



CHAPTER I

BACKGROUND AND SIGNIFICANCE

1.1 Definition of Cardiopulmonary Resuscitation

Cardiopulmonary resuscitation (CPR) is one of the most frequently performed medical interventions in the world (Cummins et al., 1997). It is used to rescue human beings who suffer from cardiopulmonary emergency (American Heart Association, 1994)

Originally, this technique was developed for victims of sudden cardiac or respiratory arrest (Kowenhoven, Jude and Knickbocker, 1960). The exceptions are patients who request not to receive such treatment (Blackhall, 1987; Council on Ethical and Judicial Affairs, American Heart Association, 1991; Ginn and Zitner, 1995)

1.2 Problems

1.2.1 Routine Application of CPR by Clinician

In health care settings, CPR is viewed as an emergency procedure that is routinely administered to patients who experience cardiopulmonary arrest. (Council on Ethical and Judicial Affairs, American Heart Association, 1991) In many hospitals, it is a standard practice to attempt CPR on any patient who has cardiopulmonary arrest regardless of the underlying disease (Council on Ethical and Judicial Affairs, American

Heart Association, 1991). Such routine application of CPR has created several other problems, such as high mortality rate after CPR attempts, continued physical suffering, vegetative stage, high cost and financial burden.

1.2.2 High Mortality Rate

In western countries, despite advances in CPR technology, the percentage of patients who are successfully resuscitated in the hospital has remained low (7%-24.3%) and unchanged during the past 30 years. (DeBard, 1981; Bedell, Delbanco et al., 1983; Mc Grath, 1987; Woog and Torzillo, 1987; Rozenbaum and Shenkman, 1988; George Jr. et al., 1989; Roberts et al., 1990; Berger and Kelley, 1994) The figure is even lower than 5 percent and close to zero for some patient groups, depending on the type and severity of their diseases. (Bedell, Delbanco et al., 1983; Rozenbaum and Shenkman, 1988; Taffet et al., 1988; George Jr. et al., 1989; Moss, 1989; Peterson et al., 1991)

In the mean time, few studies have been done in the developing world. Thus most of the literature to be quoted is from the developed countries. In Thailand, as far as we can determine, there has only been one publication on CPR, this from Siriraj Hospital in Bangkok. In this study, Suraseranivongse and colleagues (1998) showed that the mortality following CPR was very high. Only 3% of their patients survived to be discharged. At Chiang Mai University (CMU) Hospital, our preliminary study of medical records of patients who had undergone CPR attempts during 1997 reveals that the survival rate at hospital discharge was also very low. Among 104 of these cases, only three were discharged alive. There was only one patient with opium overdose who

was able to walk out of the hospital. At the request of family members, the other two patients were discharged in comatose stage.

The high death rate following CPR may reflect the fact that CPR is commonly performed on patients with terminal illnesses and this group of patients has a very poor outcome after CPR (Council on Ethical and Judicial Affairs, American Heart Association, 1991).

1.2.3 Vegetative Stage

Among several outcomes of CPR attempts, failure resulting in death is, by necessity, an acceptable risk. Other outcomes include a permanent vegetative state (Rozenbaum and Shenkman, 1988; FitzGerald et al., 1997) and the worsening of clinical status (Bedell, Delbanco et al., 1983). In a study by FitzGerald and colleagues, it was found that almost half (44% of 162 cases) of patients who survived CPR were actually alive with worse functions and were profoundly disabled. CPR attempts on patients who are unlikely to survive on a long-term basis can initiate a chronic vegetative state that requires long-term care.

1.2.4 Continued Physical Suffering

Immunization, improved food and water supplies, improvements in sanitation, and current medical advances have facilitated much better care of the young and, therefore, increased the survival of an aging population and the possibility of chronic disease, which with better care will permit those with chronic disease to survive longer. In many instances, it is possible to prolong life of these patients until their

diseases enter the terminal stage (Bayer et al., 1983). These patients with terminal illnesses have already suffered from the deterioration process of diseases, such as severe pain (Lynn, Ely et al, 2000; Claessens et al., 2000; Somogyi-Zalud et al., 2000; Roth et al., 2000), dyspnea (Claessens et al., 2000; Lynn, Ely et al, 2000; Levenson et al., 2000; Desbiens and Wu, 2000), depression (Levenson et al., 2000; Lynn, Ely et al., 2000) and confusion (Lynn, Ely et al., 2000; Somogyi-Zalud et al., 2000). Following successful CPR, they can go on living, but their lives will be marred further by severe and sometimes intolerable suffering.

1.2.5 High Cost and Financial Burden

Many of the resuscitation efforts are followed by the use of mechanical ventilation and/or admission into intensive care facility, both of which are quite costly (Detsky et al., 1981). It has been reported that family members of patients reported to have major financial burden (FitzGerald et al., 1997; Lynn, Ely et al., 2000; Somogyi-Zalud et al., 2000; Levenson et al., 2000), spend their savings, (FitzGerald et al., 1997; Levenson et al., 2000; Desbiens and Wu, 2000), become ill (Somogyi-Zalud et al., 2000; Desbiens and Wu, 2000), quit work, and lose their income (Roth et al., 2000). It is clear that inappropriate resuscitation of patients results in increased cost of care with little tangible medical benefits.

1.3 Causes of Problem

1.3.1 Patients Interests are not considered in Decision Making Process

Previous studies revealed that most terminally ill patients did not wish to receive aggressive life-support therapy when poor clinical outcomes, such as

dependence (on a respirator and/or artificial feeding), hopeless prognosis, or persistent coma, were anticipated. (Steinbrook et al., 1986; Uhlmann, Pearlman and Coin, 1988; Danis, Patrick et al, 1988; Frankl, Oye and Bellamy, 1989) Covinsky et al. (1992) found that most seriously ill patients wished treatment to be limited or withheld under certain conditions of reduced quality of life. Similarly, Molloy and Guyatt (1991) found that 88% of 119 elderly persons requested not to have even CPR done. 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, dementia and terminal situations (Emanuel, Barry et al., 1991).

A number of terminal illnesses and elderly patients, however, still received life-prolonging interventions (Goodlin et al., 1999; Baker et al., 2000). In many instances these interventions conflicted with patients' or surrogates' preferences for end-of-life care (Davidson et al., 1997). Moreover, it was found that the presence or absence of advance directive statement does not affect the level of care delivered to elderly patients in intensive care units (Choudhry et al., 1994).

Reflecting the physicians' point of view, a recent study revealed that 100% of physicians were willing to withhold CPR if a prior patient-physician discussion supported it (Choudhry et al., 1994). The majority (151/157) of physicians believed that patients should participate in decision making, especially with respect to resuscitation;

however, they only rarely discussed the issue with their patients (Bedell and Delbanco, 1984).

Most of these studies confirmed that patients preferred CPR to be limited if it is followed by certain unfavorable conditions. Unfortunately, a number of patients still received unwanted treatment.

1.3.2 Inadequate Information and Communication

Most physicians, in most hospitals, accept the ethical preposition that patients are entitled to know their diagnosis. In a study reported by Freedman (1993), however, there were a small number of cases in which patients were well informed of the diagnosis, or, although informed of the diagnosis, were not informed when diseases progressed towards a terminal phase.

Previous research also suggested that increased familiarity with CPR, whether due to past experience or education, leads to a decreased desire for this treatment. Many patients refused resuscitation when it was accompanied by mechanical ventilation (Everhart and Pearlman, 1990). In addition, the information on CPR when carefully discussed with the patients can influence desire for CPR (Murphy et al., 2000), since most of patients (Schonwetter et al., 1991) and health professionals (Kerridge et al., 1999) overestimated their survival chances following CPR. In the meantime, they also used this prognostic information to make autonomous judgments about CPR (Kerridge et al., 1999).

Physicians do believe that advanced planning and good relationships between the patient and physician are determinants of good decision-making (Hanson et al., 1999). However, a problem in communication continues to exist between patients and physicians concerning patients' preference for aggressive therapy. This situation is especially true in patients with terminal illnesses; these patients seem to be precisely those expected to benefit from earlier discussions of the merits for their terminal care. Unfortunately, these means have been underused (Haas et al., 1993; Walker et al., 1995; Goodman, Tarnoff and Slotman, 1998)

There were many instances where patients indicated a wish to discuss with physicians their own preferences for life-sustaining therapy before such therapy was required. However, there had not been a good concordance between the patients' wishes and their doctors' actions (Steinbrook et al., 1986; Uhlmann et al., 1988; Danis, Patrick et al., 1988; Frankl et al., 1989)

According to northern Thai norm, most people prefer to die with dignity and peacefully at home surrounded with their loved ones. My own experience and the result of a pilot study reveal that many elderly persons give the following wish to relatives regarding their dying place: "if there is no chance to cure, please take me home". It is also the local custom that if a person dies outside of his/her home, the body cannot be brought back inside one. The funeral ceremony and all rituals will have to be performed at the temple, adding more cost. Moreover, the cost of transporting a body back home is much higher than that of a sick person. But the most important point is that by trying to keep the life by CPR and other post-CPR maneuver at a hospital, it is disrespectful of the will of the dying person.

For the Buddhist way of life, most Buddhists accept that “to be born, to get old, to be sick and to die are natural processes of life”. They also believe that there are lives after death (Somjai, 1998). Importantly, it is generally held that if one dies peacefully, their spirits will go to heaven. According to this belief, people are very much concerned about the moment of dying and most would prefer to die in a peaceful environment.

Some patients do not have the knowledge and experience that would allow them to understand the procedure, predict the extent of discomfort following treatment or the possibility of suffering.

Information and communication are necessary to anyone who wants to make decisions effectively. It is one of the most important factors to facilitate terminal care. Currently, patients still receive inadequate information and the problem regarding communication still exists.

1.4 How to Solve Problem?

Despite the widespread use of CPR in hospitalized patients, two situation/conditions that influence whether CPR will be administered have been recognized. (Blackhall, 1987; Council on Ethical and Judicial Affairs, American Heart Association, 1991; Ginn and Zitner, 1995) First, advance directives in which patient preferences or decision regarding the use of CPR may be express in advance of cardiopulmonary arrest. Second, resuscitation should not be attempted if, in the judgment of treating physician, the procedure would be futile.

1.4.1 Identification of Futile Attempts

Vigorous efforts have been undertaken to develop criteria by which the patients for whom CPR would be futile or result in an undesirable outcome could be identified in advance. Many factors/conditions have been repeatedly shown to be strongly associated with in-hospital mortality after in-hospital CPR, such as diagnoses of metastasis cancer, sepsis, and multiple organ failure, respiratory failure. (Bedell, Delbanco et al., 1983; Rozenbaum and Shenkman, 1988; Taffet et al., 1988; Moss 1989; George Jr. et al, 1989; Peterson et al., 1991) Unfortunately, none of these factors was an absolute predictor of zero percent outcomes. Thus, the declaration of futile care remains limited.

1.4.2 Advance Directives

Combined with the declaration of futile care, advance directives may be more readily applicable. It is probably one of the best choices to reduce problem of routine CPR. This practice would optimize the chance of patients participating in making decisions that are rightfully theirs (Ruark and Raffin, 1988).

1.5 Definition and Objective of AD

Advance directive is a statement of treatment decision of patients and/or their surrogates. It is made before the actual event actually occurs and is intended to be used when patients are incapable to do so. Advance directives help to extend patient autonomy in situations where they may no longer be competent to designate their preferences (Molley and Guyatt, 1991; Lush, 1993; Pijnenborg et al., 1995).

1.5.1 Is AD Good?

Several studies have demonstrated the benefit of advance directive in terms of cost and quality of care. The use of advance directives has evoked considerable interest (Emanuel and Emanuel, 1989; Brett, 1991; Danis, Southerland et al., 1991; Emanuel and Emanuel, 1994). Generally, physicians and the public in many countries have supported the use of advance directive in health care. (Emanuel, Barry et al., 1991; Danis, Southerland et al., 1991).

1.5.2 Is AD Appropriate to Terminal Illnesses?

Aggressive therapy such as CPR on patient who either does not want it (Molley and Guyatt, 1991) or cannot benefit from it (Cullen et al., 1976; Bedell, Delbanco et al., 1983; Peterson et al., 1991; Faber-Langendoen, 1991; Ginn and Zitner, 1995) has become the important topic of interest (Pijnenborg et al., 1995), especially for terminal illnesses. These patients are often incapable of participating in the decision to use or refuse life-sustaining treatments when the need arises. (Bedell, Pelle et al. 1986; Smedira et al., 1990) So that, advance directives can permit an appropriate withholding of CPR and other undesired life-prolonging treatments (Emanuel and Emanuel, 1989; Emanuel, Barry et al., 1991; Mower and Baraff, 1993; Choudhry et al., 1994).

Many studies about the patients' viewpoint (Steinbrook et al., 1986; Everhart and Pearlman, 1990; Schonwetter, Teasdale et al., 1991) revealed that patients' preferences for most of life-sustaining treatment were stable over time (Everhart and Pearlman, 1990; Emanuel and Emanuel, 1994; Rosenfeld et al., 1996; Siegert et al., 1996). The stability period has been reported for up to 1 (Schneiderman et al., 1992) to

2 years (Emanuel and Emanuel, 1994). This finding is important because health care providers often have to act on information provided at an earlier time. It is particularly useful for the study of our study subjects as our patients have life expectancy of less than a year. Moreover, cardiopulmonary arrest is likely to occur during their hospitalization. Thus, there is little ethical justification for not discussing and deciding CPR in advance (Ruark and Raffin, 1988).

As several experts have suggested, for this group of patients, every effort should be centered on their right to withdraw from treatment and to refuse certain kinds of treatment (Smedira et al., 1990). To carry out this process properly, the patient and/or relatives should be involved whenever possible in order to make an informed decision (Freedman, 1993). CPR in terminally ill patients is an important and emotion-laden topic for many administrators, physicians and nurses for a long time. This traumatic, time-consuming, and expensive technology should be reserved for those for whom there is a reasonable chance of survival to discharge (Taffet et al., 1988).

1.6 Need to Assess Applicability of AD to Northern Thai Culture

Advance directives have been proved to be beneficial in western countries but such directives are not yet popular in many countries in the world including Thailand. The acceptability and benefits of advance directives as applied in the Thai culture need to be explored. Because northern Thais have different custom and the ways of living and dying differ from those of western countries, the application of advance directives in northern Thai culture may not be feasible and may not yield similar results. It is,

thus, important to determine the applicability and the effectiveness of advance directive in the northern Thai setting.

1.7 Psychological Support to Study Subjects

Our retrospective study of patient record reveals at least one instance of suicide in terminally ill patient. To try to prevent this problem in this study, it is necessary to provide psychological support to every patient and their family members. To do this adequately, highly qualified research assistants are required. Since we are asking sensitive questions to terminally ill patients, we believe that this additional measure will have psychological impact on our study subjects and may in turn improve the quality of terminal care. This measure has never been mentioned in previous reports of advance directives.

1.8 Selection of Research Design

The choice of study design is quite limited. A randomized controlled trial, which we consider to be the best design, is impossible, according to hospital admission policy, the structure of study unit and the rotation of clinicians. The psychological trauma of subjects and their family members precludes pre- and post-intervention study. The design to be used in this study will be a non-randomized control study, which represents a non-equivalent control group design.

1.9 Conceptual Framework

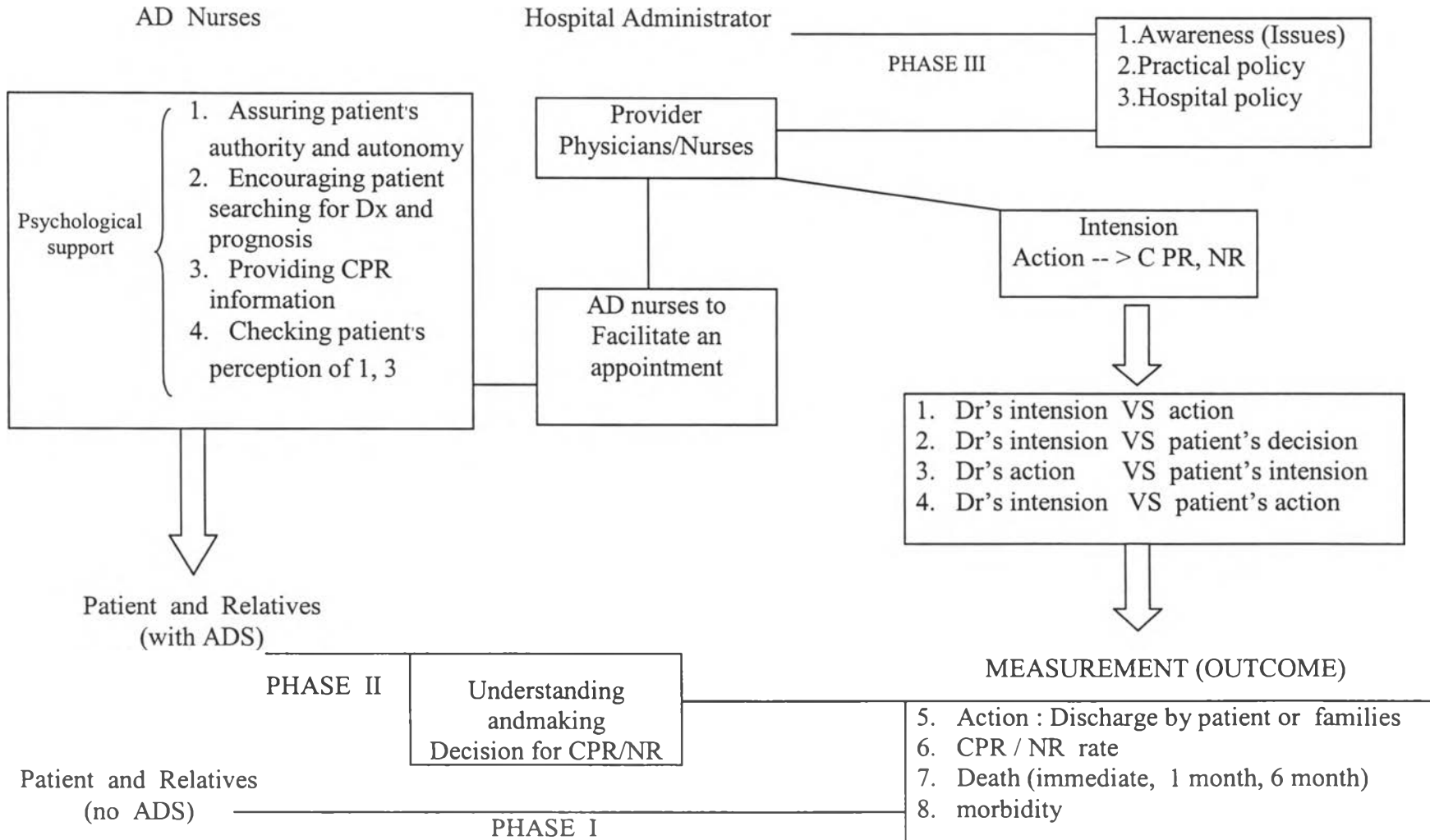
The study is based on a decision making model which relates a baseline status to outcome. (Lynn, Arkes et al., 2000) In this model, better outcomes can be achieved

through an enhancement of the participants' understanding of outcomes and preferences before making decisions, thus reflecting informed decision-making by the patients. At the time we designed this study, most researches on outcome focused on survival and prognosis of survival and provided the information to patients for their decision.

Several previous studies (Kerridge et al., 1999; Covinsky et al., 2000; Desbiens and Wu, 2000; Baker et al., 2000) failed to demonstrate the effect of understanding of the diseases and prognosis on the outcome of care since they did not include psychological support as a part of information. In this study, attempts will be made to give psychological support to all patients and relatives in the intervention group.

The framework in this study is based on the literature but relies mainly on the concept of informed decision-making (Lynn, Arkes et al., 2000). The rudimentary ideas for the framework will be presented in the literature review, in which linkages among variables found in previous studies will be discussed. The framework is portrayed in Figure 1.1. This figure shows how the variables in this study are expected to relate to each other and why.

Figure 1.1: Show the conceptual framework of the study



AD nurses will provide AD intervention to patient and families step by step as follow:

1. Assurance of patient's authority and autonomy
2. Encouraging of patient and surrogate to search for the following information from physicians: diagnoses, prognosis and likely outcomes.
3. Providing CPR information and its likely outcome by AD nurses.
4. Checking of patient's perception of authority and autonomy; diseases, prognoses, likely outcomes; CPR and the outcome in his/her specific illnesses by AD nurses.
5. Providing psychological support to every patient and families during the whole process of the study.

The AD intervention is expected to facilitate an understanding of nature of the disease, prognosis, CPR procedure and the likely outcome by each patient and the surrogate. Making decision for terminal care by using information previously obtained reflecting patients' informed decision-making, then selecting the action accordingly.

At the end of the study, the out come as measured in the intervention and control group will be compared. These outcomes are CPR/NR event, action of self-discharge by patients and/or families, patients' morbidity and mortality.

Finally, all of these results will be presented to clinician. This measured is aimed to make awareness of the problems, initiate practical and hospital policy in advance directive for terminal care in terminally ill patients.

1.10 Summary

This study is designed to implement the concept of advance directives for terminal care in terminal ill patients in northern Thai setting. The primary objective is to improve the decision making process by providing adequate information and psychological support, which in turn is expected to improve decision and outcomes of terminal care.

This study is intended to examine the effectiveness of advance directives and to determine whether advance directive is acceptable in Thailand and, if so, under what conditions and circumstances. We will identify the condition(s) and circumstance(s) when advance directives should be administered or omitted. We will also identify the important stakeholders, namely patients, surrogates, physicians, and nurses, who support or reject the use of advance directives. We will identify the measures affecting the introduction of the concept of advance directives at the system level and possibly other improvements in routine care.

1.11 Research Hypothesis

There will be no significant difference in CPR performance rate between a group of terminally ill patients who received AD for terminal care and a group of terminally ill patients who did not receive AD.

1.12 The Impact of this Study

The results may have important implications for the care of terminally ill patients in general and may provide direct psychological benefits to patients and their

families. The information may help decision-makers in deciding whether or not to initiate advance directives in each local setting. The results may reveal additional changes of practice, which might lead to more successful management for terminal care. It can also serve as baseline information for further study regarding CPR and advance directive in this hospital and also elsewhere in Thailand.