Chapter 10

Death acceptance and the meaning-centred approach to end-of-life care

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The final examination that faces all of us is how to die well. Death anxiety, just like test anxiety, in and by itself will not enable us to pass this final test. How can we best prepare ourselves to defeat this common enemy? Is there any way to cure this dread?

There is a trend in favour of hospice and palliative care over aggressive attempts to prolong lives (Teno et al., 2013). The increasing acceptance of physician-assisted suicide further indicates the need for more physicians capable of ending another person's life with dignity, empathy, and comfort.

Death anxiety is responsible for all kinds of psychological disorders (Iverach, Menzies, & Menzies, 2014), when death is perceived as an undefeatable monster capable of destroying all our cherished dreams and everything that makes happy. Religion, philosophy, and psychology all have wrestled with this perennial challenge, as attested by other chapters in this edited volume.

Down through history, human beings have developed elaborate defense mechanisms against the terror of death, both at the individual and cultural

levels, leading to a psychological state of denial (Pyszczynski, Greenberg, & Solomon, 2002; Solomon, Greenberg, & Pyszczynski, 2004). At the cultural level, its ubiquitous presence is felt, from the social functions of funeral and memorial services, religion, and entertainment, to medical care (Kearl, 1989). At the personal level, we resort to all kinds of coping responses towards this existential given. Our own death attitudes are often colored by our personal and collective experiences with the loss of loved ones and our efforts to make the terror of death more bearable.

Death attitudes and the medical professions

The medical profession has made it its mission to prolong life; their negative attitude towards death also makes it difficult for physicians to communicate the 'bad news' to patients and provide proper help during end-of-life care. Mortality is considered a medical failure (Gawande, 2014). In countries that have legalised physician-assisted suicides, such as Canada, family doctors often do not have the training and skills to end a patient's life with dignity and efficiency (Hune-Brown, 2017). Therefore, it has become more relevant today for physicians to be informed on the relevance of death attitudes and end-of-life care.

Health professionals' death attitudes and caring for the dying

Research has shown a connection between health professionals' death attitudes and the quality of end-of-life care. For example, nurses low in death acceptance tend to have negative attitudes towards end-of-life care, whereas nurses with high scores in death acceptance tend to cultivate better relationships with terminal patients (Braun, Gordon, & Uziely, 2010; Malliarou et al., 2011).

Similarly, Black (2007) studied the relationships between personal death attitudes of health professionals and communication regarding advance directives. The approach acceptance of death is positively correlated with initiating the discussion of advance directives, while negative death attitudes correlated negatively.

In a recent review article, Nia, Lehto, Ebadi, and Peyrovi (2016) reported that death anxiety is commonly experienced among healthcare providers and is associated with more negative attitudes about caring for dying patients and their families.

Physicians' personal values are also a factor in end-of-life care. Doukas, Gorenflo, and Supanich (1998) found that primary care physicians who most objected to physician-assisted death (PAD) were less likely to have executed an advance directive; furthermore, their findings suggested that personal physician values were relevant in the withdrawal of treatment in terminal care.

The above findings could be attributed to inadequate training in end-of-life issues in medical schools. Sullivan, Lakoma, and Block (2003) reported that medical students and residents in the United States felt unprepared to provide good care for the dying. They also reported that current educational practices and institutional culture in US medical schools do not support adequate end-of-life care.

Education about death attitudes in medical schools can help improve physician-patient communication and make physicians more aware of how their own death attitudes can affect terminal patients' well being and perceived meaning (Dickinson, 2007; Hamama-Raz, Solomon, & Ohry, 2000; Malliarou et al., 2011; Pollak et al. 2011; Servaty, Krejci, & Hayslip, 1996). For example, Schmi et al. (2016) found that medical residents who reported more classroom training during residency on end-of-life communication skills were more comfortable in end-of-life conversations with terminal patients.

In this chapter, we propose that death acceptance and meaning-making are capable of providing an effective antidote to death dread. We explain why this existential positive psychology approach is needed and how we can apply this meaning-centred approach in end-of-life care.

The positive psychology of death anxiety

From the perspective of second wave positive psychology (PP 2.0; Wong, 2011), all emotions, including negative ones, have adaptive value because they help enhance our resilience, meaning, and flourishing. Paradoxically, death holds the key to living a vital, authentic and meaningful life. Yalom (2008) once said that the idea of death has saved many lives. That is, we cannot life fully without becoming aware of the fragility and finiteness of life. The challenge of existential positive psychology is to discover pathways of death acceptance and living a life of significance, meaning, and lasting value. Such positive attitude towards death can enhance our well being (Neimeyer, 2005; Tomer, 2000; Tomer, Eliason, & Wong, 2008).

The positive psychology of death anxiety can be best understood in terms of the dual-system model (Wong, 2012a). According to this model, optimal adaptation depends on our ability to confront and transform the dark side of life in service of achieving positive goals. It also posits that the best defense is offense; the most effective way to protect ourselves against the terror of death is to aggressively pursue the task of living a meaningful life despite the shadow of death.

Both avoidance and approach systems are needed to be free from the prison of death fear and to motivate us to engage actively in what matters to us. From this dual-systems perspective, death fear and death acceptance can co-exist and work together for our well-being.

From death anxiety to death acceptance

Elisabeth Kubler-Ross' (1969, 2009) stage-model of coping with death (denial, anger, bargaining, depression, and acceptance) was a milestone in death studies. She has identified some defence mechanisms (denial and bargaining) and negative emotional reactions (anger and depression) involved in coming to terms with the reality of death — accepting death as the inevitable end. However, in the last fifty years, the psychology of death has been dominated by research on death anxiety (Kastenbaum, 2000; Neimeyer, 1994a, 1994b; Iverach et al., 2014). There was very little research on death acceptance. About 30 years ago, my associates and I conducted a comprehensive study of death acceptance, which led to the development of the Death Attitude Profile (DAP; Gesser, Wong, & Reker, 1988). In addition to death fear and death avoidance, we identified three distinct types of death acceptance: (1) neutral death acceptance — accepting death rationally as part of life; (2) approach acceptance — accepting death as a gateway to a better afterlife; and (3) escape acceptance — choosing death as a better alternative to a painful existence. The DAP was later revised as the DAP-R (Wong, Reker, & Gesser, 1994). Both scales have been widely used worldwide.

Three types of death acceptance

Approach acceptance is rooted in religious/spiritual beliefs in a desirable afterlife. To those who embrace such beliefs, afterlife is more than symbolic immortality, because it is typically associated with theistic religious faith or belief in a transcendental reality. Approach acceptance is based on the social construction

of life beyond the grave, thus offering hope and comfort to the dying as well as the bereaved. More specifically, Harding, Flannelly, Weaver, and Costa (2005) reported that scales that measure belief in God's existence and belief in the afterlife were both negatively correlated with death anxiety but positively correlated with death acceptance.

Escape acceptance is primarily based on the perception that death offers a welcome relief from the pain and miseries of being alive. Suicide and physician-assisted suicide are expressions of escape acceptance. For example, Cicirelli (2006) observed that when individuals experience intractable pain or loss of function, they chose to end their lives.

The construct of neutral acceptance means to accept the reality of death in a rational manner and make the best use of the limited time on earth. Cicirelli (2001) has identified four different personal meanings of death: extinction, afterlife, motivator, and legacy. Belief in the afterlife is similar to approach acceptance; extinction, motivator, and legacy can all come under the umbrella of neutral acceptance.

Once one has found something worth dying for, one is no longer afraid of death. When people are doing something significant and fulfilling, and they are totally engaged in doing what they love, they will have no time to worry about death. Thus, whether we focus on avoidance or approach to the reality of death depends on the meaning we attach to it.

Approach acceptance can incorporate neutral acceptance with regard to making the best use of our finite life on earth, but it has the additional benefit of providing hope for continued existence of one's consciousness beyond the grave. We may never know why a majority of people believe in heaven or an afterlife (Bethune, 2013), but such beliefs, regardless of whether they are based on religious or secular convictions, can be a source of comfort and hope in the face of death.

Death acceptance and meaning-making

Our capacities for meaning-seeking and meaning-making play a key role in curing the dread of death and facilitating death acceptance. We can discover something so meaningful and beautiful even in times of death, as we have already alluded to. In fact, Wong has described the meaning management theory (MMT; Wong, 2008) as a conceptual framework to understand death acceptance. MMT posits that meaning is the best protection against the fear of

death and dying because meaning management enables us to transform our fears, embrace life, and do what matters most to us.

Meaning-making can help us rise above what is beyond our control and transform our fears into courage and faith. At the same time, meaning-making motivates us to strive towards something that is bigger and longer lasting than ourselves, whether it is a cultural worldview or a personal God.

From terror management theory to meaning management theory

According to terror management theory (TMT), avoidance of death anxiety is the primary motive, because it is triggered by the terror of death. TMT contends that when people feel threatened by death salience, they resort to cultural beliefs and their self-esteem as a refuge. Wong and Tomer (2011) argue that the main thrust of TMT is unconscious and defensive. Such a defensive posture against the fear of death may create a barrier against death awareness and hinder the intention of living fully despite the terror of death.

MMT is based on existential positive psychology (Wong, 2005, 2009) — the recognition that mature positive psychology needs to be situated in the context of the dark side of human existence. MMT proposes it is more productive and fulfilling to courageously and honestly confront our death anxiety and at the same time passionately pursue a meaningful goal (Tomer et al., 2008; Wong & Tomer, 2011)

MMT provides a comprehensive framework to manage our inner life in terms of its meaning-seeking, meaning-making, and meaning-reconstruction processes in the service of survival and thriving. MMT recognises the legitimacy of unconscious defensive mechanisms proposed by TMT, but complements it by emphasising the adaptive benefits of death acceptance and meaning management (Wong & Tomer, 2011).

Wong's (2012a) dual system model provides a conceptual framework to integrate both positive and negative attitudes towards death and provide a more realistic picture of how we cope with personal death. While an avoidance life orientation condemns us to the prison of fear, a positive life orientation enables us to accept the inevitable negatives and move forward to pursue a meaningful and fulfilling life. Yalom (2008) recognises that 'everyone is destined to experience both the exhilaration of life and the fear of mortality' (p. 273). The trick is

how to keep our mind on life rather than on death. Kahlil Gibran (1994) also says: 'It is life in quest of life in bodies that fear the grave' (p. 104).

Meaning management is more than cognitive reframing or rationalisation. It actually requires a fundamental shift from pleasure-seeking to the meaning mindset (Wong, 2012b), from self-centredness to self-transcendence (Wong, 2016). Meaning therapy (Wong, 2010, 2012c) equips people to squeeze out meaning and hope from even the darkest moments of life.

Cancer patients and end-of-life care

One of the most extensively studied end-of-life populations is terminally ill patients with cancer. According to the World Health Organization (2015), cancer was the second leading cause of death globally and accounted for 8.8 million deaths in 2015. Given these high numbers, it is likely that throughout life the reader has witnessed someone's death from cancer. Thus, we consider it essential to introduce in this chapter an analysis of the meaning-related psychological problems encountered by terminally ill patients with cancer as well as the most relevant meaning-centred therapies for this population.

Loss of meaning and dignity in cancer patients

Terminally ill cancer patients are very vulnerable to suffer from loss of meaning in life and dignity, resulting in the desire for hastened death. About 17% of cancer patients reported a high desire to terminate their lives primarily because of depression, hopelessness, and loss of meaning rather than pain (Breibart et al., 2000). Similarly, Chochinov et al. (2002) observed that 47% of patients in their last months of life reported certain loss of sense of dignity. Moadel et al. (1999) interviewed 248 cancer patients regarding their spiritual and existential needs. Patients reported the need to receive help with: overcoming their fears (51%), finding hope (42%), finding meaning in life (40%), and finding spiritual resources (39%). Meaning-centred therapies for advanced cancer, some of which are presented below, aim to overcome this lack of meaning and worth in life. For instance, dignity therapy is designed to decrease suffering, enhance quality of life and bolster a sense of dignity; it provides a safe, therapeutic environment for patients to review the most meaningful aspects of their lives in a way that helps restore their core values, such as 'Family', 'Pleasure', 'Caring', 'A Sense of Accomplishment', 'True Friendship', and 'Rich Experience' (Hack et al., 2010).

Meaning, spirituality, and values

One of the core meaning-related areas in terminally ill cancer patients is spirituality, defined as 'the way in which people understand their lives in view of their ultimate meaning and value' (Muldoon & King, 1995, p. 336). The positive relationship between spirituality and well being in cancer has been widely supported (e.g., Visser, Garssen, & Vingerhoets, 2010). For example, Nelson, Rosenfeld, Breitbart, and Galietta (2002) found a strong negative association between spiritual well being and depression in terminally ill patients with cancer and AIDS. In another study with a sample of 160 cancer patients with a life expectancy of less than 3 months, McClain, Rosenfeld, and Breitbart (2003) showed that spiritual well being has an effect on end-of-life despair, including desire for hastened death, hopelessness, and suicidal ideation.

Personal values are also fundamentally related to meaning matters. One of the classic definitions understands a personal value as 'an enduring belief that a specific mode of conduct or end-state of existence is personally or socially preferable to an opposite or converse mode of conduct or end-state of existence' (Rokeach, 1973, p. 5). Fegg, Wasner, Neudert, and Borasio (2005) define values as 'cognitive representations of goals or motivations that are important to people. They can be described as emotionally and cognitively relevant principles guiding people's lives' (p. 154). Other authors understand values as 'verbally construed global desired life consequences' (Hayes, Strosahl, & Wilson, 1999, p. 206). All in all, these definitions seem to refer to values as what really matters in life.

Although values are considered to remain very stable over time, they can change for different reasons, such as socialisation, self-confrontation, cultural upheaval, therapy, or emotionally significant events (Rokeach, 1973). The experience of cancer is undoubtedly such an event. Grezsta and Sieminska (2011) reported that after the diagnosis of cancer, patients significantly gave more importance to religious morality (salvation, forgiving, being helpful, clean), personal orientation (self-respect, true friendship, happiness), self-constriction (self-control, obedience, honesty), family security, and delayed gratification. In the same time, values such as immediate gratification, self-expansion (being capable, ambitious, broadminded), and competence (a sense of accomplishment, being imaginative, intellectual) decreased in importance. Another study by Fegg et al. (2005) showed that the most important values for terminally ill patients with cancer or amyotrophic lateral sclerosis were benevolence, self-direction, and universalism, whereas power, achieve-

ment, and stimulation received the lowest importance. In comparison with healthy adults, these patients scored higher in benevolence and self-enhancement values. The data of this study suggested that security, conformity, and tradition (conservative values) can protect the patients' quality of life in the palliative care situation.

A new line of research recently commenced by Carreno et al. (2017) seems to reveal more information about the relationship of personal values and quality of life in cancer patients. Preliminary results suggest that cancer patients, either after a recent nonterminal diagnosis or terminally ill, seem to perceive shifts in the importance and dedication they give to areas such as family, intimate relationships, friendship, leisure, work, health, spirituality, and self. The highest increases of value and personal involvement are produced in the most priority areas of patients' lives, which indicates that they do a prioritisation and reaffirmation on who they are and what is worthy in life. In addition, patients not only indicate changes in what they consider important, but this is related to a greater involvement in their worthy areas, which in turn has a high impact on quality of life. Those who do not show this shift or clarification in the system of personal values indicate statistically lower spiritual well being and quality of life. Thus, these results also reflect that the clarification of the worldview, self, and personal values are relevant for a clinical perspective since they are related to quality of life and spiritual well being.

Meaning-centred end-of-life cancer care

Patients with cancer are normal people; they can present the same psychopathologies as the rest of the population. Thus, in accordance with the problems presented by each patient, the psychological intervention must be oriented either to the psychopathologic treatment or to reestablish the quality of life that has been altered by the illness, helping patients in the process of coping and adapting to cancer with psychological support and strategies from psycho-oncology.

In general, the majority of psychological interventions in oncology have the goal of improving quality of life and the adjustment to the illness of patients and their families. With regard to the specific case of patients with advanced cancer, they show a greater complexity in the management of physical and psychological symptoms. The emotional response of patients in that phase can be very wide, from passivity, anger, self-reproach, and even to the negation of

their situation. In this point, the therapy may aim to guide patients in the revision of their personal values and meaning of life.

Meaning-centred therapies for patients with advanced cancer have demonstrated enhancement in areas such as spiritual well being, quality of life, sense of dignity and meaning, depression, anxiety, and desire for death (e.g., Breitbart et al., 2010; Breitbart et al., 2012; Chochinov et al., 2011). Before presenting two of the most validated meaning-centred therapies for advanced cancer, we see it necessary to highlight the core role of personal values in the functioning of these therapies. Wong (2012d) stresses that 'meaning therapy serves the dual function of healing what is broken and bringing out what is good and right about individuals' (p. xii). Wong's 'PURE' model accounts for four ingredients involved in the definition of meaning: purpose, understanding, responsible action, and enjoyment or evaluation. According to this model, having a meaningful life and a meaningful death not only implies making sense or giving coherence to life and death, but that they are worth living as well. It is in this point that personal values play a fundamental role in meaning-centred therapies. In order for life, death, or any event to be worth living, it is necessary to clarify personal values and to live or feel that one has lived according to them.

One of the meaning-centred therapies that makes explicit personal values as the key components is dignity therapy (Hack et al., 2010). This therapy has the goal of increasing the sense of dignity of end-of-life patients. Dignity, defined as the 'quality or state of being worthy, honored, or esteemed (*Webster's new international dictionary*, 1946) is determined as patients approach death by three broad issues: (1) illness-related concerns, (2) dignity conserving repertoire, and (3) Social Dignity Inventory. The protocol of the 1 to 3 sessions of dignity therapy mainly consists of the presentation of nine questions about what is and has been meaningful in the life of the patients. It includes the final words and legacy that the patient wants to transmit to family and loved ones. These questions can be openly responded to in writings or audio-recordings which are transcribed later. Once edited, the patient identifies individuals with whom the transcription must be shared following their death.

Another scientifically validated meaning-centred therapy for advanced cancer is meaning-centred psychotherapy (Breitbart & Applebaum, 2011). This therapy was designed to treat despair, demoralisation, hopelessness, and desire for hastened death in patients with advanced cancer who do not suffer from clinical depression. Its aim is to sustain and enhance a sense of meaning

in the face of existential crisis in which patients experiment a loss of meaning, value and purpose in life. In the terms of Breitbart and Applebaum (2011):

> Meaning, or having a sense that one's life has meaning, involves the conviction that one is fulfilling a unique role and purpose in a life that is a gift. This comes with a responsibility to live to one's full potential as a human being; in so doing, one gains a sense of peace, contentment, or even transcendence, through connectedness with something greater than one's self. (p. 138)

The protocol of meaning-centred psychotherapy, both in its group or individual application (Breitbart & Poppito, 2014a, 2014b) is composed of 7 to 8 sessions in which patients reflect on the concept of meaning and the impact that cancer has produced on their identity. Within the rest of the following sessions, the therapy focuses on helping patients connect with various sources of meaning in their lives. In other words, through different exercises and conversations the therapist encourages patients to clarify their personal values and to live in the service of those values. Based on Viktor Frankl's perspective, Breitbart et al. propose four main sources of meaning: (1) creativity (work, deeds, dedication to causes); (2) experience (art, nature, humour, love, relationships, roles); (3) attitude (the stance one takes towards suffering, death, and other existential problems); and (4) legacy (meaning in a historical and familiar context — past, present, and future). Throughout these sources of meaning, meaning-centred psychotherapy intends to (a) encourage patients to seek meaning in their lives, despite the uncertainty and constrains of the illness; (b) find new ways of re-engagement to life, for example, through transcendence; (c) learn to distinguish between constrains that can be changed, and accept what cannot be changed; (d) integrate the diagnosis of cancer in the history of life of the patient; (e) express emotions and feelings; and (f) enhance psychological adjustment through the meaning of life.

Conclusion

In conclusion, the construct of meaning has an important therapeutic value in patients with advanced cancer. Sustaining and encouraging the meaning of life leads to benefits in the enhancement of spiritual and emotional well being, as well as in quality of life. Further development and validation of these meaning-centred therapies in other end-of life populations are needed.

Our review of the literature has shown that in meaning-centred end-of-life care, the personal attributes of medical professionals are as important as the intervention skills. To provide high quality end-of-life care, medical professionals need to have resolved their own fear of death and come to terms with personal mortality. In addition, they need to have resolved their personal existential struggles, regarding the meaning and core beliefs of their own lives. When healthcare professionals are aware of their own calling, personal values, beliefs, and attitudes, especially with respect to their mortality and spirituality, they create deeper and more significant connections with their patients (Puchalski & Guenther, 2012).

The quality of the presence that professionals provide in the relationship with their patients depends on their maturity and spiritual connection. From this point of view, the commitment to the self-care of professionals should be an ethical imperative. Beyond knowing the different models of therapy, whether clinicians feel called to take care of patients in an integrative way and to cultivate spirituality, they must become aware of the need to connect first with their source of well being, peace, and personal harmony, with its own spiritual dimension.

Good end-of-life care requires teamwork, which may include physicians, nurses, psychologists, and pastoral care chaplains. When the team use their collective resources and adopt a holistic approach that recognises the importance of the spiritual-existential dimension in patients and their families, it will benefit both the healthcare professionals and their patients.

Finally, we argue that better end-of-life care education is needed in medical schools, residence training, and continued education for practicing physicians. This is important not only because of increased demand for hospice and palliative care, but also because of increased demands for physician-assisted death in many countries.

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