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The Will to Live and Its Effect on 3 Nursing Home Patients

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I call heaven and earth to witness against you this day, that I have set before thee life and death, the blessing and the curse; therefore choose life, that thou mayest live, thou and thy seed;
Deuteronomy Chapter 30 Verse 19

As a specialist in Family Medicine, I have spent many years working with the dying, be they patients with no longer curable life-threatening diseases or nursing home residents with multiple degenerative conditions and co-morbidities. I have noticed that the deterioration and death of an individual does not always correlate with the severity of their medical situation. Some patients with unstable and progressive medical conditions nevertheless continue to survive unexpectedly, while others who are ostensibly medically stable nevertheless die prematurely.

One factor which may play a role in creating this disparity is the *will to live*. Recently I encountered three cases in which I assert that the *will to live* has played a central role in the patient's trajectory - each one in its own manner. This paper will present and analyze how those patients' *will to live* has had a significant effect on their life trajectory and will be followed by exploring the concept of the *will to live*.

Case 1 Clara:

Clara was a 90-year-old resident of a nursing home where I took care of her for 5 years until her recent death. She had had a hard life, having been orphaned as a child during the Holocaust. She was childless and her husband was long deceased. Her only family were a nephew and niece on her husband's side, but she had no remaining blood relatives.

Clara was wheelchair-bound with both a mild cognitive and a hearing impairment. She suffered from a wide range of medical problems, the main one being terminal congestive heart failure. When she arrived at the nursing home 5 years ago, she was totally dependent on oxygen and always had an oxygen concentrator beside her.

Clara was a feisty, demanding person, characterized more than anything by her determination to live and enjoy life. She took an active role in arts & crafts and more important, was very disciplined in the group physiotherapy sessions. For her, physiotherapy was primary in maintaining her health.

Despite the grave prognosis of CHF, she stabilized without hospitalization and was even off oxygen for several years. While recognizing the significance of the good medical, nursing and personal care that she received in the nursing home, I have come to believe that her primal will to live was paramount in keeping her alive. This was a case of a-wheelchair-bound elderly woman, with poor hearing, some cognitive deterioration living with the constant looming threat of dyspnea (subjective sensation of shortness of breath). In a situation where a patient has few positive reasons to live and some reasons not to want to live, one might expect a weakened *will to live*. However, this was not the case and she consistently strived to preserve her sense of well-being.

Case 2 Sara

Sara, at 96 years old has been a resident of our nursing home for the past eight years. She has profound dementia and rarely communicates appropriately with her surroundings. She also suffers from hypertension and diabetes and is treated reactively. If she refuses to eat, for example, this is respected. She has two daughters who visit frequently but she usually does not recognize family.

Three months ago, a general deterioration was evident in her behavior and function and two months ago, her behavior took an abrupt dip. She was often drowsy and unresponsive, occasionally to the point of being stuporous. When alert she often refused to eat or to be fed. She often refused medication, which was soon reduced to only the bare essentials. Eventually all medication was discontinued both because she usually refused and was unable to take it. Even insulin was discontinued because she was not eating. She was given only s.c. (subcutaneous) fluids. Her daughter

was informed that it was likely that this downhill course was irreversible.

This situation continued for about 2 weeks. Blood test results revealed nothing treatable. Considering her age (96), her advanced dementia, long-standing hypertension and diabetes, I surmised that her time had come, and prepared the daughters that their mother's end was near.

Then, surprisingly, she gradually began to improve. She became more alert; she agreed to eat, albeit small amounts at first. Soon her sugar levels became high enough to re-institute insulin, at first on a p.r.n. (as needed) basis and then regularly. On a visit to the nursing home one sunny day, I saw her sitting outdoors in a wheelchair with one of her daughters. Her face was alert and engaged, without her more typical far away expression. She responded to me verbally and with appropriate facial expression. When her daughter caressed her head, it was clear that Sara experienced joy from it. One month on, she is still stable.

Sara is a case of a woman who had begun dying, and with minimal cognitive faculties made a turnabout and returned to the living. Although it is not common, I have encountered this phenomenon with other residents too.

Case 3 Aliza

Aliza is a 97-year-old woman with two living children who has maintained cognitive and hearing capacities and communication skills. She has led a hard life, beginning with an unstable childhood - her parents were divorced when she was 6. She sustained numerous significant traumatic deaths: her husband 30 years ago, an older sister 11 years ago, and a granddaughter 4 years ago. After her sister died, she fell into a long depression, which was treated somewhat effectively with antidepressants. She drove a car until she was 92.

Aliza is wheelchair- bound and has developed a few medical problems including painful arthritis. Her major psychiatric problem is anxiety. Her depression has evolved into a refractory existential lack of desire to live. She has filled out an advanced directive requesting that no procedures be performed to extend her life.

Prior to admission, she had been living at home with a full-time caregiver. She had been treated with a fentanyl opiate pain patch and benzodiazepines. As her care became more demanding, her caregiver could no longer cope and left. Aliza came to the nursing home willingly but stated from the outset that she no longer wanted to live. (Israel does not allow physician-assisted suicide). My stated "contract" with her and her daughter was that I would try to provide maximal symptom control but take no steps to artificially prolong nor shorten her life.

Indeed, symptom control was easily attained. In addition to the patch, she was given benzodiazepines whenever she requested, and consequently was often drowsy. In terms of *will to live*, she often agreed to take some food and would occasionally agree to our suggestions such as sitting outside in the nursing home garden.

Because she was so weak, she needed full assistance in all the ADL (activities of daily living) including eating. Her daughter, who felt an obligation to respect her wishes not to extend her life, interpreted the assistance we proffered in eating as compelling her to eat. In a meeting with the caregivers involved, each of them insisted that they only offered help and assisted her but did not compel her to eat. It was clear to each of them when she did not want to eat and when she refused, they immediately respected her wishes.

Here was a woman who had adamantly declared that she did not want to live and yet periodically co-operated actively with eating and doing enjoyable activities such as sitting in the garden, which indicated a gap between her negative existential attitude and her positive day-to-day behavior.

Background to the topic of *will to live*

The *will to live* or *Wille zum Leben* is a concept developed by the German philosopher Arthur Schopenhauer [1], *will* being defined as an irrational "blind incessant impulse without knowledge" that drives instinctive behaviors, causing a perpetual and insatiable urge to live, which is the essence of natural existence.

In psychology, the *will to live* is the drive for self-preservation, usually coupled with expectations for future improvement in one's state in life [2].

Viktor Frankl was an Austrian psychiatrist and Holocaust survivor. As an inmate of a concentration camp, he observed firsthand that those who survived were not necessarily the healthiest, but rather those who saw a purpose in their being and significance in living. He developed his theory of logotherapy, explaining that those in the concentration camps for whom life had a purpose had a greater likelihood of surviving [3]. In his book, he quotes Nietzsche: "He who has why to live can bear with almost any how" [4].

With dying patients, one might intuitively presume that the more active the treatment, the longer people will live. However, the evidence suggests the opposite. Symptom relief rather than futile curative interventions have been shown to improve longevity [5]. My anecdotal experience in working with cancer patients transferred from oncology to home hospice care was that many of them initially demonstrated a remarkable improvement. I attribute this initial improvement both to the discontinuation of no longer effective curative interventions, such as chemotherapy, and to the provision of comprehensive supportive care. In addition to providing relief from discomfort and pain, we have come to believe that the relief of suffering increased our patients' desire to live.

The psychiatrist and researcher Harvey Max Chochinov has researched the *will to live* factor in dying cancer patients. In one

study, he found that the three main negative predictor variables of will to live were depression, anxiety and shortness of breath. The main positive predictor variable was sense of well-being [6]. Another finding was that the will to live is inherently changeable and therefore may be amenable to intervention.

In subsequent research published in 2002, he found that patients could be categorized by what he termed *clusters criteria* related to how high or low the *will to live* is. The categories are patients with sustained high will to live (58%), patients with sustained moderate will to live (11%), patients with sustained low will to live (3%), will-to-live relinquishes (18%), and will-to-live acquirers (10%) [7]. 58% of the participants had a high will to live even towards the end of life. Chochinov concluded, "For most, the wish to go on living appears to be a resilient mind-set, even among those nearing death." His study found that low anxiety, high endorsement of religious affiliation and living with a spouse were associated with a high would to live. Low will to live was associated with anxiety and dyspnea.

A later study done by Chochinov in 2005 confirmed that "existential psychiatric, social and, to a lesser degree, physical variables, are highly correlated with the *will to live*. Depression, which can color existential despair, is much more likely to be found among terminally ill patients endorsing a strong desire for death. *Hopelessness* – losing one's sense of meaning and purpose, is an important underpinning of the loss of will to live" [8]. His study found that being a burden to others and the loss of dignity are other significant negative parameters.

Discussion

Chochinov's study was done on terminal cancer patients with their cognition intact, while the cases I presented are from a nursing home, with two of the patients having compromised cognition. Nevertheless, I believe that there is enough conceptual overlap to analyze my cases in the context of Chochinov's seminal works, along with the terms I presented earlier.

Case 1 Clara who sustained a high will to live:

If we start with Schopenhauer's definition of the concept of will to live as being an irrational "blind incessant impulse without knowledge" that drives instinctive behaviors, causing an endless, insatiable striving in human existence, then perhaps Clara was endowed with an unusually high measure of this drive. In Chochinov's terms, she had "sustained high will". That, combined with optimal medical, nursing and personal care, is what may well have sustained her with terminal CHF five long years.

Case 2 Sara who sustained a high will to live:

Sara's resilience and renewed urge to live, despite suffering from advanced dementia, can again be explained by the theory that the primal urge to live is irrational and not based on cognition. She could be categorized, like Clara, as having a sustained high will to live. While this will not explain why she dipped and almost died, it can explain her resilience and return to life. In addition, she received warm, appropriate care. I believe that high cognitive function is not a necessary condition for appreciating and drawing strength from a supportive environment.

Case 3 Aliza who has a high innate drive to live but an existential desire to die:

Aliza's case is more complicated and conflictual. On one hand, despite a difficult life, she has reached the advanced age of 97 cognitively intact and physically relatively healthy. One can presume therefore, that her innate will to live is high. Also on the positive side are a caring daughter and good symptom control. On the other hand, she suffered from depression which has evolved into profound existential hopelessness. Her drive "not to live" has led her to insist on refusing treatments which could improve her quality of life, though she occasionally yields to the urge to live by accepting food and other nourishment.

Chochinov encourages caregivers to ask patients about their will to live and look for indicators where interventions can strengthen that will. Within the nursing home context, even where many residents would not be able to relate to such a question, the caregivers can still note and identify those residents who have a strong will to live. They can also note parameters such as dyspena or depression which erode the will to live, and work to treat and provide relief for those symptoms.

Summary

Whether or not caregivers look through the prism of *will to live*, it can play a role in influencing the trajectory a patient takes at the end of their life. In a comparison of two patients with the same condition, for example, where one does extremely well while the other declines, the will to live parameter may be one of the differentiating factors.

The model below entitled '*Domains of Influence on Will to Live*' depicts the various factors in a table format.

In treating the dying, be they terminal cancer patients on a relatively short, steep downhill course, or nursing home resident whose downhill trajectory tends to be more moderate, a physician is often faced with the dilemma of how actively to pursue a course of trying to maintain life. A tool which may be helpful is assessing the patient's will to live:

1. Try to assess a patient's will to live either by asking them directly if possible or asking family members and / or observing the patient's behavior.
2. Pay particular attention to interventions which can increase the will to live such as provision of symptom control and a supportive milieu.
3. Identify and treat factors such as dyspnea which can decrease the *will to live.*
4. The higher the will to live, the more actively one may try to prolong life (within reason, given the patient's condition and prognosis).

A suggested model: Domains of Influence on *Will to Live*

Legend:
↑ increased *will to live*
↓ decreased *will to live*

1. Innate ***Wille zum Leben + Chochinov (clusters)***	2. Psychological	3. Physical symptoms	4. Psychiatric	5. Existential
Clusters: (Chochinov) Sustained high will ↑ Sustained moderate will ↑ Sustained low will ↓ Relinquishers ↓ Acquirers ↑	Drive for preservation ↑ Expectation of future improvement ↑	Symptom control ↑ Caring milieu ↑ dyspnea ↓	Anxiety ↓ depression ↓	Significance of living (Frankl) ↑ Being a burden to others ↓ Loss of dignity (Chochinov) ↓ Hopelessness ↓ Existential despair ↓ high endorsement of religious affiliation ↑ sense of well being ↑ living with a spouse ↑
Degree of *will to live* can change over time				

- (1 & 2) Innate and psychological are for the most part factors people are born with.
- (3) Physical symptoms are the consequence of the medical condition(s), treatment, and the level of symptom control.
- (4) Psychiatric pathology leading to a decrease in the will to live which is sometimes treatable
- (5) Existential / philosophical / spiritual factors affecting one's *will to live*

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