

## CHAPTER 2

### ESSAY ON PALLIATIVE CARE: HOW CAN THE HEALTH CARE SYSTEM ANSWER THE NEED?

#### 2.1 Introduction

We are all born to die. According to Stjernsward (1993), 50 million people die annually and we ought to give those who are to leave life the same care and attention that we give to those who enter life, the newborns. The quality of life of the terminally ill can be significantly improved by enabling the implementation of the vast amount of knowledge available in the field of palliative care.

During the last decades medicine has changed greatly: vaccinations have nearly eradicated many diseases, the use of antibiotics resulted in a lower fatality for infectious diseases, better hygiene and living conditions had also an effect on morbidity and mortality: it is less likely that people die at a young age. This results in an older population and associated with this fact, the number of people with malignancies and chronic diseases, which are more typical for old age. These disorders create the need for palliative care: when 'cure' is no longer possible 'care' is required.

Leontine (1992) explains that palliative care finds its origin in the Latin word *pallium*, a diminutive of *palla*: a long cloak. There is also the word *pallio*, which can be translated as 'cover, surround, envelop, enclose'.

She argues that when a patient can not be cured anymore, he can be surrounded by appropriate care, so that he can live in a dignified way until the end.

Palliative care has developed most rapidly in the affluent countries of the world - Western Europe, North America, Australia and Japan - countries with well-developed and well-funded health care systems, and subsequently a large number of elderly people. If palliative care became a need in the West, the question can be asked how relevant it is worldwide, and specifically what about the need in Thailand?

In this paper I try to explore if there is a need for palliative care in Thailand. The perception of death and dying in the West today makes it clear that the need is justified there. By pointing out comparative issues in society, culture and religion about death and dying in the West and in Thailand, I can conclude that there is also a need for palliative care in Thailand. Moreover, numbers which support the global need for palliative care can be compared to statistical evidence of Thailand and support the conclusion.

To meet this need changes in the health care system will be necessary. It is not a simple task to outline a new policy and it implies a consciousness-raising of the policy-makers and the medical profession. For this reason, the educational aspects of the concerned professionals and specially those of the medical profession are of great importance.

## 2.2 What is Palliative Care?

Palliative care grew out of hospice care. According to Saunders (1993), the Latin word *hospes* first meant host. By late classical times, the word had changed and denoted a stranger, while *hospitalis* meant friendly, the welcome to a stranger. The early hospices, throughout the Middle Ages, welcomed pilgrims and other people in need. The medieval hospice, however, was not primarily associated with dying people. The first use so far discovered of the word 'hospice' solely for care of the dying was by a French lady, in 1842. Later on, hospices for incurable patients and for the dying were opened in Ireland and in England at the beginning of this century.

Slowly other institutions followed these examples, mainly in the UK and in the US. By 1992 there were fifty different countries which had hospices or ambulatory units. They all applied the 'hospice philosophy' of which the four basic principles according to Leontine (1992) are:

1. Dying is a normal process and the terminal phase is an important stage in human life.
2. If cure is not possible, the patient needs specific physical, psychological, relational and spiritual care. The leitmotiv is: 'When it is no longer possible to cure, it is your duty to care'.
3. Treatments which prolong or shorten life are not administered. All possible efforts are made to provide the patient with the best available physical, psychological, relational and spiritual comfort.
4. This care has to be provided by an interdisciplinary team.

These principles express clearly the essence of palliative care.

So while as medical intervention, palliative care may sound new, we can see from its history that it is not. It is a rediscovery of old values which have been pushed to the background by the quick evolution in medicine. Fifty years ago the medical students read in their books of pathology, at the end of a description of an incurable disease, a last advice: '*consolare et sedare*', console and soften, when there is nothing more to do. Today a more specified diagnosis is looked for and the treatment is aimed at cure. This is right, but the advice '*consolare et sedare*' has disappeared. The doctor is not enough trained in the art of consoling and softening (Leontine, 1992).

The word 'palliative' related to medicine, is defined in the Oxford Dictionary as: "that reduces pain without removing its cause: *Aspirin is a palliative (drug).*" (p. 891). 'Palliate' means: to alleviate, to lessen pain, to give temporary relief.

When we use the term 'palliative care' today, it means much more than to lessen pain, or just 'terminal care'. Terminal care has a negative implication, it only concerns the care of the dying, grief, loss and sadness. Palliative care on the other hand, affirms life rather than death: it aims to make life meaningful until the end; it helps the patient to live as actively as possible until death. It is important that the patient remains the focus of attention: the needs of the patient have to be fulfilled, not the needs of the care takers.

Palliative care is not only the physical care of the patient; it also embraces the psychological and spiritual care of the patient and his/her family. The answers cannot be give by a physician only; this requires a team approach. A patient who has to face a life-threatening disease and the

family who has to cope with the approaching loss of one of its members face a wide range of difficulties which can not be solved by one person. To understand adequately, to be able to intervene in the physical, psychological and spiritual domains, requires a lot of skills. The interdisciplinary team, bringing together individuals with a diversity of training, and sharing the goal of improving the quality of life of the patient, best fits the need. The composition of an interdisciplinary team will vary depending on the degree of development of a programme, the objectives of a programme, and available resources. Each programme will be different, although most will include as core personnel: physician, nurse, social worker, chaplain and volunteers (Ajemian, 1993).

The definition of palliative care, formulated by the World Health Organization (1990) gives a clear summary of the above:

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 their families. (p. 11)

My conceptualization of what 'palliative care' means is that it includes five main elements:

1. When cure is no longer possible, appropriate care has to be applied.
2. Total care of the patient: physical, psychological and spiritual.
3. The care focuses on the quality of life of the patient.
4. Involvement of patient and family in decision making regarding the patient's situation.
5. Necessity of teamwork.

### 2.3 What is 'Need for Palliative Care'?

Need for palliative care can be translated as the need to die with dignity. Dying with dignity means that patients should be pain-free, and that they are involved in decision taking regarding their own treatment as much as possible.

People who are in physical pain can not concentrate on other needs. According to du Boulay (1993), pain management can be achieved by giving pain-killing drugs at regular intervals, before the pain reasserts itself, instead of waiting until the patient is crying out in such pain that another dose is given. The fear for the pain which is going to come makes the patient tense and more sensitive. Once he is assured that the medicine will be given at regular intervals, the patient will become much quieter also. Whenever possible drugs should be give orally rather than by injection, this is pleasanter for the patient and is easier for relatives when nursing the patient at home.

Physical pain management is an important aspect in palliative care. The topic is treated extensively in the Oxford Textbook of Palliative Medicine (1993): physical pain is a priority, but also the emotional and spiritual pain have to be addressed. Foley (1993) explains that improved communication between patients and health-care professionals will facilitate better assessment of a pain complaint. Understanding the difference between pain and suffering, and verbalizing such differences between physical and psychological symptoms, 'will enable both the patient and the physician to make a comprehensive assessment of the symptom 'pain'.

It is essential that the public be made aware that drugs for the relief of pain can be taken indefinitely without losing their effectiveness; psychological dependence (addiction) does not occur when morphine is taken to relieve cancer pain; the medical use of morphine does not lead to abuse (Stjernsward, 1993).

Palliative care covers more than only physical pain. The World Health Organization (1990) called it a future challenge:

Freedom from pain should be seen as a right of every cancer patient and access to pain therapy as a measure of respect for this right. However, cancer pain relief cannot be considered in isolation. For most patients, suffering is not purely physical and pain is only one of several symptoms. Pain relief should therefore be seen as part of a comprehensive pattern of care which encompasses the physical, psychological, social and spiritual aspects of suffering and which has come to be known as palliative care. (p. 10)

Only when the pain is under control, the patient will be in a condition to define what quality of life means for at that time, which brings the involvement in decision making of patient and family into focus.

This issue also contributes to the need for palliative care: the patient should decide about his own quality of life, he should be involved in decision making about his own treatment.

The evolution in medical science during the last decades has been overwhelming. Often emergencies define that the physician has to take urgent decisions; there is no time for discussions because 'saving life' is a priority. But, on many occasions, the opinion of the patient could be asked for, and is not: physicians concentrate on the technical side. Kubler-Ross (1969) describes how a patient who is admitted in a hospital is often treated like a person with no right to an opinion. He will overhear opinions on his condition and discussions and questions to members of the family. He is

treated like a thing, he is no longer a person. If he tries to rebel he will be sedated. He may cry for rest, peace and dignity but he will get infusions.

Kubler-Ross (1969) wonders:

Is our concentration on equipment, on blood pressure our desperate attempt to deny the impending death which is so frightening and discomforting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being which would remind us once more of our lack of omnipotence, our own limits and failures, and last but not least perhaps our own mortality? (p.9)

Medical school prepares physicians to deal with the myriad of reversible or treatable conditions, however, there is little or no teaching on the subject of what to do when the disease cannot be reversed. This omission makes it more difficult for the physician to deal with his or her own sense of therapeutic failure when communicating with the dying patient (Buckman, 1993).

Coping with defeat is difficult for physicians, Dr. Nuland (1993) describes it as follows:

Like other highly talented people, they require constant reassurance of their abilities. To be unsuccessful is to endure a blow to self-image that is poorly tolerated by members of this most egocentric of professions. I have also been impressed with another factor in the personalities of many doctors, perhaps linked to the fear of failure: a need to control that exceeds in magnitude what most people would find reasonable. When control is lost, he who requires it is also a bit lost and so deals badly with the consequences of his impotence. In an attempt to maintain control, a doctor, usually without being aware of it, convinces himself that he knows better than the patient what course is proper. He dispenses only as much information as he seems fit, thereby influencing a patient's decision-making in ways he does not recognize as self-serving. This kind of paternalism was precisely the source of my error in treating Miss Welch, (p. 258)



The author recalls one of his patients, a Miss Welch, who was ninety-two years old, disabled and living in a nursing home. She was brought to the emergency room with a perforated stomach ulcer. Dr. Nuland proposed surgery and she refused. She explained that she had already outlived her friends and that 92 years on this planet was long enough anyway. Dr. Nuland pressured her, she gave in and he operated. She survived for a few pain-filled weeks, then died of a massive stroke. Nuland reflects: "Although my intentions were only to serve...her welfare, I was guilty of the worst sort of paternalism. I had won [over the ulcer] but lost the greater battle of human care" (p. 252).

Patients should be allowed to die a dignified death: all efforts should be made to keep the patients pain- and symptom free, and to discuss the possible alternatives of treatment with them. This is attainable by applying the principles of palliative care.

#### 2.4 How does Euthanasia fit into Palliative Care?

Patients who are afraid that they will suffer, who are convinced that they will not be able to die in a dignified way, ask for euthanasia or for this 'mercy killing'.

Not only the physical pain needs to be managed, the psychological and spiritual aspects cause pain as well. The patient has to accept himself again, to find his own self, he also has to struggle with the spiritual pain, the pain of 'being'. The spiritual pain, or the moral pain is the most difficult to treat and it is this pain which makes people ask for euthanasia (Leontine, 1995). Sister Leontine started the palliative care unit in a hospital in

Brussels, Belgium, and the experience of five years of palliative care taught her that the total management of the pain: the administration of the right doses of pain-killers, together with the psychological and relational support, do not hasten the death, sometimes it has the reverse effect.

People who have experience with dying patients are of the same opinion (du Boulay, 1993; Leontine, 1995; Finlay, 1994): patients who have to suffer unbearably will ask to make an end of their life but nearly all of them change their mind once symptoms are taken care of. It is 'the pain' that has to be killed, not the patient!

Requests for euthanasia come out of despair and hopelessness, often through ignorance. Professionals in palliative care experienced that patients, who first wished to die, could go on to enjoy lives of good quality after effective intervention was carried out by a specialist; they no longer wanted their deaths hastened (Finlay, 1994).

At the end of her biography (du Boulay, 1993) Cicely Saunders adds a chapter on euthanasia. She tells about what she wrote in 1959 in the *Nursing Times*:

This is not to deny that patients do suffer in this country but to claim that the great majority need not do so. Those of us who think that euthanasia is wrong have the right to say so but also the responsibility to help to bring this relief of suffering about. (p. 239)

She is still of this opinion after more than thirty years' experience. It has been made stronger by the developments in care, research and education that have grown during the years and by all that she has seen people achieve at the end of their lives. Surprisingly few people ask for help in ending their lives. At the end of her plea, Saunders argues:

All workers in hospice teams have met such patients who have changed their minds once symptoms are effectively tackled and assurance given that treatment now is only to enhance the quality of life and not to prolong it where that is no longer desired or indeed possible. Above all, good communication and the opportunity for a patient to make choices will ease such anxiety and bring quietness. (p. 244)

Many books and articles have been written on euthanasia (Leontine, 1995; Quill et al, 1992; Quill, 1993; Annas, 1994; Cohen et al, 1994; Duffy, 1992; Benrubi, 1992) and it remains a complex issue: giving high doses of narcotic analgesics to a dying patient to relieve pain and suffering is considered ethical even if it inadvertently hastens death, provided the clinician did not intend to help the patient die.

Quill (1993) argues that death may be foreseen as a side effect of administering high doses of analgesics, as long as it is not intended. On the other hand, should a clinician remotely intend to help a patient die, even when death is desired by a terminally ill patient with irreversible suffering, that same act would be considered as a form of medical killing. He is also of the opinion that the current ethical thinking of physicians and legal prohibitions reinforce self-deception, secrecy, isolation, and abandonment at a time when there should be more openness about it. Quill proposes that perhaps a key to humanizing medical ethics and the law, as well as clinical medicine, lies in being more forthright and explicit about our intentions and responsibilities in working with dying patients. The previous arguments all lead to one conclusion: that euthanasia is less prominent where palliative care is being properly applied, and that palliative care improves the quality of life when facing death.

## 2.5 How is Death and Dying Perceived in the West Today?

Society in the West became a death-denying society. Although the fear of death is universal, Irvine (1993) says that: "One of the most fundamental influences on society's attitude to death and dying, however, is individual's fear of death" ( p.38).

It is necessary to outline the changes that are responsible for the increased fear of death, and also for the rising number of emotional problems and the greater need for understanding the problems concerning death and dying.

Kubler-Ross (1969) explains there are many reasons for fleeing away from facing death calmly: "One of the most important facts is that dying nowadays is more gruesome in many ways, namely, more lonely, mechanical, and dehumanized; at times it is even difficult to determine technically when the time of death has occurred" (p.8).

She further describes the changes in society, which can be summarized as follows: people do not see death as a part of life anymore, they do not accept a fatal outcome of a disease as natural. Another change is the advancement in medicine, further there is the altered role of religion, and the society which changed its focus from individual to masses: ambition, prestige and numbers are more important than human relations. Leontine (1992) explains that there are three areas which underwent an evolution after the second world war: death has disappeared from daily life, the family situation has changed and the progress of medicine has changed the outlook of the hospitals.

According to Buckman (1993), society in the West is going through a phase of virtual denial of death. The main reasons for this attitude are: the lack of experience of death in the family, high expectations of health and life, materialism and the changing role of religion. The result is that the process of dying is perceived as alien and fearsome, during which the dying person is separated from the living. Kubler-Ross, Leontine and Buckman have the following points in common: death is not a part of life any more, the progress in medicine and materialism. Leontine does not mention the changing role of religion, but in my view this is also an important point. Religious beliefs have been of great solace to many dying people and it has made death more acceptable (Robbins and Moscrop, 1995).

The advancements in medicine have contributed to a different image of the health care system: hospitals today became high-technical medical business centers. Patients have to adapt themselves to the rules of this medical-technological production chain. Due to all the technical advances, the chances for an early diagnosis and an effective treatment improved tremendously. Together with the medical development, the rise in the standard of living reduced the mortality rate and people expect to have a long life. Much time and energy is devoted to research and therapeutic measures with the aim of reducing disease and extending life. All this has caused death to seem remote rather than the reality that it is a fact of life.

For all of us death is a mystery, but for many the fear of dying is greater than the fear of death. This has led to an avoidance of these issues, with no allowance for expression of the fears and loneliness associated with dying. Slowly this is now changing and the need to acknowledge approaching death is gradually being accepted as a necessity. Those who

enter a caring profession come quickly face-to-face with death. Many doctors and nurses, whose education has been largely centered around the knowledge of treatment or cure can, when faced with the fact that there is no cure, feel failure and helplessness especially when facing anguished relatives (Robbins & Moscrop, 1995). It is the nurse who is most likely to have intimate contact with death fairly soon after commencing clinical experience and who has to cope with distraught relatives.

The developments in medicine centered around 'cure', but when cure is no longer possible, the old values of 'care' have to be rediscovered. Patients who have to deal with a life threatening disease have to be surrounded by appropriate care, so that they can live in a dignified way till the end.

The health care system in the West may be well organized, but there is a missing link: the care for those patients for whom cure is no longer possible. Many people die lonely, and Rinpoche (1992) says that "All of the modern world's pretensions to power and success will ring hollow until everyone can die in this culture with some measure of true peace, and until at least some effort is made to ensure this is possible" (p. 210). Here the philosophy and the application of palliative care can provide an answer to that need.

## 2.6 How is Death and Dying Perceived in Thailand Today?

When comparing the attitude towards death and dying in Thailand to the West, we should consider the same points: religion, death as a part of daily life, medicine and materialism.

Phya Anuman Rajadhon wrote in 1953 that the culture of Thailand could be summed up in one word, religion. He also said that Thai culture tended to become secular in the progressive parts of the country; but that to the people as a whole, religious culture was still a living force (Rajadhon, 1968). This is nearly half a century ago and major changes have taken place since, but there is a fundamental truth in his words because Theravada Buddhism, as the religion of the country professed by 95% of the total population, undoubtedly has directly or indirectly exerted a strong influence on the people's everyday life (Komin, 1991).

In the teachings of the Buddha it is said that this lifespan is short and that there is a new life to which we go. There are profitable deeds to be done, and there is a life of purity to be led, so that one may induce a better rebirth, or experience enlightenment. Mindfulness of death summons self-improvement (Roscoe, 1994).

Birth, aging, illness and death are part of the life cycle and are invariably accepted by the Thai people. These beliefs are basic concepts for them and when death comes near, most of them, if not all, try to concentrate their mind on Buddhism's Triple Gem: the Buddha, the *Dhamma* and the *Sangha*.

In Thai culture people try to avoid talking about bad things, or events which are not agreeable. This means that death is never talked about directly, even black clothes are not normally worn in daily life because they are a sign of mourning; it can bring bad luck. A patient will seldom be told that his end is near, usually the physician will talk to the relatives, he will inform them that nothing more can be done (Professor Shivalee Sirilai, personal communication, October 1995).

The overall approach of medicine in Thailand tends to be paternalistic: patients and relatives trust the doctors and nurses completely and are convinced that whatever treatments they prescribe or nursing care they provide, will be for the best interest. Actions of doctors are not questioned. Or is this changing? In 1986, Dr. Pinit Ratanakul of Mahidol University wrote:

Life and death. The right to live and the right to die. How in concrete cases are we to decide which of these rights is to be honored, which takes precedence? The old responses are no longer adequate. The dean of a medical school in Thailand assured me that there were no problems here regarding this issue, since by tradition it was recognized by families, patients and doctors that the doctor's role was to do any and everything to preserve and prolong the life of patients at any cost. The graduate nursing students' case studies written from actual hospital experiences told a different story; they reported instances of lethal overdoses being given, of no-code orders written, of the withdrawal of life-support systems or orders to withhold treatments, all of which raised for them moral questions and/or placed them into conflict with other medical personnel.(p. 218-19)

Changes are definitely on their way: the society, especially in Bangkok, has changed drastically due to the economic boom of the last two decades. The evidence is shown by the kinds and numbers of cars which constitute the traffic problem, the construction of buildings, the shopping arcades, the jewelry shops and the way people are dressed. In a society where glamour and superficial appearance are so important, people will be evaluated in terms of their possessions. Human values can only be questioned. People who are so much attached to these worldly goods have a hard time when death becomes inevitable, when they are confronted with the bare fact that life cannot be bought.



There are indications that medicine has received a different outlook: the many private hospitals and private clinics seem to advertise that health is within reach if you can pay for it.

Medical staff have to live up to the standards of the society: many physicians and also nurses have a second job: some work 60 to 90 hours per week, without counting the hours they are held up in traffic. Questions arising here are: what values do these people observe? Can they be alert, kind and helpful for patients and colleagues during all these hours of care giving? If they value materialism so much, do they understand that life may have other meaning for their patients who are faced with life-threatening diseases? Are they willing to be confronted by the death of their patients and by their own mortality? These questions concern value issues and they support the need to assess the requirement for palliative care programs and the potential for implementing change in the existing situation.

Many people are dying in hospitals. The wards in the governmental hospitals do not allow much privacy. From my own studies, I found that the nurses may be kind to the patients while they are administering the necessary nursing care, but the limited number of nurses present and the amount of work do not allow them to sit next to the patient and to listen to his questions and worries. However, they try to do so, whenever the circumstances allow them. Doctors and nurses get little training concerning palliative medicine and palliative care during their study time. There is only a course about different religions which is taught in some medical colleges and nursing colleges. The above observations suggest that the medical profession in Thailand needs education on the palliative care aspects.

## 2.7 The Need for Palliative Care: Globally and in Thailand

Dr. Jan Stjernsward, Head of the Cancer and Palliative Care Unit of the World Health Organization, starts his plea to consider palliative care as a priority required for health services in the future with the following words:

Globally, the need for palliative care is a neglected area. The need today is enormous and will increase dramatically in the near future. The size of the problem must be made clear to both individuals and society, especially policy-makers and the medical profession. They must recognize that something really can be done. (p. 808)

He also states that the need for palliative care will certainly increase because of the rapid aging of the world population, the increase of deaths related to tobacco use, and the increase of AIDS. Will this also be true for Thailand?

Looking first at the aging of the population, we can see that life expectancy in the developing countries has risen from 42.2 years in 1950-55 to 61.4 years in 1993, and it is projected to reach 71.6 years by 2020-25 (Stjernsward, 1993). For Thailand the life expectancy rose from 59 years in 1970 to 68.9 years in 1991 (Griffin, 1992). Thailand will have crossed the projected life expectancy of 71.6 years by 2020, because it is on the verge of becoming a developed country. The results will be a greater need for support, including palliative care of the elderly, and this will have to be provided by a proportionally decreased working-age population, i.e., an increasing dependency ratio.

What about deaths caused by malignant neoplasms? The global mortality pattern is provided regularly by the World Health Organization. In 1985 nearly 50 million people died and cancer was the cause of 10 per cent of deaths. A projection of mortality and the causes of death in the year

2015 indicates that 62 million people will die and cancer will be the cause of 14.6 per cent of the deaths. The major increase in deaths from cancer will occur in developing countries (Stjernsward, 1993). See Table 2.1.

Table 2.1

Deaths due to Neoplasms.

Number of Deaths (in thousands) due to Neoplasms.	Developing countries:	Developed countries:
		1985: 2500
	2015: 6477	2015: 2623

Note. Source: Stjernsward, 1993.

During the last twenty years, the leading cause of death in Thailand has changed from infectious diseases to non-communicable diseases. These include malignant neoplasms (Vatanasapt, et al. 1993). See Table 2.2.

Over a period of 6 years there is an increase of 13.5 per 100,000 in deaths due to malignant neoplasms.

Lung cancers do contribute to this number: during the period 1970-1987, lung cancer was the highest form of cancer which appeared in males, even higher than uterus cancers in females (Vatanasapt, et al. 1993).

The AIDS problem is on the increase: for the year 2000, the projected global cumulative total of adult AIDS cases is close to 10 million, of which almost 90 per cent will be in the developing countries. It is estimated that tumors will develop in 10 to 40 per cent of HIV patients (Stjernsward, 1993).

Table 2.2

Malignant Neoplasm Deaths in Thailand.

Year:	Number:	Rate/100,000
1987	16,905	31.5
1988	18,284	33.5
1989	20,385	36.8
1990	22,154	39.3
1991	23,332	41.2
1992	24,961	43.5
1993	26,132	45.0

Note. Source: MOPH, 1995.

The AIDS problem in Thailand becomes more prominent: more and more young people are dying due to this disease and there is a strong taboo surrounding it. Patients with AIDS are shunned and treated as outcasts by the society. They have no place to go, and like in the old times, some are asking the monks to take care of them. Other AIDS patients who are sent home from the hospital do not receive proper care, specially regarding the pain-management. An excuse is sought by claiming that there is a danger for drug addiction in Thailand (Dr. Van den Bosch, MSF, personal communication, March 1996 ).

According to a projection of AIDS deaths in Thailand (low scenario) the number in 1996 would be 40,451 and in the year 2000 it would be 129,353 (Viravaidya, Obremsky and Myers, 1993). These numbers suggest that the deaths due to AIDS is going to increase sharply during the coming

years. Moreover, the nursing of the AIDS patients is not simple: apart from the true therapeutic issues that offer their own and new challenges in immunodepressed patients, there are important quality of life issues to be addressed regarding the balance between curative and symptomatic or palliative approaches in these patients (Stjernsward, 1993).

Looking at the above, I conclude that the numbers for Thailand, which are related to aging of the population, increases in deaths due to malignant neoplasms and a high number of deaths in AIDS patients, form a strong case for the need of palliative care in the future.

## 2.8 How can the Health Care System meet the Need?

All people will not die in hospitals and it will be very difficult to apply the palliative care-unit approach only in hospitals or other institutions. The wider provision for palliative care needs a broad approach and institutionalization should be avoided. Scientifically valid methods should be established that are acceptable and maintainable at family and community level. Practical health services research will be required, priorities must be established for the use of available resources. Governments should formulate clear palliative care policies. A stress on research into health systems rather than biomedical research will be a priority in palliative care research (Stjernsward, 1993). If this policy needs to be introduced in Thailand, it will need a considerable change in the health care system: not only the policy-makers will be involved, but also the medical profession.

This is a difficult task in a world of medicine where specialists are focused on spending considerable resources on treating advanced cancers. They should provide palliative care and the same counts for the care of AIDS patients (Stjernsward, 1993). Financial resources will have to be rechanneled and the policy-makers will hopefully decide on a rational approach.

It is likely that in the future more patients are going to die at home: in general the hospital stays are shortening because they are expensive, the population is aging and many AIDS patients will not be able to pay for the hospital costs. How many hospital beds will be available for these patients? Is the ability of existing services able to meet the demand? This calls for another skill: physicians should be able to supervise as well as provide home care (Steel & Boling, 1994). If physicians are not available to fulfill this task, by whom can they be replaced? The physician is part of the multidisciplinary team in palliative care, but what is realistic for the future implementation? In the epilogue of his book 'How We Die', Dr. Nuland (1993) also pleads for the resurrection of the family doctor:

Each one of us needs a guide who knows us as well as he knows the pathways by which we can approach death. There are so many ways to travel through the same thickets of disease, so many choices to make... . The clinical objectivity that should enter into our decisions should come from a doctor familiar with our values and the lives we have led, and not just from the virtual stranger whose superspecialized biomedical skills we have called upon. At such times, it is not the kindness of strangers we need, but the understanding of a longtime medical friend. In whatever way our system of health care is reorganized, good judgment demands that this simple truth be appreciated. (p. 266)

Every country will have to cope according to its own resources. If a limited number of physicians is available, the community nurse or health worker

could fulfill a more responsible role. The current situation and the speculations towards the future suggest an involvement of community resources and home care. Cancer programs and pain clinics will become a necessity.

With limited resources available for palliative care, rational approaches are indispensable. Even limited resources stand a chance of making an impact, provided that the relevant priorities are set and strategies are implemented. A rational approach, stressing a public-health approach rather than an institutionalized one, should be a priority (Stjernsward, 1993).

In the West, considerable interest has been shown and studies have been carried out where doctors expressed their need for more formal training: they felt incompetent and lacking in confidence when confronted by death. Dealing with death and talking to distressed relatives were major sources of stress. Their feelings were exactly mirrored by nurses, clergy and others. Teaching modules have been developed for undergraduates and postgraduates (Doyle, Hanks & MacDonald, 1993). Other countries can take advantage of the work already carried out. By doing some additional research, training needs could be identified. The basic principles will remain the same: good terminal care depends upon the mastery of basic clinical skills and their extension to the care of people who are dying as well as upon the mastery of specific skills. Communication skills are high on the agenda of essential topics in terminal care education (Field, 1993).

Training has to be added to the curricula of undergraduates first. To define these training needs, one must ask what undergraduate terminal care education is trying to achieve. What knowledge and skills are to be

imparted? What 'needs' or 'deficiencies' are to be addressed? What personal effects are sought? What moral or ethical issues should be addressed? In the UK there seem to be three main aims: the acquisition of the relevant knowledge and technical skills of symptom management and palliation (pain relief is central); the improvement of communication skills; and the bolstering of students' personal coping capacities (Field, 1993). Field also adds that the most important influence upon the quality of terminal care is the organizational arrangement of the work.

Training has not only to be provided for undergraduates, but the levels of awareness among medical trained staff and among other health care disciplines have to be increased. Post-graduate training should be introduced after the necessary information has been collected by reliable research methods, so that training needs can be defined and curricula created accordingly.

In conclusion I can say that medical and paramedical staff have to be trained if palliative care will be implemented. The basic principles of palliative medicine and palliative care should be added to the existing curricula, so that staff will be prepared to cope with the problems today and the future ones. The educational approach is eminent in this issue. Training of physicians should obtain priority since they will be the agents of change in the implementation of palliative care in the health care system.

The problem is not only a medical one: it has also economical and political implications. Policy-makers all over could make use of available matters: the World Health Organization's Pain Ladder and the WHO Cancer Care Plan (Foley, 1993), they could encourage the legislation of essential drugs so that many more people could have access to them.



## 2.9 Conclusion

In the West, palliative care is coming to be seen as a basic human right when curative care is no longer appropriate. Is it not equally appropriate for those who have never had the benefits of modern medicine? Clearly, for vast numbers in the less-developed countries, 'palliation' is all they can hope for, yet most will never receive it. For them it presents not the final 'luxury' but a basic human right which should be made available to them (Doyle, Hanks & MacDonald, 1993). This also means that professionals should use the means available. It is clear that every programme depends on the degree of its development, the objectives and available resources.

Because of the tendency towards a paternalistic approach in medicine in Thailand, the physicians have to be convinced first of the need for palliative care. If they do not support the initiative, nothing will change, everybody will go on with treating the terminally ill patient 'as if' cure would be possible. At this point a new dimension is growing and visions are changing: the beginning of palliative medicine is being applied in several hospitals, with many difficulties, but with a large amount of persuasion.

Cultural aspects may play an important role: in Thailand it may prove impossible to set up a palliative care unit according to a western model because the majority of the people believe that it will bring bad luck if you enter a ward where people die. Most people do not understand the concept of palliative care; they might understand that a hospice or a palliative care ward is the place for patients for whom the doctors and nurses refuse to care.

It is of the utmost importance that physicians and other health care professionals realize that the principles of palliative care are applicable wherever men and women suffer and die. These principles are: pain and symptom control, support and empathy, spiritual awareness, and team-caring. Palliative medicine is appropriate for the practice of all doctors everywhere, whatever their specialty, whatever their culture and religious beliefs. The relief of unnecessary suffering, whatever its cause, is the concern of us all. It is indeed a rediscovery of age-old truths (Doyle, Hanks & MacDonald, 1993).

People do not need policy decisions to change their behavior now: it doesn't take any more time than already spent, it just takes some effort to remember the patient's needs as a human being with hopes and fears. I would like to end this paper with the words of a student nurse who wrote this for her fellow students and the staff on the ward as she was dying:

If only we could be honest, both admit our fears, touch one another. If you really care, would you lose so much of your valuable professionalism if you even cried with me? Just person to person? Then, it might not be so hard to die. (p. 26, Kubler-Ross, 1975)



## 2. 10 References

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