

CHAPTER VI

DISCUSSION

This chapter will begin with a discussion of the research methods by assessing the impact that various biases may have had on the results, including a traditional description of some of the strengths and limitations.

Then, it will move onto a discussion of the results and relate the results to broader previous studies. Toward the end of this discussion we summarize the significance of this research. The last section of this study is devoted to the recommendations for immediate and future research and will finish with some concluding remarks.

The following five studies will be discussed: 6.1 retrospective study of the medical records of terminally ill patients; 6.2 attitude study in non-critically ill patients; 6.3 non-randomized control study in terminally ill patients; 6.4 focus group discussion with nursing staff; and 6.5 self-administered questionnaires for medical staff.

6.1 Retrospective Study of the Medical Records of Terminally Ill Patients

The objective of this study was to identify the proportion of CPR, the severity of the illness, and the outcome of CPR attempted in a terminal illness in a teaching hospital (Chiang Mai university Hospital). Cardiopulmonary resuscitation attempted in terminally ill patients was retrospectively assessed from the medical records of hospital deaths with one of any eight life threatening diagnoses during a 3.5 year period.

6.1.1 Strengths and Limitations

This study is the first report from Thailand, which utilizes the Utstein Guidelines for in-hospital cardiopulmonary resuscitation research. The results may have several important implications for the manner in which the baseline results will hopefully stimulate responsible clinicians to work on improving CPR practices, such as the development of CPR and DNR policies in this setting and elsewhere in Thailand.

However, the results of this study are also limited by a number of factors. The characteristics of this hospital may not be generalizable to others because it is a tertiary referral center and the expectations of the patients and families may be higher than at community hospitals and also the physicians themselves may be more aggressive and more optimistic than physicians elsewhere.

From a methodological standpoint, the most serious problem is the fact that we retrospectively collected data from the medical records; thus, the results depend critically on the accuracy of documentation on the records. For this reason, we tried to

choose variables that are likely to be documented accurately in the medical record. We also realize that the lack of a CPR flow sheet and of a CPR team who have that specific function and who were able to record the event immediately after they finished each treatment would influence the validity of the record, especially the time theme.

6.1.2 Findings Discussion

As far as we can determine, there is only one other English paper dealing with CPR in Thailand (Suraseranivongse et al., 1998). In this study, the Utstein Guidelines for in-hospital resuscitation research is first utilized in this country and it is the first report from Thailand which utilized these guidelines (Cummins et al., 1997).

In this study, we examined the inpatient charts of 411 patients who died in Chiang Mai University Hospital from January 1, 1996 through June 30, 1999 with any of the following diagnoses: 1) non-small cell lung cancer stage III or IV; 2) multi organ system failure with sepsis; 3) exacerbation of chronic obstructive pulmonary disease; 4) exacerbation of congestive heart failure; 5) non-traumatic and non-diabetic coma; 6) carcinoma of the colon with metastasis to the liver; 7) acute respiratory failure; and 8) end-stage liver disease.

Of 411, 270 (65.7%) received CPR prior to death. Almost two-third (64.0%) of the resuscitation group had a CPC = 3 and 4 within 24-48 hours prior to arrest, indicating that they were in very poor condition. In the review by DeBard (1981), at least one study suggested that approximately 11% of patients who survived initial resuscitation would undergo CPR at least one other time during their hospital stay. Our study showed a similar proportion of repeated CPR.

Since cardiopulmonary arrest is likely to occur during the hospitalization of an elderly, chronically ill, or terminally ill person, there is little ethical justification for not discussing it in advance (Ruark and Raffin, 1988) instead of repeated CPR and the prolongation of death in terminal illness.

This study also found that at least some terminally ill patients (for whom all available resources were provided) received expensive care of a kind that they may not, if better informed, have desired. In the case of the terminally ill, every effort should be centered on their right to withdraw from treatment and to refuse certain kinds of treatment (Smedira et al., 1990) and to have a larger number of choices concerning where they spend the remainder of their lives. If the patients and their families had greater decision-making power, their welfare would be enhanced and the cost of care might be reduced.

The study by Taffet et al (1988) can also be used in conjunction with other data to enable physicians to make more informed recommendations to patients and families about resuscitation. Therefore, if we use an illness as a clinical marker for being in the poor survival group, we can use the particular patient as a trigger for ongoing, thoughtful, positive discussion about resuscitation and DNR order.

The 9.5 percent frequency of DNR order in this study was comparable to the 0.4 to 13.5 percent range of frequency in the study of Zimmerman et al (1986) but less than the 14 percent incidence by Youngner et al., 1986. In this study only CPR was withheld, no other support was withdrawn.

6.1.3 Conclusions

The patients in this study were terminally ill and therefore at a higher risk for CPR. The study confirms that in many instances although communication about CPR between these patients and/or their relatives and their physicians is crucial, it is inadequate. Interventions to improve communication should target these populations and it should be started before the arrest situation occurs.

Further research should examine in more detail the specific barrier to better patient/family and physician communication and how to improve this. In addition, how the decisions to limit care are actually correlated with patient preferences and influences subsequent resource use in Thailand. These should be done with respect to the patient's rights and autonomy, the choice of treatment and place where they want to spend their remaining life. If indicated, a DNR order should be written as soon as possible.

6.2 Attitude Study in Non-critically Ill Patients

This study was specifically designed to survey ambulatory individuals who were admitted to the general medical ward of CMU Hospital. Its function was to assess the attitude and preferences of advance directives for CPR among these patients and to identify any issues which needed improvement for our ADs intervention.

6.2.1 Strengths and Limitations

6.2.1.1 Strengths

This study is different from previous studies to a certain extent, in that most of their previous samples were from developed countries. Generally, their subjects were more educated. In contrast, most of our subjects had primary education and were from the rural area. The study proved that AD is not just applicable to those educated people but also to the uneducated. However, the method of interview must be adjusted by "pace" with the patient and this technique has never been reported previously.

6.2.1.2 Limitations

This report concerns only ambulatory subjects at CMU Hospital. However, this may be arguable for two reasons. First, our study was conducted at a single site, therefore, it has a potentially limited generalizability and targets only Northern Thai people with their unique culture. Second, although we did not formally assess the mental status of the patients, all were able to participate in the interview without difficulty, and none seemed to be severely demented.

6.2.2 Findings Discussion

Our results may be different from previous studies performed in North America. Since most of their samples were from developed countries and generally their subjects had higher education and higher socioeconomic status. (Emanuel L.L. and Emanuel E.J., 1989; Emanuel L.L., Barry et al., 1991; Danis, Southerland et al., 1991; Molloy and Guyatt, 1991; Daly and Sobal. 1992; Walker et al., 1995). Conversely to us, here, a number of subjects were rural residents, undereducated and very intriguingly mostly

male. In addition, subjects were very poor. The proportion of poverty in our study subjects is higher than the majority of the Thai population (Tangcharoensathien et al., 2000). These results should be typical of northern Thai patients who are admitted to the general wards of government hospitals.

6.2.2.1 High Respond Rate

We obtained a very high response rate of interviewing compared to previous studies, 98.5% vs. 77% (Murphy et al., 1994). This might reflect the cultural specificity for rural residents and the way people think about health care workers. Moreover, the method of interviewing in an empathetic manner by taking a pacing with the patient may increase the confidence of the interviewee in expressing their attitude and preference. This may be an appropriate method of study in similar groups of subjects.

6.2.2.2 Attitude towards Advance Directives for CPR

It is fortunate that the majority of the subjects welcomed discussion of CPR issues. Most agreed that the advance planning for CPR should be discussed in advance. This is contrary to Chinese subjects, where only 37.2% of 43 elderly Chinese agreed that making an advanced directive would be necessary (Low et al., 2000). Importantly, our subjects distrust formal documents. This is probably due to the general attitude of Thai rural people against document.

However, this is not uncommon. Emanuel EJ, Weinberg et al. (1993) and Campbell and Frank (1997) found that the proportion of patients who had advance care planning "in a written document" was low. Moreover, the observation of Hanson and

colleagues summarizes that no actual decision for CPR was based on a written advanced directive but rather the patients' preference was the rationale for 41% of decisions (N=311) to withhold CPR from incompetent patients.

As to the timing, our patients agreed that the assessment of preferences should take place on a routine visit to every admitted patient. This finding is similar to previous findings (Gamble, McDonald and Lichstein, 1991).

This study indicated that many ambulatory medical inpatients want to be involved in decisions about CPR. We suggest that clinicians should take a more active role in promoting discussions of patient wishes regarding end-of life care. The patients and their families should be informed of the patient's autonomy on advance medical planning. It is appropriate for the clinician to initiate these discussions at a routine visit before the patient becomes unable to participate in the decision process. Clinicians can encourage patients to share their wishes with potential proxies. Importantly, before making any AD form, clinician are encouraged to assess whether our patients understood the risk and benefit of AD in each procedure by checking the reliability and understanding of their answers using parallel questions. Only patients who gave identical respond were accepted as the AD.

We hope the empirical studies will encourage clinicians to make discussions of end-of-life care as a routine part of their practice. In this country, further study is needed to determine who should be responsible for this valuable work and how to motivate clinicians, patients, and their families to share their wishes before the patient is incapable.

6.2.2.3 Preference for CPR and No-CPR

Although a majority of this study's subjects in both genders favored resuscitation, many (especially those who were poor) refused resuscitation when it was accompanied by mechanical ventilation and/or coma. This is probably due more to the subjects not wishing to impoverish their family by hospital care and treatment which has no real effect on the prognosis. This finding is consistent with previous studies. Walker and colleagues reported that only a small percentage of retired elderly, both who had and did not have a living will, desired CPR in the scenarios of terminal illness, functional impairment, and cognitive impairment. A number of surveys show that most persons oppose aggressive treatment in the persistent vegetative state (Emanuel, Barry and Stoeckle, 1991), dementia and terminal situations (Emanuel, Barry and Stoeckle, 1991; Miura et al., 2001). Moreover, Molloy and Guyatt (1991) found that 88% of 119 elderly persons requested not to have even CPR done.

We also found an interesting result, that females preferred "No-CPR" more than males. This is probably explained by the fact that females are usually care providers, and may not want to burden any one in her family when an adverse outcome seemed likely to her. Similar findings were observed in subjects who were not married. Those might be afraid that there would be no one to take care of them. For older adults and subjects with chronic illness, they probably have been sick and may have accepted that it will be their time.

This study confirms that prognostic information had resulted in more patients' refusal of CPR. When obtaining information about patients' resuscitation preferences

before making any specific directives, clinicians are encouraged to inform the patients gradually about the survival chances and the likelihood of post CPR condition. As a consequence, the patients may specify acceptance or refusal of selected interventions used in resuscitation and their preferences can be incorporated in any type of advance directives.

6.2.2.4 Defer Decision

Interestingly, despite the fact that northern Thai culture places emphasis on the family, all of the males who decided to defer the decision re CPR after receiving each of the four prognostic scenarios decided that their physician(s) should make the decision. In contrast, all of the females who chose to defer the CPR decision chose their family as the decision-makers; none was choosing their physician(s). Moreover, the proportion of males who decided to defer the decisions was much more than the females, but the small number of females who decided to defer their decision precluded statistical analysis in this group.

These results are quite contradictory to man's role in the society, where "man is the leader of the family" (Sutthiyano, 1988; Sethabouppha, 2002). However, in this country, especially for people in remote areas, the patients still trust and respect the physicians. For a serious medical topic, the man probably believes that if he could not make a decision on any issue, neither could anyone in his family. This is probably why all of the CPR decisions were left to the physician.

For the three female subjects, who decided to defer decision, all were from rural areas and were undereducated. They probably follow their usual patterns.

The variation in preferences might reflect cultural different, the differences in nature and severity of the illness, and the optimistic nature of the study subjects. For these reasons, patients should be assessed individually before obtaining any form of advance directives.

6.2.3 Conclusions

Our findings are different from previous studies to some extent. We obtained a very high response rate and gender specific differences that may indicate cultural different. Moreover, most of our subjects were poor, had primary education and were from the rural area. They may not be familiar with the questions and this specific information, therefore, the method of interview had been adjusted accordingly. This technique should be repeated to test its reliability in a similar group of subjects. Importantly, our patients distrusted AD documents. These feelings were respected but further investigation is needed to identify the most effective strategy to transfer the patient's need in this society.

Although some findings are similar, the survival chance after CPR and the worst condition post CPR can dramatically change their preference for CPR. The preferences of patients with various conditions might show a different picture. For the future study, we would suggest extending the study to 1) non-hospitalized; young adults aged less than 40, middle aged adults 40-59 and older adults aged 60 years and older, 2) hospitalized patients with chronic and/or terminal illness. For whom, who may need to decide soon?

6.3 Non-randomized Control Study in Terminally Ill Patients

This non-randomized control study was specifically designed to assess the effectiveness of advance directive intervention as applied to terminally ill patients who were admitted to twelve medical wards of CMU Hospital. Previously, we intended to include patients with eight diagnoses (mentioned in Section 6.1). However, the AD has never been implemented in Thailand and the proposal defense committee of the College of Public Health suggested that the study should include only patients who were really terminal. Therefore, the patients with any of the following five diagnoses were our study subjects: 1) non-small cell lung cancer stage III or IV; 2) multi organ system failure with sepsis; 3) non-traumatic and non-diabetic coma; 4) carcinoma of the colon with metastasis to the liver; 5) end-stage liver disease.

6.3.1 Methods Discussion

6.3.1.1 Change from original proposal

There were two major changes from the research proposal. First, that the original intent was to include the family to co-sign the consent for participation with the patient. However, after two-weeks of trial period, it was possible to obtain only five pairs of subjects and surrogates to participate in the study. If we follow the original proposal, it would probably take more than three years to finish collecting the data for 368 subjects. This is because the hospital policy does not allow relatives to be with the patients in general wards. We can identify relatives only during visiting hours, which is short, rushed, and usually during lunch or dinner times. However, if we adjusted to a classical norm, by obtaining only the consents of the patients, then the time will decrease more than one half. This aspect of the research was not carried out. Second,

we proposed to finish data collection in terminally ill patients for both control and advance directives groups within 12 months. However, this way was impossible for the following reasons:

During the early course of the research, major organizational changes occurred that affected the inclusion number of the study subjects. The Ministry of Public Health (MOPH) policy called for 30 Baht per visit. This meant that the patient would pay only 30 Baht when they got sick no matter what the diagnosis was. However, this policy also located the hospital for each person in a specific area which must be attained when indicated. If anyone visits directly to an unspecified hospital, they have to pay the medical cost by themselves. In addition, if the primary hospital referred any patient to another health institution, they have to pay all of the medical care cost to the referral place. This policy has directly affected the poor. During the early period of this policy the primary hospital hesitated to refer patients to other hospitals, especially those with terminal illnesses, since it might consume large amounts of their hospital budget. In addition, those patients usually have no money to pay.

The effect of the MOPH policy was put into action on June 1, 2001. It can be noticed that the number of admissions of terminally ill patients decreased during the first three months after the policy was started. Previously it was possible to include approximately 25-30 subjects/month. However, during this period, there were only 20 subjects/month. Fortunately, there has been a “rebound” and a number of patients is now the same as before the MOPH policy. Based upon the above, we settled on recruiting all controls within 8 months. This interfered with our study; it delayed

recruitment control and affected the start of the intervention, including the study with nurses and physicians.

6.3.1.2 Strengths and Limitations

6.3.1.2.1 Strengths

6.3.1.2.1.1 Sample Selection

This study is different from previous studies in terms of the population being studied. Most of our subjects were poor, had primary education and were from the rural areas. The study proved the applicability of AD in this group of subjects.

6.3.1.2.1.2 Method for Advance Directive Intervention

The interview was performed gradually, over at least three sessions by empathetic nurse-researchers who “paced” the interview according to when the subject seemed ready for the next group of questions. We also provided psychological support to all of our patients and their families. As far as we can determine, this method of AD intervention is unique and has never been reported previously.

6.3.1.2.2 Limitations

Every investigation, no matter how well planned and implemented, has specific limitations with respect either to the type of information collected or the extent to which alternate explanations for the results may be postulated. This non-randomized control study was certainly no exception to the rule. However, the identification of problems in the design or conduct of research still advances the process of scientific inquiry by allowing investigators to avoid such limitations in the future..

6.3.1.2.2.1 Study Design

6.3.1.2.2.1.1 Non-participants

The first type of bias that we were concerned was about the non- participants. In this study, the non-participants had been characterized as possible, using information available, to determine ways in which they differed from participants and to gauge the likely impact of the non-participants on the findings. First, analyses were performed by including all of the non-participants into the study sample, and then, comparing the two groups (control and intervention). Second, further analyses were attempted to compare both participants and non-participant between the control and the intervention groups. Generally, there were no significant differences by age, gender, co-morbidity or residence. However, diagnosis was the only significant difference observed between the control and intervention groups. The subjects with ESLD were admitted into the control group more than in the intervention group. Therefore, all analyses were further stratified by the two diagnoses to balance this confounder.

6.3.1.2.2.1.2 Co-Intervention

There are two possible co-interventions to this study; first is the MOPH policy, and second is that this hospital had been lunched for the hospital accreditation during the whole period of the study.

As previously mentioned, the MOPH policy (30 Baht/visit) may have an effect on AD intervention. According to the study protocol (see Chapter IV), at the beginning, the patients and relatives were encouraged to obtain the information about their diagnoses and prognoses from their physician before providing CPR information and

continuation to AD employment. These consultations were previously insufficient. Many patients were being transferred or discharged without knowing their illness.

The same as in the hospital accreditation, the patient's rights are one of the several indicators to be accredited. All hospital personnel were encouraged to respect the patient's rights.

However, this affect may likely be balanced because these two policies were implemented throughout almost the entire period of study (in both control and intervention).

6.3.1.2.2.1.4 Hawthorne Effect

The Hawthorne effect refers to the tendency of subjects to alter their behavior simply because they are being studied (Burt Gerstman, 1998). This suggests that the knowledge of being observed has an influence on the behavior and state of mind of the study participants. In this study, the Hawthorne effect could happen when nurses and physicians become aware of their participation in the study, and thus might alter their actions accordingly.

In our study, at least one preliminary study had been performed in this setting before implementing an advance directive intervention. Since data from the pilot study noted that the patients seemed to be tense when discussing the CPR issue. According to this reason, an attitude study was performed to assess the acceptability of AD for CPR and end-of-life care. However, the study was done on non-critically ill patients and was not involved with the clinicians. Moreover, to prevent this effect, the study on

physicians and nurses was performed at the end. In addition, to decrease the belief that clinicians are being observed, all record books and our blank questionnaires that we carried with us (sometimes was intentionally left on their working table) were focused on the patients' information. All of these were carried in a transparent box that anyone could observe. Therefore, with all of these efforts, the Hawthorne effect is less likely to happen.

6.3.1 Result Discussion

Having an AD has been proposed as a means for a competent person to assert his or her autonomy before he or she becomes unable to make decisions. The key hypothesis behind advance directive proposes that if an intervention enhances a person's right to choose, dying persons will not opt for technological (and costly) medical care. Physicians will honor that choice, alternative palliative care will be less costly, and an ethical saving of resources will result.

Before the results are discussed, their validity should be considered. The study on the patients, physicians and nurses showed nearly identical results, although data in each of these studies were obtained in a totally different way and during a different period of time.

6.3.2 Summary of the Major Findings

Data from the patients, physicians and nurses confirmed that AD is acceptable in this setting. Moreover, the study also proved that AD is applicable to individuals who have low education, low socioeconomic status, as well as rural dwellers, but the

method of implementation must be adjusted according to educational level and emotional status of the patients. The data also endorsed that AD could be introduced to all types of patients (non-critically and terminally ill patients).

A statistically significant decrease in the rates of CPR performance and a low CPR rate is observed in the patients who received AD as compared to those without it. Although the high death rate is typical for this population, the mortality rates at hospital discharge and at one month for the intervention were less than the control group. In contrary, CPR performance rate was quite high, 54.5% and 52.9% of terminally ill patients in the control and intervention groups still received CPR prior to death. However, the imbalance of two clinical characteristics (the CPC score and ESLD) was observed between the two groups even after adjusted with Mantel Haenzel Chi Square.

From our observations most ADs for end-of-life care had been developed in consultation with the relatives when the patients were incapacitated. For patients who were capable, information regarding prognosis and also the decline of clinical symptoms were predictive of which end-of-life care decisions were made. Whether they want to continue hospitalization or prefer to go home. Meanwhile, the majority of the subjects who stay in the hospital prefer CPR, however, most refused CPR, if it might be followed by worse outcomes. Additionally, many subjects declined treatment in the terminal stage of their illness. Importantly, the preference for in-home death is dominant; it was observed in both patients who continued in hospital and patients who decided on self-discharge.

Generally, information about diagnoses and their prognoses had affected which decisions regarding end-of-life care patients and their families made. The likelihood of a condition being terminal and previous discussions with the family of the patients dictated for clinicians the care they provided to the patients. The wishes of the patients and family were generally respected even without the formal ADs or DNR orders. From these findings, we can infer a high degree of respect for patient wishes.

In this study, few variables were associated with a patient's preference for terminal care. Therefore, our investigation suggests that the preference of patients for each procedure should be assessed individually after adequate information has been provided to them.

6.3.3 The Effectiveness of Advance Directives Intervention

The primary objective of the study is to test the effectiveness of AD as applied to terminally ill patients. However, it is interesting that we still can not give a definite answer about the effectiveness of AD because the imbalance of the two clinical characteristics (the CPC score and ESLD) are observed. However, after adjusted with Mantel Haenzel Chi Square (analysis of covariance), there is homogeneity of the two characters. Lower CPR and mortality rates at hospital discharge and at one month for the intervention group as compared to the control group may reflect several factors such as psychological effect of the patients or factor (s) related to treatment and home care. Future study must be planned to give definite answer.

However, when compared with the study in Section 6.1 (retrospective study of the medical records of terminally ill patients), in that study, 65.7% of terminally ill patients received CPR prior to death. Surprisingly, in this study, 54.5% of the patients in the control group and 52.9% of the patients in the intervention group still received CPR prior to death. Sub-analyses between patients who died and survived showed no significant differences. The results implied that those who died and those who lived have no different characteristics. These perplexing results remind us to reconsider the role of AD with clinicians. Even though the majority of physicians support the AD for CPR in terminally ill patients, one-fifth disagreed that CPR information should be discussed with the patients and 21.8% still wanted to do CPR for them without regard to the patient's or family's need. This group of physicians may perform those CPR attempts.

As suggested by Rubenfeld (1995), a more realistic appraisal of the potential role for advance directives coupled with an emphasis on education and rational treatment guidelines should promote continued improvement in the compassionate use of cardiopulmonary resuscitation. The additional discussion will be presented in Section 6.5.

Rubenfeld (1995) also summarized that early studies that examined the care received by those with and without ADs have been unable to document differences. This included a huge and excellent design such as the Study to Understand Prognosis and Preference of Outcomes and Risks of Treatments (SUPPORT) project. On a much larger scale, the results have elucidated disturbing discrepancies between physician

Covinsky et al., (2000) also found that there was no evidence that increasing the rates of documentation of advance directives results in care that is more consistent with the patients' preferences. SUPPORT documents that physicians and surrogates are often unaware of seriously ill patients' preferences. In addition, the physicians are careless about following their patients' wishes, and imply that ADs are not truly effective.

Recently, Somogyi-Zalud et al. (2002) reported that of the 1,266 patients enrolled in the Hospitalized Longitudinal Project (HELP), 72 died during the enrollment hospitalization. Most patients who died had stated that they did not want aggressive care. However, the majority (63%) of the patients received one or more life-sustaining treatment before they died, 43% were on a ventilator, and 18% received CPR.

Molloy and colleagues (2000) reported the results of their well-conducted study, in which nursing homes matched in pairs on several key characteristics which were randomly assigned. One of the nursing homes in the matched pair received systematic implementation of an ADs program and the other adhered to existing policies. The intervention consisted of the Let Me Decide directive, which included instructional and proxy components that provided a range of choices for levels of care for a serious illness. The intervention included; 1) education programs for nursing home staff that included video tapes and in-service training, use of a "health care facilitator," 2) the requirement that physicians must review and sign the directive, and 3) steps to ensure that the directive was prominently placed in the medical record and transferred with the

patient to the acute care hospital. All these components were critical to the impressive reduction in the rate of hospitalizations (0.27 per control resident compared with 0.48 per intervention nursing home resident). They also documented a reduction in resource use (saving approximately Can \$ 1700, or about US \$ 1200, per patient). With the features of the intervention combined, and none of them in isolation, it's likely contributed to this reduction in hospitalization and savings in resources for nursing home residents.

In our study, if the patients or relatives decided for the DNR, their wishes had been followed and respected. However, in the viewpoints of the patients (who continued hospitalization), families, and clinicians, AD seems to be acceptable only for DNR. No other treatment had been withdrawn from the patients except when death is predictable and they decide for in-home death (will present in Section 6.3.8). However, for patients and families who decided on self-discharge, all treatments including hospitalization were declined. In this study, we did not measure the cost of care because it was the focus of most subjects, and they were not willing to discuss this issue (data obtained from pilot study).

6.3.4 AD Employ

In our study, a number of subjects and surrogates decided on AD regarding CPR (80 of 132 pairs) by word. Those persons put efforts into controlling the medical treatment through oral declarations suggesting more than a wish; they suggest an ironclad determination. Informal expression of a patient's need could help the family make a substitute judgment. In addition, a clear understanding of the patient's wishes

regarding life-sustaining treatments, enables health care providers to advocate more effective care on the patient's behalf.

Our finding is quite different from Kerridge et al. (1998). In their study almost half (47%) of the patients preferred to express their wishes about CPR in writing and the others preferred to tell a family member or close friend.

However, feeling uncomfortable putting something in writing is not unusual. At least one study concluded that a high percentage of subjects were not completing AD because of the same reason (Sugarman et al., 1992).

Importantly, none of our subjects agreed to sign any AD document. This is probably due to the general attitude of Thai rural people against document. This finding is no surprise since it repeats the pattern of AD studies in previous reports. Several investigators in the US mentioned that advance directives and living will completion rates were very low, especially in the earlier phases of implementation but there was a gradual increase. In 1991, Gamble et al. found that no elder person had signed the living will document provided by the state of North Carolina. A year later, Sugarman et al. (1992) reported only 4 percent of Veteran's patients completed a living will. The rate gradually increased in other study groups but varied from 5-25%. (Sachs et al., 1992; Hanson and Rodgeman, 1996; Miles, Koepp and Weber, 1996; Goodman et al., 1998; Gross, 1998; Suri et al., 1999) However, at least one study suggests that a possible explanation for the low rates of ADs use by older people is that they trust their families to make decisions for them (Puchalski et al., 2000).

In the year 2000, Lee and others obtained a very high rate but with their specific measure (will discuss later in Section 6.5.2 Improvement of AD documentation)

Lately, one qualitative study in Baltimore, USA (Carrese et al., 2002) contrasted to other reports. The elderly in this study described a view that does not easily accommodate advance planning. They were resistant to planning in advance for the hypothetical future, particularly for serious illness when death is possible but not certain.

In this case, an insistence that such patients participate in advance care planning would probably be fruitless. However, in this study, they interviewed only a relatively small number of patients (n =20) who were ill, housebound, and had limited formal education.

Their study populations had similar characteristics to our study subjects in terms of low education and not much exposure to current information (house bound/ rural dweller). However the method of intervention was different from our study. In that study, each patient was interviewed only one time and it took one-two hour(s) to complete. In our study, we found that the questionnaire should not be administered in a single interview because the patients seemed to be tense and the reliability was low. Therefore, we changed the interview method. The questionnaire was administered over at least three sessions by empathetic AD nurse-researchers who “paced” the interview according to when the subject seemed ready for the next group of questions. At the first visit, to obtain consent, we introduced ourselves, explained the objective, the process of

the study and the method of selection of the subjects. After receiving signed consent, the balance of the initial interview focused on general information, including the demographic data and the subject's knowledge of their illness and prognosis. The next interview started again with the general topic and, then, moved forward to their CPR preferences and their advance planning for CPR. The CPR issue was started after trust was established. This measure seems to be effective with this group of subjects.

Previously, the AD documentation rate also varied by ethnicity (Braun, Onaka and Horiuchi, 2001). It was lower in Filipino and Hawaiian ancestry (13% and 22%, respectively) compared with adults of Japanese, Chinese and Caucasian (33%, 36% and 36%, respectively). Reasons for the high completion are not clear. Higher education and socioeconomic status have been shown to relate with higher rates of AD completion in the US (Hanson and Rodgeman, 1996; Miles et al., 1996).

Those samples contrasted with our subjects. In this study, most subjects had low socioeconomic status and low formal education but we obtained quite high AD employment rate. However, the method of implementation by pacing with the patients, the sympathetic manner of the AD nurses, and also psychological support provided to the patients may affect the results. Additionally, the high regard for the health profession by northern Thai culture may contribute to their high acceptability of AD discussion. However, for the AD documentation, it probably needs more time to be accepted or may need other affords or word transfer may be effective in this culture. All still need to be proved.

6.3.5 When AD should be Initiated

As mentioned in Chap II, AD is a statement in which persons seek to extend their right into a future time when they may not be fully competent. It allows a person to state in advance of becoming incompetent that they wish to take part in treatment decisions when no longer mentally competent. AD can be employ by that person or surrogate decision-maker or both. Since our subjects had terminal illness, and from our observation, their condition may change easily. Therefore AD should be initiated as soon as possible.

The discussion among patient, surrogate, physician and nurse should be done with adequate information. After informed discussion, the willingness whether a person wants to make a decision by themselves or defer to their surrogate should be identified in the first place, because both groups may need a different approach.

Subjects, who preferred to decide by themselves, whether by word or by formal documentation, needed to transfer these decisions to their families and other health care providers thereafter. Some did not want to make a decision and deferred the decision to their surrogate. Priority must be placed to inform and discuss with the surrogate-decision maker, if those surrogates did not participate in previous discussions. The patient is encouraged to discuss his/her needs with their surrogate and may consult with their physician and nurse if needed.

6.3.6 When AD should be omitted

All subjects who are less than 18 years of age or impaired physical or mentally or both are not ethically and legally qualified to employ AD. In this situation, a legal surrogate should be required to make decisions on the patient's behalf. However, attention must be paid to the legal surrogate who had any conflict with the patient, especially when the patient was already incapacitated. Fortunately, this situation was observed infrequently. In our study, only one of the 376 subjects had this problem. In this situation, the decision should be undertaken using medical guidance.

6.3.7 Information about Illnesses and Prognoses

Our data indicated that AD intervention had increased the proportion of patients who discussed his/her illness with their physicians. Before the AD implementation, only a small number of subjects had accurate information about their diagnosis (35.1%) and it was even smaller for the prognosis (16.5%), whereas more than half had consulted with the physicians thereafter.

A poor prognosis need not be a secret kept from the patient; they do not necessarily need 'protecting' from bad news. Honest, open discussion has been shown to be desired by most of the patients in this study and endorsed the finding by Schmerling et al., (1988).

Similarly, Johnson and Justin (1988) reported that patients wanted to be told the truth about their health and their health care, and they wanted to participate in decision-making, even while dying.

Previous literature has identified several reasons why physicians do not discuss prognosis, including uncertainty about prognosis, limited resources (including time and communication skills) to initiate such discussion, avoidance of the difficult topic of death by physicians, patients, and their families, and the desire to maintain patient and family hope.

In this study, subjects were incurably ill with a predicted survival of six months or less, many of which had functional impairments and other co-morbidity (s). They are a large subset of those patients who require the broadest range of options for treatment.

In order for the patients to make meaningful decisions about their health care, they require honest, objective, and complete information about their state of health, their prognosis, and the likely outcome of any proposed interventions. (Gilligan and Raffin, 1996)

Ideally, medical decision-making should only be done once the patient has been truly informed, has understood the risks and benefits of the procedure, and has considered his/her own value system. This requires that the physicians give their patients information relevant to individual concern so that they may choose a treatment option best suited to their goals.

This study was conducted among terminally ill patients, for whom prognostic certainty is greatest and for whom such discussions may be particularly useful. Our observation and data from the nurses suggested that the lack of information might be, in

part, from the patient's perception. Therefore, in a similar group of subjects, we would suggest changing the method of informing the patient, as previously mentioned (Chapter IV).

6.3.8 Substitute Judgment

When the patient lost their decision-making capacity, the surrogate decision-maker or proxy represents the patient's interests in specifying treatment preferences on behalf of a decisional incapacitated patient (Volicer et al., 2002). This type of planning is particularly suited to terminal illnesses, where it is common for patients and families to choose to forgo life-sustaining treatments and where undue suffering can often be avoided by anticipating medical decisions before they occur. Previously, the vast majority of designated proxy decision-makers were the patients' next of kin. Gamble et al. (1991) concluded that the majority of elderly persons ($n = 70$, 93%) in a rural county in eastern North Carolina wanted their family or spouse to make decisions about terminal care if they themselves were unable to participate.

Emanuel EJ et al. found that 82.5% ($n = 312$) of patients who had designated proxies formally by writing or informally selected their next of kin as their proxies and significantly fewer patients with formally designated proxies selected their next of kin as their proxies. They also reported that patients who had formal proxies had more detailed discussion with their proxy about specific intervention than the other.

In this study, our patients selected their next of kin and their physicians as their proxies. However, we have observed some changes to assigning the surrogate decision-

maker in different situations. For medical decisions, the proportion of family involvement was more than physicians, 61.2% vs. 37.3%. It is reversed for the CPR procedure, with the physician involvement greater than the family, 68.1% and 55.9%, respectively. Generally, the family still plays an important role for both situations but physicians more or less participate in the decisions. Respected physicians' decisions for health care is still observed in this culture. However, physicians routinely rely on family members to serve as proxy decision-makers in this setting.

This finding is similar to that of Puchalski et al. (2000). In their study, seriously ill and older patients appear to be especially likely to want their family and physician to make decisions for them. Of the 513 HELP (the Hospitalized Elderly Longitudinal Project) patients, 363 (70.8%) would prefer to have their family and physician make resuscitation decisions for them. Of the 646 SUPPORT patients, 504 (78.0%) would prefer to have their family and physician decide. Independent predictors of preference for family and physician decision-making included not wanting to be resuscitated.

In our study, no formal designation was done for a substitute decision-maker, as all had been stated by word. However, the decision to withhold treatment had no benefit to any other person. This is not the same as a property bill. Vocalization may probably be effective in this group of subjects but it has to be clearly expressed.

Substitute judgements may improve if the clinicians have more frank discussions with terminally ill patients and families about their prognoses. The intervention might take place during early admission.

Informal expression of a patient's preferences, such as decisions to deal with treatment limitation issues when a relative was sick or informal discussions regarding notorious court cases or friends suffering from similar conditions, can also help the family make a substitute judgment. All of these inputs have to be taken into consideration by both the family members and professional caregiver to arrive at a plan of optimal care that maintains not only the patient's life but also its quality and dignity.

From our observation, families participated and made rational decisions after discussion with their physicians. In each of the cases involving incompetent patients, the family members made a responsible decision, despite terrible grief. Making decisions regarding avoidance of aggressive medical intervention generates feelings of anxiety and/or guilt in many family members (Tilden et al., 2001). Tilden et al. (2001) had observed family stress associated with the withdrawn decision. This feeling can be minimized by clinician guidance and by reference to those wishes the patient expressed before becoming incapable. They also found that stress was highest in the absence of patient advance directives. In this case, the families needed to be reassured that they had already done their best for the patients. However, all of these statements must be honest too.

Preliminary studies indicate that substitute judgement may not be very accurate. (Uhlmann et al., 1988; Sulmasy et al., 1998) Happ and others (2002) found that the surrogate decision-maker chose DNR more often than decision-capable nursing home residents. This may reflect a difference in perceived treatment, a preference between elder persons and their designated surrogates.

Additionally, proxy decisions, in turn, correlated poorly with the patients' own wishes. The results of this study are consistent with previous studies. In our study, the surrogate made correct predictions for CPR in only 71.3%. It was lower than Sulmasy et al. in 1998 (79%). However, this was much better than the Covinsky et al (2000) findings. In their study, surrogate understanding of their patient's preferences is only moderately better than chance.

In our situation, this is the first AD study, and the patient and relative was never been aware about the advance medical directive. The percentage of agreement between patient and surrogate was quite acceptable at the starting point. This is strange because the CPR issue is quite a new subject among the Thai population. In addition, discussion about end-of life issues in Thai custom is uncommon, even among health care providers. In our study, it was not surprising to know that most of the physicians never initiated CPR discussion with their patient. More often they talked with a relative.

For instance, substitute judgements may be improved if clinicians have more frank discussion with all terminally ill patients and their family about their prognoses. The patients and family members will have more opportunities to reconsider and continue discussion so that the solution could be more accurate. Generally, for this society, the words of a dying person are usually respected. The substituted judgments might be effective.

6.3.9 Preference for In-home Death

For northern-Thai people, discussion about end-of-life issues in terminal illnesses is not complete if we do not mention about the dying place. The data from patients, families, nurses and physicians were concordant and strongly support the belief for in-home death in this culture.

However, for competent patients, the trigger for discussion was usually when an acute clinical event occurred with a progressive condition that has already severely compromised the quality of life as judged and defined by the patient. Generally, poor prognosis or worse clinical condition or both were the most common classic reasons for self-discharge from the hospital. However, from our observation and also personal interviews with terminally ill patients and their relatives, it was found that the truest reason for the decision to go home was preference for in-home death. At home, the patients often had time to say good-bye, make amends, right relationships, and participate, even if minimally, in the life around them. Moreover, people in rural areas prefer to perform ritual and funeral ceremony at home. The spiritual belief about the dying place was another issue of concern (in-home death vs. other place). In addition, most relatives prefer to take care, support and attain the final moment with their loved one and preferably at home.

This finding is not uncommon. Data from the 1999 Amnitrak survey suggested that 65% of Hawaii residents would prefer to die at home (Braun et al., 2001). A higher percentage was observed in the study by Karlsen and Addington-Hall (1998), and Ratner, Norlander and McSteen (2001).

In London, a random sample of cancer deaths ($n = 229$) was conducted in 1998. It was found that a fifth of the patients (21%) died in their own home. Overall, 38% were reported to have expressed a preference for place of death, 73% of whom wanted to die at home. Only 58% achieved this (Karlsen and Addington-Hall, 1998).

Ratner et al. (2001) noted that 54 of eighty-three participants expressed a clear preference for the location of end-of-life care. Of these, 82% wanted this care to be at home. Seventy-five percent of these deaths occurred at home or in a hospice residence.

Lee and Pang (1998) summarized that fifty-two percent (23/44) of patients preferred to die at home if possible (compared to 34%, 15/44, who preferred the hospital). Relatives have an almost equal preference for the patient to be at home (45%, 35/77) or in the hospital (42%, 32/77) terminally. Given the support, more (37.5%, 12/32) of those who initially wanted their sick relatives to be in hospital would prefer them to spend their last days at home.

In western countries, the results indicate that financial reasons were most likely to be given for preferring to die at home (Zusman and Tschetter, 1984). More patients with cancer could be supported to die at home, as they would prefer (Townsend et al., 1990). This is quite different from this study, where dying and performing funeral ceremonies at home might be cheaper in our country because they don't have to pay extra costs such as they would at the temple.

For our patients, by incorporating the core values of end-of-life patients and their families into care decisions, providers can offer compassionate care for the dying and avoid unnecessary and futile efforts that not only increase health care costs but often violate the spiritual, emotional, and cultural needs and wishes of the patients and their families.

Our observation noted that many of the patients who chose to die at home still need care that is palliative or less technologically intensive. They should have caretakers who are knowledgeable in techniques for providing comfort without excessive sedation. They should be in an environment designed to optimize the functional status of the individual. At the present time, such care is difficult to obtain in our country. However, in western countries, they already have such facilities in the home and the hospital with hospice care.

Patients with a terminal illness, regardless of their condition, require excellent palliative (supportive care) care. Hospitalization for short-term control of symptoms and services available for patients who are dying of advanced terminal illnesses are immediately indicated.

6.3.10 Additional Discussions

6.3.10.1 Attitude towards Advance Directives for CPR

This finding is similar to the result obtained from non-seriously ill patients. The patients with terminal illness welcomed discussion of AD regarding CPR. Most agreed that the advance planning for CPR should be discussed in advance. This study also

indicated that many terminally medical inpatients want to be involved in decisions about CPR. As to the timing, our patients agreed that the assessment of CPR preferences should take place on a routine visit to every admitted patient. The discussion comparing the attitude towards ADs for CPR with previous reports is discussed in Section 6.2.2.2.

Similarly, we suggest that clinicians should take a more active role in promoting discussions of patient wishes regarding CPR. They should inform patients and their families of the patient's autonomy in advance medical planning. It is appropriate for the clinician to initiate these discussions at a routine visit before the patient becomes unable to participate in the decision process. The clinician can encourage patients to share their wishes with potential proxies.

6.3.10.2 Preference for CPR

Although a majority of this study's subjects favored resuscitation, many refused resuscitation when it was accompanied by mechanical ventilation and/or coma. This study confirms the attitude study in non-critically ill patients, including previous reports. Prognostic information had resulted in more patients' refusal of CPR. Similar suggestions to those with non-critical illness, when obtaining information about patients' resuscitation preferences before making any specific directives, clinicians are encouraged to inform patients gradually about the survival chance, and the likelihood of post CPR condition. As a consequence, the patient may specify acceptance or refusal of selected interventions used in resuscitation and their preferences can be incorporated in any type of advance directives.

6.3.10.3 Treatment Preference in Various Stages of Health

Ideally, treatment preferences expressed before life-threatening illness occurs should be compared with those chosen at the actual moment of decision. This comparison is difficult to make because advance directives are invoked only when the patient cannot participate in decision-making (Patrick et al., 1997).

The results of this study are similar to the study in Section 6.2 (attitude study in non-seriously ill patients). Our subjects would make different advance medical directive choices about their medical care in different situations. However, when the subjects are asked to imagine themselves incompetent with a poor prognosis, they decide against medical treatments. This is consistent with the results of previous research (Lo, McLeod and Saika, 1986; Emanuel, Barry et al., 1991; Reilly, Teasdale and McCullough, 1994; Patrick et al., 1997).

The desire expressed by our subjects who received AD was not to have their lives prolonged if their medical condition was such that treatment would merely delay death. This finding is in accordance with the Gross results in 1998.

In addition, Patrick et al. (1997) concluded that more than half of their participants (n = 341) considered permanent coma a health state worse than death and were more likely to reject all treatments in coma. They also found high rates of concordance between treatment preferences and health state ratings. Concordance was remarkably stable across the 30 month observation periods for health states worse than death. Earlier reports show that the choice to forgo treatment is more stable than the

choice to receive treatment (Emanuel LL, Emanuel EJ et al., 1994; Danis, Garrett et al., 1994).

Their results suggest that treatments are easier to accept or reject if the participants have strong preferences about the outcome of their health. Previously, we thought that all of these studies were done in persons with high educational level and may poorly compare with our population, however, at least two of our studies also confirm these findings.

This similar expression was also observed in the physicians. In the study by Marik et al. (1999), most physicians indicated they would want treatment to be withdrawn themselves if death was imminent or should they be in a vegetative state

In this study, many physicians also accept as a reasonable alternative the withholding of aggressive therapy when treatments offer potentially little benefit but impose great burden. However, most of them wish to narrow the scope to apply only to patients in the "final stage of a terminal condition."

6.3.10.4 Psychological Support

Previous study in Canada summarized that psychosocial variables such as mood, depression, and uncertainty in illness did not influence directive completion (Patterson et al., 1997). However, our observation, as well as that of O'Boyle and Waldron (1997), noted that the psychological stage changed substantially with a serious illness and nearing the end of their lives. Diseases and their treatments can have significant impacts on such areas of functioning as mobility and mood.

We were aware and concerned about this problem, and in this study we provided psychological support to all of our subjects and their family members. The main objective of providing psychological support was for the patients' benefit. With those supports, we did not notice any serious psychological problems. We confirmed the later statement by using an open-ended question to identify how the patients felt regarding talking and being asked about this study's questions. Most had a positive attitude toward discussing this topic. In addition, we also received a number of letters (without our request) reflecting that patients and their families appreciated what care we had provided for them. In the mean time, by applying psychological support to the subjects and their family members, it also facilitated acceptance of death and dying that every one will face.

Previously, Connor (1992) reported that patients using interpersonal denial may respond favorably to psychosocial intervention, whereas denial scores increased for those who did not have the intervention (control).

In summary, for a similar study in terminal illness, we encourage all investigators to provide this support to their subjects.

6.3.10.5 High Respond Rate

We obtained a higher response rate at the one-month follow up for the intervention group compared to the control group. This might reflect the rapport among patients, families and AD nurses. It can be seen in the method of intervention by the AD nurses that interviewed each patient in an empathetic manner, by taking a pacing

with the patient in a non-rushing manner, revisiting several times and most importantly providing psychological support (just mentioned) to the patients and their families in the intervention group. All of which may facilitate a positive result.

6.4 Focus Group Discussion with Nursing Staff

6.4.1 Nurses Attitude towards AD for CPR and AD in Practice

Most of the nurses have a positive attitude towards AD for CPR and agreed that the advance planning for CPR should be discussed in advance. However, they were unconfident to initiate advance discussion for CPR into routine practice. Two major problems were mentioned; first was a time constraint, and second was communication skills.

All of the nurses would prefer to withhold CPR for the patients with the five terminal diagnoses if the needs of the patients or their families or both existed or if it was the physician's DNR order (both in written and verbal order). However, for those without the existence of these two factors, CPR would routinely be performed if indicated. From the study in Section 6.1, we found that the majority of attempted CPR (71.9%) was initiated by nursing personnel. When reconsidering this result with the nurses' responses, we found that the nurses' reasons for performing CPR are more complicated and risky. It depends on several factors, such as the hospital policy, and the patients' and physicians' decisions. In order to decrease the number of CPR performed and improve AD intervention, all measures have to be integrated. This discussion is presented together in Section 6.5.

6.5 Self-Administered Questionnaires for Medical Staff

6.5.1 Physicians Attitude towards AD for CPR and AD in Practice

More than one-third (34.5%) of the physicians would prefer to withhold CPR for the patients with the five terminal diagnoses observed in this study. In contrast, 21.8% still wanted to do CPR for them no matter what the patient's decision. The remaining 23 (41.8%) noted that they preferred to make the decision on a case by case basis.

The reasons for preferring to withhold CPR were that 47.4% of the physicians noted that CPR had previously proven to be futile in this group of patients and 42.1% mentioned that those patients had a very poor prognosis and a very low chance of having a normal life.

The reasons for preferring to do CPR mentioned by at least 1-2 physician (s) were that: it was ethical or it was their responsibility, there was still at least a one percent chance for survival, or it was the last treatment that the patient should have.

Those who preferred to make the decision on a case by case basis mentioned that this decision depended on several factors. It depended upon previous discussion with the patients or their families or both, its solution, and acceptance for DNR for the patient and their families or both.

From these responses, we can divide the decision making of physicians into three main groups: first for those who use a rational medical decision by medical

guidance; second for those who decide to oppose AD; and, finally, those who agree with AD and easily accept AD. For the first group, the DNR policy is immediately needed to protect the physicians from legal problems. In addition, since they are reasonable, AD knowledge and practical skill for AD discussion should be introduced. For the second group, AD education and other measures for encouragement are needed. The last group is ready for AD, and the implementation to improve their practical skills may be valuable. The comparison of this study to previous studies, including detail suggestions, is presented in Section 6.5.2.

6.5.2 Improvement of AD Documentation

As previously mentioned, advance directive is one mechanism for communicating an individual's wishes for future medical treatment. This present study indicated that the majority of all physicians and nurses believed that AD was a useful mechanism for communicating preferences. However, both physicians and nurses were reluctant to integrate advance decision making for CPR into primary care provided to patients. Two identical problems have been observed; time constraint and communication skills (truth telling for bad news and AD discussion).

To overcome this similar problem, Markson et al. (1994) provided their physicians with practical experience discussing directives with patients and they obtained high response rates of completing the directives with this measure.

Lately, Lee et al. (2000) used the Physician Order for Life-Sustaining Treatment (POLST) form in a Program of ALL-inclusive Care for the Elderly (PACE) and implemented a new advance directive care planning system. The authors point out that

within Providence ElderPlace “planning for end-of-life care (is) a priority for all participants” and that one or more care planning meetings are held with the patients, family, primary care provider, primary nurse, and social worker. The clinicians had access to POLST forms at all times and, therefore, were aware of patient preferences when decisions about transfers or initiation of therapy had to be made. The POLST form used at this place required the patients to express choices for limiting specific treatment and it also implemented the preferences by putting them into the form of doctors’ orders to limit those treatments.

Lee et al’s study not only used the POLST form, but also an advance care planning system: a process of eliciting preferences and implementing them. It is evident that a systematic approach to the process of advance care planning can increase the likelihood that patients will be asked what treatments they want and that they will get those treatments. Therefore, the patients are much more likely to have their preferences for resuscitation respected.

Several factors appear to add to the effectiveness of the POLST form. The form has been standardized statewide, which enhances recognition and respect. The shocking pink color of the form makes it hard to ignore. The orders to limit life-sustaining treatment are clearly stated on the front side of the form, making them easy to locate. The form contains physician orders about specific treatments in language acceptable and understandable to clinicians. It centralizes information, facilitates record keeping, and ensures the communication of appropriate information between the health care providers and the setting. A survey of eight geographically diverse long term adult care

facilities in Oregon, where the form was employed, showed that resuscitation preferences documented on the forms were universally followed (Tolle et al., 1998). Consistent with the form's instructions, the study subjects received high levels of comfort care and low rates of transfer for aggressive life-extending treatments.

The Lacrosse Advance Directives Study (LADS) also demonstrated that advance care planning can work (Hammes and Rooney, 1998). Eighty-five percent of the patients who died in Lacrosse, WI, during a 2-year period had AD on the chart, and the preference for resuscitation was followed more than 90% of the time.

In summary, in our study, AD intervention by educating and encouraging the patients and families is not sufficient to obtain AD documentation. Institutional support is also critical. The clinicians need to be given the time and training to lead advance care planning discussions, and the system needs to be created that makes it possible for them to discuss with the patients and their families and access the documents when needed. The clinicians must also feel confident the form is an accurate and reliable expression of the patient choices. In short, a health care system must be created along with support advance care planning systems.

6.5.3 Discussion about End of Life Issues

Discussing end-of-life care, especially CPR, is time consuming. The exigency of modern medicine, where time is a budgetable commodity, makes caring well for terminally ill patients difficult. In this study, data from the physicians and nurses mentioned this problem. Among terminally ill patients who were capable, communication about preferences for end-of-life care is uncommon.

What type of life sustaining care patients want cannot be discovered without explicit discussion. For example, whether a patient wishes that medical technology be used to preserve health but stop short of preserving a vegetative existence. Moreover, exactly how the patient's general position extrapolates to concrete decisions when confronted by a particular state of severe illness cannot be discovered without explicit discussion. This study found that the patients would have made different advance medical directive choices about medical care in different situations. Most opposed aggressive treatment or declined medical treatment in terminal illness or permanent unconsciousness. So, the clinicians are encouraged to ask the patients about their preference directly as a first step toward improving end-of-life care. However, one approach may not be the best for all patients but rather each case must be looked at individually

Furthermore, if such decisions are to reflect considered judgments, not reactions made under emotional stress, the discussion needs to be held before illness has become critical. In theory, being free of unwanted treatment means being able to decide before the patients are incapable of deciding (Holstein, 1997).

A nursing home in Boston discusses available options for care with all patients or their families early in their stay. After discussion, all of the patients were assigned to one level of desired intervention (from full intervention to comfort measure only), and reassessed at regular intervals or when the patients' clinical situation changed significantly (Tom Sterne, 1989). A similar well-developed policy has been reported in a geriatric center (Levenson, List and Zaw-Win, 1981) as well as in a teaching hospital (Quill, Stankaitis and Krause, 1986).

Consequently, discussion needs to start in the early phases of illness and any patient input discovered by such a discussion must be taken well before the final decision is needed. It cannot be completed; rather, they require at least a translation into a more comprehensive directive either by word of mouth or in written form. However, which type of directive is more effective in this culture will need to be investigated.

From the response to the questionnaires and our own observation, the majority of the physicians preferred to discuss end-of-life care with relatives. Therefore, the physicians and the consensus among family members made most of the decisions for terminal care. However, most of the final decisions relied on the surrogates' decision. In this study, the end-of-life care decision was a shared process between physicians and the patient's family members.

A shared process of responsibility is similar to Kerridge et al. (1998). The only difference was that their patients had participated in the decision. Although there were some differences in opinions between the patients and healthcare professionals, both perceive decision making at the end of life as a shared process, primarily involving the patient and doctor.

Our data suggested that discussions about end-of-life care were more likely when a patient's clinical circumstances were dire. The physicians may be more likely to discuss this issue with the sickest patients because their prognosis may be most reliable and an end-of-life decision may be more pressing for this group.

In addition, both physicians and family members tend to consider withholding CPR when death is imminent. The patient's autonomy can be improved by providing information, discussion and the decision should be made earlier before the subject is incapacitated.

Several reasons were stated for not discussing with the patient. Most of the clinicians were concerned about the patients' physical and psychological well being. Moreover, some clinicians argued that patients who slowly and progressively deteriorate would have undue anxiety if the subject of resuscitation were raised. This is similar to Charlson and others (1986), who had mentioned this earlier.

In the meantime, many physicians raised concern about the effect of discussing CPR or DNR on the doctor-patient relationship, and wondered whether this discussion adversely affects the patients' minds. However, this study confirmed a previous report by Kerridge et al. (1998) in that most terminally ill patients preferred to talk about and discuss CPR issues with their physicians.

Discomfort with talking about end-of-life care had been observed by Morrison et al. (1998) as well. However, Hawaii's medical school was working to improve end-of-life care provided by future physicians by requiring first-year students to train as hospice volunteers and continuing to add didactic and practical training related to end-of-life care to its 4-year curriculum (Tan, Kalua and Sakai, 2001).

In our study, many of the physicians and nurses mentioned the need for extra training, primarily in areas relating to communication. Clinical training provides adequate preparation for; (a) coming to terms with death and dying, (b) communication pertaining to AD for terminal illness, which might be indicated.

These findings can be summarized that end-of-life discussion in this study is particularly relevant to patients with progressive conditions, especially in the later phases of the disease when death has approached. Most of the discussions were made with family members.

Finally, as Danis (1998) suggested, the clinicians should be cognizant of the difficulty of predicting death and anticipate the need to change the goals of care by anticipating and treating bothersome symptoms of the patients and supporting decision-making.

For those individuals who have a high probability of dying, no matter what course of treatment is elected, offering and recommending comfort measures rather than curative treatment, if accepted by the patient, will undoubtedly ease the burden of dying for the individual patient (Gillick, 1994)

Pain and other physical and psychological symptoms should be treated aggressively, according to well-delineated principles of palliative care, including avoiding painful, unwanted treatments that only serve to prolong the dying process.

Patients have the right to refuse unwanted treatment, even if this would result in death, and patients who lack decisional capacity can refuse these treatments through an authorized surrogate decision-maker.

Certainly all medical decision-making is improved by better communication among clinicians, patients, and their families, regardless of whether the specific final solution is obtained.

6.5.4 DNR Policy

The “do-not resuscitate” (DNR) order has been an important restraint on the inappropriate use of CPR for terminal patients (Emanuel LL, 1989). Formal DNR policies have also improved the process by which decisions to withhold CPR are made (Rubenfeld, 1995).

Nevertheless, implementing DNR orders has proven difficult previously. This study confirmed previous documents in several aspects. We found that the right of competent patients to refuse or accept treatment is established and most clinicians agreed that the CPR decision belongs to the patient. However, in general, CPR discussion with the patient was infrequently observed. In addition, with all of these terminally ill patients, there was only one verbal DNR order in 376 cases. This perplexing result reflected the findings of international studies that surveyed far sicker inpatient samples. In the two studies, Bedell and co-workers examined patients in Boston who had either required CPR or had been the recipients of do-not-resuscitate orders. Only about 20% of these patients had been involved in their own CPR decisions (Bedell and Delbanco, 1984; Bedell et al., 1986).

Further, some physicians have been afraid to sign a DNR order, fearing that care in other ways might be compromised. Moreover, Danis, Mutran and Garrette (1996) found that having a DNR order in a nursing home does not assure that the patient's wishes to limit life-sustaining treatment will be respected once they are admitted to the hospital.

In this study, many physicians are worried regarding legal problems with written DNR orders because this policy is not available in this setting, including in Thailand. Many physicians thought that it was not necessary to write a DNR order, as long as their colleagues had been informed regarding the patient's need. In the meantime, this action is probably acceptable in this culture because most people, especially rural dwellers, place health personnel, especially physicians, with high regards. However, the situation may change in the future and we have noted several court cases dealing with this exact problem recently in other provinces in Thailand.

Guidelines and policies regarding DNR need to be developed in an effort to facilitate obtaining a DNR order before the patient arrests, and in so doing avoid a potential unwanted, invasive, and costly procedure and protect the physician from undue legal issues. All hospitals are required to have formal DNR procedures for accreditation thereafter.

Moreover, our study observed that the proxy often makes DNR decisions, since discussions are often delayed until the patients are so sick that they have become incompetent. This finding is not uncommon. The national survey in Netherlands by

Pijnenborg and others (1995) found that decisions to withhold or withdraw treatment from terminally ill patients were made without any involvement of the patients in 59% of the cases. Of these, 87% of the patients were not competent at the time of the decision.

Similarly, in a study done in an intensive care department, treatment was withdrawn or withheld in 45% of the 198 patients who died. Of these, 11% had earlier expressed a wish that their terminal treatment be limited. Only 4% had participated in the actual decision to limit treatment, and others were incompetent at the time the decision was made (Smedira et al., 1990). Additionally, it was noticed that having poor cognitive and physical function was associated with DNR decision in our study and also affected the DNR order in previous reports (Suri, et al., 1999).

However, the DNR discussion under serious circumstances is likely to confront the patients and family with the prospect of imminent death in an insensitive fashion, and many physicians correctly feel uncomfortable about such discussions. Initiating discussion at the time of a life-threatening illness, with the focus being on withholding CPR for one terminal event, is not reasonable. It is unreasonable because the time is difficult at best, and the DNR decision itself is placed out of an appropriate decision-making context.

There is good evidence that patients find discussion of CPR neither cruel nor insensitive (Stolman et al., 1990) and they wish to have such discussions earlier (Schmerling, et al., 1988). These similar findings are also repeated in this study. Our

patients wanted to have the CPR information and discussion of the CPR issue during their early admission.

Moreover, the patients wanted to participate in decisions regarding CPR and other life-sustaining therapies (Reilly et al., 1994). Schonwetter et al (1991) summarized that most people have fixed CPR decisions. In addition, Patrick and colleagues (1997) concluded that treatment preferences for most people were grounded in a consistent belief system, and it had a high validity.

In summary, for the DNR decision to be done properly, the patient should be involved whenever possible. Discussions held in advance of imminent death avoid the foreboding anxieties for both the physicians and the patients, and provide time for reflection and opportunities for on-going discussion. The interaction and the decisions made are then both improved. Finally, Do-not-resuscitate policies, and policies on advance directives for life-sustaining treatments are immediately needed.

6.6 Significant of the Study

Further, some physicians have been afraid to sign a DNR order, fearing that care in other ways might be compromised.

Our findings are different from previous studies to certain extent. In term of population being studied, the study proved that AD is applicable to individuals who have low education, low socioeconomic status, as well as rural dwellers, but the method of implementation must be adjusted accordingly. In this setting, data from the patients,

physicians and nurses confirmed that AD is acceptable for the majority of them and it could be introduced to all types of patients.

Moreover, the method of interviewing in an empathetic manner by taking a pacing with the patient may increase the confidence of the interviewee in expressing their preferences. We also provided psychological support to all of our patients and their families. These measures may have important implications for the care of terminally ill patients in general and the technique may be useful for providing any specific information to the similar group of subjects. In addition, it may provide direct psychological benefits to patients and their families.

Importantly and repeatedly with non-critically ill patients, our patients distrusted AD documents. These feelings are respected by most of health care providers. In the mean time, word telling seems to be an effective strategy to transfer the patient's need in this society. However, institutional support is also critical. The clinicians need to be given the time and training to lead advance care planning discussions. In short, a health care system must created along with support advance care planning.

Although some findings are similar, the survival chance after CPR and the worst condition post CPR can dramatically decrease their preference for CPR. In this study, our subjects would make different advance medical directive choices about their medical care in different situations. In addition, few variables were associated with a patient's preference for terminal care. Therefore, our investigation suggests that the

preference of patients for each procedure should be assessed individually with adequate information. As a consequence, the patients may specify acceptance or refusal of selected interventions and their preferences can be incorporated in any type of advance directives.

Importantly, the preference for in-home death is dominant and the spiritual belief about the dying place was another issue of concern for end-of-life care. Moreover, information regarding terminal diagnosis and poor prognoses including declination of the patients' clinical condition are also guided end-of-life care decision.

However, our observation noted that many of the patients who chose to die at home still need supportive care. In the mean time, such care is difficult to obtain in our country. Therefore, services available for patients who are dying of advanced terminal illnesses are immediately indicated.

All of the information may help decision-makers in deciding whether or not to initiate advance directives in each local setting. This study can also serve as baseline information for further study regarding CPR and advance directive in this hospital and also elsewhere in Thailand.

6.7 Future Research

In this study, only two major diagnoses have been included, in addition to the variation in the recruitment of study subjects. Some had been recruited after their first diagnosis. Many had received specific treatment for a period of time and some patients

had already reached the terminal state. Next, we would suggest repeating the similar study by extending it to other groups and recruiting those with similar stages of terminal diagnoses. In the future study, we also suggest to extend the study to 1) non-hospitalized; young adults aged less than 40, middle aged adults 40-59 and older adults aged 60 years and older.

As mentioned, the method of AD implementation is new. Therefore, this technique should be repeated to test its reliability in a similar group of subjects. Another issue brought up during the study period was the MOPH policy (30 Baht per visit). This policy should be evaluated in term of the impact on terminal care for terminal illnesses or the impact of the policy to advance medical directive. In addition, the cost of care in terminal illnesses, how the decisions to limit care are actually correlated with patient preferences and influences subsequent resource use in Thailand.

In this country, further study is needed to explore why some physicians were not interested in AD and end-of-life care, because they are the key persons of end-of-life care in Thai culture. Another key persons to make end-of-life care's decision are the patients' relatives, we may have to study how to deal with them, especially when they have different opinions among them. In addition, how to motivate clinicians, patients, and their families to share their wishes before the patient is incapable.

Importantly, we may have to consider about the opposite sided of AD in Thai people, such as the abuse of AD or DNR order by ignoring the end-of-life care in terminally ill patients, by sending these patients back home even they still suffered

from pain, dyspnea etc.; or the clinician had a conflict with the patients' relatives who disagreed with the patient's AD and used the AD to force them.

6.8 Conclusion

The current study's results must be qualified in several respects. First, a low level of education characterized this chosen study population. It might reflect that AD intervention could be applied not only to a high educational group but also to those who are undereducated. However, the method of intervention must be adjusted according to the patient's perceptions. In addition, in this culture, it is important to add psychological support, not just for the subjects' compliance but (most importantly) also for the patients' benefits.

Second, this study did not take into account all of the factors that might be expected to influence the patients' decisions in real-life situations. It has been reported that a relationship exists between socioeconomic status and resuscitation decisions. This study did not address these factors, and even the results in non-critically ill patients confirmed those previous reports because our patients did not want to discuss this issue. In addition, the influence of the physicians' recommendations on resuscitation preferences in real life situations was not addressed.

Third, incorporating advance directive discussions may allow a better understanding of patient preferences for terminal care. However, discussing resuscitation preferences would require more time and experience on the part of the informant, which might limit the use in real life. Moreover, physicians may fear that

detailed advance directive discussions could intimidate their patients. However, educational programs designed to promote informed patient decision-making might solve this problem. Enhanced educational efforts of both health care personnel and patients could increase the rate of formal advance directive. Clearly, discussion about patient preferences regarding life-sustaining treatment and advance directives are needed before the stressful moment. This study confirmed earlier studies that most patients want to be involved in CPR decision-making and many want some form of advance directive. In the future, it might also be helpful for the patients to have the opportunity to discuss with someone who has one. Studies such as ours can provide useful information about the decision-making process involved in advance medical directive and can assist in the design of patient education materials. Attention to healthy and unhealthy patients' concerns may facilitate their ability to make informed decisions regarding treatment options at the end of life. It is important for the policy maker from a judicial point of view to have a policy and be supported by the law.

Fourth, the results of this study should be interpreted in the light of the study population, consisting largely of low educated non-critically and terminally ill northern Thai patients. Findings are likely not to be applicable to other populations.

Lastly, only two major diagnoses have been included in this study, thus the findings are less likely to generalize to other populations.