

# “Should We Tell?” Living a Good Life in the Shadow of Cancer: A Personal Reflection

*Dedicated to the Loving Memory of My Mother*

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## **Abstract**

Terminal cancer poses many medical and existential dilemmas for patients, their families, and for helping professionals. I discuss my mother's experience with pancreatic cancer, and how cultivating a meditative attitude helped her to cope with her illness. The Heideggerian, Daseinsanalytic, and Buddhist perspectives on mortality, and ways of cultivating a meditative attitude are explored. Research and guidelines about doctor-patient communication across Anglo-Saxon and non Anglo-Saxon cultures point to significant cultural differences in the preferences of medical professionals and patients about disclosure, and the role of the family. Recommendations for improving guidelines on disclosures, and exceptions to disclosures to benefit patients are discussed. I argue that the most important question in dealing with patients experiencing terminal illnesses is not about disclosure or non-disclosure, but how individuals can be assisted in coping with their dis-ease rather than their disease.

Key words: cancer, disclosure, non-disclosure, guidelines, cultural differences, doctors preferences, patients' preferences, meditative attitude, Buddha, Heidegger

## **Introduction**

*Those who do not know how to live, will not know how to die, and those who cannot die, cannot live*  
Condrau (1998, p. 105)

It is said that nothing prepares you for the reality of marriage except marriage itself. So it is with death. What is the reality of living with imminent death for the patient, the family, the healthcare professionals and carers? How do we give the patient quality rather than quantity of life while he or she is living? Should we communicate, and if so, how much information should be shared with the patient? Do we continue searching for treatment options when the prognosis is poor? When is enough, enough? How do we discuss funeral and other important issues and concerns with the patient?

These were some of the medical, ethical, and existential questions and dilemmas confronting myself and my family when we were informed in October 2014 that my mother had advanced pancreatic cancer.

My mother passed away peacefully on August 2015. Her death has prompted me to reflect on, and write about dying, death, grief, and loss. During my mother's illness, I did not have the energy nor the time to look at what the literature was telling us about communicating with a patient about cancer. Nevertheless, my discussions with medical professionals and carers piqued my interest. After her death, I researched the literature: studies, research, medical policies and guidelines on this topic. The information I uncovered was illuminating, but at times, disconcerting. So my conversations with my mother became part of a larger conversation, not only about disclosure of diagnosis and prognosis, but the existential question: "how to live a good life in the shadow of cancer."

In this article there are personal elements—I draw upon my mother's experiences, my own experience, the experiences of my family members, and the support that we received from the medical and the spiritual communities. Yet, it is not only an article about personal experiences. While my mother's passing was unique to her and to us, death per se is a universal and, I believe, a relational, shared experience.

The insights from her passing have provided me with a framework to reflect on how we can help others to cope with this human experience more pragmatically and compassionately, as a member of the helping professions or as someone who is otherwise encountering another person's dying and death. I discuss the various themes that unfolded in my mother's life as an illustration of how we navigated the medical and existential dilemmas, and the lived experiences of my mother and the family, with her being an uninformed cancer patient.

### *On Learning the News*

When her doctors first informed us that my mother had pancreatic cancer, there was a sense of disbelief and a degree of denial about the diagnosis, a common response in patients and family when first confronted with the diagnosis of cancer (Johanson, personal communications, 29 December 2015; Kubler-Ross, 1969). My mother had been experiencing symptoms of indigestion, itchy skin, and jaundice. She was continually losing weight, had no appetite, and, most days, little energy. But then she was 88 years old. "Aren't her symptoms, symptoms of aging?" we asked her doctors, hoping for a positive answer. What can be done?" we inquired. They advised "Not much, given her age and her frailty." The prognosis was that she probably has "six to nine months to live."

Her gastroenterologist recommended the insertion of a stent into her bile duct (Cancer Research UK, 2014) so that the bile would flow into the bowel, relieving the symptoms of jaundice, and making her more comfortable. My mother knew that she had jaundice and consented to the procedure. The stent relieved many of her presenting symptoms. We were still hoping for the best.

### *Managing the Dis-Ease or the Disease?*

The specialists advised that given my mother's age, physical health, and the type of cancer, she was not a good candidate for surgery, chemotherapy, or extensive treatment. The "silver lining" was the oncologist's recommendation of a procedure known as intensity-modulated radiotherapy (IMRT). IMRT is "an advanced mode of high-precision radiotherapy that uses computer-controlled linear accelerators to deliver precise radiation doses to a malignant tumor or specific areas within the tumor" (Radiologyinfo.org for patients, 2015).

Hence, began the first of many dilemmas for us as her family. There were endless rounds of discussions and debates of what was best for her. "Should we seek further treatment?" "Second opinions?" Some family members did not wish to pursue any further treatments, but to let my mother's condition be. Other family members strongly advocated for second opinions and checking out treatments from overseas. I was more concerned with managing her dis-ease—her emotional states, psychological needs, quality of life and general well-being—rather than her disease. The final word came from her supervising physician, a close relative who had looked after her for many years. He advised that my mother was not in a state to travel, and that any treatment had to be undertaken locally.

According to her oncologist, the IMRT would not cure the cancer. However, the radiation could shrink the tumor, slow its progression, and allow her to enjoy minimal pain for a longer period. Additionally, the treatment could be stopped at any stage should my mother experience any significant side effects. He said that without the IMRT, the tumor could progress faster, and she could experience significant pain as the tumor grew. "But we have need to decide soon," he added, "otherwise the cancer could spread, and the IMRT would not be efficacious."

It was December 2014, a few days before Christmas. The whole family: children, in-laws and grandchildren, were gathered in Kuala Lumpur, Malaysia where she lived, to celebrate her 89<sup>th</sup> birthday. My mother enjoyed her last birthday tremendously, getting into the party spirit and

singing all her favorite Chinese songs to her heart's content. It was bittersweet. We cheered her on. Yet the need to make a decision about the procedure was urgent and we were no closer to reaching a family consensus.

To break the stalemate, and being mindful that time was of the essence, I convened a family meeting. My daughter made some pertinent observations. She reminded her uncles and aunts—"It seems like a no-brainer. The procedure has many upsides, and relatively few downsides. We are not looking at giving Ah Ma (Chinese for grandmother) a long life, but a good life and a good death." The family decided to proceed with the IMRT. My husband and I were given the unenviable task of discussing the procedure with my mother.

### Should We Tell?

#### *The Family Preferences*

Communicating bad news is an extremely difficult task for everyone involved: healthcare professionals, patients, and families. As a therapist, I have worked with many clients facing terminal illness. My clients and their families sought help in coping with their fear, stress, anxiety, and depression. In Sydney, Australia, where I practice, most patients have already been informed of their condition, even in cases where the cancer was incurable. As I discuss later, the disclosures had to do with needing patients to make an "informed consent" about their treatment.

So, by the time my clients came for therapy, the majority had already learned of "the rocky road" ahead for them. Some clients spoke of the sleepless nights lying awake, in cold sweat, wondering "How much pain and suffering will I experience before the end?" "Will I die as painfully as others that I have seen?" Some were fearful of going to sleep *per se*, worrying "When will I breathe my last breath?" "Will I still be breathing tomorrow?" Family members spoke of their sense of helplessness as they watched loved ones endure rounds of radiation, chemotherapy, and surgery, coping with the physical, emotional, and psychological tolls of the treatments.

As I worked through these emotions with clients and their families, often with them in tears, and at times outside of office hours—fear, anxiety and depression do not observe office hours—I appreciated that the differences lay, not so much in whether they knew about their condition, but their attitude in relation to their illness.

One client who was diagnosed with advanced lung can-

cer was unable to accept the prognosis. He attempted to exhaust all options including an experimental drug therapy, which left him sick and exhausted, unable to enjoy his remaining time with the family, including the day he died as he was placed on a ventilator. After his death, although his family accepted that it was his decision to undergo all the medical treatments, they were nevertheless traumatized and much saddened by his inability to spend quality time with them. They shared with me: "We never got to say a proper goodbye. We never got closure."

Another client was diagnosed with bone marrow cancer, which had metastasized. She was given a prognosis of twelve months. She accepted this prognosis, quit her job, took up guitar playing, and spent her time on the beach with her husband and daughters. During her last few days in the palliative ward, she brought her guitar, serenaded the family, the other patients and nurses, and passed away peacefully.

Both my clients had full knowledge of their diagnosis and prognosis. Yet it was their attitude, rather than the information, that made a significant difference to their quality of life. In my mother's case, we were faced with similar dilemmas of whether and how much we should communicate to her about her condition. I was mindful that there were no right or wrong approaches, just "skillful ones" as the Buddha would say. And I felt that the most skillful approach was to take my cues from my mother.

Many of my family wanted to tell her about the diagnosis of cancer. They felt that she had a right to know in order to make decisions about treatments, and to prepare for this last stage of her life. My husband and I advised against telling her that she had cancer. I suggested that we use words like "growth" rather than cancer, as the latter term carried a lot of negative associations.

Again, the family was at a stalemate. Wearing my psychologist hat, I role-played with the family the kind of conversation we might have with my mother. Below is a sample of my discussions with various family members, which went on for several days:

B (Belinda): What would you tell mother?

FM: (a family member): What the doctor told us. That she has cancer

B: What if she asked how long she has left?

FM: We could tell her that the doctors can't tell, and we don't know how long.

B: What if she asks why aren't the doctors recommending an operation or chemotherapy?

FM: (silence)

B: What if mother gets fearful and starts to feel depressed and anxious?

FM: We will be there for her.

B: Will we be there when she can't sleep or wakes up at odd hours worrying about dying? Can we be there for her 24/7?

FM: (silence).

B: What if she asks whether she will die, how soon, and whether she will suffer in pain.

FM: We will assure her that she won't suffer.

B: Is that the truth?

FM: Wouldn't you want to know if it was you?

B: I think it's about whether mother would wish to know. We need to be guided by her preferences.

FM: It is ethical to tell her the truth.

B: Which truth? The truth about her medical condition or the truth that she may experience great dis-ease and suffering as the cancer progresses? When do we start shading the "truth" and not tell her about the real prognosis, and how aggressive her type of cancer is.

FM: (silence).

B: I think that what we have to ask is: "What hope are we giving mother by telling her that she has advanced cancer and that there is no cure or treatment." What about her peace of mind, knowing that she will die soon? Is it ethical to give her information that she can't do anything about, but has the potential to cause her great emotional suffering? I think that it is a question of compassion, rather than ethics.

### *The Medical Opinions*

Prior to discussing my mother's condition with her, I sought the advice and opinions of various healthcare professionals. Their responses and the anecdotes that they shared were informative and instructive.

Her treating oncologist felt that we should consider telling her about the cancer. Another senior oncologist in Kuala Lumpur advised against it. This oncologist's own aging mother had a brain tumor and dementia, and he had decided not to tell her about her cancer. His rationale was that many elderly people like my mother, who had little education and capacity to appreciate the gravity of her

condition, if told that she had cancer, would probably only recall "the pain and suffering of someone she knew, who died from cancer." Those memories and associations," he explained, "would create unnecessary fear and suffering in her mind, especially if the prognosis is bad." The palliative care doctor and my mother's carers also recommended against telling my mother about the cancer, and shared anecdotes about the negative impact of disclosure on their patients' quality of life.

In Sydney, I learned from the oncological team that had previously treated my husband for cancer that his oncologist preferred to disclose to his patients that they had cancer when their informed consent was needed for treatment. When there were no treatment options, he preferred to use words like "growth" or "tumor," as he felt that the term cancer "was brutal" and carried negative connotations. I discovered, however, that this oncologist's compassionate approach was the exception rather than the norm.

I also learned from a general practitioner, a Chinese-born Australian, that in China, the doctors often did not tell the patients the whole truth, but that in Australia, they were ethically bound to do so. However, she agreed that sometimes she wished that she had the option not to disclose all the information, as often the patient, upon learning the diagnosis and prognosis, experienced significant anxiety and fear.

It appeared that there was no consensus among the medical professionals about disclosures. Many professionals who were working on the frontline, with real life experiences of cancer patients, were not supportive of full disclosure.

### *My Mother's Preferences*

I realized that the decision about disclosure needed to be based on compassion rather than ethical or medical considerations. I had one more person's preference to seek out—my mother's.

I received much support from my husband, Charles. He had a good relationship with my mother and she would often share with him what she could not express with her children. She knew that he had had operations for two bouts of cancer, one thirty years before, and another in 2012. During her illness, my husband and I visited with her regularly, and she looked forward to these visits. It was during these times that she was most reflective and we were able to get a good sense of her preferences and her attitude towards cancer and death. The following is a summary of one of her conversations with my husband:

Mother: You had several major health issues before. What is it like to have a major operation? What is it like to die?

Charles: I don't see it as death. I see it as a long sleep from which one doesn't have to wake up. It is quite peaceful, actually.

My mother shared with me that she found his analogy of death as a long, peaceful sleep, comforting. She said, "I am not afraid of death. I am afraid of pain. So I don't want any operation that will cause me pain and suffering." After our discussion I emailed the family. Below is an extract of my email:

Mum mentioned to Charles that there was a history of cancer in the family, but the cancer genes were all from our father's side, but none from her own family. The sense that Charles had from the conversation was that mum was concerned about cancer, but was glad there was no cancer in her family. We know that is not true [her own mother died from lung cancer]. However, it showed, as the senior oncologist told us, that the word *cancer* brings on a set of fears based on the patient's previous experiences and memories, and that the knowledge might create unnecessary anxiety at this stage.

These conversations suggested to me that my mother might well have had a sense that she had cancer, but she was hoping that it was not, as there were no cancer genes from her family's side. Additionally, my mother could have asked outright whether she had cancer. She did not. Should we disabuse her of this illusion, or do we continue to let her hope for the best? I decided that the latter approach would be more compassionate, as she needed to be psychologically strong to cope with the procedure.

Gawande (2015) related the story of his cancer patient, Jewel Douglass, who was willing to face surgery, but did not want "to take risky chances" (p. 235). According to Gawande, "I came to understand that she was telling me everything that I needed to know" (p. 240). In a similar vein, my mother was telling us everything that we needed to know: she was not asking for information about her diagnosis or prognosis. She was telling us that she did not want to undergo any treatment that might cause her pain and suffering, regardless of her condition.

In our follow-up discussions about the IMRT procedure, we realized that it was important to give my mother a narrative that was consistent with her philosophy in life in order to motivate her about the procedure and to give

her hope that she would have a better quality of life. My mother had indicated that the stent helped to relieve her jaundice symptoms and pain, and that she was pleased that the family was happy for her. This gave us a good opening. Below is another extract of my email to the family:

Charles explained that she had to see the doctors again, and that if she followed the doctors' advice, like she did with the stent, she would be continuing to give herself and her family the gift of peace of mind. He said that this was consistent with her selflessness and her philosophy of giving to the family despite personal sacrifices to herself. Mother said that she understood and that she would try and follow the doctor's advice, because it made the family happy when she was feeling better.

By framing the need for the procedure as consistent with her attitude of giving, rather than that the procedure was good for her, we hoped that she would be more accepting of any difficulties that she might encounter with the treatment, instead of giving up and saying "Better to die."

The next day I had an extensive discussion with my mother. I asked her what she understood about her medical problems. She said that she had a growth in her pancreas which caused her jaundice and various symptoms, and that the stent had relieved many of the symptoms. I explained that her doctors were recommending a procedure called IMRT to manage the growth. I outlined briefly what the procedure involved, the period of treatment, and some of the possible side effects for which the doctors would give her some medication to ameliorate. I gave her the analogy that the procedure was similar to a CT scan (which she had undergone several times). My mother's response was "I don't mind that. CT scan is not painful."

When I reassured her that my sister and I would accompany her to all the treatments, she consented to the procedure without protest. By keeping the explanation simple, and not burdening her with too many medical details, using an analogy that she understood, I felt that my mother had sufficient, but not overwhelming facts to make an informed decision about her own treatment.

In January 2015, my mother commenced her IMRT treatment, which involved her going to the hospital three times a week for five weeks. During this period, we tried to give her some simple pleasures and keep up her sense of humor. After each treatment, we would make our way to the "3-Michelin stars" hospital canteen, where my mother could select from a "gourmet" meal of "soft rice" or "soft bread," as she was unable to tolerate more complex food.

On the last day of the procedure, she even asked to be taken to her “gourmet restaurant” to celebrate the end of the treatment.

The IMRT proved to be a success. Until her death in August 2015 (a total of eight months), my mother was able to manage her pain with Ultracet, a moderate grade of pain relief medication. According to her doctors, the IMRT had shrunk the tumor and slowed its growth, and therefore the pain medication was working more efficiently. It was only three days before she died that she was put on morphine, as she was unable to take her medication orally.

My mother’s experiences suggested that the lack of knowledge that she had cancer did not negatively impact on her response to the treatment. On the contrary, if she had known that the IMRT was a short-term solution for cancer, she might have been discouraged from following it through, rationalizing that the end result would not be any different. I was comforted that in following her lead and talking about growth rather than cancer, we had minimized her fears and suffering.

After the IMRT, unfortunately, my mother had a fall, and suffered a fractured femur, which caused her a lot of pain. The doctors advised that she would need high care at home. Otherwise she could continue to stay in the hospital. My mother had always expressed a wish not to die in a hospital, or to be taken to a nursing home. We were fortunate that one of my brothers had the resources for her to stay at his house, where she was provided with round-the-clock nursing and hospice care.

While the IMRT provided my mother significant relief from continuous pain, the cancer was still casting a long shadow. So we continued to try to monitor her preferences, wishes, and concerns. Most of the discussions we had with my mother were opportunistic. As a result of the home arrangement, we had the space to share her favorite movies, music, and to laugh and talk about things that she wanted to talk about, for example, her growing up during the wars, and her life as a wife and mother.

The important questions were broached tangentially. For example, I queried “When your fracture is better, is there anywhere that you would like to travel to, or anyone that you wish to visit with?” My mother’s response was simple, “I don’t want to go anywhere. I just want people to come and visit me, and I like to spend more time with the family.” Everyone rallied around her. The family—young and old, far and near, her siblings and friends—visited frequently and spent quality time with her. It was a meaningful, poignant time for all of us.

As my mother’s condition worsened, my family wanted to find out more about her wishes for the funeral service. I casually raised the subject by mentioning the type of funeral services we had previously arranged for my father and queried which type of service she thought that he preferred? My mother responded “I don’t know what your father preferred, but I prefer a simple Buddhist service.” She expressed a wish for the service to be conducted by the Buddhist monks from the local Theravadin order that she supported and where my father’s ashes were kept. She indicated that she did not want joss sticks, just flowers and simple chants. Her overriding wish was “Keep it simple.”

So each day I learned more about my mother’s preferences and wishes, and her relationship to death and dying. And the important messages that we were getting from her was to keep things simple, and that she was at peace where she was now. As Gawande (2015) noted, “surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others, and achieving a sense their life is complete” (p. 155).

In ongoing conversations with my mother, I came to appreciate that questions like “Should we tell?” and “How much do we tell?” were largely immaterial if we took the time, and provided the space, safety, and opportunity for the patient to tell us what he or she preferred. I learned that our primary responsibility as family members or helping professionals was not to get bogged down with what to tell or how to tell it. Regardless of our roles, the gift that we could give to patients was to be present with them, and to listen mindfully to what they were really saying. In this regard, I was thankful that I was able to facilitate my mother feeling safe to do so. I felt that I had become a better therapist from my lived experience in helping her to navigate hard choices. In my mother, I found a good teacher to learn about living and dying.

## Doctor-Patient Communication and Disclosure on Cancer

### Overview

After my mother’s death, I examined the literature: research, studies, guidelines, and recommendations on communication and disclosure or “truth-telling” (Kazdaglis et al., 2010, p. 442) to cancer patients. According to Kazdaglis et al. (2010), “from a health care perspective, it

[truth]-telling] may be defined as total openness about the diagnosis and prognosis” (p. 443).

Generally, the literature can be classified into three groups. One group dealt with the disclosure of information to patients and their families—“whether,” “when,” “what,” and “how much” and the exceptions to disclosure. Another group dealt with the guidelines for more effective communication with patients—the “how to.” A third group examined patients’ and families’ preferences in relation to communication.

On reviewing the literature, a number of salient themes emerged:

There was significant variance among the helping professionals in terms of disclosure

There were significant cultural differences in relation to the type and degree of disclosure

The working assumption was that disclosing “the truth” was beneficial to patients

The guidelines for more effective doctor-patient communication were developed from the views of panels of health-care experts. These panels rarely included patients and their families

The rights of patients appeared to focus on receiving information and making an informed choice about treatment. With a few exceptions, patients did not appear to have the right to refuse to receive the information per se

The majority of the studies involved patients who had already been informed of their condition prior to their participation; studies involving uninformed cancer patients proved to be the exception.

### **Guidelines and Recommendations**

Disclosure of information to patients experiencing cancer or other life limiting illnesses were generally set out in guidelines and recommendations concerning the rights of the patients. For example, here are several:

Javashvili, G. (n.d): *Ethical and Legal Issues of Palliative Care: Explanations and Recommendations to Healthcare Personnel*

National Health and Medical Research Council (2004): *General Guidelines for Medical Practitioners on Providing Information to Patients*

National Breast and Ovarian Cancer Center (2007): *Breaking Bad News: Evidence from the Literature and Recommended Steps*

Okamura et al. (1998) *Guidelines for Telling the Truth to Cancer Patients*

Rodin et al., (2009): *Clinician-Patient Communication: Evidence-Based Recommendations to Guide Practice in Cancer*

The guidelines set out the patients’ right to information about their diagnosis, prognosis, and treatment, and full disclosure was usually recommended.

The guidelines and recommendations were based on the general principle “that patients were entitled to make their own decisions about medical treatments or procedures and should be given adequate information on which to base those decisions” (NHMRC Guidelines, 2004, p. 14). A common example of the information to be provided to patients included the following from these guidelines:

- the possible or likely nature of the illness or disease;
- the proposed approach to investigation, diagnosis, and treatment;
- the expected benefits, common side effects, and material risks of any intervention;
- other options for investigation, diagnosis, and treatment;
- the degree of uncertainty of any diagnosis arrived at;
- the degree of uncertainty about the therapeutic outcome;
- the likely consequences of not choosing the proposed diagnostic procedure or treatment, or of not having any procedure or treatment at all;
- any significant long term physical, emotional, mental, social, sexual, or other outcome that may be associated with a proposed intervention.

The guidelines and recommendations, along with their implications will be discussed at greater length in later sections.

### **Cultural Differences on Disclosure and Non-Disclosure**

Many studies and research have highlighted cultural differences in relation to doctor-patient communication and disclosure. The researchers have also identified differences across cultures with regard to patients’ preferences for disclosure and the role of family. In this section, I explore these differences, and discuss whether they reflect real cultural differences.

### Medical Professionals' Preferences

According to Kazdaglis et al. (2010), full disclosure by physicians appeared to be based on the assumption “that truth telling is always beneficial to patients...” (p. 443). Their study highlighted significant variance among physicians and cultural differences about “truth-telling” (p. 443). The authors noted that physicians in Western countries—the U.S., Finland, and Canada—were more inclined towards full disclosure. In these countries, the physicians felt that they had an obligation to fully disclose to the patient, as the patient’s right to participate in their own treatment was enshrined in law. In the U.S., the debate was not about whether or not to disclose to patients, but “how and when to tell them [the patient] the truth” (Kazdaglis et al., 2010, p. 445).

In other countries without an “Anglo-Saxon cultural background such as Japan, Greece, Turkey, Spain, Italy” (Kazdaglis et al., 2010, p. 445) full disclosure was still not commonly practiced. In Japan, for example, in the 1980s, disclosures about diagnosis to cancer patients were not commonly observed as doctors perceived it “unethical to reveal what they considered a ‘death sentence,’ and patients were also reluctant to know their true condition” (Sato, Beppu, Iba & Sawada, 2012, p. 226). However, the trend in Japan appeared to be changing towards more disclosure (Okamura et al., 1998).

### Patient's Preferences

Tan, Yaakup, Shah, Jaffar, and Omar (2012) found that Malaysian cancer patients “desire honesty from their doctors when it comes to communication of bad news” (p. 3) and that upon receiving the diagnosis, patients often requested more information about test results and treatment options. It was not clear from the study whether the patients’ desire for more information was related to diagnosis, prognosis, or both, an important distinction often overlooked in studies about patients’ preferences.

In Japan, Sato et al. (2012) found that while the rates of diagnostic disclosures have increased, the rate of prognostic disclosures by Japanese doctors remained relatively low: “...doctors are less likely to communicate life prognosis even when they tell their patients about cancer diagnosis” (p. 228). On the patients’ side, Sato et al., (2012) noted important differences in patients’ preferences for prognostic information:

While some of the participants [patients] voluntarily asked for prognosis to prepare themselves for the end of life, others were shocked by unexpected

and unilateral disclosure. Some obtained prognostic treatment from books and websites. Some preferred to remain unaware of the prognosis partly because they feared it would become a self-fulfilling prophecy” (p. 225).

According to Huang, Meiser, Butow, and Goldstein (1999), the majority of Chinese migrant patients and their families in Australia believed that “while disclosure of potentially curable disease was considered appropriate, non-disclosure of a poor prognosis was favoured to enable continued optimism and hope ...” (p. 212). The authors also found age, personalities, and educational level of the patients to be important determinants of preferences, with younger patients and those with higher education levels reflecting preferences closer to Western values, and older patients and those with lower education levels preferring to leave treatment options to their doctors. Similarly, a study by Laxmi and Khan (2013) found that for Indian patients, age and education were important factors in the preferences for information.

A large study of UK cancer centers from 34 hospitals (Jenkins, Fallowfield, & Saul, 2001), which examined the information needs of 2331 cancer patients, found that “98% of patients needed to know whether the illness was cancer, and that 95% wanted to know about their chances of cure. According to the authors, “this observation should convince health professionals that they should not withhold the truth about diagnosis on the grounds that many patients prefer not to know” and that “information about prognosis should not be avoided either” (p. 50). However, in a breakdown of responses to specific questions such as “what the chances of cure are,” the authors reported that while 98% (1909/1943 respondents) wanted all information, 77% (118/161 respondents) wanted “only good news” and 73% (118/161 respondents) would “leave up to doctor” (p. 50). In terms of raw scores, the number of participants who did not opt for full disclosure was significant, especially in an Anglo-Saxon cultural context.

Hagerty, Butow, Ellis, Dimitry, and Tattersall (2005) found that the majority of patients in Australia at the early stage of cancer desired detailed prognostic information, and that these preferences varied according to demographic, psychological, and disease variables. According to the authors, patients of Anglo-Saxon background preferred more prognostic disclosure while those from other cultures (both patients and doctors) were in favor of non-disclosure.

In Australia, the *Clinical Practice Guidelines for Communicating Prognosis and End-of-Life Issues with Adults in the*

*Advanced Stages of a Life-Limiting Illness, and Their Caregivers* (Clayton et al., 2007) recommended that health care professionals took into account patient and caregiver preferences and provided information tailored to these needs, including “giving the patient the option not to discuss it” (S83). However, the same guidelines recommended that health care professionals disclose full prognostic information to patients—the rationale being “that if information provision is not honest and detailed, patients may perceive that health care professionals are withholding potentially frightening information. . . . Therefore, it is in the patient’s best interests to offer such information rather than withhold it in an attempt to protect the patient from losing hope or being upset” (S87). In my view, the guidelines to *tailor* prognostic information to patients’ specific preferences alongside the recommendation to *fully disclose* appeared incongruent and were difficult to reconcile.

Does this variance in cancer patients’ preferences for information reflect a real cultural difference? While some of the studies found that culture does play a role, there was also evidence to suggest that these preferences were influenced by age, gender, education level, stage of cancer, and the type of information desired (Hagerty et al., 2005; Huang et al., 1999; Laxmi & Khan, 2013; Sato et al., 2012). Another consideration that might have influenced patients’ preferences was that in these studies the majority of the participants already knew about their illness. According to Kazdaglis et al. (2010), their opinions might be biased, and it was possible “that fewer patients want to know in detail about their illness than is believed by health professionals” (p. 444). Additionally, in most Anglo-Saxon and other countries where there was an obligation—ethical or legal—on the part of the medical professionals to disclose, it was not surprising that patients, once informed of their diagnosis, would wish to know more. Overall, the studies showed that patients’ preferences for more information may be a function of culture and the various factors discussed.

### **The Role of the Family**

Many studies conducted in non Anglo-Saxon cultures highlighted the importance of familial engagement. This engagement included physicians consulting with the family first as to how much information to disclose to the patient (Huang et al., 1999) and involving the family in the decision-making process (Laxmi & Khan, 2013). This represented “a divergence from usual Western practice . . .” (Huang et al., 1999, p. 212). Fujimori et al. (2007) also found that the majority of Japanese patients preferred to have their physicians take into account the feelings of their

family. Kazdaglis et al. (2010) noted similar paternalistic practices existing in Arab and Islamic cultures, such as Kuwait and Saudi Arabia.

The above findings on the role of the family appeared to be in contrast to the practices in Anglo-Saxon culture where patients, rather than family members, were initially and primarily involved in the information and decision-making process, and physicians were required by guidelines and legislation to fully disclose to patients. Hence, the research findings demonstrated a real cultural difference in relation to the role of the family. However, in my view, the practices in non-Anglo-Saxon cultures, rather than reflecting paternalistic practices, suggested that family interactions were more relational than individualistic. In many of these cultures, family members played an influential role in most important decisions (not limited to medical decisions) affecting the individual, regardless of age and gender. Current Australian guidelines have taken into account such cultural differences by recommending professionals to be “sensitive to the person’s culture, race, religious beliefs, and social background” (NBOCC recommendations, 2007, p. 19), and “to show respect for the family and the fact that they may have different views from your own about truth telling and patient autonomy (Communicating prognosis guidelines, 2007, S103).

In summary, there appeared to be real cultural differences with regard to medical professional’s preference for disclosure and with the role of the family. However, the cultural difference in relation to patients’ preferences appeared to reflect individual differences, and were influenced by various factors, culture being only one of them. Unless these multi-dimensional variables were differentiated and understood, the perception that patients in Anglo-Saxon cultures preferred more information than those from non-Anglo-Saxon cultures will continue to be perpetuated uncritically, and individual preferences overlooked.

It is recommended that more research be conducted across different cultures studying:

- informed and uninformed patients prior to their participation
- patients’ preferences for diagnostic or prognostic information or both
- patients’ preferences at different stages of their illness
- family members’ preferences
- views and attitudes of health-care professionals who are obliged to disclose, versus those who have discretion about disclosure.

In this way, regardless of which culture the professional and patient identified with, the communication between doctor and patient would be “dis-ease” rather than “disease” centered.

## Communication and Disclosure of Information

### *Determining Patients’ Preferences*

In recent times, clinical practice guidelines have been formulated to assist health-care professionals with ascertaining patient’s preferences and to promote more effective doctor-patient communication: “the how to,” rather than “the what.” This is a welcome recognition that “no one size that fits all.” Below are some examples of the guidelines and recommendations developed in various countries:

The *Good Medical Practice: A Code of Conduct for Doctors in Australia* (2014) (The Code) provides, among other guidelines, recommendations on effective communication with patients dealing with end-of-life issues and managing cultural differences:

Effective communication: “listening to patients, asking for and respecting their views about their health, and responding to their concerns and preferences” (p. 8).

End-of-life care: “... respecting different cultural practices related to death and dying” (p. 11).

In Canada, the *Clinician-Patient Communications Practice Guidelines* developed by Rodin, et al. (2009) set out some evidence-based recommendations to guide communication with cancer patients:

Assess the patient’s personal preferences for information and current understanding of their condition. For example, ask “Tell me, in your own words, what you understand about your condition?” (p. 45).

In offering prognostic information: “First, ask if the patient wants information about prognosis...” (p. 45).

The Spikes Protocol, a six-step protocol developed in the U.S. by Baile et al. (2000) for delivering bad news to cancer patients recommended, among other things, ascertaining whether and how much information patients wanted regarding their condition. The Spikes protocol is now employed in various countries including the U.S., France (Teike Lüthi & Cantin, 2011), Germany (Seifart et al., 2014) and Australia (NBOCC recommendations, 2007).

In Japan, guidelines for telling the truth to cancer patients (Okamura et al., 1998) emphasized the importance of disclosing diagnostic and prognostic information to cancer patients, and outlined communication skills for providing such information. Comparing these Japanese guidelines for disclosure to analogous ones in Anglo-Saxon cultures, there were some significant differences. For example, the Japanese guidelines did not emphasize checking out patients’ specific preferences prior to disclosure, or to consider the cultural background of Japanese patients. Additionally, although the role of family was recognized, it was de-emphasised in favour of the patient’s autonomy: “In principle, family members should not be told the diagnosis of cancer before patients are told” (Okamura, et al., p. 2). It would appear that these guidelines were premised on the assumption that more disclosure was beneficial to patients. The focus in these Japanese guidelines appeared to be in response to the lack of disclosure to cancer patients in Japan until recently. However, the question remained as to what Japanese patients actually preferred. Fujimori and Uchitomi (2009) found that “in family-centered cultures, such as Japanese culture, patients preferred that relatives be present more than patients in Western cultures did, and comparatively fewer patients preferred to discuss life expectancy in Asian cultures” (p. 214).

As discussed earlier, medical professionals in Anglo-Saxon cultures had a preference for fuller disclosure. In many of these countries, the assumption of benefit to patients appeared to be the prevailing wisdom. The question of whether disclosure per se was in fact helpful seemed to go unchallenged. Kazdaglis et al. (2010) queried whether Anglo-Saxon countries had moved too far and whether patients had lost the right not to have “the whole truth, and nothing but the truth?” (p. 445). The concerns expressed by Kazdaglis et al. (2010) applied equally to the issue of truth disclosure in Japan and other countries where patients’ preferences varied from their Western counterparts. If non-Anglo-Saxon countries moved towards greater disclosure, guidelines for tailoring disclosure to individual preferences needed to be incorporated; otherwise the pendulum towards truth-telling could easily swing too far as well.

The main limitation of the guidelines for determining patients’ preferences was that the guidelines were primarily developed from canvassing the views of healthcare experts (see NBOCC recommendations, 2007; Okamura et al., 1998; Rodin et al., 2009). As a result, there was a great variation in the recommendations (Schofield et al., 2003) and there were relatively few studies exploring the disparity between patients’ preferences and the recommended

guidelines (Schofield et al., 2001). For example, Seifart et al. (2014) found that patients' preferences for communication with their clinicians differed from the recommended Spikes protocol. One possible reason for this disparity was because the "real" experts—the patients and family members—were not included in the panel of experts, nor were their views and actual preferences solicited in the development of these practices. This lacuna needs to be addressed, as otherwise it could result in the providers (the health care professionals) rather than the consumers (the patients and their families) determining what constitutes effective and appropriate communication and disclosure.

### Exceptions to Disclosures

Generally, the guidelines dealing with doctor-patient communication revolved around diagnoses, treatment options, and outcomes, and centered on a relationship that Gawande (2015) described as "informative" (p. 200):

We [doctors] tell you the facts and figures. The rest is up to you. "Here's what the red pill does, and here's what the blue pill does" . . . "Which one do you want?" It's a retail relationship. . . . We know less and less about our patients but more and more about our sciences.

While most guidelines in Western, and recently, in some non-Anglo-Saxon countries have recommended more disclosure, studies have shown there is a great variation in patient's preferences, with some patients preferring no disclosure at all. The preference for non-disclosure is less researched or discussed, and is the focus of this section.

According to Kazdaglis et al. (2010) "it is important to reconsider the argument that telling the truth is universally 'good' for the patient" (p. 446). Some guidelines recognized that some patients may not desire any information at all regarding their illness. For example, the NHMRC guidelines (2004) and Georgia recommendations made explicit exceptions for physicians to withhold information or for patients to refuse to receive information (p. 17):

#### Withholding Information

Information should be withheld in very limited circumstances only:

- if the doctor judges on reasonable grounds that the patient's physical or mental health might be seriously harmed by the information, or
- if the patient expressly directs the doctor to make the decisions, and does not want the offered infor-

mation. Even in this case, the doctor should give the patient basic information about the illness and the proposed intervention.

The NHMRC guidelines (2004) further stated that "it is not appropriate to withhold information because the patient might be disconcerted or dismayed . . ." (p. 17) and "the doctor must try to ensure that the patient has *sufficient information and understanding* (italics added) to be able to waive his or her right to be informed and still to give valid consent" (p. 17). Similarly, the NBOCC recommendations (2007) advised professionals "to accept the patient's right not to know" (p. 16), while still requiring professionals to give patients sufficient information to make an informed consent in exercising this right.

The Georgia recommendations granted patients the "right to refuse to receive information" as follows:

#### Refusal to Receive Information

Patient has the right to refuse to receive information about his or her own health condition and proposed medical service. . . . This likewise applies [to] incurable diseases. Surely, the doctor shall ensure that the patient has no desire to learn about his or her own health condition and the details of proposed medical care. The best approach in this case is posing relevant questions to the patient during conversation and hearing the patient's opinion (p. 6).

The Georgia recommendations further set out that the exception was permitted when doctors were certain "that disclosure of full information may be harmful for a patient," but that the treating doctor needed "to coordinate [the] decision with the ethics committee and in case of absence of such committee, with other colleagues" (p. 13).

In my view, these exceptions to disclosures posed significant difficulties in their implementation, and appeared to be inconsistent with the principle of respecting patients' rights and autonomy. One can conceive of the difficulties of applying them in practice. Imagine the following scenario:

A legally competent patient consults with the treating doctor about the results of medical tests after experiencing symptoms that might be consistent with cancer. The tests show that the patient has cancer, the prognosis is bad, and the treatment options are negligible or absent. The doctor offers to discuss the test results with the patient. The patient informs the doctor that he or she does not wish to discuss the information.

What are the patient's rights and the physician's obligations in these circumstances? The NHMRC guidelines (2004) and the NBOCC recommendations (2007) required the physician to still give sufficient information so the patient could make an informed consent about waiving his or her right. This was clearly incongruent with the patient's wish not to be told. In short, the guidelines appeared to say that the doctor had to provide sufficient information about what the patient did not want to hear in order for the patient to exercise the right not to hear the information!

In my view, the type of recommendations set out in the NHMRC guidelines (2004) and the NBOCC recommendations (2007), raised a number of critical issues:

- The option to withhold information did not appear to make distinctions about the severity of the illness. In the case of terminal illness, a discussion on the diagnosis, prognosis, and lack of treatment options was bound to have a negative psychological impact on the patient.
- The guidelines did not appear to differentiate between withholding different types of information, e.g., between diagnosis, prognosis, and treatment options.
- Why was the patient not the best person to decide how much information he or she preferred to receive? Disclosing unwanted information may have the effect of unburdening the doctor at the expense of burdening the patient.
- Why was it inappropriate to withhold information because the patient "might be "disconcerted or dismayed?" (p. 17)? Doctors should be given the discretion to consider the emotional impact on the patient, rather than the obligation to furnish the patient with sufficient medical information.
- If a patient requested no disclosure, why was this request not regarded as the patient having made a decision about his or her own medical treatment and tantamount to informed consent?
- How was the autonomy of the patient respected if it was the doctor, rather than the patient, who decided what was "good for the patient?"

Although the Georgia recommendations appeared to be a more enlightened approach, one can still envisage practical difficulties and possible psychological impact on patients.

In the hypothetical scenario set out above, if a patient invoked this exception, the doctor in Georgia was permitted to accede to this request only if he or she was certain that full disclosure was not harmful to the patient, and after consulting with an ethics committee or a colleague. Can any medical professional be that sure? Would it not be too late if the doctor was wrong since we know we can't unhear what we have already heard? Would not the patient be fearful that there was something more seriously wrong and think: "Why does my doctor need to consult with an ethics committee and other doctors?" And finally, how would an ethics committee or another doctor, who presumably would not know the patient as well as the treating physician, determine whether full disclosure was harmful or not to that particular patient? So the considerations in the Georgia recommendations appeared to be based on medical-ethical-legal considerations, rather than on the psychological needs of the patient.

### Psychological Impact of Disclosure and Non-Disclosure

Kazdaglis et al., (2010) noted that there was not much research exploring the relationship between disclosing the truth and quality of life. The authors called for more evidence to ascertain whether truth telling had a positive impact on the patient's quality of life "... or is just assumed by health care professionals to be beneficial to patients" (p. 443). Equally, there did not appear to be much research that looked at the psychological impact of non-disclosure.

In Japan, a qualitative study (Maeda, Hagihara, Kobori & Nakayama, 2006) examined the psychological process of uninformed terminal liver cancer patients from the time of their hospitalization to their passing. The study found that the 59 uninformed cancer patients went through "five stages and four gates" (p. 8). The authors used the term "gates" to describe the "obvious and severe" (p. 1) feelings that each patient experienced at the end of each stage. The stages and gates ranged from stage 1 of "anxiety and puzzlement" (and the gate of "anger") (p. 8), to stage 5 of "acceptance" (and the gate of "uncontrollable grief") (p. 8). According to the authors, at stage 5, after the patients passed through the process of deep grief, they experienced a paradigm shift:

Death seems to loose [sic] its grip on the mind and it is not spoken of anymore, although thoughts of death never disappear. Patients look back over their career and life at what they can be proud of and become close to their family, who has always

been with them. They have a strong desire for warm hearted times. ...In this stage, patients spend time peacefully appreciating the people around them, gradually deepening their level of acceptance (p. 8).

The authors attributed this state of mind to various factors such as “the tradition and culture of the Japanese society as a collectivistic or interdependent culture...” (p. 8).

[F]amily relationships had priority over any other associations for these patients. Therefore, the patients strived to, above all else, value the thoughts of the family, that nondisclosure of the diagnosis was the best choice for the patient and the family in working to accept death (p. 9).

In relation to the psychological impact on the patients after disclosure, although more research would be helpful, currently there was information about such impact. Okamura et al. (1998) found that anxiety and depression including “...despair of the future, irritability, fear, insomnia and appetite loss” (p. 3) were the most common symptoms experienced by patients after receiving the news about their illness.

In Australia, the National Breast Cancer Center (2005) developed clinical guidelines on *Effectively Communicating Prognosis: Evidence From the Literature and Recommended Steps* for dealing with the psychosocial concerns of cancer patients. Some of these emotional issues included “episodes of intense, unpleasant and distressing emotions (such as anger, feeling out of control, fear and helplessness” (“Emotional issues,” para 2), and psychological issues, including depression, anxiety, traumatic symptoms, relationship difficulties, body image, and sexuality.

### Discussion on Disclosure and Non-Disclosure

Kazdaglis et al., (2010) advised maintaining a healthy balance between “the 2 ethical principles of veracity (truthfulness) and beneficence (doing good)” (p. 446). Health professionals in Asian and South-East Europe “should be more willing to answer patients’ questions truthfully when they indicate a preference to know...” (p. 446); while in the U.S. and the U.K., health professionals should perhaps adopt a more cautious attitude and identify and respect patients “who wish to know less and complying with their choice” (Kazdaglis et al., 2010, p. 446). As human beings, when confronted with information about a terminal illness, it was understandable that patients would experience a range of negative emotions. It was an existential, rather

than a medical issue. Healthcare professionals should be more prepared to take into account the needs of patients holistically, rather than just medically.

According to Edwin (2008) it was important to differentiate “therapeutic privilege” from “patient waiver” (p. 160). The former was exercised by doctors in withholding information from patients, whereas the latter was exercised by patients “waiving their rights not to know the truth about their condition” (p. 160). “In the case of therapeutic privilege, it is the doctor who is entrusted to determine that the disclosure of information mandated by the informed consent doctrine would cause the patient harm, whereas in the case of waiver the patient determines that he would be harmed by disclosure” (Edwin, 2008, p. 160). According to Edwin, “the right of those who do not want to know should also be respected” (p. 160).

If physicians were required by law to disclose, then equally, patients should be given a reciprocal right to opt for whether they wished *to receive or not receive* the information. Given research showing that patients desired more autonomy in deciding their own quality of life, guidelines giving physicians the final say in determining whether to accede to patients’ request for no or less disclosure are indefensible. Such guidelines need to be reviewed, as the assumptions underlying them do not appear to be respectful of patients’ autonomy and self-determination.

I believe that the focus of medical professionals should be about “healing” rather than “curing.” To put it more bluntly, the guidelines seem to saying, “*Doctors have a right to protect you from yourself in the short term even if you suffer in the longer term.*” Presumably, some might argue that guidelines are needed to protect patients from less experienced physicians. But burdening more experienced physicians with obligatory requirements, often at the lowest common denominator—in order to avoid the mistakes by more inexperienced doctors—does not necessarily protect patients.

The relationship between doctors and patients cannot be legislated upon, and the parties themselves should be allowed to freely navigate the “highs” and “lows.” The inefficacy of an interventionist or a piecemeal approach to social problems is best articulated by Latour (1995)—“We see only... crisis, disputes, interventions, compromises, substitutions, and orderings that get more and more complicated and engage more and more elements” (p. 275). Treating physicians should be given support to exercise their discretion and best judgment, rather than be constrained by laws and policies from doing so, for fear, perhaps, of potential

litigation for non-disclosure, negligence, malpractices, or voiding their medical insurances. In general, I believe that it would be more appropriate for guidelines and recommendations on communications with cancer patients to:

- Make a clear distinction between the disclosure of information by doctors, and the receipt by patients, especially in cases of incurable illnesses.
- Give legally competent patients an unequivocal right to make their own decisions, and allow treating physicians to use their best judgment (in consultation with the patient, and if appropriate, family members) to consider what information to disclose, without being hamstrung by law and medical guidelines. The physician's responsibility in such situations is to ascertain patients' real preferences. This discussion should be guided by principles of compassion and respect for the patients' own judgment on what is or is not beneficial.

### ***Being Present with the Patient***

In my view, the doctor-patient relationship could benefit from doctors being more patient-centered, i.e., being mindful and present with the patients' disease (their physical, emotional, and psychological states and needs), rather than their disease (their medical condition, symptoms, and treatment options). Mindful presence on the part of the doctor could foster a kind of relationship that focuses on healing, rather than curing.

An illustration of a patient-centered approach was captured by Gawande (2015) in his discussion with a palliative-care specialist, Dr Block, at his hospital:

For doctors, the primary purpose of a discussion about terminal illness is to determine what people want—whether they want chemo or not, whether they want to be resuscitated or not, whether they want hospice or not. They focus on laying out the facts and the options. But that's a mistake, Block said.

A large part of the task is helping people negotiate the overwhelming anxiety—*anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances,*" she explained. "There are many worries and real terrors." . . . There is no single way to take people with terminal illness through the process, but, according to Block, there are some rules. You sit down. You make time.

You're not determining whether they want treatment X versus Y. You're trying to learn what's most important to them under the circumstances—so that you can provide information and advice on the approach that gives them the best chance of achieving it. This requires as much listening as talking (p. 182).

Epstein (2007) pointed to two kinds of knowing with regards to doctor-patient communication and relationship: a) knowing *about*, and b) knowing from the inside. According to Epstein, most doctors focus on knowing about their patients, their names, illnesses, symptoms, medical history, etc. Knowing the patient involves the doctor relating to the patient as a fellow human being and understanding his or her emotional and psychological needs. The latter kind of knowing would enable the patient to have a relationship with the physician in which the patient does not feel defined as a patient, but as a unique individual.

This was the kind of relationship that my mother had with her oncologist. Throughout his caring for her, they enjoyed a kind of light bantering, with my mother complimenting him: "Wow, you so handsome. Are you married?" He would respond, jokingly "Unfortunately, yes." Her oncologist encouraged the family to allow my mother to partake all the "less healthy habits" that she had indulged in previously, such as her occasional cigarette, and desserts (my mother had a diabetic tendency). When one family member expressed concerns about my mother's smoking, he queried "Are you concerned about her getting cancer?" He explained that his approach to my mother's condition was "I am about living, not about dying." His sense of compassion, pragmatism and easy humor meant that my mother was not fearful of visits to his clinic, and in fact quite looked forward to the check-ups, and carrying on their humorous exchanges. I believe that his knowing my mother, rather than just knowing about her, contributed to her general sense of well-being despite her failing physical health.

### ***Our Relationship with Death and Dying***

Why is our relationship to death and dying so ambivalent? Why do conversations about death and dying among patients, medical professionals, families, and caregivers pose so many dilemmas and invoke a range of emotions.

According to Heidegger (1927/1962), human beings are "Being-towards-death" (p. 301) meaning that mortality is a fundamental characteristic of being human. Yet, people flee

from this inevitability by rationalizing death as something that will happen, but not yet (Khong, 2003). Anticipation of death, noted Heidegger (1927/1962), imbues people with the ability to look at their lives as a whole, and to take responsibility for every moment of their lives. Medard Boss (1979), a Swiss psychoanalyst who developed the existential therapeutic approach known as *daseinsanalysis* based on Heidegger's philosophy, advocated a similar approach towards death. In his teachings, the Buddha also encouraged people to accept mortality. However, death per se does not feature as prominently in Buddhist thinking as it does in Heidegger's philosophy and *daseinsanalysis*. The Buddha posited another way of addressing our existential anxiety with death: by showing that it is part of an ongoing concern with the larger issue of impermanence of everything, including human existence. From a Buddhist perspective, birth and death are the two end points of life, and it is how we live in the interregnum that is crucial. While Boss (1979) and Heidegger (1927/1962) advised people to accept death as a real possibility and to take responsibility for every moment of our lives, the Buddha counselled people to take responsibility for every moment of our lives because nothing remains the same. In short, it could be said that the *daseinsanalytic* position is: you have to live responsibly, in order to face *death* resolutely. The Buddhist position is: you have to live responsibly in order to face *life* resolutely (Khong, 1999). The difference between the Heideggerian, *daseinsanalytic*, and the Buddhist perspectives raises an interesting question: whether the lower rate of disclosure, and the preference for less information in Japan and some Asian countries points to individuals living in a culture that is more accepting of death per se as demonstrated by the Buddha's teachings.

In my view, the debate about disclosure or non-disclosure to cancer patients arises from our difficulty to accept that impermanence (including death) is natural and inevitable. It is ironic yet commonplace—as the Buddha, Heidegger and Boss have shown—that as human beings we are born knowing that we will die, and yet we avoid this most important conversation until we learn that we are dying. The conversation about death and dying has to be ongoing and part of the larger discourse about living.

### Cultivating a Meditative Attitude Rather Than Meditation Techniques

When my family agreed not to disclose the diagnosis and prognosis to my mother, we were faced with an existential dilemma: how can we give her a good life in the shadow of her imminent death?

As the matriarch of the family, my mother often voiced concerns about the future of her children, and the financial cost of her ongoing medical treatments. Her concerns caused her a lot of anxiety and would often dampen her moods. My husband and I encouraged her to practice some simple mindfulness exercises. He suggested that instead of worrying about the problems, to focus on two positive experiences daily. To our delight, as her mind was less caught up with old concerns, she got in touch with ordinary day-to-day experiences. One day she said to us, "Today, I felt the warmth of the sun on my skin in a way that I never felt before."

When she found herself ruminating about negative things, I would encourage her to observe the water in the swimming pool, and to look for two drops of water that were the same. She said that she could not find any and then shared her insights "My thoughts and problems are the same. They come and go. I don't need to worry about them constantly." During the period leading to her death, my mother stopped worrying about things that she said she "couldn't change or control."

Over the years, prior to her cancer, I had encouraged my mother to meditate using some simple Buddhist chants. Each time the chants were played, she would calm down and fall asleep. This simple meditation practice stood her in good stead during her illness. At times when pain prevented her from sleeping, listening to the chants would get her into a meditative state, and enabled her to sleep until the pain medication could be administered. Up to her death, her ability to get into this meditative state gave her a sense of equanimity and peace of mind, which I believed no medication could have provided.

Our task about giving her a good life was made much easier by my mother's attitude towards death and dying. She had often acknowledged that at age 89, her days were limited, and although she was not aware of her illness, she reminded us, "It is okay, I am 89. I am ready to go. I am not afraid of death." A meeting with two visiting Buddhist monks from the U.S. made me realize that these were not just mere expressions about aging. She embodied this attitude and state of mind in her being and in her way of living.

One of the monks, Reverend Heng Sure, who spoke Mandarin, asked her how she felt about dying. My mother replied, "When the earth is ready for me, I am ready to go. I have no fear of death. I accept that it is inevitable." She was asked about how she felt about her limited mobility. My mother responded "I used to be upset that I have to be

in a wheelchair, but now I accept my condition because my heart is peaceful.” It would appear that she was learning to be at peace with herself and with the world.

Later when I played the chants, my mother again fell easily into a meditative state. The monks were amazed at how peaceful she was. The younger monk asked whether she prayed to the Buddha each morning as part of her meditation practice. When my mother replied no, he offered to teach her. Reverend Heng Sure pointed out that there was no need to teach my mother more or new ways of being meditative. He pointed out that my mother had acquired a sense of equanimity: “She is accepting of where she is, and that the family should also accept where she is at too.” At the end of their visit, Reverend Heng Sure commented to my nephew: “Your grandmother is beautiful inside and outside (my mother had earlier mentioned to him that she was a former beauty queen). We were pleased that my mother had developed a meditative attitude rather than simply acquired a repertoire of meditation techniques.

### Funeral Rites and Services: *Balm for the Living Rather Than for the Deceased*

A few days prior to her passing, my mother was unable to drink, eat, or talk, and the doctors informed us that her life was drawing to a close. The family kept all-night vigils. On the morning of her death, we all gathered in her room. My mother’s breathing was barely audible. I led the family in meditation, and at the end of this sitting, we each took turns in sharing with her how we felt about her. I ended by whispering to her that she had been a good mother, that the family was well and thankful for her love and guidance. I added “Mother, we love you. It is alright to let go now.” Thirty minutes later, she took her last breath. My mother died so peacefully that we were not certain that she had passed away and we kept checking for signs of breathing. Later, my brother shared with us that he had previously been concerned about death being a painful process, but that seeing how “mother died such a good death, I am no longer fearful of it.”

In accordance with her wishes, a simple Buddhist ceremony was held with daily prayers conducted by Buddhist monks. The theme of her service was flowers. The room that housed her coffin was decorated with masses of flowers, and her favorite pot of orchids. One guest was heard to remark “It looked like her garden.”

Chief Reverend Dhammaratana, who conducted the evening services and talks at the wake, explained that funeral

services were meant more as a balm for the living than for the dead. He said that the chanting and prayers were a way for us to calm our minds and to use that quiet space to remember my mother and to be in a mindful relationship with her. In this way, he added, funeral rites served as objects of meditation for quiet contemplation, and had the psychological effect of helping us to remember her virtues and to accept her passing.

Chief Reverend’s wise counsel helped us enormously. As each evening prayers drew to a close, the realization that we would soon have to say our final farewell allowed us to be in touch with our sadness and loss in a way that I believe would not have been possible if we had not cultivated the same meditative attitude towards her death, as my mother did towards her dying. In death, as in life, my mother left us an invaluable legacy.

### *Conclusion: Living a Good Life in the Shadow of Cancer*

My mother had encountered many difficult experiences throughout her life

- She was born in 1926 and grew up in Malaysia during the World War II, under Japanese occupation. Being the eldest of eleven children, her education was interrupted as she had to look after the family, often hiding from the Japanese soldiers and foraging for food in the villages.
- She was married at a young age to my father into a large, wealthy family. It was difficult for her to find her place and a voice in his family, but she was kind and empathetic and became my grandfather’s favorite daughter-in-law.
- About twenty years ago, at the age of seventy, she and my father were involved in a land slide. About 22 people, including my father, died in the accident. My mother, who was traveling with my father when the car was washed over the cliff, survived. The rescuers could not believe that a seventy-year-old woman was able to “kick” herself out of the car boot as it floated in the water.

Such was her courage, spirit, and will to live. As my mother put it (in Chinese) before her death “*chet kor is chet por*” (meaning “eating suffering is good nutrition”). My husband believes that the last eight months were perhaps some of the best times of my mother’s life. According to him:

She had a traditional upbringing. She was not an intellectual. What guided her life was traditions.

All she wanted was to be a “good wife and a good mother.” She withstood all things with her dreams and her values of “what is right, fair and just.” Her basic instinct was giving love, and this was often expressed in cooking good meals. She became a good cook. One of her basic values was “to be free.” She had her family with her constantly. She was able to play whatever *mahjong* (a Chinese game similar to bridge) she could, sit by the pool, and enjoy some cooking and her occasional cigarette. Most importantly she was able to let go and experience *Peng On* (peace of mind).

Part of this paper addressed the question “Should we tell?” My mother’s experiences in living a good life while dying have shown me that this is the wrong question. Questions should more usefully be focused on uncovering patients’ preferences, and helping them to achieve these choices. According to Gawande (2015) “... our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life” (p. 241).

All of us have a right not to suffer unnecessarily. This is a natural right; it comes with being human. In my view, no additional information about her illness would have ensured my mother a better quality of life during the remaining months. If her doctors were obligated to tell her the whole truth, I would have serious concerns for her mental health and well-being. Although the pain medication had reduced her pain and given her the ability to enjoy her times with the family, I believe that it was the opportunity to shape her personal narrative—as a good mother and a good person—that gave her life continued meaning and purpose.

Kazdaglis et al. (2010) noted “although truth-telling is preferable from a philosophical point of view, when it comes to real life, theories cannot be applied so easily and may not have the results expected” (p. 446). My mother’s experiences point to the importance of medical professionals having the discretion (rather than the obligation) to tailor disclosure to individual patient’s preferences and psychological make-up. And regardless of which culture or jurisdiction the medical professionals are practicing in, they should be supported rather than constrained by the law, policy makers, and guidelines in exercising this discretion and judgement freely.

Life gives us choices even when at times the solution appears to be black or white. In reality, life is lived in shades

of grey and this is especially so when cancer casts a long shadow. I believe that my mother was able to transform her life into a rainbow of colors with multi-dimensional hues.

The most valuable insight that I learned from my mother’s passing and something that is consistent with the Buddha’s teachings is: if we accept that we all die eventually, we can get on with living. And so we prepare for the “now” moments, every moment, until there are no more moments, and the journey ends. And the only moment that we can truly be in a “good” relationship with life and death, is NOW.

My mother was not a devout, or a religious Buddhist. I would describe her as a “Sunday school Buddhist,” visiting the monks and temples on auspicious occasions, and making donations when the need arose. But I believe that she died like a Buddha: accepting the transitory nature of life, and being grateful for what unfolds for her and facing her end of life with grace, dignity, and courage.

At her service, I delivered a eulogy, part of which explained her attitude towards life and death:

From a Buddhist perspective, flowers symbolize the cycle of life and death—the young bud matures into a beautiful blossom, then fades away quietly, returning to the earth to nurture new life. Our mother’s life had a similar narrative. She bloomed when she was crowned Miss Kedah. Then she blossomed into a lovely woman, wife and mother to six children, fourteen grandchildren and seven great grandchildren. Like her flowers, she has nurtured generations with her unconditional love, caring, and compassion. Like her flowers, our mother deeply understood the cycle of life and death. Let us rejoice with her in death as we had in life.

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