Importance of Advance Care of Planning and its Measure in Palliative Care for Patients Nearing Bitter End: A Review

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Authors’ contributions

This work was carried out in collaboration among all authors. All authors read and approved the final manuscript.

ABSTRACT

Background: Palliative care aims to reduce pain and suffering in patients and their families by a thorough assessment and treatment of physical, psychological, and spiritual symptoms. As a patient's death approaches, his or her symptoms may necessitate more aggressive palliation. Support for the dying patient's family should increase as comfort measures become more intense. Palliative care after a patient's death is largely concerned with bereavement and family assistance. Palliative care near the end of life requires assisting patients and their families in understanding the nature of their illness and prognosis. Palliative care professionals can assist patients and their families in determining appropriate medical care and aligning the patient's care goals with the healthcare team's aims. Finally, palliative care at the end of life requires determining the need for a medical proxy, advance directives, and resuscitation status. Physical pain, as well as substantial emotional, spiritual, and social misery, may be present in patients throughout their final hours and

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days. As death approaches, patients in their final days require careful symptom control, and families may need support and guidance. After the death is announced, the family is notified, and grieving support is provided, the care continues.

Keywords: Aggressive; aligning; intense; medical proxy; grieving.

1. INTRODUCTION

Cancer is an abnormal growth of cells anywhere in the body. There are 200 kinds of cancer, which could be growing on any sort of tissue in the body [1]. The things which affect the tissues of a person’s body couldn’t affect the other such as, inhaling smoking tobacco can lead to lung cancer. Exposure to the epidermis along with the sun can lead to melanoma on the legs, even so, the melanoma will not lead to cancer of the lung and smoking will not lead to melanoma [2]. Aside from infection, many disorders including cancer affects many things which means there are many organs involved. In other words, there is no single cause for one type of cancer [3]. Anything that can cause normal immune cells to grow abnormally can cause normal cancer, causing substances or causative agents that follow chemical or toxic exposure, ionizing radiation, other viruses, and human genes. Cancer effects on loss of normal growth control [4]. In normal tissue, the rate of growth of new cells and the death of old cells are maintained. But in cancer, this balance is disturbed. This disruption can result from uncontrolled cell growth. Loss of cellular ability to detect apoptosis [5].

The incidence in India of cancer patients of males was 679,421 (94.1 per 100,000) and among 712,758 women (103.6 per 100,000) by 2020. One in 68 men (lung cancer), one in 29 women (breast cancer), and one in 9 Indians will develop cancer during their lifetime. The main reason that the risk of cancer increases is due to our growing health. And researchers who follow these new statistics think that about two-thirds of the increase is because we live longer. Further, they think, it is due to changes in cancer levels in different age groups [6].

1.1 Palliative Care

Various side effects are seen during treatment with cancer and chemotherapy. But once a patient has received this treatment, it is necessary to find relief from the pain. Cancer treatment and their side-effects usually occur at simultaneously [7]. It is called minimally invasive and supportive care. While starting the treatment it is very necessary to start palliative care. The patients who got minimum care and treatment for cancer usually have less symptoms, improved health, and are happier with their treatment [8].

Fig. 1. Flowchart of advance care of planning in palliative care for patients

Palliative care is an important part of integrated care and treatment to reduce, stop or treat cancer. Studies show that reduced care which improve the quality of living which will also help to feel more happier with the treatment which patient get [9]. The treatment can be start reducing when patient learn that he had cancer and will continue to take this type of rehabilitation and medical treatment. For example, cancer survivors with persistent or new symptoms or side effects after treatment have been eliminated and may receive comfort care [10].

2. TYPES OF PALLIATIVE CARE

2.1 Social

It is very difficult to interact with your near ones about what they are going through, or exactly what they are feeling. Social worker plays a key
role in this situation, for example. Organizing family reunions and getting more relevant information regarding disease conditions and various services. Sometimes patient and family caregivers get frustrated, and social worker helps them in understanding what they want and how he/she should help caregivers [11].

2.2 Sentimental

If an individual is suffering from cancer can be dealing with various sensitive thoughts, like sadness, and may have tearful behaviour, have many different emotions, such as sadness, anxiety, or anger. It can lead to more stressful life[12]. A helping group, counsellor, psychiatrist or another health care provider who can help patient to understand and deal with these feelings. To get help, talk to the health professional about what actually patient is feeling. There are more ways to deal with this situation and get over it[13].

2.3 Devotional

Suffering from cancer can lead to many religious questions. It is very difficult for an individual to accept that he/she is suffering from cancer. After surviving cancer, he/she could be looking for a bigger aim[14]. The religious leader or community members can assist them spiritually if they belong to a religious community such as a church, synagogue, or another organisation. Whether or not he is a believer, the hospital pastor can offer spiritual support[15].

2.4 Mental

The way that brain operates can be affected by cancer symptoms, therapy, and medication. If patient didn’t get enough sleep, for example, they may feel agitated and have trouble thinking effectively. And might also be concerned about how well your treatment is working [16].

Exercise, counselling, meditation, and possibly drugs are among the mental health options available to aid with anxiety, depression, and sleep issues. A therapist, support group leader, or psychologist may recommend that you engage in stress-relieving activities such as yoga, art, joining a cancer survivor group, or volunteering for a cause that you find meaningful [17].

2.5 Economical

Cancer therapy can be quite expensive. For both the patient and the relative, this can be a source of worry and concern[18]. These issues can be addressed with the help of a social worker or a financial counsellor. They can, for example:

- Discuss health care team related to cost of care.
- To get more information related to insurance and its billing.
- It helps you to apply for medical leave or medical payment.
- Finding some schemes to give low cost or free of cost treatment.

2.6 Physical

Cancer's side effects and therapy are influenced by a variety of factors. These factors include cancer kind, stage, treatment, and overall health[19]. The following are examples of possible side effects:

- Pain
- Exhaustion (severe fatigue)
- Nausea, vomiting, and weight loss
- Respiratory issues, such as shortness of breath
- Sleep issues

Anti-nausea drugs, physical therapy, and nutritional support are examples of palliative care for side effects. For help with negative physical consequences, visit a dermatologist, a sleep specialist, a pain specialist, or another professional[20].

2.7 Palliative Care after Cancer Treatment

2.7.1 For children

Parents may be concerned about the treatment's adverse effects as their child prepares to begin cancer treatment. Children, on the other hand, have access to minimal care. Regardless of age or stage of sickness, it is a crucial aspect of the child's treatment approach[21].

Before baby begins cancer treatment, speak with a health care team. In case of diminished care, inquire about side effects and treatment alternatives. Notify child's health-care provider if any new or changing adverse effects occur so that they can be treated as soon as possible[22].

2.7.2 For caregivers and children

Palliative treatment isn't just for cancer patients. It can also involve caregivers’ and cancer patients’ children's support. A person with cancer frequently receives essential physical, practical,
and emotional support from family and friends. Stress, worry, despair, and frustration can affect caregivers as well. Palliative care can assist caregivers in balancing timely care while also improving their own quality of life[23].

If a cancer-stricken parent, they might need some extra help from their kids. This could include everything from after-school care to dinner preparation assistance. Taking care of a health will enable you to provide better care to others. Reduced care for caregivers and other family members may be possible with the support of a healthcare team or social worker[24].

2.7.3 For older adults

Palliative care is especially crucial for people over the age of 65. Chemotherapy, in particular, can cause negative effects in older persons. Furthermore, body may not recover from surgery as rapidly as it has in the past[25].

2.8 Principles and Issues in Palliative Care

2.8.1 Lack of evidenced-based interventions

Oncology is a field that is always changing. Despite this, cancer claims the lives of approximately 562,000 Americans each year. Despite advancements in cancer therapy, there is still a need for better comfort care[26].

Palliative care has a tainted reputation. Various groups have been pressed by the ongoing care that this designation will bring as a result of so many efforts concentrated on this area. From country to country and culture to culture, there are disparities in how these notions are used. The word "supportive care" is sometimes used in conjunction with the term "treatment-related correlative," which refers to the actions made to help the patient while they are undergoing treatment. Factor control, blood transfusions, and anti-emetics are some of the therapies that may be used. Supportive care has recently taken over some of the psychological and spiritual aspects of care. When a patient passes away, it is frequently referred to as a last resort[27].

When research-based evidence, clinical knowledge, patient preferences, and values are all combined, quality palliative care is attained. This combination is what defines evidence-based practise. Efforts to improve evidence-based practise in palliative care have been continuing, but barriers have arisen due to the unique nature of this patient population, as well as the ethical and moral issues that arise when using traditional randomised trials[28].

2.8.2 Moral and legal problems in illness care

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2.8.3 Challenges for the future of palliative care

The four norms of conduct that govern clinical practise – independence, gender equality, profitability, and justice – should also apply to decreased care. Nurses have the ability to inspire patients. It is our responsibility to ensure that patients receive all of the information they require to balance the benefits and drawbacks of various treatment options. It also entails making a concerted effort to give patients as much influence over their care as feasible. Unfortunately, there are situations when excellent professional judgement, ethics, and the law come into conflict. To provide complete care, health care workers must be aware of what is true and what is a myth. When a community has a significant need, many organizations will step forward to try to meet that need. Reduced care is the same way. Many local and national activities have sought to solve these concerns after the release of the support and identifying information on the absence of care in the area[30].

2.9 Consistency in Practice

It's a difficult undertaking to figure out how to provide consistency in service delivery. It is put to the test on a regular basis through policy, internationally recognised operating standards, and the establishment of compliance panels. A
2.9.1 Research issues in palliative care

The data was found to be weaker in the palliative care area than in the multi factorial aetiology area. It is frequently stated as a barrier to care research, as it alleviates the concern that end-of-life patients are at increased danger and that putting themselves in a situation where they can be used is unethical. Anxiety about danger is linked to a lack of commitment and decision-making. Patients in a relaxed condition, on the other hand, are not immune to this danger, and researchers must employ ways to establish whether a patient is capable of making an informed decision about whether or not to participate in research[32].

2.9.2 Outcome measurement

When it comes to decreased care, it's critical to re-evaluate the standard paradigm of outcome measurement. This adds to the necessity of progressing this science. While the predicted outcome is not the cure for the sickness, the combined diseases that appear to be linked are the proper targets to aim for. According to recent data, hospice has been the fastest expanding Medicare benefit in the last 25 years (although less than 3 percent of all Medicare costs). It has been proven that registering for Medicare Hospice coverage reduces Medicare spending in the final year of life. Reports on the financial effects of comfort care are scarce[33].

2.9.3 Care during the final days of life

Many people who have been diagnosed with cancer will die as a result of their illness. Oncology nurses are uniquely qualified to care for patients in their final days due to their extensive training in symptom management. Furthermore, oncology nurses are aware of the psychological and spiritual problems that these patients and their families have and are able to address them. Oncology nurses frequently form long-term relationships with patients and their families, allowing them to provide continued care at a difficult period. Although the majority of dying patients have few symptoms and many of them are manageable, significant issues can arise that might cause the death process to become confused [34].

Oncology nurses with advanced training can help these patients die peacefully; boosting the patient's understanding as well as the knowledge of all loved ones present during the treatment. Finally, many people have limited comprehension of the death process because death is no longer practised at home or in institutions [35].

2.9.4 Signs for final days of life

Some symptoms are frequent in the final days of life, but their prevalence and other symptoms have yet to be fully researched. Pain was reported by more than 40% of patients with colon and lung cancer in their final three days of life, and delirium was reported by more than 25% of them. Overall prevalence of these symptoms has been confirmed in studies of patients in various stages of dying who were referred to comfort care facilities, most of whom were malignant. Pain, anorexia, constipation, weakness, nausea, dyspnoea, cough, and delirium are all prevalent symptoms, according to these and other research[36].

2.10 Management for Certain Sign and Symptoms

2.10.1 Pain sensation

Pain is common as cancer progresses, but it becomes more common as the disease progresses. The diagnosis and treatment of pain are thoroughly covered, and the solutions recommended are crucial for people in their final days. Testing for mental impairment, drug delivery when the oral route is no longer available, and family and specialist worries that opioids hasten death are all part of end-of-life pain treatment [37].

2.10.2 Assessment of painful sensation

Pain is common as cancer progresses, but it becomes more common as the disease progresses. The diagnosis and treatment of pain are thoroughly covered, and the solutions recommended are crucial for people in their final days[38].

2.10.3 General changes as death nears

Patients will experience weakness, weariness, and anorexia in addition to the symptoms listed above. It's also possible to have nausea and vomiting. Urine or faeces may be used by patients. Until total care is provided, a lot of assistance with everyday routines and...
cleanliness will be required. When family members witness the death of a loved one, they require additional support because nutrition has such a strong feeling of nourishing in our culture. Patients’ families may try to push them to eat or drink, resulting in cravings or mistreatment[39].

2.10.4 After-death care

Physical rehabilitation has been included in post-mortem care so that loved ones can view the patient as naturally as possible. Cleaning and rehabilitating the patient, as well as removing tubes and equipment, assists family members in creating a positive remembrance of their loved one, enabling a healthy grief process. Cultural customs must be taken into account. Autopsies, for example, may be objected to by Jewish and Muslim families who believe that the body belongs to God or Allah and should be preserved even after death. A male sufferer can only be cared for by another man in Islam, while the body should not be removed for a few hours in Buddhism to enable air to flow freely[40].

2.10.5 Health education to family and patient

The patient and his or her family are at the centre of care, particularly in the final days of life. Patients may be aware that they are dying, and consistent communication between the patient, his or her family, and the healthcare professional is required. Open communication and education help patients and families make informed decisions about end-of-life care. Patients and their families may be afraid of dying. Many people in our community have never witnessed death and, as a result, require clear instructions on how to cope with the physical and mental changes that occur at this time. Examine the family’s comprehension of their loved one’s circumstance, as well as their willingness to talk about it[41].

3. DISCUSSION

End-of-life care is in higher demand than it has ever been, and family physicians are particularly qualified to deliver it. We can interact with our patients in ways that many other physicians can’t because of the durability of our physician-patient relationships and the whole-person attitude that was key in our training. One of the most difficult aspects of end-of-life care is predicting life expectancy[42]. According to one study, we overestimate life expectancy 63% of the time. Because of our strong ties with our patients, primary care physicians may have a particularly difficult time predicting life expectancy. Fortunately, tools and norms are emerging to assist us in doing so in a more impartial manner. Delivering terrible news to our patients and their families is one of the most difficult tasks we, it’s frequently far easier to keep trying for an improbable treatment than to have the painful conversation about letting someone die naturally[43]. The intelligent physician, on the other hand, recognises when it’s time to shift from cure to palliation, and when this happens, patient and family satisfaction rises. The greatest time to discuss advance directives with patients is before they reach the end of their lives, or even during routine physical examinations. This informs the patient that advanced planning is socially and medically appropriate, and encourages them to consider and execute an advance directive[44]. End-of-life care entails reaching out to patients when they are at their most vulnerable. When a patient realises his or her death is approaching, it is a period of immense personal growth. One of the most satisfying aspects of practising medicine is assisting patients on their journey. It necessitates acclimating to our own mortality and breaking down boundaries between ourselves and our patients. Physicians who provide end-of-life care are aware that it is acceptable to develop emotional attachments to their patients and to experience the range of human emotions that they do[45].

4. CONCLUSION

Palliative care is critical for patients with acute diseases and their families to provide the finest treatment possible in order to improve quality of life and provide quality end-of-life care, which is much more than just comfort in dying. It is preferable to live a better life with more quality than to live a lengthy life with less. Consider protecting the privacy and confidentiality of patients, as well as communicating with them honestly and compassionately, treating them with kindness, dignity, and respect for their beliefs and cultures, in order to create and sustain helpful relationships. I discovered that palliative care was developed for the purpose of improving quality of life, which I previously believed was a paternal responsibility. Regardless of other symptoms, such as physical, psychological, social, or spiritual, symptom management is an important aspect of palliative care. Patients and their families play a key role in symptom management, which focuses on teamwork and
communication with patients and their families in order to give a high quality of life. In order to offer care for patients and their families in palliative care, the nurse’s responsibility should be to exhibit love, sympathy, and patience.

COMPETING INTERESTS
Authors have declared that no competing interests exist.

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