Short Paper

A Concept Analysis of Quality of Dying and Death (QODD) for Non-cancer Patients: From the Perspective of Palliative Care

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ABSTRACT

Palliative care has the potential to play significant role in better quality of dying and death for non-cancer patients. The purpose of this review is to determine the definition of quality of dying and death for non-cancer patients. MEDLINE (1990-2015) and Google Scholar (1999-2015) were searched using keyword terms 'quality of dying or death', 'good or bad death'. In the 13 definitions of QODD, the most common terms are related to patient's decision-making. The most common second terms are related to medical and social support. Final terms are related to psychological support. In order for the social and psychological aspects of death awareness and acceptance to take place, the dying person's suffering should be reduced and they must be relieved of pain. Furthermore, it is rapidly increased percentages of non-cancer patients among those utilising specialist palliative care services in the countries at the top of the quality of death ranking such as United Kingdom and the United States. Unlike cancer disease, non-cancer diseases need to longitudinal supportive system. Palliative care will be effective intervention to manage symptoms of non-cancer patients and treat intercurrent medical condition is appropriate. In conclusion, QODD should be combined of psychological, medical and social support as external role and their patient's decision-making as internal role in palliative care research.

＜Key-words＞
Quality of dying and death, non-cancer patients, palliative care, end of life, quality of life

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Ⅰ. Introduction

The life expectancy has increased rapidly since the onset of industrialization and modernization. The physical health and mental health have also spotlighted with the frequent uses of the terms of the quality of life (QOL) and well-being (Kohara, Han, Tanaka, et al., 2013). In contrast, death may still be so far from daily experience that its possibility may be denied or come as a surprise. Medicine is also charged with promoting the view that death is a failure, rather than something normal that may be put off but that will happen eventually (WHO, 2004).

A taxonomy of QOL for dying persons defined quality of life for patients and for loved ones at the end of life (Stewart, Teno, Patrick, et al., 1999). This framework also included a separate domain labeled the quality of dying, defined as a personal evaluation of the dying experience as a whole, including a subjective evaluation of concepts according to expectations and values (Patrick, Engelberg & Curtis, 2001). Therefore, the quality of dying and death (QODD) pertains to the period leading up to death, although there is ambiguity about when the transition to the dying phase occurs (WHO, 2004). QODD closely related to field of palliative care. Palliative care tends to focus on symptom management and relief, but that patients primarily value communication at the end of life (Trotta, 2007).

Palliative care has been historically developed with the focus on cancer. However, recent rapid global ageing and changes in disease prevalence, which are particularly evident in developed countries, have brought renewed attention to palliative care for chronic non-cancer diseases (Oishi & Murtagh, 2014). Functional status declined at different time point in Cancer and non-cancer diseases. Most patients with malignancies status usually declined quite rapidly in functional status when they get closer to death. However, non-cancer diseases like end stage heart disease, end stage lung disease, and dementia the patient's functional status gradually declined compared to terminal cancer patients. Non-cancer diseases have to supported services at home, like Meals on Wheels and home health aides, then institutional long-term care facilities are central to good care for these patients (Lynn & Adamson, 2003). Palliative care services may change over time in patients with cancer and non-cancer diseases, and also different set of goals in care (van der Steen, Tadbruch, Hertogh, et al., 2014). For example, palliative care has three goals to different stages of dementia, prolongation of life may remain a priority in patients with mild dementia, maintenance of function in moderate dementia and maximization of comfort in severe dementia (EAPC, 2013). Palliative care integrates the psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until death (WHO, 2004). Many researchers have defined the QODD in the field of palliative care, but these definitions are similar and subjective, and not explained separately for patients with cancer or non-cancer (Hales, Zimmermann & Rodin, 2010).

Therefore, the purpose of this paper is to review definitions of the QODD and to summarize the definition of QODD for patients with non-cancer diseases.

Ⅱ. Methods

1. Literature sampling

We searched published studies that reported on the development, validation of measures the QODD. We also searched reviewed reports on palliative care in patients with non-cancer diseases.

Papers were obtained from searches of MEDLINE (1999-2015) and Google Scholar (1999-2015) using the keyword search terms 'quality of dying', 'quality of death', 'good death' and 'bad death'. In the second part, the keywords were 'palliative care' 'end-of-life care', 'review' and 'non-cancer'. All databases were restricted to those published in English between January 1990 and September 2015.

20 articles identified for study selection. Exclusion of 7 studies that did not explained about definition of QODD. A total of 13 papers met the inclusion criteria.

2. Inclusion criteria

Studies were included in this review if they met the following criteria: (1) review or clinical report that measured QODD in patients with non-cancer disease, (2) also indicated about definition of QODD.

3. Exclusion criteria

Studies were excluded if they were (1) unpublished studies, abstracts or dissertations, (2) studies without measured QODD, (3) not written in English language, letters, editorials, and case reports.

4. Dementia and heart failure in non-cancer diseases

The quality of life of patients with severe dementia or heart failure (HF) is frequently poor, and many deaths in hospital, even among non-cancer patients who have received long-term community-based care (Formiga, Espel, Chivite, et al., 2002; Formiga, Olmedo, Lopez, et al., 2004). We selected these chronic diseases as most common non-cancer disease.

Ⅲ. Findings

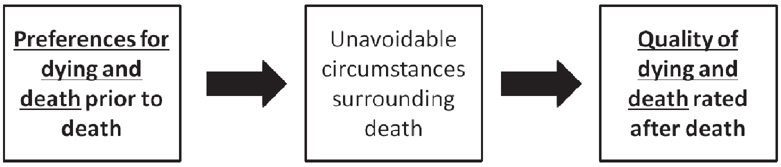
1. The definitions of QODD

In the 13 definitions of QODD, the most common terms are related to patient's decision-making. Patient's decision-making is included 'maximizing the autonomy of the patient's wish', 'sanctity of life', 'dignity', 'personal growth and acceptance', 'a person's preference for dying', 'patients' and families' wish', 'patients' wants and needs are met', 'individual's own strategies', and 'needs of the dying'. The most common second terms are related to medical and social support. Medical support is included 'culture, type and stage of disease', 'minimizing pain and suffering', 'physical comfort', 'appropriate medical care', and 'avoidable distress and suffering for patients, families, and their caregivers'. Social support is included 'social support', 'the moment of death agree with observations of how the person actually died as reported by others', 'cultural and ethical standards', 'social recognition of patient's decision-making', and 'broader social orders'. Final terms are related to psychological support. Psychological support is included 'peaceful', 'minimize psychological distress for dying and their families', 'spiritual exploration', 'life review', and 'the opportunity to mend relationships and say good-byes'.

<Table 1> The definitions of QODD

	Paper authors	Definition
1	Hales, Zimmermann & Rodin, 2008	The quality of dying and death in subjectively determined with numerous factors that influence its judgement, including culture, type and stage of disease, and social and professional role in the dying experience. Quality of dying and death is broader in scope than either quality of life at the end of life or quality of care at the end of life, although there is overlap among these constructs.
2	Sears, Sowell, Kuhl, et al., 2006	The notion of quality of death implies a health outcome minimizing pain and suffering, maximizing the autonomy of the patient's wishes, and respecting the sanctity of life.
3	Ethunandan, Rennie, Hoffman, et al., 2005	A good death is one that is pain free, peaceful, dignified, at a place of choosing with relatives present and without futile heroic interventions.
4	Tsai, Wu, Chiu, et al., 2005	A good death is one in which a patient's suffering is reduced as much as possible and death is accompanied by dignity; includes awareness, acceptance, arranging will, and appropriate timing of death.
5	Carr, 2003	A good death is characterized by physical comfort, social support, acceptance, and appropriate medical care, and it should minimize psychological distress for dying and their families.
6	Long, 2003	A gradual process that allows time for personal growth and acceptance, spiritual exploration, life review, and the opportunity to mend relationships and say good-byes.
7	Jones & Willis, 2003	Pain free, dignified, and one in which active resuscitation never occurs.
8	Curtis, Patrick, Engelberg, et al., 2002	Quality of dying and death is the degree to which a person's preferences for dying and the moment of death are consistent with other's observation of how that person actually died.
9	Bridge, Roughton, Lewis, et al., 2002	Quality of death is quality of life of the client in the last 2 days alive.
10	Patrick, Engelberg & Curtis, 2001	The degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died as reported by others.
11	Wenger & Resenfeld, 2001)	A death that is free from avoidable distress and suffering for patients, families, and their caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.
12	Mak & Clinton, 1999	Good death as "one in which patients' wants and needs are met".
13	Kearl, 1996	Dying well involves both the individual's own strategies and the social recognition of their attempts. Deaths become good "when they serve not only the needs of the dying but also those of the survivors and of the broader social orders as well".

According to Patrick et al.(Patrick, Engelberg & Curtis, 2001), QODD experience and indicates that preferences are moderated by the unavoidable circumstances surrounding death (Figure 1). Although the timing for measurement is not contained in the model shown in Figure 1, preferences of persons who are dying by definition must be assessed prior to death and the reports and ratings of the QODD obtained from others after death.

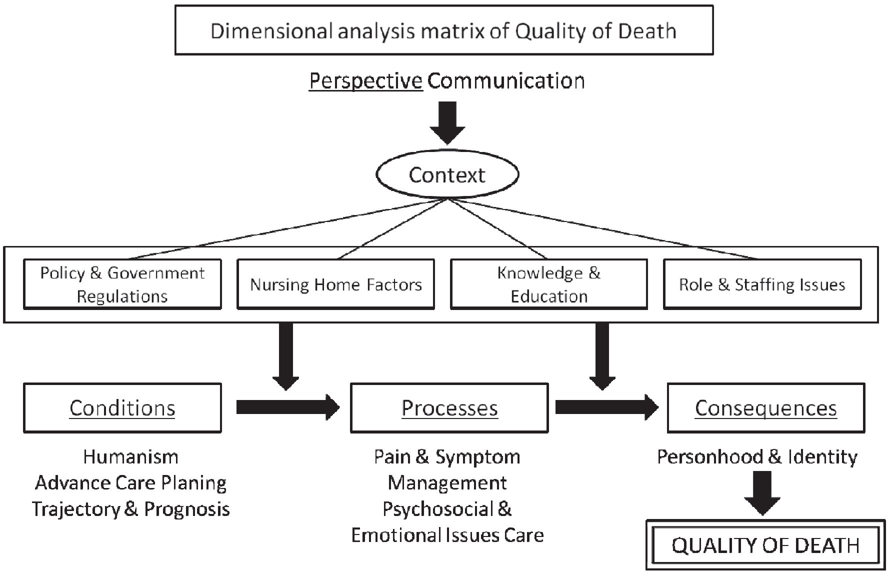


<Figure 1> Conceptual model for measuring QODD

2. The relationship between QODD and palliative care

In order for the social and psychological aspects of death awareness and acceptance to take place, the dying person’s suffering should be reduced and they must be relieved of pain (Weisman, 1978). As the hospice movement developed from its inception in 1967 (Stoddard S, 1978), the good death philosophy has expanded to incorporate notions of control on the part of the person who is dying (Logue, 1994). The practice of palliative care has grown from the original hospice movement. In the Australia, Like the hospice movement, palliative care continues to serve, to some extent, as a symbolic critique of how dying people are managed in highly medicalised settings (Siebold, 1992).

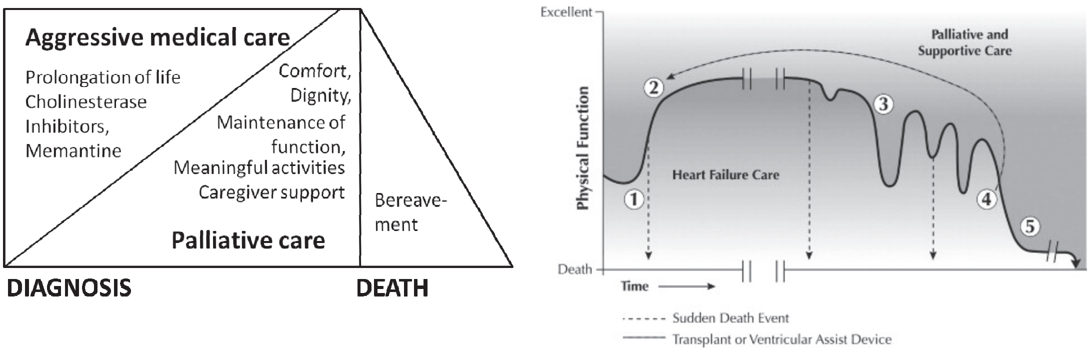
WHO defined palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2013). According to Trotta et al. (Trotta, 2007), quality of death is the explanatory matrix for palliative care in the nursing home generated by this dimensional analysis (Figure 2). Quality of death depicts a complex social phenomenon situated within an overarching perspective of communication. Several contextual elements are both barriers and facilitators to palliative care, and have a direct impact on conditions, processes, and consequences. As shown in the figure 2, the ultimate consequence of palliative care in the nursing home is quality of death.



<Figure 2> Dimensional analysis matrix of quality of death

3. Palliative care for patients with non-cancer diseases

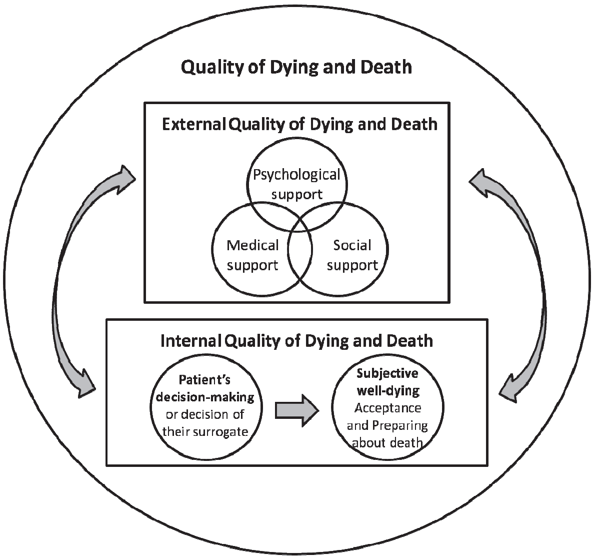
There are increasing percentages of non-cancer patients among those utilising specialist palliative care services in the United Kingdom and the United States(the national council for palliative care, 2013; NHPCO, 2014). Clinicians will be faced with Alzheimer's disease (AD) patients, who will require a special approach to care both from psychosocial and medical aspects in all stages of their dementia for the indefinite future. In an absence of curative strategies, palliative care that is attempting to improve symptoms of these AD patients and treat intercurrent medical condition is appropriate. However, aggressive care and palliative care are not mutually exclusive and both can be provided at the same time. Aggressive care may be more important in the earlier stages of the AD, while palliative care may predominate in later stages (Figure 3: Left) (Volicer & Simard, 2015). It is also palliative or supportive care need to manage and cope with heart failure (HF) should be provided concurrently with evidence-based disease-modifying interventions in comprehensive HF care (Figure 3: Right) (Goodlin, 2009).



<Figure 3> Types of care in dementia(Left) and HF(Right)

Ⅳ. Considerations and Conclusions

In our literature review, QODD might have consisted of external QODD and internal QODD. As shown in figure 4, External QODD is a criterion or measurement for better QODD from outside networks. It contained three overlapping circles which means the three support; psychological, medical and social support. In the other hand, internal QODD is own authority from yourself. We found the patient's decision-making was the majority of terms in definitions of QODD. The patient's decision-making may lead to subjective well-dying. Advanced dementia patients are possible to difficult in decision on your own due to severe cognitive impairment. Instead of patients, their surrogate makes a decision. There is a complementary relationship between external QODD and internal QODD (Figure 4). Therefore, QODD implies the result which is constantly complement between psychological, medical and social support, and patient's decision-making.



<Figure 4> the definition of QODD for non-cancer patients

According to Hattori et al., the antecedents of good death are broad. They include the holistic nature of the dying person and the family in the past and present, and for future preparations. In addition, the quality of health care contributes to the quality of death. Articles in anthropology and social sciences had greater focus on cultural differences in perceptions of good death than did those in medicine and nursing (Hattori, McCubbin & Ishida, 2006).

Individuals with advanced dementia cannot make decisions about their end-of-life care and, their decisions have to be made by their surrogates. The decisions either can be made on the basis of the patient's previous wishes, or, when these wishes are not known, on the basis of the patient's best interest as perceived by the surrogate. The patient's wishes could be made formal by a living will that was completed before the patient acquired dementia or may be in the form of verbal communication expressing patient's philosophy regarding end-of-life care (Volocer, 2005). Advanced HF should provoke a re-evaluation of medications, dietary sodium consumption, and interventions that might improve the patient's status (Hauptman & Havranek, 2005). At a shift in focus of care, such as the end of life, clinicians ought to re-evaluate all treatments relative to the goals of care, and discontinue therapies that are burdensome or that do not provide symptomatic relief. Because medications and treatments that address the neurohormonal and sympathetic disarray in HF improve symptoms, these should be continued to the extent that blood pressure and function tolerate (Goodlin, 2009). Little is known about the consequences of good death. Researchers have not fully explored the family bereavement or rituals for family and health care professionals after a person died (Hattori, McCubbin & Ishida, 2006).

In the other hand, there are some studies including the need for a commonly accepted definition of spirituality, the appropriate application of spiritual care in palliative care settings, clarification about who should deliver spiritual care, the role of health care providers in spiritual care, and ways to increase scientific rigor surrounding spirituality and spiritual care research and practice (Burgener, 1999; Cohen, Mount, Strobel, et al., 1995; Tsevat, Sherman, McElwee, et al., 1999). According to Puchalski et al., Patients should be encouraged and supported in the expression of their spiritual needs and beliefs as they desire and this should be integrated into the treatment or care plan and reassessed periodically. Written material regarding spiritual care, including a description of the role of chaplains should be made available to patients and families. Family and patient requests specifically related to desired rituals at any point in their care and particularly at the time of death should be honored (Puchalski, Ferrell, Virani, et al., 2009). Spiritual care may be possible as one of the dimension improving external QODD.

In conclusion, QODD should be combined of psychological, medical and social support as external role and their patient's decision-making as internal role in palliative care research. These roles complement each other. Given this knowledge, future research would be able to refer on measuring QODD for non-cancer patients.

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