



Vijaya Udumala JMJ

Abstract

Providing adequate supportive services for the families of palliative care patients is a core principle of palliative care. Caring for a patient with terminal illness at home involves a considerable commitment on the part of family caregivers, and attention must be given to the caregiver's needs as well as those of the patient. Enhanced supportive care strategies can ameliorate the challenges facing families of palliative care patients cared for at home. All health professionals need to improve the standard of family-centred palliative care, and more evidence-based approaches are required. There is a growing trend for people with a terminal illness to remain at home, where practicable. Despite the input offered by professional palliative care services, care within the home usually relies primarily on a family member or friend. Indeed, without the support of caregivers, home palliative care would be impossible for many people. This article outlines current issues related to home-based palliative care for enhancing the quality of this care.

Keywords: Palliative care, Care giver, Quality of life, Family coping.

Introduction

The term "Palliative Care" is used to describe the care and support that is provided to people who have a life threatening illness. The World Health Organisation states;

"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and families" (WHO).

Palliative care means that the client's comfort and dignity become the priority and adequate support is provided to them and others in the family. It has been said that palliative care is about "adding life to years, not years to life".

Palliative care is expected to be holistic and multidisciplinary; it is provided to both the patient and their family. Effective communication between the patient, the family and health care providers is integral to optimal palliative care. One method of facilitating communication is a family meeting, also referred to as a family conference. Family meetings between the patient, their family and health care

professionals are undertaken for multiple purposes including the sharing of information and concerns, clarifying the goals of care, discussing diagnosis, treatment, and prognosis and developing a plan of care for the patient and family carers

Family palliative care is a philosophy of comfort driven care and support delivered by Family members for those with a life-limiting illness.

The focus on a patient's quality of life has increased greatly during the past twenty years. In the United States today, 55% of hospitals with more than 100 beds offer a palliative-care program, and nearly one-fifth of community hospitals have palliative-care programs. A relatively recent development is the concept of a dedicated health care team that is entirely geared toward palliative treatment: a palliative-care team.

How do families cope?

When the question of palliative care is raised, we may feel confused, overwhelmed and frightened. We may experience many reactions - for example: shock, disbelief, a sense of unreality, numbness, sadness, fear, anxiety, anger, guilt, emptiness, hopelessness, helplessness, and other intense feelings. It is important for us to know that these feelings and thoughts are all experienced by many other families and are not unexpected at such a difficult time. They are natural expressions of the feelings family experiences when

Author Affiliation: Professor, St. Joseph's College of Nursing, Nallapadu – 522 005, Guntur, AP.

Correspondance: Sr. Dr. Vijaya Udumala JMJ, Professor, St. Joseph's College of Nursing, Nallapadu – 522 005, Guntur, AP.

they cannot protect their dear one from a life-threatening illness.

Many families experience great turmoil as a result of what are major changes. Sometimes families find that their experience of the good days can be affected by the knowledge of their dear one's illness. It can be hard to balance the needs of the patients, and family members. Some patients find it helpful to live one day at a time, to maintain some routine, and also be flexible when making plans.

The Need for Family Centred Palliative Care

Palliative care is especially suited to patients with incurable, progressive illnesses and often is centred on the needs of patients and their families at the end of life. Historically, palliative care has been provided most often to cancer patients with in ones family by his family members. Fitzsimons et al (2007) claim that chronic illness is the "modern epidemic" and the major cause of death and disability in the developed world today. Yet despite the establishment of hospices and home care, fifty-three-per cent of patients die in the family. This common scenario world over emphasises the need for quality Family Palliative care approach.

Compassionate care given through Family centred palliative care offers patients the most advanced quality of life care available today. Family-centric care helps to ease the pain, symptoms and stress of chronic or life-limiting illness or injury. Thus, the mission of Family Centred Care is to provide compassionate, quality comfort care that enhances the lives of people with life-limiting illness and their families.

Family Palliative Care provides empathetic care, a complete continuum of care - unlike any other hospice. Family centred approach has the following benefits:

- Family is committed to quality patient care, continuous caregiver's support and education.
- Family is able to provide hospice care in homes, through skilled nursing and assisted living facilities.
- Family can be empowered to offer innovative programs such as massage and pet therapy, expressive art and music and the quality of life program.
- There is possibility of collaboration of family members with the palliative care physicians/nurses/

other care givers with in the area of residence when necessary.

Home based Palliative care

Many families wish to care for their patients at home because they feel secure there and are better able to control their daily routine. It also increases the opportunity for the siblings, friends and family of the patients to assist with their care. Families may find the support of a palliative care service helpful when they are at home. Palliative care providers have a range of services on offer for families including nursing, counselling, bereavement support, and in some cases complementary therapies such as music therapy and massage.

Role of the Family in Palliative care

Palliative care should be available wherever patients are – at home, in hospitals, in hospices, etc. In developing countries, most patients die at home, and the family plays an important role in palliative care. If the patient agrees, and if appropriate, the patient's family should be involved and empowered in joint decision-making, should be constantly kept informed of medical decisions, including changes in carers and treatment, and should be trained in best practices of palliative care. The patient's family and other carers can be taught to give home-based care.

Role of Friends and significant others

Most patients feel that the greatest help they receive is the care and support given to them by their friends and others important to them. One of the best things patients can do at this difficult time is their willingness to accept the help and support offered by those closest to them. Friends should be invited to support patients in any way they can, even if they don't know what to say or do. Patients may need their practical help such as in preparing meals, feeding them or taking care of their children.

Role of Health care Team

The health care professionals who may be involved in patients' care include doctors, nurses, social workers, occupational and physiotherapists, educational officers and chaplains. To ensure that patients are not overwhelmed with offers of assistance

it is important that a member of the team take on the role of coordinator. Some families find it helpful to keep a note of all the people involved and their contact numbers, as well as questions they may wish to ask. Family meetings can also be organised for all the staff involved in patient care as well as key family members. These meetings can be an information session to prepare the family for things that might happen during the palliative phase of their patient's illness. Alternatively, families are encouraged to make times with individual staff members as needed.

Meetings with Family members

Family meetings are commonly recommended as a useful way for health care professionals to convey information, discuss goals of care and plan care strategies with patients and family carers. Research has demonstrated that family meetings are one potential method of interaction that may facilitate optimal care planning and support and seem to be commonly used in palliative care. Family meetings provide an ideal avenue to inform, deliberate, clarify and set goals for future care, based on discussions between health professionals and the patient and family.

Guiding principles for conducting family meetings

- Family meetings can be a useful way to assist patients and family members to clarify goals of care, consider site of care options, and to share information. Ideally they provide a safe environment where issues and questions can be raised and appropriate strategies agreed upon.

- Strategies to support family carers are a core component of palliative care; hence service providers have a responsibility to *offer* family meetings based on need.

- Service providers should view family meetings as mutually beneficial. They are not only potentially valuable for patients and family carers; they may also provide a resource effective way to explain what the service can and cannot offer.

- Family meetings should not be saved for 'crisis' situations. Instead, a preventative approach is advocated where issues are anticipated before they become major dilemmas. Hence a proactive rather than reactive approach to care is fostered.

- Ideally, family meetings are *offered* routinely on admission, and conducted at a pertinent time thereafter.

- Facilitators of family meetings require appropriate skills in group work, therapeutic communication and palliative care. Hence the multidisciplinary team should determine who conducts the family meeting and presumably this may change depending upon skills, knowledge of the family and resources.

- Suitable resources should be available to patients and family members who attend the meeting in order to complement the verbal information (e.g brochures about services available, carer guidebooks, treatment and drug information, etc).

Caregiver Training to Family members
Participation in "Caregiver Training" for Family members offers instruction for caregivers:

- To become familiar with physical care and safety of the caregiver and patient

- To review of medications

- To train themselves on medical equipment, including care of patient's bed, oxygen tank, nebulizer, wheelchair, stairs, feeding pumps etc.,

- To develop basic patient skills such as positioning, bathing and feeding.

- To be able to interact on caregiver concerns with doctors, nursing staff, physical therapist and social worker and other experts

- To attain greater personal confidence and skill level in caring for a loved one.

A 2000 report for the U.S. Department of Health and Human Services finds that residents enrolled in Family Palliative care are

- Less likely to be hospitalized in the final 30 days of life;

- More likely to be assessed for pain;

- Twice as likely to receive daily treatment for pain;

- More likely to receive pain management in accordance with clinical guidelines;

- Less likely to have physical restraints, receive parenteral/intravenous feeding, receive medications by means of injection or have feeding tubes in place.

- Benefit more from complementary services, like expressive music; provide meaningful interaction and stimulation than those in long-term care settings.
- Support for family carers is a core function of palliative care.

Conclusion

A dedicated team of family members provide comprehensive care that enhances the patient's quality of life by providing skilled nursing care, symptom management, education, support and help with personal care, such as bathing, feeding and dressing. Home based palliative care gives patients and caregivers the opportunity to choose what is best, without disrupting continuity of care.

The Palliative Home Care Program helps patients carry on with daily life in spite of their illness and improves their ability to tolerate medical treatments. Overall, Family palliative care approach helps patients make the most of life and offers patients the best possible quality of life during their illness.

References

1. D. Fitzsimons et. al. The Challenge of Patients' Unmet Palliative Care Needs in the Final Stages of Chronic Illness. *Palliative Medicine* 2007; 21: 314.
2. Fineberg IC. Preparing professionals for family conferences in palliative care: valuation results of an interdisciplinary approach. *Journal of Palliative Medicine* 2005; 8(4): 857-866.
3. Hansen P, Cornish P, Kayser K. Family conferences as forums for decision making in hospital settings. *Social Work in Health Care* 1998; 27(3):57-74.
4. Hudson PL, Aranda S, Hayman-White K. A psycho-educational intervention for family caregivers of patients receiving palliative care. *Journal of Pain & Symptom Management* 2005; 30(4): 329-341.