

# Understanding the concept of a “good death” among bereaved family caregivers of cancer patients in Singapore

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## ABSTRACT

*Objective:* The aim of this study was to examine the concept of a good death from the perspectives of both the dying person and the family caregiver, as perceived by bereaved family caregivers of advanced cancer patients.

*Method:* The data were gathered from five focus group discussions and one face-to-face qualitative interview conducted over 8 months among 18 bereaved family caregivers recruited from a local hospice. The transcripts of the focus groups and the interview were entered into NVivo Version 8 and were analyzed using the thematic approach.

*Results:* A good death may be understood as having the biopsychosocial and spiritual aspects of life handled well at the end of life. Five major themes were identified. These were preparation for death, family and social relationships, moments at or near death, comfort and physical care, and spiritual well-being. Differences were also noted in what is important at the end of life between the patients and caregivers. Having a quick death with little suffering was perceived to be good by the patient, but the family caregiver wanted to be able to say a final goodbye to the patient. Patients tend to prefer not to die in their children’s presence but the children wished to be present for the final moment. In addition, family caregivers reported it was important for them to be able to give the patients permission to die, to feel recognized for the efforts made, and to have had a fulfilling caregiving experience.

*Significance of results:* Whereas there are global attributes of a good death, our findings suggest that patients and family caregivers may define a good death differently. Therefore, there is a need to respect, address, and reconcile the differences, so that all parties may have a good experience at the end of a person’s life.

**KEYWORDS:** Good death, End-of-life care, Palliative care, Bereaved family caregivers, Multicultural society

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## INTRODUCTION

The concept of a good death is of fundamental importance in end-of-life care research. A primary goal of end-of-life care is the experience of a good death by the patient and the family. What exactly constitutes a good death? Some of the common themes emerging from existing studies include death during sleep and

a quick death (Hughes et al., 2008), maintaining dignity, maintaining pride (Hirai et al., 2006), being prepared (Steinhauser et al., 2000a), minimizing burden to others (Teno et al., 2001; Tong et al., 2003), pain and symptom control (Payne et al., 1996a; Steinhauser et al., 2000b; Patrick et al., 2001; Hughes et al., 2008; De Jong & Clarke, 2009), withholding unnecessary treatment for prolongation of life (Singer et al., 1999; Tong et al., 2003; Miyashita et al., 2008a), contribution to others (Steinhauser et al., 2000b) and spirituality (Tong et al., 2003). In one quantitative study conducted by Miyashita and colleagues (2008b), 10 core domains of a good death were identified. These were environmental comfort; life completion; dying in a favorite place; maintaining hope and pleasure, independence, and physical and psychological comfort; good relationship with medical staff; not being a burden to others; good relationship with family, and being respected as an individual. In another study, Carr (2003) reported a positive relationship between the quality of death and the surviving spouse's psychological adjustment. The painful death of a spouse and the perceived physician negligence were associated with increased anxiety and anger (Carr, 2003).

A review of current studies suggests that there is no shared understanding of what a good death is. Rather, it is subject to interpretation, depending upon the perspective and experience of a person (Kehl, 2006), and frequently influenced by culture. For example, in two studies conducted by Payne and colleagues (1996), the components of a good death identified by patients included dying in their sleep without pain, dying quietly with dignity, and dying suddenly (Payne et al., 1996a). A death was perceived to be good to the hospice staff if there was adequate symptom control, family involvement, peacefulness, and lack of distress (Payne et al., 1996b). In another study, Steinhauser et al. (2000a) reported that physicians tended to rely more on the biomedical-based perspective in how they conceptualize a good death, whereas other hospital staff (such as social workers, nurses, chaplains, and volunteers) tended to adopt a broader range of attributes.

This study was conducted with the aim of achieving two goals. The first was to look at the bereaved family caregivers' perception of what makes a good death for the patients and for the family caregivers, respectively. Most of the studies to define a good death, both qualitative and quantitative, have been conducted in developed nations outside of Asia (Payne et al., 1996a,b; Steinhauser et al., 2000a, 2000b; Patrick et al., 2001; Teno et al., 2001). In Asia, published studies were largely conducted in Japan (Hirai et al., 2006; Miyashita et al., 2007; Sanjo et al., 2007; Miyashita et al., 2008a; Murakawa & Ni-

hei, 2009) and Taiwan (Leung et al., 2009). Therefore, the second goal of the study is to examine further the concept of a good death in Asia. Because of the multi-ethnic population of Singapore, the concept of a good death may be different from other countries of Asia.

## METHOD

This study examined the experience of family caregivers who were living with and taking care of an advanced cancer patient during the last weeks of life. Ethics approval was obtained from the National University of Singapore Institutional Review Board and the SingHealth Centralised Institutional Review Board A.

### Recruitment Procedures and Informants

Potential informants were identified and recruited from a local hospice and a hospital palliative care service. They were invited to participate in the study if they were: (1) a family member who was the main decision maker and was most knowledgeable about the circumstances of the patient's death, and (2) bereaved between 6 and 18 months before the study began. A total of 25 informants, 23 from the hospice and two from the hospital service, were recruited successfully. Seven focus group discussions and one individual in-depth interview were conducted over the study period of 8 months.

Data from one focus group discussion which consisted of five informants was excluded for data analysis because the discussion was not captured by the audio-recorder due to a technical fault, and the notes taken were too brief, and therefore subject to various interpretations. Data from two informants who were recruited from the hospital service were also excluded because the deceased were non-cancer patients. Moreover, the data emerging from these two informants were different from those from the other 23 informants recruited from the hospice service, and they deserved further study and separate analysis from the one performed for this article. Therefore, a total of seven informants were excluded from data analysis, and only data obtained from the remaining 18 informants recruited from the hospice were reported in this article. Among the 18 informants (Table 1), the majority were Chinese (77.8%), female (83.3%), and had received either secondary or vocational education (55.6%). Their ages ranged from 25 to 79, with a mean age of 49.2 years. Adult children of the patients formed the largest pool of informants among the bereaved caregivers. The characteristics of the 16 deceased were as follows: age range between 45 and 88 years, mean age of 65.8 years; 11 out of 16 were

**Table 1.** Demographic profile of the family caregivers and patients

Demographic characteristics	Family caregivers (n = 18) <sup>a</sup>	Patients (n = 16)
<b>Age</b>		
Mean (range)	49.2 (25–79)	65.8 (45–88)
<b>Sex</b>		
Female/Male	14/4	11/5
<b>Ethnicity</b>		
Chinese/Malay/Others	15/1/2	15/1/0
<b>Marital status</b>		
Single/Married	3/9	1/12
Divorced/Widowed	1/5	0/3
<b>Educational status</b>		
No education/Primary	1/0	1/3
Secondary or vocational	10	6
Diploma	1	1
General degree/Postgraduate degree	5/1	2/3
<b>Primary cancer</b>		
Lung/Colon/Breast		5/5/2
Pancreas/Ovarian/Soft tissues		2/1/1
<b>Relationship to deceased patient</b>		
Children/Spouse/Sibling	12/5/1	
<b>Main place of care in the last 30 days</b>		
Home with hospice home care service		14
Inpatient hospice		2
<b>Place of death</b>		
Home with hospice home care service		10
Inpatient hospice		4
Hospital		2

<sup>a</sup>Two of the informants were a pair of sisters and another two informants were a married couple.

female. In addition, it may be interesting to note that the majority of the patients were taken care of in their own homes during the last 30 days of life (87.5%), and died in their own homes (62.5%) (Table 1).

### Data Collection

The focus group sessions were conducted on the premises of an organization not involved in the care of the deceased, and the only individual in-depth interview was conducted in the vicinity of the university. A neutral venue was chosen because of the possibility that some bereaved individuals might have experienced discomfort returning to the premises of the organization that used to care for the deceased.

The informants were asked to discuss their experience of living with and taking care of a loved one

during the last few weeks of life, and what made or would have made the end-of-life care comfortable and meaningful. Probing questions were asked when there was a need to clarify a comment or to get more details. All the focus group discussions were moderated by a trained volunteer and observed by IMHW. The interview was conducted by IMHW. Four of the five focus group discussions analyzed, as well as the interview, were conducted in English, whereas the remaining one focus group discussion analyzed was conducted in Mandarin. A focus group consisted of an average of three participants and lasted an average of 2 hours. The individual interview lasted 1 hour. All the focus group discussions and the individual interview were audio-recorded with permission from the informants, later transcribed verbatim, and entered into NVivo version 8.

Several steps were taken to ensure trustworthiness and authenticity as required in qualitative research practice. To ensure trustworthiness of the data, we have included the voices of almost all the informants to be represented in the text and to have their stories treated with fairness and balance. To ensure authenticity in the inquiry process, we made efforts to recruit informants from different races with the purpose of seeking informants who potentially had different interpretations, and made efforts to appreciate the perspective of others by taking the stance of a learner during the interview inquiry (Patton, 2002; Denzin & Lincoln, 2005).

### Data Analysis

Data were coded and thematically analyzed using initial, focused, and axial coding schemes (Charmaz, 2006). The second author went through a set of sampled codes independently and a comparison for theme agreement and disagreement was made with GLL, who then applied the same coding scheme to the remaining transcripts. After identifying 23 attributes, GLL collapsed them into five major themes, which were confirmed by IMHW and CG. Although the five major themes were presented as conceptually independent for patients and caregivers, attributes overlapped among them. For example, attention spent on physical care and comfort of a patient may be primarily associated with the end-of-life care for the patient, but it may also affect how the caregiver perceived the patient's dying process. Similarly, the attributes overlapped among the themes. For example, experiencing death without the presence of children may be primarily associated with moments near death but it may also affect the family relationship.

The illustrative quotes were used to substantiate the findings, and they have been edited for ease of

reading, without compromising the content. Repeated words were deleted and grammatical inconsistencies found in the spoken language were corrected. An unidentifiable case code has been added after each quotation when used.

## RESULTS

Payne et al. (1996a) suggested that the notion of a good death can be interpreted as the death event itself or the dying process. In this study, a good death was analyzed in both ways — identification of attributes related to preparing, facing, and experiencing the last weeks of life, and the death event itself — for the dying person and for caregiver, respectively. The text showed that it is important to handle the biopsychosocial and spiritual aspects of life at the end of life well, so as to achieve a good death. As such, five major themes identified included preparation for death, family and social relationships, moments at or near death, comfort and physical care, and spiritual well-being (Table 2).

### Preparation for Death

To be mentally ready for the death and to have a say in personal death and funeral arrangements were the two sub-themes that emerged from this theme.

#### *Mental Readiness for the Death*

Awareness of the illness and acceptance of the imminence of death were reported to be important factors for the patients and caregivers at the end of life.

He actually said something so sweet. He said, “It’s okay, I know I have to die. It’s not I’m so terrified of death, I have already lived up to 82, I have lived up to a ripe old age, you know” (Informant M, aged 49, Chinese).

The palliative care team gave me not only a lot of material, but also moral support. Then my own faith as a Christian; knowing that death is something we all have to face and it is the separation that hurts. Eventually it [the death] doesn’t really [hurt]; it’s not such a great tragedy... so it’s a matter of accepting it when the time comes. (Informant X, aged 79, Chinese)

#### *Having a Say in Personal Death and Funeral Arrangements*

Five informants shared that the deceased participated actively in planning their own funeral arrangements. It appears that the experience enabled these patients to make personal and social preparations to get themselves ready for the death,

**Table 2.** *Categorical definition of a good death for patients and caregivers*

<i>Important Components in a Good Death</i>			
<b>For patient</b>	<b>n</b>	<b>For caregiver</b>	<b>n</b>
<i>Preparation for death</i>	8 <sup>a</sup>	<i>Preparation for death</i>	3
Mental readiness for death	5	Mental readiness for death	3
Having a say in personal death and funeral arrangements	5		
<i>Family and social relationships</i>	6 <sup>a</sup>	<i>Family and social relationships</i>	8 <sup>a</sup>
Having a positive experience	5	Giving the dying to die	4
Having visits from friends	4	Meeting the dying person’s preference for place of death	4
Human touch from healthcare professionals	1	Having a fulfilling experience	2
		Given recognition	1
<i>Moments at or near death</i>	5	<i>Moments at or near death</i>	7
A dignified death	2	Proper grieving and closure	5
A quick death	2	To be present for the death	1
Dying in sleep	1	Saying goodbye to patient	1
<i>Comfort and physical care</i>	5 <sup>a</sup>	<i>Comfort and physical care</i>	4 <sup>a</sup>
Providing physical comfort	5	Patient had no pain	3
Having a preferred caregiver	2	Not to prolong life unnecessarily	2
Encouraging independence in daily activities	1		
<i>Spiritual well-being</i>	4 <sup>a</sup>	<i>Spiritual well-being</i>	1
Meeting religious needs	4	Meeting religious needs	1
A meaningful life	2		

<sup>a</sup>The total number is not a summation of the sub-themes, as more than one sub-theme could be reported by an informant.

and it was also a meaningful experience for the caregivers.

She did not want her funeral to be held at my home. She went down to the place and said, “Okay, I want my funeral to be here.” So I said, “Mum, it doesn’t mean [you will get] the place you want. If there is a body there before you, too bad, you know.” She said, “Okay, first choice [this], second choice [that]” So, all that has been arranged. . . I walked through with her . . . from A to Z (Informant G, aged 47, Chinese).

Mum told me what color she wanted to wear. When I asked her if she wanted a wig, she said no. She told me where the wake should be held, and that she wanted to be buried. Everything was done. It was actually a good feeling. (Informant J, aged 44, Chinese)

### Family and Social Relationships

Seven sub-themes emerged from this theme. The opportunity for a dying person to enjoy a positive experience, receive support from friends, or experience the human touch from healthcare professionals during the dying process were reported to be important. For the caregiver, the ability to give the dying person permission to die, meet the dying person's preference for place of death, or have a fulfilling experience in caregiving with their efforts being recognized were reported to be important.

#### *Having a Positive Experience*

The informants reported that it was imperative to give the dying loved ones positive experiences such as a social outing, a happy time together, or just a quiet time together, in the last weeks of life. A positive experience has left informant N with fond memories and good feelings, as shown in the excerpt below.

What was very good was that I brought her out the week before she passed on. I stayed near Orchard Road and I brought her up to Orchard Road to see the Christmas lights. She passed on after Christmas . . . I was very thankful to God, at least I could bring her out of the house . . . to see the Christmas light-up at Orchard Road (Informant N, aged 48, Chinese).

#### *Having Visits from Friends*

Friends were perceived as a significant source of support for the dying person, as shown in the following excerpt.

I found that my sister had very good support. All of a sudden when she got sick, her ex-classmates from secondary school and pre-university came [to visit her]. They were wonderful people. Somehow all got reconnected, all the relationships from the school days. (Informant N, aged 48 Chinese).

#### *Human Touch from Healthcare Professionals*

Informant R seemed to suggest that the human touch from healthcare professionals gave "value" at the end of life. This is illustrated in the following excerpt.

[H]e was left on his diaper [in the ward] as he was from home. I took off his shirt because it was really soiled, and he was vomiting blood with the oxygen mask [on]. I knew that was blood, and I told him to turn to the side. No one came to assist me. This is shocking. That part I really grieved. Not his going home because as Christian [I] know I will meet him again. . . I asked the nurse, "Can someone come and help me? The signal is going on, he is not well." But they looked at me as though they were waiting for him to die (Informant R, aged 47, Chinese)

Above, it can be seen that the lack of action and empathy from healthcare professionals may deny a patient a dignified death, which could be interpreted by the family caregiver as a "bad death".

#### *Giving the Dying Person Permission to Die*

Four informants shared that they had spoken to and given permission to their loved one to die. At the same time, the informants also prepared themselves mentally for the death of their dying loved one.

We are also mentally prepared. Upon seeing him suffering, we let him go. At the end, I told him, "Are you ready to go? You just go and do not worry about us." And he died a few days later (Informant V, aged 59, Chinese).

I sleep with him on the same bed; I cared for him. Every night putting him at ease and I would tell him things like. "Bob, if you have to go, you go; if God calls you. Never mind, I will come and join you." It just came out like that; it was very voluntary (Informant W, aged 56, Chinese).

#### *Meeting the Dying Person's Preference for Place of Death*

The importance of enabling their dying loved one to die at the preferred place of death was emphasized by four informants.

I was very clear that towards the end part of her life she would be taken care of by the family at home. Because it was a journey for her and us, I wanted to give her the best kind of care in a very safe, very clean, and very quiet environment, at home rather than in the hospital or the hospice. So that was very clear in my mind that it was the kind of care that I wanted to give to her. She also wanted to stay at home towards the end (Informant F, aged 47, Chinese).

We respected [our mother's] decision even though we knew that bringing her back to Malaysia was going to be costly. Out of good-will, we managed to do that for her (Informant Y, aged 38, Malay).

### *Having a Fulfilling Experience*

Positive meanings were made by two informants when they shared the end-of-life caregiving experience.

I was already prepared last year and I wrote in to ask for early retirement . . . I got my retirement approved so I spent the last 3 months with him. . . that to me was fantastic; to be able to spend total time with him, the journey with him. . . to me, that was precious quality time with him, with my loved one (Informant W, aged 56, Chinese).

### *Given Recognition*

Informant N reported that she felt good about being recognized for all her effort in taking care of her sister. The finding suggested that not only the patient, but the caregiver too needed the experience of self-worth.

She actually thanked me for taking care of her and that's a very nice comfort she gave. She said I was her precious sister. Indeed, I did give her my very best, not the fullest best but the best of my ability to take care of her (Informant N, aged 48, Chinese).

### **Moments At or Near Death**

Six sub-themes emerged that involved the dying process and the state of the patient near death. As such, what was important at the end of life for the patient was to have a dignified death, in constant sleep during the last stage of life, or to have a quick death. In contrast, for the caregivers, it was having proper grieving and closure, being present for the patient's death, or saying goodbye to the patient. The caregivers seemed to prefer that the patient be awake and have a slower death, so as to allow the caregivers time to achieve closure with the patient.

### *A Dignified Death*

Two informants reported that the patients chose not to die in front of their children. As suggested in the quote by Informant V, her husband at his deathbed still found it imperative to maintain his pride in front of the children.

He [husband] did not want his children to see him. He said, "I do not want to let my children see me in this state. I want them to know that their father is very strong." He wanted his dignity. I said, "It's alright; let your children come in to show their concern for you, to let them know. At least, [let them] help [you], take care of [you]; let them show their sense of concern." "No, no." Sometimes, when

they wanted to help, he chased them away, "You go out. You go out" (Informant V, aged 59, Chinese).

### *A Quick Death*

As reported by two informants, the patients perceived quick death as an essential element at the end of life. As reflected in the excerpt, the underlying advantage of having a quick death was freedom from becoming a burden to the family.

It was just two days and she was gone. It was very good for her. She is someone who does not like to be bedridden, to be someone who constantly needs people to take care of her, even for the basic things like going to the toilet (Informant Q, aged 31, Chinese).

### *Dying in Sleep*

Informant M shared that it was a blessing for her father to be able to sleep to his death in the last month. It was perceived as a good death because constant sleep implied freedom from pain.

He never went to hospital. My dad was very blessed; he actually spent the last one month or so sleeping a lot. For some reason he got very tired, so he just slept and slept (Informant M, aged 49, Chinese).

### *Proper Grieving and Closure*

Proper grieving and closure was perceived as essential for the caregivers at the end of a patient's life.

I believe in proper grieving. It is actually very normal for people to grieve . . . I feel that I have the right to cry, so at the third night [during wake], I just went full blast. Everybody was looking at me but I just did not care. So it was actually proper grieving (Informant P, aged 25, Chinese).

My mum was only there [hospice] for three days. The doctor called me up on the third day and said [my mum's time was near] . . . The main important thing was that we all rushed down. We tried to soothe my mum, clean her, call all the grandchildren down and talk to her. She seemed very happy . . . My brother would talk to her. . . "Do not worry, just go happily, everything will be well taken care." . . . Everything was very peaceful, so I am very happy with that (Informant H, aged 57, Others).

### *To be Present for the Death*

It was reported by informant U that she was grateful to be present at her mother-in-law's deathbed.

I am thankful to God that I was able to be by her side before her death . . . I have been working in a bank for 20 over years, and thus I always returned home late, sometimes 9, 10 o'clock at night. Everyone is about to go to bed when I returned home. I was sacked two days before her death. However, I am thankful to God as He has His timing (Informant U, aged 50, Chinese).

### *Saying Goodbye to the Patient*

It was emphasized by informant S that it was important for her to be able to say goodbye to the patient on the final day itself, even if it meant over the phone.

I was not there [hospice] . . . I had a doctor appointment that day. They called me and said, "You better come, she can't make it." . . . anyway, I told my brother, "Switch on the phone and the loud speakers," and I spoke to my mum . . . I kept talking to her . . . "Go in peace, don't you worry about us, we love you" so, I kept saying and telling her as if she is still alive (Informant S, aged 59, Others).

## **Comfort and Physical Care**

Five sub-themes emerged from this major theme. Provision of physical comfort, having a preferred caregiver, and encouragement of independence in daily activities was perceived as important to the dying persons. On the other hand, the patient having no pain and no unnecessary prolongation of life was perceived as important to the informants.

### *Providing Physical Comfort*

The importance of physical cleanliness and comfort for the dying person was most frequently reported among the bereaved caregivers. As reflected in the excerpt, provision of a soothing atmosphere for the dying loved one was important at the end of life.

Most important is that she is put in a very comfortable environment . . . no hospital, machines, chips, nurses coming in and out, so she has a very personalized, very private and conducive home environment for her to pass away. Cleanliness is also important; to make her comfortable and that she has no bed sore (Informant F, aged 47, Chinese).

### *Having a Preferred Caregiver*

According to informant X, it was perceived as a good death to patients if they were taken care of by a desired family member.

It is important that during the last week of his life, a person whom the patient accepts, and not someone he does not agree with, takes care of him. My husband would never dream of me bringing in a nurse however tired I am. He woke up 3 times at night, I took him to pee, took him to bed. Sometimes I was so tired that I wished there was someone else to take over. But for him, he was used to me. He would be very unhappy if I brought in someone else. Thus, I had to soldier on and do it on my own. That was most important for him (Informant X, aged 79, Chinese).

### *Encouraging Independence in Daily Activities*

Having autonomy in activities of daily living, such as the ability to "do, eat what they want", was expressed by Informant F as an essential element for her dying husband at the end of life.

### *Patient Had no Pain*

Three informants reported that it was essential for them, as caregivers, to know that their dying loved ones did not suffer from pain before death.

The process of dying is the part that I worry the most because some can be very painful . . . I want my dad to go through this stage in the least painful manner . . . When they are in pain we are helpless. The worst thing is when a person is in pain, you just do not know what to do besides giving him pain-killer (Informant M, aged 49, Chinese).

I can't feel her pain but inside me I feel the heartache of seeing her in pain. And this is, we don't know how to express it out. I know [she is] in pain, poor thing, 24 hours in pain from day one . . . Hopefully the medicine can help her with her pain (Informant N, aged 48, Chinese).

### *Not to Prolong Life Unnecessarily*

Prolonging life unnecessarily was not desired at the end of life. In fact, informant X shared that both the patient and family had decided not to give further treatment to prolong life unnecessarily upon the patient's second admission to hospital.

[W]hen we were about 2 weeks before his death, second admission to the hospital and the doctor wanted to give antibiotics. That was the time where we got the children in to support my view not to give him antibiotics so that he can pass away without delay. No [antibiotics] because he was already suffering so much (Informant X, aged 79, Chinese).

## Spiritual Well-Being

The dying loved one meeting his/her religious needs and having lived a meaningful life were two important aspects of the spiritual well-being reported by the informants.

### *Meeting Religious Needs*

Four informants reported that the dying loved ones viewed meeting their religious needs as important. Whereas some looked forward to church friends visiting them, others would say their prayers. One patient even asked her children to do prayers for her. In addition, informant H reported that meeting the religious needs of the patient was important to her as a caregiver too. We could therefore infer that for people with a religious faith, their perceived good death may have followed a more religiously orientated belief in the hope of entry into Heaven (Mak & Clinton, 1999).

My mum is a Christian. She accepted [her condition] straight away. She was positive and she prayed as all Christian do. She did not pray for a change in condition; she just took each day as it came. In fact by not looking at the end, taking a day as it came, I think it helped her to face it (Informant Q, aged 31, Chinese).

It's good they have the last prayer there for her. At least, I'm happy. And I'm happy that some of the nurses there will still pray for her (Informant H, aged 57, Others).

### *A Meaningful Life*

The importance of enabling the patient to find meaning or purpose to life was reported by two informants. As captured in the excerpt, the ability to contribute to the well-being of others provided a purpose to life for the patients.

He [suffered from cancer in soft tissues] was a renal patient and he volunteered to be the chairman of the renal friends. They [medical social workers] said, "You have done a good job, you have contributed, so I think you can leave." So, that helped ... (Informant W, aged 56, Chinese).

## DISCUSSION

This study identified 23 attributes and five major themes encompassing the biopsychosocial and spiritual aspects of life as important components of a good death in Singapore. Generally, our findings concur with the attributes found in the existing Western palliative care research, such as being prepared

(Steinhauser et al., 2000b), not being a burden to others (Teno et al., 2001; Tong et al., 2003), pain and symptom control (Payne et al., 1996a; Steinhauser et al., 2000b; Patrick et al., 2001), avoiding unnecessary prolongation of life (Singer et al., 1999; Tong et al., 2003), contribution to others (Steinhauser et al., 2000b) and spirituality (Tong et al., 2003). Interestingly, the implied need for "control" was heard extensively, such as having a choice of caregiver, after-death arrangements, and the person to accompany self in the final moments before death. This provides a special insight for caregiving, as the dying process entails losing control. The concept of "hope" was also heard, and this included hope for physical comfort, lack of pain, good quality of life, and maintenance of dignity throughout the dying process, as well as hope that the family will be all right. The findings indicate that what is important at the end of life in Singapore shared many attributes with what was important in Western countries.

This study also revealed interesting findings that had not been much discussed in existing studies. First, the caregivers felt the need to give the patient permission to die so that the patient need not worry about them. Second, the caregivers felt the need to be acknowledged by their dying loved one for their care. Third, the caregivers expressed the need for a fulfilling caregiving experience. These three components suggest that dying is a process that involves both the dying person and those they leave behind. A good death is one that meets the needs of the dying person and also those of the family caregivers. Therefore, the quality of the relationship between the dying person and their family is an important component at the end of life. This concurs with the Confucian concept of relational-self as discussed in Ho (1995), in which selfhood is identified in relation to the individual's place in society and membership in the social network.

The different views held by the dying person and the family caregiver about what is important at the end of life were also interesting, despite that both views were obtained from the same group of bereaved family caregivers. First, the dying person was eager to have a quick death or die in sleep. As suggested by existing studies and literature, having a quick death or dying as one sleeps may mean an escape from pain or from becoming a burden to the family (Payne et al., 1996a; Steinhauser et al., 2000b; Patrick et al., 2001; Teno et al., 2001; Tong et al., 2003). However, the caregivers did not wish for a death that would take them by surprise, but for a death that would allow proper closure. Second, the caregivers wanted to be present at the death. In contrast, the dying person might choose not to die in



front of the loved ones. One possible explanation was the wish of the deceased to minimize the family burden and to make the bereavement process easier for the family (Vig et al., 2002). Another possible explanation is that culturally, relationship orientation remains highly prized, and the parent–child relationship is regarded as the most important relationship among Asian people, such as the Chinese (Li, 2001). As such, parents on their deathbed might wish to preserve their dignity by leaving a positive impression with the loved ones. This reflects a form of “dignity-conserving repertoire” discussed in Chochinov (2006, p. 93). A similar finding was also found in the Japanese experience (Hirai et al., 2006), in which “maintaining pride” was identified as one of the components of a good death. Finally, as shown in Table 2 (the frequency counts in italics), the most important category defining a good death for a dying person was “Preparation for death”, whereas for the family caregivers, it was “Family and social relationships”. This finding therefore suggests a difference in what is important at the end of life for the dying patient and for family caregiver.

The results of our study have implications for clinical practice. The heterogeneous and multifaceted views of what is important at the end of life suggest that in the process of planning for end-of-life care, the patient and family should be asked what might be important for them during the last weeks of life and the death itself. Moreover, the fact that the patient and family caregiver may hold different views of what is important at the end of life implies the need to engage them in a discussion so as to achieve consensus about goals for attaining a meaningful and culturally appropriate end-of-life experience for both parties.

Our study has several limitations. The first limitation was the low participation rate. Speaking about death remains a taboo in Singapore. Our experience strongly advocated the engagement of potential participants prior to inviting them to participate in the study. Second, interviewing bereaved family members as a proxy of the deceased means that it is possible that what is important for the patient at the end of life may not be fully expressed by the family members. Third, some of the themes identified were only from one focus group, which suggests that the themes were not exhaustive. Additional focus group discussions, which are not feasible in this study because of limited resources and low participation rate, might identify more themes. Despite the limitations, the strength of our study was that the family members were not speaking of a hypothetical scenario but were reflecting on their experiences of living with and taking care of a close, terminally ill family member at the end of life.

## CONCLUSIONS

In conclusion, the local findings on what constitutes a good death bear many similarities to the findings of studies done in other cultures. However, because of the way we conducted our study with the bereaved family caregivers, we were able to identify differences in the perception of what is a good death from the perspectives of a dying person and a family caregiver, as perceived by the bereaved family caregivers. Our findings therefore suggest a need to respect, address, and reconcile the differences in the concept of a good death, so that all parties may have a good experience at the end of a person’s life.

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