Exploring the Will to Live and Distinguishing Depression at End of Life

Discussing the will to live with older adults may foster a more person-centered perspective on end of life than the current healthcare focus.

Among the best predictors of an older adult’s wish to prolong life is their will to live (Carmel and Mutran, 1997) and depression (Lawton, 2001). Although the will to live and depression are associated (Chochinov et al., 2005; Carmel, 2011), they are distinct phenomena. The will to live is a psychological expression of the natural drive of human beings toward life. Existing across the life cycle, this will becomes more consciously salient during health crises and at the end of life. An individual’s will to live may activate personal choices at the end of life. In contrast, clinical depression is a treatable disease that also impacts end-of-life planning.

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Moody (2010) points to the need to honor an older person’s will to live, as evidenced by their end-of-life decisions and, at the same time, urges practitioners to assess and respond to older adults with depression: “Failing to diagnose and treat late-life depression could consign untold numbers of older people to self-imposed death by neglect under the label of self determination, but regarding anyone who refuses treatment as suffering from mental illness is disrespectful of the patient’s autonomy.”

Defining Will to Live and Valuation of Life
Will to live and recognizing the inevitability of death are essential aspects of human existence (Yalom, 1980). Freud identifies these existential elements as the life force, Eros, versus death drive, Thanatos. We will explore how this dynamic manifests as we age—as a dance or a wrestling match.

For elders, life force and acceptance or even desire for death depends upon many factors. As practitioners in the field of aging, we should ask ourselves: For how long, for whom, and under what circumstances does this persistence continue? Humanities scholars long have explored these issues, and now there is intriguing social science research that may help us find answers to these important questions in our era of longevity.

Sara Carmel and colleagues conducted six large research studies on older Israelis’ will to live, encompassing rational and instinctual underpinnings, which can be self-assessed...
(Carmel, 2001). The studies measure will to live through one direct question: “If you could describe your will to live, on a scale of 0 to 5, would you say that it is: 5=very strong, 4=strong, 3=intermediate, 2=weak, 1=very weak, 0=no will to live?”

To validate hypothesized associations between a will to live and indicators of psychological well-being and quality of life, one needs specific criteria. Though longer reliable and valid scales have been developed, the one-item scale is just as good as a measure, similar to the single-item self-assessed health measure (Carmel, 2011).

Will to live was found to be an important indicator of general well-being, encompassing psychological and physical dimensions. When life was not threatened, older adults’ will to live was quite strong (Carmel and Mutran, 1997; Carmel, 2001, 2011).

Not surprisingly, a greater will to live strongly correlated with wishes to prolong life, even when subjects were hypothetically severely ill (Carmel and Mutran, 1997). In the studies, will to live decreased with advanced age, as did decisions to prolong life. Will to live was weaker among women than men (Carmel and Mutran, 1997; Carmel, 2001, 2011), and moderated a decline in life satisfaction common when close to death (Carmel, Shrira, and Shmotkin, 2013). Psychosocial indicators of well-being and fear of death affected will to live more than health factors (Carmel, 2001). Additionally, will to live was a significant predictor of older Israelis’ survival over a seven-and-a-half-year follow-up (Carmel, Baron-Epel, and Shemy, 2007) and over a ten-year follow-up in a Finnish study (Karpipinen et al., 2012).

Valuation of life is a related concept that aims to capture a person’s active attachment to life (Lawton, 2001). The concept is cognitive-affective in nature, composed of attributes such as hope, purpose, futurity, and perseverance, distinct from health, psychopathology, and end of life. Valuation of life is a broader subjective perspective than will to live and leads to a stronger will to live. In Lawton’s work with colleagues, it was shown to relate to years of desired life under varied health conditions, controlling for multiple personal background and psychosocial factors, including depression. Longitudinally over a two-year period, it moderated for the effect of health, though recent research using the Valuation-of-Life Scale (Jopp, Rott, and Oswald, 2008) found health explained twice as much variance in valuation of life than socio-demographic or social factors.

Will to Live, Depression, and Suicide

Will to live not only reflects one’s general well-being, but also the motivation to “hold on to life.” Research on community dwellers (Carmel, 2001, 2011) and clinical samples (Chochinov et al., 2005) finds the will to live is related to multiple physical and psychological aspects of living, the importance of which varies in different life circumstances.

In contrast to the ubiquitous nature of will to live as a human condition, depression is not a normal part of life or aging. Depression occurs across the life course in all races, genders, and ages (Blazer, 2009). Depression is, however, the most common mental illness in late life and decreases quality of life (Blazer, 2009).

Depression refers to a range of sub-types, but not to temporary feelings of sadness or to “having a bad day or attitude.” Major Depressive Disorder (MDD) is its clinical diagnosis, with specific symptoms (American Psychiatric Association, 2013). MDD is a marked change in mood lasting two weeks or more, characterized by pervasive sadness, plus loss of interest and pleasure in daily activities and impaired functioning. In addition, there are physical symptoms: changes in weight, sleep, and the presence of fatigue are presentations of depression, particularly in older adults. Feelings of extreme worthlessness and thoughts of suicide are a “red flag” for MDD.
A review of the epidemiology of depression reports that 8 percent to 16 percent of community-dwelling older adults have depressive symptoms. However, the incidence of MDD is quite low, ranging from 1 percent to 4 percent (Blazer, 2009). Older adults are less likely to experience MDD than adults in other age groups. Women are more likely to experience MDD than older men. Although people ages 85 and older have a higher frequency of depression, age is not a factor when gender, disability, cognitive impairment, and poverty are controlled for (Blazer, 2009). Lawton (2001) concludes that it is the severity of depression that is related to denial of end-of-life treatment. Thus, MDD is important in end-of-life decisions.

Depression is the leading cause of suicide. However, the relationship of will to live, depression, and suicide is complex. Older Americans may commit suicide with no sign of MDD (Brody, 2007). The Centers for Disease Control and Prevention (CDC, 2011) reports suicide as the tenth leading cause of death for Americans, with people ages 45 to 64 most likely to take their lives. This group had a rate of suicide of 18.6, compared to a rate of 16.9 for people older than age 85. The age-adjusted gender differences in late-life suicide are remarkable—of those who died from suicide in 2011, 78.5 percent were men and 21.5 percent were women (CDC, 2011). Suicide rates differ for racial and ethnic groups: whites have the highest rate at 14.5, the Native American rate is 10.6, with other ethnic groups much less likely to commit suicide—those rates are from 5.2 to 5.9 (CDC, 2011).

The American Foundation for the Prevention of Suicide (www.afps.org) provides resources and suggestions for what to do when you suspect someone is having thoughts of suicide: Take it seriously, ask questions and express concern, encourage professional help, take action immediately if there is a threat with a plan to take action, do not leave the person alone, and follow up with them on whether or not they have sought treatment.

All practitioners are responsible for conveying that depression is a treatable cause of emotional suffering for older persons. Only half of depressed older adults in the United States were recognized, and fewer than 10 percent sought treatment (Unützer et al., 2001). Resources and training on evidence-based model depression care programs (Grypma et al., 2006) can be found on the following sites: IMPACT, impact-uw.org; PEARLS, www.pearlsprogram.org; and Healthy Ideas, www.careforelders.org/healthyideas.

Decisions about Death
In the United States, dying is predominately relegated, by 80 percent to 85 percent, to people older than age 65, most of whom have chronic illness. The Agency for Healthcare Research and Quality reports that only 22 percent of the chronically ill and 50 percent of the severely ill had filled out an advanced directive. Among people with such a directive, 12 percent had consulted their physician about end-of-life planning. Most older adults gave cues that they would be open to a discussion about death, with only 5 percent of patients finding this dialogue too difficult to bring up (Kass-Bartelmes and Hughes, 2003).

According to patients who are dying and their families who survive them, lack of communication with physicians and other healthcare providers causes confusion about medical treatments, conditions, and prognoses, as well as the choices patients and their families need to make about end-of-life care (Kass-Bartelmes and Hughes, 2003).

The Geriatric Practitioner’s “Take” On Will to Live
We used will-to-live research as a heuristic perspective from which to question healthcare professionals about the implications of the will to live in practice. Even though health professionals are responsible for eliciting patients’ end-of-life decisions, there is no evidence that
they explore the more encompassing issue of the will to live. We conducted in-person interviews with twelve experienced geriatric practitioners and educators: four physicians, four nurses, and four social workers. Half of these key informants were from Israel and half from the United States.

The following questions were asked of each practitioner: “What are your thoughts on this concept of will to live as it relates to geriatric practice?” “Do you think it would be advantageous to incorporate will to live into geriatric practice?” And, “What else would you like to share with us around this topic of will to live and geriatric competencies?”

The incidence of Major Depressive Disorder is quite low in community-dwelling elders, ranging from 1 percent to 4 percent.

Each interview was recorded, transcribed, and analyzed for content themes. The following paragraphs contain a small (but illustrative) portion of the practitioner comments.

When asked if will to live was relevant to their geriatric practice, interviewees’ immediate, spontaneous response was “Yes, we see will to live expressed in our practice.” Though none of the interviewees had integrated will to live into their practice or teaching, one practitioner said, “It is an implied concept in geriatrics so it feels familiar, implicit, and understood.”

All interviewees recognized will to live as being distinct from other assessed aspects of late life. “This is not about depression, it is measuring something different,” said one. “I agree that will to live is very different than ‘quality of life,’ for example,” said another.

Depression was contrasted with will to live, in relationship to end of life: “Will to live does not perfectly correlate with mental health, we see this often with patients,” and “They can feel as if life is not worth living without depression, there is a decision-making process that is independent from depression.”

“With age, one is supposed to be getting ready to die. One can have a great life, but still be ready to let go when the time comes, while someone with a miserable life is fighting to hold on.”

Interviewees pondered the relationship of will to live to stage of illness, treatment, and care setting, as well as to the underlying personality construct of “being a fatalist or a fighter.” These characteristics, in turn, related to expectations for change or stability in one’s will to live.

The majority of interviewees emphasized contextual change, summarized succinctly: “Will to live may change because of different factors. It is influenced by their cultural beliefs, disease burden, and mood status.” Others pointed out the potential to interact and intervene.

“First of all, we must educate people that will to live is dynamic—not all people want to live to the same degree, and not all the time. In times of crisis, a patient can feel deep despair due to, or from fear of, suffering. We, the caregivers, may be able to bring an influence, some balance . . . ”

The cultural aspects for both older persons and practitioners in will-to-live exchanges were well-recognized. “Because of cross-cultural differences, how do we know that people mean the same thing when they respond to will to live?”

Religious and cultural expectations would be more linked to the will to live even than self-perceived health. Nurses have a difficult time asking about end-of-life preferences, and many nurses have their own religious and cultural background issues with the topic.

The relationship of differences of opinion between family members and older persons on will to live and end-of-life decisions is another important consideration: “I have seen that with the elderly, some may have lost their will to live, but keep this fact hidden from family members. The elderly may not want to disappoint the family members who are working so hard to care for them.”
Conversations around will to live were framed by practitioners as needing certain considerations. “I think that it is important to use the will-to-live questionnaire only after getting to know the patient and creating a bond of trust with her/him.” Several health professionals stressed that young practitioners would need to be prepared to ask about will to live. “These are particularly important and difficult for students, young adults, to project themselves into the world of an older adult.” And all practitioners must have a “deep awareness that their own perspective and lived experience will not reflect for another the understanding of life worth living or why life has value.”

**Will to live is influenced by cultural beliefs, disease burden, and mood status.**

On the whole, this small group of seasoned practitioners thought that asking the will-to-live question would enrich their knowledge of patients’ lives. “Will to live is personal-goal focused, which is very different from typical geriatric assessment.”

There will be variations by discipline in relating will to live to practice. Will to live is a more holistic approach, and not pathological. It is related to incorporating the patient’s perspective.

However, one practitioner summarized the next steps needed to put will to live into practice, saying, “The will-to-live answers would simply lead to more research. What are we to do with this information, where is the decision tree?”

**Discussion**

We began this article by asking three questions related to the persistence of will to live: How long? For whom is will to live diminished? And, under what circumstances does will to live decline?

Length of life, or chronological age, is a varying factor in will to live, depression, suicide, and end-of-life planning. Age is not the predominant factor in will to live (Carmel and Mutran, 1997; Carmel, 2001), however, it declines with advanced age as incidence of depression (Blazer, 2009) and suicide (CDC, 2011) increase. The oldest old encounter a time of life when a convergence of factors leads to the consideration of death and executing advanced planning (Lawton, 2001).

The second question, “For whom is will to live diminished?” requires much more investigation than what is presented in the research here. A more international perspective is needed, as it requires more understanding of differences in will to live related to national, ethnic, and socio-economic groups. Practitioner feedback highlighted the need for considering cultural differences in will-to-live discussions. In MDD depression rates, there were no major racial and ethnic differences in the United States (Blazer, 2009), though suicide varied markedly between races and ethnicities (CDC, 2011).

Within the research presented, gender arises as a significant variable. For Israelis living in the community, women’s lower levels of will to live were explained by different variables than men’s higher will to live (Carmel, 2001). Women’s will to live was most related to psychosocial factors such as self-esteem and fear of death, but for men, physical symptoms and disease were most significant (Carmel, 2001). Understanding these gender variances is important, considering women have higher rates of major depression (Blazer, 2009), and men have higher suicide rates (CDC, 2011).

When it comes to the third question, “Under what circumstances does will to live decline?” both research and responses of healthcare professionals stress the importance of the care environment: Are subjects in the community or in an institution? The variables related to will to live and depression are psychosocial, depending upon one’s religiosity, subjective well-being, self-esteem, fear of death, quality of life, and living arrangements. They also are related to
physical health, including the number and severity of chronic illnesses and disability. Depression is a significant variable, but one that explained only a portion of will to live (Carmel, 2001, 2011). Social circumstances involving family relationships were key factors in will-to-live discussions and end-of-life planning. Interestingly, the research varies in the degree of influence of psychosocial versus health factors (Carmel, Baron-Epel, and Shemy, 2007; Lawton, 2001; Jopp, Rott, and Oswald, 2007).

**Conclusion**

Lawton (2001) proposed that valuation of life and will to live are part of a developmental process leading to an increasing awareness of one’s mortality. He asserts that throughout the life cycle people prepare for their eventual dying process. Largely latent and at times highly conscious, awareness slowly becomes clearer. Early gerontologists like Kastenbaum (1966) noted the increasing awareness of one’s mortality as a part of human development. This may explain the general decline in will to live for the oldest old (Carmel, 2011), and the desire to talk about and complete end-of-life planning (Kass-Bartelmes and Hughes, 2003). As one practitioner noted, one task of old age is to get ready to die. Lawton (2001) points to the move from earlier interest in the subjective representations of death in societies that deny the phenomenon (Kastenbaum, 1966) to a focus on end-of-life treatment within a healthcare perspective. Interesting research by Levy and colleagues (2000) found that giving subliminal negative stereotypes of older persons significantly changed older adults’ end-of-life decisions, but not those of younger persons.

Healthcare professionals’ addition of the construct of will to live into their perspective of end of life may help older adults develop an awareness of mortality that is more holistic, yet supports specific treatment decisions. However, practitioners also noted the need for increased skill and sensitivity in recognizing their own approach to death.

Recognizing as Carmel did (2001) that will to live is a paramount existential issue of religions and philosophy, scientific investigation of will to live may add understanding of the role of advanced age in approaching issues of life and death, while being alert to assessing and treating depression (Moody, 2010). Further guidance and research is needed, as one practitioner had asked, “What to do with this information, where is the decision tree?”

Research on valuation of life demonstrated its complex role in health decisions, leading Lawton (2001) to point to “the need to search for other antecedents (and better measures) for the resolute will to live even under very adverse conditions.”

The researchers and the small group of experienced geriatric professionals and educators viewed will to live as a distinct and overarching concept that would allow them to know more about the subjective world of elders, as well as how to negotiate treatment toward more patient-directed regimens in general and for more successful end-of-life planning.

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