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## Understanding the plight of the terminally ill population

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## Understanding the plight of the terminally ill population

### Abstract

The emotional, physical, social, and relational experiences of the terminally ill population were investigated. The literature strongly stated that the dying process, though physically and psychologically taxing, need not be devoid of meaning. It was also discovered that though patient disease trajectories and emotional experiences are highly individualized many helpful generalizations can be made. The research findings support the belief that mental health practitioners have much to offer the dying person as he or she wrestles with impending death.

UNDERSTANDING THE PLIGHT OF THE TERMINALLY ILL  
POPULATION

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Master of Arts

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The emotional, physical, social, and relational experiences of the terminally ill population were investigated. The literature strongly stated that the dying process, though physically and psychologically taxing, need not be devoid of meaning. It was also discovered that though patient disease trajectories and emotional experiences are highly individualized many helpful generalizations can be made. The research findings support the belief that mental health practitioners have much to offer the dying person as he or she wrestles with impending death.

“It is impossible that anything so natural, so necessary, and so universal as death, should ever have been designed by Providence as an evil to mankind.”(Swift, n.d.). Dying is as much a part of one’s existence as being born; yet, modern day American society continues to struggle with end of life issues (e.g., Moller,1996; Rosenberg,1998; Wogrin, 2001).

Death is enshrouded in mystery which makes it unpredictable, intimidating, and altogether frightening (e.g., Kubler-Ross, 1969; McNamara, 2001; Tobin,1999). The taboo nature of the topic has fueled the fiery spread of “death illiteracy” and discomfort (Pearson, & Stubbs, 1999). Avery D. Weisman asserts that most people “postpone, put aside, disavow, and deny deaths relevance” until that moment in time when death is no longer avoidable (Kastenbaum, 2004, p.11). When confronted with dying and death, we are forced “to acknowledge the dreadful uncertainty that underlies our own fragile lives” (McNamara 2001, p.135).

Facing the impending loss of one’s own life in a well adjusted manner requires much personal contemplation, preparation and fortitude as well as outside support (Tobin, 1999). Dying, if handled with the same care and concern as living, can be an enriching experience for both the patient and his or her inner circle of loved ones (Byock,1997; Kubler-Ross, 1969).

In the words of Elizabeth Kubler-Ross, “it would take so little to remember that the sick person too has feelings, has wishes, has opinions, and -most important of all- has the right to be heard” (1969, p.22). In order to be therapeutically effective when working with the terminally ill population mental health practitioners must first gain insight into the plight of the dying person.

### Receiving a Terminal Diagnosis

#### *The Emotional Roller Coaster Ride*

It has been said that death is both “an event and a process” (de Vries,1999, p. 361; Orbach, 1999, p.10). Much like a roller coaster ride, terminal illness can be a complicated journey of “rising hope and plummeting despair” (e.g., Lair, 1996; Moller,1996, p.68 & 69; Wogrin, 2001). Fleeting positive responses to medical treatment, new treatment options, and much fought for remissions allow hope to rise while dreaded relapse, always the dark cloud looming overhead, sneaks in to steal fragile joy (Pearson & Stubbs, 1999).

Many ups and downs and twists and turns, may take place during the course of a terminal illness. Yet unavoidably, along each person’s disease trajectory there comes a point in time when living demands preparation for dying (e.g., Kubler-Ross,1969; Lair,1996; Tobin, 1999; Wogrin, 2001).

*Loss of Hope*

Patients are often ill prepared to forego their valiant fight for life in surrender to certain death (e.g., Staton, Shuy & Byock, 2001; Tobin, 1999; Winchester-Nadeau, 1998). There seems to be an unconscious rebellion against dying buried deep within the human psyche; and this innate drive for survival is not easily compromised (Kubler-Ross, 1969). When a terminal prognosis is given, a painful shift in thinking is required (e.g., Lair, 1996; McNamara, 2001; Pearson & Stubbs, 1999). Moving from hope for a cure to loss of hope can be a difficult transition to bridge (e.g., Lair, 1996; McNamara, 2001; Staton et al., 2001). It is deeply imbedded in human kind to “leave the door open for hope”, hope for a cure, hope for a miracle, hope for a remission, and hope for more time (Kubler-Ross, 1969, p. 127 & 149).

### The Physiological Implications of Terminal Illness

*Medical Decision Making*

Though the physiological progression of dying, as “organs are affected and shut down”, remains virtually the same for all, the exact course an illness will take is unpredictable (Staton et al., 2001, p. 69). As symptoms and unanticipated complications develop, new treatment options are introduced which may lead to

further, often times invasive and painful procedures (e.g., Byock, 1997; deVries, 1999; Staton et al., 1969). With each new surprise the patient is forced to wrestle with what direction to take next (Staton et. al., 2001). The dying person and his or her loved ones face ongoing, agonizing decision making (e.g., Pearson & Stubbs, 1999; Staton et al., 2001; Tobin, 1999).

All the while medical choices are being made there is an underlying awareness that every act serves to prolong life not necessarily cure the illness (Wogrin, 2001). Decisions must be made in regard to medication, pain management, food and fluid intake, and home care versus institutional care (Byock, 1997; Pearson & Stubbs, 1999) Also weighing heavily on the dying person is whether or not to accept death delaying interventions like surgery, antibiotics, resuscitation, ventilators, and respirators (e.g., Byock, 1997; Staton et al., 2001; Wogrin, 2001)

The bittersweet burden of choice between quality of life and quantity of days certainly confounds the decision making process (e.g., Byock, 1997; McNamara, 2001; Tobin, 1999). Yet, inevitably, the patient along with his or her significant others must answer the ever looming question: "When is enough, enough?" (Pearson & Stubbs, 1999, p. 47).

*Physical Suffering and Pain*

The intense pain associated with terminal illness is a complicated weaving together of the physical, emotional, and psychological effects of dying (Byock, 1997; Tobin, 1999). Physical pain is often exacerbated by the patient's maladaptive thoughts, feelings, fears, and concerns (Byock, 1997). Further complicating matters is the fact that effective pain management is often allusive which adds to both the physical and emotional stress load of the dying patient (e.g., Byock, 1997; Staton et al., 2001; Wogrin, 2001).

Physical suffering is an unavoidable yet common denominator among the dying (e.g., Byock, 1997; Tobin, 1999; Wogrin, 2001). Terminal illness brings with it a "chronic, regular, persistent, constant, often inescapable pain" (Lair, 1996; Moller, 1996, p. 68). This pain may result from invasive treatment interventions as well as worsening disease conditions caused by tumor growth, the spread of malignancies to other parts of the body, and systemic complications (e.g., Byock, 1997; McNamara, 2001; Pearson & Stubbs, 1999). Physical discomfort interferes with the dying patient's ability to fully engage in what remains of his or her life (e.g., Byock, 1997; Kubler-Ross, 1969; McNamara, 2001; Wogrin, 2001).

It should also be added that many patients struggle to weigh the costs and benefits of pain medication ( Byock, 1997; Staton et al., 2001). Medication not only diminishes physical discomfort but also dulls one's senses (McNamara, 2001). Patients often fight against the use of pain medication in order to remain coherent during their final days (Wogrin, 2001).

### *Physical Helplessness*

As the disease progresses, true physical helplessness is forced upon the dying person (e.g., Mc Namara, 2001; Pearson & Stubbs, 1999; Tobin, 1999). Side effects like fatigue, loss of strength, pain, nausea, confusion, and dizziness make it difficult to provide self care ( e.g., Byock, 1997; Pearson & Stubbs, 1999; Staton et al., 2001). The dying person has little choice but to accept more and more help (e.g., Kubler-Ross, 1969; Staton et al., 2001; Wogrin, 2001). Everything from personal grooming, feeding, bathing, and toileting, to transportation, and decision making eventually falls on the mercy of caregivers (Wogrin, 2001). This dependency on others is oftentimes considered the rawest form of humility (Byock,1997). The loss of one's dignity can be one of the many cruel consequences of declining health ( e.g., McNamara, 2001; Staton et al., 2001; Tobin, 1999).

## Emotional and Psychological Aspects of a Terminal Diagnosis

### *Coping Strategies*

The emotional and psychological struggles of the dying are many (e.g., Kastenbaum, 2004; Kubler-Ross, 1969; McNamara, 2001; Pearson & Stubbs, 1999; Tobin, 1999). A complicated, pervasive sense of grief and loss settles in immediately upon diagnosis, endures throughout the course of an illness, and lasts far beyond death for those left behind (Wogrin, 2001).

Coping strategies are often employed as unconscious efforts to soften the blow to one's psyche (Kubler-Ross, 1969). Such strategies are often discussed in terms of general phases or stages (e.g., Kubler-Ross, 1969; Lair, 1996; Tobin, 1999). Coping stages not only vary in intensity and duration, but may also coexist (e.g., Kubler-Ross, 1969; Lair, 1996; Tobin, 1999). Furthermore, an individual may float back and forth between stages throughout the course of their illness (e.g., Kubler-Ross, 1969; Lair, 1996; Tobin, 1999). Many commonalities exist among members of the dying population as they attempt to cope first with illness then with imminent death (e.g. Kubler-Ross, 1969, Tobin, 1999; Wogrin, 2001).

Typically, there is an initial sense of shock and wonder upon learning that death

is near (e.g., Kubler-Ross, 1969; Staton et al., 2001; Tobin, 1999). Patients often move from astonishment to denial with thoughts like “No, this is impossible! I cannot be dying! There must have been a mistake” (Kubler-Ross, 1969). At this time, there may be an almost desperate psychological attempt to flee from reality (e.g., Kubler-Ross, 1969; Lair, 1996; Tobin, 1999).

It is important to note that both shock and denial have utility-the psyche is afforded the luxury of dealing with devastating news in small, manageable doses (Kubler-Ross, 1969; Tobin, 1999). Yet, as is often the case, what is helpful can also be hurtful. If persistent, the failure to grasp the magnitude of the situation can impede one’s healthy movement forward (Lair, 1996; Tobin, 1999; ).

Along with a terminal diagnosis comes an immense amount of uncertainty and apprehension (e.g., Byock, 1997; McNamara, 2001; Ryan & Deci, 2004; Wogrin, 2001). Though certain aspects of terminal illness (like general declining health) are foreseeable, others (like specific new symptoms and complications) are not (Wogrin, 2001). What cannot be predicted cannot be planned for, and what cannot be planned for cannot be prepared for (McNamara, 2001). When an individual begins to experience fear it is a sign that the truth is settling in and he or she is beginning to deal with reality (Tobin, 1999).

As the possibility of death is reckoned with, anger often sets in

(e.g., Kubler-Ross, 1969; Pearson & Stubbs, 1999; Tobin, 1999). The dying person may become enraged, bitter, and consumed with feelings of resentment ( e.g., Kubler-Ross, 1969; Lair, 1996; Byock, 1997). Such strong emotions may be targeted towards God, loved ones, and helping professionals as well as those who enjoy good health (Kubler-Ross, 1969; Tobin, 1999; ). The patient may be avoided and or rejected by others as a result of his or her prickly disposition (Kubler-Ross, 1969). This may lead to a heart wrenching emotional if not physical isolation from loved ones and caregivers (Kubler-Ross, 1969).

When the dying patient realizes he or she can no longer deny or ignore their illness' progression, a pervasive sense of loss often settles in (e.g., Byock, 1997; Orbach, 1999; Pearson & Stubbs, 1999). The thought processes and emotions experienced at this time aid the dying person in preparing for "the final separation from this world"(e.g., Kubler-Ross, 1969; Tobin, 1999; Wogrin, 2001).

A certain degree of grief, anxiety, and depression are natural and necessary when coping with approaching death ( e.g., Kubler-Ross, 1969; Lair, 1996; Wogrin, 2001). Dying individuals may mourn squandered opportunities, mistakes, regrets, and "roads not taken" while at the same time reckoning with current and future losses (Tobin, 1999). Though illness related depression serves a purpose, it

is important to seek treatment if it becomes debilitating and/or outgrows its usefulness (Byock, 1997; National Institute of Mental Health [NIMH], 2002).

If a patient has worked through the preceding stages and has had time to adjust to his or her declining condition, a growing acceptance of his or her unavoidable “fate” will emerge (Kubler-Ross, 1969; Lair, 1996). The subtle movement toward acceptance may be difficult to recognize; especially if it occurs shortly before death when communication becomes more difficult (Lair, 1996).

During this time, the dying person will be neither angry or depressed but will look toward death with what Kubler-Ross calls a “quiet expectation” (1969, p.124). This resignation to death does not signify defeat, but rather acknowledgement of yet another necessary life transition (Tobin, 1999).

### *The Impact of Terminal Illness on Significant Relationships*

Terminally ill patients long to remain connected to their families and social networks (Staton et al., 2001). Sadly, very few people have the capacity for talking about death or for talking with the dying (Wogrin, 2001). This deficiency may ultimately lead to a heartbreaking emotional separation from the dying person; allowing “silence and pretense” to take the place of meaningful conversation and memory making (McNamara, 2001, p. 80). Rewarding opportunities and

precious moments are missed if the aforementioned gap is not bridged (e.g., Kubler-Ross, 1969; Tobin, 1999; Wogrin, 2001). Open, straightforward, candid conversations are essential if cathartic relational tasks are to be completed (Wogrin, 2001).

Complicating matters is the fact that both the patient and his or her significant others may deny the importance of, or be uncomfortable talking about, issues related to illness and death (e.g., Byock, 1997; Pearson & Stubbs, 1999; Staton et al., 2001). Often times, the dying person's level of acceptance and or death related comfort level is out of sync with that of his or her loved ones (Byock, 1997; Pearson & Stubbs, 1999). This lack of emotional synergy may lead to the patient "stuffing" his or her feelings and thoughts out of personal discomfort or in an effort to protect significant others (Wogrin, 2001). Family and friends may do likewise (e.g., Byock, 1997; Kubler-Ross, 1969; Pearson & Stubbs, 1999).

It goes without saying that terminal illness wreaks havoc in the daily life of a family (e.g., Pearson & Stubbs, 1999; Staton et al., 2001; Wogrin, 2001). Family roles are changed along with operational dynamics as day to day activities are interrupted by the imposing needs of the ill person (Byock, 1997).

The dying person may develop a keen sense of uselessness which often fuels

feelings of worthlessness (e.g., Byock, 1997; Staton et al., 2001; Wogrin, 2001).

To be served and not be able to reciprocate is a cruel attack on an individual's ego, pride, and self concept (e.g., McNamara, 2001; Tobin, 1999; Wogrin, 2001). As a result, feelings of frustration, guilt, resentment, and anger may develop as the dying person loses sight of the value he or she holds in the family unit (Pearson & Stubbs, 1999).

### *Social Ramifications of a Terminal Diagnosis*

Often ignored is the fact that each person is part of a larger social whole and society requires much from its members (Moller, 1996). Attributes like youth, vigor, strength and mobility are highly valued in our country (Byock, 1997). Dying in the absence of such assets may be mistakenly viewed as a personal shortcoming (Wogrin, 2001). Feelings of weakness, failure, and embarrassment often creep in when the patient perceives the loss of his or her productivity (Byock, 1997). The dying patient not only faces losing his/her place in the family as a productive, contributing, necessary player, but also in the workplace, and community at large (e.g., Byock, 1997; McNamara, 2001; Pearson & Stubbs, 1999).

### Implications For Counselors

The terminally ill person faces ongoing struggles in virtually every domain of life (e.g., Byock, 1997; Lair, 1996; Wogrin, 2001). Among other issues, the

patient slowly grapples with grief, physical decline, loss of control, and dependence on others (Pearson & Stubbs, 1999). Mental health practitioners have an important role to play in helping the dying person give voice to, and move through, their physical and emotional pain toward a peaceful death (e.g., Haley, Larson, Kasl-Godley, Neimeyer, & Kwilosz, 2003; Kubler-Ross, 1969; Lair, 1996; Tobin, 1999).

Many people are incapable of viewing death as anything other than a tragic, cruel, twist of fate (e.g., Byock, 1997; Moller, 1996; Staton et al., 2001). In fact, “the concept of dying well is so foreign to most” that there is often a failure to make the best out of the dying experience (Byock, 1997, p.36). Contrary to popular belief, death can be approached not only with grace but also with the expectation of rich rewards and human growth (e.g., Byock, 1997; Kubler-Ross, 1969; Tobin, 1999; Wogrin, 2001). Convincing the dying person that meaning can be found even during the worst of times may prove challenging but worthwhile in the end (e.g., Byock, 1997; Frankl, 1959; Lair, 1996; Orbach, 1999).

It is important to respect the unique nature of each person’s dying experience (e.g., Byock, 1997; Lair 1996; Wogrin, 2001). Just as there is “no one right way to

live there is no one right way to die” (Wogrin, 2001, p.58). According to Beverly McNamara, the modern day good death occurs when a patient can say with certainty “I am dying my way” (2001, p.43). Helping patients sort out their own personal definition of a “good death” aids them in planning and preparing for the end of life (e.g., Byock, 1997; Tobin, 1999; Wogrin, 2001). Because so much of a terminal illness is unpredictable and uncontrollable, it is important to help dying patients identify areas in which they can impact outcomes while they are still coherent enough to do so (Petersen, Heesaker, & Marsh, 2001; Wogrin,2001). For example, if patients have the foresight to plan ahead they may decide where to die (home or hospital), which treatment options to accept and which to decline (pain medication, invasive procedures), and whether or not to be resuscitated in the event of a cardiac/respiratory crisis (e.g., Staton et al., 2001; Tobin, 1999; Wogrin, 2001). On an interpersonal level, patients can be encouraged to partake in estate planning, funeral arrangements, letter/memoir writing, and audio/video recorded messages to loved ones (e.g., Byock, 1997; Tobin, 1999; Wogrin,2001). The much hoped for result is “to empower the patient to take control of their own dying process” (Viney, Walker, Robertson, Lilley, & Ewan, 1994).

Mental health practitioners can also be influential in keeping the lines of communication open between the dying person and his or her significant others

(Lair, 1996). They may serve as facilitators, mediators, consultants, and guides as patients endeavor to express themselves in meaningful ways. If communication is open, so then are the channels leading to enriching encounters with loved ones (e.g., Kubler-Ross, 1969; Byock, 1997; Tobin, 1999). If all parties involved are willing and able, old wounds, resentment, bitterness, and guilt can be addressed (Lair, 1996; Wogrin, 2001). Positive affect like love, gratitude, appreciation, and shared sorrow can also be expressed (Tobin, 1999).

In order to be therapeutically effective, it is recommended that helping professionals approach the dying person with much empathy, sensitivity, respect, dignity, and compassion (e.g., Byock, 1997; Kubler-Ross, 1969; Wogrin, 2001, p.16). Within the safe confines of a well constructed relationship, mental health practitioners can assist their dying patients with the exploration, identification, and healthy expression of death related thoughts and feelings ( e.g., Counselman, 1997; Lair, 1996; Orbach, 1999; Tobin, 1999). Ultimate peace and acceptance are attainable when patients are afforded the freedom to experience the full range of their emotions (Kubler-Ross, 1969; Tobin, 1999).

### Conclusion

Having the courage to step inside the world of the dying is perhaps the most significant contribution a mental health practitioner can make to the terminally ill

population. Though not for the faint hearted, partnering with a patient as he or she struggles to live through the dying process can be rewarding (e.g., Byock, 1997; Kubler-Ross, 1969; Lair, 1996). Pearson and Stubbs assert that “When you escort a dying person to the threshold between life and death you also embark on an unfathomable journey.” (1999, p. 19).

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