

# Dignity, Memory, and Final Wishes of Dying Children

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## Dear Editor:

Dignity therapy (DT) is one of the most studied brief psychotherapeutic interventions in palliative care today.<sup>1</sup> It enables patients nearing death to share memories, wisdom, hopes, wishes, and dreams with those who will soon grieve their loss. The key elements of DT are based on the Model of Dignity in the Terminally Ill<sup>2</sup>; and focus on important roles, accomplishments, and especially, the notion of generativity, which, according to developmental psychologist Erik Erikson, comprises leaving a lasting mark on the world and contributing to the next generation. Since the model is based on a cohort of older patients, largely with end-stage cancer, DT has exclusively been considered for dying adults. Given its ability to enhance end-of-life experience, the question is often raised as to its role among dying children.

Up until now, the answer has been, we simply have no evidence to suggest that DT might be an appropriate option for terminally ill children. Julião et al. reported a revised version of DT for adolescence, positing several metaphors and tasks to make it more developmentally appropriate.<sup>3</sup> Although this adaptation was based on input from a qualified expert panel, it has yet to be implemented. Schuelke and Rubenstein's study: <https://www.liebertpub.com/doi/10.1089/pmr.2020.0015> offers important insights, suggesting that DT, revised to meet the needs of dying children and adolescents, has a place within the pediatric palliative care therapeutic armamentarium.<sup>4</sup> Although all participants reported positive outcomes, the revisions needed to make DT suitable in this context are worthy of reflection.

Shortly after the death of nine-year-old Madeline "Maddie" Dibello, members of her immediate family took part in DT by way of proxy. Afterward they reported feeling peaceful, with the mother indicating that the final document reflected how the family felt about her child. Other studies have described DT by proxy, with health care providers and family members of patients with dementia reporting heightened sense of dignity, meaning, and appreciation of who the resident was as a person.<sup>5</sup>

Upon completing his DT, 19-year-old Alex Unger had his sister create the cover art for his generativity document. This is consistent with Julião et al. who suggested that art, photography, video, or audio recordings can embellish legacy

documents of adolescent patients.<sup>3</sup> Sixteen-year-old Miracle Akbar held a party at which she read her generativity document, whereas Shahd Shahroor had her document translated into her family's native tongue of Arabic and took great pride in the document being used for educational purposes. Although perhaps motivated by altruism, her reaction also suggests comfort in knowing her story will be told.

By adding art, video, photography, and similar creative embellishments, young people—or their proxies—are able to engage in a process that provides lasting testimony to their lives. Perhaps the one thing that all of these cases illustrate is that being remembered, and the ability to appreciate the notion of being held in the memory of those left behind, is critical when considering DT for child and adolescent patients. By enabling the preservation of memory, DT can help fulfill the final wishes of children nearing death.

## References

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