PROMOTING A GOOD DEATH: AN AGENDA FOR OUTCOMES RESEARCH – A REVIEW OF THE LITERATURE

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Outcomes research is topical in discussions about health-related research. Its emphasis on effectiveness creates an important opportunity for nurse researchers to strengthen the linkages between theory, outcomes research and nursing practice but, before care can be more effective, it is logical to establish patients' desired outcomes. A thorough review of the implications of this requirement for the care of hospice patients is needed, but is lacking in the literature. Therefore, the literature on a 'good death' is reviewed as a step towards assisting hospice patients to achieve what they regard as an acceptable death. The starting point is to define more clearly what it means to die a good death. The relationship between hospice care and achieving a good death is then examined.

Introduction

The death awareness movement has been active in the West since 1967. However, few studies have clarified what it means to die a 'good death' and death itself remains a mysterious and taboo subject in many societies, including the Chinese community of Hong Kong. This is hardly surprising because it is, after all, only recently that researchers have shown an interest in describing the attributes of a good death, and there is always a delay before the concepts investigated by social scientists find their way into everyday nursing practice.

Therefore, regardless of cultural background, people come to death with a variety of beliefs, attitudes, superstitions, fears and hopes.[1] Furthermore, most studies of dying present a negative and dismal picture of the process.[2–4] Certainly, it is only recently that researchers have shown an increasing, although insufficient, interest in describing the elements of a good death,[5–11] and that dying people themselves have been encouraged to influence the process. However, the literature emphasizes the need to understand the elements of a good death from the perspective of the patient in order that appropriate care can be delivered to meet highly individual and complex needs.

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As long as there has been language and people have expressed grief, death has been accepted as a universal phenomenon and, in this sense at least, as something not to be feared,[12] but with the renaissance came a sense of individuality, marked by intense personal insecurity about death. This personal identification with death led to notions of what it means to die well, which could be inferred from what people said about the death of others and from what they thought about how they wanted to die when their time came. More explicit notions of what it means to die a good death have arisen from the work of sociologists, anthropologists and psychologists.[13] For example, it is well known that Glaser and Strauss[14–16] studied the behaviour of dying patients and developed ideas about levels of awareness of impending death and about dying trajectories more generally. Although Glaser and Strauss were careful not to privilege one form of dying trajectory over others, many health professionals have assumed it is better to die in full awareness that one is dying, rather than to die in a context in which impending death is not openly acknowledged. Similarly, the theory of death and dying developed by Kübler-Ross[17] has become widely accepted among members of the health professions, and is still valued despite the fact that Kübler-Ross herself has become in later life a poor role model for her former ideas. Despite her own problems in accepting her current disabilities, there is still popular acceptance of what Kübler-Ross described as the 'stage of acceptance', and such 'acceptance' has become regarded as a key element in dying a good death, at least in the West. Weisman[18] has further encouraged belief in the possibility of a good death, with notions of a very good or an appropriate death. More recently, Kellehear[8] has pointed out that, despite its development and influence on health professionals, the concept of a good death is inadequately defined. At the same time, there is little doubt that the work that has been done on death and dying has largely ignored social and cultural responses to dying,[13] and insufficient attention has been given in Hong Kong to the possibility that ideas about a good death may be different in Chinese communities to those known from studies of death and dying in the West.

Outcomes research and good death

Outcomes research has become a topic of discussion in health-related research. As outcome studies are often patient driven, the emphasis on patient care creates an important opportunity for nurse researchers to strengthen the linkages between theory and nursing practice. One important aim of nursing intervention relates specifically to caring for hospice patients. However, evidence of the effectiveness of nursing interventions aimed at helping hospice patients to attain the death they desire is scarce. One of the reasons is that patients' desired outcomes are seldom identified. Therefore, it is logical to believe that nurses need more information about their patients' desires before they can help them to achieve the death they prefer. However, there is little to draw on in pursuing this ideal owing to the limitations and perspectives of existing research, and to the lack of a systematic review of what can be inferred about a good death from the literature that is available.

Hospice care

If the literature on death and dying is unclear on what it means to die a good death, perhaps scrutiny of the hospice movement can throw some light on what it means to die well.

The introduction and development of hospice care has grown contemporaneously with the literature on death and dying, and has provided care for the dying since its inception in 1967. As hospice services have grown in England,[19] North America[20] and Australia,[21] and have been introduced in Hong Kong,[22] one essential goal of hospice work has become to facilitate patients to achieve a good death.[23] Although it may be an impossible ideal, a euphemism, or even a misnomer, the success of any hospice programme depends ultimately on how effectively staff can competently promote what patients regard as a good death. Put at its simplest, the death awareness movement, which has been active since 1967,[24] expects that hospices will provide patients with the conditions for dying as comfortably as possible. However, 'without adequate pain relief, quiescence of nausea, and other debilitating symptoms the remaining quality of life is drastically damaged, and an appropriate death rendered impossible.'[25]

As the influence of the hospice movement has grown, expectations reflecting the wish to have a good death have become more common in both western[10] and eastern cultures. However, few studies have been able to operationalize the meaning of a good death and it is only recently that researchers have shown interest in describing its characteristics.[7–10] Systematic research designed to explain the essential components of a good death in eastern societies is particularly lacking. In the West, such studies as there have been tend to reflect the ideas and constructs of nurses and the ways in which they impact on ethical decisions in the workplace.[26] Therefore, what is known about a good death is largely known from the perspective of the nurse.[5,6,9,11,13,26] However, according to transpersonal caring concepts such as those promoted by Watson,[27] nurses need to enter more purposefully into the phenomenal field of patients and to provide care on a basis that has been negotiated. Consequently, more researchers should enter into 'a dialogue and dialectical engagement with these realities in such a way that both the observer and the observed enjoy the status of co-creators in a human project characterised by its innovation and unpredictability' (Moccia, p. 8).[28] Moreover, Shneidman[1] also highlights the need to learn from patients because one cannot help being moved by the great human spirit in the voices of these dying persons.

Good death

In western culture, a good death has been variously defined. The simplest definition is one in which patients' wants and needs are met.[9] Other descriptive terms and labels have also been proposed. For example, Blauner,[29] Hinton,[30] Shneidman[31] and Weisman[18,25] have used the concept, 'appropriate death'; others have used the term ' healthy death',[32] 'correct death',[33] 'happy death',[34] or 'peaceful death',[35] while the use of the term 'good death' has continued.[5,8,26,36–39] It is more difficult to find reference to these concepts in Chinese literature.

Nevertheless, there is a common Chinese saying to the effect that 'a good birth is not as good as a good death'. Despite the variation in adjectives, all these phrases point to a common possibility, that it is possible to die in a way that is consistent with one's principles. However, it is important to identify what this means and some possibilities will be considered.

An alternative for euthanasia?

Some nurses assert that the wishes of patients and their relatives are not adequately considered in the terminal stages of illness, or when hospice patients wish to die because of their physical state. Furthermore, the degree to which nurses believe they can influence the clinical decisions taken in these circumstances varies among institutions.[6] Such matters are made even more difficult for nurses because there is no consensus on euthanasia. From such confusion, Davis and Slater[5] conclude that nurses' deep concerns about patients' wishes are not always respected. Therefore, the term, good death can be taken by some people to mean 'euthanasia', including by some hospice patients, some relatives and some nurses.[5,6,40,41] However, Kellehear[8] holds that the concept of a good death has little to do with the theory and philosophy of euthanasia. He explains that this term is often too broadly translated from its Greek sources to mean dying well rather than assisting a patient to die painlessly and more quickly. If Kellehear's etymology is accepted, the terms 'good death' and 'euthanasia' are not equivalent, although euthanasia in its narrower sense could still be argued to be an element in some good deaths.

Elements of a good death

Rather than relating to an assisted and timely death, a good death may be viewed as involving a more complex set of relations and preparations. In this view, a good death does not occur as a single act, but as a series of social events.[13] Furthermore, from the perspective of hospice staff, a death may be perceived as 'good' if it goes well overall.[11] What then does the literature imply are the characteristics of this broader concept of a good death? Arguably, there are seven elements that can be identified, each of which will be examined briefly.

Comfort or relief from pain and suffering

One of the most commonly cited elements of a good death is freedom from pain.[18,25,39,42,43] To elaborate, the state of freedom from pain, which accounts in part for the confusion between a good death and euthanasia, emphasizes that the sufferings of the patient should be reduced, and his or her emotional impoverishment should be kept to a minimum.[18,25] From this perspective, it is also important that troublesome and debilitating symptoms should be controlled to enable a good death to be achieved.

Therefore, nurses see a good death as one in which the patient is comfortable,[42] alert and pain free.[26] Hence, alertness must be considered in any notion of a good

death. The World Health Organization[39] connects the concepts of freedom from pain and alertness by stating that:

> one of the essential elements of a 'good death' is freedom from [the] pain that dominates consciousness and [which leaves] the patient physically and mentally capable of reaching whatever goals he or she may want to achieve before death (p. 52).

Left out of consideration is the concept of a 'natural death', of which there are two kinds: those that occur unexpectedly and are desirable because they are assumed to be free from fear and pain; and those in which medical intervention is kept to a minimum. Certainly some people actively reject the idea of medical intervention to prolong life. For them, a good death is one where the only medical intervention that takes place is that of pain relief, which highlights once again the importance of being free from pain and suffering.[44]

Openness or being aware of dying

Theories of awareness of dying stem from the seminal work of Glaser and Strauss.[14–16] These authors studied the behaviour of dying patients and those who cared for them, developed ideas that relate to the awareness or otherwise of impending death, and conceived of the process of dying as a social trajectory. Their work has led to the belief that a good death is a form of passage in which everyone involved is aware of and accepts the imminence of death, and in which the dying person has resolved socio-emotional and material concerns.[18] What authors seem to agree on is that having an awareness of dying is an essential step in achieving a good death[8,18,37] because acceptance of one's mortality is a prerequisite for one's final departure if one is to die with a sense of inner freedom and without narcissism.[37] It is in this sense that Metcalf and Hungtington[45] have pointed out that the death awareness movement has popularized the notion of openness as an element of a good death.

Completion or accepting the timing of one's death

There is another sense in which death is essentially 'good' only when it occurs 'on time'. 'To die at the right time in the right way – those are the hallmarks of a sterling death' (Shneidman, p. 29),[31] but when is the appropriate time to die?

A common view is that a timely death is one that occurs 'when a person has completed his span of life, his powers wane, and the eventual increasing decline suggests that it is time for the individual to depart this life' (Hinton, p. 43).[30] It is also widely believed that death is timely if it is appropriate to one's time of life.[31] Furthermore, beliefs about causes of death, places of death and the means of disposing of human remains are complementary to notions of a good death.[46]

Maslow[36] has described his personal feelings about a meaningful (timely) death after a serious heart attack that occurred soon after he had completed writing a book that was important to him:

> I had really spent myself. This was the best I could do, and here was not only a good time to die but I was even willing to die. This is what David Levy called the 'completion of the act'. It is like a good ending, a good close. I think actors and dramatists

> have that sense of the right moment for a good ending, with a phenomenological sense of good completion – that there is nothing more that you could add (p. 16).

Furthermore, as people approach death, they may possess a sense of readiness related to their style of life, to their situation in life, and to their mission (aspirations, goals, wishes) in life.[31]

Kearl[38] has pointed out that the time at which death normally occurs in the life span and how long it typically takes for people to die, shape both cultural beliefs about death and individual fears. Furthermore, he explains that the quality of the relationship between the dying person and the family is an important element in a good death because death is a dual process that simultaneously involves the dying and those they will leave behind.

Therefore, people usually refer to having a good death when they are about to die in old age and[30,38,46] when they have completed their life's tasks and all their unfinished business.[31,36,42] In dying a good death people recognize and resolve possible residual conflicts and satisfy whatever personal wishes remain.[18] The duration of the dying process is another important criterion,[38] reflecting the belief that death should occur at the proper time and be neither too abrupt nor unduly prolonged.

Patients have been reported to express that it is the right time to depart[30,31,36,38] and to die without despair, depression or suicidal ideas.[47] Some have claimed to feel good and noble, to have experienced meaningful lives, and to have embraced salvation.[31] Others have expressed the feeling of a good ending, of a willingness[36] and a readiness to die.[31] However, these feelings vary among people with different religious beliefs. For example, a Hindu may take a good death to be one that occurs when 'one has lived a long life marked by the fulfilment of the legitimate worldly goals of righteous actions, religious devotions, wealth, progeny (particularly sons), and good name (even fame) in a society' (Madan, p. 429).[48]

Control or acceptance and autonomy

Dying a good death is associated with a sense of acceptance[7,9,17] and of appreciation for having lived according to the best standards possible.[18,25,49] However, achieving a good death is a gradual process.[18] It begins when a patient becomes aware of impending death and accepts that nothing more can be done. Once it has been accepted that death will not be long in coming, the literature stresses that patients might need help to give meaning to their lives.[47] Therefore, a good death is one in which patients die accepting that they are at the end of their lives, but believing that their lives have had meaning.

These principles converge on the notion of control. Weisman[18] repeatedly stresses that the dying individual must not lose control. 'He should be able to yield control to others in whom he has confidence. He also has the option of seeking or relinquishing significant key people' (pp. 39–40). In other words, the notion of a good death involves mastery over the biological occurrence that is death[50] in an environment of emotional care and support that mitigates one's discomfort and isolation.[42] Implicit is the imperative for the person to retain a sense of control until the very end.[13,25,32,48,51,52] By choosing the time, place and means of body disposal,[46,48] the person extends their influence of control and autonomy even

beyond the moment of death. Respect for patients' autonomy and good communication among patients, families and health professionals complement these elements of a good death. Therefore, health professionals are exhorted to acknowledge patients' autonomy and to accommodate their wishes by allowing them more control over the dying trajectory by establishing a partnership in decision making.[53]

Optimism or keeping hope alive

The ways in which people live through their final days reflect their personal philosophy, maturity, and sense of self-realization.[31] People's need to have a sense of hope,[30] their desire to live, their sense of enjoyment of life, and their determination to keep mobile and to 'fight back' are all related to the sense of hope.[9] In the West, good deaths are those that demonstrate control over events and can be seen to equate to a kind of victory over nature. For people with a religious faith, their concepts of a good death appear to follow the more religiously orientated belief in hope of entry into heaven.[44]

However, not only dying persons but also their families and caregivers should have opportunities to experience self-worth, dignity and freedom of choice during the natural passage from life to death.[49] These elements play a crucial role in what might be regarded as a form of sharing in the present,[54] in which mutual emotional and social support sustains the hopes of dying persons and their families. It is the absence of what might be called such 'mutuality' that leads to hopelessness because the experience of supporting and being supported transforms the dread of abandonment and the terrors of isolation into hope.[25]

Readiness or preparing for departure

Smith and Maher[32] support Kellehear's belief in the importance of public preparations for death, noting that taking farewell of family, friends and staff is an essential element in the patient's quest to seek a final resolution. Weisman[18] also notes the importance of patients being able to resolve residual conflicts and to satisfy any of their remaining wishes. To achieve a good death, people complete their unfinished business and make personal and social preparations to ready themselves for their final moments.

Location or living with one's choice about where to die

People are responsible for the consequences of where they choose to die. Those who choose the hospice have a different set of challenges to those who choose to die at home, although neither route is easy, and there can be no one road to death. For the hospice patient, the nature of the setting and the experiences of fellow patients are relevant to achieving a good death. However, Samarel[9] has described how the perceptions of registered nurses determine how nurses interact with terminally ill hospice patients. His data reveal that it was the responsiveness of patients, rather than whether they were acutely or terminally ill, that determined the quality of the nurses' interactions. It follows that the preferences of nurses can

have a significant influence on quality of life in the final days of life, and therefore on the prospects of achieving a good death.

The importance of the place of death and of culture in a stronger sense is demonstrated by Madan,[48] who reports from his study of Hindu villagers (Pandits) that a good death is a 'great passing on', which does not just happen but is achieved if one can let go or renounce the 'life-breath' in full consciousness, at a time and place of one's choosing. With such things achieved, one dies in a state of dignity. In general, Pandits prefer to die at home, in the house in which they have lived, because they regard their house as a microcosm of the universe.

For McDonald and Carroll,[46] the hospice movement appears to provide a more acceptable option for dying patients than institutional settings. In their view, hospice services delivered in the home seem to be particularly suitable for supporting a person towards a good death.

However, Johnston and his colleagues,[55] report that, within a hospice, a positive experience of a fellow patient's death is typically helpful. They report that hospice patients who have witnessed a death are found to be significantly less depressed on standardized measures of emotional distress. On the other hand, witnessing a death is a key experience for all patients and needs to be worked through slowly and sensitively.

Conclusion

There have been a number of research studies looking at the perception of a good death from the points of view of health professionals such as nurses and hospice co-ordinators. Few, if any, have obtained data directly from patients themselves. Therefore, almost nothing is known about dying patients' preferences and no outcome measures using the concept of a good death are available to demonstrate the value of terminal care. As the beliefs of nurses and hospice co-ordinators may not be the same as those of patients, more research is required to ensure that the preferences of patients can be taken into account in the development of outcome measures for hospice care. Of equal importance is the need to identify cultural differences in perceptions of a good death, especially from the perspectives of members of eastern cultures. By such endeavours it may be possible to provide more culturally appropriate care to hospice patients (here in Hong Kong) and to demonstrate the importance of taking culture into account when designing methods for assessing health outcomes among those who are terminally ill. Meanwhile, the elements of a good death gleaned from the literature may be of use to hospice nurses and may assist in exploring hospice patients' concerns. They will at least provide a starting point from which to assess the quality of hospice care.

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