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Terminal Illness with Special Reference to Non-Hodgkins Lymphoma: Implications for Pastoral Care and Counselling

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Abstract

Terminal illness presents enormous challenges that go beyond physical decline, including experiences of pain, fear, depression, and anxiety associated with impending death. It is not just an individual concern but a family illness, profoundly affecting the lives of all family members when one of them is diagnosed. This paper addresses the psycho-social and spiritual impact of terminal illness by examining a case study from Manipur with special reference to a patient with Non-Hodgkin's Lymphoma. The analysis of the case study also found that they are not aware of the benefit of seeking professional counselor or help. The role of a pastoral counsellor is vital, providing support at every stage of the illness by addressing the psychosocial and spiritual dimensions. This study suggests Cognitive Behavioral Therapy (CBT) as an appropriate therapeutic counselling approach in such crises which can be integrated with resources from pastoral care to acquire strategies for coping mechanisms and manage the stress of life-threatening illness.

Introduction

Terminal illness is a condition or a disease that cannot be adequately treated or cured which will eventually cause death. Depending on their condition and treatment, a terminally ill may live for days, weeks, months or even years. The modern medicine has turned previously fatal illness into chronic diseases and hence most people live for many years with the symptom burden of one or more serious illnesses, functional or cognitive impairment, and dependence on care from family or society. Because life expectancy is increasing, people with a terminal illness are living with more complex needs than before and need care and support. Terminal patients experience pain, fear, depression or anxiety associated with oncoming death, and family and caregivers may also struggle with psychological burdens. According to *The Times of India* dated May 12, 2018 at least 62 people in the country take their lives every day while not being able to cope with a terminal or chronic ailment.[1]

[1]Sumitra Debroy, "62 people suffering from terminal illness kill themselves daily" https://timesofindia.indiatimes.com/india/62-people-suffering-from-terminal-illness-kill-themselves-daily/articleshow/64130539.cms (accessed on 25th November 2024)

Thus, terminal illness is inevitably a family illness for the life of everyone in the family is changed when one member of the family experience diseases.[2]There is often a lack of awareness and understanding what the patient and caregiver faces mentally, physically, emotionally, psychologically and spiritually in addressing terminal illness. Therefore, this paper attempts to address the effect of terminal illness by looking into a case study with special reference to Non-Hodgkins Lymphoma patient from the Manipur[3] and the need for holistic pastoral care and counselling.

1. **Definition of Non-Hodgkins Lymphoma**

Non-Hodgkins lymphoma[4] is a cancer that starts in white blood cells called *lymphocytes*, which are part of the body's immune system that helps fight infections and some other diseases. It also helps fluids move through the body. NHL is a heterogeneous group of malignancies that arises from two distinct lymphocyte types, B or T lymphocytes, at various stages of differentiation. While 60–75 % of NHL develops or presents in the lymphoid tissues, such as lymph nodes, spleen, and bone marrow, it can occur in almost any tissue and ranges from the more indolent follicular lymphoma to the more aggressive diffuse large B-cell and Burkitt's lymphomas.[5]

According to Globocan (2012), the estimated incidence of NHL is 5/100,000 (385,741) New cases, with a mortality rate of 2.5/100,000 (199,630 deaths) worldwide.[6]Within India, the incidence is several-fold higher in urban cancer registries compared to rural areas; the incidence being higher in metropolitan cities and Indian immigrants suggesting that urban lifestyles and economic progress may increase the cancer incidence. The estimated mortality rate due to NHL is higher in India than western countries. Globocan reports that the ratio of mortality to incidence[7] in India is 69.7%. This reflects the poor overall 5-year survival below the global average.[8] NHL affects mostly older population and has higher male to female ratio.[9] Delayed diagnosis resulting in advanced stage of NHL, inadequate or improper treatments due to limited facilities, affordability of chemotherapy drugs, lack of expertise at district hospitals, the inability to complete the NHL treatments, and poor follow-up are the possible inherent factors responsible for the higher mortality in India.[10]

[2] Kenneth J. Doka, *Counselling Individual with Life Threatening Illness* (New York: Springer Publishing Company, 2009). p. 14.
[3] Manipur is a state in northeastern India with Imphal as its capital. It borders the Indian states of Assam to the west, Mizoram to the south, and Nagaland to the north and shares the international border with Myanmar.

[4] Hereafter the acronym NHL for Non-Hodgkin's Lymphoma will be used in the paper.
[5] Brian C.-H. Chiu and Ningqi Hou, "Epidemiology and Etiology of Non-Hodgkin Lymphoma," in *Non-Hodgkin Lymphoma: Pathology, Imagining and Current Theology*, edited by Andrew M. Evens & Kristie A. Blum, vol. 165 (Switzerland: Springer, 2015), p. 2.
[6] J. Ferlay et al, GLOBOCAN 2012 v1.0. Cancer Incidence and Mortality Worldwide: IARC Cancer Base No. 11. Lyon, IARC, 2013. http://globocan.iarc.fr(accessed January 14, 2025).
[7]Incidence is a measure of disease that allows us to determine a person's probability of being diagnosed with a disease during a given period of time. Therefore, incidence is the number of newly diagnosed cases of a disease.
[8]Reena Nair, Neeraj Arora & Mohandas K. Mallath, "Epidemiology of Non-Hodgkin's Lymphoma in India," *Oncology,* vol. 91, no. 1 (July 2016): p. 18.
[9] Brian C.-H. Chiu and NingqiHou, "Epidemiology and Etiology of Non-Hodgkin Lymphoma," in *Non-Hodgkin Lymphoma: Pathology, Imagining and Current Theology*, p. 1.
[10]Reena Nair, Neeraj Arora & Mohandas K. Mallath, "Epidemiology of Non-Hodgkin's Lymphoma in India": p. 18.

2. Causes of NHL

The exact cause of NHL is unknown. However, there are multiple conditions that are associated with an increased risk of developing the disease:

2.1. Lifestyle factors

Cigarette smoking and consumption of alcohol have been associated with NHL. A recent study suggested that exposure to environmental tobacco smoke is associated with a higher risk of follicular lymphoma for both children and adults.[11] Some studies also found positive associations with intake of meat, particularly red meat. A study from Mumbai did show a seven-fold higher risk in red meat eaters.There are multiple pathways through which meat intake might impact NHL risk, including modulating the immune response through meat and its constituents (e.g., fat and protein), carcinogens, and mutagens. An excess risk of NHL has been associated with a higher intake of dietary fat, including total fat, animal fat, saturated fat, and transfatty acids. One recent study reported that phytanic acid, a saturated fatty acid obtained primarily through the consumption of ruminant meat and dairy products, is positively associated with risk of NHL, especially follicular lymphoma.[12]Hair coloring products contain compounds that are mutagenic and carcinogenic inanimals. Several studies reported excess NHL risk associated with the use ofhair dyes, particularly long-term use of dark permanent dyes. These findings were supported by recent reports from the InterLymph with more than four times as many cases and controls.[13]

2.2. Chemical and Drugs Exposures

A number of occupations have been associated with increased risk for the developmentof NHL, including farmers, pesticide applicators, benzene workers, rubberworkers, petroleum refinery workers, dry cleaners, firefighters, and chemists. Common exposures in these occupationsinclude benzene, pesticides, herbicides, and other organic solvents. Epidemiologic studies suggest that an excess risk of NHL among farmers is related to the use of phenoxyacetic acid herbicides, organophosphate insecticides and fertilizers. Solvents have been associated with an increased risk of NHL, especially in occupational studies of rubber workers, aircraft maintenance workers, and dry cleaners.[14]

2.3. Changes in the Immune System

Lymphocytes (the cells from which lymphomas start) are immune system cells, so changes in the immune system seem to play an important role in many cases of lymphoma:

2.3.1. People with immune deficiencies (due to inherited conditions, treatment with certain drugs, organ transplants, or HIV infection) have a much higher chance of developing lymphoma than people without a weakened immune system.

[11]Ibid., p. 10.
[12]Ibid., p. 11.
[13]Ibid., p. 12.
[14]Ibid., p. 13.

2.3.2. People with certain autoimmune diseases (where the immune system constantly attacks a certain part of the body) have an increased risk of lymphoma.

2.3.3. People with certain chronic infections are also at increased risk, probably because the immune system is constantly making new lymphocytes to fight the infection, which increases the chances for mistakes in their DNA.[15]

2.4. Change in Genes

DNA is the chemical in the human cells that makes up the genes, which control how a person cells function. Some people inherit DNA mutations from a parent that increase their risk for some types of cancer. Having a family history of lymphoma does seem to increase a person risk of lymphoma. Gene changes related to NHL are usually acquired during life, rather than being inherited. Acquired gene changes can result from exposure to radiation, cancer-causing chemicals, or infections, but often these changes occur for no apparent reason. They seem to happen more often as a person age, which might help explain why most lymphomas are seen in older people.[16]

3. Signs and Symptoms

NHL can cause many different signs and symptoms, depending on the type of lymphoma and where it is in the body. Sometimes it might not cause any symptoms until it grows quite large.Some common signs and symptoms of NHLare enlarged lymph nodes, chills, weight loss, fatigue (feeling very tired), swollen abdomen (belly), feeling full after only a small amount of food, chest pain or pressure, shortness of breath or cough, severe or frequent infections, easy bruising or bleeding, fever (which can come and go over several days or weeks) without an infection, drenching night sweats, and weight loss without trying (at least 10% of body weight over 6 months).

4. Diagnosis

4.1. Biopsy

4.2. Computed tomography (CT or CAT) scan

4.3. Magnetic resonance imaging (MRI)

4.4. Positron emission tomography (PET) or PET-CT scan

5. Treatment

5.1. Chemotherapy (drugs)

5.2. Radiation

5.3. Immunotherapy, including monoclonal antibodies

5.4. Tyrosine kinase inhibitors

5.5. Stem cell transplant

[15] The American Cancer Society https://www.cancer.org/cancer/non-hodgkin-lymphoma/about/what-is-non-hodgkin-lymphoma.html (accessed on 15th January, 2025)

[16] Ibid.

5.6. Surgery, in rare cases[17]

6. Case study

Mr. K is a 54-year-old man from Manipur was diagnosed with stage IV NHL cancer. A year before the diagnosis, he had persisting pain in his knee, for which he underwent medical treatment. His Orthopaedists prescribed heavy doses of medication stating that fluid has accumulated in his knee. While he was attending this health issue, he noticed a painful lump in his hips. Again this concern was addressed with heavy doses of medication by another doctor. After a year of struggle, he was referred to an oncologist where he was diagnosed of Stage IV NHL. Mr. K and his family were shattered to learn the result of the diagnosis. They could not understand how this happen even after taking all the preventive measures and medicine prescribed by the previous doctors. He received six chemotherapy because of the severe bone marrow suppression. During this process, he had severe diarrhoea and fatigue, drastically lost his weight, and experience excruciating pain to the point that he even begged his son to share his pain. He also underwent multiple radiation therapy.

Despite these treatments for one full year, his lump continued to grow leaving Mr K in a very painful situation. Finally, his oncologists explained to Mr K and his family that his illness was terminal as all curative options had been exhausted and that nothing could be done to reverse the course of his disease. This led the patient and family to a state of shock, resulting in emotional distress. A state of denial was observed in the family members and the patient himself. It was reported that Mr K told the doctor “I want you to do everything possible to make me live.”Mr K had always been in control of his life and became angry and depressed that he was losing his battle against cancer and could do nothing. He now had withdrawn and is unwilling to talk about anything except his physical pain and fear of leaving his loved ones. He became very critical of everything that was done for him, and spends all day complaining. His family members were devastated and helpless. They needed a lot of support, and found in the well-wishers and pastor who come to visit them.

7. Case Analysis

7.1. Through interaction with Mr K and family, it was found that his terminal illness was the result of wrong diagnosis and side effects of heavy doses of medication.

7.2. The feeling of the doctor letting them down was observed during the interaction.

7.3. It was also partly due to the ignorance of the family members who thought that the lump on his hips was just a part of the weight gain.

7.4. State of denial was observed with the patient and the family members when the result of the diagnosis was communicated to them.

7.5. It is also observed that the patient could not accept his terminal state of illness and responded in anger, resentment, bitterness, fear of death and losing loved ones and was going into depression.

[17] Ibid.

7.6. After one whole year of care giving, the family members were physically and mentally exhausted, devastated, and helpless but continue the noble task out of their love for their father.

7.7. It was observed that moral, emotional and spiritual support was received by the patient and the family members from the church members, well-wishers and pastors who came to visit them.

7.8. No mention of seeking professional counsellor during the interaction indicates that they were not aware of the benefit of seeking professional help in such a time as this.

8. Coping Terminal Illness with Cognitive Behavioural Therapy

Beliefs system and thinking are seen as important in determining and affecting behaviour and feelings of a terminally ill.[18] Cancer represents one of the most feared diseases by people because some of its pain, invasion, the imminence of death, and the most common side effects caused by medical treatments - all this knowledge and experience will form beliefs to guide their behavior.[19]In the case of patients with advanced cancer like Mr K, cognitive behavioural therapy interventions will produce beneficial effects, such as behavior change, decreased sadness and depression among others, and help patient to acquire strategies for coping mechanisms. Cognitive behavioral therapy intends to encourage thinking focused on positivism and hope in how patients perceive their disease process until the end of their lives. Cognitive therapy, along with the cancer treatments is useful because many times stress response and subsequent psychological disorders depend almost always on the inadequate interpretation of the everyday events in life.[20]Thus, the therapist can help the terminally ill to identify the negative and positive behaviors and encourage the positive behaviors while discouraging the negative ones.[21]

Treating cancer patients using cognitive behavioral psychotherapy has the following benefits: it is effective in "reducing emotional burden" that characterizes patients and their families at different stages of the disease, intervention can occur in a short period of time and used to treat problems related to the control ofsymptoms and types of participation of the patient and his family; it emphasizes self-control and self-efficacy, which allows greater adherence to treatment, increase effectiveness and decrease their side effects, also improves mental regulation, on the other hand cancer patients require a short-term psychotherapy, and for this reason is common intervention models used in crisis.[22] Thus, psychological intervention is a highly relevant treatment that affects emotional health of sickness so that the patient can combat stress levels, anxiety and depression that could reduce effectiveness of treatments to fight the disease and also to minimize the stress level of the family members.

[18] Richard S. Sharf, *Theories of Psychotherapy and Counselling: Concepts and Cases*, 5th Edition (Australia: Brookes/ Cole Cebgage Learning, 2012), p.8.
[19]Guzmán-Castellanos Selene et al., "Palliative Care, Impact of Cognitive Behavioral Therapy to Cancer Patients," *Procedia - Social and Behavioral Sciences* 217 (2016): p. 1063.
[20]Ibid., p. 1064.
[21]Ezamo Murry, *An Introduction to Pastoral Care and Counselling* (New Delhi: ISPCK, 2018), p. 183.
[22]Guzmán-Castellanos Selene et al., "Palliative Care, Impact of Cognitive Behavioral Therapy to Cancer Patients," p. 1064.

9. Implications for Pastoral Care and Counselling

The above presented case is a reflection of the experience of terminally ill patient such as NHL which is one of the most difficult situations that individuals and their families ever have to face.In dealing with patients afflicted with incurable diseases which will eventually lead to death, it is important for a pastoral counsellor to know about the successive stages in this progression from life to death and to understand them. Kubler Ross (1970) reports stage of denial, although usually this is a temporary response that is replaced by partial acceptance, followed by anger expressed in 'Why me?', and often the anger can be directed against caretakers, doctors or pastors. This is followed by fear and anxiety of loneliness, pain, loss of family, friends and death. Next is the stage of bargaining usually with God, to delay the end. The final stage is that of acceptance, which is not necessarily a happy stage, but the time when the patient stops fighting his/her illness and may regard death as a relief.[23] These different stages are coping mechanisms to deal with a difficult situation and throughout there is usually a hope of a miracle cure. Similar stages occur with family members, for they can also engage in denial, express anger, even at the terminally ill, and attempt to bargain, become depressed, and reluctantly accept the situation.

Thus, the terminally ill and the family members as in the case study manifests variant behaviour patterns, attitudes and needs where cognitive behavioural therapy can be applied by the pastor or counsellor. Great care is required in uncovering feelings of hostility, anger, fear, repulsion and frustration. The patient too must be encouraged to express his feelings; this will relieve tension, and make it easier for the family to accept the reality of what is going to happen.[24] Open communication within the family must be developed or supported during this stressful time.[25]The purpose of the pastor or the counsellor working with the terminally ill is, not to preach and instruct but listen to the patients with empathy and understanding, total acceptance of where the client is on his or her journey and helping them to find psychological and spiritual peace.[26]When a patient believes the pastor is listening to them in a non-judgmental way, they feel encouraged to talk openly about their fears.

Pastor and counsellors can also help clients find meaning in their lives and in the illness. The failure to find meaning in life can create a deep spiritual pain as individuals may feel their life has become empty or meaningless. Counsellors can facilitate the integration of life events and experience to create meaning by providing time for this reflection and encouraging exploration of events that have been witnessed or things the individual has done.[27]Pastors should encourage the terminally ill patients not deny reality but help to face reality to perform important tasks such as deciding how to live the balance of their lives in a meaningful way and preparing loved ones for their death. This will allow them to feel more comfortable making plans and

[23] As cited in EzamoMurry, *An Introduction to Pastoral Care and Counselling*, p. 205.
[24]Osa Maria Teran Gonzalez, "Family Therapy and Terminal Illness, in *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community*, vol. 3, no. 2, (1988): p. 30.
[25]Darlene Daneker, "Counsellors Working with the Terminally Ill,"in *American Counselling Association*VISTAS 2006, online, p. 3.https://www.counseling.org/Resources/Library/VISTAS/vistas06_online-only/Daneker.pdf (accessed on 10th January, 2025)
[26]Helen Jackson Bleicher.*The Experience of Counseling the Terminally Ill and the Best Counseling Practices* (Omaha: University of Nebraska, 2011). p. 22. https://digitalcommons.unomaha.edu/studentwork/11/ (accessed 10th January 2025)
[27]Darlene Daneker, "Counselors Working with the Terminally Ill," p. 5.

facing death without extensive fear and worry.[28] Thus, to reduce the level of anxiety and to support the family, cognitive behavioural therapy can be also beneficial with families of terminally ill patients.

At the advanced stage where curative treatments are no longer useful, considered incurable disease and patient's condition deteriorates progressivelyand approaches death, the attention of palliative care increases.[29] Therefore, pastors and counsellors have an important role concerning the provision of psychological and spiritual care of the patient and family in palliative care. It is observed that palliative care patients are usually not in the focus of pastoral care.[30] Therefore, pastors can play an important role in palliative patients, collaborate with health care professionals and training in palliative care issues so that they are well equipped to help relieve physical, psychosocial and spiritual problems of the terminally ill.

Conclusion

This study reveals that the diagnosis of a terminal illness or a potentially terminal illness creates a crisis for the individual and the family. It disrupts the family's equilibrium as they face moments of crisis, terrible trial and frightening encounters with mortality. Cognitive Behavioral Therapy is appropriate in this crisis because it attempts to change the perspective and behaviour of the ill person from pessimism to optimism and helps people find more helpful ways of thinking and acting to cope with the stress of life threatening illness. Therefore, the responsibility of a pastoral counsellor is to extend support to them through each stage and focus should be on the psychosocial and spiritual aspects of dying of the terminally ill and their family. They may normalize emotions during a difficult time, provide spiritual support, educate about normal physical, emotional, and social changes, and assist in managing practical problems. Thus, working with terminally ill individuals can be challenging and rewarding for pastors and counsellors as they help to enhance quality of life and maintain a purpose in life to those who are terminally ill and impending death.

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