Palliative care; role of family physicians

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Abstract

Palliative care is the holistic approach to provide relief to patients suffering from life threatening diseases and their families throughout the disease. This is mainly through the prevention and relief of suffering by means of early identification, comprehensive assessment and management of physical, psychosocial and spiritual problems. With the rise of elderly population in the world patients needing palliative care will also increase. Family physicians who are closest to the community and easily accessible has a major role to play in providing palliative care. Their broad knowledge, long standing relationship with patients and their families, ability to carry out home visits and coordinate with other health care resources place them in an ideal position to address complex issues faced by patients. Keeping up to date with knowledge, acquiring counseling skills, non availability of guide lines and medications, lack of support from team and time constraints are the challenges faced by family physicians in providing palliative care. With the aging population, demand on palliative care resources will increase markedly in the next few decades. Developing palliative care models, improving the skills and opportunities for doctors to learn sound palliative care principles have to be initiated without a delay in order to meet the challenges of the future.

Keywords: General practitioners, primary care, palliative care

Introduction

Palliative care is holistic approach to provide relief to patients who are suffering from life-threatening illnesses and their families. In most clinical situations, the principal aim is to cure the disease and relieve symptoms, but in palliative care, main aim is to improve the quality of life of patients as well as their families who are facing complex issues associated with the disease. This is mainly through the prevention and relief of suffering by means of early identification, comprehensive assessment, and treatment of pain and other problems such as physical, psychosocial, and spiritual.[1]

Palliative care also affirms life and regards dying as a normal process. Since it is a natural process, it is wise neither to hasten nor to postpone death. Therefore, treatment should integrate the psychological and spiritual aspects of patient care. Palliative care calls for a support system to help patients live the rest of the life as actively as possible and for the family members who need to develop coping skills and go through their own bereavement. To achieve these goals, a multidisciplinary approach is essential.[1]

Palliative care is not a terminal event. It ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues throughout the disease process until death and into the family’s bereavement period [Figure 1].[2]

Palliative Care’s Place in the Course of Illness

Patients with advanced cancer and HIV/AIDS are the most common recipients of palliative care. In addition, patients with cirrhosis and liver failure, cerebrovascular accidents, Parkinson’s disease, etc., also benefit from it.[2,3] Patients who need palliative care can be of any age.

There are a large number of programs which provide this palliative care in a variety of settings such as hospitals, outpatient settings, community programs within home health organizations, and hospices. Within these settings, there are teams of physicians, primary care doctors, nurses,
Role of Family Physicians

Family physicians/general practitioners (GPs) play a key role in providing palliative care as they are the closest to community and easiest to access. In addition, home visits are also possible to GPs when compared to other doctors who are engaged with ward work. GPs can build up a close rapport with patient and family since most of the patients know their family doctors for years and they are aware of the background of these patients and know the resources available for them. Therefore, family physicians are in a position to provide maximum support and care with the available resources. These patients can be continuously followed up by GPs, and they can communicate and coordinate with other medical professionals as well as caregivers regarding the patient’s current situation and attend to their problems. Furthermore, relevant referrals to specialists and other resources can be arranged. In that case, GPs can provide extended care to needed ones by coordinating with other resources such as nurses, physiotherapists, occupational therapists, and social workers.

In terminal stages, 74% of the patients and family members are reluctant to admit patients to hospitals. They want to spend the rest of their life comfortably with their loved ones. Therefore, they tend to approach the family doctor for relief of pain and other symptoms and difficulties. It has been revealed that 90% of care of patients in their last 12 months takes place at home with the support of the GPs and community nurse teams.

There are four main components of palliative care which may be carried out in the hospital or in the patient’s home. They are physical care and medical treatment, psychological care, social care, and spiritual care.

The most important part of physical care in a patient with terminal illness is to keep him as comfortable as possible until death. Therefore, relief of pain and symptomatic management of other problems are extremely important. A GP may have to manage whole lot of symptoms such as weakness, fatigue, drowsiness, loss of appetite, nausea and vomiting, mouth problems, dysphagia, hiccups, ascites, constipation and diarrhea, bed sores, cough and breathlessness, bleeding, edema, and some psychological conditions such as anxiety and depression as well. Diet is another aspect of physical care. The primary care doctor should advise the caregivers to give adequate food and liquid to the patient in a form that can be easily swallowed and digested by the patient.

Psychological care is the management of the psychological needs of the dying patient and the close relatives. Psychological distress is common among people needing palliative care and is an understandable response to a traumatic and threatening experience. Patients draw on their own inner resources to help them to cope, and many derive emotional support from family and friends. Some patients, however, are likely to benefit from additional professional intervention. To provide psychological care to the dying patient, the doctor should know the patient’s personality and the way that patient views death. Primary care doctors are ideal for this because of their long-term relationship with patients and family members. In fact, some families consider their family doctor as a family friend. Therefore, a family doctor is in a unique position to provide comprehensive care to the patient while keeping a good doctor-patient relationship. The GPs should make sure that the psychological status of the patients and carers are assessed at key points of the disease and given appropriate psychological support. This can be done by being patient’s bedside, communicating effectively while showing concerns, touching the patient when appropriate, active listening to patient’s fears, frustrations, hopes, and needs. Primary care doctors can reassure the patient and make them comfortable. Patients should be given hope when it is possible so that they may live the remaining part of their life in good psychological health.

The social impact of cancer is considerable and can reach beyond the patient and immediate family. Patients may need support with personal care, advice on employment issues and assistance in securing financial benefits. GP, being an active member of the community, will be able to help the patient with these needs or direct to relevant services. All such support may be provided informally or formally, in either a planned or reactive manner.

The diagnosis of life-threatening disease can lead patient to re-examine their beliefs, whether philosophical, religious or spiritual in nature. The needs of patients for spiritual support are, however, frequently unrecognized by health and social care professionals, who may feel uncomfortable discussing spiritual issues. GPs are aware of local community resources for spiritual care. Moreover, they themselves may be able to provide spiritual support to the patient due to the close relationship with the patient.

The primary care doctor should also provide emotional support to the family members by offering counseling and supportive psychotherapy. They need help to face the reality of impending death of their loved ones.

The Current State of Palliative Care

The requirement of palliative care resources and hospice programs will continue to increase markedly in the next few decades as a result of the growth of the aging population living with chronic, debilitating, and life-threatening illness and because of increasing clinician interest in effective approaches to the care of such patients.
Geriatric population of Sri Lanka in 1981 was 6.6% which increased to 12.4% by 2012. Geriatric population is expected to double (24.8%) by 2041. With the increase of geriatric population, there is an increasing tendency to die in their usual place of residence, which may be a private residence or an aged care facility. Thus, the role of GP in palliative care is becoming more significant.

**Challenges Faced by Family Physicians**

Keeping up to date knowledge with latest management techniques regarding physical and psychosocial symptom control and acquiring counseling skills are important for GPs when managing patients who are suffering from a terminal illness. Some GPs feel uncomfortable when confronted with dying patients because of their perceived inability to keep up to date knowledge about the latest management techniques. However, patients appreciated the care which their GP give, particularly when he or she takes the time to explain what is happening. GPs knowledge of physical symptom control has been shown to be adequate, but they are aware that they need specific psychosocial and counseling skills to work in palliative care.

Nonavailability of proper guidelines is another problem encountered by GPs. Therefore, providing palliative care is a challenge for newly practicing GPs because of lack of recommended guidelines as well as the lack of previous experience.

Time is a fundamental component of palliative care. Most GPs indicate that time is a barrier to increased involvement in the palliative care of their patients. GPs will not be able to provide appropriate care because they have to address all the physical and psychological complaints of the patients and the caregivers during a single visit.

Nonavailability of medications and equipment are also problems faced by GPs. Lack of support from a team and specialists is a pitiful situation for family doctors because they have to manage the patient single-handedly, which ideally should be managed by a multidisciplinary team.

With the aging population, demand on palliative care resources will increase markedly in the next few decades. Coupled with this, changes in the demographics and work patterns of the general practice workforce will lead to difficulties in achieving the goal of home palliative care for people with a terminal illness unless structural initiatives are put in place.

**Models of Palliative Care**

There are several models of palliative care. However, there is no model that fits every organization or institution. Thus, palliative care delivery must be individually integrated into specific care settings. Some of them are:

In Western Australia, the Silver Chain Hospice Care Service provides, for the city of Perth, a multidisciplinary care team comprising doctors, nurses, allied health professionals, volunteers and spiritual and counseling support. Local GPs who have had additional training in palliative care are usually recruited. This model contrasts with other programs that prefer to use doctors attached to palliative care teams from hospitals, or hospices who liaise with the patient’s own GP.

In Queensland, the Ipswich Palliative Care Network model incorporates a public inpatient unit, a general practice-run hospice, and domiciliary nursing services. GPs are expected to provide palliative care, and educate the community to ensure patient care.

The Canadian Hospice Palliative Care Association model this is a model based on national principles and norms of practice. It was developed to guide the process of providing care to patients and families through both the illness and bereavement experiences and the development and function of hospice palliative care organizations.

Gold standard framework which aims to improve the quality of palliative care provided by the primary care team by developing practice-based organization of care of dying patients. It mainly focuses on optimizing continuity of care, teamwork, advanced planning (out of hours), symptom control, patient, carer, and staff support.

The TLC (T – timely and team oriented, L – longitudinal, C – collaborative and comprehensive) model of care in the elderly - in this model, palliative care is defined as care aimed at improving the quality of life of persons nearing (but not necessarily at) the end of life and facilitating the transitions before death.

The TLC model provides a promising potential framework for designing interventions to address current palliative care shortfalls and improve both the quality of remaining life and process of dying for older persons and their loved ones.

**Conclusion**

Attending to palliative care needs of the community is a responsibility of primary care doctors. They are in a unique position to provide comprehensive care to the patient. To make it possible for terminally ill patients to remain at home for most or all of their remaining life, they should have access to a GP.
who is knowledgeable and skilled in palliative care. He should be prepared to make home visits and provide after-hours’ cover, has access to a palliative care team and has access to an inpatient facility to manage acute changes in the patient’s condition. Developing palliative care models, improving the skills and opportunities of all doctors to learn sound palliative care principles have to be initiated now if the profession is to be as prepared as possible to meet the challenges of an aging society.

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References
1. WHO | WHO Definition of Palliative Care; 2015. Available from: http://www.who.int/cancer/palliative/definition/en/. [Last cited on 2015 Jul 29].
2. Arnold R. Clinical practice guidelines for quality palliative care. Brooklyn, NY: National Consensus Project for Quality Palliative Care; 2004.
3. De Silva N. Lecturer Notes in Family Medicine. Colombo: Vishwa Lekha; 2006.
4. Tylor K, Jackson K, McBride T, Ahmed S. End of Life Care. Edinburgh: The Stationery Office; 2008.
5. Department of Census and Statistics. Census of Population and Housing 2012. Battaramulla: Department of Census and Statistics; 2012.
6. Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. Palliat Med 2002;16:457-64.
7. Hanratty B. Palliative care provided by GPs: The carer's viewpoint. Br J Gen Pract 2000;50:653-4.
8. Reymond E, Mitchell G, McGrath B, Welch D. Research into the Educational, Training and Support Needs of General Practitioners in Palliative Care. Report to the Department of Health and Ageing. Brisbane: Mt Olivet Health Services; 2003. Available from: http://www.mtolivet.org.au/Research/Research%20Projects/Research_projects.htm. [Last accessed on 2014 Aug 08].
9. Boakes J, Gardner D, Yuen K, Doyle S. General practitioner training in palliative care: An experiential approach. J Palliat Care 2000;16:11-9.
10. Mitchell G, Price J. Developing palliative care services in regional areas. The Ipswich Palliative Care Network model. Aust Fam Physician 2001;30:59-62.
11. Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M. A Model to Guide Hospice Palliative Care. Ontario: Canadian Hospice Palliative Care Association (CHPCA); 2004.