

# Perspectives of good death and dying among patients with cancer, their caregivers, and health care providers: qualitative study

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## ABSTRACT

**Background.** Social backgrounds, cultural beliefs, ideologies and experiences of well-being all affect people's perspectives on good death and dying.

**Objective.** To describe the perspectives of patients with cancer, caregivers and health care providers on good death and dying.

**Design.** Qualitative study using constant comparative method.

**Setting.** Southern Philippines Medical Center in Davao City, Philippines.

**Participants.** 7 patients with cancer, 5 caregivers, and 8 health care professionals.

**Main outcome measures.** Concepts of good death and ideal dying process from interviews with study participants.

**Main results.** Of the 20 participants, 16 were females and 4 were males, with ages ranging from 16 to 64 years old. Three interrelated themes emerged from the interviews. First, participants recognize that an omnipotent force external to the self controls when and where death happens and the circumstances around death. Second, participants believe that good death happens when one is ready for it. Readiness for death entails having lived life according to one's purpose in life, achieving emotional closure with loved ones, and having accepted that death is near. Finally, for our participants, the ideal dying process happens at home, is free of uncomfortable symptoms, and is experienced with the family and friends of the dying person.

**Conclusion.** Participants in this study recognize that an external force controls the time and place of and circumstances around death. For our participants, good death happens when one is emotionally ready for it, and it is important to provide physical and emotional comfort to an actively dying person.

**Keywords.** spirituality, readiness, comfortable dying, constant comparative method

## INTRODUCTION

Death in cancer is unique and greatly feared because it is commonly associated with a long dying process, as opposed to the relatively "quick death" in other causes of mortality. However, this protracted phase near the end of life can give patients more control over what happens to them and their environment while they are dying. Terminally ill patients with cancer can potentially control pain, discomfort and other symptoms, and they relatively have ample time to settle their interpersonal issues and say goodbye to their loved ones before they die.<sup>1</sup>

Dying is the multi-dimensional process that leads to death. The process of dying affects not only the physical body, but also one's psychosocial aspects and immediate social environment—i.e., family, relatives, friends, etc.<sup>2</sup> Several studies done among Western cultures asked terminally ill patients, as well as their families and health care providers, about what they consider important at the end of life. Frequent responses included optimum pain control,<sup>3-7</sup> being in-

volved in making diagnostic and therapeutic decisions,<sup>3,8</sup> psychosocial support, from the family,<sup>6,7,9</sup> spiritual support and having meaningful emotional closures with loved ones.<sup>3,4,10</sup>

Many notions tend to be strong in particular cultures. In Muslim societies, having a sense of self-esteem, projecting a positive image of the dying person among his or her relatives, and assuring economic and social

## IN ESSENCE

Concepts of good death and dying vary across different cultures.

In this study, notions on good death and dying include: that life and death are controlled by an external omnipotent force; that good death happens when one is ready for it; and that, ideally, active dying is symptom-free and happens at home with one's immediate family and friends around.

Discussions and planning for advance care prepare terminally ill patients and families for events around active dying and death.



security of the family, are regarded as very important psychosocial states that must be attained before a person dies.<sup>11</sup> Some cultures take great care in avoiding posthumous physical distortions, fatal wounds, or bad odors and make sure that a person's body looks as normal as possible after death as part of preserving the dead person's self-esteem.<sup>11</sup> Among Asians, good death is associated with having physical and psychological comfort, having a natural death, and being respected as an individual.<sup>5</sup> As to the manner of dying, one study among adults with lung cancer reported that patients describe a good death to be peaceful, pain-free and quick, and to occur during sleep.<sup>12</sup> Patients preferred a quick death, with little suffering and not amidst their children's presence. Some patients expressed fear of being seen by their children in a state of vulnerability as they die.<sup>6</sup> In an Asian study among bereaved families of patients with cancer, caregivers said that being physically present during the final moments and being able to bid goodbye to their dying loved ones are important to them.<sup>6</sup>

Filipinos have close-knit families. It is common and expected among Filipinos to personally take care of family members and relatives during times of illness. The concept of hospice and palliative care has not yet gained a firm foothold among Filipinos since its movement began in late 1990s<sup>13</sup> probably because of this prevailing approach to caregiving. Many patients with cancer who are brought to the hospital for hospice care usually believe that they may eventually have complete cure. Health care practitioners also tend to be more aggressive than what is called for when managing patients with terminal illness. Many physicians hesitate withholding therapy or making do-not-intubate and do-not-resuscitate orders during appropriate situations.<sup>14</sup> Because of insufficient knowledge and experience, health care practitioners have difficulty in helping patients make advance directives for end-of-life care.<sup>15</sup> To date, there are no established procedures or guidelines in preparing Filipino patients and their families for death. A strong basis for such guidelines would be the different notions of good death among those who are likely to have pondered more deeply on death. We did this study in order to describe notions of good death and the ideal dying process among patients with cancer, their caregivers, and health prac-

tioners who provide medical care for them.

## METHODS

### Research team and reflexivity

This study was done in Southern Philippines Medical Center (SPMC), a tertiary government hospital in Southeastern Philippines. SPMC has fully departmentalized wards and outpatient clinics, as well as a Children's Cancer and Blood Diseases Unit (CCBDU). The Department of Family and Community Medicine (DFCM) in SPMC runs a Hospice and Palliative Care Training Program (HPCTP), to which most of the hospital's patients with cancer needing their services are referred.

One of us (ARDL) conducted all the interviews. The two other authors (RJS and MEAC) helped in the planning, data analysis and reporting of the results of this study. All of us were trained in Family Medicine, have strong background and training in client-centered counselling, and are consultants in SPMC. Two of us (ARDL and RJS) subspecialize in Hospice and Palliative Care. Two of us are females, and one is male.

### Study design, participants and setting

In this qualitative study, we utilized the constant comparative method<sup>16-18</sup> to identify and characterize notions of good death from interviews among patients with cancer and their caregivers, and among health care practitioners.

All in all, we were able to interview seven patients with cancer, five caregivers, and eight health care professionals who responded to our poster invitation to join the study. We already knew four of the patients prior to their participation in the study since they have been referred to us for palliative care. As Hospice and Palliative Care consultants, we (ARDL and RJS) have been active in the management of the four patients for 6 to 12 months prior to the actual interviews for this study. For each of the three other patients, our interview for the study was our first in-depth conversation. The five caregivers who participated in our study were relatives of five of the seven patient participants. All of them decided to join after each of their patients signified participation in the study. We all personally knew the eight health care professionals we interviewed for this study. They have been working either in the CCBDU, in HPCTP, or in the outpatient clinic of the DFCM in our institution for at

least 3 years.

We obtained written informed consent from all participants. Prior to the actual interviews, we asked each of the participants to answer a two-page questionnaire that includes questions on their clinical and demographic data. The questionnaire also contained the four questions of the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD PHQ-4DA) to screen the participants for clinical depression and generalized anxiety disorder.<sup>19</sup>

### Data collection

For each participant, we did a one-time, face-to-face, individual interview in a secluded room in SPMC. We carried out the interviews using four general questions taken from the objectives of this study, namely—“What is your concept of a good death?” “For you, what is the best way to die?” “Where is your preferred place of death?” and “Who would you like to be present when you die?” We asked subsequent questions after each of these general questions to probe their main answers. All interviews were audio-recorded. We were given written permission by all participants to audio-record the interviews. Each interview ran for an average of one hour.

### Data analysis and reporting

We transcribed all the interviews verbatim. All three of us (ARDL, RJS, MEAC) read and coded the transcripts separately. Two of our colleagues (JGLA and ASC) with background in social research also helped us in coding and analyzing the transcripts (see acknowledgment). We identified themes from among the participants' answers to each of the four general questions by noting emerging or recurring notions of good death and the ideal dying process. We also used the answers to the probe questions to further characterize the properties of the emerging themes and triangulate our findings. Five more colleagues (SSBE, CXDL, RCR, ELLB, JJSA) helped us in preparing this report (see acknowledgment). We lifted quotations that could best illustrate the emerging themes that we identified from the transcripts. We then translated the non-English quotations to English and incorporated them in the results portion of this report. Translation was contextual, rather than literal. The initials that appear after the quotations in the results section are codes and are not the real initials of the participants.

## RESULTS

### Description of participants

Among the 20 participants included in this study, 16 were females and 4 were males. All of the seven patients with cancer were females, with ages ranging from 16 to 64 years old. Four of the patients were single, while three were married. Six of them completed high school education, and one graduated from a college course. Of the seven patients, three were Catholics, two were Protestants and two were Muslims. As to family life cycle stage, one patient was an unattached young adult, three belonged to families with adolescents, one came from a launching family, and two were from families in later years. The patients have been having cancer for less than one to four years. All of them have been informed about their illness. Their diagnoses and cancer staging as of the time of interview include colon cancer stage IV, cervical cancer stage III, rhabdomyosarcoma stage IV, osteosarcoma stage IV, chronic myelogenous leukemia, and breast cancer stage II.

The caregivers who participated in our study were five family members—two mothers, a son, a husband and a niece—of the seven patient participants. Their ages ranged from 22 to 47 years old. The youngest caregiver had a college degree and was single, while the rest graduated high school and were married. Two of them were Muslims, two were Catholics and one was Protestant.

The health care providers included in our study were five physicians and three nurses, with ages ranging from 27 to 36 years old. Two of them were males and six were females. Five were single and three were married. Six were Catholics, one was Muslim and one was Protestant.

All twenty of the participants were screened with the PRIME MD PHQ-4DA and were negative for anxiety and depression.

### Emerging themes

Three interrelated themes emerged from the interviews that we processed: the control of life, dying and death is external; a good death is something that one is ready for; and, it is ideal for one to die comfortably.

**Recognition of an external locus of control.** Death is regarded as universal and something that inevitably happens to everyone. It is an event at the end of life. A mother of one of our patient participants

said that one ought to accept that death eventually happens.

*"...bug-os jud na madawat na nimo na taman nalang ka diru. (...it is absolutely important that you accept that your life ends at that point.)"*

- WR, 36 years old, mother and caregiver of a patient with rhabdomyosarcoma stage IV

An external omnipotent force beyond one's control willfully determines, as if through a master plan, the mundane course of one's life, including the time of, place of and circumstances around one's death. This deference to an all-powerful other externalizes the locus of control of life, dying and death and helps one come to terms with the inevitability of death. To Christians among our respondents, this omnipotent force is God; to Muslims, it is Allah. Two of our participants said,

*"...sa akoo, wala ka nag-suffer sa imong sakit, and you have your family with you... maabot man ang oras na kubaon na gyud ka sa Ginoo. (...for me, as long as you do not suffer, and you have your family with you... time will really come when God decides to take you.)"*

- OE, 29 years old, Catholic, female nurse

*"Si Allah na lang babala kung asa ko niya kubaon. (As to where I die, I leave it to Allah.)"*

- DL, 45 years old, housekeeper, Islam, female patient with colon cancer stage IV

This omnipotent force that people believe in is also the source of meaning and purpose of one's life. How one is supposed to live life is something that one seeks for and discovers through a strong relationship with the omnipotent force. A person can lead a good life by living it according to how the omnipotent force has meant it to be lived. A life well lived ends in a good death.

These notions of death provide the contexts on which to view the other emerging themes in this study.

**A good death is something that one is ready for.** Having experienced and understood cancer and having been told about the prognosis of their illness, patients in our study were aware that death for them is imminent. For patients with cancer, a good death is something that one has prepared for. One is ready to die if one has found

meaning and purpose in life, and when life has been lived according to one's perceived meaning and purpose. Two patients from among our participants said,

*"Para sa akin, nabuman nako ug eskwela. Kanang fulfilled ang pamati. Pero kung will talaga ni God na kunin ako, tanggap ko po. Naay acceptance na dapat. (To me, since I have already finished schooling, there is this sense of fulfillment. So if it is God's will to take me, I accept it. There should already be acceptance.)"*

- CY, 18 years old, female patient with rhabdomyosarcoma stage IV

*"Fulfilled ka, murag nabuman na tanan. (You feel fulfilled, as if everything is done.)"*

- BR, 33 years old, female patient with cervical cancer stage III

Fulfillment comes from being able to live life according to how one perceives the omnipotent force has planned it to be. This makes it easier for one to say, as life is about to end, that "all is done" and openly accept death. As how our participants put it,

*"If you have had a good life then you have lived your life fully."*

- OE, 29 years old, female nurse

*"Malipayon sa kamatayan—kanang naay peace ug nadawat na. (Dying can be happy if one has peace and has accepted that death is imminent.)"*

- OJ, 33 years old, daughter and caregiver of patient with breast cancer stage II

Despite the uncertainty of one's exact time of death, one can still be ready to die. Readiness to die is dependent not only on being at peace with one's self, but also on having had a good relationship with others. Emotional closure and resolution of conflicts with loved ones happen when a person has settled differences with them and do not harbor any negative feelings towards them. Our participants said,

*"Kana jud kinabanglan preparado ko ug nadawat nimo. (What is important is that I'm prepared and have accepted [that death is coming].)"*

- FT, 47 years old, husband of patient with cervical cancer stage III

*"Yung mamatay ka na masaya. Kung may kasalanan ka, nag-sorry ka na. Apil ang fulfillment ug acceptance. ([You have a good death] when you die happy, when you have already asked for forgiveness for the wrong things you have done, and when you have fulfillment and acceptance.)"*

- HN, 18 years old, student, female patient with chronic myelogenous leukemia

*"Para sa akoo ang konsepto sa good death is kanang hapsay ang imong relasyon sa pamilya ug sa imong sarili nga mubiya sa diring kalibutana nga wala kay dalang kabiubos, wala kay dalang aligutgot ug, sama sa gwapo imong relasyon sa pamilya, ang imo pud panghuna-huna is maayo pud. Kumbaga ready na ka. (My concept of good death involves having a good relationship with your family and yourself, having peace of mind before you die, and leaving this world without disappointment or bitterness. In other words, being ready [before you die].)"*

- WN, 33 years old, male physician

**It is ideal for one to die comfortably.** Our participants associate good dying process with physical and emotional comfort. Physical comfort depends on where and how one experiences dying. Most of our participants, not only those diagnosed with cancer but also caregivers and health care providers, associate good death with the absence of pain. Dying comfortably means not experiencing any agonizing pain or labored breathing. Our participants said,

*"Kanang painless ug comfortable. ([I want dying to be] painless and comfortable.)"*

- UD, 64 years old, female patient with breast cancer stage III

*"Para sa akin, yung hindi nahibirapan, kanang di gud nimo makita na naghingalo o nag-suffer. (For me, [dying] should not be agonizing, and [the dying person] should not be gasping for breath or suffering.)"*

- SR, 27 years old, female nurse

*"Gusto nako sa balay ra, pamati man gud nako na kung sa ospital, daghan pang sakit na ikumaw... (I want to die in our home, I believe that dying in a hospital involves unnecessary pain...)"*

- DL, 45 years old, female patient with colon cancer stage IV

Dying at home is desirable because it provides emotional comfort during the final moments of life. The preference to die in a hospital setting may also be associated with providing physical comfort for the dying person. One physician from among our participants said that she prefers to die at home, but that she would want her family members to die in the hospital, presumably after providing them appropriate medical care.

*"Kung ako, sa balay with my loved ones. Pero, kung family members, gusto ko sa hospital. (For me, I want [to die] at home with my loved ones around. However, for my family members, I want them [to die] in a hospital.)"*

- AK, 36 years old, female physician

A person's last moments of life are best spent together with loved ones. The presence of family members and friends also affords emotional comfort for the dying person and provides the last opportunity for everyone to exchange goodbyes. Two of our participants said,

*"My immediate family and mga close friends. Kanang palibutan ko sa mga taong nag-love sa akoo. (My immediate family and close friends. [I want to be] surrounded by those who love me.)"*

- CY, 18 years old, female patient with rhabdomyosarcoma IV

*"Sa balay siguro kay close sa pamilya, then matan-aw tan-aw siya or kauban pud ang family sa pagpanam. ([It is best to die] at home, with family members who can watch over the dying person and who will be there when the person goes away.)"*

- IB, 35 years old, male, nurse

## DISCUSSION

### Key results

From this study, we were able to identify three interrelated notions of good death and dying among patients with cancer and their caregivers, and among health care providers, namely—the recognition that something external to the self is controlling life and death, including the time and place of death and the circumstances around it; one can have a good death if one is ready for it; and, physical and emotional comfort while one is dying makes for a good death.

### Interpretation

The reference to an omnipotent force—that is beyond one's control and that determines life, the meaning and purpose of one's life and one's eventual death—is a unique emerging theme in our study. The belief that a supreme being determines a person's life and death is strong in Filipino culture.<sup>20 21</sup> When diagnosed with life threatening illnesses, patients are likely to experience spiritual distress, seeking emotional refuge from or expressing anger to a higher power, considering their illness as punishment from life's poor choices, questioning the meaning of life, and even questioning the presence of the higher power in times of suffering.<sup>22</sup>

Religious spirituality affects how Filipinos approach decisions around health, healing, life, and death. Muslims believe that Allah predetermines the exact timing and place of death. The concept of good death centers on the importance of dignity, privacy and family security, and emphasizes on the value of spiritual and emotional support for the dying person.<sup>11</sup> The phrase “*Si Allah na lang babala*” (“[I] leave it to Allah”)—or “*Ang Diyos na lang babala*” (“[I] leave it to God”) for Christians—implies that the speaker entrusts everything to Allah, God or any external force.<sup>23</sup> Another study pointed out that, for Filipinos, good death happens when one comes “to peace with God.”<sup>27</sup> This courteous regard for a force other than the self is a strong attribute of Filipino religious spirituality. Spirituality helps in creating awareness of the present condition, in coping with illness, and in finding end-of-life comfort.<sup>24</sup> The externalization of the locus of control of one's life and death is a way of recognizing the limits of the self and of accepting the inevitability of death.

People on some cultures prefer to be unaware of the imminence of death and to live a life free of the feeling of confronting an approaching death.<sup>5</sup> In palliative care, death is expected as part of the natural course of the patient's illness, and sudden death is uncommon. The lack of preparedness for death can result in complicated grief among bereaved family members and caregivers.<sup>25</sup> Our participants emphasize the importance of being ready for death. The “readiness to die” referred to by our participants involves being fulfilled as a person after living one's life according to one's spirituality.

Readiness presupposes an ideal state that

one ought to prepare for or ought to work towards,<sup>6</sup> even if one's future is uncertain in the face of an illness that may soon lead to death.<sup>26</sup> Reaching that ideal state means being ready for death. This mindset is expected since death is itself the inevitable end that, in a way, one has to prepare for and work towards. Like the first emerging theme in our study, this theme showcases the religious spirituality of Filipinos. For our participants, the ideal state of readiness involves having done the things that one ought to do in life, being at peace with oneself, and having positive emotional closure with loved ones. Each of these elements of readiness has a layer of religiosity. What one ought to do in life and being at peace with oneself are based on religious beliefs regarding one's purpose in life. Emotional closure with loved ones involves asking for forgiveness and seeking reconciliation from people one has wronged.

Desiring comfort at the end of life has been described in previous studies.<sup>4-6 8 9 11 12</sup> Avoiding discomfort is human nature. The comfortable dying process described by our participants entails physical comfort, with dying occurring at home in the presence of family and friends. Chronically ill patients may actually want to die alone or die at a time when their caregivers are away from them for a short time.<sup>27</sup> Our participants' articulation of wanting to die with loved ones around them speaks of the relationship-centeredness of their approach to these final moments of life.<sup>28</sup> Being able to ask or grant forgiveness, say goodbye, or express gratitude<sup>6</sup> in person translates to emotional comfort not only for the person who is actively dying but also for the family and friends who are physically present.

### Strengths and limitations

Unlike previous studies that asked questions about good death through surveys,<sup>3 5 7 11</sup> the findings of this study were based on interviews with participants. The constant comparative method of analysis that we employed in this study enabled notions of good death to emerge from the interviews. The notions that emerged demonstrate that the participants' concepts of good death are akin to the Filipinos' general approach to life, characterized by strong religious spirituality and close-knit relationships with family members and friends.

This study had a few limitations. Because

we invited participants using a poster announcement, interviews were limited to those that we did with the volunteers who responded to our invitation. Our study did not have representation from male patients with cancer. Only three religions (Catholic, Islam and Protestantism) were represented in this study. It is possible that new themes will emerge from interviews with people with sociodemographic profiles that are different from those of our participants.

### Implications

A patient-centered care plan for terminally ill patients can be designed to revolve around the emerging themes that we have gleaned from our study. Advance care planning and discussions can be initiated to prepare the patients and families for end-of-life events.<sup>25</sup> Our themes on spirituality, readiness and comfort are all important aspects of advance care planning and end-of-life discussions that should be acknowledged and addressed. Resolution of spiritual issues would facilitate acceptance and readiness that may eventually affect the quality of the experience of dying. It is common notion that physicians' responsibilities do not include addressing spiritual concerns,<sup>24</sup> therefore the subject of spirituality presents a challenge to physicians and health care providers. Although spiritual or religious discussions should not be forced, it should be understood that religion and spirituality influence ethical and medical decisions.<sup>29</sup>

Future research in this area can include perspectives from male patient participants and those from other religions or ideologies, and can explore how these attributes help shape notions of good death and dying process. The implications of the patients' experience of illness, as well as the influence of family roles and professions, on notions of good death are also worth exploring in future studies.

### Good death and dying

For our participants—patients with cancer and their caregivers, and health care providers—good death happens to a person who is ready to die. One is ready to die after gaining a personal understanding of the meaning of life and achieving one's perceived purpose in life. A strong religious influence, especially among Filipinos, underlies this spiritual outlook in life. The meaning and purpose in life spring from one's belief

in an external omnipotent force. Because death is universal and inevitable, it is also regarded as a phenomenon that is controlled by an external force. A fitting end for a life well lived is a symptom-free active dying process that happens at home, where family and friends are present to provide emotional comfort to the dying person.

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### Ethics approval

This study was reviewed and approved by the Department of Health XI Cluster Ethics Review Committee (DOH XI CERC reference P13103101).

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