CHAPTER II

LITERATURE REVIEW

In this chapter, a review is focused on the terminally ill patients, the problems found in terminal care and the advance directives for terminal care.

2.1   Definition of Terminal Illnesses

For the purpose of this study, the 1983 definition of terminal illness by Bayer et al. is used. They have defined terminal illness as an illness in which, on the basis of the best available diagnostic criteria and in the light of available therapies, a reasonable estimation can be made prospectively and with a high probability that a person will die within a relatively short time. The overall 6-month mortality for the following illnesses was 47% (SUPPORT Principal Investigators, 1995; Schroeder, 1999). These diagnosis are: 1) non-small cell lung cancer stage III or IV; 2) multi organ system failure, with sepsis; 3) non-diabetic and non-traumatic coma with Glasgo-coma score of 3; 4) carcinoma of colon with metastasis to liver; 5) end-stage liver disease. Previously, several studies found that these groups of patients have limited life expectancy either with or without treatment. To demonstrate the survival time and mortality rate in these patients, these studies are summarized in Table 2.1

Table 2.1: Mortality rates and the survival time for patients with specific diagnoses

Carcinoma of the Colon with Metastasis to Liver

Sources	Results
Gorog, Toth and Weltner. 1997 (N= 47)	- The mean survival for all patients (N=47)= 4 months - The median survival for solitary hepatic tumor (N=13) = 11 months - The mean survival for multiple hepatic tumor (N=34) = 7.5 months
Petrelli et al., 1985(N=36)	- 1 month mortality after hepatic resection = 14%
Fortner et al., 1983 (N=9)	- 1 year survival =8 cases - 2 year survival =1 case
Baden and Andersen, 1975 (N=105)	- Median survival=10 months (range from 6 – 12 months)
de Brauw et al., 1987 (N=83)	- Median survival = 8.4 months
Stehlin Jr et al., 1987 Hepatic resection (N=108)	- Post operative mortality = 6.5% - Median survival for palliative resection =13.9 months
Stehlin Jr et al., 1987 Infusion therapy in advanced disease of colorectal cancer (N= 138)	- 50 patients (36%) had positive response, - of these, 13 patients (26% of 50) survived 18 months. - 42 patients (31%) had negative response, none of them survived to 18 month. - The 46 patients (33%) were not evaluated.
Stehlin Jr et al., 1987 Infusion therapy in advanced disease of Hepatocellular CA (N=38)	- 5 patients had positive response, 2 of this 5 (40%) survived 18 months. - 14 patients (37%) had negative response, none of them survived to 18 months - 19 patients (50%) were not evaluated.

Table 2.1:   Mortality rates and the survival time for patients with specific diagnoses (cont.)

Sources	Results
Non Traumatic Coma	
Sacco et al., 1990 Prospective cohort' 2 wk outcome (N=169)	- Of 169 patients with Glasco Coma Score (GCS) determinations within 72 hours, 66.9% were dead or in persistent coma within 2 weeks from the onset. - Of the 88 patients with initial GCS of 3-5, 85.2% were dead or in persistent coma. - Of the 61 patients with hypoxic or ischemic coma, 78.7% were dead or persistent comatose.
Levy et al., 1985 Prospective observation for 1 year (N=210)	- The death rate associated with hypoxic- ischemic coma of six or more hours was high: 42 (20%) died within 24 hr, 86 (41%) by the end of 3 days, 134 (64%) by the end of first week. Only 19 (10%) survived one year after the onset of coma.
Hamel et al., 1995 prospective cohort, 2-months outcome (N=596)	- At 2 months 69% had died, 20% had survived with known severe disability, 8% were known to survive without severe disability, and 3% survived with unknown functional status.
Levy et al., 1981 Prospective (N=500)	- 81 patients (16%) had independent life within the first year; 61% died without recovery from coma, 12% never improved beyond the vegetative state, 11% regained consciousness but remained dependent on others for daily activities
Sazbon et al., 1993 (N=100) Follow up patients with a history of 30 days or more of unconsciousness of non-traumatic coma	- 20 recovered consciousness within 5 months of injury but continued to suffer from major disability. - 31 of the remaining patients died within 6 months following injury, 49 remained unconscious until death.

Table 2.1:   **Mortality rates and the survival time for patients with specific diagnoses (cont.)**

Sources	Results
Sepsis	
Brun-Buisson et al., 1995 Prospective cohort 2-month survey N=742 severe sepsis N=310 culture negative severe sepsis	- 28-day mortality was 56% in patients with severe sepsis, 60% in those with culture-negative severe sepsis.
Non Small Cell Lung Cancer Stage III or IV	
Jeremic et al., 1999 (N=50)	Median survival time was 7 months.
Breathnach, 1999 (N=124)	Median survival of 10 months from the time of diagnosis.
Chidel et al., 1999 (N=34)	The median overall survival was 6.9 months and disease-free survival for all patients was 3.3 months.
Cellerino et al., 1991 (N=128)	Median survival was 34.3 weeks in patients treated with chemotherapy vs. 21.1 weeks in best support care; the difference was not significant
Shaw et al., 1992 (N=18)	The median duration of survival was 7.8 months
Hespanhol et al., 1995 N=411	The overall median survival was 4.3 months.
Ferguson et al., 1999 N=27 (man=16,woman=11)	Median survivals for stage IIIB, IV after resection for man 6.8 months, women 33.3 months.
Helsing et al., 1998 (N=48)	Median survival for chemotherapy was 29 wk. Median survival for support care = 11 wk
Rizzo, 1998 (N=103)	Patients treated with chemo-radiotherapy N=63, survival time range from 8.4 month and 9.6 months Patients treated with thermo therapy N= 40, survival time range from 13.2 and 13.4 month

These results indicate that the survival time of these groups of patients is quite varied, but limited, depending on the severity of illness and the stage of disease at the time of first diagnosis.

2.2 Previous Studies Reflecting the Problems of Terminal Care Provided to Terminally Ill Patients

The care for the terminal illnesses has become a topic of sharpened debate. (Bayer et al., 1983; Roth et al., 2000; Levenson et al., 2000) The conditions under which people die, the attitude and practice of the health profession toward them, and the ability of dying patients to control or modify the circumstances of their death have attracted wide attention. The following reports from several well-designed studies give insights into the problems found in the terminal care provided to patients during their last six months of life.

In 1995, a first publication of a large study intended to characterize the care in terminal illness called SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) was published. (SUPPORT Principal Investigators, 1995; Schroeder, 1999) SUPPORT was a prospective, multi-center study to evaluate the preference, decision-making and outcomes of seriously ill, hospitalized adults. The study attempted to understand and then correct the problems identified among severely ill, hospitalized patients. SUPPORT explored a fundamental human concern for terminal care. (Schroeder, 1999).

The overview of problems is presented in Table 2.2.

Table 2.2   Suffering of patients during their last 6month of life. Remark (-) represents of not mentioned in the report.

Sources Diagnosis and number of patients	Pain	Dyspnea	Depression, anxious	Confusion	Financial burden	Family impact	**Disable**
McCarthy et al., 2000 CA Colon = 316/520 NSCLC = 747/939	✓	-	✓	✓	✓	-	-
Claessens et al., 2000 COPD = 1008 NSCLC = 939	✓	✓ Severe	-	-	-	-	-
Somogyi et al., 2000 ARF and MOSFS = 1295	✓ Severe	-	-	✓ Severe	✓	✓ Physical, emotional	-
Roth et al., 2000 ESLDC = 575	✓ moderate, Severe	-	-	-	✓	✓ leave work	✓
Levenson et al., 2000 Exacerbation CHF 539/1404	✓ severe	✓ severe	✓	-	✓ marked	-	✓
Somogyi – Zalud et al., 2000 Elderly = 1266	✓ Severe	✓	-	-	✓	✓	✓
Lynn, Ely et al., 2000 COPD = 416/1016 who died within 1 year of study entry	✓ severe	✓ moderate, severe	✓	✓ severe	✓	✓ ill, quit work physical, emotional suffering	-

Several kinds of problems, including physical, psychological and economic problems, were discussed in the reports. The details of these problems are summarized, as follows:

2.2.1 Pain and Suffering

SUPPORT Principal investigators (1995) found that in the second week of an observation in one or more of nine life-threatening diagnoses, 22% of patients reported being in moderate to severe pain for at least half of the time. Similarly, results of the interviews with surrogates (conducted after patients had died) revealed that 50% of all conscious patients who died in the hospital experienced moderate or severe pain for at least half of the time during their last three days of life. Lynn and associates (2000) also found that serious pain and confusion affected about 25% of COPD patients.

Severe pain is common in cancer patients; more than one-quarter of patients with cancer experienced serious pain three to six months before death and more than 40% were in serious pain during their last three days of life (McCarthy et al., 2000). McCarthy et al. (2000) also found those patients with colon cancer and non-small cell lung cancer experienced significantly more pain and confusion as death approached. Similarly, severe pain was observed in 28 % of patients with lung cancer (Claessens et al., 2000; Lynn, Zhong et al., 2000). Roth and associates (2000) found that one-third of patients with end stage liver disease with cirrhosis (ESLDC) suffered from moderate to severe pain most of the time. The high burden of pain in the latter group appears to be comparable to that reported for patients with lung and colon cancer.

2.2.2   Dypsnea

Lynn and associates (2000) showed that the majority of patients with COPD reported moderate to severe dyspnea most or all of the time. In another study, severe dyspnea occurred in 32% of patients with lung cancer and 56% of patients with COPD. (Claessens et al., Lynn, Zhong et al., 2000) Levenson et al. (2000) concluded that the number of patients reporting severe pain or dyspnea increased as death approached and 63% of the patients' surrogates reported that patients were severely short of breath during the three days before death.

2.2.3   Depression

McCarthy et al. (2000) found that dying patients with colon cancer and non-small cell lung cancer were modestly depressed and anxious during their last three days of life. On the contrary, depressed mood and anxiety scores increased significantly as COPD patients neared death in the hospital (p = 0.005). Median depression scores were also increased as death approached in patients with congestive heart failure. (Levenson et al., 2000).

2.2.4   Disability and Dependency

Lynn and associates (2000) found that patients with COPD had increased their dependencies in activities of daily living. Fortunately, approximately 90% of patients had a caregiver at home if needed. Levenson et al. (2000) also concluded that as death approached, patients' illnesses became more severe. Median Acute Physiology Scores for hospitalized patients rose from 33 in 3-6 months interval before death, to 44 within the last 3 days of life. The number of functional impairments increased as death approached.

Similarly, elderly patients became completely dependent when death approached and reported increasing functional impairments and limited quality of life. (Somogyi-Zalud et al., 2000) Roth and associates (2000) found that most of patients with ESLDC spent their last few days completely disabled.

2.2.5 Hospital Resource Used

Patients with COPD (Lynn, Ely et al., 2000) spent 15-22% of their time in hospital, and more than 75% of patients spent about half of their days in the hospital throughout the last 6 months of life. Most spend time in ICU. Similarly, Somogyi-Zalud and colleagues found that the use of intensive care was prevalent in elderly patients despite their advanced aged. Of those who died on the index hospitalization, 54% received care in ICU. Among the remaining patients, 20% stay in ICU.

2.2.6 Family Burden

McCarthy et al. (2000) reported that families of patients dying with cancer incurred significant financial burden during the last six months of life. In a study of patients with acute respiratory failure or multi-organ failure with sepsis, Somogyi et al. (2000) found that families of 42% of these patients reported one or more substantial burdens. Importantly, a major financial loss was the most frequently reported burden even though more than 90% of patients had medical insurance. Families of survivors tended too report more problems. This trend was statistically significant for loss of savings (p = 0.003). The exception to this was that someone else in the family became ill, which was reported more by families of patients who did not survive the index hospitalization (p = 0 .001).

Families of patients with ESLDC (Roth et al., 2000) reported loss of most income and the need to leave work or other activities in order to care for patients. Similar to other reports on congestive heart failure patients, Levenson et al. (2000) found that patients' illnesses had marked financial impact on their families, with 23 % of the patients' families reporting the loss of most or all of family savings by the time of patient's death.

2.3 Patients' Needs vs. Pattern of Care Provided

In 1995, SUPPORT investigators (SUPPORT Principal Investigators, 1995) performed a 2-year prospective observational study to describe the process of decision-making and patient outcome. The summaries of studies regarding patients' needs and care provided are presented in Table 2.3.

A total of 4,301 adults hospitalized with one or more of nine life-threatening diagnoses with an overall 6-month mortality rate of 47% were included. The results revealed that 31% of patients preferred that CPR be withheld, but only 47% of their physicians accurately reported their preference. Nearly half (49%) of the 960 patients who indicated a desire for CPR to be withheld did not have a DNR order written during their hospitalization.

Table 2.3: Show the summary of some SUPPORT studies

Authors	Year	Title	Subjects	Major Findings
Roth et al.	2000	Dying with end stage liver disease with cirrhosis: Insights from SUPPORT	575	- Patients were young and often had low incomes, had high burden of pain. - Most rated their quality of life as poor or fair, and multiple co morbidities were common. - Most preferred CPR, but DNR orders and order against ventilator use increased near death.
Jaagosild et al.	1998	Outcomes of acute exacerbation of severe congestive heart failure: quality of life, resource use, and survival	1,390	- Quality of life was reported to be good, very good, or excellent in more than haft of patients. - Health perceptions improved after acute exacerbation of severe CHF.
Levenson et al.	2000	The last six months of life for patients with congestive heart failure	539	- As death approaches, illness became more severe, disability and presented of unfavorable symptoms more frequently. - Patients preferred not to be resuscitated more common. - However, there is no significant decrement in quality of life as death approaches.

Table 2.3:   Show the summary of some SUPPORT studies (Cont.)

Authors	Year	Title	Subjects	Major Findings
Somogyi - Zalud et al.	2000	Elderly person's last six months of life: findings from the Hospitalized Elderly Longitudinal Project	417	- Patient reported increasing functional impairments and limited quality of life. - The majority preferred comfort care. - A substantial number of patients were in severe pain. - Before death, the majority had measures in place to limit aggressive care.
McCarthy et al.	2000	Dying with cancer: patient's function, symptoms, and care preferences as death approaches.	Metastatic Colon cancer = 316 Lung cancer = 747	- Patients were characterized by functional decline and poorly controlled severe pain and confusion. Although patients increasingly prefer comfort care as they near death, many die in severe pain.
Lynn et al.	2000	Living and dying with chronic obstructive pulmonary disease	416	- Patients with advanced COPD often have substantial co morbidities and burden symptoms. - Preferences for DNR orders and decisions not to use mechanical ventilation increased as death approach.

Table 2.3:   Show the summary of some SUPPORT studies (Cont.)

Authors	Year	Title	Subjects	Major Findings
Claessens et al.	2000	Dying with lung cancer or chronic obstructive pulmonary disease: Insights from SUPPORT	Stage III, IV NSCLC = 939 Acute exacerbation COPD = 1,008	- Both groups of patients preferred comfort care, but dyspnea and pain were problematic. - Patients with COPD were more often treated with life – sustaining interventions than lung cancer.
Somogyi – Zalud et al.	2000	Dying with acute respiratory failure or multi organ system failure with sepsis	1,295	- Patients reported functional impairments and reduced quality of life. - Limitations to aggressive treatments were implemented when death was imminent. - Physical and emotional suffering were substantial.
Hamel et al.	1999	Patient age and decision to withhold life – sustaining treatments from seriously ill, hospitalized adults	9,105	- Older age was associated with higher rates of decision to withhold ventilator support, surgery, and dialysis.

In a study of 520 patients with colon cancer (316 with liver metastasis) and 939 patients with stage III or stage IV non-small cell lung cancer (747 died within 1 year of their index hospitalization), it was found that as patients with cancer progressed toward death, the patients' functional status declined significantly. (McCarthy et al., 2000) As death approached, patients favored comfort measures over life-extension, and about two-thirds wanted to forego resuscitation within the three-day period before death.

In a study of 1,016 COPD patients (416 cases had two or three co morbid conditions), Lynn and associates (2000) found that a preference of DNR orders was expressed by 29% of patients who were long-term survivors, by 43% of those who survived to leave the hospital but who lived less than one year, and by 42% of those who died during the index hospitalization. In all subgroups, (in 56% of the 1-year survivors and in 66% of those who died either during the initial hospitalization or within a year) comfort care was preferred over life-sustaining care. Only few patients were given DNR orders before enrollment in the study. Of those who died during the index hospitalization, 75% had a DNR order, whereas only 38% of those who died within the year and 16% of those who lived more than a year had a DNR order during their index admission.

With regards to preference for DNR, inpatients with COPD in this study wanted the DNR order and comfort care in 40-50% and 60-70% respectively, and neither preference changed with proximity to death. Ten percent more outpatients had a preference for DNR and for comfort care, but outpatients also evidenced a substantial rise in both measures in their last month. The majority of patients were willing to die

rather than be in a coma, on a ventilator, or with a feeding tube. Self-reported quality of life was rarely better than "fair" or "poor" with about 80% of patients throughout the last 6 months of life.

In another prospective cohort study on patients with stage III or IV non-small cell lung cancer (n = 939) and acute exacerbation of severe COPD (n = 1,008) reported by Claessens et al. (2000), it was shown that 60% of patients in both groups preferred comfort-focused care. Up to 81% of patients with lung cancer and 78% of patients with COPD were unwilling to have mechanical ventilation indefinitely; however, a high percentage of patients with COPD who died during the index hospitalization still received mechanical ventilation (70.4%), tube feeding (38.7%), and cardiopulmonary resuscitation (25.2%). Although hospitalized patients with either lung cancer or COPD preferred comfort-focused care for their dyspnea and pain, patients with COPD were more often treated with life-sustaining interventions than inpatients with lung cancer. In caring for patients with severe COPD, considerations should be given to implementing palliative treatments more aggressively, even while remaining open to provision of life-sustaining interventions.

In 2000, Somogyi et al. described the dying experience of patients with acute respiratory failure (ARF) or multiple organ system failure with sepsis (MOSFS). A total of 1,295 of 2,956 (44%) adult patients with ARF or MOSFS who died during the enrollment hospitalization were studied. It was found that the quality of life before hospitalization was reported as fair by 87% of patients. At the time of death, 79% of the patients had a DNR order and 31% had an order to withhold ventilator support. The

average time from the DNR order to death was 2 days. Orders to forgo ventilator support were written, on average, 3 days before death. Dying patients spent an average of 9 days on a ventilator. Ventilator treatment was actually stopped in 76% of patients with the order to forgo ventilator support. Both for resuscitation and for ventilator use, the discussion of the issue tended to be documented only 1 day before the order was written, and most orders were preceded by documented discussion.

In this group of patients more than 70% of patients stated that they would rather die than survive in a coma. Similar to other reports, these patients also wished to avoid being permanently attached to a ventilator, tube feeding, living in nursing home, being in pain, and being confused. More than half of the patients who died had a preference for comfort care. At the time of death, 80% had DNR order, and 30% had a documented decision to forgo ventilation support. Unfortunately, limitations to aggressive treatments were usually implemented only when death was imminent.

Roth and associates (2000) investigated the pattern of care and end-of-life preferences for patients dying with ESLDC. Of 575 patients with ESLDC, 166 died during the index hospitalization, and 168 died in the following year. Most rated their quality of life as poor or fair, and multiple co morbidity was common. Patients with liver disease were young, likely to be male, and often had low incomes. Most patients (66.8%) preferred CPR, but DNR orders and orders against ventilator use increased near death.

In a prospective cohort study by Jaagosild and associates (1998), 1,390 adult patients hospitalized with an acute exacerbation of severe CHF were followed. The overall quality of life was reported to be good, very good, or excellent in 58.2% of patients at 180 days. Patients with worse functional capacity were more likely to die. Health perceptions among the patients with available interview data improved at 60 and 180 days after acute exacerbation of severe CHF.

A similar design was used in a study done by Levenson et al. (2000). They analyzed 539 of 1,404 (38%) patients with the diagnosis of an acute exacerbation of CHF, who died within 1 year of entry into the study and about whom data were collected within the last 6 months of life. The patients who died were predominantly white, male, well insured, and most often reported a caregiver available at home if needed. The perceived quality of life did not change appreciably, with 29% to 58 % of patients reporting well to excellent quality of life at all intervals before death. As death approached, patients were more likely to prefer DNR status; the percentage of patients preferring DNR rose from 33% at 6 to 3 months before death to 47% at 1 month to 3 days before death (P < .05). The frequency with which DNR orders were written for hospitalized patients also increased as death approached.

In conclusion, as death approaches the last 6 months of life of patients with congestive heart failure, as illness becomes more severe, and as disability and the experience of certain symptoms more frequent, patient preference not to be resuscitated becomes more common. Fortunately, there is no significant decrement in the quality of life as death approaches. Many patients enjoy good to excellent quality of life.

Since most of our study subjects are quite old, we should have some information about the end of life for the elderly. Somogyi-Zalud and colleagues (2000) identified the characteristics of patients 80 years and older during the last six months of life. They divided patients into three groups: those who died during the index hospitalization, those who died within 1 year of enrollment, and those alive at 1 year. Patients who died while in the study were almost 2 years older compared with the survivors (p= 0.001). Congestive heart failure, pneumonia, and pulmonary problems were more common among patients who died while in the study. The baseline quality of life was most commonly reported as "fair" in all three groups. Half of the 1-year survivors rated their quality of life as "good," "very good," or "excellent," whereas less than one-quarter of non-survivors did so.

Forty-three percent of those who died received ventilator treatment whereas only 6 percent or less of all other study patients received this care (p = 0.001). Eighty-one percent of those who died had the DNR order. Discussion regarding DNR took place in 76% for those who died during hospitalization, in 35% of those who died during follow up, and in 20% of those who survived 1 year. The preference for comfort care was about 70% in all three groups. In addition, the majority of patients who preferred comfort care also had measures in place to limit aggressive care before death.

In this group of elderly patients, the quality of life was reported to be fair by the majority of patients both before admission and while in the hospital. More than 70% of patients indicated that death was more acceptable than permanent coma, and more than 60% of the patients would choose death over ventilator dependence.

A higher proportion of the patients who died within a year expressed their preference for DNR. More than 50% of this group of patients preferred DNR in contrast to 41% of the survivors. Preference for DNR was increased in both inpatients and outpatients. Fifty percent of patients had a DNR order in the period of 6 months to 1 month before death. This number increased to 78 % during the last month of life ($p = 0.001$). Eighteen percent of the patients had an order to withhold ventilator use in the 6- to 3-month period. The number increased to 42% during the last month of life ($p = 0.001$).

2.4   Problems of Care in Terminal Illness: Summary

Most patients preferred comfort-centered care. In contrary, a substantial amount of unrelieved suffering, in the forms of physical, psychological and economical burden, borne by patients and their families necessitates a need for better symptom control and better access to all terminal care. These patients were all seriously ill and their dying proved to be predictable, yet discussions and proper decisions in advance of death were uncommon. Nearly half of all DNR orders were written quite late, e.g. during the last two days of life. The final hospitalization for up to half of all patients in many studies occurred in generally undesirable states, such as being in the intensive care unit, receiving mechanical ventilation, or while in a comatose state. Families reported that up to half of all patients, who were able to communicate in their last few days of life spent most of the time in moderate or severe pain. It appears that physicians do not know what kind of care their patients' want; care is provided inconsistent with patients' will.

2.5   Provision of Psychological Support to Terminally Ill Patients

Generally, persons with serious losses, which are not life threatening, do have intense emotions, but in time, they come to see beyond the losses to a continuation of life. For patients with terminal illness, however, their intense problems do not just go away; the issues are continually about their life and their death and about the meaning of each issue holds for them. (Coulombe, 1995) These dying people often experience a range of strong emotions (denial, anger, bargaining and depression) before coming to accept the near prospect of their death. (Claxton, 1993) In order to provide proper psychological support to individuals who suffer from any illnesses effectively, the understanding about coping in individuals with illness and preparing to respond effectively may be useful.

2.6   Coping in Individual with Illness

Liposki described common categories of the meaning of illness and disease that reflect the past personal experiences, knowledge, cultural background, and beliefs of the sick people. For example:

(1) Illness as a challenge: This common view of illness inspires active and generally adaptive coping strategies. Disease or disability is seen as like any other life situation, which imposes specific demands and tasks to be mastered which is accomplished by any means available. The related attitudes and coping patterns tend to be flexible and rational. Timely seeking of medical advice, cooperation, information seeking, rationally modulated activity, and finding substitute gratification are some of the related and desirable coping strategies.

(2) Illness as an enemy: Disease is viewed as an invasion by inimical forces, either internal or external. The usual emotional concomitants of this meaning are anxiety, fear and/or anger. These feelings inspire the readiness to flight or fight or helpless surrender, depending on the current appraisal by the subject of his/her capacity to resist. In its extreme pathological form, this attitude may be frankly paranoid and others may be blamed for having caused or aggravated the illness. Free-floating anxiety or hostility may appear. Coping strategies reflect this attitude and take various forms of defense against danger and attack. Some degree of denial and projection are common, although regressive dependency and passivity may express a sense of helplessness and readiness to surrender. (Lazarus and Folkman, 1984)

From several studies mentioned in previous section, it was found that terminal ill patients usually expressed a sense of depression and anxiety. (Lynn, Ely et al., 2000; Levenson et al., 2000; McCarthy et al., 2000) In our preliminary study, at least one terminally ill patient committed suicide. Thus, caregivers must try to help patients to cope with their incurable physical problems and prevent additional serious psychological problems. In order to achieve this goal effectively, caregivers will have to take into account the cultural differences in health care beliefs and practices between the developing countries and industrialized countries and by cultural and religious beliefs; including beliefs regarding the causes of illnesses.

2.7 The Beliefs of Thai People

In Thailand, people believe that illness is caused either by physical factors such as biology or environment, or supernatural events or witchcraft (Golomb, 1985). Thai

Buddhists also believe in continuous cycles of suffering caused by karma. Buddhism links suffering from severe diseases to the concepts of karma and merit making. (Ratanakul, 1988:310)

Arising from the karmic explanation of disease, people generally believe that providing emotional support to those who are ill is an important part of care. They are frequently unwilling to employ services that are failed to provide emotional support. Similarly, Lynn et al. (1999) suggested the quality improvement strategies in this area should include bereavement support and advance planning.

For northern Thai patients with terminal illness, we still have inadequate information that is supported by proper research inquiry. However, most of them are expected to be Buddhists and have certain beliefs with respect to illness, death and dying. Whether the religion and belief will reflect the interpretation of illness by our terminally ill patients will need to be explored.

Based on these perspectives, psychological support will be provided to all patients and their families in the proposed study. It is aimed at serving the patient 's beliefs for end of life care and also to prevent psychological problems.

2.8   Provision of Patient Centered Care

Generally, persons who care for the dying or terminally ill patients will face three types of patients, who will require different types of responses. The three types are patients who welcome death, patients who accept death, and patients who fight

death. (Taylor, 1994) For the last type, nurses can help patients and their families express their feelings and possibly proceed onto acceptance by offering support and being prepared to listen.

For all types of patients, the caregivers must keep the care patient centered. The approach with each individual must be unique according to patient's experiences, culture background, and the belief of illness, life and death. To serve this adequately, highly qualified research assistants will be selected. All research assistants will be trained in order to provide psychological support effectively. In addition, close supervision will be maintained throughout the period of the study.

2.9   The AD Intervention in Terminal Illness

All of our patients are expected to have severe suffering from their diseases, which were previously found to have very poor outcome after CPR. (Lynn, Ely et al., 2000; Claessens et al., 2000; Lynn, Zhong et al., 2000; Somogyi-Zalud et al., 2000; Roth et al., 2000; Levenson et al., 2000; McCarthy et al., 2000) As Blackhall (1987) pointed out previously, early discussion of the potential risks and benefits of CPR could serve to bring patients and families to term with the inability of medicine to postpone death indefinitely. This measure would reduce the number of CPR performed as a cruel false last hope when imminent death is a medical certainty.

By providing sufficient comfort measures, giving accurate information and encouraging patient participation in their care, the quality of terminal care may be significantly improved. In this way, the application of advance directives for terminal

care in the terminal ill patients may help establish a formal way by which the caregivers can express their respect for patient's autonomy.

2.10 Definition of Advance Directive

Advance directives have been defined in a variety of terms. Lush (1993) expressed advance directives as the documents which enable people to decide what will happen to them, or who will make decisions on their behalf, if a time comes when they are no longer able to participate in discussion or decision about their own health care. Advance directives allow people to designate an advocate who will make health care decisions on their behalf (proxy directive) or to give instruction about the type of care that they want if they become incompetent (Molley and Guyatt, 1991). Similarly, Schneiderman and Arras (1985) stated that advance directives can be proxy directives, allowing individuals to designate proxy decision makers, or instruction directives, allowing persons to indicate specific treatments they wish employed or withheld; or they can be a combination of both proxy and instruction directives.

2.11 Type of Advance Directive

Advance directive can be presented in the form of a patient self-determination act (PSDA), a formally written advance directive, informal advance care arrangements (by word of mouth), or just a discussion between patients, physicians and proxies on advance care planning and treatment preferences. (Emanuel, Weinberg et al., 1993)

Some researchers used the formal advance directive alone or in combination with the informal type. For example, formal advance directive can be in a form of a

general statement, a therapy specific statement, or a therapy specific statement combined with the designation of a proxy and with prior patient physician discussion. (Mower and Baraff, 1993).

In the USA, most advance directives are present in the written form. Two common examples of the written advance directives are the living will and the durable power of attorney for health care (DPAHC). The living will is a nationally distributed document that expresses the patient's wishes regarding medical care should they become incompetent to decide (Society for the right to die, 1985). The DPAHC creates a simple and legally protected procedure whereby people can indicate treatment preferences in various situations and designate an "attorney in fact" who is empowered to make medical decisions should patients become unable to decide for themselves. The "attorney in fact" must be explicitly informed of the patient's wishes in order to make clear-cut decisions (Gilfix and Raffin, 1984). It stands as a clear expression of the patient's wishes.

2.12 Advantage and Disadvantage of Certain Types of Advance Directive

A proxy directive has the advantage of granting a surrogate the legal power to act in a substituted judgment or best interest capacity on behalf of the incompetent patient in the real-time clinical situations. Its major disadvantage is that the surrogate decision-maker, either through ignorance or emotional conflict or imposed interpretations of best interests, may fail to conform to what the patient would have wanted under that circumstance (Schneiderman and Arras, 1985). Indeed, there are considerable evidence of poor correlation between patient wishes and insight/decision

of those who would be likely to act on behalf of the patient, such as physician (Lynn, Ely et al., 2000; Claessens et al., 2000; Lynn, Zhong et al., 2000; Fischer et al., 1998) or spouse.]

The instruction directive also has its limitations. First, its language is set at the time of execution and, thus, presents a patient with the difficulty of attempting to describe within the space of a page or two what he or she would wish under the whole host of unpredictable future circumstances. As a result, a patient who lacks understanding of specific complex procedures will not ordinarily be able to judge the indications, benefits, or risks of many procedures they would face. Furthermore, a patient's clinical condition is not usually static; thus, it is not unreasonable for a patient in the course of an illness to change his or her mind about life saving treatment (Schneiderman et al., 1992). For example, fear, pain, or a sense of hopelessness might cause some patients to temporarily resist resuscitative measures. Conversely, an initially enthusiastic patient, after experiencing the relentless progression of a burdensome disease, might begin to have different thoughts about life prolongation (Schneiderman et al., 1992).

2.13 Effectiveness of the Advance Directive

The effectiveness of advance directive has been measured in variety outcomes. Some researchers counted the presence or placement of advance directive document in patients' charts (Danis, Southerland et al., 1991; Brown et al., 1999), some measured the actual discussion of AD (Kerridge et al., 1999), others may count the decision-making, some used preference but most of them measured the number of living will or

the durable power of attorney for health care (DPAHC). Sachs, Stocking and Miles (1992) measured the presence of a living will, a durable power of attorney for health care, or a physician's note describing a discussion of advance directives.

In summary, advance directive is a statement of treatment choice of a person to assist in his or her future care. It allows competent persons to extend their right of self-determination into the future. They are intended for their future care when they become unable to make choices. Advance directives can be in the form of a formal document (using written form) or an informal discussion (stating their choices by words) and/or a proxy. Each type has their advantages and limitations on actual application. One should carefully select a form of advance directive that is most suitable to a particular group of patients and to the culture.

2.14 Previous Studies for AD

Empirical research on the use of advance directive started to appear in the early 1990's (Molley and Guyatt, 1991; Emanuel, Barry et al., 1991; Brett, 1991; Danis, Southerland et al., 1991; Schneiderman et al., 1992; Emanuel, Weinberg et al., 1993). Three important categories of research in the use of advance directive will be discussed in this section: the study concerning the types of advance directives, the feasibility and the effectiveness of advance directive, and the studies of using various audiovisual aids (AV) to improve the actual use of advance directive.

2.15   The Study Concerning the Types of Advance Directive

There are many types of advance directives that one may choose for a particular patient group. Three types of advance directive studied by Mower and Baraff (1993) were: general statement, therapy specific, and therapy specific combined with the designation of a proxy and prior patient-physician discussion. In this study, the researchers mailed three separate surveys to the full-time faculty staffs of the Department of Medicine in a teaching hospital. Each survey included hypothetical patient scenarios of critically ill comatose patient paired with a previously completed AD. Physicians were asked to decide, based on their interpretation of AD, whether they would initiate or withhold life sustaining and other medically indicated treatments.

It was found that advance directives were generally more effective in causing physicians to withhold life-saving therapies, such as CPR and mechanical ventilation, than non-life saving treatments (Mower and Baraff, 1993). The therapy specific AD combined with designation of a proxy and prior patient-physician discussion was significantly better than the general statement AD for all categories except for the simple diagnostic test and for pain medications. The detailed therapy-specific AD produced more uniform interpretation by physicians and was more likely to result in the withholding of most therapies (Mower and Baraff, 1993).

Emanuel and colleagues (1993) assessed the association between implementation of the patient self-determination act (PSDA) and (1) the use of formal, written advance directives, (2) the use of informal advance care arrangements (by word of mouth), and (3) discussion between patients and their physicians and proxies on

advance care planning and end-of-life treatment preferences. In this study, a pre-post interview was performed in 579 patients who were either discharged from acute care hospitals 1 month before the implementation of the PSDA (pre-PSDA group, 258 cases) or at 5 months after implementation (post-PSDA group, 321 cases).

It was found that only 60.9% of the patients in the pre-PSDA cohort had some kind of advance care planning whereas 72.6% of the post-PSDA cohort did (p=0.01). However, there was not a significant increase in the proportion of patients who had advance care planning in a form of written document (p=0.11). Implementation of the PSDA was not associated with a significant change in the proportion of patients who discussed advance care planning or end-of-life issues with their physicians (p=0.25). In contrary, there was an increase in the proportion of patients who had poorer health who spoke with their physicians (15.4% pre-PSDA vs. 24.8% post-PSDA). Importantly, the implementation of the PSDA was associated with an increase in the proportion of patients who had general discussions with their proxies about end-of-life issues (p=0.024). Patients with formal proxies had detailed discussions significantly more frequently than other patients (p<0.001).

In 1993 Mower and Baraff investigated the utility of the type of advance directive in influencing physicians' willingness to withhold specific therapies. Respondents were more likely to withhold CPR when given a therapy-specific advance directive (Mower and Baraff, 1993). When a proxy and prior patient-physician discussion supported a therapy specific advance directive, 100 percent of physicians were willing to withhold CPR.

As far as we can access, only a small number of studies investigated the usefulness of various types of AD. All of them used the written form, which was considered the most acceptable type of AD in the western countries. Most of the studies employed mail survey and interview (Mower and Baraff, 1993; Emanuel, Weinberg et al., 1993). The results generally indicated that the therapy specific AD combined with designation of a proxy and prior patients-physicians discussion was significantly better than others (Mower and Baraff, 1993). Up to now, there has been no report on the use of AD from Thailand, so the type of AD to be used most effectively in this country and/or for the selected groups of patients in Chiang Mai remains to be determined.

2.16   Studies on Feasibility and Effectiveness of AD

In 1991 Emanuel and colleagues investigated the attitude of patients towards planning, perceived barriers to such planning, treatment preferences in four hypothetical scenarios, and the feasibility of using an advance directive. The study was done by surveying 405 outpatients, 30 primary care physicians and 102 members of the general public and by asking them to complete the advance directive. Ninety-three percent of the outpatients and 89% of the members of general public were in favor of the use of advance directive. Of the perceived barriers to issuing advance directive, the lack of physician initiative was among the most frequently mentioned barrier.

Based on the four scenarios, the outpatients refused life-sustaining treatments in 71% percent of their responses. The highest percentages were found in the following scenario: persistent vegetative state, dementia with a terminal illness, 85 and 87 percent respectively. Although a large proportion of respondents expressed their desire of some

form of planning, few had actually made explicit arrangements for it. In contrast, 57% of the outpatients and 74% of the members of general public reported having a will concerning the disposal of their estate. In their report, the authors disclosed that they had included only 4-13% of participants from each category and excluded quite a large number of patients. Moreover, the study subjects were more highly educated than the general population; thus, their results may not be readily generalizable.

Danis et al. (1991) conducted a prospective study over a two-year period to investigate the effectiveness of advance directive for life sustaining care in a nursing home. A total of 126 competent residents of the nursing home and 49 family members of incompetent patients were interviewed. It was found that about half of the competent patients (72 patients, 57 %) thought that there would come a time when they would want their doctor to stop keeping them alive. Forty-one patients (33%) wanted their doctor to keep them alive as long as possible. The remaining 13 patients (10%) did not know how they felt about these statements. For specific treatment choices, the patients were most willing to receive life-sustaining treatment during the critical illness and least willing to receive such treatment during permanent unconsciousness.

In this study, family members of the incompetent patients consistently preferred to have life-sustaining treatments withheld from the patients more frequently than the competent patients did for themselves. Thirty-six family members (73%) agreed that they would be a time when they would want a patient's doctor to stop keeping the patient alive; six family members (12%) disagreed, seven (14%) did not know how they felt about this statement. When they were asked about specific treatments, their choices

paralleled those of competent patients with the inclination to choose life-sustaining treatment diminishing as the conditions became less reversible. In the analysis of 96 outcome events (hospitalization or death in nursing home), the actual care was consistent with previously expressed wishes in only 75% of the time. Interestingly, the presence of written advance directive in the medical record was not consistent with the actual care (Danis, Southerland et al., 1991).

In a survey of changes in the nursing home practice in 10 states in the USA following the implementation of the patient Self Determination Act, Teno, Branco et al. (1997) found that the implementation of the PSDA made a modest increase in the documentation of living wills. In contrast, DNR and orders to forgo artificial hydration and nutrition remained the same. The rate of chart documentation of living wills increased from 4.2% in 1990 to 13.3% in 1993, and DNR orders increased dramatically from 31.1% to 51.5%. The rates of do-not hospitalize (DNH) order and orders to forgo artificial hydration and nutrition remained less than 8% in both years. They found striking variations in advance care planning among the ten states. In 1990, having a DNR order varied from 10.1% to 69.2% across the ten states. With the exception of Oregon, where 69.2% of patients already had a DNR order, other states detected the 1.5- to 3.1- time increase in the rate of DNR orders in 1993 compared with 1990. (Teno, Branco et al.,1997)

In another study Teno, Lynn and colleagues (1997) focused upon the impact of AD on decision about resuscitation in the period before and after AD were promoted by the Patient Self-Determination Act (PSDA). An observational cohort study conducted

in the 2-year period before (PRE) and the 2-year period after (POST) the PSDA was supplemented with a randomized controlled trial of an intervention to improve decision-making in the period after PSDA (POST+SUPPORT). In the last section, the investigators provided a nurse to facilitate communication among patients, surrogates, and physicians on the preference for treatment alternatives and, when clinically appropriate, to encourage completion and utilization of AD.

It was found that before the PSDA (PRE), 62% of the patients were familiar with a living will and 21% had an AD. These rates were similar in the POST and POST+SUPPORT cohorts. Remarkably, the directive was mentioned in the medical records in only 6% of the PRE cohort, but this proportion rose to 35% and 78% for the POST and POST+SUPPORT cohorts, respectively ($P < .001$). There was no significant difference in the rate of medical record documentation of discussions about resuscitation between the POST patients who had and who did not have AD (38% vs. 33%, respectively). Also there were no differences in the rate of DNR orders among those who wanted to forgo resuscitation (58% vs. 54%), and the frequency of attempted resuscitations (9% vs. 17%).

Patients with AD more often reported that their preferences about resuscitation were discussed with a physician (e.g., 30% for those POST patients with no AD and 43% with an AD, $p < 0.05$). Importantly, only 12% of patients with AD had talked with a physician when completing the AD and only 42% reported ever having discussed the AD with their physician. By the second study week, only one in four physicians was aware of patients' AD. Thus, it appears that, in these seriously ill

patients, AD per se did not substantially enhance physician-patient communication or decision-making about resuscitation. This lack of effect was not altered by the PSDA or by the enhanced efforts from nurses, although these interventions increased documentation of existing AD. Current practice patterns indicate that increasing the frequency of AD is unlikely to be a substantial element in improving the care of seriously ill patients. (Teno, Lynn et al., 1997; Danis, Southerland et al., 1991).

In the same year (1997), Teno, Licks and associates also evaluated whether the lack of effect of advance directives (AD) on decision-making in POST+SUPPORT cohort might arise from the content of the actual documents. Advance directives placed in the medical records were abstracted for date of completion and content of additional written instructions. From the medical records of 4,804 patients, a total of 688 directives were collected from 569 patients. The majority of these directives (66%) were in the form of durable power of attorney whereas 31% were standard living will or other forms of written instruction (3%). Only 90 documents (13%) provided additional instructions for medical care beyond naming a proxy or stating the preferences of a standard living will. Only 36 documents contained specific instructions about the use of life-sustaining medical treatment, and only 22 of these directed forgoing life-sustaining treatment in the patient's current situation. For these 22 cases, the treatment course was consistent with the instruction for nine patients. In two cases, patients may have changed an inconsistent directive after discussion with hospital staff. Advance directives placed in the medical records of seriously ill patients often did not guide medical decision-making, beyond naming a healthcare proxy or documenting general preferences in a standard living will. Even when specific instructions were present, care was potentially inconsistent in half of the case (Teno, Licks et al., 1997

In 1998, Teno, Stevens and colleagues reported their attempts to examine whether physicians unilaterally disregarded advance directives. Fourteen hospitalized, seriously ill adults were randomized to receive an intervention in the form of patient-specific information on prognosis. Specially trained nurse was employed to facilitate decision making by the patients. To be included in this study, patients who reported having an AD had to meet at least one of the criteria of severity: were comatose, had objective estimate of prognosis for surviving 2 months of 40% or less, or died during the hospital admission.

It was found that advance directives played an important role in decision making of only 5 out of 14 cases; but even in those cases, life-sustaining treatment was stopped only when the patient was absolutely, hopelessly ill. In two cases, the family member wrongly reported that the patient had an AD, and in the remaining seven cases, AD had a limited role. Importantly, this limited role could not be traced to a single explanation. In many cases, it turned out that, despite the patients' serious illnesses, their family members and physicians did not see them as absolutely and hopelessly ill. Hence, AD was not considered applicable to them. On the other hand, in those cases in which AD did have an impact it was evidenced that open negotiation between a surrogate and the caregivers yielded a transition in the goals of care.

In a review of 15 research articles by Glick and associates (1998), three main barriers to the completion and effective use of advance directives were summarized: (a) lack of education or knowledge (of the patients) regarding advance directives, (b) difficulties with paperwork completion, and (c) discordance between patients, family members, or proxy and the service provider.

2.17 Studies on the use of Audiovisual Aids to improve the Actual Use of AD

A number of recent studies examined the use of various AV aids to improve the use of advance plan for health care, especially in the field of terminal care. In a pilot study by Murphy, Sweeney and Chiriboga (2000) the use of an interactive multimedia CD-ROM educational program on AD was evaluated. Study subjects consisted of 31 elderly men and women in a senior citizen center. The effectiveness of the CD-ROM intervention was measured by changes in knowledge and attitude toward AD. Subjects achieved a statistically significant change in the posttest knowledge scores and reported a high degree of satisfaction and ease in using the computer program. Whether this CD-ROM program can actually change AD practice remains to be investigated.

In 1999, Brown and associates compared the effectiveness of written materials only versus written materials and an educational videotape on the use of advance medical directive in a population-based, randomized controlled trial with a 3-month follow up. The main outcome measure was the proportion of subjects who placed a directive in their medical record for the first time. The placement rate increased almost identically in both groups, e.g. from 21.2% to 35.0% in the written materials-only group vs. from 18.9% to 32.6% in the group receiving the videotape (95% CI, -0.04, 0.04, p =0.952). Mailing of the written materials substantially increased placement of an advance directive in the medical record, but the addition of videotape did not.

In another randomized cohort trial reported in 1996 by Siegert et al., the effect of advance directive videotape on patient comprehension of advance directive concepts and preferences for resuscitation was examined. Thirty-six residents of an extended

care and rehabilitation center were enrolled: 16 subjects were asked to watch advance directive videotape and 20 subjects reviewed another health-related videotape. Structured interviews were conducted three times for pretest, posttest, and delayed posttest evaluations.

The results revealed that the mean comprehension score improved significantly from pretest to delayed posttest ($P < 0.001$). However, score changes were not significantly different between the two video groups ($P = 0.39$) and there were no significant score differences between the two video groups. The advance directive videotape did not significantly affect resuscitation preferences or comprehension of selected advance directive concepts. It is possible that the preference for resuscitation was already decided without the involvement of this media.

Yamada et al. tested another multimedia intervention in 1999. In this prospective, randomized controlled, single blind study, the effect of a multimedia educational package about advance directive and CPR on the knowledge, attitude and activity toward AD and the life-sustaining treatments was studied in elderly veterans attending general medicine clinics. Sixty-two and 55 veterans, who are 70 years of age or older and able to make medical care decisions, were respectively assigned to the experimental and control groups. The control group received a handout about AD, which was available at the clinic. The experimental group received the same handout and an additional handout describing procedural aspects and outcomes of CPR and they also watched videotape about AD. Patients' attitude and action toward AD, CPR and life-sustaining treatments were recorded before the intervention and then 2 to 4 weeks after.

Only 27.8% of subjects stated that they knew what an AD was in the pre-intervention questionnaire. This proportion improved in both the experimental and control groups (87.2% experimental vs. 52.5% control). The stated knowledge of what an AD was, however, was higher in the experimental group (odds ratio =6.18, p<0.001) and this effect, although diminished, persisted in the follow-up questionnaire (OR = 3.92, p = 0.003). Prior to the intervention, 15% of subjects correctly estimated the likelihood of survival after CPR. This proportion improved after the intervention in the experimental group (OR = 4.27, p =0.004), but did not persist at follow-up. In the post-intervention questionnaire, only a few subjects in both groups stated that they discussed CPR or AD with their physician on that day (OR = 0.97, p = NS). This study indicated that AV aids might improve short-term knowledge of CPR and of AD but did not stimulate advance care planning activities.

It appears from these studies that for these important issues of advance planning for terminal care, the AV aids cannot replace direct human communication. They may temporarily change the knowledge and attitude but does not promise the practice. They may be even more limited in their applications in the Thai society since these technologies are quite new and only a few patients have previous experience with them.

2.18   Factor Affecting the Stability of Advance Directive

Advance directives are intended to extend patient autonomy into the period of mental incompetence. However, for advance directives to fulfill this objective, patients' choices must be reasonably consistent over time. Several researchers have investigated the stability of AD for life-sustaining treatment.

In 1988, Danis and associates surveyed the preferences of patients who had already experienced intensive care and of their families. Subjects who were at least 55 years old, admitted to ICU for at least 24 hours, and lived within a 95-km radius of the hospital were interviewed. A family member was interviewed if the patient had died or was incompetent.

One hundred ninety-three patients met the study criteria and 160 (83%) of them or their family members agreed to participate. The willingness to undergo intensive care was determined by the hypothetical questions under actual and ideal circumstances. It was found that 70% of patients and their families were willing to undergo intensive care unit again to achieve any prolongation of survival. The authors concluded that elderly patients with previous intensive care unit hospitalizations and their families were generally extremely willing to undergo intensive care regardless of their age, functional status, perceived quality of life, hypothetical life expectancy, or the nature of their previous intensive care unit experiences (Danis, Patrick et al., 1988). The majorities were willing to utilize intensive care even for one month of survival. In contrast, families of patients who died in the hospital or within a month after discharge from the hospital were less receptive to intensive care than the surviving patients.

Everhart and Pearlman and Rosenfeld et al. attempted to assess a short-term stability for AD. In 1990, Everhart and Pearlman interviewed elderly veterans, who had survived the medical intensive care unit (ICU) or coronary care unit stays for at least 48 hours, to determine their preferences for life-sustaining treatments. A follow up interview was conducted at one month after the patients were discharged or transferred

from the ICU using the same questionnaire in order to assess the changes of their preference as health status improved.

Of the 34 patients who met the inclusion criteria, 30 (88%) agreed to participate in the first interview, seven were lost to follow up, two died before the follow up and one declined to be interviewed for the second time. Twenty patients remained for stability testing. It was found that most patients desired resuscitation for their current health situation. Fewer patients wanted other treatments. A high percentage of patients favored therapies in the current health situation than in other scenarios. The authors also found that the patient's acceptance of a specific life-sustaining treatment under one scenario did not ensure acceptance of other types of life-sustaining treatment under the same conditions. These findings suggested that patient preferences were difficult to predict. In the current health scenario, the most common reason for wanting resuscitation was a desire for continuation of interpersonal experiences with family and friends (5%). The "chance for cure" was the most frequent explanation for acceptance of mechanical ventilation (38%).

In this study, the choices to forgo life-sustaining treatments were most often attributed to fear of becoming a "care taking burden" in all scenarios. For example, in the current health scenario, patients reported this reason for refusing resuscitation (50%) and artificial hydration and nutrition (20%). Other major reasons for refusal of a life-sustaining treatment were "natural time to die"; "physical limitations;" and "no chance for cure." Importantly, despite the change in health status and mood over the 1-month period after leaving the ICU, the majority of patients did not change their preferences regarding any of the life-sustaining treatments.

Rosenfeld and colleagues evaluated a two-month stability of AD. Of 5,941 patients who survived at least 2 months of study entry, 2,110 patients could be interviewed at 3 days and 2 months later. The sample for analysis constituted of 1,590 patients (75% of those interviewed). Using the percentage of the total group in either the stable CPR or stable DNR GROUP assessed the overall preference stability.

The overall preference stability was reported as 80%. At the two-month interview, 314 patients (20%) had changed their CPR preference: 179 (11.3%) changed to favor DNR and 135 (8.5%) changed to CPR. Patients who initially chose DNR were twice as likely as those who chose CPR to change their preference (31% vs. 15%). For patients initially choosing CPR, those who continued to prefer CPR at follow up were significantly younger (58 vs. 63 years) and had a lower baseline depression score (meaning fewer depression symptoms) than patients whose preference changed to DNR. For patients initially preferring DNR, the ones who desired CPR at follow-up were younger (64 vs. 67 years), more likely to be male (56% vs. 41%), and had improvement in depression score compare with those who continued to prefer DNR (Rosenfeld et al., 1996).

In the study by Rosenfeld and colleagues, it was found that age and greater baseline depression were significantly associated with the change from preferring CPR to DNR at follow-up. Among patients initially preferring DNR, male and initial admission diagnosis of acute respiratory failure or multi-organ system failure with sepsis or malignancy were associated with change in preference to CPR at the follow-up interview whereas age, greater baseline depression, and worsening depression score were associated with continuing to choose DNR at follow-up.

In 1994, Emanuel, Emanuel et al. reported the longest study of the stability of advance treatment decision. A total of 495 out of 829 outpatients (60%) and 102 out of 135 members of the general public (76%) agreed to participate in the prospective cohort study. Subjects were asked to complete a written AD, which included four illness scenarios with 11 treatment choices in each, as part of the questionnaire. A second and third interviews were conducted after the 6- and 12-month intervals in 296 patients and 78 members of the public, and 154 patients, respectively (no general public interview was completed in the third interview). Most subjects made moderately stable decisions when using scenario and treatment specific directives, and stability improved after they reviewed the decisions, especially among those who had discussions with their physicians. The AD was considered reliable in reflecting the patients' choices even after 1 to 2 years after completion.

In summary, a number of studies had examined the stability of patient preferences on resuscitation over the period of 1 month to 2 years and also various factors associated with the choice of treatment or changes in the treatment preferences. Life-sustaining treatment preferences appear to be stable in up to 80% of the subjects over the study period and the stability is slightly affected by illness experience.

2.19   Who should be involved in the Decision-Making?

To explore the issue on decision-making, Kerridge and associates performed a cross-sectional survey in the USA. Five hundred and eleven healthcare professionals (64%) and 152 patients (58%) agreed to participate.

It was found that 80% of the patients and 99% of the healthcare professionals thought that the patients' views should be taken into account when making decision concerning CPR. More patients than healthcare professionals indicated that doctor should be the main decision-maker. Two-thirds of all respondents regarded the patient's wishes, diagnosis and quality of life as important factors.

Most respondents (82%) felt comfortable discussing CPR, but only 29% of the patients and 57% of the healthcare professionals had actually discussed CPR with the others (P<0.001). Forty seven percent of patients and 69% of healthcare professionals preferred to express their wishes about CPR in writing; the rest preferred to tell a family member or close friends. Most patients and healthcare professionals wanted their views to be present in their medical records.

2.20 Proper Information for Patients

Common sense indicates that adequate and accurate information is important to good and effective decision-making. Yet, some researchers mentioned that provision of information and good understanding of the information by patients was still problematic in the application of AD. Fischer and colleagues in 1998 found that a number of patients had the misunderstanding about CPR and mechanical ventilation. Sixty-six percent of patients did not realize that most patients require mechanical ventilation after undergoing resuscitation. None of the 43 patients who discussed about mechanical ventilation had a good understanding of it; 67% did not know that patients generally could not talk while on ventilators; 46% expressed serious misconceptions about ventilators. In other study, it was reported that most of older adults had little or

no accurate knowledge of CPR (Godkin, and Toth, 1994). The knowledge deficit and misconception should be addressed in planning the use of AD involving CPR decision-making process. The information should include diagnoses, prognosis, CPR procedures and the outcome of CPR in specific illness.

2.21 Summary

Several of the previously mentioned studies clearly documented many shortcomings of care actually delivered to patients with terminal illness. The preference for comfort care strongly expressed by patients with terminal illness will not be effective if clinicians and other care- providers do not respect the patient's right and do not take them in to consideration while providing care. The terminal care and advance directive should be provided simultaneously with psychological support.