

DOMICILIARY, PALLIATIVE, AND TERMINAL CARE

Yoram Singer

Palliative Care Unit, Division of Health in the Community, Faculty for the Health Sciences, Ben Gurion University of the Negev, Beer Sheva, Israel

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Summary

Palliative care is that branch of medicine concerned with the alleviation of suffering of patients afflicted with an incurable illness. This includes the control of physical, emotional, and spiritual suffering using pharmacological and non-pharmacological means. Most people much prefer to spend as much time as possible in the familiar surroundings of their home. When done properly, by means of an interdisciplinary medical team, the care of patients at home is an excellent alternative both for the patients and their families. It is also a cost effective alternative to institutionalized care.

The means available for good symptom control are easily available, simple, and cheap to use, needing very few sophisticated technology. Opioids are an extremely effective means for good pain control, having an extremely high safety profile. Other common symptoms such as vomiting and constipation can also be simply and effectively managed.

1. Introduction

Until the beginning of the twentieth century, most people when they became ill were treated at home and home death was the most common occurrence. With the development of modern medicine, including innovative diagnostic and treatment modalities, more people are turning to hospitals and other health-care facilities to get treatment in an effort to forestall disease progression and death. There is a belief that the science of medicine has the power and know-how to cure all diseases and to prolong life without exception. With time, both diagnostic and treatment modalities are becoming progressively sophisticated, requiring more complicated and expensive equipment. Thus many treatments can now be offered only in a hospital. The resources required for this sort of treatment are enormous. There is now a debate as to whom and for what such treatment is warranted. In parallel, with an increase in the standard of living, families are becoming smaller, the number of children per family decreasing. Also, with the huge increase in accessibility of transportation and availability of effective communication modalities, these small families are dispersing more and more. Thus resources essential for good home care and support are increasingly less available. Studies have shown that for successful home palliative care of terminally ill patients there must be one main caregiver available 24 hours a day, preferably a close family member at the patient's side. There ought to be at least one more support provider. Obviously this has profound consequences in terms of resources needed by the family, especially in the case of a young family with dependent young children.

The goal of this section is to throw some light on the possibility of effectively treating terminally ill patients at home. Basic concepts and treatment modalities of palliative care will be dealt with. There will be an emphasis on home care. This is by no means a comprehensive outline of palliative care. It is intended to give readers some basic idea of what can be done. More in-depth information is easily available in the suggested reading indicated in the bibliography.

2. Palliative Care . . . When to Begin?

Although palliative care, including all forms of symptom control, is usually not the ultimate goal on diagnosis of a life-threatening condition, it should be considered part of the global treatment plan in all cases. In most cases, at the time of diagnosis patients are already suffering from a variety of complaints including pain. On discovery of the nature of the illness, there are invariably symptoms such as anxiety depression and anger. All of these can be effectively addressed and alleviated. If effective symptom control is administered concurrently with the other medical treatment, ultimately well-being will be improved. This in itself is a desirable goal. It has also been shown that with an improvement in well-being, there is a diminution in the use of medical facilities. Recent evidence indicates that well-being and, with this, hope both have a positive

effect on survival in cases of life-threatening illness. Thus more clinical trials in oncology are measuring success not only in terms of chemical markers in the blood or tumor size, through various imaging techniques; but also in terms of well-being and quality of life. Thus all hospitals and all ambulatory or community-based health-care providers should have ready access to palliative care facilities or at least a consultation service.

2.1. Case I

Mr. R. is an 80-year-old former railway worker. Nine months ago he was diagnosed with lung cancer. At the time of diagnosis it was decided, after consultations, that no treatment to modify the course of his disease was worthwhile. He is married and the father of five children and 15 grandchildren, most of who live in the same town. His wife, who is two years younger than him, has severe congestive heart failure and is barely able to take care of herself. Until two weeks ago the couple were able to lead a fairly independent life. Home help would come for two hours a day to clean the apartment and help the wife take her daily bath. The husband did the shopping and the wife was able to do the cooking. During the past two weeks the husband's condition has been steadily deteriorating. He can now hardly muster the energy to get out of bed to go to the toilet. He has increasing pain and increased difficulty in breathing. One night at 2.00 a.m. the wife calls one of the children because her husband has woken up with extreme shortness of breath and has lost control of his bowels. An emergency doctor who is called does not know what can be done and suggests hospitalization. The patient begs to be left at home, saying that he wants to die at home in his own bed.

What are the available options (see *Section 2.5. Discussion of Case I*)?

2.2. General Prerequisites

In general, the delivery of good palliative care requires amazingly few resources and those resources are usually simple: few medical interventions, few sophisticated medical technologies, and a very limited variety of medications. However, for the successful delivery of good care highly trained and motivated personnel are necessary, at least as a support system.

During the terminal phase of disease, it is essential if the treatment is to be successful that medical personnel and patients together with their families be able to understand and to accept the inevitability of death. It must be understood that nothing more that will prolong life has any use or sense to it. All too often, even when it is clear that there will be no benefit to oncological therapy in terms of deferring death or even in improving quality of life, active treatment is offered. This is not only very expensive but it is also unethical, causing false hopes. This form of therapy should thus be discouraged, especially during the advanced stages of disease. It must, however, be also added that certain forms of chemotherapy and radiotherapy do have a beneficial effect in symptom control. In these cases it is wise to consider this option.

2.3. Palliative Care at Home

Although the basic principles of good palliative care apply whether patients are treated at home or in any institution, there are specific prerequisites that should be applied if home-care is to be successful.

The fact is that studies in different parts of the world show that, when asked, most people (around 80%) state that if the appropriate support was available they would like to die at home. However, in the Western world only between 15% and 30% do finally end up dying at home. There are many reasons for this discrepancy but apparently the lack of appropriate domiciliary support systems is partly to blame. In fact, there are many places in the world where the only access to a doctor is at the hospital.

One of the most important prerequisites for a successful home service is easy and prompt availability and easy accessibility of the service to patients and their families. This is usually done through both good electronic communication systems such as cellular phones and regular initiated home visits by all members of the palliative care team. Naturally, as death approaches, patients' conditions change quickly. Consequently, the stress for families increases and at this time the frequency of home visits increases. It is important that the home care team begin work with families before this final period. In this way the familiarity and trust needed for the team to be able to support families during the final extremely stressful period can be well established.

The second prerequisite for successful home terminal care is having one main caregiver who can attend to a patient's needs 24 hours a day. This should ideally be a close family member but can also be a friend or a hired caregiver. Ideally, the main caregiver should have the support of someone else on an as-needed basis. Sooner or later terminally ill patients become bed bound and need total nursing care. The function of home hospice teams is to advise, support, and guide patients and caregivers. This includes good symptom management, but even more important is to provide the necessary psychological and spiritual counseling. This should be done using hospice-initiated as well as family- and patient-initiated home visits. It has been shown that in this way lay people can provide adequate nursing care to the terminally ill.

It has been shown that with time and experience most of the treatment necessary for good palliative care can indeed be done at home without the continuous on-site supervision of medical professionals. Thus, for example, even the more difficult nursing tasks such as washing bed-ridden patients can be taught by hospice nurses. Medical procedures such as parenteral fluid administration, parenteral drug administration, and even procedures such as blood transfusions and ascites tapping can be done in the home setting with ease. The administration of parenteral drugs and fluids is better done using the subcutaneous route, a procedure called hypodermoclysis.

One of the main objectives in domiciliary palliative care is to overcome physical suffering such as pain and nausea, thus enabling the important psychosocial and spiritual issues to be addressed in appropriate depth. The goal of teams now will be to enable patients and their families to perform the necessary closure, the necessary farewell, to come to terms with the unfortunate fate of the terminality of the condition. There is time and place for forgiveness, for thanking, for regret—all the important things that make for a better death and a better bereavement process.

2.4. Comprehensive Home Palliative Care Service

This must constitute comprehensive palliative care teams consisting of a core team of expert nurses, doctors, social workers, psychologists, physiotherapists, and occupational therapists. A bereavement team should be an integral part of the program. Teamwork is an essential part of any home-based program. Ideally, there is also an affiliated group of volunteers who help with the various activities of the core team. Usually, the nurses do the main treatment and coordination of care. They use the rest of the medical and paramedical personnel as consultants. However, any variation of this model may be appropriate.

The goals of any home-based palliative care program are many and varied. They include:

- The delivery of comprehensive palliative care to patients and their families.
- The provision of the best quality expert advice and consultation to any other health-care professional needing it.
- The provision of bereavement advice to families and to any other health-care professionals needing this.
- The provision of the necessary education to all other health-care professionals needing this.

Ideally, there should be an appropriate and available database for research purposes. Thus comprehensive palliative care programs act not only as service providers, but also as a resource center for other health-care providers, both in the community and in hospitals. It thus provides education in all aspects of palliative care, including the physical, psychological, and spiritual alleviation of suffering to patients and to their caregivers.

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Biographical Sketch

Dr. Yoram Singer is the director of palliative care services in the Negev region of Israel. He emigrated to Israel from Switzerland at the age of 19. After compulsory military service he completed his medical studies at the Hebrew University in Jerusalem. Following two years in southern Africa in a rural hospital he completed a five-year residency program in community and family medicine. He has established a university-based community teaching clinic, training both medical students and family medicine residents. After doing a one-year fellowship at the McGill University palliative care service in Montreal, Canada, he became the director of palliative care services in the Negev region of Israel. This includes a network of home-based hospice units, a university hospital palliative care consultation service, and a university-based palliative care teaching unit. He is also deeply involved in research projects in palliative care.