Challenges of implementing family-based dignity intervention

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Dignity therapy is a brief individual psychotherapy intervention aimed at reducing psychological distress and promoting the dignity of patients in advanced stages of cancer (1). Originally designed for terminally ill patients, it provides them with an opportunity to share important life experiences, unfinished business, wishes, and hopes with their loved ones (2). This intervention has shown potential benefits for the mental health of patients suffering from terminal illnesses, including reduced depression, anxiety, and demoralization (3).

While Dignity Therapy was initially intended for end-of-life patients, many families of treated individuals have also reported benefiting from it (4-7). Family members often serve as the primary emotional and social support source during treatment and recovery. However, research has revealed that family caregivers experience higher levels of depression, anxiety, sleep disturbances, and social isolation. Unfortunately, the needs of caregivers are often neglected in healthcare settings, leading to their identification as a neglected group (1). Consequently, it becomes crucial to address their psychological and emotional needs alongside those of the cancer patient. To this end, a study focused on family caregivers of patients in advanced stages of cancer and introduced a family-based dignity intervention.

Instead of interviewing patients directly, this intervention shifted attention to their family caregivers. The family-based dignity intervention involved conducting interview sessions with caregivers, where they were asked questions related to their experiences. During these sessions, caregivers could share memories, reflect on life, and express their wishes regarding their family member with cancer (9). Such conversations benefitted family caregivers, who felt seen and understood within the caregiving environment. Participating in the family-based dignity intervention allowed them to feel acknowledged by healthcare staff and highlighted the importance of their psychological concerns, especially within the palliative care team (9).

Engaging in the family-based dignity intervention provided a safe and supportive atmosphere for caregivers to express their feelings without fear of judgment. They found comfort in freely expressing their emotions and were encouraged to do so, leading to a sense of satisfaction and relief. The intervention helped reduce stress and anxiety while strengthening their sense of hope. Furthermore, it assisted family caregivers in preparing for and adapting to loss and the grieving process (9,11). Caregivers reported improvements in emotional connections with their family members and opportunities to express gratitude and share lessons learned from their loved ones. This approach enabled family members to express their true feelings and alleviate the burdens associated with caregiving (9,13). It also empowered them, increasing their motivation to provide care and make up for past shortcomings (9,11). In fact, half of the family caregivers stated that the family-based dignity intervention reduced their suffering related to caring (12).

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Despite the benefits of the family-based dignity intervention for families with a member suffering from advanced stages of cancer, our study highlighted several challenges and implementation issues. One common challenge was coordinating the interview sessions. It was essential to create a calm and uninterrupted environment for the participants to focus on sharing their feelings and experiences. However, leaving the patient alone with the caregiver to participate in the intervention sessions often caused concern, as caregivers worried about potential disruptions to the patient’s timely care (9). Additionally, caregivers were responsible for coordinating care and obtaining rare chemotherapy drugs from various pharmacies, which consumed significant time and posed challenges to their participation in the study (9).

Another challenge of the family-based dignity intervention was the participants’ fear of the interview content being revealed to the patient. They believed knowledge of the interview content triggered strong emotional responses from participants. Some considered the interview manuscripts as emotional testimonials, addressing the possibility of losing their family member and preparing for their death. Revisiting the interview documents evoked emotions such as grief, loss, lack of foresight, and separation anxiety. This emotions sometimes led to self-blame as participants felt responsible for their loved one’s deteriorating condition, leaving them anxious and saddened by their inability to make any alterations (9).

Another implementation challenge of the family-based dignity intervention was addressing the topic of death. This topic arose frequently during the intervention (9,13). To mitigate this challenge, the intervention for each participant was conducted before the patient’s discharge from the hospital, ensuring continued access to the participants. Furthermore, some caregivers were hesitant to participate in the intervention as they were unwilling to leave their loved one, especially when their physical and mental condition was unstable. They preferred activities that would alleviate the burden on their patients rather than focusing on their own needs. This prioritization of the patient’s needs and self-sacrifice is a common phenomenon in Asian cultures, where family members tend to disregard their well-being when a loved one is ill and concentrate solely on the needs of the afflicted family member (9,14).

Given the implementation challenges identified in the context of the family-based dignity intervention in Iranian patients, further studies should be conducted to explore the benefits and address these challenges. By doing so, healthcare providers can better support the community of family caregivers for patients in advanced stages of cancer experiencing pain and suffering while caring for their affected family members. Taking steps to alleviate their distress and promote their well-being is crucial.

In conclusion, Dignity Therapy, initially designed for terminally ill patients, has demonstrated positive effects in reducing psychological distress and promoting the dignity of individuals with advanced stages of cancer. The family-based dignity intervention, focusing on family caregivers, has provided a platform for emotional expression, comfort, and healing. Despite challenges such as coordination issues, caregiver self-sacrifice, and emotional intensity, the intervention has indicated valuable in addressing the needs of both caregivers and patients. Further research are necessary to optimize the benefits and overcome the challenges associated with the family-centered dignity intervention, ultimately fostering support and reducing the suffering experienced by family caregivers.

References


