CHAPTER V

RESULTS

The findings from patients, physicians and nurses are presented in this chapter. Section 5.1 shows the retrospective study results from the medical records of terminally ill patients. Outlined first is an explanation of the inclusions and exclusions of the medical records. This is followed by a general description of the demographic and clinical characteristics, pre-event functional capacity of the study sample, observations for cardiopulmonary resuscitation (CPR), precipitating causes of cardiopulmonary arrest, and the results of CPR. Section 5.2 presents the findings from the attitude study in non-seriously ill patients. It starts with an explanation of the participants and exclusions, then, a description of the demographic characteristics of the patients and the results of the attitude study.

Section 5.3 presents all results from the non-randomized control study in terminally ill patients. Outlined first is an explanation of the research participants and exclusions. This is followed by a general description of the population being studied, including the characteristics of the total population. The demographic and clinical characteristics of the study sample, starting with the controls, followed by the interventions, and then comparison between these two groups, observations for CPR, the final in-hospital event, and the follow up study. The latter part is aimed to answer the three primary research questions. Section 5.4 summarizes the issues brought up by several qualitative focus groups with the nursing staff. Section 5.5 presents the study of

the physicians. This section contains a description of the participants and exclusions, demographic characteristics of the participants, and the results obtained from the questionnaire.

The findings from the data are presented in Section 5.6 in the form of advance directives (ADs) intervention provided to terminally ill patients. This will be presented sequentially as posed in the research questions (Chapter III), by answering the eight secondary research questions. Other results are displayed in Section 5.7 and lastly, Section 5.8 is a summary of the study results.

5.1 Retrospective Study of the Medical Record of Terminally Ill Patients

Medical records of terminally ill patients who died in Chiang Mai University (CMU) hospital from January 1, 1996 until June 30, 1999 were searched by computer for eight diagnoses:1) non-small cell lung cancer stage III or IV (NSCLC); 2) multi-organ system failure with sepsis (MOSFS); 3) exacerbation of chronic obstructive pulmonary disease (COPD); 4) exacerbation of congestive heart failure (CHF); 5) non-traumatic and non-diabetic coma (Coma); 6) carcinoma of colon with metastasis to liver (Colon cancer); 7) acute respiratory failure; 8) end-stage liver disease (ESLD).

5.1.1 Inclusion and exclusion

Table 5.1 presents the number of patients who had CPR attempted and no-CPR before death. It was possible to identify 532 hospital deaths with one or more of the eight diagnoses; however, 118 medical records were missing and three other records

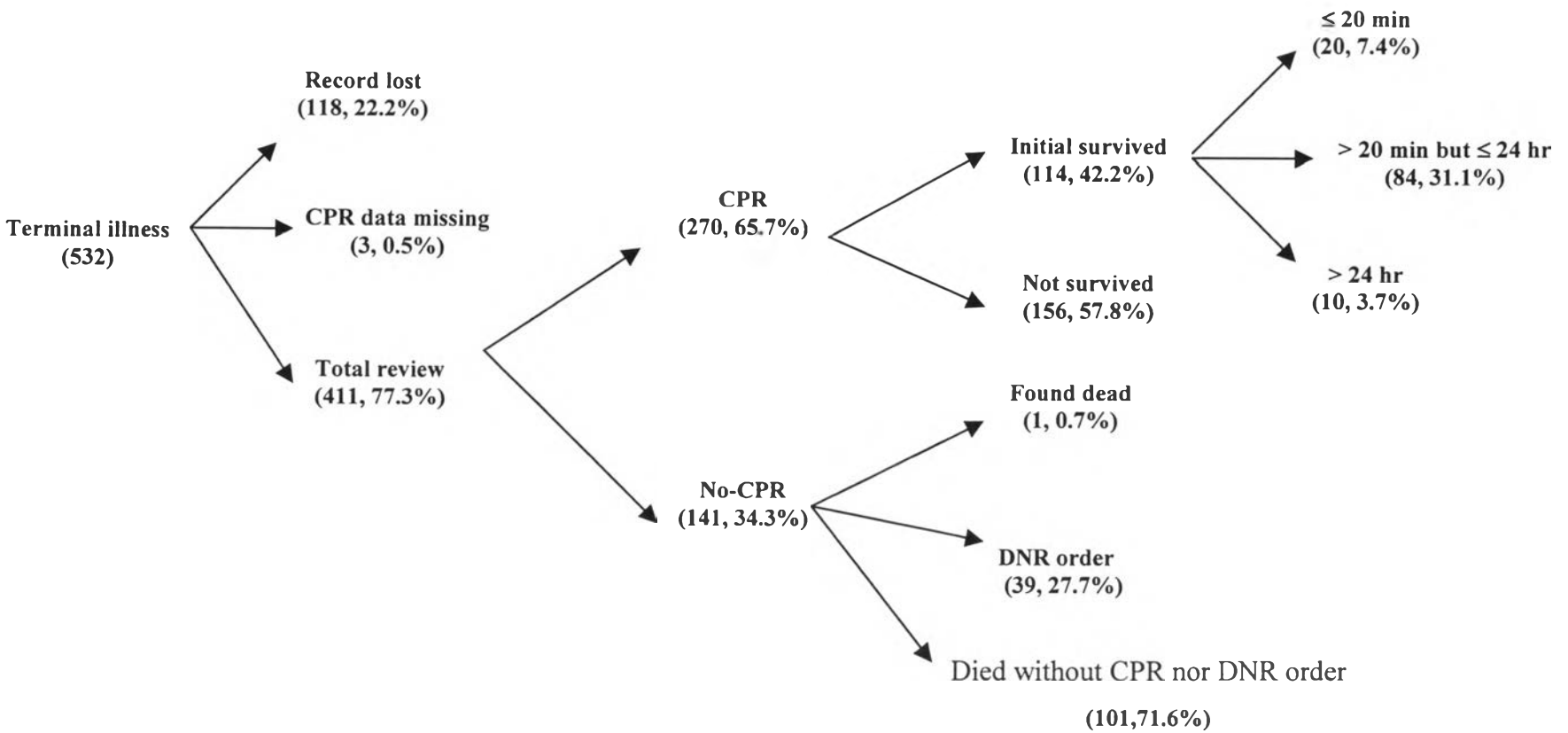
were subsequently excluded due to missing data. The remaining 411 records (77.3%) were, then, reviewed using the Utstein Guidelines for in-hospital CPR research.

5.1.2 Results

Of 411 terminally ill patients who died during the 3.5-year study period, 58.6% were male and 71.1% were aged 50 years or older. The majorities of the patients suffered from non-cardiac/medical illnesses (92.0%) and were admitted on a non-scheduled/emergent basis (90.5%). Half of the cases had two or more diseases as major causes of death.

Overall, resuscitation was performed in 270 cases (65.7%). There was considerable variation from year-to-year: 58.6% during 1996; 76.9% during 1997; 65.8% during 1998; and 45.2% during the first six months of 1999.

Table 5.1: Number of terminal ill patients who had CPR attempted and no-CPR before dead



Among those who were resuscitated, 114 (42.2%) initially survived but all subsequently died. The number of patients who had a return of spontaneous circulation for ≤ 20 minutes (20, 7.4%), > 20 minutes but ≤ 24 hours (84, 31.1%), and for more than 24 hours (10, 3.7%), respectively. The frequency of CPR performed varied from 1 to 6 times, with the majority of cases (79.6 %) receiving CPR only once.

Among the 141 of 411 (34.3%) cases, who expired without resuscitation, one case was found dead; the DNR order was written or verbally expressed in only 39 cases. For the remaining majority (101 cases), whom we assumed that the resuscitation attempt was considered futile, neither CPR nor DNR orders were recorded.

Table 5.2 shows the number of patients with the specific diagnoses, CPR attempted or no-CPR, cerebral performance categories (CPC) score. Among the subjects who were included in the study, MOSFS (n=138, 33.6%) was the most common diagnosis, the second most common diagnosis was NSCLC (n=133, 32.4%) and followed by the COPD (n= 72, 17.5%). For the remaining five diagnoses, less than 6 percent of subjects in each diagnosis was included in this study. Meanwhile, the proportion of CPR attempted was higher in the patients with COPD (87.5%) and acute respiratory failure (87.5%) followed by the CHF (83.3%), ESLD (75.0%) and MOSFS (73.2%). The number of CPR attempted in other diagnostic groups was varied from 25.0%-54.2%.

Pre-event functional capacity, as measured by the CPC score within 24-48 hours before the arrest, were generally poor: 63.3% had a CPC of 3 and 34.8% had a CPC of 4. Before the arrest, 143/411 was already comatose.

Among the 141 cases, who expired without resuscitation, after excluding the one patient who was found dead who had a CPC of 3, the CPC scores for pre-event functional capacity for 140 cases were very poor. Seventy-four cases and 65 cases had CPC scores of 3 and 4, respectively. Only one case had a CPC score of 2; this patient died suddenly of massive hemoptysis from lung carcinoma.

Table 5.2 : Number of patients with the specific diagnoses, CPR attempted or no-CPR, Cerebral Performance Categories (CPC) score

Diagnosis and use of CPR	No. of	Pre-event Functional capacity CPC score			
	Cases (%)	1	2	3	4
NSCLC	133 (32.4)				
CPR	59 (44.4)	-	3(5.1)	48(81.4)	8(13.6)
No CPR	74 (55.6)	-	1(1.4)	53(71.6)	20(27.0)
Multi-organ system failure	138 (33.6)				
CPR	101 (73.2)	1(1.0)	-	63(62.4)	37(36.6)
No CPR	37(26.8)	-	-	11(29.7)	26(70.3)
COPD	72(17.5)				
CPR	63(87.5)	-	-	49(77.8)	14(22.2)
No CPR	9(12.5)	-	-	5(55.6)	4(44.4)
Congestive heart failure	24(5.8)				
CPR	20(83.3)	1(5.0)	1(5.0)	14(70.0)	4(20.0)
No CPR	4(16.7)	-	-	2(50.0)	2(50.0)
Coma	24(5.8)				
CPR	13(54.2)	-	-	4(30.8)	9(69.2)
No CPR	11(45.8)	-	-	-	11(100.0)
Colon cancer	4(0.9)				
CPR	1(25.0)	-	-	-	1(100.0)
No CPR	3(75.0)	-	-	3(100.0)	-
Acute respiratory failure	8(1.9)				
CPR	7(87.5)	-	1(14.2)	3(42.9)	3(42.9)
No CPR	1(12.5)	-	-	-	1(100.0)
End-stage liver disease	8(1.9)				
CPR	6(75.0)	-	-	4(66.7)	2(33.3)
No CPR	2(25.0)	-	-	1(50.0)	1(50.0)
All diagnoses					
CPR	270(65.7)	2(0.7)	5(1.9)	185(68.5)	78(28.9)
No CPR	141(34.3)	-	1(0.7)	75(53.2)	65(46.1)
Total	**411 (100.0)**	**2(0.5)**	**6(1.4)**	**260(63.3)**	**143(34.8)**

Table 5.3 : Number of patients with the specific diagnoses, CPR attempted or no-CPR, intervention in place at time of cardiopulmonary arrest

Diagnosis and use of CPR	No. of Cases	Intervention in-place at time of cardiopulmonary arrest		
		ECG	ICU	MV
NSCLC	133	30 (22.6)	2 (1.5)	54 (40.6)
CPR	59	10 (16.9)	1 (1.7)	28 (47.5)
No CPR	74	20 (27.0)	1 (1.4)	26 (35.1)
MOSFS	138	72 (52.2)	35 (25.4)	108 (78.3)
CPR	101	50 (49.5)	27 (26.7)	80 (79.2)
No CPR	37	22 (59.5)	8 (21.6)	28 (75.7)
COPD	72	31 (43.1)	10 (13.9)	57 (79.2)
CPR	63	26 (41.3)	6 (9.5)	48 (76.2)
No CPR	9	5 (55.6)	4 (44.4)	9 (100.0)
Congestive heart failure	24	16 (66.7)	4 (16.7)	16 (66.7)
CPR	20	12 (60.0)	4 (20.0)	13 (65.0)
No CPR	4	4 (100.0)	-	3 (75.0)
Coma[f]	24	7 (29.2)	2 (8.3)	24 (100.0)
CPR	13	6 (46.2)	-	13 (100.0)
No CPR	11	1 (9.1)	2 (18.2)	11 (100.0)
Colon cancer	4	1 (25.0)	1 (25.0)	1 (25.0)
CPR	1	1 (100.0)	1 (100.0)	1 (100.0)
No CPR	3	-	-	-
Acute respiratory failure	8	5 (62.5)	2 (25.0)	8 (100.0)
CPR	7	4 (57.1)	2 (28.6)	7 (100.0)
No CPR	1	1 (100.0)	-	1 (100.0)
ESLD	8	4 (50.0)	1 (12.5)	6 (75.0)
CPR	6	2 (33.3)	-	4 (66.7)
No CPR	2	2 (100.0)	1 (50.0)	2 (100.0)
Total	411	166 (40.4)	57 (13.9)	274 (66.7)
CPR	270	111 (41.1)	41 (15.2)	194 (71.9)
No CPR	141	55 (39.0)	16 (11.3)	80 (56.7)

[ECG] Electrocardiographic monitoring. [ICU] Intensive care unit admission. [MV] Mechanical ventilation.

* ECC, ICU and MV were not applicable to every patients who had CPR attempted or no-CPR.

Table 5.4 : Number of patients with the specific diagnoses, CPR attempted and the result of CPR

No. of cases with the specific diagnoses	No. of CPR attempted	Unsuccessful	< 20 min	>20 min < 24 h	➢ 24 h
	Column %	Row %	Row %	Row %	Row %
NSCLC	59 (21.9)	37 (62.7)	3 (5.1)	16 (27.1)	3 (5.1)
MOSFS	101 (37.4)	52 (51.5)	6 (5.9)	40 (39.6)	3 (3.0)
COPD	63 (23.3)	43 (68.3)	8 (12.7)	12 (19.0)	-
CHF	20 (7.4)	10 (50.0)	-	9 (45.0)	1 (5.0)
Coma	13 (4.8)	7 (53.8)	2 (15.4)	3 (23.1)	1 (7.7)
Colon cancer	1 (0.4)	-	-	1 (100.0)	-
Acute respiratory failure	7 (2.6)	4 (57.1)	-	3 (42.9)	-
ESLD	6 (2.2)	3 (50.0)	1 (16.7)	-	2 (33.3)
All diagnoses	270 (100.0)	156 (57.8)	20 (7.4)	84 (31.1)	10 (3.7)

Table 5.3 presents a number of patients with the specific diagnoses, CPR attempted or no-CPR, intervention in place at time of cardiopulmonary arrest. Among 411 cases, only 166 (40.4%) had EKG monitoring (111 in CPR group, 55 in non-CPR group) at the time of arrest. Fifty-seven cases were admitted in the ICU (41 in CPR group, 16 in non-CPR group). 284 were intubated (202 in CPR group, 82 in non-CPR group) and 274 (66.7%) were on mechanical ventilation (194 in CPR group, 80 in non-CPR group) at the time of arrest. The numbers of patients with MOSFS who had EKG monitoring, were admitted in the ICU, and were on mechanical ventilation were higher than other diagnostic groups. Of 138 patients with MOSFS, 72 (52.2%) had EKG monitoring, 35 (25.4%) were admitted in the ICU, and 108 (78.3%) were on mechanical ventilation at the time of arrest. Again, the numbers of patients who were not successful after CPR attempted was higher in this group (n= 52, 19.3%), followed

by the COPD (n = 43, 15.9%) and NSCLC (n = 37, 13.7%) (Table 5.4). Only 10 patients were survived longer than one day after CPR attempted but all died later on.

Patients who were intubated or who had mechanical ventilation were more likely to be resuscitated (p = 0.001 and 0.003, respectively). Success following CPR attempts was more likely in patients who had previously been resuscitated before admission than those who were not (p = 0.016). On the other hand, there were no significant differences between the CPR and non-CPR groups with regard to IV fluid provision and the use of intra-arterial catheter and other intravenous medications.

At the time of the arrival of first health care personnel, the initial conditions of 411 patients were reported as having apnea (104 cases, 25.3%), pulselessness (187, 45.5%), and unconsciousness (67, 16.3%). It should be mentioned that nursing personnel were able to detect warning signs prodromal to apnea, pulselessness or unconsciousness. For example, 30 patients (7.3 %) had air hunger or bradypnea, 162 patients (39.4 %) were found to have a slow or thready pulse and 2 patients (0.5 %) had a decrease in responsiveness to stimuli. Many patients had more than one sign.

Abnormal cardiac rhythms found in 270 resuscitated cases were asystole (78, 28.9 %), bradycardia (19, 7.0 %) and ventricular tachycardia/ventricular fibrillation (16, 5.9%). Only 9 patients (3.3%) had normal rhythm, whereas 4 (1.5%) had other cardiac rhythm. Fifty-eight cases (21.5 %) were not being monitored at the time of arrest. Remarkably, 86 patients (31.9 %) had been monitored at the time of arrest but their cardiac rhythms were not mentioned in the records.

CPR for the 270 cases was initiated by either nursing personnel (194 cases, 71.9%), or medical students (39 cases, 14.4 %) or physicians (37 cases, 13.7 %). Two levels of CPR were attempted: intubation and cardiac compression in 77%, intubation and cardiac compression, including defibrillation in 21.9%. The remaining cases had intubation or defibrillation only.

At the time of arrest, all available resources except resuscitation were provided to 23 cases (16.4%), intravenous fluid and intravenous medication to 79 cases (56.4%), intravenous fluid, gavage feeding and intravenous medication to 68 cases (48.6%). Only 4 cases (2.9%) were not receiving any kind of treatment.

Only 26 records (6.3%) mentioned that the physician had informed the relatives of the patient's condition and/or prognosis. The majority of cardiopulmonary arrests occurred in general wards (69.8%) and ICU (13.9%). Autopsy was requested in 13 cases (3.2%).

5.2 Attitude Study in Non-Critically Ill Patients

As mentioned, AD for terminal care is new in this country. Before starting the main project, a study of the acceptability of AD for CPR was tried in non-critically ill patients.

5.2.1 Participants and exclusions

Participants were randomly selected from the non-seriously ill patients who were admitted to the seven adult medical wards (three female and four male wards)

from November 1, 2000 until December 31, 2000. Of the first 200 subjects approached, 197 (98.5 %) agreed to participate in this study. Two males refused to participate because they were "too tired" and "too ill" to talk and one female refused because she was waiting for a relative to decide but was discharged before this happened. Replacements were found for the subjects who refused to participate to achieve a sample size of 200.

5.2.2 Demographic Characteristics of Participants

Of the 200 participants, 129 (64.5%) were male, which was comparable to the gender distribution of medical inpatients at CMU. Just over half (52.0%) were 45 or more years of age, 71.0% were married, 77.5% were rural residents, and 124 (62%) were admitted with chronic illnesses (Table 5.5). Eighty percent were poor (no regular income, unstable income, or yearly personal income $\leq$ 33,600 Bath/year (~ 760 USD). More than half (57.5%) of these poor were those with no regular income. All were Buddhist and 75.0% had primary education (Grade 4-6). Because we sampled the male and female wards separately, the demographic data is presented by gender. The only statistically significant difference was that a higher percentage of females (93.0%) than males (72.9%) were poor ($p = 0.001$).

Table 5.5 : Demographic Characteristics of the 200 ambulatory patients

Characteristic	Male n (%) N= 129	Female n (%) N= 71	Total n (%) N= 200	Difference Male vs Female P-Value*
1. Age (years)				**0.246**
<45 Years	**58 (45.0)**	**38 (53.5)**	**96 (48.0)**	
Less than 30	17 (13.2)	13 (18.3)	30 (15.0)	
30 to 44	41 (31.8)	25 (35.2)	66 (33.0)	
≥45 Years	**71 (55.0)**	**33 (46.5)**	**104 (52.0)**	
45 to 59	41 (31.8)	18 (25.4)	59 (29.5)	
60 or more	30 (23.2)	15 (21.1)	45 (22.5)	
2. Marital Status				**0.646**
Married	**93 (72.1)**	**49 (69.0)**	**142 (71.0)**	
Not- Married	**36 (27.9)**	**22 (31.0)**	**58 (29.0)**	
Single	24 (18.6)	13 (18.3)	37 (18.5)	
Widowed	8 (6.2)	8 (11.3)	16 (8.0)	
Divorced	4 (3.1)	1 (1.4)	5 (2.5)	
3. Personal Income (Bath/year)				**0.001****
≤ 33,600	**94 (72.9)**	**66 (93.0)**	**160 (80.0)**	
No regular income	62 (48.1)	53 (74.7)	115 (57.5)	
Unstable income	31 (24.0)	11(15.5)	42 (21.0)	
33,600 baths or less	1 (0.8)	2 (2.8)	3 (1.5)	
> 33,600	**35 (27.1)**	**5 (7.0)**	**40 (20.0)**	
33,601-60,000 Baths	17 (13.2)	2 (2.8)	19 (9.5)	
More than 60, 000 Baths	18 (13.9)	3 (4.2)	21 (10.5)	
4. Usual Place of Residence				**0.730**
Rural	99 (76.7)	56 (78.9)	155 (77.5)	
Urban	30 (23.3)	15 (21.1)	45 (22.5)	
5. Type of Illness				**0.756**
Acute Illness	48 (37.2)	28 (39.4)	76 (38.0)	
Chronic Illness	81 (62.8)	43 (60.6)	124 (62.0)	

*P-value by chi-square with (1) Degree of Freedom

**P < 0.01

5.2.3 Results

5.2.3.1 Attitude towards Advance Directives for CPR

Nearly all of our subjects (97%) thought that it was a good idea to discuss the advance planning for CPR with all admitted patients on a routine basis. Interestingly, our subjects distrusted formal documents and they preferred to give their preferences regarding ADs orally to surrogate(s).

5.2.3.2 Preference for CPR

Table 5.6 shows the preference for CPR by prognostic scenario. After explaining the CPR procedure but excluding a presentation of the chance of survival to hospital discharge scenarios, most subjects (87.5 %) said that they would prefer to have CPR. This proportion was lower (68.5%) when the scenario was presented where the chance of survival to discharge was between 7-24% (as in acute onset of disease) and even lower (45.5%) when a scenario was presented where the survival was 0-5% (as in some specific diseases). Only 27.5% said they would prefer to have CPR if it was possibly followed by living permanently on mechanical ventilation or by a coma, or both.

Table 5.6 : Preference for CPR by prognostic scenario

Prognostic scenario	**Preference of CPR** **N = 200** **n (%)**
1. No information	175 (87.5)
2. If survival 7-24 %	137 (68.5)
3. If survival 0-5 %	91 (45.5)
4. If CPR follow by mechanical ventilation or by coma or both	55 (27.5)

5.2.3.3 Preference for CPR by Gender

The preferences for CPR in both genders were varied depending upon the level of prognostic information. In addition, these preferences also varied by age, marital status, personal income, and type of illness.

For males, after explaining the CPR procedure without a presentation of the chance of survival to hospital discharge scenarios, most males (88.4%) preferred to have CPR (Table 5.7). This proportion was lower (61.3%) when the scenario was presented where the chance of survival to discharge was between 7-24% (Table 5.8) and even lower (47.3%) when a scenario was presented where the survival was 0-5% (Table 5.9). Only 36.4% would prefer to have CPR if it was possibly followed by living permanently on mechanical ventilation or by a coma, or both (Table 5.10).

The proportion of CPR preferences for male were also varied depending upon demographic variables, such as age, marital status, personal income, place of usual

resident and type of illnesses. For example, after explaining the CPR procedure without a presentation of the chance of survival to hospital discharge scenarios (Table 5.7), male who were 45 years or less were more likely to decide for CPR more than those who were older (91% vs. 85.6%). The similar proportion was observed for those who were married and not married (88.2% and 88.9% respectively). However, for personal income, male who had higher income (>33,600) were more likely to decide for CPR more than those who had lower income (≤33,600) (94.3% vs.86.2%). Male who had usual resident in rural area was less likely to decide for CPR than urban dweller (86.9% and 93.4%, respectively) and those with acute illnesses preferred CPR more than those with chronic illnesses.

The proportion of CPR preferences was lower when the scenario was presented where the chance of survival to discharge was between 7-24% (Table 5.8) in all demographic variables. Male who were 45 years and younger preferred CPR more than older male (84.5% vs. 42.3%). Those who were married were less likely to decide CPR than those who were not married (57.0% and 72.2%, respectively). Male who had higher income (>33,600) preferred CPR more than those who had lower income (≤ 33,600) (65.7% vs.59.6%). Male who had usual resident in rural area was less likely to decide for CPR than urban dweller (60.6% and 63.3%, respectively) and those with acute illnesses preferred CPR more than those with chronic illnesses (93.3% vs.91.1%).

The proportion of CPR preferences was even lower when the scenario was presented where the chance of survival to discharge was between 0-5% (Table 5.9) in all demographic variables. Male who were 45 years and younger preferred CPR much

more than older male (70.7% vs. 28.2%). Those who were married were less likely to decide CPR than those who were not married (46.2% and 50.0%, respectively). Male who had higher income (>33,600) preferred CPR more than those who had lower income (≤33,600) (60.0% vs.42.6%). Rural dweller was less likely to decide for CPR than urban dweller (45.5% and 53.3%, respectively) and those with acute illnesses preferred CPR than those with chronic illnesses (76.7% vs.69.1%).

The proportion of CPR preferences were decreased markedly when the scenario was presented if CPR was possibly followed by living permanently on mechanical ventilation or by a coma, or both (Table 5.10). Male who were 45 years and younger preferred CPR more than older male (56.9% vs. 19.7%). Those who were married were less likely to decide CPR than those who were not married (31.2% and 50.0%, respectively). Male who had higher income (>33,600) preferred CPR more than those who had lower income (≤33,600) (51.4% vs.30.9%). Rural dweller was less likely to decide for CPR than urban dweller (35.4% and 40.0%, respectively) and those with acute illnesses preferred CPR more than those with chronic illnesses (59.0% vs.39.3%).

An similar pattern of CPR preference was observed in the females. These preferences were varied depending upon the level of prognostic information and it decreased with worse prognostic information. However, the proportion of CPR preference decreased markedly when a scenario was presented where survival was 0-5% (as in some specific diseases) (Table 5.9) and if CPR was possibly followed by living permanently on mechanical ventilation or by a coma, or both (Table 5.10).

In general, the pattern of CPR preference was similar in both genders. The preference decreased with worse prognostic scenarios but the proportion of males who preferred CPR were higher than the females.

5.2.3.4 Preference for No-CPR

Table 5.11 presents the odds ratio (OR) of preference for no-CPR associated with demographic variables among the scenario with different prognostic probabilities. The preference for no-CPR varied depending upon the level of prognostic information. It differed by gender, age, marital status, personal income, and type of illness.

Females were more likely to prefer no-CPR when compared to males. When no prognostic information was provided, females were more likely to say they preferred no-CPR when compared to males (OR = 5.37, 95% C.I. = 1.47-19.58). If the survival chance was 0-5% with CPR, the OR of the preference of the females for no-CPR was three times more than that of the males (OR = 3.10, 95% C.I. = 1.47 –6.54). However, in the scenario where CPR might be followed with mechanical ventilation or coma or both, females said they would prefer no-CPR seven times more than males (OR = 7.58, 95% C.I. = 2.91 – 19.76).

Similar results were also observed in different age groups. Subjects who were 45 years and older (older adults) who were presented with the scenario in which the survival chance with CPR was 7-24% preferred no-CPR four times more than the subjects who were less than 45 years (younger adults) (OR = 3.96, 95% C.I. = 1.28 – 12.26). Meanwhile, when the scenario indicated that the survival chance with CPR was

0-5%, or when the scenario was that CPR might be followed with mechanical ventilation or by coma or both, older adults said they would prefer no-CPR approximately 2-3 times more than younger adults (OR = 2.85, 95% C.I. = 1.33 –6.12 and OR = 2.37, 95% C.I. = 1.02 –5.50, respectively).

Subjects who were not married were more likely to decide in favor of no-CPR compared to those who were married. However, the OR of preferences varied among 3.87, 3.40, and 2.34, depending on which of the following scenarios were presented: no prognostic information, a survival chance of 7-24% with CPR, and a survival chance of 0-5% with CPR, respectively.

Subjects who had low income (personal income ≤ 33,600 Baht/year) were more likely to decide that no-CPR would be their preference as compared to those who had higher income. Increased ORs of preference for no-CPR associated with low income had been observed in two scenarios: when the survival chance was 0-5% with CPR (OR = 3.26, 95% CI =1.01-10.56), and if CPR might be followed by mechanical ventilation or coma or both (OR = 7.88, 95% C.I. =2.65-23.47).

Finally, the odds ratio of preferring no-CPR differed between patients admitted for chronic illness and patients admitted for acute illness. A significant OR was observed only in the scenario in which CPR might be followed by mechanical ventilation or coma or both. Subjects with chronic illness were more likely to express a preference for no-CPR as compared to those with acute illness (OR = 3.12, 95% C.I. = 1.40 – 6.98).

Table 5.7 : Difference in preference for CPR "If no information regarding prognosis survival given"

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
GENDER	129	114	5	10	71	61	10	-
		(88.4)	(3.9)	(7.7)		(85.9)	(14.1)	
AGE								
<45	58	53	4	1	38	35	3	-
		(91.4)	(6.9)	(1.7)		(92.1)	(7.9)	
≥45	71	61	1	9	33	26	7	-
		(85.9)	(1.4)	(12.7)		(78.8)	(21.2)	
MARITAL STATUS:								
Married	93	82	2	9	49	44	5	-
		(88.2)	(2.1)	(9.7)		(89.8)	(10.2)	
Not-Married	36	32	1	1	22	17	5	-
		(88.9)	(8.3)	(2.8)		(77.3)	(22.7)	

*Deferred: Decision to be later by physician(s) or family

Table 5.7 : Difference in preference for CPR "If no information regarding prognosis survival given" (Cont.)

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
PERSONAL INCOME (Bath / Year):								
≤ 33,600	94	81	3	10	66	57	9	-
		(86.2)	(3.2)	(10.6)		(86.4)	(13.6)	
> 33,600	30	33	2	-	5	4	1	-
		(94.3)	(5.7)			(80.0)	(20.0)	
USUAL RESIDENCE								
Rural	99	86	4	9	56	48	8	-
		(86.9)	(4.0)	(9.1)		(85.7)	(14.3)	
Urban	30	28	1	1	15	13	2	-
		(93.4)	(3.3)	(3.3)		(86.7)	(13.3)	
TYPE OF ILLNESS								
Acute Illness	46	45	1	-	28	26	2	-
		(97.8)	(2.2)			(92.6)	(7.1)	
Chronic Illness	73	69	4	-	43	35	8	-
		(94.5)	(5.5)			(81.4)	(18.6)	

*Deferred: Decision to be later by physician(s) or family

Table 5.8 : Difference in preference for CPR "If information provided that survival 7-24% before expression of preference for CPR"

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
GENDER	129	79	7	43	71	58	11	2
		(61.3)	(5.4)	(33.3)		(81.7)	(15.5)	(2.8)
AGE								
<45	58	49	2	7	38	34	4	-
		(84.5)	(3.4)	(12.1)		(89.5)	(10.5)	
≥45	71	30	5	36	33	24	7	2
		(42.3)	(7.0)	(50.7)		(72.7)	(21.2)	(6.1)
MARITAL STATUS:								
Married	93	53	4	36	49	43	5	1
		(57.0)	(4.3)	(38.7)		(87.8)	(10.2)	(2.0)
Not-Married	36	26	3	7	22	15	6	1
		(72.2)	(8.3)	(19.5)		(68.2)	(27.3)	(4.5)

*Deferred: Decision to be later by physician(s) or family

Table 5.8 : Difference in preference for CPR "If information provided that survival 7-24% before expression of preference for CPR" (Cont.)

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
PERSONAL INCOME (Bath / Year):								
≤ 33,600	94	56	6	32	66	54	10	2
		(59.2)	(6.4)	(34.0)		(81.8)	(15.2)	(3.0)
> 33,600	35	23	1	11	5	4	1	-
		(65.7)	(2.9)	(31.4)		(80.0)	(20.0)	
PLACE OF USUAL RESIDENCE								
Rural	99	60	5	34	56	45	9	2
		(60.9)	(5.1)	(34.3)		(80.3)	(16.1)	(3.6)
Urban	30	19	2	9	15	13	2	-
		(63.3)	(6.7)	(30.0)		(86.7)	(13.3)	
TYPE OF ILLNESS								
Acute Illness	30	28	2	-	27	23	4	-
		(93.3)	(6.7)			(85.2)	(14.8)	
Chronic Illness	56	51	5	-	42	35	7	-
		(91.1)	(8.9)			(83.3)	(16.7)	

*Deferred: Decision to be later by physician(s) or family

Table 5.9 : Difference in preference for CPR "If information provided that survival 0-5% before expression of preference for CPR"

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
GENDER	129	61	24	44	71	30	39	2
		(47.3)	(18.6)	(34.1)		(42.3)	(54.9)	(2.8)
AGE								
<45	58	41	10	7	38	20	18	-
		(70.7)	(17.2)	(12.1)		(52.6)	(47.4)	
≥45	71	20	14	37	33	10	21	2
		(28.2)	(19.7)	(52.1)		(30.3)	(63.6)	(6.1)
MARITAL STATUS:								
Married	93	43	14	36	49	23	25	1
		(46.2)	(15.1)	(38.7)		(46.9)	(51.0)	(2.1)
Not-Married	36	18	10	8	22	7	14	1
		(50.0)	(27.8)	(22.2)		(31.8)	(63.6)	(4.6)

*Deferred: Decision to be later by physician(s) or family

Table 5.9 : Difference in preference for CPR "If information provided that survival 0-5% before expression of preference for CPR" (Cont.)

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
PERSONAL INCOME								
(Bath / Year):								
≤ 33,600	94	40	21	33	66	26	38	2
		(42.6)	(22.3)	(35.1)		(39.4)	(57.6)	(3.0)
> 33,600	35	21	3	11	5	4	1	-
		(60.0)	(8.6)	(31.4)		(80.0)	(20.0)	
USUAL RESIDENCE								
Rural	99	45	19	35	56	28	26	2
		(45.5)	(19.2)	(35.4)		(50.0)	(46.4)	(3.6)
Urban	30	16	5	9	15	2	13	-
		(53.3)	(16.7)	(30.0)		(13.3)	(86.7)	
TYPE OF ILLNESS								
Acute Illness	30	28	7	-	27	13	14	-
		(76.7)	(23.3)			(48.1)	(51.9)	
Chronic Illness	55	38	17	-	42	17	25	-
		(69.1)	(30.9)			(40.5)	(59.5)	

*Deferred: Decision to be later by physician(s) or family

Table 5.10 : Difference in preference for CPR "If information provided that CPR may be followed by need for permanent mechanical ventilation and/or coma before expression of preferences"

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
GENDER	129	47	53	29	71	8	60	3
		(36.4)	(41.1)	(22.5)		(11.3)	(84.5)	(4.2)
AGE								
<45	58	33	18	7	38	4	33	1
		(56.9)	(31.0)	(12.1)		(10.5)	(86.9)	(2.6)
≥45	71	14	35	22	33	4	27	2
		(19.7)	(49.3)	(31.0)		(12.1)	(81.8)	(6.1)
MARITAL STATUS:								
Married	93	29	38	26	49	5	43	1
		(31.2)	(40.9)	(27.9)		(10.2)	(87.8)	(2.0)
Not-Married	36	18	15	3	22	3	17	2
		(50.0)	(41.7)	(8.3)		(13.6)	(77.3)	(9.1)

*Deferred: Decision to be later by physician(s) or family

Table 5.10 : Difference in preference for CPR "If information provided that CPR may be followed by need for permanent mechanical ventilation and/or coma before expression of preferences" (Cont.)

Difference in Decision BY		Decision re CPR By Males				Decision re CPR By Females		
		Yes	No	Deferred*		Yes	No	Deferred*
		n	n	n		n	n	n
	N	(%)	(%)	(%)	N	(%)	(%)	(%)
PERSONAL INCOME (Bath / Year):								
≤ 33,600	94	29	50	15	66	6	57	3
		(30.9)	(53.2)	(15.9)		(9.1)	(86.4)	(4.5)
> 33,600	35	18	3	14	5	2	3	-
		(51.4)	(8.6)	(40.0)		(40.0)	(60.0)	
PLACE OF USUAL RESIDENCE								
Rural	99	35	43	21	56	8	45	3
		(35.4)	(43.4)	(21.2)		(14.3)	(80.4)	(5.3)
Urban	30	12	10	8	15	-	15	-
		(40.0)	(33.3)	(26.7)			(100.0)	
TYPE OF ILLNESS								
Acute Illness	39	23	16	-	27	7	20	-
		(59.0)	(41.0)			(25.9)	(74.1)	
Chronic Illness	61	24	37	-	41	1	40	-
		(39.3)	(60.7)			(2.4)	(97.6)	

*Deferred: Decision to be later by physician(s) or family

Table 5.11 : The odds ratio (OR) of preference for no-CPR of non-critically ill patients by demographic variables when the different level of prognostic scenario was provided

The OR of Preference For no-CPR By	The level of prognostic scenario							
	No Information		If survival 7-24%		If survival 0-5%		If CPR follow by MV and/or by coma	
	OR (95% CI)	P- Value	OR (95% CI)	P- Value	OR (95% CI)	P- Value	OR (95% CI)	P- Value
GENDER Female/Male	5.37 (1.47-19.58)	0.011	2.11(0.70-6.33)	0.183	3.10 (1.47-6.54)	0.003	7.58 (2.91-19.76)	< 0.001
AGE Age ≥45/ <45	1.85 (0.57-6.05)	0.306	3.96 (1.28-12.26)	0.017	2.85 (1.33-6.12)	0.007	2.37 (1.02-5.50)	0.045
MARITAL STATUS: Not Married/Married	3.87 (1.21-12.37)	0.022	3.40 (1.13-10.22)	0.029	2.34 (1.03-5.28)	0.042	0.75 (0.31-1.77)	0.508
PERSONAL INCOME ≤33,600/ >33,600	0.37 (0.08-1.80)	0.217	0.90 (0.17-4.80)	0.904	3.26 (1.01-10.56)	0.049	7.88 (2.65-23.47)	< 0.001
PLACE OF RESIDENCE Urban/Rural	1.01(0.25-4.05)	0.988	1.05 (0.31-3.64)	0.933	1.92 (0.83-4.46)	0.129	1.21 (0.46-3.21)	0.701
TYPE OF ILLNESS Chronic/Acute	3.44 (0.87-13.52)	0.077	1.29 (0.43-3.86)	0.652	1.49 (0.70-3.19)	0.304	3.12 (1.40-6.98)	0.006

5.2.3.5 Defer Decision

Differences in preference to defer decision re-CPR and the information provided regarding the chance of survival is presented in Table 5.7-5.10. For all of the four scenarios, the males preferred to defer their decision regarding CPR more than the females. 10-44 males (7.7%- 34.1%) decided to defer their decision, and all deferred to their physicians; in contrary, only 2-3 of 71 females deferred their decision, and all to their relatives.

The preference to defer the decision for CPR in males varied depending upon the level of prognostic information. It differed by age, marital status, personal income, and usual residence.

In all scenarios, the proportion of male subjects who were 45 years or older, married, a rural dweller, and had low income (personal income $\leq$ 33,600 Baht/year) preferred to defer their decision more than those of younger age, not married, an urban dweller, and had higher income. The exception was found only in the scenario in which CPR might be followed by mechanical ventilation or coma or both. In this scenario, the proportion of those who had higher income (personal income > 33,600 Baht/year) and were urban dwellers deferred their decision more than those who had lower income or were rural dwellers.

5.3 Non-Randomized Control Study in Terminally Ill Patients

The focus of this research was to examine ADs for terminal care in terminally ill patients. Data from terminally ill patients were collected over a fourteen-month

period, from April 1, 2001 through May 31, 2002. Data from the controls were collected over eight months and data for the intervention groups were collected over six months.

5.3.1 Research Participants and Exclusions

A total of 448 terminally ill patients were admitted during the fourteen months of the study. In the first eight months, 217 patients were admitted and were included as the control subjects. In the last six months, 231 patients were admitted and, therefore, were the intervention subjects. Of 448 terminally ill patients, only 376 met the eligibility criteria.

The demographic characteristics of the subjects (with inclusion of non-participants) are shown in Table 5.12. Of the 217 control subjects, 139 (64.1%) were admitted with NSCLC, 34.1% (n=74) was admitted with ESLD and only four patients (1.8%) were admitted with other diagnoses. Therefore, the majority of subjects (98.2%) were admitted with the two diagnoses (NSCLC and ESLD). Sixty-seven patients (30.9%) had been diagnosed with other co-morbidity. Approximately two-third (n=143, 65.9%) were male. One hundred and one subjects (46.5%) were 60 or more years of age. Almost three-fourths (72.8%) was rural dwellers.

Similarly, of the 231 intervention subjects, approximately 90% were admitted with the two diagnoses. 160 (69.3%) were admitted with NSCLC and 48 (20.8%) were admitted with ESLD. Meanwhile only 23 (10.0%) were admitted with other diagnoses. Almost thirty percent (n=68) had other co-morbidity. 148 subjects (64.1%) were male.

Nearly half of them (n=111, 48.1%) was 60 years or older. Approximately, three-fourths (72.8%) was rural dwellers.

Generally, there were no significant differences by age, gender, co-morbidity and residence between the patients who were admitted during the control and the intervention period. The only significant difference noted was for the diagnosis. When compared between the two major diagnoses, the proportion of patients admitted with NSCLC in the control (64.1%, [57.7-70.4, 95%CI]) and in the intervention period (69.3%, [63.3-75.2, 95%CI]) were not seem to be different. However, the proportion of patients admitted with ESLD was higher in the control group than in the intervention group, 34.1% (27.8-40.4, 95%CI) and 20.8% (15.5-26.0, 95%CI]), respectively.

Briefly, the majority of subjects to be included to this study were the patients with two diagnoses, NSCLC and ESLD. Therefore, sub-analysis will further stratified by the two diagnoses.

Table 5.12 : Baseline demographic characteristic of the control and intervention groups before exclusion

Characteristic	Control N=217 n (%) [95% CI]	Intervention N=231 n (%)[95% CI]
Diagnosis		
NSCLC	139 (64.1) [57.7-70.4]	160 (69.3) [63.3-75.2]
ESLD	74 (34.1) [27.8-40.4]	48 (20.8) [15.5-26.0]
Other	*4 (1.8) [0.1-3.6]*	*23 (10.0) [6.1-13.8]*
Co-morbidity		
Present	67 (30.9) [24.7-37.0]	68 (29.4) [23.6-35.3]
Not-presented	150 (69.1) [63.0-75.3]	163 (70.6) [64.7-76.4]
Gender		
Male	143 (65.9) [59.6-72.2]	148 (64.1) [57.9-70.3]
Female	74 (34.1) [27.8-40.4]	83 (35.9) [29.7-42.1]
Age/Years		
40-49	54 (24.9) [19.1-30.6]	57 (24.7) [19.1-30.2]
50-59	62 (28.6) [22.6-34.6]	63 (27.3) [21.5-33.0]
60≤	101 (46.5) [39.9-53.2]	111 (48.1) [41.6-54.5]
Residence		
Urban	59 (27.2) [21.3-33.1]	54 (23.4) [17.9-28.8]
Rural	158 (72.8) [66.9-78.7]	177 (76.6) [71.2-82.1]

** For subject who were not oriented, all information were obtained from surrogate

A summary of the recruitment process and reasons for nonparticipation is presented in Table 5.13. Of 448 terminally ill patients, 72 (16.0%) were later excluded.

5.3.1.1 Exclusion from the Controls

Of the 72 patients who were excluded, 29 (13.4%) were from the control group. The majority (n = 18, 8.3%) of these subjects had been discharged or transferred to other units before it was possible to interview them. One subject died before an interview was possible. Ten subjects (4.6%) were excluded because of impaired clinical functioning on admission to the ward.

5.3.1.2 Exclusion from the Interventions

Of the 72 patients who were excluded, 43 subjects (18.6%) were excluded from the intervention group. Of these, 26 (11.2%) were discharged or transferred to other units, and one (0.4%) died before an interview was possible. A further eleven subjects (4.8%) were excluded due to clinical impairment on admission to the ward. Five subjects (2.2%) refused to participate in the study, four of whom stated that they were to tired to talk, and one who was waiting for their family to decide but was discharged before we could contact the relatives.

5.3.1.3 Comparison of Inclusion and Exclusion between the Controls and Interventions

Generally, there were no significant differences by the number of exclusion from the control group (13.4%, [8.8-17.9, 95%CI]) and the intervention groups (18.6%, [13.6-23.6, 95%CI]), in the case of discharge or transfer before the interview was possible, death or clinical impairment. The only significant difference noted was for subject refusal. There were five subjects (2.2%, [0.3-4.0, 95%CI]) in the intervention group who refused to participate but none (0%, [0.0-0.0, 95%CI]) in the control group.

The final sample size was 188 subjects in each group. The overall participant rate was no significant differences, 86.6% (82.1-91.2, 95%CI) and 81.4% (76.4-86.4, 95%CI) for the control and intervention groups, respectively.

As presented in Table 5.14, most subjects who were excluded for any reason were in two diagnostic groups: non-small cell lung cancer (NSCLC) and end stage liver disease (ESLD). Similar to those who were included (previously mentioned), therefore the characteristics of subjects with these two diagnostic groups who were included and excluded were presented. Among the subjects who were excluded due to discharge or transfer, NSCLC was the most common diagnosis, since most were admitted for chemotherapy only for a short time. The second most common diagnosis was ESLD, since the patients were coming shortly for direct ethanol injection.

Table 5.13 : Summary of subject recruitment process and reasons for nonparticipation for total admission to the control and intervention groups

Reason for Exclusion	Total N = 448 n (%)	Control N = 217 n (%)	[95% CI]	Intervention N = 231 n (%)	[95% CI]
Discharge/transfer before Interview possible	44 (9.8)	18 (8.3)	[4.6-12.0]	26 (11.2)	[7.2-15.3]
Death before interview possible	2 (0.5)	1 (0.5)	[-0.4-1.4]	1 (0.4)	[-0.4-1.3]
Impaired clinical functioning on admission to ward	21 (4.7)	10 (4.6)	[1.8-7.4]	11 (4.8)	[2.0-7.5]
Too ill	7 (1.6)	3 (1.4)		4 (1.7)	
Mentally incompetence	4 (0.9)	2 (0.9)		2 (0.9)	
Impaired hearing	10 (2.2)	5 (2.3)		5 (2.2)	
Subjects refusal	5 (1.1)	-	[0.0-0.0]	5 (2.2)	[0.3-4.0]
Total excluded	72 (16.1)	29 (13.4)	[8.8-17.9]	43 (18.6)	[13.6-23.6]
Participation rate	376 (83.9)	188 (86.6)	[82.1-91.2]	188 (81.4)	[76.4-86.4]

Table 5.14 : Summary of reasons for exclusion describe by specific diagnosis for total admission to the control and intervention groups

Exclusion reasons/ Type of Illness	Total N = 72 n (%)	Control N = 29 n (%)[95% CI]	Intervention N = 43 n (%)[95% CI]
Discharge/transfer before Interview possible			
NSCLC	31 (43.0)	13 (44.8) [26.7-62.9]	18 (41.8) [27.1-56.6]
ESLD	12 (16.6)	5 (17.2) [3.5-31.0]	7 (16.3) [5.2-27.3]
CA colon	1 (1.4)	- [0.0-0.0]	1 (2.3) [-2.2-6.8]
Death before interview possible			
NSCLC	2 (2.8)	1 (3.5) [-3.2-10.1]	1 (2.3) [-2.2-6.8]
Impaired clinical functioning On admission to ward			
Too ill			
NSCLC	5 (6.9)	2 (6.9) [-2.3-16.1]	3 (7.0) [-0.6-14.6]
ESLD	2 (2.8)	1 (3.5) [-3.2-10.1]	1 (2.3) [-1.6-10.9]
Mentally incompetence			
ESLD	4 (5.6)	2 (6.9) [-2.3-16.1]	2 (4.7) [-1.6-10.9]
Impaired hearing			
NSCLC	9 (12.5)	5 (17.2) [3.5-31.0]	4 (9.3) [0.6-18.0]
CA colon	1 (1.4)	- [0.0-0.0]	1 (2.3) [-2.2-6.8]
Subjects refusal			
NSCLC	3 (4.2)	- [0.0-0.0]	3 (7.0) [-0.6-14.6]
ESLD	2 (2.8)	- [0.0-0.0]	2 (4.7) [-1.6-10.9]

NSCLC : Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease; CA colon: Cancer of colon with multiple metastasis to liver.

The characteristics of subjects with NSCLC who were included and excluded were presented in Table 5.15. A total of 299 patients with NSCLC, 139 patients were included as the control subjects and 160 patients were the intervention subjects.

Of the 139 control subjects, 118 were included into the study and 21 were latter excluded. Of the 21 subjects who were excluded, 13 (6.0%) had been discharged or transferred to other units before it was possible to interview them. One subject (0.5%) died before an interview was possible. Seven subjects (3.2%) were excluded because of impaired clinical functioning on admission to the ward.

Table 5.15 : Comparison of subject inclusion and exclusion in the control and intervention groups for subjects with stage III and IV non-small cell lung cancer

Inclusion/ Exclusion	**Control N = 139 n (%)[95% CI]**	**Intervention N = 160 n (%) [95% CI]**
Discharge/transfer Before interview possible	13 (6.0) [4.5-14.2]	18 (7.8) [6.4-16.1]
Death before Interview possible	1 (0.5) [-0.7-2.1]	1 (0.4) [-0.6-1.8]
Impaired clinical functioning On admission to ward	7 (3.2) [1.4-8.7]	7 (3.0) [1.2-7.5]
Subjects refusal	- [0.0-0.0]	3 (1.3) [-0.2-4.0]
Total excluded	21 (9.7) [9.2-21.1]	29(12.5) [12.2-24.1]
Included	118 (84.9) [78.9-90.8]	131 (81.9) [75.9-87.8]

For subject who were not oriented, all information were obtained from surrogate

Of the 160 intervention subjects, 131 were included and 29 were excluded from the study. Of the 29 exclusion, eighteen subjects were discharged or transferred to other units before it was possible to interview them. One subject (0.4%) died before an interview was possible. Seven subjects (3.0%) were excluded because of impaired clinical functioning on admission to the ward. Three subjects refused to participate in the study.

Generally, the proportion of patients with NSCLC included and excluded in the control and intervention groups were similar. 84.9% (78.9-90.8, 95%CI) and 81.9% (75.9-87.8, 95%CI) were included and twenty-one (9.7%, [9.2-21.1]) and 29 (12.5%, [12.2-24.1]) were excluded from the control and intervention, respectively.

Table 5.16 presented the characteristics of subjects with ESLD who were included and excluded. There were 122 patients with ESLD admitted during the study period, 74 patients were included as the control subjects and 48 patients were the intervention subjects.

Of the 74 control subjects, 66 were included into the study and 8 were latter excluded. Of the 8 subjects who were excluded, 5 (6.8%) had been discharged or transferred to other units before it was possible to interview them. Three subjects (4.1%) were excluded because of impaired clinical functioning on admission to the ward. Of the 48 intervention subjects, 36 were included and 12 were excluded from the study. Among the 12 subjects who were excluded, 7 subjects (14.6%) were discharged or transferred to other units before it was possible to interview them. Three subjects

(6.3%) were excluded because of impaired clinical functioning on admission to the ward. Two subjects (4.2%) refused to participate in the study.

In summary, there were no different between those who included and excluded in the control and the intervention groups. 89.2% [82.1-96.3, 95%CI]) was included in the control group and 75.0% [62.8-87.3, 95%CI] was included to the intervention. Meanwhile 10.8% (3.7-17.9, 95%CI) and 25.0% (12.8-37.3, 95%CI) were excluded from the control and intervention, respectively.

Table 5.16 : Comparison of subject inclusion and exclusion in the control and intervention groups for subjects with end-stage liver disease

Inclusion/ Exclusion	**Control N = 74 n (%)[95% CI]**	**Intervention N = 48 n (%) [95% CI]**
Discharge/transfer Before interview possible	5 (6.8) [1.0-12.5]	7 (14.6) [4.6-24.6]
Impaired clinical functioning On admission to ward	3 (4.1) [-0.4-8.5]	3 (6.3) [-0.6-13.1]
Subjects refusal	0 (0.0) [0.0-0.0]	2 (4.2) [-1.5-9.8]
Total excluded	8 (10.8) [3.7-17.9]	12 (25.0) [12.8-37.3]
Total included	66 (89.2) [82.1-96.3]	36 (75.0) [62.8-87.3]

NSCLC: Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease.

For subject who were not oriented, all information were obtained from surrogate

5.3.2 Description of the Study Sample by Diagnosis

5.3.2.1 The Population Characteristics

The average age of the total population was 58.0 years (Standard deviation [SD] =11.0). 64.6% were male, 83% were married, and the majority (67.6%) had completed only preliminary school. Almost all (98.4%) were Buddhist, 73.7 % lived in rural areas, and most lived with family members (97.6%).

As previously mentioned, 97.9% of the control and 88.8% of the intervention groups were in two diagnostic groups (NSCLC and ESLD). Only a small number of subjects with other diagnoses including multi organ system failure with sepsis (MOSFS), non-traumatic and non-diabetic coma, and cancer of colon with metastasis to liver (CA colon) were included. Therefore, analyses of the demographic and clinical characteristics were further stratified by two major diagnostic groups, NSCLC and ESLD.

It should be mentioned at the beginning that most baseline demographic information was obtained from the patients. However, for patients who were not oriented, this information was gathered from their surrogate.

5.3.2.2 Demographic Characteristics of the Controls

From April 1, 2001 through November 30, 2001, there were 217 patients admitted in the study units who were eligible as the control subjects. Of these, 188 were included as the control.

The demographic of the study subjects are summarized in Table 5.17. Of the 188 patients, 123 (65.4%) were male. Forty-three percent were 60 or more years of age with a mean of 57.0 years (SD=10). The majority (83.0%) was married. Approximately two-thirds had primary education (≤ Grade 4-6). More than three-fourths had no income or had irregular income. Almost all were Buddhist (98.4%) and 71.8% were rural dwellers. Most (96.8%) lived with someone else. The majority of the patients lived with their spouse and their children (68.1%).

5.3.2.3 Demographic Characteristics of the Interventions

From December 1, 2001 through May 31, 2002, 231 patients were admitted and, therefore, were eligible as the intervention subjects. Of these, 188 were included as the interventions.

Of the 188 patients, 120 (63.8%) were male. Almost fifty percent were 60 or more years of age with a mean of 58.0 years (SD=12). The majority (83.0%) was married. Almost seventy percent had primary education (≤ Grade 4-6). More than 80% had no income or had irregular income. Almost all were Buddhist (98.4%) and 75.5% were rural residents. Most (98.4%) lived with someone else. The majority of the patients lived with their spouse and their children (68.6%).

5.3.2.4 Comparison of the Baseline Demographic Characteristics of the Controls and the Interventions

In order to assess whether or not the observed association between the AD intervention and the reduction in the rate of CPR performance was biased, the baseline demographic and clinical characteristics (see Section 5.3.2.7) of the subjects were

compared between the control and intervention groups. The baseline demographic characteristics included; gender, age, marital status, education, occupation, religion, and persons with whom the patient lived with.

5.3.2.4.1 Gender

In the total sample, the number of males was higher than the number of females. In the control group, 123 (65.4%, [58.6-72.2, 95%CI]) were male, and in the intervention group 120 (63.8%, [57.0-70.7, 95%CI]) were male. Meanwhile, 34.6% (27.8-41.4, 95%CI) and 36.2% (29.3-43.0, 95%CI) of the subjects in the control and intervention groups were female, respectively. The proportion of males and females was not significantly different between the control and intervention groups. The result was similar with the excluded patients who were not oriented.

Table 5.17 : Baseline demographic characteristic for total sample to the control and intervention groups

Characteristic	Control N=188 n (%) [95% CI]	Intervention N=188 n (%) [95% CI]
Gender		
Male	123(65.4) [58.6-72.2]	120(63.8) [57.0-70.7]
Female	65(34.6) [27.8-41.4]	68(36.2) [29.3-43.0]
Age/Years		
Mean (SD)	57 (10)	58 (12)
Range	40-85	40-96
Categorized values:		
40-49	52 (27.7) [21.3-34.1]	51 (27.1) [20.8-33.5]
50-59	55 (29.3) [22.8-35.8]	48 (25.5) [19.3-31.8]
60≤	81(43.0) [36.0-50.2]	89 (47.4) [40.2-54.5]
Marital Status		
Married	156 (83.0) [77.6-88.4]	156 (83.0) [77.6-88.4]
Unmarried	32 (17.0) [11.6-22.4]	32 (17.0) [11.6-22.4]
Single	9 (4.8)	6 (3.2)
Widowed	23 (12.2)	26 (13.8)
Education		
≤ Grade 4-6	124 (66.0) [59.2-72.7]	130 (69.1) [68.7-81.6]
≥ Grade 9	64 (34.0) [27.3-40.8]	43 (22.9) [18.4-31.3]
Grade 9	7 (3.7)	11 (5.9)
Grade 12	20 (10.6)	10 (5.3)
Occupational school	16 (8.5)	6 (3.2)
Bachelor or higher	21 (11.2)	16 (8.5)
No Schooling	-	*15 (8.0)*

For subject who were not oriented, all information were obtained from surrogate

Table 5.17 : Baseline demographic characteristic for total sample to the control and intervention groups (Cont.)

Characteristic	Control N=188 n (%) [95% CI]	Intervention N=18 n (%) [95% CI]
Occupation		
Regular income	46 (24.5) [18.3-30.6]	33 (17.6) [12.1-23.0]
Government officer	27 (14.4)	17 (9.0)
Business employ	19 (10.1)	16 (8.5)
Irregular income	84 (44.7) [37.6-51.8]	95 (50.5) [43.4-57.7]
Agricultural	55 (29.3)	66 (35.1)
Labor	29 (15.4)	29 (15.4)
No-income	58 (30.9) [24.2-37.5]	60 (31.9) [25.3-38.6]
No job	58 (30.9)	60 (31.9)
Residence		
Urban	53 (28.2) [21.8-34.6]	46 (24.5) [18.3-30.6]
Rural	135 (71.8) [65.4-78.2]	142 (75.5) [69.4-81.7]
Religion		
Buddhist	185 (98.4) [96.6-100.2]	185 (98.4) [96.6-100.2]
Other	3 (1.6) [-0.2-3.4]	3 (1.6) [-0.2-3.4]
Person who patient live with		
Living with someone	182 (96.8) [94.3-99.3]	185 (98.4) [96.6-100.2]
Spouse	24 (12.8)	25 (13.3)
Spouse & children	128 (68.1)	129 (68.6)
Children	25 (13.3)	24 (12.8)
Parent/relative	5 (2.6)	7 (3.7)
Living alone	6 (3.2) [0.7-5.7]	3 (1.6) [-0.2-3.4]

For subject who were not oriented, all information were obtained from surrogate

After stratification into the two diagnostic groups, among those with NSCLC, the proportion of males in the control ([59.3%, 50.5-68.2, 95%CI]) and intervention groups (60.3%, [51.9-68.7, 95%CI]) did not differ. Among the subjects with ESLD, the proportion of males and females was similar to that previously mentioned, there were more males than females. Generally, there was no difference by gender between the control and intervention groups.

5.3.2.4.2 Age

The average age of the subjects in the control was 57.0 years (SD = 10.0, range = 40.0 to 85.0), but was slightly older, 58.0 years (SD = 12.0, range = 40.0 to 96.0) among the subjects in the intervention group.

Age was categorized into 3 groups: young adult (40-49 years), middle-age adult (50-59 years), and elder person (≥ 60 years). However, more than forty percent in both groups were categorized in the latter group. No differences in the proportion of subjects in the age categories were observed between the two groups in total sample.

Similar findings were noted when those who were not oriented were excluded, and no differences in the proportion of subjects in the age categories were observed between the two groups.

After stratification by the two diagnostic groups, there was still no difference in age between the control and intervention groups among patients with NSCLC (Table 5.18). Approximately half of the NSCLC patients in both groups were 60 years or

older. In contrast, among those with ESLD, 39.4% (27.6-51.2, 95%CI) of the control and 36.1% (20.4-51.8, 95%CI) of the intervention group were young adults; 31.8% (20.6-43.1, 95%CI) of the control and 30.6% (15.5-45.6, 95%CI) of the intervention group were middle aged adults; and only 28.8% (17.9-39.7, 95%CI) of the control and 33.3% (17.9-48.7, 95%CI) of the intervention group were elder persons. In summary, the majority of the subjects with ESLD were younger adults but the majority of the patients with NSCLC were elderly. Generally, there was no difference by age between the control and intervention groups.

Table 5.18 : Age distribution for total sample to the control and intervention groups and stratify by diagnosis

Diagnosis Age/Years	Control N n (%) [95% CI]	Intervention N n (%) [95% CI]
Total Sample	**N=188**	**N=188**
40-49	52 (27.7) [21.3-34.1]	51 (27.1) [20.8-33.5]
50-59	55 (29.3) [22.8-35.8]	48 (25.5) [19.3-31.8]
60≤	81 (43.0) [36.0-50.2]	89 (47.4) [40.2-54.5]
NSCLC	**N=118**	**N=131**
40-49	24 (20.3) [13.1-27.6]	30 (22.9) [15.7-30.1]
50-59	32 (27.1) [19.1-35.1]	37 (28.2) [20.5-36.0]
60≤	62 (52.5) [43.5-61.6]	64 (48.9) [40.3-57.4]
ESLD	**N=66**	**N=36**
40-49	26 (39.4) [27.6-51.2]	13 (36.1) [20.4-51.8]
50-59	21 (31.8) [20.6-43.1]	11 (30.6) [15.5-45.6]
60≤	19 (28.8) [17.9-39.7]	12 (33.3) [17.9-48.7]

For subject who were not oriented, all information were obtained from surrogate

5.3.2.4.3 Marital Status

Eighty-three percent of the subjects in both the control and intervention groups were married. Few subjects were single and no one was divorced. The proportion of subjects that was widowed was similar between control and intervention groups (12.2% vs. 13.8%). When all unmarried (single and widowed) persons were grouped together and compared to those who were married, the proportion of each did not significantly differ between the control and intervention groups. In each stratum, defined by diagnosis, approximately 80- 91 percent of the subjects were married and a small number were unmarried. Similar findings were observed, and no differences in the proportion of subjects in each group.

5.3.2.4.4 Education

The subjects were assigned to one of three levels of education (completed grade 4-6 or less/completed grade 9 or more/no schooling) (Table 5.19). More than sixty-five percent of the subjects in the intervention (75.1%, [68.7-81.6, 95%CI]) and control groups (66.0, [59.2-72.7, 95%CI]) completed only grade 4-6 or less. Fifteen subjects in the intervention group had never been to school.

A higher proportion of the control group (34.0%, [27.3-40.8, 95%CI]) completed grade 9 or more, occupational school, or university degree as compared to the intervention group (22.9%, [18.4-31.3, 95%CI]).

However, when those with no schooling were excluded, no statistical differences were identified between the control and intervention group in the proportions who completed grade 9 or higher, and in the proportion who completed

grade 4-6 or less. Similarly, when the patients who were not oriented were excluded from the analysis, no statistical differences were identified between the control and intervention groups with respect to the two levels of education.

Table 5.19 : Description of education for total sample to the control and intervention groups and stratify by diagnosis

Characteristic	Control N n (%) [95% CI]	Intervention N n (%) [95% CI]
Total Sample	**N=188**	**N=188**
≤ Grade 4-6	124 (66.0) [59.2-72.7]	130 (75.1) [68.7-81.6]
≥ Grade 9	64 (34.0) [27.3-40.8]	43 (22.9) [18.4-31.3]
No Schooling	-	*15*
NSCLC	**N=118**	**N=131**
≤ Grade 4-6	73 (61.9) [53.1-70.6]	95 (81.2) [74.1-88.3]
≥ Grade 9	45 (38.1) [29.4-46.9]	22 (18.8) [11.7-25.9]
No Schooling	-	*14*
ESLD	**N=66**	**N=36**
≤ Grade 4-6	47 (71.2) [60.3-82.1]	20 (55.6) [39.3-71.8]
≥ Grade 9	19 (28.8) [17.9-39.7]	15 (41.7) [25.6-57.8]
No Schooling	-	*1 (2.8)*

For subject who were not oriented, all information were obtained from surrogate

In the subgroup with NSCLC, the proportion of the subjects who had low education (≤ Grade 4-6) and higher education (≥ Grade 9) were seem to be different. The proportion of the subjects who had low education in the intervention (81.2%, [74.1-88.3, 95%CI]) was higher than the control group (61.9%, [53.1-70.6, 95%CI]). In

contrast, the proportion of the subjects who had higher education in the control (38.1%, [29.4-46.9, 95%CI]) was more than two times higher than the intervention group (18.8%, [11.7-25.9, 95%CI]). When those with no schooling were excluded, there was still significant difference between the control and intervention groups with respect to the two levels of education.

In the subgroup with ESLD, the proportion of subjects who had low education in the intervention group (55.6%, [39.3-71.8, 95%CI]) was not significant differences from the control group (71.2%, [60.3-82.1, 95%CI]). Similarly, the proportion of subjects who completed at least Grade 9 in the intervention group (41.7%, [25.6-57.8, 95%CI]) was not differ to the control group (28.8%, [17.9-39.7, 95%CI]). When those with no schooling were excluded, no statistical differences were identified between the control and intervention group in the proportions who completed grade 9 or higher, and in the proportion who completed grade 4-6 or less.

In general, most of the subjects in the control and intervention groups had low education.

5.3.2.4.5 Occupation

Table 5.20 shows the distribution by occupation, which was categorized by three major occupations that depended on the type of expected income (regular income/ irregular income/no income).

Approximately thirty percent of subjects in the control and the intervention groups had no job and no regular income. Of those in the control group who worked, almost 30% were in agriculture, 15.4% were laborers, and 24.5% were government

officers or employed in the business sector. In the intervention group, 15.4% were laborers, a similar proportion as in the control group. In contrast, the proportion for those who worked in agriculture was higher (35.1%) but the proportion who worked in the government and business sectors was lower (17.6%). However, the proportion of subjects who worked in each occupation group was not significantly different between the control and intervention groups.

Table 5.20 Description of occupation for total sample to the control and intervention groups and stratify by diagnosis

Diagnosis/ Occupation	Control N n (%) [95% CI]	Intervention N n (%) [95% CI]
Total Sample	**N=188**	**N=188**
Regular income	46 (24.5) [18.3-30.6]	33 (17.6) [12.1-23.0]
Government officer	27 (14.4)	17 (9.0)
Business employ	19 (10.1)	16 (8.5)
Irregular income	84 (44.7) [37.6-51.8]	95 (50.5) [43.4-57.7]
Agricultural	55 (29.3)	66 (35.1)
Labor	29 (15.4)	29 (15.4)
No-income	58 (30.9) [24.2-37.5]	60 (31.9) [25.3-38.6]
No job	58 (30.9)	60 (31.9)
NSCLC	**N=118**	**N=131**
Regular income	31 (26.3) [18.3-34.2]	20 (15.3) [9.1-21.4]
Irregular income	50 (42.2) [33.5-51.3]	71 (54.2) [45.7-62.7]
No-income	37 (31.4) [23.0-39.7]	40 (30.5) [22.6-38.4]
ESLD	**N=66**	**N=36**
Regular income	15 (22.7) [12.6-32.8]	8 (22.2) [8.6-35.8]
Irregular income	32 (48.5) [36.4-60.5]	19 (52.8) [36.5-69.1]
No-income	19 (28.8) [17.9-39.7]	9 (25.0) [10.9-39.1]

NSCLC: Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease

For subject who were not oriented, all information were obtained from surrogate

When stratified by diagnoses, the pattern of occupation seems to be similar in both NSCLC and ESLD. The proportion of those who had irregular income was dominant, followed by the proportion of those with no-income. There were not significantly different between the control and intervention groups with respect to each occupation group.

5.3.2.4.6 Residence

The majority of the subjects in both the control and intervention groups were living in rural areas. The proportion of rural dwellers in the control group was 71.8% (65.4-78.2, 95%CI) and 75.5% (69.4-81.7, 95%CI) in the intervention group. No significant difference in the proportion of rural and urban dwellers was noted between the control and intervention groups. A non-significant finding was observed when the patients who were not oriented were excluded from the analysis.

The results after stratification by diagnostic group were similar. There was no significant difference between the control and intervention groups in the proportion of urban and rural dwellers among subjects with NSCLC and ESLD. The proportion of rural dwellers seems to be larger than urban dweller in the control and the intervention groups.

5.3.2.4.7 Religion

An identical number of subjects (185, 98.4%) in the control and intervention groups were Buddhist (Table 5.14). Only three subjects in each group were of other religions. No significant difference in the proportion of those who were Buddhist and other religion was noted between the control and intervention groups.

5.3.2.4.8 Persons Whom the Patients Live With

Almost all of our study subjects lived with someone else (Table 5.14). Only 6 (3.2%) control subjects and 3 (1.6%) intervention subjects lived alone. The majority (68.1% - 68.6%) in both groups lived with their spouse and their children. The remaining subjects lived with their spouse, children, parents and other relatives.

5.3.2.5 Clinical Characteristics of the Controls

Table 5.21 shows the baseline clinical characteristics for the total sample in the control and intervention groups. The baseline clinical characteristics included; diagnosis, CPC score, co-morbidity, mental status and psychological stage.

Of the 188 control patients, 62.8% were diagnosed with NSCLC, 35.1% were diagnosed with ESLD, and only 4 patients were diagnosed with other diagnoses. Therefore the majority of subjects were in the two diagnoses (NSCLC and ESLD).

Sixty-three patients (33.5%) were diagnosed with other co-morbidity. Of this, 32 patients (17.0%) had one co-morbidity, 26 patients (13.8%) had two co-morbidities and only 5 patients had three co-morbidities.

Of 188, the proportion of control subjects with CPC of 1 and 2, representing those still capable of daily activity was 42.6%. In this category, the proportion of subjects with CPC of 1 and 2 were similar (21.8% and 20.8%, respectively). The proportion of subjects with CPC of 3 and 4, representing dependency on daily activity, were higher (57.4%) than those with CPC of 1 and 2. The majority in this category was

patients with CPC of 3 (n=104, 55.3%), and only a small number had a CPC of 4 (n=4, 2.1%).

For mental status, at the initial assessment, ninety-one percent were alert and oriented and only 9.0% were confused or were in a coma. However, for the psychological state, 58.5% of the subjects (n=110) were in the acceptance stage and 32.5% (n=61) were in the non-acceptance stage. The remaining (9.0%) were excluded from the analysis because they were in a coma or having mechanical ventilation and their psychological wellbeing was not assessable.

5.3.2.6 Clinical Characteristics of the Interventions

Of the 188 intervention patients, 69.7% were diagnosed with NSCLC, 19.1% were diagnosed with ESLD, and 21 patients (11.2%) were diagnosed with other diagnoses. Similarly, the majority of subjects were in the two diagnoses (NSCLC and ESLD). Meanwhile, 58 subjects (30.9%) had been diagnosed with other co-morbidity. Of these, most of them (n=40, 21.3%) had one co-morbidity. The remaining 15, 2 and 1 subjects had two, three and four co-morbidities, respectively.

For the CPC score, the proportion of intervention subjects with CPC of 1 and 2, representing those still capable of daily activity was 68.6%. In this category, the proportion of subjects with CPC of 1 was more than CPC of 2 (38.3% and 30.3%, respectively). The proportion of subjects with CPC of 3 and 4 (31.4%), representing dependency on daily activity, was much less than those with CPC of 1 and 2. The

majority in this category was patients with CPC of 3 (24.5%), and only 6.9% (n=13) had a CPC of 4.

At the initial assessment, ninety-one percent were alert and oriented and only 9.0% were confused or were in a coma. For the psychological stage, 56.4% (n=106) of the subjects were in the acceptance stage and 65 patients (34.6%) were in the non-acceptance stage. The remaining (n =17, 9.0%) were excluded from the analysis because they were in a coma or having mechanical ventilation and their psychological wellbeing was not assessable.

5.3.2.7 Comparison of the Baseline Clinical Characteristics of the Controls and the Interventions

As previously mentioned, it is important to assess whether or not the observed association between the AD intervention and the reduction in the rate of CPR performance was biased, the baseline clinical characteristics of the subjects were also compared between the control and intervention groups.

5.3.2.7.1 Diagnosis

One hundred and eighteen subjects (62.8%, [55.9-69.7, 95%CI]) in the control group and 131 subjects (69.7%, [63.1-76.3, 95%CI]) in the intervention group were diagnosed with NSCLC, the most common diagnosis in the study sample. The next most common diagnosis was ESLD (35.1% of the control and 19.1% of the intervention subjects). Only a small number of the subjects had other diagnoses (multi-organ system failure with sepsis, non-traumatic and non-diabetic coma, and cancer of the colon with

liver metastases) in both groups. Statistical comparisons were made only using the two diagnoses (NSCLC and ESLD).

Table 5.21 Baseline clinical characteristic for total sample to the control and intervention groups

Characteristic	Control N=188 n (%) [95% CI]	Intervention N=188 n (%) [95% CI]
Diagnosis		
NSCLC	118 (62.8) [55.9-69.7]	131 (69.7) [63.1-76.3]
ESLD	66 (35.1) [28.3-41.9]	36 (19.1) [13.5-24.8]
OTHER	4 (2.1) [0.1-4.2]	21 (11.2) [6.7-15.7]
MOSFS	-	7 (3.7)
Non-traumatic Non-diabetic coma	1 (0.5)	9 (4.8)
CA colon	3 (1.6)	5 (2.7)
Co-morbidity		
Present	63 (33.5) [26.8-40.3]	58 (30.9) [24.2-37.5]
One co-morbidity	32 (17.0)	40 (21.3)
Two co-morbidity	26 (13.8)	15 (8.0)
Three co-morbidity	5 (2.7)	2 (1.1)
Four co-morbidity	-	1 (0.5)
Not-presented	125 (66.5) [59.7-73.2]	130 (69.1) [62.5-75.8]
CPC score		
Independent	80 (42.6) [35.5-49.6]	129 (68.6) [62.0-75.3]
CPC 1	41 (21.8)	72 (38.3)
CPC 2	39 (20.8)	57 (30.3)
Dependent	108 (57.4) [50.4-64.5]	59 (31.4) [24.7-38.0]
CPC 3	104 (55.3)	46 (24.5)
CPC 4	4 (2.1)	13 (6.9)

NSCLC: Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease; MOSFS: Multiple organs system failure with sepsis; CA colon: Cancer of colon with multiple metastasis to liver. CPC score: Cerebral performance categories.

Table 5.21 : Baseline clinical characteristic for total sample to the control and intervention groups (Cont.)

Characteristic	Control N=188 n (%) [95% CI]	Intervention N=188 n (%) [95% CI]
Mental Status		
Orientated	171 (91.0) [86.9-95.1]	171 (91.0) [86.9-95.1]
Not oriented	17 (9.0) [4.9-13.1]	17 (9.0) [4.9-13.1]
Confused	13 (6.9)	4 (2.1)
Coma	4 (2.1)	13 (6.9)
Psychological State		
Acceptance	110 (58.5) [51.5-65.6]	106 (56.4) [49.3-63.5]
Other	61 (32.5) [25.8-39.1]	65 (34.6) [27.8-41.4]
Denial	12 (6.4)	15 (8.0)
Anger	2 (1.1)	-
Bargaining	18 (9.6)	18 (9.6)
Anxiety	22 (11.7)	18 (9.6)
Depression	2 (1.1)	10 (5.3)
Fear	5 (2.6)	4 (2.1)
Unable to access	*17 (9.0)* [4.9-13.1]	*17 (9.0)* [4.9-13.1]

NSCLC: Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease; MOSFS: Multiple organs system failure with sepsis; CA colon: Cancer of colon with multiple metastasis to liver. CPC score: Cerebral performance categories.

Generally the proportion of subjects with NSCLC in the control and the intervention group were similar but the proportion of subjects with ESLD were different. The proportion of subjects with ESLD in the control (35.1%, [28.3-41.9, 95%CI]) was more than in the intervention group (19.1%, [13.5-24.8, 95%CI]).

5.3.2.7.2 Co-morbidity

A summary of the number of co-morbidity and stratify by diagnosis is presented in Table 5.22. Sixty-three subjects (33.5%) in the control and 58 (30.9%) in the intervention group had been diagnosed with other co-morbidities. In the control group, seventeen percent had one co-morbidity and 13.8 percent had two co-morbidity. The most common co-morbidity was pulmonary disorder (n = 30, 30.3%), followed with gastrointestinal disorder (n = 28, 28.3%). In the intervention group, 21.3% (n = 40) had one co-morbidity, and 8.0% (n = 15) had two co-morbidities. Again, pulmonary disorder was the most common co-morbidity (n = 34, 42.5%). There was no significant difference between the proportion of subjects in the control and intervention group with co-morbidity. A mean of co-morbidity in the control was 0.52 (0.4-0.64, 95% CI). A mean of co-morbidity in the intervention group was 0.43 with (0.32-0.53, 95% CI). Similarly, there was no significant difference between the proportion of subjects in the control and intervention group with co-morbidity. Within the disease-specific subgroups, for NSCLC and ESLD, there was no difference in the proportion of the subjects with co-morbidity between the control and intervention groups.

Table 5.22 : Summary of the number of co-morbidity presented in control and intervention groups for total sample and stratify by two diagnoses

Co-morbidity	Control N n (%)[95% CI]	Intervention N n (%)[95% CI]
TOTAL SAMPLE	**N=188**	**N=188**
Present	63 (33.5) [26.8-40.3]	58 (30.9) [24.2-37.5]
One co-morbidity	32 (17.0)	40 (21.3)
Two co-morbidity	26 (13.8)	15 (8.0)
Three co-morbidity	5 (2.7)	2 (1.1)
Four co-morbidity	-	1 (0.5)
Not-presented	125 (66.5) [59.7-73.2]	130 (69.1) [62.5-75.8]
NSCLC	**N=118**	**N=131**
Present	27 (22.9) [15.3-30.5]	29 (22.1) [15.0-29.2]
Not-presented	91 (77.1) [69.5-84.7]	102 (77.9) [70.8-85.0]
ESLD	**N=66**	**N=36**
Present	34 (51.5) [39.5-63.6]	14 (38.9) [23.0-54.8]
Not-presented	32 (48.5) [36.4-60.5]	22 (61.1) [45.2-77.0]

5.3.2.7.3 CPC

Table 5.23 shows the description of the Cerebral Performance Categories (CPC) score between the control and intervention groups and stratified by the two diagnostic categories. Apparently, the clinical condition of the subjects in both groups was quite different. For example, the proportion of the control subjects with a CPC of 3 and 4, representing dependency on daily activity, was almost double that in the intervention

group (57.4%, [50.4-64.5, 95%CI] vs. 31.4%, [24.7-38.0, 95%CI]). Meanwhile, the proportion of the subjects in the intervention group with CPC of 1 or 2, representing those still capable of daily activity, was larger than in the control group (68.9% [62.0-75.3, 95%CI]) vs. 42.6% [35.5-49.6, 95%CI]). A significant difference was observed between the control and intervention groups with respect to the CPC score. These results implied that the control subjects had worsened clinical condition than the intervention subjects.

It was found that most subjects with a CPC score of 4 were those in the other diagnosis group, which was largely made up of patients in a non-traumatic and non-diabetic coma. In the intervention group, 9 of 13 subjects were patients with non-traumatic and non-diabetic coma.

After categorization, among subjects with CPC of 3 or 4, the number of subjects in the control group with NSCLC was almost 2 times greater than in the intervention group. Meanwhile, the proportion of the subjects in the intervention group with CPC of 1 or 2 was larger than in the control group (72.5% vs. 48.3%). The proportion of the subjects with NSCLC who were independent (CPC 1 or 2) and dependent (CPC 3 or 4) was significantly different between the control and intervention group.

For ESLD, the proportion of the subjects in the intervention group with CPC of 1 or 2, was larger than in the control group (80.6% [67.6-93.5, 95%CI]) vs. 33.3% [22.0-44.7, 95%CI]). The proportion of the control subjects with a CPC of 3, was more than triple that in the intervention group (66.7%, [55.3-78.0, 95%CI] vs. 19.4%, [6.5-

32.4, 95%CI]). Similarly, a significant difference was observed between the two groups.

Table 5.23 : Summary of CPC score for total sample to the control and intervention group and stratify by diagnosis

Diagnosis / CPC score	Control N=188 n (%) [95% CI]	Intervention N=188 n (%) [95% CI]
TOTAL SAMPLE	**N=188**	**N=188**
Independent	80 (42.6) [35.5-49.6]	129 (68.6) [62.0-75.3]
CPC 1	41 (21.8)	72 (38.3)
CPC 2	39 (20.8)	57 (30.3)
Dependent	108 (57.4) [50.4-64.5]	59 (31.4) [24.7-38.0]
CPC 3	104 (55.3)	46 (24.5)
CPC 4	4 (2.1)	13 (6.9)
NSCLC	**N=118**	**N=131**
Independent	57 (48.3) [39.3-57.3]	95 (72.5) [64.9-80.2]
CPC 1	30 (25.4)	54 (41.2)
CPC 2	27 (22.9)	41 (31.3)
Dependent	61 (51.7) [42.7-60.7]	36 (27.5) [19.8-35.1]
CPC 3	57 (48.3)	34 (26.0)
CPC 4	4 (3.4)	2 (1.5)
ESLD	**N=66**	**N=36**
Independent	22 (33.3) [22.0-44.7]	29 (80.6) [67.6-93.5]
CPC 1	11 (16.7)	15 (41.7)
CPC 2	11 (16.7)	14 (38.9)
Dependent	44 (66.7) [55.3-78.0]	7 (19.4) [6.5-32.4]
CPC 3	44(66.7)	7 (19.4)

5.3.2.7.4 Mental status

During the initial assessment, the majority of the subjects in both the control and intervention groups (91.0%) were alert and oriented, and less than 10% were not oriented. For those who were not oriented, in the control group, 6.9% (n=13) was confused, and 4 (2.1%) were in a coma. In contrast, for those who were not oriented in the intervention group, 13 (6.9%) were in a coma and 2.1% (n=4) was confused. No significant differences were noted between the two groups with respect to mental status.

Stratification by diagnostic group showed no differences between the control and intervention groups among the subjects diagnosed with both NSCLC and ESLD.

5.3.2.7.5 Psychological stage

The psychological stage of the subjects is presented in Table 5.21. Generally, more than 55% of the subjects in both the control and the intervention group were in the acceptance stage at the initial assessment. Seventeen subjects in the control group and 17 subjects in the intervention group were excluded from the analysis because they were in a coma or having mechanical ventilation and their psychological well being was not assessable. Among the subjects whose psychological well being could be assessed, 61 (32.5%, [25.8-39.1, 95%CI]) in the control group and 65 (34.6%, [27.8-41.4, 95%CI]) in the intervention group were in a non- acceptance stage such as anxiety, bargaining, denial, anger, depression and fear. Only some subjects were found in the latter three categories of non-acceptance. There were no significant differences between the control and the intervention groups with regard to the proportions in an accepting psychological stage.

After stratification into the two diagnostic categories, no significant difference in the psychological stage was identified among the subjects diagnosed with either NSCLC or ESLD.

5.3.2.8 Summary

Briefly, there were no significant differences by age, gender, marital status, education, occupation, religion, or residence between the control and intervention groups. Similar observations were noted for clinical characteristics; no significant differences between the control and intervention groups were identified in the proportion in the mental status, psychological state and presentation of co-morbidity. The exceptions were for the diagnostic group (ESLD) and average CPC score.

5.3.3 Investigation to Confirm the Diagnosis

The study sample was comprised of subjects with five diagnoses, namely NSCLC, ESLD, MOSFS, non-traumatic and non-diabetic coma, and cancer of the colon with liver metastases. Several investigations had been performed to confirm these diagnoses.

5.3.3.1 Non-Small Cell Lung Cancer

This study included 118 subjects with NSCLC in the control group and 131 subjects with NSCLC in the intervention group. NSCLC were diagnosed with an appropriate method (Table 5.24). To confirm the diagnosis, a lung biopsy was performed on 55 (46.6%) in the control group and 51 (38.9%) in the intervention group. Pleural fluid for cytology was used in 58 (49.2%) in the control group and 45 (34.4%)

in the intervention group. Fine needle aspiration was performed on 16 (13.6%) in the control group and 24 (18.3%) in the intervention group. Pleural tapping was performed on 24 (20.3%) in the control group and 36 (27.5%) in the intervention group. Pleural resection was performed on 5 (4.2%) in the control group and 1 (0.8%) in the intervention group. The most common investigation observed in both groups was chest X-rays which were performed on approximately 92% to 93% of the subjects to determine their general condition. A CT Scan of the chest was done on 65.3% of the control subjects and 73.3% of the intervention subjects to confirm metastatic disease. Lymph node biopsies, bone scans, and alpha-fetoprotein (AFP) tests were also common in both groups.

Table 5.24 : Summary of investigations to confirm the diagnosis: Non-small cell lung cancer for the control and intervention groups

Type of investigation	Control N = 118 n (%)	Intervention N = 131 n (%)
To confirm diagnosis		
Lung biopsy	55 (46.6)	51 (38.9)
Cytology	58 (49.2)	45 (34.4)
Fine needle aspiration	16 (13.6)	24 (18.3)
Pleural Tapping	24 (20.3)	36 (27.5)
Resection	5 (4.2)	1 (0.8)
To confirm metastasis disease		
CT Scan of chest	77 (65.3)	96 (73.3)
Ultrasound abdomen	17 (14.4)	23 (17.5)
Lymph node biopsy	37 (31.4)	64 (48.8)
CT Scan of abdomen	7 (5.9)	7 (5.3)
CT Scan of Brain	22 (18.6)	12 (9.2)
MRI	12 (10.2)	6 (4.6)
Bone Scan	42 (35.6)	61 (46.6)
Colonoscopy	11 (9.3)	11 (8.4)
Abdominal tapping	-	1 (0.8)
To determine general condition		
Chest X-rays	110 (93.2)	121 (92.4)
Liver function test	3 (2.5)	1 (0.8)
Alpha feto protein	44 (37.3)	42 (32.1)
CEA	7 (5.9)	5 (3.8)

5.3.3.2 End Stage Liver Disease

ESLD was the second most common diagnosis of the subjects included in this study. There were 66 subjects in control group and 36 subjects in the intervention group with ESLD (Table 5.25).

In all 66-control subjects with ESLD, AFP testing was done to confirm this diagnosis. Ultrasounds of the abdomen, abdominal tappings, and CT scans of the abdomen were done in 74.2%, 22.7% and 25.8% of the subjects, respectively. Liver function tests were also common (62.1%) to determine the general condition of the liver. To confirm metastasis disease, colonoscopy, lymph node biopsy and carcinoembryonic antigen (CEA) tests were done (36.4%, 15.2%, and 31.9%, respectively).

Similarly, in 36 subjects of the intervention group with ESLD, all had AFP tests. Ultrasounds of the abdomen, liver biopsies, CT scan of the abdomen and fine needle aspirations of the liver were performed (69.4%, 55.6%, 36.1%, and 19.4%, respectively). It tended to confirm the diagnosis. Additionally, CEA test, colonoscopy, and gastroscopy were noted in 30.6%, 25.0%, and 16.7% of subjects, respectively; these tests were performed to identify metastatic lesions. However, liver function tests were also performed in half of the subjects.

Table 5.25 : Summary of investigation to confirm the diagnosis: End stage liver disease for the control and intervention groups

Type of investigation	Control N = 66 n (%)	Intervention N = 36 n (%)
To confirm diagnosis		
Fine needle aspiration	13 (19.7)	7 (19.4)
Alpha feto protein	66 (100)	36 (100)
Abdominal tapping	15 (22.7)	1 (2.8)
Liver biopsy	-	20 (55.6)
Resection	1 (1.5)	2 (5.6)
Ultrasound abdomen	49 (74.2)	25 (69.4)
CT Scan of abdomen	17 (25.8)	13 (36.1)
To confirm metastasis disease		
CT Scan of chest	3 (4.5)	1 (2.8)
Lymph node biopsy	10 (15.2)	3 (8.3)
CT Scan of Brain	3 (4.5)	1 (2.8)
MRI	3 (4.5)	1 (2.8)
Gastroscopy	-	6 (16.7)
Lung biopsy	-	1 (2.8)
Cytology	4 (6.1)	1 (2.8)
Bone Scan	1 (1.5)	2 (5.6)
Pleural Tapping	-	1 (2.8)
Colonoscopy	24 (36.4)	9 (25.0)
CEA	21 (31.9)	11 (30.6)
To determine general condition		
Chest X-rays	10 (15.2)	5 (13.9)
Blood Ammonia	9 (13.6)	1 (2.8)
Liver function test	41 (62.1)	18 (50.0)

5.3.3.3 Multiple Organ System Failure with Sepsis

During a study period, only seven patients with MOSFS were included in the intervention group and none in the control group (Table 5.26). Colonoscopy, AFP, and magnetic resonance imaging (MRI) were performed in five subjects (71.4%). Chest X-rays, CEA test, and liver function tests were done in four subjects (57.1%).

Table 5.26 : Summary of investigations to confirm the diagnosis: Multi-organ system failure with sepsis for the control and intervention groups

Type of investigation	Control N = 0 n (%)	Intervention N = 7 n (%)
To confirm diagnosis		
Colonoscopy	-	5 (71.4)
Alpha feto protein	-	5 (71.4)
MRI	-	5 (71.4)
CT Scan of brain	-	3 (42.9)
Ultrasound abdomen	-	1 (14.3)
Cytology	-	1 (14.3)
To determine general condition		
Chest X-rays	-	4 (57.1)
CEA	-	4 (57.1)
Liver function test	-	4 (57.1)

5.3.3.4 Non-Traumatic and Non-Diabetic Coma

Only one subject in the control group and nine subjects in the intervention group were included with non-traumatic and non-diabetic coma (Table 5.27). For the one subject in the control group, only the CT scan of the brain was done to confirm the diagnosis. A CT scan of the brain was the most common investigation (77.8%) in the intervention group. AFP test, chest X-rays, colonoscopy, and CEA tests were done in 22-33% of the patients as well.

Table 5.27 : Summary of investigations to confirm the diagnosis: Non-traumatic, non-diabetic coma for the control and intervention groups

Type of investigation	Control N = 1 n (%)	Intervention N = 9 n (%)
To confirm diagnosis		
CT Scan of Brain	1 (100.0)	7 (77.8)
To confirm other disease involvement		
CT Scan of chest	-	1 (11.1)
Alpha feto protein	-	3 (33.3)
Colonoscopy	-	2 (22.2)
To determine general condition		
Chest X-rays	-	2 (22.2)
CEA	-	2 (22.2)
Blood Ammonia	-	1 (11.1)

5.3.3.5 Cancer of the Colon with Metastasis to Liver

Few subjects were included with colon cancer with liver metastases. There were 3 cases in the control group and 5 in the intervention group (Table 5.28).

All three subjects in the control group had abdominal CT Scans. In addition, fine needle aspiration of the liver, MRI, abdominal ultrasound, and liver resection was done in one to two of the subjects to confirm the diagnosis. Lymph node biopsies, pleural tapping, CT scans of the chest and gastroscopy were performed in two subjects to search for distant metastases. One subject had a chest X-ray and two subjects had blood ammonia tests.

In the intervention group, to confirm the definite diagnosis, three subjects had a colonoscopy (60%), two had an abdominal ultrasound (40%), two had abdominal CT scans (40%), two had cytological tests (40.0%), one had a liver biopsy (20%) and one had AFP testing (20%) performed. Additionally, one had a lung biopsy (20%), one had a lymph node biopsy (20%), two had a gastroscopy (40%) and one had pleural tapping (20%) to confirm metastatic disease. To determine the general condition of the subjects, blood for CEA, liver function test, and chest X-rays had been done in 5 subjects (100%), 4 (60 %) and 1 (20%), respectively.

Table 5.28 : Summary of investigation to confirm the diagnosis: Cancer of colon with metastasis to liver for the control and intervention groups

Type of investigation	Control N = 3 n (%)	Intervention N = 5 n (%)
To confirm diagnosis		
Ultrasound abdomen	1 (33.3)	2 (40.0)
CT Scan of abdomen	3 (100.0)	2 (40.0)
Magnetic Resonance Image (MRI)	1 (33.3)	-
Fine needle aspiration	2 (66.7)	-
Cytology	-	2 (40.0)
Resection	1 (33.3)	-
Alpha feto protein (AFP)	-	1 (20.0)
Colonoscopy	-	3 (60.0)
Liver biopsy	-	1 (20.0)
To confirm metastasis disease		
CT Scan of chest	2 (66.7)	-
Lung biopsy	1 (33.3)	1 (20.0)
Lymph node biopsy	2 (66.7)	1 (20.0)
Pleural Tapping	2 (66.7)	1 (20.0)
Gastroscopy	2 (66.7)	2 (40.0)
To determine general condition		
Chest X-rays	1 (33.3)	1 (20.0)
CEA	-	5 (100.0)
Liver function test	-	3 (60.0)
Blood Ammonia	2 (66.7)	-

5.3.4 Observation for Intervention regarding CPR, death and AD

As mentioned previously, the AD was implemented to all subjects in the intervention group. The subjects in the control group received traditional care. To evaluate the effectiveness of AD intervention, the outcomes expected from the implementation of AD were measured in both groups. The outcomes were CPR event, death rate and AD employment (AD employment is presented in a later section).

5.3.4.1 CPR performance

Several outcomes needed to be measured to test the effectiveness of the AD intervention. Among those, CPR performance rate was the most important indicator. During the index hospitalization, 376 terminally ill subjects were observed. Of these, 188 subjects were in the control group and another 188 were in the intervention group. A summary of CPR performance during hospitalization is presented in Table 5.29. Of all 376 terminally ill subjects who were observed, 33 subjects (8.8%) had CPR attempted, 342 subjects (90.9%) were hospitalized without CPR, and interestingly, only one subject (0.3%) gave the do-not-resuscitation (DNR) order.

Table 5.29 : Comparison of CPR performance during hospitalization for the control and the intervention groups after exclusion of the DNR order

Terminal Event	Total N=376	Control N=188 n%[95% CI]	Intervention N=188 n%[95% CI]
Terminal Event			
CPR done	33	24 (12.8) [8.0-17.5]	9 (4.8) [1.7-7.9]
CPR not done	342	164 (87.2) [82.5-92.0]	178 (94.7) [92.1-98.3]
DNR order	1	-	1 (0.5)

Of the 33 subjects who had CPR performed, 24 subjects were in the control group and nine were in the intervention group. The frequency of CPR performance was 12.8 percent (8.0-17.5, 95%CI) in the control group as compared to only 4.8 percent (1.7-7.9, 95%CI) in the intervention group. These observations imply that the AD intervention possibly reduced the resuscitation rate in patients who received AD by 50% as compared to terminally ill patients who did not receive the AD intervention.

For those hospitalized without CPR, the higher proportion was in the intervention group than in the control group, 94.7% (92.1-98.3, 95%CI) and 87.2% (82.5-92.0, 95%CI, respectively). After exclusion of the subject with the DNR order, the proportion of subjects with and without CPR attempted was significantly different between the control and intervention group.

5.3.4.2 Death and Living in the Hospital

A summary of survival and mortality during hospitalization is presented in Table 5.30 Of the 376 subjects, 315 (83.8%) left the study hospital alive and 61 (16.2%) died in hospital.

Of the 315 subjects who left the study hospital alive, 144 (76.6%, [70.5-82.6, 95%CI]) were in the control group and 171 (91.0%, [86.9-95.1, 95%CI]) were in the intervention group. The survival rate of the hospital discharges in the control group was lower when compared to the intervention group.

Of the 315 subjects who left the study hospital alive, 256 (68.1%) were discharged, 51 (13.5%) decided for self-discharge and eight (2.2%) were transferred to other hospitals near their home.

Of the 61 subjects who died during index hospitalization, 44 were in the control group, and 17 were in the intervention group. The mortality rate of the hospital discharges of the two groups was 23.4% (17.4-29.5, 95% CI) and 9.0% (4.9-13.1, 95% CI), respectively.

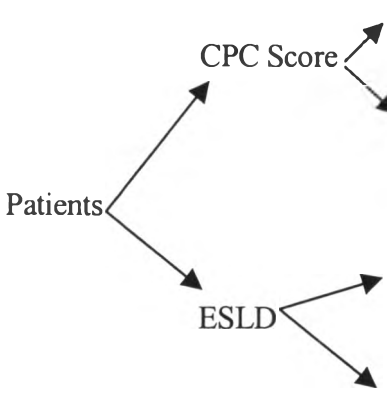
Table 5.30 : Survival and mortality in hospital for the control and the intervention groups

Result	Total N=376	Control N=188 n%[95% CI]	Intervention N=188 n% [95% CI]
Final Result			
Dead	61 (16.2)	44 (23.4) [17.4-29.5]	17 (9.0) [4.9-13.1]
Alive	315 (83.8)	144 (76.6) [70.5-82.6]	171 (91.0) [86.9-95.1]
Discharge	256 (68.1)	109 (58.0)	147 (78.2)
Self-Discharge	51 (13.5)	32 (17.0)	19 (10.1)
Transfer	8 (2.2)	3 (1.6)	5 (2.7)

When all subjects who had survived hospitalization (discharged/self-discharge/ transferred) were combined and, then, compared with those who were dead, a significant difference was observed between the control and intervention group with respect to the number of dead and living. The mortality rate of the hospital discharges in the control group was higher than the intervention group.

Since the imbalance of two baselines clinical characteristic (CPC Score and a number of patients with ESLD) were observed, therefore Mantel-Haenszel Chi-Square or Covariate analyses were calculated from the following 2 x 2 tables, as presented in Figure 5.1.

Figure 5.1 : The number of dead and not dead of the subjects in the control and intervention group subcategories by the CPC score and the diagnosis of end-stage liver disease.



		Intervention	Control
CPC 1 & 2	Dead	12	21
	Not dead	117	59
CPC3 & 4	Dead	5	23
	Not dead	54	85
ESLD+	Dead	2	19
	Not dead	34	47
ESLD-	Dead	14	24
	Not dead	117	94

1. Calculated expected a_1 from each 2x 2 Table

CPC 1&2 = 129 x 33/209 = 20.36

CPC 3&4 = 59 x 28/167 = 9.89

ESLD+ = 36 x 21/102 = 7.41

ESLD- = 131 x 38/249 = 19.99

$\Sigma E(a_1)$ = 20.36 + 9.89 +7.41 +19.99 = 57.65

2. Calculated variance from each 2 x 2 Table

CPC 1& 2 = 129 x 80 x 33 x 176/209 x 209 x 208 = 6.59

CPC 3 & 4 = 59 x 108 x 28 x 139/ 167 x 167 x 166 = 5.35

ESLD+ = 36 x 66 x 21 x 81/ 102 x 102 x 101 = 3.84

ESLD- = 131 x 181 x 38 x 211/249 x 249 x 248 = 12.36

ΣV_1 = 6.59 + 5.35 + 3.84 + 12.36 = 28.14

3. Calculated Z MH

Σ Observe (a_1) = 12 + 5 + 2 + 14 = 33

Σ Expected (a_1) = 57.65

ΣV_1 = 28.14

$\sqrt{\Sigma V_1}$ = 5.30

Z_{MH} = (Σ Observe - Σ Expected (a_1)) / $\sqrt{\Sigma V_1}$

Z_{MH} = (33 – 57.65) /5.30 = - 4.65

4. Continuity correction

Z_{MH} = (12+5+2+14) – 57.65 – 0.5/$\sqrt{28.14}$

= (33 – 57.65 – 0.5) / 5.30

= - 4.74

5. (Z_{MH}) = (- 4.74) x (-4.74) = X_{MH} = 22.516

Test homogeneity

1. Calculate X^2 from 2 x 2 Table then combine Chi square

(9.43+ 3.62 +6.33 +3.76) = 23.14

2. $X^2_{MH} - X^2$ = 22.516 – 23.14 = 0.624
3. 4 > 3.84
4. p value > 0.05
5. Therefore, there is homogeneity of the tables subcategorized by CPC score and diagnosis of end stage liver disease. This indicates that MH chi-square can be used to adjust for imbalances in CPC score and diagnosis of end stage liver disease and that the statistical difference between the effectiveness of AD and control is real.

Interestingly, during our observation period, consent for self-discharge was signed for 51 subjects. Thirty-two of these subjects (17.0%) were in the control group and 19 (10.1%) were in the intervention group. The reasons for self-discharge are summarized in Table 5.31. Most decided to go home when their condition deteriorated and/or they realized that their prognosis was poor. Personal interviews revealed that a common reason for the decision to go home was a preference for in-home death. This preference was expressed by all except one control subject and two subjects in the intervention group.

Similar reasoning was observed in those who were transferred to other hospitals after being informed about their prognosis. They preferred to be in hospitals close to their homes for supportive care. Then they could move home when they felt death was close at hand.

Table 5.31 : Reason for self discharge of the control and the intervention groups

Reason	Control N=32	Intervention N= 19
Poor prognosis	8 (25.0)	2 (10.5)
Poor prognosis and worse condition	7 (21.9)	11 (57.9)
Worse condition	7 (21.9)	3 (15.8)
Patients want to go home	3 (9.4)	1 (5.3)
Worse condition and patients want to go home	1 (3.1)	-
After realized the diagnosis and prognosis, patient and family decided to go home	5 (15.6)	-
Do not need CPR and intubation	1 (3.1)	-
Not specify	-	2 (10.5)

For subject who were not oriented, all information were obtained from surrogate

5.3.4.3 CPR/Dead

A summary of CPR performance and mortality in hospital for the control and the intervention groups is presented in Table 5.32. Among the 188 control subjects, 24 (12.8% [8.0-17.5, 95%CI]) had CPR attempted and 44 (23.4% [17.4-29.5, 95%CI]) died in the hospital. Of the 188 intervention subjects, 9 (4.8% [1.7-7.8, 95%CI]) had CPR attempted and 17 (9.0% [4.9-13.1, 95%CI]) died in the hospital. The proportion of subjects with CPR attempted and dead was significantly different between the control and intervention group.

Again, when the CPR performance rate was calculated using the mortality of hospital discharges in each group as a denominator (control = 24/44; intervention = 9/17). The proportion of CPR/dead in the control group was 54.5%. The proportion of CPR over dead in the intervention groups was 52.9%.

Table 5.32 : CPR performance and mortality in hospital for the control and the intervention groups

Result	Control N=188 n%[95% CI]	Intervention N=188 n% [95% CI]
CPR done	24 (12.8) [8.0-17.5]	9 (4.8) [1.7-7.8]
Dead	44 (23.4) [17.4-29.5]	17 (9.0) [4.9-13.1]

This result indicated that the attempted CPR rate was still quite high in both groups. Therefore, several analyses were done to identify the demographic and clinical characteristics associated with survival and mortality at hospital discharges.

A comparison of the demographics, clinical characteristics, and a presentation of the co-morbidity of the subjects who were alive during hospitalization in the control and intervention groups are summarized in Table 5.33- Table 5.35.

Among the subjects who lived, age, gender, urbanity of residence, diagnosis, psychological state, and presence of co-morbidity were not significantly different. The exception was for the CPC score. The proportion of the control subjects with a CPC of 3 and 4 was almost double that in the intervention group. The proportion of the subjects in the intervention group with CPC of 1 or 2 was larger than in the control group. A significant difference was observed between the control and intervention groups with respect to the CPC score.

Among the subjects who died, the identical statistical analyses were also tried but the results were invalid because so few of these subjects were in the intervention group.

Table 5.33 : Comparison of demographic characteristic of the subjects who were alive during hospitalized in control and intervention groups

Characteristic	Control N = 144 n [95%CI]	Intervention N = 171 n [95%CI]
Gender		
Male	88 (61.1) [53.1-69.1]	111 (64.9) [57.8-72.1]
Female	56 (38.9) [30.9-46.9]	60 (35.1) [27.9-42.2]
Age/Years		
40-59	82 (56.9) [48.9-65.0]	94 (55.0) [47.5-62.4]
60≤	62 (43.1) [35.0-51.1]	77 (45.0) [37.6-52.5]
Marital Status		
Married	119 (82.6) [76.5-88.8]	140 (81.9) [76.1-87.6]
Unmarried	25 (17.4) [11.2-23.5]	31 (18.1) [12.4-23.9]
Residence		
Urban	41 (28.5) [21.1-35.8]	41 (24.0) [17.6-30.4]
Rural	103 (71.5) [64.2-78.9]	130 (76.0) [69.6-82.4]

For subject who were not oriented, all information were obtained from surrogate

Table 5.34 : Comparison of clinical characteristic of the subject who were alive during hospitalized in control and intervention group

Characteristic	Control N = 144 n [95%CI]	Intervention N = 171 n [95%CI]
Diagnosis		
NSCLC	94 (65.3) [57.5-73.1]	117 (68.4) [61.5-75.4]
ESLD	47 (32.6) [25.0-40.3]	34 (19.9) [13.9-25.9]
Other	3 (2.1) [-0.2-4.4]	20 (11.7) [6.9-16.5]
CPC score		
CPC 1 and 2	59 (41.0) [32.9-49.0]	117 (68.4) [61.5-75.4]
CPC 3 and 4	85 (59.0) [51.0-67.1]	54 (31.6) [24.6-38.5]
Mental Status		
Orientated	129 (89.6) [84.6-94.6]	155 (90.6) [86.3-95.0]
Not oriented	15 (10.4) [5.4-15.4]	16 (9.4) [5.0-13.7]
Psychological State		
Acceptance	80 (55.6) [47.4-63.7]	96 (56.1) [48.7-63.6]
Other state	64 (44.4) [36.3-52.6]	75 (43.9) [36.4-51.3

NSCLC: Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease; Other diagnosis represented Multiple organs system failure with sepsis; Cancer of colon with multiple metastasis to liver; non-traumatic and non-diabetic coma. CPC score: Cerebral performance categories.

Table 5.35 : Comparison of co-morbidity presented in subjects who were alive during hospitalized in control and intervention groups

Co-morbidity	Control N = 144 n [95%CI]	Intervention N = 171 n [95%CI]
Present	44 (30.6) [23.0-38.1]	55 (32.2) [25.2-39.2]
Not-presented	100 (69.4) [61.9-77.0]	116 (67.8) [60.8-74.8]

Sub-analyses were done in the control group to compare the demographic and clinical characteristics of those who died with those who lived (Table 5.36 –Table 5.39). In the control group, no significant differences were observed by age, gender, marital status, residence, diagnosis, CPC score, mental status, psychological state and presentation of co-morbidity between those that died and those who did not. (Table 5.36 to Table 5.38). However, those who died were more likely to be male (OR =2.47, 95% C.I. = 1.11-5.53), as presented in Table 5.39.

Sub-analyses were then repeated among the intervention group to compare the demographic and clinical characteristics of those who died with those who lived (Table 5.40 – Table 5.42). In this group, there were no significantly different characteristics noted between those who died and those who did not die (Table 5.40).

Table 5.36 Demographic characteristic of the subjects who were dead and alive during hospitalized in the control group

Characteristic	Dead N=44 n [95%CI]	Alive N=144 n[95%CI]
Gender		
Male	35 (79.5) [67.6-91.5]	88 (61.1) [53.1-69.1]
Female	9 (20.5) [8.5-32.4]	56 (38.9) [30.9-46.9]
Age/Years		
40-59	25 (56.8) [42.2-71.5]	82 (56.9) [48.9-65.0]
60≤	19 (43.2) [28.5-57.8]	62 (43.1) [35.0-51.1]
Marital Status		
Married	37 (84.1) [73.3-94.9]	119 (82.6) [76.5-88.8]
Unmarried	7 (15.9) [5.1-26.7]	25 (17.4) [11.2-23.5]
Residence		
Urban	12 (27.3) [14.1-40.4]	41 (28.5) [21.1-35.8]
Rural	32 (72.7) [59.6-85.9]	103 (71.5) [64.2-78.9]

For subject who were not oriented, all information were obtained from surrogate

Table 5.37 : Clinical characteristic of the subject who were dead and alive during hospitalized in the control group

Characteristic	Dead N=44 n [95%CI]	Alive N=144 n[95%CI]
Diagnosis		
NSCLC	24 (54.5) [39.8-69.3]	94 (65.3) [57.5-73.1]
ESLD	19 (43.2) [28.5-57.8]	47 (32.6) [25.0-40.3]
Other Diagnosis	1 (2.3) [-2.1-6.7]	3 (2.1) [-0.2-4.4]
Non-traumatic	-	1 (0.7)
Non-diabetic coma		
CA colon	1 (2.3)	2 (1.4)
CPC score		
CPC 1 and 2	21 (47.7) [33.0-62.5]	59 (41.0) [32.9-49.0]
CPC 3 and 4	23 (52.3) [37.5-67.0]	85 (59.0) [51.0-67.1]
Mental Status		
Orientated	42 (95.5) [89.3-101.6]	129 (89.6) [84.6-94.6]
Not oriented	2 (4.5) [-1.6-10.7]	15 (10.4) [5.4-15.4]
Confused	1 (2.3)	11 (7.6)
Coma	1 (2.3)	4 (2.8)
Psychological State		
Acceptance	26 (59.1) [44.6-73.6]	80 (55.6) [47.4-63.7]
Other state	18 (40.9) [26.4-55.4]	64 (44.4) [36.3-52.6]

NSCLC: Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease; MOSFS: Multiple organs system failure with sepsis; CA colon: Cancer of colon with multiple metastasis to liver. CPC score: Cerebral performance categories.

Table 5.38 : Comparison of co-morbidity presented in subjects who were dead and alive during hospitalized in the control group

Co-morbidity	Dead N=44 n [95%CI]	Alive N=144 n[95%CI]
Present	**19 (43.2)[28.5-57.8]**	**48 (33.3) [25.6-41.0]**
One co-morbidity	9 (20.5)	34 (23.6)
Two co-morbidity	8 (18.2)	11(7.6)
Three co-morbidity	2 (4.5)	2 (1.4)
Four co-morbidity	-	1 (0.7)
Not-presented	**25 (56.8) [42.2-71.5]**	**96 (66.7) [59.0-74.4]**

Table 5.39 : The Odds Ratio of dead and alive by gender, age, and marital status of patient in the control group

Dependent variable	OR	95% CI	p-value
Gender (Male/female)	2.47	1.11-5.53	0.028 *
Age/ year ($\leq 59/ \geq 60$)	1.00	0.51-1.99	0.988
Marital status (Married/Not married)	0.90	0.36-2.25	0.823
Residence (Rural/Urban)	1.06	0.50-2.26	0.877

The Odds Ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

For subject who were not oriented, all information were obtained from surrogate

* p value < 0.05

Table 5.40 : Demographic characteristic of the subjects who were dead and alive during hospitalized in the intervention group

Characteristic	Dead N = 17 n(%)[95%CI]	Alive N = 171 n(%)[95%CI]
Gender		
Male	9 (52.9) [29.2-76.7]	111 (64.9) [57.8-72.1]
Female	8 (47.1) [23.3-70.8]	60 (35.1) [27.9-42.2]
Age/Years		
40-59	5 (29.4) [7.8-51.1]	94 (55.0) [47.5-62.4]
60≤	12 (70.6) [48.9-92.2]	77 (45.0) [37.6-52.5]
Marital Status		
Married	16 (94.1) [82.9-105.3]	140 (81.9) [76.1-87.6]
Unmarried	1 (5.9) [-5.3-17.1]	31 (18.1) [12.4-23.9]
Residence		
Urban	5 (29.4) [7.8-51.1]	41 (24.0) [17.6-30.4]
Rural	12 (70.6) [48.9-92.2]	130 (76.0) [69.6-82.4]

For subject who were not oriented, all information were obtained from surrogate

Table 5.41 : Clinical characteristic of the subject who were dead and alive during hospitalized in the intervention group

Characteristic	Dead N = 17 n(%)[95%CI]	Alive N = 171 n(%)[95%CI]
Diagnosis		
NSCLC	14 (82.4) [64.2-100.5]	117 (68.4) [61.5-75.4]
ESLD	2 (11.8) [-3.6-27.1]	34 (19.9) [13.9-25.9]
Other Diagnosis	1 (5.9) [-5.3-17.1]	20 (11.7) [6.9-16.5]
MOSFS	1 (5.9)	6 (3.5)
Non-traumatic Non-diabetic coma	-	9 (5.3)
CA colon	-	5 (2.9)
CPC score		
CPC 1 and 2	12 (70.6) [48.9-92.2]	117 (68.4) [61.5-75.4]
CPC 3 and 4	5 (29.4) [7.8-51.1]	54 (31.6) [24.6-38.5]
Mental Status		
Orientated	15 (88.2) [72.9-103.6]	155 (90.6) [86.3-95.0]
Not oriented	2 (11.8) [-3.6-27.1]	16 (9.4) [5.0-13.7]
Confused	-	1 (0.6)
Coma	2 (11.8)	11 (6.4)
Alert/confused	-	4 (2.3)
Psychological State		
Acceptance	10 (58.8) [35.4-82.2]	96 (56.1) [48.7-63.6]
Other	7 (41.2) [17.8-64.6]	75 (43.9) [36.4-51.3]
Denial	1 (5.9)	14 (8.2)
Bargaining	-	18 (10.5)
Anxiety	4 (23.5)	14 (8.2)
Depression	-	10 (5.8)
Fear	-	4 (2.3)
Unable to access	*2 (11.8)*	*15 (8.8)*

NSCLC: Stage III and IV non-small cell lung cancer; ESLD: End stage liver disease; MOSFS: Multiple organs system failure with sepsis; CA colon: Cancer of colon with multiple metastasis to liver. CPC score: Cerebral performance categories.

Table 5.42 : Comparison of co-morbidity presented in subjects who were dead and alive during hospitalized in the intervention group

Co-morbidity	Dead N=17 n(%)[95%CI]	Alive N=171 n(%)[95%CI]
Present	3 (17.6) [-0.5-35.8]	55 (32.2) [25.2-39.2]
One co-morbidity	2 (11.8)	38 (22.2)
Two co-morbidity	-	15 (8.8)
Three co-morbidity	-	2 (1.2)
Four co-morbidity	1 (5.9)	-
Not-presented	14 (82.4) [64.2-100.5]	116 (67.8) [60.8-74.8]

5.3.5 Mail Follow up

One month after the study, 315 questionnaires were mailed to the subjects who were discharged alive. Therefore, letters were sent to 144 controls and 171 subjects in the intervention group. A summary of the mail follow up and reasons for non-response is presented in Table 5.43.

Of the 315 subjects to whom questionnaires were sent, 220 responded and 95 were later excluded. Of the 220 who responded, 84 of them were controls and 136 were subjects in the intervention group. Thus, the response rate was only 58.3% in the control group but it was higher (79.5%) in the intervention group. Of the 95 exclusions, 60 were from the control group and 35 were from the intervention group.

Of the 60 non-respondents in the control group, the questionnaires for 9 (6.3%) subjects that we sent were returned because there was no receiver. The remaining 51 (35.4%) questionnaires seemed to be delivered, but the subjects did not return the questionnaires. Of the 35 non-respondents in the intervention group, 28 (16.4%) were returned due to no receiver and 7 (4.1%) seemed to be delivered, but completed questionnaires were not received.

Table 5.43 : Summary of the mail follows up and reasons for exclusion from the control and the intervention groups

Mails follow up	**Total N=315**	**Control N=144 n(%)[95%CI]**	**Intervention N=171 n(%)[95%CI]**
Mail Response	220 (69.8)	84 (58.3) [50.3-66.4]	136 (79.5) [73.5-85.6]
Exclusion	95 (30.2)	60 (41.7) [33.6-49.7]	35 (20.5) [14.4-26.5]
Reason for Exclusion			
Mail return: no receiver	37 (11.7)	9 (6.3)	28 (16.4)
Missing	58 (18.4)	51 (35.4)	7 (4.1)

5.3.6 Death and Life at the One Month Follow Up

A summary of responses to the mail questionnaire is presented in Table 5.44. Of the 84 control subjects who responded to the questionnaire, 70 (83.3%) subjects had died and 14 (16.7%) were alive and their condition had improved. Of the 136 subjects in the intervention group who responded to the questionnaire, 65 (47.8%) had died but 71 (52.2%) were alive. Among those who were alive, 14 (10.3%) noted that their conditions was stable and 42 (30.9%) replied that their condition had improved. In contrast, 15 (11.0%) subjects mentioned that their conditions had worsened.

Table 5.44 : Summary of responses to mail questionnaire of the control and intervention groups

Questionnaire response	Control N = 84	Intervention N = 136	Total N = 220
Dead	70 (83.3)	65 (47.8)	135 (61.4)
Alive	14 (16.7)	71 (52.2)	85 (38.6)
My condition is stable	-	14 (10.3)	14 (6.4)
My condition is better	14 (16.7)	42 (30.9)	56 (25.4)
My condition is declined	-	15 (11.0)	15 (6.8)

A summary of survival and mortality at one month for the control and intervention groups is showed in Table 5.45. When all subjects who had died during hospitalization were combined with those who died at one month, then, were compared with those who were survived at one month, a significant difference was observed between the control and intervention group with respect to the number of dead and living. Again, analysis was repeated under the assumption that all non-respondents in the controls and interventions were expired and a similar finding was observed. However, there were no significantly different among those who died at one month between the control and intervention groups.

Table 5.45 : Summary of survival and mortality at one month for the control and intervention groups

Result	Control N = 188	Intervention N = 188
Final Result		
Survive	14 (7.4) [3.7-11.2]	71 (37.8) [30.8-44.7]
Dead	174 (92.6)[88.8-96.3]	117 (62.2) [55.3-69.2]
In hospital	44 (23.4) [17.4-29.5]	17 (9.0) [4.9-13.1]
At 1 month	70 (37.2) [30.3-44.1]	65 (34.6) [27.8-41.4]
Assumed dead	60 (31.9) [25.3-38.6]	35 (18.6) [13.1-24.2]

5.4 Focus Group Discussion with Nursing Staff

A focus group involves a number of people with common experiences or characteristics who were interviewed by a moderator for the purpose of eliciting ideas, thoughts and perceptions about a specific topic or certain issues linked to the area of interest (Holloway and Wheeler, 1996:144). In this study, the focus group discussion was conducted to gather more information on AD for CPR in order to gain a better understanding of traditional practice and beliefs in terminal care and the acceptability of an advance directive for terminal care in terminally ill patients. Three focus groups were organized. One group had twelve head nurses, and the other two groups had seven and nine senior nurses, respectively. The participants (except for the head nurses) were recruited through random selection 1-2 nurse(s) per ward. All of the participants were contacted two weeks in advance of the interviews and reminded two-three days before they started. None of the nurses asked refused to participate in the study.

5.4.1 Response

The people who are interviewed in a focus group usually have similar roles or experiences (Holloway and Wheeler, 1996, p. 144). Three focus groups were set up. The first group consisted of all 12head nurses, the second group with nine senior nurses working in ICU and Sub- ICU and the third group with seven senior nurses working in general medical wards. All of the participants were those who had experience caring for terminally ill patients and who were familiar with the PI who had been working in this area for almost two years. Merton and King (1990) stress the importance of educational homogeneity within the group. If group members have similar educational backgrounds, the chance for contribution from all members is greater. Indeed, most of our participants graduated from the same nursing school as the PI. They were very willing to participate and provided useful information. In nursing research, familiarity between participant and researcher could be useful because the "warm-up" time, the time where informants get to know each other to facilitate interaction, is shorter, thus, the researcher can focus on the topic immediately.

Holloway and Wheeler (1996) also mentioned that the environment for a focus group is important. The room must be big enough to contain the participant and the tape recorder, which needs to be placed in an advantageous location, where they can all be heard and recorded. In order to provide an environment where the participants were free from work and to prevent uninvited observers from interrupting the group process, the focus groups were held in a conference room with air-conditioning. As suggested by Merton and King (1990), a spatial semi circle of seats was arranged. A top quality tape recorder was placed in the middle. The discussions were held in an informal setting to create a comfortable atmosphere and feeling.

An informed consent was used to explain that the conversations would be audio taped and that the participants' responses would not be disclosed to their supervisors or friends who did not participant in the discussion groups.

From the beginning, the PI explained the ground rules, so that all of the group members knew how to proceed. The discussions were generally phrased as open-ended questions, which were intended to bring out opinions and encourage participation. The topic for discussion was developed based on previous information obtained from AD intervention in terminally ill patients. The discussion also covered information provided to terminally ill patients, attitude towards ADs for CPR, and ADs in actual practice.

The principal investigator (PI) and research assistant facilitated the focus group meetings. The research assistant noted all information. The discussions were audio taped to ensure complete information. All tapes, fieldnotes and memos were dated and labeled. A wide margin was left on the transcript for coding and categorizing.

After the discussion, the PI listened to each tape several times before making transcripts to write a more complete summary of the discussion using the notes as a guideline. This brief summary report was completed as soon after the discussion as possible to avoid difficulty in remembering distinctions among the focus group members.

In general the transcription process could be difficult because peoples' voices vary, however, for this study the moderator could remember all of the participants'

voices. She coded the paragraphs and sentences by extracting the essence of the ideas within them and using labels which were put into the margin of the transcript. Through a reduction of these codes into larger categories, themes and ideas were found. Krueger (1994) claims that not all data deserves to be of equal importance. The PI searched for priorities and important themes from the vast amount of data that reflected the responses of the group.

The PI repeated this process with each focus group discussion and compared the transcripts. The major themes which arose from each discussion were then connected with each other; the topics in one interview overlapped with those of the other focus groups. Once these theme had been formulated, the patterns described and their meaning interpreted, the literature connected with these ideas was discussed. All appropriate literature became part of the data.

5.4.2 Results from the Focus Group Discussions

The results obtained from the three focus groups are presented in this section; information about illness, attitude towards AD for CPR, AD in actual practice and the preference for in-home death. The results are presented sequentially in group order, starting from the head nurse and the two groups of senior nurses.

5.4.2.1 Head Nurses (HN)

5.4.2.1.1 Information about Illness

The head nurses were asked their opinions about the provision of information to patients regarding their illnesses and prognosis, and if they thought this information was being provided. Most of the participants agreed that the information provided to

the patients and their relatives was a very important issue, especially for terminally ill patients. Generally, the physicians were responsible for providing information about illness and prognosis.

> Miss N: Generally, the patients were very concerned about the prognosis. One question always arose: "Am I going to survive?"
> "How will I be?" In the meantime, the patients asked for this information more frequently and they knew more about themselves. The physicians had more skill to provide this information compared to the previous time and looked like they realized that it was their responsibility and were used to it. Previously, it seemed like they didn't want to give this information.
> Miss S: After HA, this was much better. In the meantime, the doctors talked with the patients more often than previous times. If Ajarn (PI) evaluated it now, Ajarn would get a better result, you would realize that the patients knew more (about their illness).
> Miss C: Yes, if Pee (Elder sister: PI) collected data now, the information would be very much improved.
> PI: Did you believe that the physicians had improved in this area (providing information)?
> Miss N: Very much.
> Miss C: Yes, yes.
> Other HN: Yes, yes

5.4.2.1.2 Attitude towards Advance Directive for CPR

The head nurses were asked about their attitude towards AD for CPR. Most of the nurses agreed that every patient had the right to decide for CPR by her/himself but the decision should be made with sufficient information. Information was one of the

most important considerations for all of the head nurses. The informant needed communication and counseling skills.

> Miss S: It was very difficult to start talking (with the patient), especially for those who were still capable, they (patients) needed a lot of information before they could decide. Now, the physicians talk more and it was better.
> Miss W: If the patients were capable, they didn't want to answer this question. They still had hope that they would be cured and they could be discharged home. The exception was for those who had a worse condition, most of these patients realized they wouldn't make it (not survive). In this situation, the patients would say they didn't want any more treatment and they wanted to return home.

The psychological well-being of the patients was another important consideration for all of the head nurses.

> Miss S: As Ajarn said, from the statistics, only 7-24% would survive after CPR. I thought, this (information) was destroying their hope for survival. The patient might think that the chance was very low, they would die for sure. For the patients who had a poor condition, yet their relatives still had hope, we were not brave to rush to ask this question.
> PI: Not rushed, nothing was rushing.
> Miss S: Before asking this question, we had to reconsider several times.

The nurses commented that after the patients were made aware of their prognosis, most decided that they were opposed to receiving CPR and their relatives generally agreed with this decision. However, without previous discussion with the

patient, the relatives might feel guilty if they decided to withhold CPR. Therefore, some CPR was performed at the request of the family.

> Miss A: In our culture, if the relatives did not allow us to do CPR, they might feel guilty that they had ignored their parent. (ทิ้งพ่อ ทิ้งแม่)

One nurse also mentioned the problematic situation in which a relative disagreed with the patient and still wanted all possible treatments tried.

> Miss S: Some relatives wanted to keep the patient alive as long as possible (ยื้อสุดฤทธิ์) even we told them about the patient's condition before and after the procedure.

In this situation, further discussion was needed to identify a final decision.

> Miss S: In our custom, if we thought CPR was futile (for terminal illness), we had to make a clear discussion with the relatives. The relatives needed to be reassured that they had done their best. Because the relatives might feel guilty if they decided no-CPR for their parent. It implied that they ignored their parent which is a sin.

In this setting, the head nurses also observed that before the DNR decision, the physicians had already provided all available treatment to their patients.

> Miss P: The physicians have done their best. (หมอช่วยเต็มที่แล้ว)
>
> Miss C: Yes, the doctors provided all available treatment.

Some of the nurses mentioned that discussing CPR with patients and relatives was time-consuming and may be impractical because most clinicians were very busy. More importantly, they were very concerned that the informant should have communication skills for truth-telling (especially for bad news) in this context that required sensitivity.

Meanwhile, many of the nurses did not feel confident about discussing end-of-life care with the patients and most worried that such discussions with patients capable of understanding may hurt and discourage them.

5.4.2.1.3 Advance Directive in Actual Practice

The nurses reported that the physicians generally discussed AD for CPR with a relative when a patient was already incapable or clinically impaired. Some of the physicians had also discussed AD with their patient but the nurses observed it less frequently. Importantly, if patients with terminal illnesses or their relatives requested that CPR not be performed, their wishes were respected.

> Miss N: Most of the time the physicians asked the relatives whether they wanted the patient to be intubated/resuscitated, but did not ask the patient.
> PI: What would you do if the patient or relative or both said "No, no CPR"?
> All HN: No, means no.
> PI: If the patient said no CPR, were you going to do it?
> All HN (answer immediately): No.
> Miss C: No meant no, just let us know.
> Miss P: No was no.

Miss S: If they didn't want to be resuscitated, we won't do it.

PI: I see, how could you help them, if they didn't want to be resuscitated, did you write or .....?

Miss C: The physicians usually documented this request in their records and transferred the message to their colleagues (physicians and nurses).

Miss S: Lately, the recognition and respect of patient's rights had been improved. Sometimes, the patients requested that mechanical ventilation was stopped for a while (such as during daytime). This preference would also be allowed, but with close observation.

Miss N: The patient's right was introduced in the year 2001. (ปี 44 มีสิทธิ ผู้ป่วยเข้ามา)

Miss C: HA was just introduced, Pee. (HA พึ่งเข้าพี่)

Miss P: If the patients' conditions declined, we had to contact their relatives. The physicians always requested to discuss with the relatives.

Miss S: If the patient was still in good condition, we didn't ask whether they wanted CPR, we were afraid they might think that we want them to die. It might discourage them.

PI: Were there any patients who asked for no-CPR?

All HN: Yes, there were (มี มีสิ).

PI: What did you do (in order to help them)? (ที่ผ่านมาทำอย่างไร)

Miss C: We informed the physician. (and the physicians would follow the same process as previously mentioned)

For the nurses, they most frequently recorded this message in the Kardex and then passed on the message to others (following their shift) verbally. Therefore, all nursing personnel were well informed regarding the wish of their patients.

However, none of the nurses had ever seen this on an AD document for a Thai patient. The request for no-CPR was stated by word and it seemed to work effectively.

In the meantime, a consent form for no-CPR was available that required the physician to inform the patient before they sign it.

5.4.2.1.4 Preferences for In-Home Death

The topics about in-home death were discussed in the focus groups of the head nurses. Many of the head nurses mentioned that in relation to death and dying, a patient's culture must be taken into consideration. For example, most northern Thai individuals still preferred "in-home-death." Patients with chronic illness, who realized they were very sick, mentioned their needs to their close relatives. "If it could not be cured, may I go and die at home". (ถ้ารักษาไม่หาย ขอไปตายที่บ้าน)

Generally, the patients came to the hospital because they had hope that it would help them survive. However, when the prognosis was poor, many of them wanted to return home. The relatives also tried to follow the wishes of the patient. Accordingly, all of the head nurses had been informed by the relatives that "if the patient will not survive or the condition gets worse, please let me know. We will go home".

> PI: Have you heard about "If one died elsewhere, the spirit could not return home"? (ตายนอกบ้านวิญญาณไม่กลับบ้าน)
>
> All HN: Yes, yes. (อันนี้ใช่)
>
> All HN: A lot. (เยอะมาก)
>
> Miss S: The spirit won't return home. (วิญญาณไม่กลับบ้าน) I have heard this three times after meal. (This implied that this message has been mentioned very often)

The preference for in-home death and the traditional belief that the spirit would remain at home only if that is where death happened was observed by the head nurses, especially among the patients with a rural residence. The nurses stated that self-discharge was mainly due to this reason.

5.4.2.2 ICU and SUB-ICU Nurses

5.4.2.2.1 Information about Illness

Similarly, the nurses were asked their opinions about the provision of information to patients regarding their illnesses and prognosis, and if they thought this information was being provided. Generally, the physicians were responsible for providing information about illness and prognosis. The nurses helped to arrange the discussion between families and the patient's physician, and assist in clarification. They were also responsible for informing the relatives if the patient's condition declines.

Since most of the ICU patients had serious conditions and were non-responsive, this information was generally provided directly to the relatives. However, after the hospital had applied for hospital accreditation (HA), this information was provided to a higher proportion of the patients.

> Miss Su: Previously, we (nurse) had to inform the relative about the patient's condition. What was the physicians' plan for treatment? After HA, they (the physicians) talked more. We tried to arrange the discussion between the physicians and relatives in every case.
>
> Miss O: Starting from admission to critical unit, the physician was responsible to explain to the relatives about the patient's condition, and the tentative plan for treatment. The relative had to sign the consent for treatment agreement with the physician, nurse, and a witness (other

relative). So both the physicians and relative(s) would meet each other at least once.

PI: Did the doctors explain to the patient and relatives?

Miss O: Patient! Relatives more often than the patient.

Miss Su: Most of the ICU patients were non-responsive, we generally discussed with their relatives.

PI: The patients were unresponsive so … explain it to (their) relatives.

Miss O: We (nurse) and the physician discussed with the relatives.

Miss Su: Now communication was much better. We won't hear "we would do tracheostomy, tomorrow" and "what was a tracheostomy" left for the nurse (to explain) any more. Now, the physicians knew this was their responsibility but they still talked too brief. We still had to clarify.

PI: How about the information that we provided to the patient, was it better?

All nurses: Better.

PI: Were we providing information regarding diagnosis and prognosis effectively?

Miss A: It was up to the physician, some physicians explain very well, some talk briefly but I think 80% of the patients/relatives had been informed, was that right? (looking at other nurses for their responses)

Other nurses: Yes, yes.

PI: In your opinion, was it effective?

Miss Su: For critically ill patients, the first question from the relative was "Was he/she going to survive?" "How long could he/she survive?"

PI: How much percent of the patients have been informed?

Miss Su: Eighty in ICU, was that right?

Other nurses: About that.

5.4.2.2.2 Attitude towards Advance Directive for CPR

The nurses were asked about their attitude towards ADs for CPR.

Miss Su: In chronic illnesses, most of the patients who continue their treatment still have hope, they love their life. If we told them (about their prognoses) like this, they might not accept it and they might become discouraged and die.

Miss O: There was also variations among the physicians, some physicians never give up even when their relative wanted to take the patient back home but the physicians wanted to try.

PI: What was the reason for this decision?

Miss O: It was different for each. Some physicians were concerned about the cost, was it futile? Some provided the treatment, whatever they thought was appropriate.

PI: Did they accept it if the relative requested for no-CPR?

Miss O: No, it was not an experiment, but they would provide treatment, the way they thought was good.

PI: Could anyone change?

Miss O: No, on one. However, some physicians would consider about the cost-benefit. If it made the patient suffer more and then he died, they did not want to prolong the suffering.

Most of the nurses agreed that every patient had the right to decide for CPR by her/himself but the decision should be made with sufficient information and in a careful manner. Information was one of the most important considerations for all of the nurses. The informant needs communication and counseling skills.

5.4.2.2.3 Advance Directive in Actual Practice

The nurses were asked their opinions about the provision of AD in actual practice. Similar to the head nurses, the nurses reported that the physicians generally discussed AD for CPR with the relatives when a patient was already incapable or clinically impaired. The nurses also commented that after their relatives were made

aware of the patient's prognosis, most decided against CPR and their needs were respected.

PI: How about (the AD for) terminal illnesses?

Miss Su: For this group, if we notice that the patient's condition was not good (the patient was incapable or the condition was getting worse), we would encourage the relatives to discuss with the physicians and decide whether they want CPR or no-CPR to be performed for the patient. Generally, if the condition declined, heart rate slowed down and the relative knew the CPR process, most decided against CPR and preferred to let the patient die (peacefully). (ปล่อยให้ไปเถอะ) Only a few (relatives) still needed CPR, therefore, some patients had been resuscitated ten times (at their relatives' request).

Miss O: In this group, we even explained the result of CPR.

Miss Su: In one case, we allowed them to observe when we resuscitated and they saw a result, the patient was resuscitated 7 times but his relatives still wanted to try. In this case, I remembered we performed CPR 15 times, and finally the patient expired. At that moment, the patient could not decide but the relative did not accept it.

PI: How about another? Was there any patient/relative who requested for no-CPR?

All nurses: A lot.

Miss Su: Most of these patients had a terminal illness. They wouldn't respond after CPR. Their hearts were in a bad condition, after CPR, it would continue beating for only a short period.

PI: What did they say after we explained the result of CPR?

Miss A: No, no-CPR.

Miss A: In fact, most of them (even those with chronic illnesses) had been referred to many hospitals (before admitted to this hospital). When they had an acute health problem, many went to the private hospital and transferred to the government hospital thereafter.

PI: What would you do if the patient said "no-CPR"?

Miss S: If they said so, the physicians generally agreed, was that right? (Looking at other nurses for agreement)

Other nurses: Shaking their head implied that they agreed.

Miss Su: If we explained that the patient's condition was not good, the following step would be resuscitation. Most of the relatives would say "no", especially for chronic illnesses, they (patient and relative) had discussed it together, the patient usually told their relatives "if it's time (to die), take Mom/Dad home". (ถ้าเติงเวลาแล้ว เอาอี่ป่อ/อี่แม่ปึกบ้านเน่อ)

Miss S: Now, the patient's right is important. It did not matter whether the physician wanted to try or not. If the patient said "no" it meant no.

Miss A: If it had been discussed previously (and the solution was no-CPR), there was no need for any written form.

Miss P: During admission we were concerned about the patient's (critical) condition, if we could help them, save their life. We would not talk about CPR yet if the condition was stable; the physicians would provide all treatment until....

PI: Until..... what?

Miss P: Until the condition declined, we would ask whether they (relatives) wanted CPR or not.

Miss I: For CPR, if it had not been discussed, we preferred to do CPR because we did not know their relatives' needs but if it had been discussed, we would follow those solutions.

5.4.2.2.4 Preferences for In-Home Death

Similar topics about in-home death were discussed in the focus groups of nurses and similar findings were found.

Miss Su: In northern Thai culture, if it was time (to die), they wanted to go back and die at home. (ถ้ายังไง ก็เอาไปตายบ้าน) If one died outside the

home, the spirit could not return home and the funeral ceremony had to be performed outside the home. If it occurred in their home, this ceremony could be performed at home.

PI: Was it the real belief?

Miss S: Yes, it was. When the patients' condition declined, we usually talked with their relative. 2-3 decisions were observed, the patient wanted to go home or their relative wanted to bring the patient back home or both. We would stop them and discussed with them in cases where the patient wanted to continue to be hospitalized but the relatives wanted to take the patient home.

Miss Su: This was similar to the Chinese, but for the Chinese all of the organs had to be completed. I was not sure whether it was only my family, if it could be cured, we would continue treatment but if it was not curable, there was no need for hospitalization.

PI: How about you?

Miss O: Most would go home, if the condition declined.

Miss Su: They had to put on seven layers of clothing before the patient died.

5.4.2.3 Nurses from General Medical Wards

5.4.2.3.1 Information about Illness

Similar to the previous two groups, the nurses were asked their opinions about the provision of information to patients regarding their illnesses and prognosis. All of the nurses stated that the physicians were responsible for providing information about illness and prognosis and the nurses assisted in clarification. Most of the participants mentioned that the information provided to the patients and their relatives was a very important issue.

PI: Who was responsible for informing about the diagnosis and prognosis?

All nurses: The physicians.

PI: How about the nurses? Were we responsible for this?

Miss A: For prognosis, no.

Miss P: No.

Miss A: For diagnosis, we might help if they had been informed by the physicians and needed clarification.

PI: How about if they had never been informed, did we explain?

Miss A: No, if the physicians did not tell them, we would not. Because, in this hospital, patients had complicated diseases, it was very difficult to explain and some patients needed many specialists.

Miss S: We had to make sure that the physicians had informed them and we only clarified.

Miss A: If they needed more information than they had had from the physicians, we could explain. However, if they had never been informed, we would not.

Miss P: An information is very important. Adequate information might change the patient's mind.

All nurses: Yes.

With respect to who should be informed about a patient's prognosis and if the illness was terminal, the families had been informed more often than the patients. However, some physicians informed both the patients and their relative(s).

PI: Who had been informed?

Miss P: Most of the time, the relatives.

PI: Did they inform the patient?

Miss P: Yes, but only a few, in some cases. The patients were well-conscious, I saw them talk with the patients (with terminal illnesses) who had chemotherapy.

PI: Was it a lot?

Miss P: No, not much. Most were relatives.

PI: How would you feel about this?

Miss A: I thought it was wrong.

Miss A: It was wrong in the first place. The physicians performed the examination for the patient but informed the relatives, not the patient. If the physicians were afraid that the patients might have psychic trauma, they should counsel them before providing this information. For example, after the physicians had done the biopsy, if he suspected that the patient might have cancer, they should refer this patient for counseling.

By withholding the information and not saying anything, the patient might suspect something.

Miss P: Anxious.

Miss A: They might wonder. It (a situation) might be even worst.

PI: How about others?

Miss P: Some relatives requested "please don't tell him, she has cancer". This relative was well-educated.

Miss Su: I also had similar experience as Pee' P (Miss P).

But the physician refused what the relative asked for. He said "I have to take care of the patient not the relative. I will decide whether I should tell him at this moment or not but the patient must know the result."

Miss S: Some relatives were in denial themselves.

Miss Su: Yes, yes.

The nurses approximated from their observation that about fifty percent of the patients in general medical wards had been informed about their illnesses. The percentage of patients to whom information was provided may be higher but there was variation based on patient perception. Sometimes the patients did not understand what their physician had explained. This misunderstanding may be caused by the generation

gap between the physicians and patients. The informant needs communication and counseling skills.

PI: What percent of the patients/relatives had been informed?

Miss A: It was very hard to say. In this hospital, the physicians informed everyone but the perception of the patients was varied. Sometimes, the information was given 100 percent but the patients could perceive only 50 percent. There was some communication gap because the physicians were from a newer generation and the patients were old.

Miss S: May I add my opinion? It depended upon several factors. For example, the personality of the physicians, the education of the patients, the time of admission. Some physicians had communication skills and could explain very well, some talked too short. Our patients also had a low educational level, sometimes they did know what to ask and some were afraid to talk with the physicians. The admission time was important, if it was the night time, the physicians and nurse may have limited time and of course they might be sleepy.

PI: Was it effective?

Miss P: Much better.

Miss A: It was much better than before the HA.

Miss P: During HA, it might be 80%. In the meantime, it was probably 50%, was that right?

Other nurses: Shaking their head implied that they agreed.

Miss S: For the physicians, it was hard to say (estimate). For nurses, such as nursing procedure, we explain it to the patients, I thought it was much better. When explaining anything regarding the diagnosis and prognosis, we must be concerned about the law.

Miss Su: We must be very careful about this.

Miss P: We have never been trained to be a counselor.

5.4.2.3.2 Attitude towards Advance Directive for CPR

The nurses were asked about their attitude towards AD for CPR. Most of the nurses agreed that every patient has the right to decide for CPR by her/himself but the decision should be made with sufficient information. Information was one of the most important considerations for all nurses.

> PI: Who should decide for CPR or no-CPR for the patients?
> Miss A and Miss P: It was the patient's right, wasn't it?
> PI: How about others?
> Other nurses: The same.
> Miss A: The patient had the right to refuse certain kinds of treatment, they could write it down. I obtained this information from the head nurse's conference.
> Miss S: OK, we accepted and respected their right. We had 10 rules for the patient's rights. However, this decision should be made after the nurses and the physicians had provided adequate information.
> Miss P: Providing complete information may change their decisions. However, after discussion, we would follow those solutions.

5.4.2.3.3 Advance Directive in Actual Practice

As in the previous two groups, the nurses were asked their opinions about the provision of AD in actual practice. The nurses commented that after patients/relatives were made aware of their prognosis, most decided that they were opposed to receiving CPR and the nurses and the physicians generally agreed and respected the decisions. However, they had to make sure that the decision had been made with sufficient information.

Miss P: If they realized the (poor) prognosis, most relatives would say "no resuscitate, no intubate".

PI: If they said "no resuscitation", were we going to do CPR?

Miss P: We would first inform the physicians, then the physicians would discuss with the relative again. We also considered their illnesses, if it was terminal and if CPR would be futile and if both the physicians and relative agreed for no-CPR, then no resuscitation.

PI: How about, if those who had 5 terminal illnesses said no-resuscitation?

Miss P: NO, no no. If they decided like this, we would not resuscitate. We would provide the best care without CPR. We would give all essential medication but no resuscitation.

PI: Had you ever performed CPR on a patient who said "no for CPR"?

Miss A: In that case, no.

Other nurses: No.

Miss A: Generally, if they did not want anything. If they needed to terminate at home, most of them would sign out from the hospital.

PI: Had you ever seen the situation like the patient did not want CPR but they still performed CPR...?

Miss A: No, ...

Other nurses: No.

5.4.2.3.4 Preferences for In-Home Death

Many of the nurses mentioned that most northern Thai individuals still preferred "in-home-death." Patients with chronic illness, who realize they are very sick, mention their needs to their close relatives. When the prognosis was poor, many of them wanted to return home. Their relatives also tried to follow the wishes of the patient.

Accordingly, all of the nurses except one in this group had been informed by the relatives that "if the patient would not survive or the condition gets worse, please let me know. We will go home".

PI: Had the relatives ever informed you "if the patient will not survive or the condition gets worse, please let me know. We will go home". They preferred in home death.

Miss P: Yes, the same.

Miss P: Generally, patients, especially those who were old, they would tell their relative that "if it was not possible to cure, take me home, do not intubate".

PI: What was a reason?

Miss P: The patient might not want any more suffering or was afraid of pain. They probably accepted that it was the time to die, they had been sick so long.

PI: How about you?

Miss S: It was a belief in some groups, some provinces did not believe.

Miss A: The patients with chronic illnesses, who had been sick for a long time, they realized that he/she would die someday. Similarly for their relatives, they accepted that the patients were old and had suffered.

In addition to their belief that if one died in the hospital, the body should not return home, especially for rural dwellers. They had to perform a ceremony at a temple. I had observed many events when the patients were real terminal, their relatives asked me "how long could he/she survive, how many hours?" They preferred to keep the patient alive until they got to their home.

PI: How about you?

Other nurses: The same.

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The nurses approximated from their observation that about fifty percent of patients in general medical wards and eighty percent of ICU patients had been informed about their illnesses. The percentage of patients to whom information was provided may be higher but there was variation based on patient perception. Sometimes patients did not understand what their physician had explained. This misunderstanding may be caused by the fact that most of them were rural residents and had a low educational level. With respect to who should be informed about a patient's prognosis and if the illness was terminal, the families had been informed more often than the patients. However, some physicians informed both the patients and their relative (s).

Since most of the ICU patients had serious conditions and were non-responsive, this information was generally provided to direct relatives. However, after the hospital had applied for hospital accreditation (HA), this information was provided to a higher proportion of the patients. In the meantime, the patients knew more about themselves and asked for this information more frequently.

5.4.3.2 Attitude towards Advance Directive for CPR

Nurses were asked about their attitude towards ADs for CPR. Most nurses agreed that every patient has the right to decide for CPR by her/himself but the decision should be made with sufficient information. Information was one of the most important considerations for all nurses. From their observations, the patient could decide better if they were gradually informed. The nurses commented that after patients were made aware of their prognosis, most decided that they were opposed to receiving CPR and their relatives generally agreed with this decision.

Nurses also mentioned the problematic situation in which a relative disagreed with the patients and still wanted all possible treatments tried. In this situation, further discussion was needed to identify a final decision.

Some nurses mentioned that discussing CPR with patients and relatives was time consuming and may be impractical because most clinicians were very busy. More importantly, they were very concerned that the informant should have communication skills for truth telling (especially for bad news) in this context that required sensitivity.

Meanwhile many nurses did not feel confident about discussing end-of-life care with patients and most worried that such discussions with patients capable of understanding may hurt and discourage them.

5.4.3.3 Advance Directive in Actual Practice

The nurses reported that physicians generally discussed AD for CPR with a relative when a patient was already incapable or clinically impaired. Some physicians had also discussed ADs with their patient but nurses observed it less frequently.

Importantly, if patients with terminal illnesses or their relatives requested that CPR not be performed, their wishes would be respected. Physicians usually documented this request in their records and transferred the message to their colleagues (physicians and nurses). For nurses, they most frequently recorded this message in the Kardex and then passed on the message to others (following their shift) verbally. Therefore, all nursing personnel were well-informed regarding the wish of their patients.

Lately, the recognition and respect of patient's rights have improved. Sometimes, patients request that mechanical ventilation is stopped for a while (such as, during daytime). This preference would also be allowed, but with close observation. However, none of the nurses had ever seen this on an AD document for a Thai patient. The request for no-CPR was stated by word and it seemed to work effectively. In the meantime, a consent form for no-CPR was available that required the physician to inform the patient before they sign it.

Many nurses mentioned that in relation to death and dying, a patient's culture must be taken into consideration. For example, most northern Thai individuals still preferred "in-home-death."

Patients with chronic illness, who realize they are very sick, mention their needs to their close relatives. Generally, patients come to the hospital because they have hope that it will help them survive. However, when the prognosis is poor, many of them want to return home. Relatives also try to follow the wishes of the patient. Accordingly, all of the nurses except one in every group had been informed by relatives that "if the patient will not survive or the condition gets worse, please let me know. We will go home".

In this setting, the nurses also observed that before the DNR decision, the physicians had already provided all available treatment to their patients. However, without previous discussion with the patient, relatives may feel guilty if they decide to withhold CPR. Therefore, some CPR was performed on the request of the family.

5.4.3.4 Preferences for In-Home Death

Similar topics about in-home death were discussed in the focus groups of nurses and similar findings were found. The preference for in-home death and the traditional belief that the spirit would remain at home only if that is where death happened was observed by the nurses, especially among the patients with a rural residence. The nurses stated that self-discharge was mainly due to this reason. In addition, the nurses also mentioned about the cost and the difficulty of transferring the body home. Lastly, self-discharge was also done so the family could be with the patients during their last moments and could perform ritual ceremonies for the patient.

According to these results, most wishes for end-of-life care could not be provided in-hospital. The nurses believed that the place of death was important and should be included as an end-of-life issue in AD.

5.5 Self-administered Questionnaires for Medical Staff

5.5.1 Participants and Exclusion

A one-month study of physicians was conducted from June 15, 2002 until July 15, 2002. There were 106 physicians working in the Medical Department. Forty of these physicians were faculty instructors, and 62 were in residential training.

During this period of physician study, eleven left for other countries and only 95 physicians were eligible for the study. Of those 95, 40 were not included because one physician refused to participate because he was very busy, three had not been involved in terminal care for a long time and the remaining 36 questionnaires were not returned.

In the end, 55 physicians agreed to participate and gave informed consent. The response rate was 57.9%.

5.5.2 Demographic Characteristics of Participants

The demographic characteristics of the physician participants are shown in Table 5.46. A higher proportion was male (61.8%). The mean age was 32.1 years (SD = 10.0), and ranged from 23.0 to 57.0 years. More than half were 30 years of age or younger. Thirty- seven (67.3%) participants were single and the remaining 18 participants (32.7%) were married. Of the respondents, 31 (56.4%) had a MD degree only, 22 (40%) had completed both MD and Board of the Internal Medicine programs, and 2 (3.6%) had finished MD, Board of the Internal Medicine and Ph.D. degrees. Twenty-four participants (43.6%) were faculty members, and the remaining participants were still in residential training. More than half (54.5%) of the entire group had working experience of more than three years.

The demographic characteristics were described in the two groups of physicians (faculty instructor and resident) (Table 5.47). The significant differences were noted between the faculty instructors and residents with respect to all demographic variables, excepted gender.

Table 5.46 : Description demographic characteristic of participants

Characteristic		Number (%) N = 55
Gender		
	Male	34 (61.8)
	Female	21 (38.2)
Age/Years		
	Mean (SD)	32.1 (10.0)
	Range	23-57
	Categorized Values:	
	23-30	30 (54.5)
	> 30	15 (27.3)
	Missing data	10 (18.2)
Marital Status		
	Single	37 (67.3)
	Married	18 (32.7)
Education		
	MD	31 (56.4)
	MD, Board of Internal Medicine	22 (40.0)
	MD, Board of Internal Medicine and Ph.D.	2 (3.6)
Position		
	Instructors	24 (43.6)
	Resident	31 (56.4)
Experience as Physician		
	≤ 3 years	25 (45.5)
	> 3 years	30 (54.5)

Table 5.47 : Participants demographic characteristic by working position

Characteristic	Instructor N = 24 n(%)[95%CI]	Resident N = 31 n(%)[95%CI]
Gender		
Male	19 (79.2) [62.9-95.4]	15 (48.4) [30.8-66.0]
Female	5 (20.8) [4.6-37.1]	16 (51.6) [34.0-69.2]
Age/Years		
23-30	3 (12.5) [-0.7-25.7]	28 (90.3) [79.9-100.7]
> 30	14 (58.3) [38.6-78.1]	- [0.0-0.0]
Missing data	7 (29.2) [11.0-47.4]	3 (9.7) [-0.7-20.1]
Marital Status		
Single	7 (29.2) [11.0-47.4]	30 (96.8) [90.6-103.0]
Married	17 (70.8) [52.6-89.0]	1 (3.2) [-3.0-9.4]
Education		
MD	- (0.0) [0.0-0.0]	31 (100.0) [100.0-100.0]
Higher than MD	24 (100.0) [100.0-100.0]	- (0.0) [0.0-0.0]
Work experience		
≤ 3 years	3 (12.5) [-0.7-25.7]	22 (71.0) [55.0-86.9]
> 3 years	21 (87.5) [74.3-100.7]	9 (29.0) [13.1-45.0]

5.5.3 Results from the Questionnaire

Fifty-five physicians responded to the questionnaire. The results will be summarized in three parts; information about illness, attitude towards ADs for CPR, advance directive in actual practice, and preferences for in-home death. Additional findings will be presented in Section 5.7.

5.5.3.1 Information about Illness

Information about terminal illnesses may be provided to either patients or direct relatives or both. In cases where the patient was incapacitated, information would be unquestionably provided to the relatives. However, in cases where the patient was capable, we wanted to identify the person whom the participating physicians would prefer to inform about the diagnosis and prognosis. More than forty percent of the participants (41.8%) stated that they would prefer to inform the relative. The instructors were more likely to prefer telling a relative than the residents (45.8% vs. 38.7%). The variations between male and female physicians were also observed. Therefore, responses to questions between the male and female physicians were sub-analyzed. and further stratified in both groups (instructor and resident). The male physicians were more likely to inform a relative than the female physicians, 47.1% and 33.3%, respectively (Table 5.48). Similar results were also observed in both instructor and resident (Table 5.51).

Furthermore, almost forty percent (38.2%) preferred to inform both the patient and their relative. The instructors were less likely to prefer informing both than the residents (33.3% vs. 41.9%). In contrast, the female physicians were more likely to

prefer informing both than the male physicians (Table 5.48 and Table 5.51). Meanwhile, twenty percent of both the instructors and residents would prefer to inform the patients alone. However, the proportion of the female physicians were more likely to prefer telling the patient alone than the male physicians (23.8% and 17.6%, respectively) (Table 5.48).

In the scenario in which the patient was capable, 21 participants (38.2%) remarked that they had informed the majority of their patients about their illness. The female physicians were more likely to do this than the male physicians (52.4% vs. 29.4%). The female resident (62.5%) had done this more than the female instructor (20.0%). Meanwhile, 7 responded that they had provided this information in some cases. However, 11 participants (20.0%) had told all of their patients about their illnesses.

Interestingly, the proportion of respondents who had informed relatives was much higher than those who had informed their patients. More than eighty percent (n = 45) noted that they informed every relative about the patient's illness.

To identify the density of providing this information, our data indicated that almost two-thirds (n = 35, 63.6%) of the participants had given this information to a patient and/or their relatives within the past week. However, the residents were much more likely to have done this than the instructors (77.4% vs. 45.8%). Similarly, the female physicians were much more likely to have done this within the past week than the male physicians (85.7% vs. 48.5%), as presented in Table 5. 49.

5.5.3.2 Attitude towards Advance Directive for CPR

The majority of the participants (89.1%) agreed that the patient had the right to decide whether or not they would have CPR. However, only half (50.9%) thought that it was appropriate to inform all terminally ill patients regarding CPR and allow them to decide in advance. Interestingly, the proportion of female physicians who agreed with these two topics was more than the male (Table 5. 49 and Table 5.52). One-fifth (20.0%) of all physicians disagreed that CPR information should be discussed with the patients. One quarter (n = 14, 25.5%) preferred to decide on a case by case basis depending upon psychological status, religion and the culture of the individual. Only one participant mentioned that it would probably be difficult to do so in Thai culture.

Table 5. 48: Comparison of responses to questions between the male and female physicians

Question/Response		Male Frequency (%)	Female Frequency (%)
1.In cases where the patient was capable, who was the person that you would prefer to inform about the diagnosis and prognosis.			
a) Patient		6 (17.6)	5 (23.8)
b) Relative		16 (47.1)	7 (33.3)
c) Both the patient and relative		11 (32.4)	9 (42.9)
2.In cases where the patient was capable, how often that you have informed the patient about the terminal diagnosis and prognosis?			
a) Every patients		7 (20.6)	4 (19.0)
b) The majority of the patients		10 (29.4)	11 (52.4)
c) In some patients		1 (2.9)	6 (28.6)
d) Never inform		3 (8.8)	1 (4.8)
e) Other		2 (5.9)	-
3. In the scenario in which the patient was capable, how often that you have informed the relative about the terminal diagnosis and prognosis of the patients.			
a) Every cases	26 (76.5)	19 (90.5)	
b) The majority of the cases	6 (17.6)	1 (4.8)	
c) In some case	1 (2.9)	1 (4.8)	

Table 5. 49 : Comparison of responses to questions between the male and female physicians

Question/Response	Male Frequency (%)	Female Frequency (%)
1. When was the last time that you have informed the patient/relative about the terminal diagnosis and prognosis?		
a) Last week	17 (50.0)	18 (85.7)
b) Last month	8 (23.5)	1 (4.8)
c) Last 3 months	2 (5.9)	-
d) Last year	6 (17.6)	2 (9.5)
e) Other	1 (2.9)	-
2. Was it appropriate to inform all terminally ill patients regarding CPR and allow them to decide in advance.		
a) Yes, it was	16 (47.1)	12 (57.1)
b) No, it wasn't	8 (23.5)	3 (14.3)
c) Other	8 (23.5)	6 (28.6)
3. In Thai culture, was it a good idea to provide CPR information to all admitted patients and allow them to decide about CPR in advance?		
a) Yes, it was	9 (26.5)	10 (47.6)
b) No, it wasn't	12 (35.3)	5 (23.8)
c) Other	13 (38.2)	6 (28.6)
4. Had you ever asked the patients who were terminally ill whether they wanted to have CPR performed or not?		
a) Yes	10 (29.4)	9 (42.9)
b) No	23 (67.6)	11 (52.4)
c) Other	1 (2.9)	1 (4.8)

Table 5. 50 : Comparison of responses to questions between the male and female physicians

Question/Response	Male Frequency (%)	Female Frequency (%)
1. Had you ever asked the relative of terminal ill patient whether they wanted to have CPR performed or not?		
a) Yes	31 (91..2)	21 (100.0)
b) No	2 (5.9)	-
c) Other	1 (2.9)	-
2. If the patients with terminal illnesses requested that they did not want to have CPR, would you prefer to follow their wishes?		
a) Yes	32 (94.1)	18 (85.7)
b) Other	1 (2.9)	3 (14.3)
3. Would you write a DNR order if it was medically indicated, and all of the medical team agreed that the patient should not be resuscitated?		
a) Yes	17 (50.0)	9 (42.9)
b) No	15 (44.1)	6 (28.6)
c) Other	2 (5.9)	6 (28.6)

Table 5. 51 : Comparison of responses to questions between the male and female physicians

Question/Response	Instructor		Resident	
	Male N = 19	Female N = 5	Male N = 15	Female N = 16
1.In cases where the patient was capable, who was the person that you would prefer to inform about the diagnosis and prognosis.				
a) Patient	4 (21.1)	1 (20.0)	2 (13.3)	4 (25.0)
b) Relative	9 (47.4)	2 (40.0)	7 (46.7)	5 (31.3)
c) Both the patient and relative	6 (31.6)	2 (40.0)	5 (33.3)	7 (43.8)
2.In cases where the patient was capable, how often that you have informed the patient about the terminal diagnosis and prognosis?				
a) Every patients	1 (5.3)	2 (40.0)	6 (40.0)	2 (12.5)
b) The majority of the patients	7 (36.8)	1 (20.0)	3 (20.0)	10 (62.5)
c) In some patients	1 (5.3)	3 (60.0)	-	3 (18.8)
d) Never inform	3 (15.3)	-	-	1 (6.3)
3. In the scenario in which the patient was capable, how often that you have informed the relative about the terminal diagnosis and prognosis of the patients.				
a) Every cases	14 (73.7)	4 (80.0)	12 (80.0)	15 (93.7)
b) The majority of the cases	4 (21.1)	-	2 (13.3)	1 (6.3)
c) In some case	1 (5.3)	1 (20.0)	-	-

Table 5. 52 : Comparison of responses to questions between the male and female physicians

Question/Response	Instructor		Resident	
	Male N = 19	Female N = 5	Male N = 15	Female N = 16
1. Was it appropriate to inform all terminally ill patients regarding CPR and allow them to decide in advance.				
d) Yes, it was	8 (42.1)	1 (20.0)	8 (53.3)	11 (68.8)
e) No, it wasn't	6 (31.9)	-	2 (13.3)	3 (18.8)
f) Other	4 (21.1)	4 (80.0)	4 (26.7)	2 (12.5)
2. In Thai culture, was it a good idea to provide CPR information to all admitted patients and allow them to decide about CPR in advance?				
d) Yes, it was	2 (10.5)	1 (20.0)	7 (46.7)	9 (56.3)
e) No, it wasn't	5 (26.3)	1 (20.0)	7 (46.7)	4 (25.0)
f) Other	12 (63.2)	3 (60.0)	1 (6.7)	3 (18.8)
3. Had you ever asked the patients who were terminally ill whether they wanted to have CPR performed or not?				
d) Yes	7 (36.8)	3 (60.0)	3 (20.0)	6 (37.5)
e) No	12 (63.2)	2 (40.0)	11 (73.3)	9 (56.2)
f) Other	-	-	1 (6.7)	1 (6.3)

Table 5. 53 : Comparison of responses to questions between the male and female physicians

Question/Response	Instructor		Resident	
	Male N = 19	Female N = 5	Male N = 15	Female N = 16
1. Had you ever asked the relative of terminal ill patient whether they wanted to have CPR performed or not?				
d) Yes	17 (89.5)	5 (100.0)	14 (93.3)	16 (100.0)
e) No	2 (10.5)	-	-	-
f) Other	-	-	1 (6.7)	-
2. If the patients with terminal illnesses requested that they did not want to have CPR, would you prefer to follow their wishes?				
c) Yes	19 (100.0)	5 (100.0)	13 (86.7)	13 (81.3)
d) Other	-	-	1 (6.7)	3 (18.8)
3. Would you write a DNR order if it was medically indicated, and all of the medical team agreed that the patient should not be resuscitated?				
d) Yes	5 (26.3)	3 (60.0)	12 (80.0)	6 (37.5)
e) No	13 (68.4)	-	2 (13.3)	6 (37.5)
f) Other	-	-	2 (13.3)	6 (37.5)

In response to the question "in Thai culture, is it a good idea to provide CPR information to all admitted patients and allow them to decide about CPR in advance?", similar proportions of the participants (34.5% vs. 30.9%) responded to this question in an opposite direction to what they thought would be appropriate. However, the remainder (n = 14, 25.5%) remarked that their response to this question depended on the individual patient. The proportion of the instructors who thought ADs for CPR was not a good idea was higher than the residents (25.0% vs. 16.1%). In contrast, the proportion of the female physicians who thought ADs for CPR was a good idea was higher than the male physicians (47.6% vs. 26.5%)(Table 5. 49) and this result was repeated in both instructor and resident subgroups (Table 5.52).

5.5.3.3 Advance Directive in Actual Practice

More than sixty percent (61.8%) of the participants had never asked their patients who were terminally ill whether they wanted to have CPR performed or not. Only 35.2% (n=19) had ever asked this question and the female physicians were more likely to have done this than the male (Table 5.49 and Table 5.52). Most (n = 52, 94.5%) had addressed this question with a relative. However, if patients with terminal illnesses requested that they did not want to have CPR, the majority of physicians (90.9%) agreed and followed the wish of their patients.

In response to the question concerning whether or not the participant would write a DNR order if it was medically indicated, and all of the medical team agreed that the patient should not be resuscitated, less than half (n = 26, 47.3%) would write a DNR order. Subgroup analysis showed that the residents would be more likely to write

this order than the instructors (n = 18, 58.1% vs. n = 8, 33.3%), as presented in Table 5.53. In addition, the male physicians were more likely to write this order than the female (n=11, 50.0% and n=9, 42.9%, respectively) (Table 5.50).

5.5.3.4 Preferences for In-Home Death

Confirming the finding from nurses, data from physicians supported the fact that many patients preferred to die at home. Nineteen (34.5%) physicians estimated that 26-50% and 15 (27.3%) physicians estimated that 51-75% of terminally ill patients preferred to go home (decided for self-discharge) when they realized that their prognosis was poor. Moreover, seven physicians (12.7%) estimated that 76-100% of the patients had requested to go home. Even though the estimated proportion varied between physicians, most had observed the preference to go home in at least some patients.

The physicians stated that the patients had several reasons for self-discharge and some may have more than one reason. Of fifty-five physicians, 33 (60.0%) stated that the most common reason was the preference for in-home death. In addition, 17 (30.9%) physicians mentioned that the patients needed to be with their family during the end stage of their life. Moreover, the relatives also preferred to take care of and attend the last moment with their loved one. Meanwhile, 11 physicians (20.0%) remarked that northern Thai people had a traditional belief about in-home and out-of-home death. Many believed that if one died in their house, their spirit would remain and they could protect their family members. However, they believed that if one died in another place, their spirit would not get back to the home and the body would not be allowed to return

home. Some physicians (8, 14.5%) mentioned economic reasons for hospitalization. A similar number (8, 14.5%) noted the difficulty and cost of transferring the body after the patients had died.

5.6 Results

5.6.1 AD Employ

In this study, AD was implemented to the 188 subjects in the intervention group. Of these, it was possible to identify 132 (70.2%) surrogates to participate in the study. Interestingly, of the 132 pairs of subjects and their surrogates, eighty pairs (60.6%) wanted to employ AD for CPR and 17 pairs (12.9%) did not want to employ AD (Figure 5.6.1). AD agreement was 73.5%. However, they wanted to do this by word of mouth. All were hesitant to sign an AD document, preferring to transfer this message to each other orally.

Figure 5.6.1: Agreement for AD Employ

		Surrogate		Total
		Yes AD	No-AD	
		n (%)	n (%)	N=132
Patient	Yes AD	80(60.6)	13 (9.8)	93 (70.5)
	No-AD	22(16.7)	17 (12.9)	39 (29.5)

5.6.2 Discussion about CPR

Generally, we saw that the physicians seldomly initiated discussion about resuscitation with terminally ill patients or their families. Of 188 subjects, the physicians had discussed the prognoses and end-of-life care with family members in only 50 cases (26.6%). Of the fifty cases, there were 12 subjects who were in comas or became comatose, 7 cases who had CPR, one DNR, six cases who had critical condition (CPC of 3) and 19 cases who decided for self-discharge and five cases who had been transferred to other hospital.

For 12 subjects who were in comas, after discussion, six families decided that they would like the patient discharged and another six wanted the patient to stay in the hospital. In the latter group, three requested the best supportive care and that no-CPR be given, and the remaining three had left the decision to the attending physicians with no specific requests. Their clinical conditions progressively deteriorated. Five of them died shortly afterwards without resuscitation and one was signed out from the hospital. The reason for self-discharge in all cases was a preference for in-home death. No previous discussion, however, between the physicians and the families occurred for another three subjects who were in a coma and died without resuscitation.

The results from the focus groups with nurses and the responses from the physicians could be summarized by saying that end-of-life discussions, especially for CPR, was uncommon in terminally ill patients who were still capable. These discussions would be initiated only when death was truly imminent; most were done with relatives when the patients were already incapacitated.

Clinicians did not initiate end-of-life discussions with their patients because they were concerned about their patients' physical and psychological well being.

More commonly, discussions were about the diagnosis. Table 5.54 presents prior knowledge of illness and previous experience regarding terminal care in the AD group. Our primary assessment noted that 68.6% of the subjects stated that they had been informed about their diagnosis. Of these, approximately half (35.1%) had received wholly accurate information. On the other hand, 12.2% had received only partially accurate information. For example, subjects who had been diagnosed with cancer would be told they had a tumor. The remaining, 45.7% did not know their diagnoses.

Approximately forty percent of our patient participants believed they knew their prognoses. Unfortunately, less than half of these (16.5%) realized that their prognoses were poor. Moreover, nine percent thought they had big tumors but the size would decrease after chemotherapy or radiation therapy, suggesting to them that their illnesses would be cured.

As part of the AD intervention, we tried to inform patients who were unaware of their diagnoses and prognoses or who had received incorrect information that it is the patient's right to obtain this information. We encouraged them to talk with or consult with their physicians. Ultimately, 127 (67.6%) of the subjects stated they had communicated with their physicians and obtained accurate information.

Table 5. 54 : Prior knowledge of illness and previous experience regarding terminal care in advance directive group

Question/Response	Yes	No	Not applicable
		Frequency (%)	
Know diagnosis correctly	66 (35.1)	109 (58.0)	13 (6.9)
Know prognosis correctly	31 (16.5)	144 (76.6)	13 (6.9)
Have seen mechanical ventilation	93 (49.5)	69 (36.7)	26 (13.8)
Have seen Intensive Care Unit (ICU)	47 (25.0)	115 (61.2)	26 (13.8)
Have seen CPR	45 (23.9)	125 (66.5)	18 (9.6)
Have been on mechanical ventilation	9 (4.8)	153 (81.4)	26 (13.8)
Have been admitted to ICU	1 (0.5)	162 (86.2)	25 (13.3)
Had CPR attempted	7 (3.7))	167 (88.8)	14 (7.4)

Not applicable: unable to communicate due to impaired clinical condition

N = 188

5.6.3 CPR Attempted and Patient Physician Discussion regarding CPR

Nine patients had CPR attempted on them. None of the physicians of these patients had initiated discussions about CPR, even though one subject was comatose. As part of the AD intervention, we encouraged the patients and their families to consult with their physicians.

Of the nine subjects in the intervention group who had CPR attempted, two were clinically impaired and unable to communicate their wishes. Six subjects requested CPR in the case of cardiopulmonary arrest; the remaining one subject (11.1%) specified "no-CPR". Of the seven whose wishes were known, care regarding CPR was consistent with the patients' wishes in 6 cases (85.7%).

For those who had CPR attempted, respiratory depression was the most common precipitating cause of cardiopulmonary arrest; all but one had this problem. Hypotension and cardiac arrhythmia were also identified in 5 and 3 cases, respectively. Five subjects had two precipitating causes of cardiopulmonary arrest.

Within 24 hours of attempted CPR, six subjects had died. The families of the remaining three subjects desired to bring the patient home (self-discharge) with a ventilation bag. Unfortunately, one subject died on the way home and the other two subjects died at their homes. The reason for self-discharge was a preference for in-home death.

Interestingly, only one DNR order was made in the intervention group and none in the control group. In this case, the physicians and family members had discussed the

patient's illness and its prognosis. After discussion, the family preferred to have supportive care only and no intubation or resuscitation. These preferences were respected, having been transferred by word to other health personnel and the patient expired without CPR.

5.6.4 Patients' Conditions and Circumstances when AD should be Performed or Omitted

5.6.4.1 Advance Directives Performance

ADs should be initiated during an early phase of their illness because patients' physical and mental status may change thereafter. Moreover, after discussion and decision had been made, the AD should ideally be disseminated by word or documented as soon as possible. The AD should be conveyed to the surrogates, such as family members, physicians, and nurses.

Data from patients, physicians and nurses suggested that ADs could be made for patients in any condition with terminal illnesses. Patients with clinically significant terminal illnesses, such as those with a CPC score of 4, in whom death and the need for resuscitation were predictable, were the most common group to which end-of-life care discussions had been performed. This condition had triggered the physicians to inform the relatives about the poor prognosis and consult the relatives about end-of-life care in 80% of the cases (12/15). After the relatives had observed a deterioration of the patient's condition for a period of time and had been informed by the physicians, all of them accepted the truth that death was imminent. Most of those who preferred in-home death would decide to self-discharge.

For all terminally ill patients who had a critical condition, death and the need for CPR would be expected even if the patients were alert and oriented. This serious situation also alerts the physicians to discuss end-of-life care with the relatives but not with the patients. Most were afraid that discussing it with the patients might hurt their feelings. After being well informed, all of the relatives preferred the best supportive care until the condition was stable enough for the patient to go home.

After the terminally ill patients who were still capable were well informed about the diagnoses and prognoses, two major decisions were observed. Some subjects decided to employ AD and some preferred in-home death and were given the consent for self-discharge.

Beside the AD for CPR, our observation had focused on supportive treatment, such as artificial ventilation, analgesia, artificial hydration and nutrition. All of which had been provided to terminally ill patients if indicated. No evidence of withdrawal of those treatments had been observed. The DNR decision was the only life-sustaining treatment that was withheld and accepted by physicians, families, and nurses. The exception was found when the patients or families decided to go home. In this case, most of the treatment was discontinued, with the exception of a ventilation bag to keep the patient breathing.

Finally, whether people want to decide or not by themselves, the advance medical directives should be started quite early. Our data confirmed the failure of late decisions.

5.6.4.2 When AD should be omitted

Surrogates who have different opinions than the patient or other family members should not be invited to make decisions regarding the AD. Of the 376 subjects in this study, we had noted only one situation like this. This patient had been diagnosed with ESLD and hepatic encephalopathy. He had a history of heavy drinking. He was confused and his condition was very critical and terminal. The legal surrogate complained that the subject was drunk and left to her all the responsibility for his children all the time. She also stated, "Don't do anything more. It looks like he won't survive." "I'm very poor". I don't have money." " If he dies I will donate his body to the hospital." "I don't have money for transportation and no money for the funeral". Finally, the subject died and his body was donated to the hospital for study. In this case, the decision for treatment should have been made based on medical indicators.

5.6.5 Physicians and Family Discussion regarding CPR without Patient Involvement

Six patients in our study were in serious condition with a CPC score of 3. They were still conscious enough that the family had discussed the prognosis and end-of-life care with the physicians without patient involvement. After the family realized the prognoses, five relatives preferred the best supportive care only. In addition, the family of the other patient requested no-CPR. One subject who had observed this situation was very angry and he had refused all treatment, signing out from the hospital thereafter.

5.6.6 The Agreement between Family Decision and the Patient Statement about CPR

Of the eighty pairs of subjects and their surrogates who decided to communicate their AD wishes orally, concordance in decision-making was observed in 57 pairs and the percentage of agreement was 71.3%. Interestingly, of the 57 pairs who were in agreement, fifty-five pairs (68.8%) preferred to have CPR performed for the patients if they went into cardiopulmonary arrest and only two pairs did not prefer to have CPR performed.

Of the 23 pairs of patients and surrogates who were not in agreement regarding CPR, fourteen patients stated they preferred to have CPR if they went into cardiopulmonary arrest but their surrogate preferred that CPR not be attempted. In contrast, nine patients preferred no-CPR but the surrogate preferred CPR.

5.6.7 The Agreement between Physician Decision and the Patient Statement about Resuscitation

5.6.7.1 Physician's decision

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 on them. The remaining 23 (41.8%) noted that they preferred to make the decision on a case by case basis. Therefore, 62.6% of physician may perform CPR. Similarly, 63.8% of patients preferred to have CPR.

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%

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CPR with the patients and their family starting from the first visit about possible diagnoses (differential diagnoses), and through visits where prognosis and treatment options were discussed. The decision regarding CPR would depend on these discussions. Treatment would then follow what decisions had been made.

Nurses also endorsed this process. Practically, CPR was usually performed if it had not been discussed previously and the patient or their family had made no decision. However, if they had been informed about the wishes of the patients or their families, whether orally or by DNR order, those were respected. They also remarked that discussions about CPR were observed infrequently on general wards when the clinical condition of the patients did not indicate they were necessary. CPR was discussed more often in the ICU. However, after hospital accreditation (HA), it was performed more regularly.

For terminally ill patients, the decision about CPR made in previous discussions seemed to be an important factor in the decision made by almost one-half of the physicians whether to perform CPR or not. After discussion, the final decision made by the patients or their families was generally respected by the clinicians.

5.6.7.2 Patient Statement about Resuscitation

Most patients (n = 136,72.3%) in this study agreed that in Thai society, it is a good idea to discuss CPR with all admitted patients.

It should be remarked that a number of patients who were unable to communicate due to impaired clinical condition (not applicable) in each question might

be different because each question was addressed gradually and "paced" with the patients. A summary of the responses to the questionnaire is presented in Table 5. 55 to Table 5.56.

After the CPR procedure was explained to those who were capable, 137 subjects (72.9%) made a decision about whether they would want a clinician to try to revive them or not if their heart stopped (Table 5.55). Of the 137 deciding, 120 (63.8%) preferred to be resuscitated and only 17 (9.0%) did not want CPR (Table 5. 56). Interestingly, for the situation that CPR may be followed by living permanently in a coma or with mechanical ventilation, nearly half of the subjects (n = 80) said they opposed CPR but only 14 subjects said they still preferred to have it done. As compared to CPR, a smaller number of the subjects (109, 58.0%) preferred to have mechanical ventilation if they stopped breathing.

Table 5.55 : Summary of itemized responses to questions from the questionnaire with a 2-point response option (Decide/ Not-decide)

Question	Decide	Not-decide	Not applicable
	Frequency (%)		
If your heart stopped beating, would you want clinician to try to revive it?	137 (72.9)	23 (12.2)	28 (14.9)
Suppose you stop breathing, would you want to have artificial ventilator to help you breathe?	124 (66.0)	36 (19.1)	28 (14.9)
Suppose that you become ill and still no treatment available yet. You are in coma and unable to care byself, would you want the physician to continue providing treatment without improvement of your condition?	85 (45.2)	75 (39.9)	28 (14.9)
If the doctor looking at the case are quite sure that if they are revived patients with specific illnesses and serious conditions. It is impossible to cure but patients may remain alive in coma stage if they have an artificial respirator. This could required for an indefinite period of time. Under this circumstances, would you want them to revive if they could?	94 (50.0)	65 (34.6)	29 (15.4)

Not applicable: unable to communicate due to impaired clinical conditions

N = 188

Table 5. 56 : Summary of itemized responses to questions from the questionnaire with a 4-point response option (Yes/No/I don't know/Up to physician)

Question	Decide		Not-decide		Not applicable
	Yes	No	I don't know	Up to Physician	
	Frequency (%)				
If your heart stopped beating, would you want clinician to try to revive it?	120 (63.8)	17 (9.0)	6 (3.2)	17 (9.0)	28 (14.9)
Suppose you stop breathing, would you want to have artificial ventilator to help you breathe?	109 (58.0)	15 (8.0)	9 (4.8)	27 (14.3)*	28 (14.9)
Suppose that you become ill and still no treatment available yet. You are in coma. and unable to care byself, would you want the physician to continue providing treatment without improvement of your condition?	21 (11.2)	64 (34.0)	17 (9.0)	58 (30.8)*	28 (14.9)
If the doctor looking at the case are quite sure that if they are revived patients with specific illnesses and serious conditions. It is impossible to cure but patients may remain alive in coma stage if they have an artificial respirator. This could required for an indefinite period of time. Under this circumstances, would you want them to revive if they could?	14 (7.4)	80 (42.6)	5 (2.7)	60 (32.0)**	29 (15.4)

Not applicable: unable to communicate due to impaired clinical conditions

* one subject stated "up to his son"

** two subjects stated "up to his son"

5.6.8 The Discrepancy between Physicians' Intention and Practice

Almost ninety percent of the physicians (n = 49, 89.1%) agreed that it was the patients' right to decide for themselves whether or not to receive CPR. A similar proportion (90.9%) responded that if patients requested no-CPR, they would follow their wishes. Moreover, 16 (29.1%) physicians would inform their colleagues (physicians and nurses) of the patient's preference, 7 (12.7%) would ask their patient to sign a consent form for DNR; 2 physicians would inform a relative, and one physician preferred to have the relative co-sign the DNR consent. Three physicians preferred to note the patient's preferences in their medical record. However, only one physician stated that he would write a DNR order. Lastly, three physicians stated that they would withhold CPR themselves. Most (n = 52, 94.5%) stated they preferred to discuss CPR with the relatives when their patient's condition had deteriorated such that CPR was likely or death was imminent.

In actual practice, more than 60 percent of the physicians (n =34, 61.8%) had never asked their patients about their preference for CPR. Only 19 (34.5%) had previously discussed this issue with at least one of their patients. Most of the discussions about CPR were done with the relatives. However, after discussion, most of the physicians followed the decision made by the patients or their relatives and this message was orally communicated to other care providers. Nurses would make a remark in the Kardex and then report the decision to the following shift. Previously, this way of doing things had been quite effective in regards to withholding CPR.

5.7 Other Results

5.7.1 Factors Affecting Preferences for End-of-Life Care

Several analyses were done in order to identify what patient characteristics predicted their preferences and the ability to decide about end of life care. The association between preferences for CPR and demographic characteristics are presented in Table 5.57 to Table 5.59. First, the results for the whole sample are presented, and then the results within the group of patients with NSCLC and ESLD are presented.

5.7.2.1 Preferences for CPR by Demographic Variables

In the whole sample, the subjects who had low education (≤ Grade 4-6) were less likely to have CPR than those who had high education (≥ Grade 9), OR = 0.30, 95% CI =0.10-0.82 (Table 5.57). Age, gender, marital status, and residence were not associated with preferences for CPR.

Similar findings were observed in the subset of patients with NSCLC (Table 5.58). Subjects who had high education (≥ Grade 9) were more likely to decide to have CPR than those who had low education (≤ Grade 4-6), OR = 0.13, 95% CI = 0.38 - 0.46).

In contrast with the whole sample and NSCLC, however, gender was found to be an important predictor of CPR preference in subjects with ESLD (Table 5.59). In this group, males were sixteen times more likely to prefer to have CPR as compared to females (OR =16.50, 95% CI = 1.35- 201.29). However, no association was identified between CPR preference and other variables.

All analyses indicated that age, gender, marital status, education, and residence in the total sample, as well as in subjects with NSCLC, were not associated with the ability to decide about CPR. This is presented in Table 5.60 to Table 5.61.

Table 5.57 : The odds ratio of preferences for CPR by gender, age, marital status, education and residence of Total sample

Dependent variable	OR	95% CI	p-value
Gender (Male/female)	1.29	0.40 - 4.11	0.670
Age/ year (≤ 59/ ≥ 60)	1.07	0.36 - 3.21	0.900
Marital status (Married/Not married)	1.30	0.27 - 6.27	0.745
Education (≤ Grade 6/ ≥ Grade 9)	0.30	0.10 - 0.82	0.021*
Residence (Rural/Urban)	0.60	0.20 - 1.83	0.368

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

P – value < 0.05

Table 5.58 The odds ratio of preferences for CPR by gender, age, marital status, education and residence of patient with non-small cell lung cancer

Dependent variable	OR	95% CI	p-value
Gender (Male/female)	0.66	0.19-2.29	0.507
Age/ year (≤ 59/ ≥ 60)	1.00	0.31-3.23	0.995
Marital status (Married/Not married)	1.06	0.21-5.36	0941
Education (≤ Grade 6/ ≥ Grade 9)	0.13	0.38-0.46	0.002**
Residence (Rural/Urban)	0.36	0.11-1.19	0.094

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

** p-value < 0.005

Table 5.59 The odds ratio of preferences for CPR by gender, age, marital status, education and residence of patient with end stage liver disease

Dependent variable	OR	95% CI	p-value
Gender (Male/female)	16.50	1.35-201.29	0.028*
Age/ year (≤ 59/ ≥ 60)	0.63	0.06-6.96	0.706
Marital status (Married/Not married)	8.33	0.41-170.66	0.169
Education (≤ Grade 6/ ≥ Grade 9)	1.88	0.17-20.61	0.607
Residence (Rural/Urban)			

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

Table 5.60 : The odds ratio of decided or not-decided for CPR by gender, age, marital status, education and residence of total sample

Dependent variable	OR	95% CI	p-value
Gender (Male/female)	1.05	0.39 – 2.83	0.917
Age/ year (≤ 59/ ≥ 60)	0.87	0.34 – 2.26	0.780
Marital status (Married/Not married)	1.60	0.44 – 5.88	0.476
Education (≤ Grade 6/ ≥ Grade 9)	1.42	0.44 – 4.57	0.562
Residence (Rural/Urban)	0.91	0.33 – 2.55	0.857

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

Table 5.61 : The odds ratio of decided or not-decided for CPR by gender, age, marital status, education and residence of patient with non-small cell lung cancer

Dependent variable	OR	95% CI	p-value
Gender (Male/female)	1.15	0.59-4.06	0.372
Age/ year (≤ 59/ ≥ 60)	1.05	0.40-2.81	0.918
Marital status (Married/Not married)	1.45	0.43-4.94	0.552
Education (≤ Grade 6/ ≥ Grade 9)	2.06	0.44-9.64	0.359
Residence (Rural/Urban)	1.44	0.44-4.69	0.545

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

5.7.3 Medical Treatment in Coma

In response to the question, "suppose that you become ill but no treatment is available and you are in a coma and unable to care for yourself, would you want a physician to continue providing treatment without improvement of your condition?" Only a small number of the subjects (n = 21,11.2%) stated that they would prefer to continue medical treatment (Table 5.56). In contrast, 64 subjects (34.0%) would refuse treatment. Meanwhile, 30.8% would leave this decision to their physicians and one subject would leave the decision to a relative.

5.7.4 Substitute Decision Maker

In the situation in which the patient was unable to make medical decisions by himself or herself, almost half of the subjects (48.4%) preferred to have their family make the decisions. In addition, 12.8 percent would want their family to decide together with the physician. Meanwhile, 24.5% preferred to have the physicians make medical decisions for them without the input from the family.

The family members whom the patients had selected to be their surrogate decision-maker were their spouse (25.0%), children (21.3%), parent (1.0%) and the remaining chose their spouse and direct relatives. Therefore, most chose either a spouse or direct relatives. A patient could possibly select all of their direct relatives, for example, their spouse and all four children, to make medical decisions.

5.7.5 The Association between Diagnostic and Prognostic Information and End-of-Life Care Decisions

Another set of analyses was performed to identify whether or not the patient's knowledge of diagnostic information was associated with the decision about end-of-life care (Table 5.62 - Table 5.63). In the whole sample and in the NSCLC subgroups, knowledge about diagnosis was not significantly associated with their decision regarding CPR, artificial ventilation or medical treatment in coma and terminal illness or with their decision for CPR if it might be followed by artificial ventilation and/or by coma.

The associations between decisions about end-of-life care and knowledge about their prognosis were similar to those with knowledge about their diagnosis. There were no significant associations in the total sample or the NSCLC subgroups (Table 5.64 - Table 5.65).

Table 5.62 : The odds ratio of knowing the diagnosis and decision regarding end-of-life care of Total sample

Decision option	OR	95% CI	p-value
CPR (Yes CPR/No-CPR)	1.02	0.35 – 2.96	0.965
Artificial breathing (Yes/No)	0.95	0.30 – 2.98	0.924
Medical treatment in coma and terminal illness. (Yes/No treatment)	0.71	0.21 –2.41	0.578
If CPR may be followed by artificial breathing and/or coma (Yes CPR/No-CPR)	0.50	0.10 –2.43	0.390

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

Table 5.63 : The odds ratio of knowing the diagnosis and decision regarding end-of-life care in Patient with non-small cell lung cancer

Decision Option	OR	95% CI	p-value
CPR (Yes CPR/No-CPR)	0.90	0.27-2.98	0.861
Artificial breathing (Yes/No)	0.63	0.18-2.16	0.458
Medical treatment in coma and terminal illness. (Yes/No treatment)	0.74	0.21-2.62	0.635
If CPR may be followed by artificial breathing and/or coma (Yes CPR/No-CPR)	0.61	0.12-3.14	0.555

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis.

Table 5.64 : The odds ratio of knowing the prognosis and decision regarding end-of-life care of Total sample

Decision option	OR	95% CI	p-value
CPR (CPR/No-CPR)	0.90	0.14 – 5.78	0.912
Artificial breathing (Yes/No)	0.78	0.16 – 3.75	0.754
Medical treatment in coma and terminal illness. (Yes/No treatment)	0.63	0.10 – 3.84	0.612

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

Table 5.65 : The odds ratio of knowing the prognosis and decision regarding end-of-life care in Patient with non-small cell lung cancer

Decision Option	OR	95% CI	p-value
CPR (CPR/No-CPR)	0.33	0.04-2.70	0.300
Artificial breathing (Yes/No)	0.48	0.06-4.01	0.494
Medical treatment in coma and terminal illness. (Yes/No treatment)	0.89	0.16-5.05	0.894

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis.

The ORs for the association between knowledge of the diagnosis and the ability to decide or not-decide for end-of-life care are presented in Table 5.66. Interestingly, out of the total sample, the subjects who knew their diagnosis were less likely to decide for end-of -life care than those who did not know their diagnosis. The ORs for associations between knowledge of their diagnosis and the ability to make the following end-of-life decisions were; CPR (OR = 0.30, 95% C.I. = 0.12 – 0.75), artificial breathing (OR = 0.24, 95% C.I. = 0.11 – 0.52), medical treatment in coma (OR = 0.22, 95% C.I. = 0.11 – 0.43), and CPR if it might be followed by artificial breathing and/or by coma (OR = 0.17, 95% C.I. = 0.08 –0.34).

Similarly, the subjects with NSCLC who knew their diagnosis were less likely to decide for all options for end-of-life care when compared to those who did not know their diagnosis (Table 5.67). The ORs ranged from 0.18 to 0.24.

In those with ESLD, the association with knowledge of their diagnosis was only observed for two options (Table 5.68). The subjects who had knowledge that they had ESLD were less likely to decide on medical treatment in coma and terminal illness (OR = 0.15, 95%C.I.= 0.03 – 0.89); and to decide for CPR if it might be followed by artificial ventilation and/or by coma (OR = 0.17, 95% C.I. 0.04 – 0.82).

Table 5.66 : The odds ratio of knowing the diagnosis and the ability to decide or not decide for end-of-life care of Total sample

Decide/Not decide option	OR	95% CI	p-value
CPR	0.30	0.12 – 0.75	0.010*
Artificial breathing	0.24	0.11 – 0.52	< 0.001**
Medical treatment in coma and terminal illness.	0.22	0.11 – 0.43	< 0.001**
If CPR may be followed by artificial breathing and/or coma indefinitely	0.17	0.08 – 0.34	< 0.001**

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

* p-value < 0.05

** p-value < 0.005

Table 5.67 : The odds ratio of knowing the diagnosis and the ability to decide or not decide for end-of-life care in Patient with non-small cell lung cancer

Decided/Not-Decided Option	OR	95% CI	p-value
CPR	0.24	0.09-0.69	0.008 *
Artificial breathing	0.18	0.07-0.46	< 0.001**
Medical treatment in coma and terminal illness.	0.23	0.11-0.49	< 0.001**
If CPR may be followed by artificial breathing and/or coma indefinitely	0.18	0.08-0.39	< 0.001**

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis.

* p-value < 0.05

** p-value < 0.005

Table 5.68 : The odds ratio of knowing the diagnosis and the ability to decide or not decide for end-of-life care in Patient with end stage liver disease

Decide/Not decide Option	OR	95% CI	p-value
CPR	1.00	0.08-12.40	1.000
Artificial breathing	0.59	0.10-3.29	0.549
Medical treatment in coma and terminal illness.	0.15	0.03-0.89	0.036 *
If CPR may be followed by artificial breathing and/or coma indefinitely	0.17	0.04-0.82	0.027 *

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

* p-value < 0.05

The associations between knowledge of their prognosis and their ability in end-of-life care decisions are shown in Table 5. 69 to Table 5.71. Among the subjects in the whole sample, or in the ESLD subgroup, who knew about their prognosis, it was not associated with the ability to decide or defer decision for end-of-life care. However, in the subjects with NSCLC, those who knew their prognosis were more likely to decide for medical treatment in coma and terminal illness (OR = 3.35, 95% C.I 1.25-8.96) and decided for CPR if it might be followed by artificial breathing and/or coma (OR = 3.56, 95% C.I = 1.32-9.62).

The ORs of past experience for terminal care and the decision making regarding end-of-life care are shown in Table 5.72 - Table 5.73. All analyses indicated that past

experience for terminal care in the total sample as well as in subjects with NSCLC were not associated with the decision making regarding end-of-life care.

The ORs of past experience for terminal care and the ability to decide or not-decide for end-of-life care are presented in Table 5.74 - Table 5.75. Similarly, there were no significant associations in the total sample or the NSCLC subgroups.

Table 5.69 : The odds ratio of knowing the prognosis and the ability to decide or not decide for end-of-life care of Total sample

Decide/Not decide option	OR	95% CI	p-value
CPR	1.45	0.46 – 4.59	0.526
Artificial breathing	2.29	0.97 – 5.38	0.058
Medical treatment in coma and terminal illness.	0.77	0.31 – 1.95	0.583
If CPR may be followed by artificial breathing and/or coma	0.94	0.37 – 2.35	0.890

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis.

Table 5.70 : The odds ratio of knowing the prognosis and the ability to decide or not decide for end-of-life care in Patient with non-small cell lung cancer

Decided/Not-Decided Option	OR	95% CI	p-value
CPR	0.77	0.21-2.90	0.701
Artificial breathing	2.15	0.80-5.80	0.131
Medical treatment in coma and terminal illness.	3.35	1.25-8.96	0.016*
If CPR may be followed by artificial breathing and/or coma indefinitely	3.56	1.32-9.62	0.012*

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

* p-value < 0.05

Table 5.71 : The odds ratio of knowing the prognosis and the decision to decide or not decide for end-of-life care in Patient with end stage liver disease

Decided/Not-Decided Option	OR	95% CI	p-value
CPR	10.00	0.75-132.66	0.081
Artificial breathing	4.12	0.65-25.89	0.131
Medical treatment in coma and terminal illness.	1.14	0.21-6.16	0.877
If CPR may be followed by artificial breathing and/or coma indefinitely	1.42	0.26-7.76	0.688

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis.

Table 5.72 : The odds ratio of past experience for terminal care and the decision-making regarding those specifics end-of-life care of total sample

Past experience (Seen or not seen)/ Decision-making (Yes I want or No, I don't want)	**OR**	**95% CI**	**p-value**
CPR (Seen CPR/Not seen CPR)	0.70	0.24 – 2.03	0.507
Artificial breathing (Seen/Not-seen)	0.46	0.14 – 1.54	0.209

The odds ratio (OR) and 95% confidence interval (CI) resulted from multivariable analysis.

Table 5.73 : The odds ratio of past experience for terminal care and the decision-making regarding those specifics end-of-life care in patient with non-small cell lung cancer

Past experience (Seen or not seen)/ Decision-making (Yes I want or No, I don't want)	**OR**	**95% CI**	**p-value**
CPR (Seen CPR/Not seen CPR)	0.88	0.25-3.12	0.842
Artificial breathing (Seen/Not-seen)	0.63	0.17-2.24	0.471

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

Table 5.74 : The odds ratio of past experience for terminal care and the ability to decide or not decide for those care of total sample

Past experience (Seen or not seen)/ Decide or not decide	OR	95% CI	p-value
CPR (Seen CPR/Not seen CPR)	2.65	0.75 – 9.42	0.132
Artificial breathing (Seen/Not-seen)	1.24	0.59 – 2.61	0.573

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis

Table 5.75 : The odds ratio of past experience for terminal care and the ability to decide or not decide for those care in patient with non-small cell lung cancer

Past experience (Seen or not seen)/ Decide or not decide	OR	95% CI	p-value
CPR (Seen CPR/Not seen CPR)	2.25	0.61-8.26	0.222
Artificial breathing (Seen/Not-seen)	1.63	0.71-3.77	0.253

The odds ratio (OR) and 95% confidence interval (CI), based upon multivariable analysis.

5.8 Summary of Study Results

This study indicates that ADs are applicable in this setting. Data from patients, physicians and nurses confirmed that an AD is acceptable and is effective in reducing the number of times CPR was attempted. The data also endorsed that ADs were possible for any type of patients (non-critically and terminally patients) including those with low education and rural dwellers, but the method of implementation must be adjusted accordingly.

From our observations, most ADs for end-of-life care had been developed in consultation with the relatives when the patients were incapacitated. However, for the 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. Meanwhile, the majority of the subjects who stayed in the hospital preferred CPR. Most refused CPR, however, if it might be followed with worst prognoses. Additionally, many declined treatment in the terminal stage of their illness. In contrast, many of those who did not want further treatment decided for self-discharge. Importantly, the preference for in-home death was observed in both the patients who continued in hospital and the patients who were self-discharged.

Generally, information about diagnoses and their prognoses had an effect on which decisions regarding end-of-life care the patients and their families made. The likelihood of a condition being terminal and previous discussions with the family of the patients dictated the care that the clinicians provided to the patients. The wishes of the patients and family were generally respected even without the formal ADs or DNR

orders. To protect clinicians from possible legal problems in the future, a DNR policy was immediately indicated. 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.