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Terminally Ill Patients and Social Work Interventions

Jiji.T.S.[1]
Rakesh T.P.

Abstract

Human emotions have different meanings and impact on different people.The most common emotion presented by human beings on the loss of a loved one is called grief. The process of grieving creates many chemical and emotional changes or physicaland psychological changes in the human body and mind. The various stages of grief´ are denial, anger,bargaining, depression, and acceptance, or DABDA (D-Denial, A-anger,B-bargaining, D-depression and A- acceptance).The mental health professionals working with such victims mainly focuses on helping or enabling the clients to get out of that negative emotion in a non-destructive way. Though grieving is painful it is important that those who have suffered a loss be allowed to express their grief. It is also important that they be supported throughout the process. The bereavement support for the family who is experiencing the loss of a family member or close loved ones needs to be initiated much before that person succumbs to inevitable death. The professionals dealing with such individuals are usually qualified and trained to lessen the severity of possible emotional setbacks and other related issues prevailing in the lives of those who are more vulnerable to feel alienated owing to the absence of the loved one whose life was endangered.

Keywords

grief, caregiver, intervention, terminally ill

Introduction

Terminal illness is generally used to describe patients with an advanced disease and a drastically reduced lifespan, with perhaps onlymonths or weeks to live. The intensity of emotional turmoil in the life of a terminally ill person depends on many factors such as age of patient, level of education, religious belief, previous experience of illness, social support, financial stability, personality and medical factors such as pain to name a few characteristics (Goodhead and McDonald, 2007).The level of adjustment to such a worsening situation depends to some extent on the way by which the bad news is delivered to that person. In many cases, but not all, the patient would only have reached the terminal phase of the illness after a period of declining health and failed treatment. Although many scholars have explored death anxiety, only a few have examined the effective clinical treatment approaches for individuals struggling with death anxiety especially among the terminally ill. Perhaps this may be related to therapists' and researchers' own personal death anxiety. Counselling psychologists take pride in the field's ongoing goal to increase multicultural sensitivity among researchers and therapists alike. Therefore, counselling psychologists should challenge their unfounded beliefs among the underserved populations, such as terminally ill persons, by exploring their own hesitations and beliefs related to death and dying.

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[1] Both authors are affiliated to Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST), Medical College. P.O., Trivandrum-11, Kerala, India. Email: tsgiji@yahoo.com

As more of the population grows older and technological advances allow persons with a terminal illness to live longer, it is more likely that counselling psychologists will have to face clients diagnosed with a terminal illness, who are experiencing these death anxieties. The emotional support and enabling hands in the life of such victims play a vital role in helping them to get adjusted to that life threatening time period. While revealing or disclosing the bad news to the patient as well as the family, utmost care should be taken to fulfill their right to know and also their privacy needs has to be respected properly. Though it is sure that the prognosis of the treatment is not that hopeful as others may wish it to be, both the patient and related family members need to be encouraged to be faithful and to adhere to the treatment as much as possible which not only helps to postpone the unwanted worsening of the illness but also helps in inculcating a sense of responsibility among the family members.

Humans and all living organisms share two universal experiences, birth and death. Some postulate that humans are the only primates with the cognitive ability to realize that they will eventually die, which creates death anxiety. Some believe that death anxiety impacts each one’s day-to-day life. Even if death anxiety is not ubiquitous, it is likely to arise when battling a terminal illness. Beginning with Freud, many psychologists such as Becker (1973), Feifel (1990) and Kübler-Ross (1969) have suggested and researched the impact of death anxiety on human functioning.

Common Clinical Features seen among the Terminally Ill

Depression: Depression is the major side of an anxiety prevailing phase. When evaluating a terminally ill patient, a holistic approach has to be taken. The patient may havevarying degrees of restlessness, tiredness, loss of appetite, insomnia and nightmares all of which could be attributed to the physical illness; therefore when assessing terminally ill patients greater weight must be given to psychological symptoms such as hopelessness, guilt and worthlessness than to somatic complaints (Ando et al.,2008). The dysphoric mood at this stage usually occurs when relatives or friends visit and spend time with them cracking silly jokes in order to loosen their stress. Many patients express a wish to die by themselves or plead with the others to help them to end their life rather than suffer the ever increasing agony of illness(Baker, 2005). A number of factors are associated with an increased suicide risk such as hopelessness, poorly controlled pain, poor social support, delirium, alcohol abuse, recent bereavement, advanced age, poor socio economic status and also particularly of the male sex. Cancer patients have twice the risk of committing suicide than the normal general population. Patients with a previous history of depression or suicide attempts are also at increased risk.

Anxiety:When dealing with a diagnosis of terminal illness, the initial reaction is one of disbelief, which is swiftly followed by anxiety and depressive symptoms. Patients may have difficulty in sleeping, eating, and have intrusive thoughts about their illness. These emotions usually subside over a couple of weeks. However, in some patients these symptoms persist and interfere with their ability to function. Anxiety may hinder the patient from continuing medication and treatment as they fear that it is of no use to alleviate their disease as they would wish it to be. A number of physical factors such as hypoxiacan precipitate anxiety which is also associated with panic attacks. Metabolic disorders such as hypoglycaemia and hypocalcaemia can be present with anxiety.Delirium is also important in the differential diagnosis as anxiety symptoms can appear in an agitated delirium.

Management of anxiety and depression: Many may resort to antidepressants and anti anxiety therapies. This requires the intervention of well trained therapists or counsellors whose sessions with the patients can help them to relieve their worries at least for a short span of time by restoring their faith in life. The main purpose of such intervention is not just adding days to their life but adding quality life to their days.

According to Elisabeth Kübler-Ross(1969),the most common stages of grief seen among the terminally ill patients include denial, anger, bargaining, depression and acceptance. On hearing the news of a life endangering illness one quite often feels a sense of denial like ‘I must not have this, something has gone wrong, may be the result is not mine or the doctor might have made a wrong diagnosis'...it goes on in similar lines. Then again when they are told that it is true then they start feeling angry towards the person or people who have revealed the dreadful news to them. Slowly this stage follows a stage of bargaining or some sort of self compulsion non-verbally that let this news be false which later leads them to feel depressed. And finally when they realise that all their hopes are in vain they try to assimilate that unfortunate event in their life. This is the most seen pattern among almost everyone on hearing about an accident or death of an intimate one. They feel an empty nest syndrome, aloofness, hopelessness, helplessness as if life is full of darkness. There is no way to continue anymore as there is no hope. Some at this stage resort to spiritual powers thinking that a higher power beyond our capacity decides the faith and destiny of each and every creature in this universe. Professor of Clinical Psychology at Columbia University, George Bonanno, argues in his book, *The Other ideas of Sadness*, that grief is so highly individualized and personal, that no two people grieve in the same manner Terminal illness is a medical term popularized in the 20th century to describe a disease that cannot be cured or adequately treated and is reasonably expected to result in the death of the patient within a relatively short period of time.

Dealing with Grief

Dealing with anticipatory grief is a crucial phase in the life of relatives of the terminally ill(Cheng et al., 2010). It usually starts before actual death. Thinking of a life ahead without the presence of their loved one, often puts the closely related ones into a life of confusion anduncertainties. They often feel that they are left alone in this world and they are the only ones with such a problem and no one is there to share their responsibilities. The diagnosis of terminal illness has profound implications for the patient, caregivers, family, and friends. Similar to a stone being thrown into a pool of water, the effects of the illness ripples throughand changes life forever. Many primary care physicians and caregivers take regular care of these patients in the terminal stages of the disease and play an important role in the grief process. Primary care physicians should be able to identify grief, develop strategies for the management of grief in patients, families, and themselves, and be able to recognize abnormal grief.

All human beings should expect to suffer losses during their life span and be prepared to experience the process of grief. Grief not only puts them in emotional distress but also in physical problems like sleeplessness, nightmares, loss of appetite, depression, vomiting or nausea, headache, diarrhoea, and often cardiological ailments for those who are more prone to such diseases. Some may feel guilty of their relative's pathetic condition thinking that they are indirectly responsible for their condition and if they had addressed it on time, this worsening would not have come so early(Bosma et al., 2010).

According to Worden (2008) in his book on Grief counselling and grief therapy says that there are four types of complicated grief reactions: (1) chronic grief reactions, (2) delayed grief reactions, (3) exaggerated grief reactions, and (4) masked grief reactions. Chronic grief reactions are excessive in duration and do not lead to an appropriate conclusion. Often people with chronic grief reactions would have had confused or ambivalent relationships with the deceased, and there may have been issues related to alcoholism and abuse. Delayed grief reactions are inhibited, suppressed, or postponed responses to a loss that tend to resurface at a later date and often appear as an excessive reaction to a subsequent loss or event. Exaggerated grief reactions are excessive and disabling responses to a loss in which the bereaved feels overwhelmed and resorts to maladaptive behaviour. Often, such responses include depression, anxiety, various phobias, and panic attacks. Masked grief reactions occur when individuals experience symptoms and behaviours that cause difficulty but fail to see or connect that they are related to the loss. Masked grief is often expressed in psychosomatic or physical symptoms (Worden, 2008).

At this stage some patients deny treatment thinking that if more medications are applied, it may lead to unnecessary reactionsas theywish the rest of the life to be less miserable. While others resort to more expert opinions amidst their financial constraints. Some of them prepare their loved ones to get used to such a condition by means of prayers, or spiritual followings.The final stage of grief actually begins with the funeral and the celebration of the life of the now-lost family member. This is a time of mixed emotions, to be sure, including both sadness and relief. If the family has successfully negotiated the previous stages, however, this final stage also opens yet another door: to collective as well as personal renewal. It can be a celebration of life as much as it is a marking of a loss. It can be a time of creativity and planning, as the family decides, for example, how it will commemorate anniversaries and birthdays.

Pain management: Deborah Whiting Little (1999: 68) in her book *The Family Handbook of Hospice Care says that* "control of pain is really the heart of terminal care. People do not fear death so much as they fear unrelieved pain and being alone with their suffering."Psychological distress often causes suffering in terminally ill patients and their families and poses challenges in diagnosis and treatment. Increased attention to diagnosis and treatment of depression can improve the coping mechanisms of the patients and their families.Most of the terminally ill patients experience physical pain or discomfort. Physical pain is our body's internal regulatory system alerting us that there is something wrong. Thus pain can be an important indicator of issues that need to be addressed. Physical pain can be acute (sudden) or chronic (long-lasting), and both need to be addressed.

The fear of physical pain may occupy much of the patient's thoughts. It can also bring stress and tension, which can prevent pain medications from working properly. Diagnosing and treating depression in terminally ill patients involve unique challenges. Evidence of hopelessness, helplessness, worthlessness, guilt, and suicidal ideation are better indicators of depression in this context than neuro vegetative symptoms. Although terminally ill patients often have suicidal thoughts they are usually fleeting. Sustained suicidal ideation (the recurrent thoughts of committing suicide)should prompt a comprehensive evaluation. Clinicians should have a low threshold for treating depression in terminally ill patients. Psycho stimulants, because of their rapid onset of action, are useful agents and are generally well accepted / tolerated. Selective serotonin re-uptake inhibitors and tricyclic antidepressants may also be used. The focus is always to offer optimal pain control and to reassure the patient that their pain will be managed. The goal of pain management is to relieve and prevent the pain from recurring.

To manage pain, it is important to assess it. Healthcare professionals and family members can ask a patient the following questions: Deborah Whiting Little, in her book The *Family Handbook of Hospice Care asks like this:*

- Where is the pain?
- On a scale of zero to ten, with ten being excruciating, how intense is it?
- It is continuous or does it come and go?
- Can you describe it? Does it throb or ache?
- What seems to help it? What makes it worse?

Alternate Therapies to deal with Pain:

Integrative therapies can complement other therapies and allow the care team to take a holistic approach to the loved one's hospice care. These therapies can help provide comfort and improve quality of life during a patient's final months or days.

Some therapies for patients and family members are discussed below.

Massage therapy, reflexology, healing touch, and Reiki[2]are hands-on therapies that provide comfort and relieve symptoms through the use of physical manipulation of muscles or through energy healing. They may also help the patient to deal with pain, anxiety, or sleeplessness.

Aromatherapy can provide many benefits to patients and family members. Some essential oils may help alleviate nausea or fatigue, while others may help with anxiety and depression.

Music Therapy: Music can be soothing, relaxing, nurturing, energizing, or comforting. It may provide the following benefits:

- Reduce anxiety and stress
- Promote relaxation
- Strengthen family bonds
- Trigger memories or initiate reflection on one's life

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[2] Reiki is a Japanese technique for stress reduction and relaxation that also promotes healing. It is administered by "laying on hands" and is based on the idea that an unseen "life force energy" flows through us and is what causes us to be alive.

- Improve alertness
- Reduce one's perception of pain or nausea
- Create joyful experiences

Art therapycan help individuals explore their emotions through the use of various art mediums. It provides an outletfor creative, non-verbal expression of their feelings. Guided imagery, meditation, or other relaxation techniques can help patients and family members reduce anxiety and put their minds and bodies at ease. These techniques may be done individually or with the guidance of a trained instructor or counsellor.

Acupuncture or acupressure may be used to help reduce pain and nausea. Some patients who have had an ischemic stroke (a stroke caused by clotting, not a hemorrhage) also find it to be beneficial, as it promotes relaxation. The American Academy of Medical Acupuncture asserts that acupuncture can open up blood vessels to help blood flow and decrease the risk of clotting (National Hospice and Palliative Care Organization, 2011).

Hospice Care for the Terminally Ill

Hospice programmes generally share certain common characteristics. Hospice staff can administer pain medications, provide nursing care, and offer emotional support. Before and after a death, emotional support is extended to caregivers too. Many programmes offer bereavement counselling for a year after a death. The hospice team typically includes specially trained doctors, nurses, aides, social workers, counsellors, therapists, people who offer spiritual care, and volunteers. Hospices must be licensed in most states. Those providing services covered by Medicare or Medicaid must be certified by the Centres for Medicare and Medicaid Services. In England, Hospice programmes may also be accredited by the Joint Commission or the Community Health Accreditation Programme, but there is no national requirement for this. Hospice services are covered nationwide under Medicare. Many private insurers and health maintenance organizations also offer coverage in USA (National Hospice and Palliative Care Organization, 2011).

Hospice care focuses on improving the quality of life for persons and their families faced with a life-limiting illness (Chochinov, 2006). The primary goals of hospice care are to provide comfort, relieve physical, emotional, and spiritual suffering, and promote the dignity of terminally ill persons. Hospice care neither prolong nor hasten the dying process. As such, it is palliative not curative.

The Council on Scientific Affairs of the American Medical Association espouses a model of care that considers both the caregiver and patient as a single unit of care. The caregiver becomes a partner with the physician and patient. During end-of-life care the patient’s caregiver becomes naturally intertwined within the physician-patient relationship, and as a valid stakeholder often becomes the ultimate surrogate decision-maker for the patient. Failure to win the caregiver's trust or involve caregivers in the end-of-life health decisions can comprise quality of care and prevent adequate symptom relief (Chochinov et al., 2011).

The Caregiver Burden

Caregivers living with their patients have more personal needs than caregivers who do not live with their patients. The majority of patients with terminal illness report a need for assistance but relatively few receive assistance from paid caregivers. Many of them rely on family members and friends for help with transportation, housework, nursing, and personal care. A recent study of caregivers of patients with metastatic cancer provides insight and understanding about the care giving experience and details of the burdens and unmet needs of caregivers (Breitbartet al.,2010). Findings indicate that physicians need to be attentive to patient quality of life issues and attempt to provide assistance. Caregivers may need assistance in balancing care giving with other families, financial, and work responsibilities. It is also important for physicians to communicate effectively with the patient and caregiver and acknowledge the importance of care giving.

Terminally ill people have complex physical and psychological needs. As a result, their caregivers may experience high levels of burden, and some caregivers are unable to cope with this burden. Thus, it is important to determine the various factors that may influence the caregiver's burden, so that healthcare professionals may implement strategies to reduce the caregiver's burden.

In addressing the complicated needs of a seriously ill patient, it is often easy to overlook the needs of the carers. Without understanding and without guidance in each of these areas, family members who are forced by circumstances to cope with prolonged grief are vulnerable to serious psychological consequences, including depression, guilt, and debilitating anxiety. These circumstances can even lead to physical illness. Family relations are vulnerable and may rupture as a result of a resurgence of unresolved issues that are unearthed as a result of a prolonged terminal illness in a loved one. Even loving couples may find their relationships in jeopardy as a consequence of the unwanted lifestyle changes that may occur.

What families need now—and will need in the future—is guidance for how to anticipate and deal with such issues. The main family member, who is the sole carer, may find it difficult to do all the other household chores along with the patient's care.There are some carers who are so diligent, and spend all their time at the hospital that carer fatigue sets in and they become ill and exhausted themselves. Such carers need counselling and help as to how to pace out their work over a prolonged and long illness. Each family has their own way of communicating and it is important to know whether issues are openly discussed, or if information is being withheld from certain members of the family. In all cases open communication should be encouraged, as this allows for more supportive relationships to develop. Relationships where the carer is ambivalent or dependent on the patient, may later lead to a difficult bereavement (Hooyman and Kramer, 2006).

World Health Organization confirms that the caregiver and patient should be considered as a single unit in the relationship they form with the physician (Fleming and Hagan, 2010). This means that caregivers have an equal stake in discussions about treatment, prognosis, and health care planning. Physicians should therefore be simultaneously sensitive to the needs of patients and their caregivers. Open and honest communication, including listening to caregivers' opinions, is very important. Recognition and validation of the care giving role, compassionate bedside manners, and attention to caregiver's quality of life issues also contribute in giving the caregiver satisfaction and trust in the physician. Ongoing emotional support and early referral to appropriate services may be very beneficial to this important group of people.

Despite the negative impact of care giving on the lives of these caregivers, the caregivers' personal coping resources such as their sense of coherence and re-framing appear to reduce their perceived burden. Caregivers who are able to confront the challenges of care giving are generally found to experience a reduced caregiver's burden feeling and experiences personal growth through the process of care giving. Hence, caregivers may also benefit from the process of care giving.

Role of Social Workers

The role of a social worker in dealing with the terminally ill and their family is multifaceted. It starts right from the diagnosis and goes on with the treatment modalities and finally even into the bereavement support (Kramer, 1998). Many patients whose life is endangered seek the support of others for relieving their fear of impending doom. Some may resort to religious rituals while others hesitate to continue medications as they feel that it may lead them to end their life with many negative outcomes as part of the treatment reactions**.**

The counsellor or social worker working in this field can provide them unconditional moral and emotional support by achieving a good rapport with them and their family (Cagleand Kovacs, 2009).They should give them the assurance that the therapist is a reliable source to alleviate their unwanted overwhelming tensions and worries related to their treatment and its outcome. They can explain positively to them the negative and positive sides of continuing treatment and how it will in turn lead to positive outlook and hope to face the balance of their life with courage. Here comes the relevance of palliative care. Its main purpose is to reduce the pain as well as delay the worsening of the illness to its possible extent. The social worker in the palliative team can educate the terminally ill person's family in the adaptive ways to deal with them and how to prolong hope in the continuance of their life by providing them peaceful atmosphere in the family through words and deeds. Educating them also helps the family provide hands on care to the patients, for proper usage of medications, for knowledge about disease progression, signs and symptoms of dying, normal grief response, and coping with stress (Lieberson, 1999).

Social workers can encourage the family of the terminally ill to engage the dying person in family gets to-gathers , family prayers and if possible some social occasions outside the home. All these will help them to inculcate a sense of belonging, self worth and dignity in the terminally ill. Adequate listening to their problems are quite essential in reducing the anxiety among the patients. When they see or feel that their feelings and emotions are well taken care of, their unnecessary fear of death may slowly wither away as they begin to feel comfortable with their own people around them.

Social workers attend to both practical needs and counselling needs of patients and family, based on initial and ongoing assessment arranged for durable medical equipment, discharge planning (from hospital to home), and funeral/burial arrangements, serve as liaison with community agencies and assist the family in finding services to address financial needs and legal matters(Reese and Raymer, 2004). They also provides counselling related to family communication and assesses the patient's and family's anxiety, depression, role changes and caregiver stress. Finally they provide general grief counselling.

In short the role played by the counsellors or social workers include the following:

- Maintaining acceptable quality of life during advanced stages
- Coping with deteriorating physical condition
- Confronting existential, spiritual, and religious issues
- Planning for the remaining affected family and friends

Ethical and Legal Issues

The contemporary practice of palliative care raises important ethical issues that deserve thoughtful consideration.Patients have a right to refuse life-sustaining treatment, even if they die as a consequence. Here the patient must have the ability to comprehend the available choices and their risks and benefits, to think rationally and to express a preferred treatment . Informed consent and refusal to life-sustaining treatment has three elements:

- Adequate information must be conveyed to the patient
- The patient must be able to decide, and
- The patient must have freedom from coercion.

Conclusion

In the future, the task of caring for the dying patients will probably shift increasingly from medical personnel to family and friends because many people prefer not to die in a hospital. The burden resulting from this choice is likely to take a toll on the caregivers' health. The hospice care or home care though of recent origin, has got worldwide acceptance owing to its efficacy in dealing with the family member who is ill by reducing their burden of the tiresome hospital atmosphere which enables both the carers and the care receiver to spend their valuable time of their life with the loved ones and also in the familiar environment. Social workers and other related professionals working in this field needs to concentrate equally both on the training for the carers in giving effective care as well as on taking care of their own physical and psychological health. We can hope that in this new millennium both science and ethical standards will intertwine to deliver adequate and more promising service in dealing with such a serious social issue.

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