

Deciding for oneself: Good-Death Discourse in Taiwan

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1. Introduction

As Taiwan keeps moving towards an aging society, there has been increased attention to the issue of the quality of the end of life. As people increasingly spending their final days in hospital, the biomedicine gradually takes the main role of shaping the dying process, transforming the concept of death and dying. The “unnatural” prolongation of life by life sustaining treatment makes public concern whether patients are living or suffering. Questions have been raised about the adequacy of life sustaining treatment and how to have a “good death” in hospital.

Although medical professions dealt with the life and death issue, medical researchers have little analysis of what is good death. They are more interested in defining what is “Medical Futility”, which means providing treatment for patients even there is no hope or benefit for patients to cure (Schneiderman, Jecker & Jonsen 1990). Much of the available literature about good death are from psychology and nursing disciplines. Psychologists pay attention to emotional reaction toward death, dying and bereavement (Kübler-Ross 1969). Nursing research focuses on how to provide holistic care for dying patients. However, those discipline have not dealt with the cultural meaning of good death, and the social influence caused by the concepts. This study attempts to show how people narrate the good death stories, which help us understand the social organization of death and dying in the modern society.

The major objective of this study was to investigate how good death discourse was produced to govern social groups in Taiwan. Many sociologists have argued that “good death” could be an ideology or a discourse (Bury 1997, Hart, Saninbury & Short 1998, Tsai 2004). According to Foucault (1972), discourse is ways of constituting knowledge, social practice, forms of subjectivity and power relationship (p. 108). The good death discourse could legitimate a new form of social control and normalize behavior and choice (Hart, Saninbury & Short 1998). The good death discourse could form categories among good patients and bad patients. Sociologists need to critically inspect two dimensions: one is whose interest does the good death discourse serve, the other is how the good death discourse affect the dying people’s action. The study aims to contribute to the area of medicine and aging research by exploring how people interpret and implement the “good death”.

2. Method

The study uses narrative analysis in order to gain insights into values in the good death stories. Analyzing narratives helps us realize how people interpret good death, and what purpose are they serve to tell the story. Narrative shows actors’ intentions and goals

(Richardson 1990, Davis 2008). People use narratives to organize their experience into comprehensible episodes. Narratives are used for reasoning and representing the world. The data analyzed in this study include news from public media, books about medical insights written by doctors, booklets and media produced by Ministry of Health and Welfare, and information released by the social groups promoting hospice palliative care. These data were chosen because the material represents the viewpoint of public, medical profession toward the medicalized hospital death. This study explores how the narratives differentiate good death from bad death, constructing causal relations between medical events, and illustrating actors in the dying scene. The data were searched from 1990's till now. Because from 1990's there were emerging conversation of complaint about the problem of death, especially the medicalized hospital death.

3.Finding

Narratives contains a wide range of components which may be used to analyze, according to the characteristic of particular discourse. This study focuses on the dimensions of narrative to investigate the discourse: characters, setting, events, narrator, audience, causal relations.

3-1. Characters

The cast of characters includes four dominant roles, including medical profession, patients, family members, along with medical technology and treatment. In the different version of narrative, the characters may cast hero, helper, or villain. Usually we are familiar with a kind of story that doctors play as life-saving hero. Doctors resuscitate the dying patient with the help of medical treatment and life support. This kind of heroic intervention story commonly end happily with grateful patient, pleased family, accomplished doctor, and helpful medical technology. Even if the doctor fails to save patient's life, most of actors would think at least they have tried their best. Without regret among the family and medical profession accord to a certain kind of good death.

However, in some cases, medical professions may be blamed as villain, who hindered patients' good death attainment. When medical professions aggressively intervene patients, some people deem there is more suffer rather than benefit. Those blames depict medical profession as saving life not for altruism but for self-interests. Self-interest divides into two dimensions: economic interest and death denial norm. On one hand, some people supposed doctors prolong incurable patient's life for case payment from National Health Insurance. On the other hand, in the death denial norm, death is not a natural event but a failure of medicine. Some doctors feel they are incompetent if they cannot stave off death, so they use aggressive treatment until the patient passes away. Some aggressive treatments are labeled as futile medical care under certain circumstance, which obstruct the possibility of peaceful good death.

Technology and the hospital institution have been taken as the sources of distortion for our experience of death and dying. Life-saving takes the price. Almost all of the patients' orifice were stuck by ducts of medical machines, such as ventilator, hemodialysis machine, extracorporeal membrane oxygenation (ECMO). After using those life sustaining treatments,

patients' bodies became porous, impaired or being edema. When passing on, they are usually surrounded by the medical professions and machines instead of their loved ones and family.

In some narratives, family members may be a culprit of patients' bad death. On some cases, family members hold an unrealistic hope for curing patients. Even when the patient is critically ill and having unstable vital signs, a family member asks medical professions to keep on resuscitating till all the family member get together to seeing patient last time. And the medical decision made by the family member could be influenced by the norm of filial piety(孝道). In Confucian philosophy, filial piety means a norm that children respect and take care of their parents. Most of the people feel uneasy to give up the chance to save their parents, being afraid of scolded as against filial piety. On other cases, some family members do not let the patient die due to economic interest, as the patient has generous retirement pension. For example, in 2016 the Control Yuan investigated a domestic abuse regarding medical futility. An old principal was kept alive by a ventilator for eight years because his children wanted to have his retirement pension with 18 percent preferential savings rate. Besides the pension, the national health insurance is the other possible reason for self-interest. Some family members request doctors not to discharge from hospital too early, because the caring expense is much cheaper in hospital with subsidies than home nursing care.

Although the plotline is all about the patients, but they usually do not play the leading role in the narratives. On one hand, the patients lack of consciousness may not have chance to convey their thought. On the other hand, medical professions usually regard patients as totally dependent on their family and lacking a decision-making ability. These premises makes medical professions give priority to family members to make decision rather than patients. Some researches criticized this kind of circumstance as family patriarchy (Lei 2015), family depriving the right of patients and silencing them.

3-2. Setting, events, and causal relations

Narratives happen on a specific time and space and consists of a sequence of events. The events follow a temporal sequence from the beginning to the ending. People make sense of those sequences as causal relations.

In a medicalized hospital death, setting is on the diagnosis and treatment site. Events occur in a plot containing four major elements: symptomatic, diagnosis, decision of treatment, and dying and passing away. A narrative begins with the patient's symptomatic description, explains why the patient is hospitalized. Then the doctors give diagnosis suggestion about the illness, evaluating whether the patient is curable or incurable. After realizing the symptom and diagnosis, the patients and family members need to decide the preferable treatment, whether palliative care or prolong life treatment. The choice of treatment influences the patient's end of life.

Traditionally, Taiwanese ideal model of death is "die of old age in their sleep"(壽終正寢). The scene describes the elderly lying in home, accompanied by family members and loved ones. This kind of death is deemed decent and culturally appropriate. People who have good death are regarded as having good fortune and God's blessing. On the contrary, there

also have “bad death” in the cultural categories. The traits of bad death might entail some circumstance such as dying alone, death with impaired body, and death from unnecessary suffering and prolonged pain. Comparing the attributes of bad death helps us realize consensus on what constitutes a good death.

Peaceful good death is preferable for most of people. However, as the death and dying becomes highly medicalized, it is getting difficult to attain the ideal model of good death. The medicalized hospital death emerges as a new kind of social problem. According to the famous medical sociologist Conrad (1992)’s definition, the medicalization describes the process that the non-medical issue is defined by the medical discipline by degrees. The key aspect of medicalization is a definitional issue. Experts use medical language to describe the problem, probe it through medical prospects, or use the medical treatment to intervene. The sociologist's concern is about unintended consequences of medicalization, like the diffusion of medical profession’s jurisdiction and the power of social control. Because the biomedicine almost holds the responsibility for death and dying, the degree of death of medicalization is relatively high. Most people are no longer dying in the community-centered and religious way, but relying on the medical profession. According to the Ministry of the Interior’s census in 2016, above half of the Taiwanese have their final days in hospital. Some of terminally ill patients undergo aggressive treatment and are kept alive against their wish. The treatment may cause patients suffering. People thought that is suffering and lack of dignity, preventing patients from having good death.

Public media illustrate the plotline of having bad death due to lack of consensus among patients, family members and medical professions. In some cases, family members felt regret that they didn’t know how the patient’s suffering advanced. In a common scenario, doctors suggest using ventilators to help the patient breath and keep on treating. The patients and family members agree to put on a ventilator or other life supports. However, when the patient and family members want to quit the life support, they find that it is more difficult to withdraw than withhold the treatment. The family members usually express if they had known the treatment is so painful and cannot benefit the patient, they would not have consented the treatment.

The booklet published by Hospice Foundation of Taiwan (2013) shows some elements of good death, like making the Advance Care Plan ahead. It contains some typical stories as example. It shows a patient Mr. Wang being unconscious due to the stroke, and his son and daughter disputing whether to treat him aggressively or care him in palliative way. The booklet comments that “If Mr. Wang have discussed the advance directive with his family members beforehand, that chaos would not happen, and Mr. Wang would have fulfilled his wish to have good care in his end of life”. Besides the booklets, the News headings present strong images that patients’ autonomy benefits good death. The reporters used some metaphors to stress the relationship between patients’ autonomy and good death, like “Deciding for yourself”, “Booking the tickets toward good death”, “Be your own boss in your life”. Those metaphors emphasize the importance of patients’ autonomy and advance directive and underline the causal relations that advance directive helps people have great chance to have good death.

3-3. Theme, narrator and audience

There are two themes under the good death discourse. The first major theme is that everyone is at risk for not having good death. The good-death narratives present everyone is under the risk of dying in an unwanted way. The risk of medicalized hospital death could be a kind of discourse. From Foucault's governmentality perspective, risk discourse encourages individuals to engage self-regulation (Lupton 2005). It promotes individuals to engage risk-avoiding practices and be "good citizens". In the good death discourse, the good patients make advance directive as risk-avoiding practices, conveying their end-of-life wish in advance so as not to confuse family members and medical professions. The second major theme is one of choice. A good death is no longer by nature process, by chance, by one's fortune, or following God's will. To achieve a good death one needs to plan ahead and decide for themselves. The narratives presume patients could prevent the bad death if they activate their autonomy and make advanced directives. In this situation, the natural has been replaced by the right and obligation to choose (Kaufman 2005). Everyone is presumed to being responsible for their own good death.

The public, medical professions and legislations are dynamically shaping the good death discourse. After passing a proposal of bill, Taiwan government inaugurated the Hospice Palliative Care Act in 2000 and Patient Right to Autonomy act in 2015. The legislations enable patients to make an advance directive, which is a legal document that represents the patients' will, like choosing whether they want to have life sustaining therapy in the end of life. The advance directive includes some options about whether using CPR to resuscitate in the critical moment, as known as Do Not Resuscitate (DNR), and under what circumstance they would withdraw or withhold the life sustaining treatment. If the patients are incapable to make decision by themselves due to the illness, others could follow the patients' will according to the advance directive.

The patient right of autonomy was becoming a key concept in the end-of-life decision making in Taiwan after the Hospice Palliative Care Act passed the Legislative Yuan in 2000. The concept of autonomy originated from the Patient Self Determination Act in the US, which secured patients a right to decide whether to withhold or withdraw life-sustaining treatments in advance. However, in Taiwan, the concept of autonomy has a dynamic relationship with the family. Because the right of end-of-life decision making is owned not only by the patient but also the relatives. Most studies in the field of medics and law, through an individualistic view, rather have mainly focused on the definition of autonomy and seldom dealt with the meaning of autonomy in the social interaction.

The default audience of good death narrative is mainly the public. The government makes health education about patients' autonomy to inform the public about the importance of advance care plan and advance directive.

4. Conclusion

This study aims to investigate how good death discourse is produced to govern social groups in Taiwan. The study found that the good death narratives are produced in the context of promoting Hospice palliative care and Patient autonomy policy. Hence the good death narratives stress the causal relationships that patient autonomy and advanced directive secures the patient's good death. And the themes of risk and choice are emphasized in the

narratives. The main characters in narratives include medical professions, patients, family members, along with medical technology and treatment. In a different version of narrative, the characters may cast hero, helper, or villain. The good death discourse has some unintended consequences such as categorizing the good death and bad death, overestimating the effectiveness of patient autonomy and advanced directives. The good death discourse could legitimate a new form of social control and normalize behaviors and choices. The good death narrative constructs a simple correlation between good death and patient autonomy, but fail to show the complexities of lay-profession relationships, social institutions and bureaucratic practice. The study intends to remind that the correlation between good death and patient autonomy is not purely linear, since it involves more complicated relationships among medical institution and social interaction. A further study is recommended with more focus on how the good death discourse constrains or increases the dying people's choice. Realizing the good death discourse helps us discern the social classification about the culturally appropriate death and the unwanted death.

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