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Dignity

Robert E. Enck, MD¹

Wise man lookin' in a blade of grass
Young man lookin' in the shadows that past
Poor man lookin' through painted glass
For dignity

Dignity,
Bob Dylan's Greatest Hits
Volume 3
November 15, 1994

Bob Dylan's take on dignity is certainly interesting and worthy of contemplation. Another older concept of dignity, however, was espoused by the 16th century German philosopher, Immanuel Kant. It is important to recognize that Kant's extensive writing and influence on philosophy and medical ethics is more than the following simplistic explanation of moral agency. To start, a moral agent is (1) an individual who is capable of making moral judgments about the rightness and wrongness of actions and (2) an individual who has motives than can be judged morally. According to Kant, the capacity for moral agency gives an individual a moral respect and dignity. Furthermore, moral autonomy is the ground of dignity of human nature.¹

So, now that there is an understanding of moral agency, is there some approach to further dignity as the end of life nears? The results of a randomized controlled clinical trial of a novel new approach, called dignity therapy, to allay distress and suffering at the end of life, may help.² This individualized therapy is a brief psychotherapy designed to not only alleviate distress but enhance the end-of-life experiences of terminally ill patients. It offers patients the chance to reflect on important aspects of their lives or what they want most remembered. The therapeutic process begins with a framework of questions. Key elements of these questions are as follows and the reader is encouraged to read the report for completeness:

- Life history
- How to be remembered
- Important roles
- Accomplishments
- Things left to say
- Hopes and dreams for loved ones
- Passing along learned life lessons

- Advice for your family to help prepare for the future

Each session guided by a trained therapist is audiorecorded, transcribed, and given to the patient as a generativity document to share with individuals of their choice. This document contains expression of love and regret and, most importantly, a recounting of memories.

The first study of dignity therapy to determine its feasibility and impact on various psychosocial and distress measures was reported³ in 2005. In this study, 100 terminally ill patients participated from Australia and Canada. Most patients had breast cancer and 44 were women. The mean age of all patients was 63.9, ranging from 22 to 95, and the median length of survival from the initial interview to the time of death was 51 days. The vast majority of patients were satisfied with dignity therapy and most reported a heightened sense of dignity (76%), an increased sense of purpose (68%), and a higher sense of meaning (67%). Less than half (47%) reported an increased will to live and 81% felt that it had been or would be helpful to their family. Postintervention measures showed a small but significant improvement in suffering and depressive symptoms. Dignity therapy, not surprisingly so, was found to be extremely helpful to the patients' family members and found that the generativity document was comforting to them during their period of grief. One limitation of this study was the older age of the patients with end-stage cancers and whether this therapy is applicable to all age groups across all terminal illnesses.

The success of this phase 1 trial generated the previously mentioned randomized controlled clinical trial of dignity therapy. Patients aged 18 or older with a life expectancy of 6 months or less were recruited from sites in Canada, United States, and Australia. Slightly less than half (49%) were men and the mean age of all the patients was 65.1, ranging from 22 to 102. Gastrointestinal was the commonest cancer site followed by lung, breast, and genitourinary. The median survival was 110 days. All patients were randomly assigned in a 1:1:1 ratio to 1 of the 3 study groups, namely, dignity therapy, standard palliative care, or client-centered care. Client-centered care was a supportive psychotherapeutic approach focusing on the here-and-now issues. Patients were asked about their

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current symptoms and management. Patients randomized to the standard palliative care approach were provided the complete access to palliative care support services available to all study patients.

Of the 441 randomized patients, 326 completed the study providing data for analysis. Over the 3 groups, there was no difference in the primary outcomes of psychosocial, spiritual, and existential distress. However, for the secondary outcomes, dignity therapy was reported to provide more help, better improvement in quality of life, increased sense of dignity, altered family views of the patient, and comfort for the family. Although dignity therapy was unsuccessful in alleviating the various dimensions of distress, the authors suggest that this nonpharmacological treatment is a viable therapeutic approach to enhance the end-of-life experience for patients and families facing death.

In an accompanying editorial,⁴ Nekolaichuk notes some concern over the lack of significant primary outcomes with dignity therapy as compared to client-centered and standard palliative care. Research into psychosocial interventions poses substantial challenges, especially using the randomized clinical trial. First, often the best patients participate excluding the frail and highly distressed patients making the study population less heterogeneous. Second, random assignment to different groups does not ensure that all groups are the same. Third, standardization of psychosocial interventions across multiple study sites is a significant challenge. For example, patients in the standard palliative care and client-centered groups may have received psychosocial interventions other than dignity therapy which equally helped relieve distress. Fourth, the concept of distress is very complex and selection of psychosocial interventions to measure this is difficult at best. In addition to randomized controlled clinical trials, Nekolaichuk encourages considering other approaches for demonstrating the effectiveness of these interventions in the future.

Recognizing that the median age of these 426 patients participating in these 2 trials was more than 63, the question of the influence of age on dignity is relevant. In a tangential study, Woolhead et al⁵ studied the differing ways dignity is viewed in older individuals. Appreciating that the term dignity is rarely defined and scant research has been done relative to older person's experience of dignity, 72 patients participated in focus group discussions exploring this issue. The majority of participants were female (79%) and the median age was 72 with a range of 50 to 70 years. They found that dignity was an important concern of older people and qualitative analysis conceptualized dignity into 3 categories:

- Dignity of identity (self-respect, self-esteem, pride, integrity, and trust)
- Human rights (equality and human entitlement to dignity)
- Autonomy (independence, self determination, and freedom of choice).

Although the relation between this study and dignity therapy appears obscure, Woolhead et al's study does give some glimmer of insight into how older people conceptualize dignity and its impact on their lives, and even the significance of a therapy such as dignity therapy.

Now that we have wandered along the paths of rock and philosophical icons, navigated the results of dignity therapy as a nondrug intervention in the terminally ill, and attempted to understand how aging affects how we view dignity, do we really understand the term dignity, or are we just as confused as those who try to define it? Woolhead et al⁵ seem to confirm Kant's theory of the importance of autonomy and dignity. Even Bob Dylan singing "Young man lookin' in the shadows that past" lightly touches dignity therapy and reviewing life's experiences. Maybe, how you define dignity is not so hard after all.

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