Effects of family-centered values in elder's end-of-life decision making - Perspectives of seniors in Taiwan and compared to seniors in New Zealand

以家庭爲中心之價值觀對老年末期醫療抉擇之影響：比較台灣年老者與紐西蘭老人之觀點

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摘要

由於醫療科技的快速進步，可以預期的是，在不久的將來，大部分之疾病將可以獲得治療或控制。老化及過度文明即將成爲人類死亡之主要原因。是故，在處理末期及死亡的問題上應著重在老人之族群。

本研究將 112 位受訪老人之深度訪談資料分析，結果發現老年人對死亡過程雖持有看法,但並未促成他們對自己的死亡預做準備。高達 72%的受訪老人並不期待高科技能在他們死亡過程中扮演角色，而將近 60%的老人指出，當他們即將要死亡時，並不會期待醫療介入幫忙。然而，老人們不期待醫療能幫得上忙並不代表著他們在臨死前不要被送到醫院。我們所察覺的現象是;許多老人家是寧願不要去想它，以致於沒有立下任何有關末期醫療之預囑;而即使真的不要醫療介入，大部分老人也會爲了求得家庭之和諧，而寧願將末期醫療之決定，全權交由子孫來爲他們做主。基於「孝道」，許多子孫會傾向遵循社會慣例而附合現代醫療之作法;即用盡一切可能的方法，設法延長父母之生命。因此，造成今日許多老年人被迫在末期靠著機器來維生，完全違反他們之初衷。這種複雜之現象及撤除末期維生設施之兩難處境，在今日醫療社會處處可見，經常被拿出來討論。

爲了改變台灣社會這種臨死前使用高科技醫療維生之「慣例」，需要進一步討論由儒家思想衍生出的家庭價值觀，並與其他文化做對照來了解家庭之價值觀造成延長生命之主張與維持生活品質兩者間衝突之軌跡。紐西蘭並非東方文化(non-eastern culture),然其生活環境優良，重視家庭及人本教育，老年人的生活態度更是開朗豁達，往往是國人退休移民之優先選擇，正可選定與台灣做一個對照。

經由不同文化之比較，本研究所揭示的是，在尊重老年人自主之前題下，個人醫療選擇權以外的其他價值觀也應被尊重。不但不能輕忽家庭在決定老年人末期醫療處置上的功能，更應了解尊重家庭之決策對成全老年人維持整體和協(holistic whole)的心願意義非凡。然而，重要的前題是整個社會應儘速在老年死亡之議題上達到一個共識。據此，醫療上才能訂立出一個標準，知道何時可以放手。進一步的說，不僅是老年人本身，包括所有醫療人員及社會大眾，均應檢視自己的生命價值觀及對死亡及死亡過程之看法。如此，才能確信自己能夠站在維護人類死亡之尊嚴上，貢獻出自己的專業。

1. Introduction:

A typical comment from the in-depth interview data of seniors came from a 78-year-old Taiwanese man about his end-of-life wishes:

"...anyhow, I cannot put my next-of-kin in a conflict or embarrassing situation to just let me go... With this sense, I would prefer to leave it and follow whatever they decide for me ...when it comes..."

Likely because of this and similar ideas among the elderly population, the following situation occurs often in Taiwanese society:

An 82 years old man had been bed-ridden because of a stroke for more than 3 years. He was finally sent to the hospital when he was unconscious and in a very bad condition. The Doctor asked the family's opinions about giving sustaining treatment (i.e. endo-trachea tube to connect respirator) to avoid his death. After several consultations (including with relative health professionals like me) and struggles in family meetings, the family was ultimately afraid of violating filial piety. The authority of the family decided to continue his life-sustaining treatments, knowing that this would only prolong his death.

This case reflects that even now in Taiwan, the family plays a dominant role in the dying process of elderly patients. As clinical practitioners in Taiwan, our moral conscious agrees with the Western ethical view that competent patients should be regarded as the first priority in their medical decision-making, and that surrogates should make decisions solely base on his or her belief of what the patient would choose were he competent. However, in reality, we are only familiar with the family's point of view in end-of-life decision-making, and know very little about senior patients' own wills. To ignore the will of elderly patients and to follow instead the family's decision has always left a shadow in the mind of the care giver. However, a previous exploration (of the elderly patients' wills about their end-of-life), might give many caregivers a great release since it is also the elder's will to hand in their authority of end-of-life decision-making to their next-of-kin, and to follow whatever they will decide for them. However, is it ethical for care givers to simply follow the young generation's demands to rescue a frail, old life at all costs, especially when such a task is futile? Is it possible to alter the situation of using intensive medicine as a **"ritual custom"** in the dying process of elderly people in Taiwan?

This is a very common and familiar situation in current Taiwanese medical society, which makes us reconsider the effects of family-centered values in elder's end-of-life decision-making. To explore the influence of family values on end-of-life issues, we will focus on senior's attitudes toward their life and death, and compare these attitudes with those of another culture, to better understand the trajectory of conflicts about end-of-life issues in our society.

2. Methodology

Participants and Data collection

In-depth interviews were conducted with 112 seniors (persons 60 years and older) in Taiwan. To establish comparison with a non-Eastern culture sample, 25 seniors of New Zealand were interviewed by the same interviewer in the following year.

Qualitative data was collected through two stages of interviewing. Persons who agreed to participate were first given an initial written survey of four questions that asked them to give open responses on their images of life, personal feelings of health and long life, expectations from medicine and their general attitude towards biotechnology. The purpose of these initial questions was two-fold; firstly, to inspire in-depth thinking on the research topic in advance of the more detailed second interview, and secondly to give participants a chance to confirm to themselves their willingness to discuss the topic in detail. The participants then consented (in writing) to the next stage, a structured interview with 15 main written questions. Tape recordings were used during the one to two hour long interviews. No one refused an audio tape recording. The reasons for the smaller sample size in New Zealand were simple economic limitations for the time required to conduct sufficient interviews and for confirmation of the transcripts from recordings.

Analysis

All interviews were transcribed verbatim, and entered into a computer as data. Then, qualitative data analysis using a content analysis method was conducted to examine the key ideas that people had regarding life and death. The analysis steps began with listening to participants' verbal descriptions, followed by reading and re-reading the verbatim transcriptions or written responses. Significant statements were then identified and extracted. These statements were then recorded in a data management file for ease of ordering later in the process. For the final phase, the essential relationships among these statements were identified and comments categorized them into key concepts. All significant statements in the comments were thus placed into one or two categories depending on the number of different ideas that they contained. In this paper comparisons between the frequencies of key concepts are made using percentages, following accepted methods of descriptive bioethics research (Macer, 1994).

Trustworthiness

Open-ended interviewing techniques, tape recordings, and verbatim transcriptions from those tapes were used to increase the accuracy of data collection. The transcripts were reviewed and coded independently by two researchers drawing upon their expertise in clinical medicine and bioethics. The two stages of data collection were designed to increase validity. Ideally, after completing the initial written survey the

participants would immerse themselves in the questions for a few days, and then be prepared to give deliberate answers during the lengthier in-depth interview in the second stage. The qualitative methodology, features of the density of data collection, and the inductive way of analysis were all chosen to maximize the validity of the motifs in order to study seniors' attitudes.

3. Result

Perfect end-of-life

A question of "According to your imagination, what is the perfect end-of-life?" was asked, categories that were used for analyzing the responses to the question are illustrated with the result in Table 1.

Table 1: Perfect end of life with comparisons between Taiwan and NZ seniors

Reasons	**Seniors Taiwan**	**%**	**Seniors NZ**	**%**
comments/N respondents	***154/112***	***1.4***	43/25	***1.7***
Quick, suddenly	28	25.0	8	32
At peace, with spirit	15	13.0	8	32
Enjoy a fullness of age	35	31.3	3	12
During sleep, unconscious	21	18.8	15	60
No worry or regret	10	8.9	0	0-
Up to God, religious	11	9.8	0	0
Never consider that	20	17.9	2	8
Do not bother children	10	8.9	3	12
Not inauspicious or premature death	3	3.0	2	8
Others:(keep silence)	5	4.4	0	0
Time to say goodbye	0	0	1	4
Family around	0	0	1	4

Expectation of medicine when dying

To answer the question of "About dying, what do you expect from medicine?" more than half the elderly persons said they expect "nothing" from medicine in both countries. Only 22% senior in Taiwan and 4% in New Zealand who expect medicine to rescue their life. (Table 2)

Table 2: Expectations from Medicine when dying with comparisons between Taiwan and NZ seniors

Reasons	Seniors Taiwan	%	Seniors NZ	%
N comments/N respondents	***192/112***	***1.71***	***41/25***	***1.64***
Nothing (not really)	58	51.8	13	52
Try to rescue	25	22.3	1	4
Make it quicker, Euthanasia	29	25.9	9	36
Make me comfort, no pain	18	16.1	11	44
Holistic care	10	8.9	2	8
Depends on the doctor	10	8.9	3	12
Do not try to consider that	22	19.6	0	0
Let it be decided by my junior generation	13	11.6	2	8

General life attitude

The most common comments in response to the question of "How do you see your life?" were "*Just follow the natural way*" (50%) in Taiwan. In New Zealand, more than half of the seniors who were interviewed said that they appreciated having children and families, and admitted that their families brought them great joy and made their lives very enjoyable. This was similar to the category of *"family and children are the core center of life"* identified in Taiwan.(Table 3)

Table 3: Comments on their view of their life with comparisons between Taiwan and New Zealand

Reason	Seniors Taiwan	%	Seniors NZ	%
N comments /N respondents	**180/112**	**1.6**	**47/25**	**1.9**
Just do and follow the natural way	56	50.0	-	-
(got to accept what I got)	-	-	6	24
To give and take, a meaningful life	36	32.1	1	4
Family and children are the core center of life	27	24.1	-	-
(I've got a good life with good family)	-	-	13	52
Since I worked hard, life is now getting easier	26	23.2	7	28
Enjoy the rest of my time	13	11.6	-	-
(I have been enjoying my time)	-	-	18	72
Health is my only hope now	12	10.7	0	0

4. Discussion

I. Conflicts exit within the attitude toward death in Taiwan

According to the results of the interviews, seniors' views on the 'perfect

end-of-life' and their 'expectations of medicine when dying' were narrated as follows:

For the concepts of a perfect-end-of-life, one third of the seniors tended to believe in "enjoying the fullness of age," which means to die of natural death or aging, with no disease. For example, some common comments are: *"To die in bed of your old age...", "if only I can lie on my pillow I will be satisfied... It is sad to die in an accident or a violent death in a wrong age."* Or *"...better to die naturally of old age, without cause or reason."* The second most frequent idea was for a "quick death," and then "death during sleep, or when unconscious." Besides, one fifth said that they have never considered their death and commented *"it doesn't matter, any way you die"* or *"up to my fate, it is useless to think about it."*

When asked about their expectations of medicine when dying, most seniors (60%) stated that they have no expectations, stating reasons like, "*I am old enough, ready to return," "Life and death should be by nature...I would recognize life's pattern and flow with nature."* Or *"Good death should be without medicine."* One even said, *"Death has nothing to do with medicine..."* Twenty-eight percent said they wanted to make death quicker. Only one fourth of the comments were in the category of "try to rescue life till the last moment". There was 21% of people expressed that they do not try to consider death because they cannot imagine the situation.

However, when seniors say that they do not expect anything from medicine, this does not mean that they would not go to the hospital in their last moments. This consideration must be seen alongside the previous examples of seniors' statements, and may also explain the prevalence of intensive medicine used in the dying process of the elderly.

According to these comments about the perfect end-of-life, and expectations of medicine when dying, many elderly persons have disclosed that death is not always a bad thing. For example, an aged death is considered as bliss and a blessing, and only an immature death such as dying in an accident or in an inappropriate period of life is recognized as an ill omen which should be avoided absolutely. A perfect end-of-life should coordinate with the harmony of nature, in order to follow ones bliss. Also, due to the belief in fatalism, people may not wish to dominate their end-of-life by choosing what they want from a medical service. Many of them prefer not to consider it and just leave it to "what it should be" or to be decided by the young generation.

On the contrary, beyond these attitudes toward death, none of the interview subjects have left advance directives. Almost none of them would even talk to their children about their concerns. Instead, they preferred to believe that their children would act in their best interests at that time. More than that, they also have concerns about not putting their children in a situation of conflict by promising or thinking about their death. Therefore, a big conflict surrounding seniors' attitudes towards death is that the seniors' expectations of their end-of-life did not guide them to plan for their death.

II. Family value in Taiwan

Our findings from in-depth interviews have confirmed that the family-centered nature of seniors is a key part of their concept of life. Many seniors stated; "family and children are the core center of their life" when they response to the question "how do you see your life?" Confucian's ideas emphasize that the family is the original source of everything; these ideas were revealed clearly in the seniors group. For example, they had universal ideas that life is inherited from your parents and ancestors, and passed onto your children and offspring (Dreher, 2000). When a person is young, their effort is put towards rearing the young generation. In turn, the young generation is expected to provide for their elderly parents; this is a favorable situation that most expect as their final target in life. Moreover, a worthy life is recognized as a good return from your children and the meaning of life can be achieved by an immortal life, which is continued by ones' descendents (Hsin et al. 2005).

In addition to all of the above, according to Confucian ethics of "gradation love," a natural tie of affection within the family is regarded as the most important relationship in Chinese society (Tsai 1999). Essentially, an incapacitated elderly will expect to receive a return of the full love they have given to their families. They expect their family to represent their best interests, as well as total loyalty and consideration from the young generation (Bowman et al. 2001). For seniors, this ultimate fortune of life is the so-called "reaching a status of bliss". These invulnerable concepts support seniors when they face the cruel reality of the decline of their physical and social status. We may suppose that in this culture, full social welfare or even generous medical pay can never replace the function of the family in living a fulfilled aged life. (Hsin et al. 2003).

III. "Customary Ritual" –use of high-tech medicine in elderly people's dying process

The concepts of filial piety and the inviolability of the body derived from Confucianism have made a deep impression on the Chinese cultural tradition, which has also influenced end-of-life attitudes that Western and Eastern scholars have mentioned on many occasions. For example; 1) Filial piety virtue is socially expected, and a person's long life implies that his family has filially taken care of him (Qiu, 1991). 2) Because of the "inviolability of the body," Confucian society has a negative bias against euthanasia, especially for the elderly (Doering, 2001). 3) In Taiwan, family paternalism plays an important part in medical decision-making in end of life issues (Tai, 2003). 4) And the virtue of loyalty to family may explain the prevalence of the family in medical decision-making (Veatch 2001).

With these rooted social norms, nowadays in Taiwan intensive medical service is often used as a "customary ritual" in end of life situations; this lets the young

generation "show" and "prove" that they care for the life of their elderly parents. Many people believe that their parents' life must be sustained at all efforts and costs. For fear of violating filial piety to the elderly, no-one would like to take the responsibility to stop the end-of-life medicine, even if it may be pointless and absolutely futile.

On the other hand, the result of the study indicated that the elder's original thoughts about death included a desire to enjoy their fullness of life as a perfect end-of-life, and to expect nothing from medicine when dying. Seniors also viewed a definite end (death) as a return to nature(回歸自然), and expressed that "life" should return to its source like "ten thousands things"(萬物各歸其根) (Jeng, 1999). Accordingly, the dying process of an aged senior should be treated as a natural event to "let be." However, these original ideas about death have been twisted by modern medicine, and nowadays high-tech deaths are very usual in hospitals. We may ask: Can a Confucian family-centered view be a burden to a family when making a decision about seniors in their end-of-life?

IV. A comparison with another culture (New Zealand)

Eastern people like to define their living style with the feature of family-centered thinking, while in the Western world; individualism and personal autonomy are much more valued. However, according to the interview data, 80-90% seniors of NZ seniors declared that family or children were the most important lives in addition to their own, and more than half expressed that they receive enjoyment of their life from their family or children (Hsin 2005). These NZ seniors desire independence, and do not want to impose upon their younger generation by expecting to be looked after; however, these seniors also treasured their family as their main concern. These ideas are demonstrated through their end-of-life thinking. For example one stated; *"Really, it's not for me. It's for what they* (family) *feel... I'm sorry but I can't help it but die. Their decision would be right for me... If I was so sick, I couldn't make my own decision, it doesn't matter to me...."* Or *"If I have to die ...I think a short illness and a peaceful death would be the best for my family"*

We may also consider Family values through seniors Life attitudes. In response to the question "how do you see your life" more than half of the seniors in the NZ group said that they appreciated having children and families, and expressed that their families brought them great joy and made their lives very enjoyable. However, instead of saying *"Family and children are the core center of life"* like the seniors in Taiwan, many seniors of New Zealand expressed, *"I've got a good life with a good family."* Additionally, a very high percentage of New Zealanders concluded their life as *"I have been enjoying my life"*, while in Taiwan, people tended to say; *"I will enjoy the rest of my life."* Many Taiwanese seniors were satisfied with their present life by feeling life is easier now. According to the Taiwanese seniors' definition, their children's

achievements contribute to living an easier life. Compared to New Zealanders, seniors in Taiwan seem to rely on their family and children more to contribute to their future life.

V. Values other than autonomy in end-of-life decision-making

Autonomy is the foundation of human dignity; however it is not the only value important to the dying elderly. In non-Western cultures, individual autonomy is not always the first priority, instead "harmony" and "familial autonomy" are more pressing and practical ethics, and were discussed on many occasions during the interviews with Taiwanese seniors. Interestingly, these perspectives from Eastern views are sometimes underplayed in debates about end-of-life issues, as respect for autonomy is often given precedence in Western culture. This paper showed that debates cannot be overlooked, especially given the multi-cultural nature of societies like New Zealand.

As previously mentioned, traditionally seniors in Taiwan believe that to reach a status of bliss, one must have a strong binding relationship with family; the young generation must return the loyalty given to them when they were young, by representing their elder's best interests when they have become incapacitated. The authority of medical decisions then transfers to the next-of-kin, giving the old and frail satisfaction in having someone to make decisions for them (Bowman et al. 2001). Consequently, even if their children's decision does not match their will, fighting for the right to make their own decision is against the imperative of keeping harmony within the family. For a respected elderly, it is the ultimate honor to have the young generation stand up for your benefits, and make decisions for you (Hsin, 2003).

Similarly, in the non eastern culture of New Zealand, many seniors also expect their family to manage such decisions, and trust others to make decisions for them. For example, *"I do not think my family would put me down...and it would depend on my doctor to make the decision."* Most of them are not enthusiastic about leaving a written document like a "living will" to show their wishes about their end-of-life medicine. Even if some admitted to leaving advance directives, these directives were intended for use only in narrow circumstances. Thus, as a result, many of them would comment "my directives will be to follow what my family decides for me." Family values are obviously put in a higher position than making one's own choice; they are the mainstream values in elderly group, especially for their end-of-life issues.

VI. Factors to influence end-of-life decision making of elderly in New Zealand and Taiwan

According to the above, a brief conclusion of favorable factors that influence end-of-life decision making of the elderly in New Zealand include: the strong drive to live a worthy and qualified life; open attitudes when talking about their life and death; and the desire of senior people to consider their family's situation and have

deliberative ideas to show their affection to family in a dying event. Additionally, the medical system and family relationships will not reinforce or conflict with one another, and will therefore not force unnecessary treatments upon seniors or otherwise cause them to be treated in a wrong way when dying. However in Taiwan, there are many complicated factors which might influence elders' end-of-life decision making in adverse ways: strict social norms that children should be loyal to their parents in their final years, and rooted ideas about keeping family harmony and following the imperative propriety of 'hsiao' Additionally, there is the belief of fatalism, which prescribes that people should not dominate their end-of-life and just let it be "what it should be." Finally, the most practical matter in contemporary Taiwan is that the National Health Insurance system has created less conscious care recipients; the young generation would prefer to commit to the modern medical system, and leave their elder parents on high-tech life-sustaining therapies. However, there are also favorable factors in Taiwan that could be guided appropriately to improve a high quality death. For example, seniors' attitudes derived from Taoist thinking that death is just a return to nature(回歸自然) and a perfect end-of-life, may coordinate with the harmony of nature to follow one's bliss (Dreher, 2000).

As a result, compared to seniors in Taiwan, NZ seniors have less worry about their own death and seldom think that they will be put into a wrong situation when dying. This difference in attitudes may in general be attributed to the family doctor system or their independent and open attitude toward death. However, my concern is that different interpretations of family values is the other point which has made the end-of-life situation a clear margin to put respect wishes of each member.

4. Conclusion

When people are advanced in their age, values other than autonomy play a more important role in their lives, such as family harmony, or the so-called "reaching a status of bliss"(福氣) in Taiwan. This can be seen in both data from Taiwan and the non-Eastern culture of New Zealand. Thus, the function of family to make decisions for the end-of-life care of seniors should be respected in order to fulfill the elder's will of maintaining a "harmonious whole." However, family values derived from Confucianism should be interpreted in a modern light. For example, sharing affections among family and the propriety of death and dying should not cause strain to both generations. Finally, since most seniors in Taiwan can accept death and dying as a rest and a return to one's origin that is in keeping with seniors' Taoist thinking about human life, this may help to steady the idea of a natural death. Regardless whether the family, the seniors, or even the doctors decide what to do for end-of-life medicine, the priority of society must be to reach a consensus on seniors' death issues that is coordinate with seniors' ideas of a perfect end-of-life. And accordingly, medicine should set proper margins on when to stop. Furthermore, not only seniors, but every caregiver and the public should examine their own values about death and dying, and

reassess how much they can contribute to a qualified human dying process.

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