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Dignity Therapy: A Narrative Intervention for End-of-Life Care

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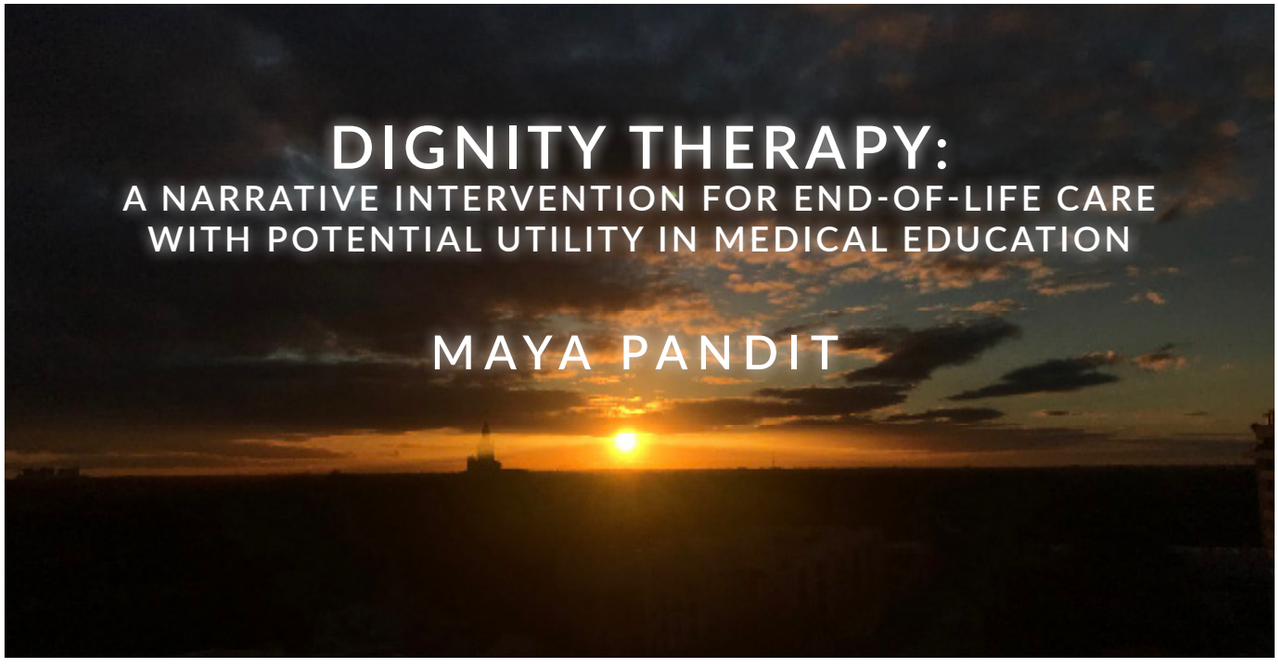

DIGNITY THERAPY:
A NARRATIVE INTERVENTION FOR END-OF-LIFE CARE WITH POTENTIAL UTILITY IN MEDICAL EDUCATION

MAYA PANDIT

Introduction:

Providing quality end of life care poses unique challenges to caregivers and healthcare workers. From the patient perspective, the end-of-life experience is often frightening and difficult to navigate. Patients are faced with the complexities of managing not only their physical conditions but also their emotional, spiritual and psychological needs. Several studies have revealed that terminally ill patients lack a sense of dignity and meaning in their lives, and often view themselves as a burden on providers and caregivers.1,2 Dignity therapy (DT), a structured and individualized intervention that enables patients to reflect on their life trajectory, relationships and achievements, has been proven to be beneficial to patients approaching the end of their lives.2 DT enables trained workers to utilize a set of questions that invite a patient to speak about various aspects of their life, values, accomplishments and relationships in order to maintain a sense of life's meaning, decrease mental distress and promote peace through reflection (Table 1).1 DT includes questions that incorporate themes of continuity of one's legacy, desire to maintain one's role, pride and sense of self, and addressing concerns about the challenges of one's death on those around them.1 DT can be a one-on-one therapy between provider and patient, but often also incorporates caregivers and loved ones. DT also enables patients to share answers and discussions with chosen persons in the form of a "generativity document" that is passed on to those closest to the patient.1

Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
What are your most important accomplishments, and what do you feel most proud of?
Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
What are your hopes and dreams for your loved ones?
What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other[s])?
Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
In creating this permanent record, are there other things that you would like included?

"Dignity Psychotherapy Question Protocol" by Chochinov et al, 2005.

Evidence Based Benefits:

DT has been widely studied in terminally ill patient populations and has consistently been shown to decrease suffering and promote a sense of fulfillment in the terminally ill. Interviews with patients who engaged in a DT exercise have revealed that DT increased their sense of meaning and purpose and reduced suffering and depression. For example, one study that included terminally ill patients receiving home-based palliative care services in Canada and Australia revealed that 91% of participants were satisfied with DT, 76% reported a greater sense of dignity, and 67% showed a greater sense of meaning and decreased depressive symptoms.3 Many DT studies have focused on patients with advanced stage cancers. A phase II Randomized Controlled Trial (RCT) of DT in the United Kingdom which included 45 patients with advanced cancer who were randomly allocated to a DT group or a control group found that the DTgroup reported more feelings of hope than the control group at 1 and 4 weeks follow up.4 Similarly, out of 15 patients with stage IV colorectal cancer who underwent DT, 100% reported satisfaction with DT, 78% reported an increased sense of dignity and purpose and 88% revealed that DT had been helpful for their family.5 Family members have gained a sense of solace during grief by reviewing generativity documents.6

Barriers to Implementation:

While DT has several proven benefits, there are several barriers to its widespread implementation, such as preferences of family members and comfort level of patients, which impede its use and limit the participation of terminally ill patients in intervention studies. One study revealed that family members refused participation of patients due to a feeling that issues discussed and included in a generativity document could lead to harm of a patient's social network.6 Providers of DT have also perceived several barriers to implementation, including strong emotional involvement leading to feelings of discomfort, and feeling inexperienced to handle the topics covered by DT.7 There is a need for specific DT training in order to motivate providers to provide sensitive therapy while also accounting for their own emotional needs. Providers must be trained to address the emotional responses of patients throughout the therapy.7 Providers have also sensed discomfort from patients in answering personal questions with an unfamiliar person, suggesting that DT may possibly garner better responses and participation if implemented by persons known to the patient.7 The time commitment required of providers for DT and lack of recognition and/or financial compensation have also been mentioned as barriers, suggesting that having specific administrative and institutional resources and support for such therapies may enable more motivation amongst providers.7

Research has also revealed challenges in employing DT in patients of various cultures. One study sought to explore the acceptability of DT in Danish culture and revealed that although DT was still relevant and feasible in Danish culture, adjustments would be necessary to remain culturally relevant.8 For example, Danish patients were less likely to talk about topics that would be deemed as self-praise and therefore refused to discuss accomplishments or pride.8 A study in Japan revealed that patients were reluctant to participate in DT if they perceived that their death would be better without being aware of their passing and coped with their impending death through denial.9 Furthermore, Japanese cultural communication is less verbal and direct and therefore patients in this population were less likely to value spoken or written closure for themselves or loved ones.9 In order for DT to be implemented successfully and respectfully within diverse communities in the US, it is important for trained professionals to consider cultural differences and provide open discussion about the content and purpose of DT to empower patients to make educated decisions regarding their participation.

Potential Utility in Medical Education as a Reflective Tool:

The utility of DT specifically has not been widely explored in the context of medical education; however, the benefits of narrative medicine as a reflective tool have been studied across medical specialties. Studies have shown that engaging in writing allowed students to develop greater empathy and sensitivity in patient interactions, reflect upon their own emotional and psychological processes and challenge negative reactions.10,11 Furthermore, narrative medicine exercises have allowed students to develop strong communication skills and fostered interprofessional collaboration, suggesting an important role in professional enrichment.12,13 Given the proven benefits of reflective writing in medical education, integration of DT in health curricula could similarly be a useful tool for emotional processing and responding to end-of-life care issues in particular. This could take the form of training students in administration of DT and allowing them to utilize DT standardized questions while on clinical rotations with terminally ill patients. Students may reflect upon their DT experience through writing or through a more structured approach by completing pre- and post- surveys on patients and caregivers to assess the efficacy of the intervention. By promoting the use of DT early in medical education, future physicians can not only be equipped to provide specialized, sensitive care to the terminally ill but also experience firsthand the emotional reactions, psychological processes and unique concerns of this patient population.

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Art: "What We Learn" by Asim Ahmed