



Diverse Approaches to Meaning-Making at the End of Life

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mental health and palliative or hospice care be engaged early and often during care progression.

Of course, a team approach demands continuity of communication across team members and an awareness of each regarding what has been said both within the team and by individual team members, patients, and families. It is important that team members are cognizant of each other's informational roles and responsibilities, and what has been communicated about the diagnosis and prognosis must be documented in hospital records. But by adapting to the realities of contemporary medical practices and embracing a team approach, treating physicians should be able to focus on what they do best and will ultimately provide better care for their patients. ■

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Diverse Approaches to Meaning-Making at the End of Life

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Saracino et al. (2019) offer substantial evidence from psycho-oncology and palliative care research to demonstrate the positive psychological effects of two existentially-oriented therapies—Dignity Therapy and Meaning Centered Psychotherapy. Saracino et al. introduce readers to the role of clinicians as potential shepherds of the meaning-making process at the end of life, with evidence of the psychological benefits of these therapeutic processes to terminally ill patients. These therapies follow in the spirit of Elisabeth Kübler-Ross's (1969) groundbreaking work to promote the value of attending to dying patients' lived experiences and need for meaning at the end of life. Importantly, however, Kübler-Ross's ideas have resonated far beyond her home discipline of psychiatry and her original population of interest, terminally ill patients. In what follows, we expand Saracino et al.'s discussion of existential psychotherapies at end of life along two axes: (1) To include specific interdisciplinary

approaches to creating meaningful self-integration and self-transcendence from the fields of psychology, gerontology, nursing, and pastoral care; and (2) To illustrate positive psychological effects of existentially-oriented therapies in both ill patients and healthy elders. To that end, we provide a high-level overview of narratively-informed therapeutic techniques, followed by specific therapies accompanied by empirical support.

Narrative therapeutic techniques derive from the same theoretical lineage as narrative theory in the social sciences. The crux of narrative theory is that we humans make sense of our lives through the stories we tell about them. Our actual lives are then shaped by this meaning-making process in ways that influence our identities, our understanding of ourselves, and our behaviors. The meaning-making process of authoring our own life stories is one that begins in emerging adulthood and continues for the remainder of our lives. Near the end of life,

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we begin to transition from the authors of our own life stories to the readers of these stories—we are driven to see these stories as satisfactory and integrated. Reed (2014) has used observational and experimental methods to understand the phenomenon of a closely-related drive, that toward self-transcendence. Self-transcendence—a feeling of integration with others, the environment, and “something greater,” as well as cohesiveness of oneself across time—increases as one’s awareness of personal vulnerability and mortality increases. We might think of the thread which connects self-integration and self-transcendence in old age as the generative desire to pass on not just material possessions but also life stories rife with spiritual and ethical lessons. Indeed, Reed and colleagues have found over many studies that a feeling of self-transcendence is integral to well-being at the end of life, and can be increased through psychotherapeutic interventions such as those discussed below.

Psychotherapy is a context that provides guidance for individuals to approach life-closing with intentionality, as well as a context for researchers to explore relationships between subjective lived experience and psychological phenomena. For example, research on the structure of well-being in older adult narratives found that individuals ($N=40$; $M=72.3$ years) who told their life stories as increasingly positive and stable over time had higher scores on well-being and ego integrity than those who told increasingly negative or variable life stories (Sherman 1994). Similarly, narratives of healthy late midlife adults ($N=128$; $M=66$ years) demonstrated ego integrity found in life stories was significantly and positively correlated with overall well-being and regret resolution (Torges et al. 2008).

Applying narrative theory to clinical, end-of-life settings suggests a number of noteworthy narratively-informed therapeutic techniques as an expansion on Saracino et al. (2019). These include life review, reminiscence therapy, spiritual listening and blessing, ethical wills, and narrative therapy, all of which draw on an individual’s life story and intimate relationships to provide life-closing rituals.

Life review is a naturally occurring psychological phenomenon in older people and describes the inner experience of reminiscing about or “reviewing” past life events, in particular detecting unresolved and unintegrated life events so that these may be reconsidered and integrated meaningfully. This process has also been found to occur in younger adults who are facing death due to terminal illness. A systematic review by Keall et al. (2015) included 14 studies in which psychologists, social workers, or nurses facilitated some form of life review interventions with patients in palliative care. Statistically significant improvements were found in 11 of 14 studies: for example, on measures such as patient talkativeness, spirituality, overall quality of life, mood (anxiety and depression), happiness, meaning, hope, self-efficacy, and seeking out further psychological resources.

Therapeutic life reviews are typically conducted as part of a patient-provider structure and are one version of “reminiscence therapy,” a broader term which also includes other intervention programs. Reminiscence interventions examine the entire lifespan from youth and adulthood to the present (older adulthood) and future, and explore themes such as early memories, norms and values, life story turning points, meaning of life, spirituality, and identity. Pinquart and Forstmeier (2012) conducted a meta-analysis of 128 studies which included some form of reminiscence. Strikingly, they found positive effects of reminiscence interventions on all assessed outcomes, with effects maintained at follow-up for depression, other indicators of mental health, life satisfaction, ego integrity, cognitive performance, and death preparation.

Reminiscence therapy used in the context of pastoral care may translate to a framework of spiritual listening and blessing. Consider “The Soul’s Legacy,” a fifteen-week group reminiscence program which uses a life review process to facilitate participants’ connection to their soul, their story, the divine, close others, and their mortality (Grewe 2017). The centerpiece of this intervention is the giving and receiving of blessings between close others as a form of legacy creation and self-transcendence. Grewe (2017) studied healthy older participants in church settings ($N=34$, $M=71.3$ years). Pre- and post-test comparisons demonstrated increases in the number of participants who felt at peace with their mortality, gratitude about their lives, and increased comfort with sharing their feelings with loved ones. Notably, there was also an increase in the number of people who felt ambivalent about difficult decisions they had made in their lives. Sherman (1994) also found that reminiscence increased the complexity with which participants viewed their own life stories.

Community-based practices situated in oral traditions have more recently been taken up by clinicians as tools for meaning-making at the end of life. For example, the ancient Jewish tradition of creating an “ethical will” serves the purpose of passing down one’s moral and ethical resources accrued after a lifetime of spiritual and communal engagement and growth. Ethical wills can be completed by any person at any stage of health, either alone or in partnership with a healthcare professional or loved one. Research suggests suffering may be reduced following ethical will interventions (Gessert et al. 2004), though this is an admittedly underexplored area.

Lastly, narrative therapy is a formal psychotherapeutic technique often construed as involving narrative co-construction between the client and therapist. Because personal narratives are informed by dominant cultural narratives which individuals unconsciously and consciously adopt, modify, and resist in constructing their own stories, destructive aspects of these master narratives are sometimes the target for disruption in narrative therapy (White and Epston 1990). Narrative therapy seeks to incorporate previously neglected but significant stories into the life story, and to have these new narratives witnessed by others, with the ultimate goal of living the

improved narratives. Initial research about narrative therapy is promising but very limited, with little research on conducting narrative therapy with older adults.

Kübler-Ross had a tremendous impact on shifting the medical and lay “master narratives” of death and dying. She powerfully called attention to the duty of clinicians and researchers to care for the subjective experience of the final chapters of life. Each of the preceding interventions—whether from psychology, gerontology, nursing, or pastoral care—share her insight that individuals in the final chapters of life tend to be highly concerned with existential questions of dignity and meaning, and these concerns are of great therapeutic importance. Researchers and clinicians of diverse disciplines continue to build on Kübler-Ross’s legacy by creating and refining evidence-based practices to increase the well-being not only of terminally ill patients but patients facing the end of life in general. ■

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The Underappreciated Influence of Elisabeth Kübler-Ross on the Development of Palliative Care for Children

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In the history of palliative care, all roads lead back to Dame Cicely Saunders, a remarkable social worker/nurse/physician who promoted the concept of total pain and founded the first modern hospice. Her work revolutionized the care of dying adults (Clark 2016). However, Saunders’ influence on the development of pediatric palliative care is more complicated. We are conducting an oral history project that explores the roots of pediatric palliative care. Thus far, we have interviewed 31 individuals who were instrumental in this field’s development. Through these interviews, we identified another famous

physician who directly supported this early development: Elisabeth Kübler-Ross. Kübler-Ross was a Swiss-American psychiatrist who wrote the groundbreaking book *On Death and Dying* (Kübler-Ross 1969). Her work increased Western society’s openness to discussing death. She also took an interest in the impact of childhood death on families, culminating in the book *On Children and Death* in 1983 (Kübler-Ross 1983). Yet, her influence on the care of dying children has been underappreciated. In this paper, we explore the influences of both these foundational figures through excerpts from oral histories.

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