

Health Care In The Terminal Phase Of Disease

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Abstract

Health care is the core activity of nurses and technicians at all levels of health care. Health care can be provided in homes, hospitals and specialized institutions. Special attention must be directed to patients who are at the terminal phase of the disease.

Keywords: Health care; Illness; Palliative care; Caregiving

Introduction

Caring for people when the end of their life is approaching combines many of the legal, moral and ethical debates of our time [1]. The rise of the hospice movement, the acceptance of the idea of death with dignity and the care of the dying as a speciality have all made their contribution to legal and ethical issues related to the dying client. In this area, some of the legal issues relating to the care of the dying are outlined and broadly related to the care situation. As medical science advances, a thin line is developing between those who are being prevented from dying and those who are being prevented from living, creating a legal and ethical maze for health care personnel. It is also necessary to consider the situation of those who have attempted to take their own life and the attitude of the law towards suicide.

Providing comfort, especially at the end of life, is neither a new concept nor a departure from the traditional responsibilities of the caring professions [2]. Until the middle of the twentieth century, the cure of disease and the prevention of death were largely beyond the capability of those who ministered to the sick by trying to relieve their pain. With the development of biotechnology, the obligation to provide care became the obligation to provide cure, where cure often meant prolonging life, and a focus on comfort was reserved for those times when "nothing more could be done." Rather than an inevitability, death was often perceived as a failure of skill and the very notion of dying made professionals feel uncomfortable, even guilty. Increasingly sophisticated science and technology inflated both professional and lay expectations about the power of medicine. The resulting belief that cure is always possible led to a perceived requirement to "do everything" and a sense of defeat whenever patients did not recover or improve.

The clinical arena is a pivotal interface between health care policy and culture, with physicians having a great deal of power

in clinical decision-making, and organized medicine exercising a great deal of political power in health care policy decisions [3]. Because both health care policy and culture-specific ideas about death and aging inform clinical decision-making, physicians' perspectives are crucial in the examination of care and meaning in late life.

Nursing, medicine, and the law, for example, do not reflect a conceptually unified set of goals and purposes [4]. Rather, they have developed, as do all professions, in response to a series of shifting perceptions of important human tasks. Thus one is likely to have serious difficulty discovering the way in which nurses, physicians, or lawyers aid us in coping with the world, caring for other individuals, or curing or resolving problems. This is in part the case because the service goals that determine professions are a heterogeneous accretion of purposes, as much determined by historical accident as clear conceptual necessity. In addition, learned professions possess not only goals directed to societal or client service, but to the development and maintenance of knowledge and skills. This distance between the altruistic and intellectual goals of learned professions introduced a major complicating factor in the description of professions and their relations with their clients. In addition, professions are modes of gaining a livelihood. As a result, they become natural vehicles for developing and protecting special financial and social perquisites. Much of what one associates with being a nurse, physician, or lawyer is a reflection of often longestablished social divisions of power, prestige, and financial advantage. This is probably nowhere more true than in the contrast between the positions of nurses and physicians.

Telling someone that their illness cannot be cured and that they will now need palliative care has the capacity to impinge on all aspects of personhood [5]. The autonomous person becomes disempowered, and no longer has total control over the near and distant future. The immediate effects can be physical, emotional, intellectual, social and spiritual.

Physical reactions can include nausea, vomiting, tachycardia, fainting, weak legs and dry mouth, to name but a few. Emotionally, there may be numbness, anger, and feelings of hopelessness and frustration. Intellectually, there may be an inability to receive or understand the message given, accompanied by an inability to recall simple and well-known facts, e.g. personal telephone

number. Even when surrounded by family and friends, the person may feel isolated and alone and unable to perceive these people as a resource. Spiritually there may be a loss of faith and intense distress about that. There may be a resulting overall feeling of loss of purpose and direction.

Chronic Illness

The increasing prevalence of chronic illness is posing considerable challenges to health systems [6]. Chronic illness requires complex models of care, involving collaboration among professions and institutions that have traditionally been separate. Healthcare still builds largely on an acute, episodic model of care that is ill equipped to meet the long-term and fluctuating needs of those with chronic illness. Patients may receive care from many different providers, often in different settings or institutions, even when they have only a single disease, such as diabetes. They are frequently called upon to monitor, coordinate or carry out their own treatment plan, while receiving limited guidance on how to do so. Consequently, in order to provide better support for patients, there is a pressing need to bridge the boundaries between professions, providers and institutions through the development of more integrated or coordinated approaches to service delivery. In response, health professionals, policy makers and institutions in many countries are increasingly recognizing the need to respond to those with complex health needs and are initiating new models of service delivery designed to achieve better coordination of services across the continuum of care.

Health Care

“Care” is without doubt among the most important concepts in healthcare [7]. The very word “healthcare” bears witness to this fact, indicating what the healthcare system as a whole and the individual actions taking place within healthcare are all about—namely, to provide care. The concept of care plays an important role for the professional identity of caregivers, and it is part of the expectation of care receivers. This can easily be forgotten given that in public and academic discourse, issues such as costs, prevention, the just distribution of scarce resources and the patient’s personal responsibility often figure more prominently than care.

Care is not only a descriptive concept, it also conveys a normative orientation. The term “care” enables one to evaluate different courses of action in healthcare. What is more, different courses of action can correspond more or less closely to what one perceives as good care. As there are standards and guidelines for and best practices of good care, care providers can ask themselves whether what they do constitutes good care. The question of whether the healthcare system as a whole as well as specific regulations and practices within healthcare live up to the ideals of good care is always subject to debate.

Socioeconomic stability may interfere with good care in individual cases, since, for example, the amount of time care providers can allocate to individuals is limited by the number of cases they are expected to manage. Determining what constitutes

good care is hence usually a matter of finding reasonable compromises. In healthcare settings, a typical compromise involves finding a balance between optimal care for individuals on the one hand and the institutional demands of providing care to many care receivers over long periods of time as well as the limits of what can legitimately be asked of individual care providers on the other.

In today’s healthcare arena there is pressure to ensure that all patients have fast access to effective treatment [8]. This treatment is to be delivered by efficient health and social care practitioners. These practitioners should be able to attend to the patient’s physical needs while giving emotional support and treating the patient with kindness and respect. When people are ill or frail, they are often at their most vulnerable and they rely on the integrity of the people caring for them.

How the patient perceives their care can have a huge impact on their recovery. Health and social care professionals face a huge challenge to meet each patient’s expectations of how their care and treatment is delivered; these professionals will be working across a vast range of patient perceptions.

Palliative Care

Palliative care is still regarded as an emerging specialty, less than 40 years having passed since Dame Cecily Saunders founded St Christopher’s Hospice, offering inpatient facilities to the dying [9]. Over recent years, development in this area has been rapid, and now includes a wide variety of methods for the delivery of care to that patient group, adding care at home, day care, palliative interventions in acute units and care of the elderly, amongst others, to the original inpatient provision. Whilst cancer patients remain the largest group receiving palliative interventions, it is becoming increasingly recognised that people suffering from chronic, progressive illnesses, which will eventually become terminal, will require the same type of end-of-life care. Neurological conditions such as motor neuron disease and Parkinson’s disease, dementia, diseases related to organ failure such as cardiac and renal conditions and chronic obstructive pulmonary disease (COPD), and many other chronic and acute illnesses would all benefit from this type of input at the appropriate stage. The literature also reflects the growing recognition of end-of-life requirements of care home residents, highlighting an increasing awareness of the wide spectrum of need for palliative care in the general population and resulting in a desire for education, by health professionals, in order that they can feel equipped to offer appropriate interventions to their client group.

Palliative care is a developing field of practice which is growing as the population lives longer with long-term conditions, a higher incidence of cancer, and complex needs in co-morbidity of conditions. Many health professionals working in palliative care are lone practitioners, which will continue as care in the community continues to be developed. The practitioners working in hospices and palliative care are often pioneering new ways of working as there is little evidence based practice as a resource.

In palliative care the need to determine a sense of meaning and purpose in life is significant. If one considers life as meaningless and empty of purpose or reason this can be depressing and lead to a sense of regret and overwhelming sadness. Finding meaning and purpose in one's life may only be considered towards the end of that life, whenever that is. This involves thinking of achievements, of relationships, of love shared, and of things left undone. For some there is a sense of becoming a burden at the end of their life and of guilt, and depression. A readjustment to the acceptance of being terminally ill has to occur before people can begin to reflect and make sense of their life. This is a painful experience. For some patients it can be isolating as no one wants to speak of death and dying. The need to address one's actions and relationships through life, and to be at peace with oneself appear to be paramount at the end of life. What matters to the person at core through life, matters at death. For children and young adults there are varying degrees of understanding of events occurring around them, and their emotional experience must be considered. Health professionals working in palliative care have an important role here to support the patient, whatever age, and the family.

The unprecedented growth in the numbers and the needs of the chronically ill [10], especially the elderly; the availability and widespread use of costly medical technologies that may prolong life without restoring health or functional independence; exponential cost increases due both to larger numbers of persons turning to the health care system for help and to per-capita increases in health care spending attributable to technological advances and overuse; the crippling impact of employer-based health insurance on the American economy and the lack of government control over rising drug and device pricing; the failure to recognize and treat the pain and other distressing symptoms experienced by seriously ill people; and the consequent widespread dissatisfaction with and confusion about the medical care system—all form the context and justification for attention to medical care of the seriously ill and those approaching the end of life and the rapid recent growth of the field of palliative care.

Palliative care relieves suffering and improves the quality of life of the living and the dying [11]. More than 30 million people suffer unnecessarily from severe pain and other symptoms each year. This is unethical, because simple, effective methods and approaches for palliative care exist that can be applied at the community level and therefore with the possibility of covering all those in need. Much is known in palliative medicine, but this knowledge is not benefiting most of those who are in need of it. In spite of all the efforts over the last 2 decades, most people who need palliative care are not getting it. To close the "Know-Do Gap," a public health approach for establishing palliative care according to World Health Organization (WHO) principles, as a part of countries' National Health Plans and integrated into their Health Care Services, seems to offer the most rational strategy for achieving worldwide coverage. A public health approach in palliative care means improving life through organized efforts of society, such as collective and social actions and involvement of the government's health care systems at all levels, as well as through organized community efforts of the people.

Through the development of technology we are faced with the question of human helplessness experienced by the person who is in the terminal phase of the disease [12]. The process of dying, in all its uniqueness and universality, surpasses the dimension of the human consciousness and sub consciousness, and requires a multidisciplinary approach of the team members who take care of the patient and cooperate with the members of their family. The base of the palliative approach is a relationship based on understanding, sensibility, empathy, flexibility, open and two-way doctor-patient communication and diverse communication in the social network. Communication in palliative care requires knowledge, competencies and skills in the peculiarity of doing that job, which is a difficult and demanding process. One of the most important and necessary skills in the palliative care communication is knowing how to hear and listen. It is a kind of listening where it is really important to show to the patient that you are really listening what he tells you, asks or feels. In the moment when medical procedures and interventions that include patients who suffer from terminal diseases do not show positive outcomes, the palliative care alleviates the human suffering. Through the implementation of palliative care, which is not recognized enough as a priority in the public health care, especially in developing countries, we could improve the quality of life of patients and members of their families.

Caregiving

The care, support, and sustention provided by the caregiver differs from the health care and medication provided by health care workers [13]. The care means sustention in carrying out basic life activities which implies the activities that the closest relatives of the user are able to (that they do not work, to live in the same household, if the user has them at all). The care which is defined as the care as it is provided by a caregiver must be crystal clear separate from the health care which is taught in health care faculties and still in secondary medical schools, which is an integral part of the nurse/technician's activity. Continuous quality education of the caregiver can result in knowledge from this field, but the authority of the caregiver is always under the supervision of healthcare professionals. Supervisions of health professionals, primarily nurses/technicians are necessary, initially often, sometimes on a daily basis, and later on occasionally, depending on the degree of the depending skills and knowledge of the caregiver.

Individual care-givers or institutions who care for terminally ill patients are inevitably confronted with serious ethical questions. Important decisions must be taken regarding the respective roles of the patient, the family and the care-givers in the decision-making process [14]. What should the patient know? What should family members or friends of the patient know? To what extent can scientific research on terminal patients be justified? Can a patient be allowed to refuse life-prolonging treatment? How can the limited available resources be fairly distributed?

Caregiving is a national issue that continues to increase in importance over time [15]. People are living longer than ever

before, and diseases that once meant a shorter life span now have available treatments. Instead of shorter life spans, individuals may be living with chronic illnesses and disabilities that require ongoing care. Many adult caregivers provide informal unpaid care to adults with chronic illnesses and disabilities. The mental and physical health of caregivers, their social support system, coping strategies, and levels of stress and burden remain a major focus of research, as evidenced by a number of recent literature reviews and meta-analyses. The positive aspects of caregiving experiences are receiving increased attention as well. Some caregivers derive positive meaning from the caregiving role, whereas others experience both positive and negative affect. Some caregivers even show stability and increases in their level of optimism over time.

Informal or family caregiving is defined as the behavioral expression of one's commitment to the welfare of another family member [16]. It usually refers to the provision of unpaid care to another individual in the family, household, or social network that has physical, psychological, or developmental needs. Informal caregivers are often laypersons who take up their roles without formal preparation, adequate knowledge, resources, and skills needed to perform their tasks.

First, family caregivers are often called upon to assist with complex medical and nursing tasks. Informal caregivers are often relied upon to monitor adherence to treatment, with some caregivers expected to learn how to deal with complicated treatments (e.g., home-based dialysis), administer medications, provide symptom management, and accompany the ill person to medical visits. They often negotiate financial and administrative responsibilities, and navigate the intricacies of the healthcare system. In many countries, formal care resources, for example visiting nurses or physical therapists, are often limited and sporadic; as a result, many caregivers' needs remain unmet. Second, caregivers provide practical care. Caregiving may include assistance with basic activities of daily living (e.g., buying groceries), personal care (e.g., help with bathing), and helping with administrative tasks or searching medical information. Third, caregivers provide emotional care, including listening to worries and providing companionship. Fulfilling these tasks requires many hours of care and often brings substantial personal, financial, and mental health costs to the caregivers.

Caregiving at the end of life can follow one of three trajectories of dying [17]. Some patients die suddenly, others experience a steady but predictable decline, while still others have long periods of illness interspersed by crises, one of which proves fatal. The demands on family caregivers differ in duration and intensity. Caregivers' adaptability can be taxed to the degree that they may become ill and even die before the person whom they are caring for. Caregivers experience both positive and negative effects of caregiving.

There isn't a single point in an illness when caregiving begins, and while it ends at death for the care recipient, caregivers' recovery can extend for months or even years. Most family caregivers are not trained for what they do; this can make the

tasks of caregiving more difficult. Most caregivers are women, but almost one-third of family caregivers are men. Men are effective caregivers yet they are not immune to the strains of caregiving. Most men describe their caregiving on the basis of responsibility and obligation without expectations of reciprocity. There have been few studies of men as caregivers, especially at the end of life. One study found that men who were caregivers at the end of life did not talk about their stress and did not readily seek assistance or support.

Conclusion

Physical and psychological health are key elements of quality of life, and based on these data, each person can evaluate his health condition. When discussing the health care needs of people who need it, it is necessary to consider special standards of health care. Patients in the terminal phase of the disease deserve to be provided with quality health care which will ease their suffering. The range of health care for patients in the terminal phase of the disease will be determined by a team in which must be a doctor, a nurse, a psychologist, a psychiatrist, a mentor, a carer and other professionals.

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