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計畫名稱：善終：有慢性病的老人和其家屬的觀點

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**Abstract**      關鍵字: 有慢性病老人, 家屬, 自主權, 善終

人口的老化是整個世界的趨勢, 近年來西方國家鑑於多數老人罹患慢性病, 而且他們的死因主要是無法控制的慢性病和其併發症, 因此將緩和醫療和善終的觀念應用在老人慢性病生命末期的醫療照護上。在台灣, 家屬通常決定老人生命末期是否繼續接受積極的治療, 但是他們的決定不一定是老人的意願, 也可能沒有和老人溝通過。

這個研究計畫的主要目的是要了解患有慢性病的老人和其家屬對“善終, 生命末期治療和病人自主權”的看法。這個研究以立意樣本, 收集到 94 對居住在台灣南部 60 歲或以上患有慢性病的老人和家屬的資料。

在病人自主權上, 大多數的老人(82%)和家屬(77%)都主張要讓病患知道癌症末期的診斷。54%的老人, 19%的家屬認為讓病人做醫療決定不會增加病人的負擔。84%的老人認為家屬應該尊重病人的決定。這些資料顯示出老人比一般人想像的更注重病人的自主權, 希望在醫療上有更多的決定權。在維生醫療措施的使用上, 病人和家屬均傾向於不再使用侵入性的治療, 例如手術或心肺復甦按摩, 特別是失智或陷入不可逆的昏迷狀態時。在善終上, 老人認為最重要的是安詳無疼痛和不刻意延長生命的死亡, 只有 21%認為靈性需求的滿足很重要。這個研究顯示尊重病人自主權是一般人, 包括老人, 的意願, 談論死亡不是必然的禁忌。

As the world population grows older, death is occurring later in life. Many older adults suffer from serious chronic illnesses before dying from complications of these illnesses. Although medical technology has made it possible to extend further the lives of older adults, these efforts sometimes result in great suffering before death. Thus, gerontologists in Western countries have recently begun to advocate palliative care and good death in the care of older adults with severe chronic illnesses. In Taiwan, the family usually makes decisions regarding end-of-life treatment for an older patient, but these decisions may not necessarily be consistent with the patient's wishes, especially if the wishes have not been conveyed. The purpose of this study is to explore perceptions of good death, end-of-life care decisions, and patient autonomy in older adults with chronic illnesses and their families.

A convenience sample of older adults with chronic illnesses and their families was drawn from southern Taiwan, of which 94 pairs completed the interview. The majority of the older adults and their families believe that a terminal diagnosis should be disclosed to the patient. Fifty-four percent older adults versus 19% of family members ( $p < 0.01$ ) believe that making health care decisions is not a burden to the patient. Fifty-six percent of older adults versus 39% of family members ( $p < 0.05$ ) believe that patients have the right to terminate their lives if there is no cure. Regarding to life sustaining treatment, both older adults and families would forgo invasive treatment such as surgery or CPR if cognitive function was impaired or the patient was in an irreversible coma. Older adults considered dying peacefully, no pain, without artificially prolonging life, short dying period, and love ones present as components of a good death. Only 13% rated remaining mentally alert and only 21% rated fulfilling spiritual needs as essential in a good death. This research found that older adults value patient autonomy and patients' rights in decision making. Dying peacefully without artificially prolonging life is a part of their wishes for a good death.

Key Words: older adults with chronic illnesses, family, patient autonomy, good death

## A. Background, Significance and Purpose

Scientific and technological advances in medicine have successively extended the human lifespan throughout the 20<sup>th</sup> century. One consequence of these developments is that life-prolonging treatments are often used to fight death to the very end and at times without the patient's consent. As a result, many people have watched their loved ones undergo prolonged suffering and an undignified death, particularly the terminally ill and the very old. After years of heated public debate, the Patient Self-Determination Act was passed in the United States in 1991 (Kleepies, 2004). In 2000, a similar but more limited act entitled “安寧緩和醫療條例” was passed in Taiwan, allowing a terminally ill person to forgo cardiopulmonary resuscitation and related treatments (行政院衛生署, 2000). This option has been elected primarily by cancer patients.

In Quebec, Canada, 73% of life-prolonging treatment decisions occur in persons over the age of 65, 79% of whom are living with chronic illnesses (Shidler, 1999). In the United States, 80-85% of deaths occur in those 65 and older, the majority due to irreversible chronic illnesses, such as congestive heart failure, pulmonary ailments, diabetes, kidney failure, and Alzheimer's disease (Hogan, Lanney, Gabel, & Lynn, 2000). In 2004, people 65 and over composed 9.5% of the total population of Taiwan (行政院主計處, 2005). With its high rate of mortality, there is a great need to help this population achieve a “good death.” End-of-life care issues must take older adults into consideration, albeit using a framework and model different from those developed for hospice care (Skilbeck & Payne, 2005).

Good death is also referred to as good enough death, dying well, beautiful death, and exemplary death (Leichtentritt & Rettig, 2000). The meaning of good death depends largely on one's society and culture and may change and evolve with time (Walters, 2004). Kastenbaum (2004) stresses that good death should be consistent with the values held by the society. Although patient autonomy was listed among the top ten indicators of good death in hospice care at Taiwan University Hospital (陳, 2001), family members are still the primary decision maker. Is personal autonomy and control a culture-specific value or a universal value (Skaff & Gardiner, 2003)? Should interventions be developed to enhance personal control and autonomy for end-of-life planning? Since the Patient Self-Determination Act and “安寧緩和醫療條例” are based on respecting patient autonomy and the patient's rights to decide life-sustaining treatments, it is important to look at how older adults and their families perceive patient control in the context of good death.

Discussing end-of-life issues with patients and their families in time-strained hospital settings is especially difficult. Health care providers may not have the time to answer patients and their families. The patients and families may not necessarily understand their options or make well-informed decisions, especially if they have had little exposure to advanced medical technology (Perrin, 2004). Therefore, it is important that discussion take place within the community setting and while the cognitive function of the older adult is still intact.

Although studies of good death are hardly new, research in Taiwan has largely focused on patients suffering from cancer. There is a paucity of literature on the perception of end-of-life care and good death in older adults and their families. The purpose of this study is twofold: 1) to

explore personal control and autonomy, end-of-life care, and good death from the perspective of community-dwelling older adults with chronic illnesses and their families; and 2) to examine communication barriers between older adults and their families. Knowledge generated from this study may help communication of end-of-life issues among patients, their families, and health care providers.

## B. Literature Review

### Good death

In the dying experience, a good death is described as free of pain and other distressing symptoms, clean and neat, preserving the integrity of the body (Chao, 1997), brief in the duration of the dying process, dying peacefully, having dignity, being at home or in a homey environment, being able to finish business, accepting death, and resolving spiritual conflict (Leichtentritt & Rettig, 2000; Ternestedt, Andershed, Eriksson, & Johansson, 2002; Vig & Pearlman, 2004).

Social context is an essential element of good death in all cultures but is valued especially highly in many Asian cultures. Many Japanese perceive good death as being surrounded by a caring family when dying, not being a burden on the family, and having fulfilled their familial responsibilities (Long, 2001). Korean nurses consider having a good relationship with the family and not being a burden on the family as part of a good death (Kim & Lee, 2003). A study of Chinese hospice patients in Hong Kong found that good death meant accepting the timing of one's death, which included fulfilling obligations as a child and as a parent (Mak, 2002). In Taiwan, Chao (1997) observed some clients letting go of their attachment to loved ones and the world while others preferred to be with their loved ones at the time of death. Research on Americans has found that having time to say goodbye, continuing to be loved, and resolving conflicts are elements of a good death (Good et al., 2004; Pierson, Curtis, & Patrick, 2002).

Patient autonomy and control have been found to be the central characteristics of good death in most Western countries, such as Britain (Masson, 2002), Australia (McNamara, 2004), the Netherlands (Pool, 2004), and the Americas (Vig, Davenport, & Pearlman, 2002). Individualism emphasizes the individual's rights and full autonomy and control during the dying process, which includes diagnosis, prognosis, treatment and advance care planning. Personal control, however, was not listed as an important element in studies of Korean nurses (Kim & Lee, 2003), nor in Japanese adults (Long, 2001). Patient autonomy has been advocated in Taiwan and is listed in the guidelines for hospice care, but without further investigation it is difficult to determine if perceived control and autonomy play an important role in "good death" for Taiwanese older adults. It is a void this study will begin to address.

### Personal control and older adults

Personal control is not just an abstract value but thoroughly embedded in Western culture and daily life. Dignity is expressed through control of body functions, body image, emotions, and personal space (Volker, Kahn, & Penticuff, 2004). Studies have demonstrated that perceived control serves as a buffer against illness-related stress (Ganellen & Blaney, 1984). A sense of control also plays an important role in preventing illness, disability, and deterioration (Ebersole, Hess, & Luggen, 2004). Older adults may feel that they have gradually lost control over their own bodies and their environment and in the worst case that they are controlled by their chronic

disorders. The loss of health and functional abilities is often the precursor to loss of control. If a sense of control is not regained, older adults may lose the motivation to exert control and mastery in their lives, resulting in withdrawal, self-care deficits, and dependency (Ebersole, Hess, & Luggen, 2004). Research has found that a strong sense of personal control is a key marker of successful aging (Krause, 2003) and nurses are strongly advised to reinstitute personal control with older patients by allowing them to make decisions regarding their care (Ebersole, Hess, & Luggen, 2004). Older adults with chronic illnesses may gradually relinquish control in some areas of life while maintaining control in other domains. These studies, however, were conducted in the US. The present study asks if Taiwanese elders share the same values of personal control and autonomy.

#### Family perspective on end-of-life care

Families play significant roles in helping patients experience a good death, but they often undergo a great deal of stress themselves and may require support when confronted with the uncertainty of the dying process in their loved ones. Wilson and Daley (1999) conducted a qualitative study that interviewed family members whose loved ones died in long-term care settings. The family members felt more at ease when they were certain that everything was being done to keep the client comfortable. Being included in the decision-making process with regard to treatments was important to family members. They also valued provisions for spiritual care, such as visits from the clergy.

A quantitative study of end-of-life care found that many family members felt patient needs regarding pain (24.2%) and dyspnea (22.4%) were not satisfied. Family members also reported that the patient did not receive enough emotional support from health care providers (50.2%) and were concerned about physician communication of medical decisions (23.9%). Family members of those dying at home with hospice services were more satisfied with the end-of-life care received by the client (Teno et al., 2005).

#### Communication between older adults and families

“Dying” is difficult to predict in the elderly population and, when death is impending, older adults may not be able to express their wishes for end-of-life care due to cognitive impairment or severe disability. Therefore, patients’ families are often confronted with the issue of withholding or withdrawing life-prolonging interventions. Furthermore, some studies suggest that many patients have received end-of-life care inconsistent with their preferences because of poor communication (Hickman, 2002). Death-related issues, however, are taboo in many Asian cultures and may prevent families and older adults from engaging in discussion about end-of-life care. Although it violates the medical ethical codes regarding truth telling, many patients’ families beg health care providers to hide negative diagnoses and prognoses from patients. Many families of older adults likewise still consider it disrespectful to broach discussion of such issues with them, since speaking of death is often thought to hasten it (邱, 胡, 陳, 周, 1999). This study hopes to examine the communication barrier between families and older adults with regard to end-of-life issues, such as whether they still consider death taboo when discussed in the community setting.

### C. Methodology

A cross-sectional descriptive and correlational design was used to collect data for the study. Participants were recruited from the southern Taiwan area.

Included in the study were men and women over the age of 60 who have been diagnosed with at least one chronic illness (e.g. cardiovascular disease, pulmonary ailments, diabetes, kidney failure, and arthritis) and were living in the community. Exclusion criteria included those who could not hear or communicate (aphasia) and those who suffered from cognitive impairment. Those hospitalized or living in long-term care facilities were excluded from the study

Inclusion criteria for the family member were a familial relationship with the older adult, living in the same household or nearby, and likely to be the older adult's health care surrogate.

A convenience sample was used for the study. A total of 94 pairs of older adults and their families completed the interview.

The instruments used in this study are: the Geriatric Depression Scale, The Life Support Preferences Questionnaire, Measure of Patient Autonomy, and the concept of good death.

### D. Results and Discussion

Table 1 presents demographic data. The majority of family members are children who have obtained higher education and have better self-rated health.

Table 1 *Demographic Characteristics of the Sample (N = 94 pairs )*

Variables	<u>Older Adults</u>	<u>Families</u>	Variable	<u>Older Adults</u>	<u>Families</u>
<u>Age</u>	70.9 (8.8)	38.8 (12.7)	<u>Religion</u>		
<u>Gender</u>			Buddhists or Taoist	73.3%	65%
Male	46%	34%	Catholic or Christian	8.8%	6.4%
Female	53%	66%	Agnostic or Atheist	18.1%	26.0%
<u>Education</u>			<u>Health</u>		
Illiterate to elementary	61.7%	7.4%	Bad or very bad	37.3%	10.7%
Junior to high school	23.4%	24.4%	Average	51.5%	38.3%
Junior college and above	14.9%	68.2%	Good or Excellent	11.7%	51.0%

Table 2 presents the views of the patients and families with regard to patient autonomy. There were significant differences between the older adults and their family members on the following items: More family members than older adults believe that making a health care decision is a burden to the patient ( $p < 0.001$ ). Fewer older adults than family members believe that health care providers should have the family's consent before disclosing a terminal diagnosis or prognosis to the patient ( $p < 0.05$ ). More older adults than family members believe that the patient has the right to terminate his or her life if there is no cure ( $p < 0.05$ ). More family members than older adult favor the Hospice Act or health decision surrogates ( $p < 0.05$ ).

Table 2 *The Perspective of Older Adults and their Families with Regard to Autonomy*

( $N = 94$  pairs)

Variables	Older Adults $n = 94$	Families $n = 94$	Chi-square	P-value
Hospice Act is important	34%	55%	8.16	0.017
Health decision surrogate	39%	59%	8.54	0.036
Patient makes final decision	59%	62%	2.00	NS
Making decision is not a burden	54%	19%	21.99	<0.001
Tell patient his/her diagnosis	82%	77%	2.28	NS
Family's consent to tell diagnosis	64%	84%	11.12	0.004
Tell patient his/her prognosis	45%	44%	2.96	NS
Family's consent to tell prognosis	57%	80%	11.89	0.003
Pt. decide artificial feeding	52%	38%	9.08	0.059
Family should respect pt	84%	77%	5.59	NS
Right to terminate life if no cure	56%	39%	12.66	0.027
Favor legislation for euthanasia	55%	44%	8.81	NS
Pt. decides organ donation	88%	90%	3.13	NS
Pt. makes funeral arrangements	62%	73%	8.00	NS

Table 3 presents the life support preferences of older adults and their family members. These data demonstrate that cognitive functional impairment or an irreversible coma is a major reason to forgo further treatment, especially invasive procedures such as surgery or cardiopulmonary resuscitation. Since starvation is considered a cruel act in Asian cultures, 40-50% of subjects favor artificial nutrition regardless of health conditions.

Table 3 *Preferences Regarding End-Of-Life Care (N=94 pairs)*

	Antibiotics			Surgery			CPR			Artificial Nutrition		
	Yes	Unsure	no	Yes	Unsure	no	Yes	Unsure	no	Yes	Unsure	no
Severe cognitive impairment, physically unaffected												
Older Adults	52	18	30	32	21	48	22	16	62	45	12	43
Families	56	11	33	36	19	47	27	12	61	52	6	42
Constant shortness-of-breath, cognitively unaffected												
Older Adults	62	17	21	32	14	54	39	22	39	53	12	35
Families	68	13	29	43	18	39	31	14	55	69	11	30
Coma with no chance of recovery												
Older Adults	30	17	53	15	13	72	13	11	76	39	14	47
Families	31	9	59	9	11	80	7	4	89	41	4	55
Coma with slight chance of recovery												
Older Adults	31	18	51	20	11	69	15	13	72	39	17	44
Families	40	13	47	17	14	69	11	6	83	45	6	49
Terminal cancer without pain												
Older Adults	39	17	44	13	12	75	12	12	76	39	11	50
Families	40	12	48	11	7	82	10	5	85	44	7	49
Terminal cancer with constant pain												
Older Adults	46	13	41	14	10	76	12	9	79	39	7	54
Families	48	12	40	16	9	75	9	11	80	49	10	41

With regard to good death, older adults rated dying peacefully (76%), no or minimum pain (63%), without artificially prolonging life (60%), surrounded by love ones (59%), and short dying period (55%) as the most important. Fewer older adults rated remaining mentally alert until death (13%), lived until a key event (18%), and spiritual needs (21%) as important to a good death.

This study demonstrates that both older adults and their families value patient autonomy and the patient's rights to health information. Family members, however, still tend to believe that making medical decisions will increase the patient's burden and that health care providers should ask the family's consent before disclosing a terminal diagnosis to the patient. As a result, family members who make decisions in the clinic for their older parents may not necessarily be complying with their parents' wishes.

It is commonly believed that spiritual care is very important to end-of-life care. In this

sample, however, only 21% of older adults rated spiritual care as essential; this may be due to the fact that only 27% of older adults said that religion was very important to them.

#### E. Self-evaluation of the study results

Three modifications have been made to the original proposal in conducting this study. First, the proposed study was intended to combine qualitative and quantitative designs. However, investigator encountered difficulty when collecting qualitative data: Many participants did not feel comfortable having their interviews taped. Since the study took place over only 8 months (December 2005 to July 2006), the investigator did not collect enough qualitative data for comparison with quantitative data and validity assessment of the instrument. However, the investigator plans to continue collection of qualitative data. Second, in order to recruit enough subjects in such a short period, the age of the older adults in the inclusion criteria was lowered from 65 to 60, so long as they suffer from some chronic illness. Third, since the potential subjects were community-dwellers and involved other activities, it was difficult to find a suitable time to interview the older adults and their family members, thus, investigator collected data not only from Tainan City, but also from other locations in the southern part of Taiwan.

Although speaking about death is thought to be a taboo, especially when conversing with older adults, many were happy to share their views on “good death” with the data collectors. Nevertheless, there is the potential bias that those who did not want to talk about death may have used different excuses to avoid being interviewed. Due to the large proportion of older adults who will die from chronic illnesses, providing quality end-of-life care to this population is becoming a global public health issue, and the health care community holds the responsibility to educate the public whether such discussion is taboo or not.

Due to the limited space in this report, only part of the analyzed data has been presented. Over the next 6 months, the investigator plans to prepare several manuscripts for publication based on this study. In fact, some of the study results have been submitted to the 31<sup>th</sup> Midwest Nursing Research Society conference for presentation. Another abstract will be submitted to the 59<sup>th</sup> Annual Conference of the Gerontological Society of America.

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