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Article 95

Legacy Work: Helping Clients with Life-Threatening Illness to Preserve Memories, Beliefs, and Values for Loved Ones

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Legacy is popularly understood in today's culture as referring to the idea of leaving something of oneself behind for future generations. Frequently legacy has been understood in two primary ways. First, it can indicate a material legacy—that appropriation of material and familial possessions to family or friends after one's death, or a financial bequest to an institution or cause. Second there is the biological legacy—that inheritance of genetic traits with susceptibility to certain health conditions passed through the generations. However, the phenomenon of legacy as an aspect of aging or terminal illness has been understudied in the end of life literature, especially from the perspective of transmitting values and beliefs to loved ones left behind (Hunter, 2008a, 2008b; Hunter & Rowles, 2005). The psychosocialspiritual concept of legacy work has historical roots in the field of music therapy (Cadrin, 2006; West, 1994). More recently the gerontological (Moremen, 2005; Werth, Gordon, & Johnson, 2002) and the palliative care fields (Chochinov, 2007) have begun to acknowledge the importance of helping individuals leave behind a legacy for loved ones. However, there is a paucity of literature about legacy work in counseling, which is probably indicative that clinical counseling applications of legacy interventions are underutilized in practice (for an exception, see Rayburn, 2008, which, while not specifically using the term legacy, included similar concepts).

As individuals approach the end of life, it is not uncommon for them to question whether others will remember them and if their living or dying has had any meaning. Doka (2009) described spiritual needs for individuals who were dying, such as the need for a transcendental hope that their lives would last beyond death in the memories of

others, and the need to know that life has had value or has not been wasted. Impending death often elicits a search for meaning and establishment of one's "place in the universe" (Moremen, 2005, p. 310), an almost universal concern. Meaninglessness about life can result in despair or hopelessness, while the knowledge that aspects of one's life can transcend death can provide comfort to the dying (Chochinov, 2002; Rayburn, 2008; Sulmasy, 2006). Such psychosocial distress is as significant to the person dealing with a life-threatening illness as is physical suffering, and might even be of greater concern (Chochinov et al., 2005), adding significance to the importance of leaving behind some kind of permanent legacy.

At the end of life, possible tasks for the dying person may include the need to make amends, to attend to any unfinished business with loved ones, and to share the meaning of her or his life with those who remain. Essential to sharing meaning is narrative, and the individual may desire to communicate not only values and beliefs but also life stories with surviving loved ones. Part of this process can be that effort of "documenting one's life, [to leave a] legacy for future generations" (Cadrin, 2006, p. 109). Legacy may be understood as a way for the dying to write the ending of their story to impart to future generations from the perspective of their experience and wisdom (Hunter, 2008a, 2008b; Hunter & Rowles, 2005; McAdams, 1993). Schaie and Willis (2000), in their stage model of adult cognitive development, described the Legacy Creating Stage for an older person anticipating the end of life. Suggested activities during this stage included conducting a life review, writing an autobiography, and documenting an oral or written history with pictures, heirlooms, or possessions. Additionally, the creation of legacy as a "generativity document" is one aspect of Chochinov's Dignity Therapy, a therapeutic approach utilized in palliative care (Chochinov et al., 2005, p. 5521). The palliative care provider or mental health counselor interviews someone who is dying, helping that person determine what information he or she considers most important for others to know and remember. The interviews are then transcribed, reviewed, edited, and returned to the author for distribution to loved ones.

Creating a legacy can conserve the dignity of the one dying by allowing for personal agency and control over some aspect of the dying process, by maintaining hope for the meaning of a life lived, and by recognizing the value and worth of the dying person (Chochinov, 2007; Hunter, 2008a, 2008b). Through such stories, not only does one's life continue, but one also develops an understanding of the world and a sense of her or his own life (McAdams, 1993). The self of the person is refined to its essence by understanding that enables the creation of identity, and according to Hunter, identity is innately linked to legacy (2008a). Vaillant (2002) posited that adults in Erikson's (1963) generativity stage of life were the keepers of meaning, and thus were responsible for preserving the past and conveying wisdom to the younger generations. Vaillant (2002) further described the task of generativity as that of investing in something that will outlive oneself.

Conversely, despair in the dying can result from the fear that one has not been important to others, that his or her suffering was without meaning, or that life itself was without purpose. Serious life-threatening illness raises existential questions regarding the value of life and relationships. Fears of dying and separating from life as one knows it are often eclipsed by the fear of meaninglessness (Rayburn, 2008; Sulmasy, 2006). Additionally, loss of independence, role and relational changes, betrayal by one's own

body, and pain and suffering are negative parts of the dying process. Accompanying these changes is the anticipation of the grief of saying goodbye to loved ones and friends. A sense of the transcendent realm of death can be facilitated by recognizing that life has had meaning and value, and this can result from meaning-engendering activities such as visiting with and giving bequests to loved ones, reminiscing over photos, or compiling stories (Chochinov, 2002; see also Frankl, 1963). Construction of a legacy with the guidance of a sensitive counselor can help the person cope with the process of dying and hopefully even improve the quality of the life that remains.

Legacy Work With the Terminally Ill

Two well known contemporary examples of individuals who have done legacy work are Dr. Randy Pausch, professor at Carnegie Mellon University, and Mr. Tony Snow, the former press secretary for the G. W. Bush presidency. Pausch, invited to deliver a Last Lecture speech at Carnegie Mellon in 2007, was in fact dying of pancreatic cancer at the time of the lecture. Pausch (2008) stated that in this last lecture, he desired for his children to be able to hear his voice, to know what kind of a man he had been, and above all to know that he loved them. In his speech he articulated not only his goals and beliefs but also told a unique story for each child about times they had shared during his life.

Similarly, Snow, who died in 2008, left a legacy document for the nation by sharing his personal faith in the face of walking through what he termed “the Valley of the Shadow of Death.” In Snow’s interview, he shared lessons he had learned, not about how to die but about how to live (Snow, 2007). Yalom articulated that same existential aspect of legacy: “Learning to live well is to die well: and, conversely, learning to die well is to learn to live well” (1998, p. 185).

As counselors, we have an “ethical imperative” to comfort and facilitate the dying and their families as much as possible (Rayburn, 2008, p. 95). This necessitates a sensitive awareness that dying encompasses more than just the physical end of life but also includes psychosocial, spiritual, and existential sufferings as well. It is essential that counselors recognize the importance of the whole person’s response to death: the psychological, interpersonal relational, societal, and spiritual aspects. In today’s medicalized health care system, it is not uncommon for the psychosocialspiritual aspects of dying to be ignored in the face of overwhelming attention to medical issues (Werth, 2005; Werth et al., 2002). Often health care providers and even mental health counselors are reluctant or fearful to inquire about the existential and spiritual concerns of the dying person, partly due to fears of crossing ethical boundaries. Avoiding this conversation can exacerbate the dying’s despair, pessimism, or loss of hope. Loss of hope can not only lower the quality of the person’s remaining life but has been demonstrated to also hasten death (Werth, 2005).

Tasks of the terminally ill include managing and coping with a myriad of physical symptoms, such as pain, possible incapacitation, altered body responses, and even a sense that one’s own body has been a traitor. Added to the physical demands, there are interpersonal issues, such as role changes, altered relationships, fears of becoming a burden, or perhaps some relational estrangement and distance. Autonomy or self-determination is important, especially in western cultures, allowing the individual to

make her or his own decisions about the quality of the remaining life. Existential or spiritual matters tend to assume greater importance in the face of death, and exploration of life's meaning and purpose and leaving a legacy become issues of concern (Werth et al., 2002). Advanced directives, living wills, hospice and palliative care have greatly improved the process of dying. Treatment of the dying, however, needs to be broader, including such essentials as a person-centered focus of attending to the individual's feelings, a communication of respect, and a stance of understanding. Counselors must recognize that the crisis of dying includes spiritual, emotional, and relational aspects. The dying may need assistance to alter their concept from that of being alive and healthy to recognizing that they are in fact dying (Doka, 2009).

Dying individuals usually know that they are dying, and they often desire an opportunity to talk about dying. Ventilating their feelings and fears if possible, beginning the process of disengagement, and saying goodbye are necessary tasks. Yet, the topic of death is marginalized in today's death-fearing and death-defying society. Talking about death is often especially awkward for family members who may avoid this conversation in an attempt to protect their loved one by being evasive or deceptive (Doka, 2009).

Legacy work allows opportunity for the dying to tell their stories about their lives before they die (Hunter, 2008a). Legacy can be a vehicle for clarification and communication of not only stories, but of values, beliefs or an expression of love. Additionally, a legacy can provide a sense of continuity to those who remain living after a loved one's death, a type of linking object that enables the survivors to still feel a sense of connection in the relationship, albeit a symbolic connection rather than a physical relationship (Neimeyer, 2000; Worden, 2009). This symbolic immortality can provide influence beyond the grave, helping grievers to both bridge the gap between past, present, and future, and to form meaningful reconstructions of their new lives (Humphrey, 2009, p. 140).

Implementation of Legacy Work With the Dying

Previously the counselor typically has not been the professional who was present with the dying. Historically within the medical model, dying has occurred in the hospital, and the social worker and the chaplain have been the primary psychosocial supports for the dying individual. However, medical advances and more aggressive treatments for various life-threatening illnesses have made it possible for the extension of life in many individuals. As a result, it is more likely today that mental health counselors will be working with clients who have been diagnosed with such illnesses but may be in remission or non-acute phases in that time of the "living-dying interval" between diagnosis and death (Doka, 2009, p. 25). Also given the increase in the aging demographics of today's world with many older persons experiencing multiple chronic illnesses, more counselors will be likely to provide counseling services to clients who may be facing death, and timing is important in the introduction of legacy work.

Therefore, it is vital for the counselor to be sensitive to the dying individual's physical condition before introducing the idea of legacy work. If introduced too early, there is a risk of causing the individual to lose hope or to experience despair by the tacit communication of the inevitability of death that the person may not be ready to acknowledge. Conversely, if introduced too late, the opportunity to do the work, or to

gain the positive benefits from legacy, may be lost. West (1994) identified a helpful theoretical framework of four phases of dying that can enable the counselor to assess an appropriate time for introducing the idea of legacy, understanding that the “dying will be living and dying at the same time” (p. 117).

In the initial phase, the individual may be experiencing an acute illness state and may have just learned that the condition is terminal. At this point, the idea of legacy work may simply be too overwhelming for an already vulnerable individual trying to assimilate serious information while also possibly experiencing extreme affect and fears. The final phase is also an inappropriate time to attempt legacy work because the individual is actively dying. All the energy and focus of the person is on the dying process; the person may even have become unresponsive. Legacy work should already have been completed according to West’s model (1994).

West (1994) suggested that the middle two phases are ideal for introducing this concept of legacy work to the dying individual. The second phase, stabilization, is often a plateau period in which the person is beginning to adjust to the possibility of dying. There may be a remission accompanied by a period of increased energy that is necessary for this type of processing. The individual is experiencing fully living although still dying. In the face of the urgency of getting one’s affairs in order legacy work can foster a sense of personal control and renewed goals for sharing important information. The third phase is when the disease is progressing relentlessly, regardless of treatment, and the person has a heightened awareness of the imminence of death. Legacy work can now be especially therapeutic in helping the dying identify what has been valuable in his or her life and making some sense of meaning about it.

Examples of Legacy Work Interventions

In introducing legacy work, a helpful place to begin is to ask the individual to share favorite childhood memories or significant events during her or his life. This can be further expanded to include favorite songs, poems, inspirational verses or readings, or pictures. Typical legacy interventions may include creative activities such as art, music, photo albums, or writings of stories or poetry. Collages, scrap books, and photo story albums are also popular. The types of media used are as individual as the people creating the legacies. It is not uncommon for an individual with a musical interest to compile a collection of favorite songs or hymns to tell a story. A personal favorite example of the authors is the duet of “Unforgettable” (Gordon, 1951) in which Natalie Cole superimposed her singing over the vocal tracks of her father, Nat King Cole, making a beautiful tribute to her father’s legacy of music and creating a legacy of her own (Sadler-Gerhardt & Hollenbach, 2010). Another example would be the poignant drawings of children incarcerated in the concentration camps from *I never saw another butterfly...Children’s drawings and poems from Terezin Concentration Camp, 1942-1944* (Volavková, 1993).

A common counseling intervention, especially with the older client or with one who is experiencing a life-changing transition, is a life review. The life review is actually a type of legacy activity during which individuals can consider their past decisions and choices while reflecting on the meaning of their lives. Ideally, this would become a positive opportunity for them to face impending death with a spirit of hope and integrity.

The opportunity to process relationships, bequeath values, and move towards growth and self actualization can occur during a life review (Davis & Degges-White, 2008), and can be a means of “leaving a footprint on the sands of time” (Rayburn, 2008, p. 105). This can enhance the process of making sense of life and earlier events by developing new perspectives, and also provide opportunities to communicate values and beliefs (Davis & Degges-White, 2008). Additionally, the activity of a life review can help lessen the dying person’s sense of isolation by that symbolic reconnection with other loved ones who have previously died via internal representations of continuing bonds (Worden, 2009).

Similarly, an ethical will can become an important legacy (Baines, 2003, 2006). Many people report that they have a Last Will and Testament to apportion their material possessions, or a Living Will, defining their wishes for specific types of treatment decisions and identifying those who can decide for them if necessary at the end of life. An ethical will is a means to leave behind a spiritual legacy of a person’s values and beliefs, a type of “love letter from the heart” (Baines, 2008). Baines also recommended encouraging a client to write an ethical will at times other than when facing death, such as in times of national disasters, significant transitions and turning points in life (e.g., engagements, births, midlife), or times of challenging life events (e.g., illness). Originally based in the oral tradition of the Hebrew scriptures where Jacob blessed, advised, and admonished his sons (Gen. 49, New International Version), there are other examples from the Christian scriptures (e.g., Jn. 15-18) and from East African spirituality. According to East African beliefs Sasa is that moment when a person physically dies, and Zamani is the time when the *memory* of a person’s life dies (Baines, 2008).

Included in an ethical will might be the kinds of things the person would want younger generations to know about her or his personal roots, such as the names of great-grandparents, community histories, and religious or spiritual values. Important decisions linking the past with the present and ultimately future generations would also be significant to pass on. Many families desire that sense of transcendence, of being a part of something bigger than just their own lives, and find that an ethical will can be a means of imparting wisdom and heritage to future generations (Baines, 2006, 2003). Baines’ viewpoint is that “if we don’t tell our stories, and the stories of who we come from, no one else will, and they will be lost forever” (2003, p. 143). Living on in the hearts and memories of loved ones will be an individual’s values, beliefs, lessons, hopes, and love.

Conclusion

Legacy work has been primarily used with the dying in the hospital and facilitated by a music therapist. However, it is an intervention that fits nicely within the holistic developmental conceptualization of counseling and can be used with clients who may not be dying. The concept of generativity, of imparting wisdom or history to future generations, can be important in major life transitions as well as at the end of life (Baines, 2006). With the increased aging population and the expanded utilization of hospice and other palliative care options, there are more possibilities for counselors to be involved in the treatment of individuals who may be interested in doing some legacy work. However, there is a paucity of literature in the counseling arena about legacy, as well as of interventions targeted at the distress in maintaining quality of life and dignity in the dying (Chochinov, 2002). One of the authors (JGH) has utilized legacy with a number of aging

clients who have been very receptive and enthusiastic about the process of reminiscence and storytelling. Additional types of legacy interventions with a solid theoretical foundation would be important areas of future research that could make real contributions to counseling practice and to the end of life literature.

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