reaches the heavenly abode. For example, there were thorny paths to tread which would result in the foot bleeding, and the soul wouldn’t have food to eat which is why some of the rituals involved offering food to the departed soul. This is when I actually began to realize that she has left me. I cried inconsolably when I had to leave her ashes in the holy river during the rituals, as it was the last physical

remnant of her. Yet, I still hadn't come to terms with her permanent absence from my life. Her soul continued to linger around me.

Once the ritual period was over and all relatives including my children left home, it slowly began to reflect on my loneliness. I was filled with both sadness and anger at the same time. I started cursing the same God that I had believed in all my life, out of rage. I began thinking that when there are so many evil people living happily in the world, why did my wife—such a peaceful, innocent person—have to die, leaving all of us in misery. I began thinking that all the good I had done in my life had gone in vain, and I was being punished for no reason. Other times, I would cry for days together in sadness, asking God why he didn't choose me instead of her. I began thinking of all those times when I had hurt her and felt extremely guilty. I wanted just one chance to prove my love to her but I knew I was negotiating for the impossible. I was just a living corpse. I was even prompted to end my life and join my wife in the eternal world, but before I could attempt this, the Almighty intervened.

I was taken to Sri Ramanashrama and some other spiritual places by friends, to unload my agony. I had unusual experiences during my stay at the ashram; I would see her image in various forms in my mind and hear her telling me the purpose of my life. I was taught that until the loved ones “let go” of the departed soul, it wouldn't attain ‘moksha’; it would linger around in this hapless

world. With these experiences, I realized that visiting spiritual places would bring in some peace but still wouldn't provide me permanent relief. At this nasty juncture, I was introduced to the Art of Living by a friend. I joined reluctantly, but soon completed several courses there and became an ardent devotee of Guruji. The essence of Guruji's training courses and preaching through discourses, books, etc. is about "living in the present", by being a non-participant witness of all happenings, including those affecting our body and mind. I was taught how to detach mind and body even while experiencing pleasure or pain, joy or grief, love or hatred, etc. This was easier said than done, of course, but the meditation and other breathing exercises I was taught helped me in the process. We were also taught to experience being 'hollow and empty', observe silence, and serve others, all of which are components in understanding the concept – "Who am I?" Like most of us, I had also read a bit about 'Jeevatma' and 'Paramatma', but mere bookish knowledge wouldn't suffice. One has to experience the changes within, in order to appreciate these spiritual teachings. At around the same time, my daughter conceived; this strengthened my belief that the soul of my wife would incarnate within the family soon after departure. I began seeing a new life in taking care of my grandchild and would express all my love for my wife on my children and grandchild.

Thus, with an inkling of spiritual light, I was able to shed my pessimism and disinterest in life, and regain my original optimism, philanthropy, “love and serve” philosophy, etc.

She wasn't just my wife, she was my very life. The 'Jeevatma' of my wife had now become the 'Paramatma'. Dispelling my cancerous grief, spirituality has given me back my God, who is once again my driving force in life.”

Stages of grief and spirituality

As established by Kubler-Ross, the stages of grief are denial, anger, bargaining, depression, and acceptance. A common misconception is that these stages have to occur in the same sequence and exist in tight compartments. More often than not, these stages are found to co-exist and can skip or occur in any order. There are various spiritual aspects in people's reaction to death or loss. In the case discussed above, the phrases “Why choose her?” or “I started cursing the same God that I had believed in all my life, out of rage” highlight the anger, directed towards God. Similarly, saying “I did not feel as if she was gone; her soul lingered around me” denotes the denial phase. The phase of depression comes through when the person talks about feeling guilty, sad, and having thoughts of ending his life and joining the departed one in the other world. Bargaining can be sensed when he questions why God couldn't choose him instead of his wife and begs God for another chance to prove his love for her. Acceptance of illness by the patient in the vignette has also been associated with spirituality, as perceived when the narrator says “strong seeds of philosophy sowed within her helped her endure the suffering”. Later on, the acceptance of bereavement happens through different types of spiritual interventions which he has described. The belief that the soul will not attain *moksha*, or liberation, if he doesn't ‘let go’ makes a lot of people come to terms with reality and resolve their grief.

Grief and culture

Varma, in his article *Cultural Psychodynamics in Health and Illness* (Varma, 1986), talks about the existence of “cultural defenses”, similar to individual defense mechanisms, to allay anxiety. This mechanism is provided in the form of

institutions, customs, traditions, rituals, sanctions, prohibitions, folkways, and symbolisms, and is readily available for use of all members of the society in appropriate situations. A good example of cultural defenses can be seen during mourning. Elaborate customs exist in almost all cultures to permit this communal mourning. In India, the process usually lasts for 13 days in Hindu families, with specific rituals and activities to be held. This permits family members to come together, to talk about the deceased, and to relive their life with the deceased. This is precisely what is recommended in the treatment of grief reaction, and the ritual facilitates this 'natural psychotherapy' treatment at a group level, to permit an optimal resolution of the bereavement. The case vignette also illustrates how the rituals helped in uncovering the emotions of the person in denial, and how the explanation of the *mantras* during rituals helped him find a deeper meaning to life after death, thereby alleviating his distress.

Belief in the 'afterlife'

People who believe in heaven or an afterlife find comfort in believing that the deceased soul is in a better place and close to God. A study by Dawn M Hawthorne (Hawthorne, Youngblut, & Brooten, 2015) examined parental spirituality and grief after the death of infants, and found that greater use of spiritual activities including life-after-death beliefs in bereaved parents was associated with lower symptoms of grief and mental health issues (depression and post-traumatic stress). The *Bhagavad Gita* recites, "Just as a man casts off his worn-out clothes and puts on others which are new, so the embodied casts off worn-out bodies and enters others that are new." According to the *Gita*, death is not final and it subscribes to the doctrine of immortality. The book *Bardo Thodol* (The Tibetan Book of the Dead) and the *Kathoupanishad* of the Hindus, both deal with events during dying, following death and during rebirth. Such beliefs reduce the suffering of having lost a dear one permanently and brings hope in the form of reincarnation of the soul. As described in the case vignette, the person finds solace in believing that his wife's soul was reincarnated as his grandchild.

What is the significance of spirituality in grief?

The relevance of spirituality in palliative care, bereavement, and grief is immense and in varied forms. Grief makes non-spiritual people turn spiritual and triggers a new search for meaning in life.

Assessment of spirituality in grief

Knowing about the spiritual and religious beliefs of people can help palliative care and mental health professionals in appraising their spiritual needs when required. Hence, an assessment of the spiritual needs of the patient with terminal illness, and their close relatives, is of utmost importance. A few structured methods of assessing spiritual aspects are available and can be used (Chaturvedi, 2007). However, there aren't many tools for assessing spiritual issues and tapping into spiritual concerns found in India. Thus, there is a need for an indigenous interview and development of measures to assess spirituality in palliative care and grief. Balboni et al. reported that most patients with advanced cancer in their study, had never received any form of spiritual care from the treating team (Balboni et al., 2013). Patients view spiritual care as an important and beneficial component of end-of-life care, so treating physicians and nurses should pay attention to the same. Spiritual concerns are also valid in caregivers of terminally ill patients, and are likely to continue from the period of anticipatory grief to the grieving period. Therefore, the assessment and care of spiritual distress in caregivers should also be similar to that of patients.

Intervention for spiritual distress in grief

Spirituality also has an important role to play in both individual and group therapy for grief, and it would be beneficial for mental health professionals to be sensitive as well as informed about the same. Spiritual distress can be managed using individual or group methods, by mental health professionals or religious/spiritual persons. Palliative care services and hospices should provide a secular, silent place, for the bereaved person to spend some time with themselves. There should also be provision for the bereaved to speak to a religious or spiritual person, as preferred by the bereaved.

In conclusion, it is clear that spirituality issues are likely to mask the grieving process. Palliative care professionals should be aware of the importance of spirituality at the end-of-life stage and after death. Clinicians should also be sensitive towards the beliefs of patients, and possess skills to assess as well as imbibe spirituality in their holistic care.

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ABOUT THE BOOK

This book covers various perspectives of psychological and spiritual distress, an integral but often overlooked domain in palliative care setting. With the objective of enhancing the skills of those involved in providing care in palliative care setting, the chapters in the book elaborate upon techniques to accurately identify, as well as effectively attend to this complex and challenging area. The contributing authors have dealt with each area extensively, but in a manner that ensures that the book is suitable for a wide audience including mental health professionals, medical and surgical oncologists, nursing staff, lay counsellors, and all other professionals any one working in a palliative care setting.

Both, the authors for the chapters as well as the editors of this book, have rich and extensive experience in this field. They have actively collaborated with various palliative care centres in providing psychological support to individuals, care givers and the medical professionals working with terminal patients.

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