

Senior Capstone Research Paper

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Adding Value to the Life of Terminally Ill Patients Through Legacy Art Projects

Jeannine Millner

Fontbonne University

REL496

## Outline

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## I.

## THESIS STATEMENT AND BACKGROUND

It is the rare human being who is facing a life-threatening illness, or is approaching the end of their life, who can readily see the value in developing and clarifying a legacy for their surviving loved ones and those who will come after them. They are often caught up in the necessary pragmatic responsibilities of tending to legal matters, planning their funeral, or just keeping up with doctor appointments. The research of hospice nurses Maggie Callanan and Patricia Kelley explores understanding the special awareness, needs, and communications of the dying and is the impetus for the thesis statement of this paper which posits that, rather than giving up, the terminal patient can be helped to continue living until they die, experiencing a time of personal growth for all involved through the creation of legacy projects.<sup>1</sup>

Use of the words *project*, *work*, and *art* (as they relate to one's legacy) will occur interchangeably throughout this paper but essentially share the same meaning: *the integrated experiences of memory-making gifts of art intended for loved one, and those not yet born.*

"People do not know when they will fall sick and die, and they often put off planning for such events. However, EOL [end-of-life] preparation and decision making is an ongoing process that requires time, research, reflection, discussion, and empathetic support from loved ones, legal representatives as well as health and social care professionals."<sup>2</sup>

My mentor, palliative and hospice care physician, Dr. Ken Pettit, writes, "...we prepare for death like we prepare for a final exam in college ...not until the night before. We know it's

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<sup>1</sup> Final Gifts (p. 13)

<sup>2</sup> Handbook of Thanatology (p. 115)

coming, but we pretend we have all the time in the world. We don't face reality until it hits us in the face."<sup>3</sup> Pettit also believes that if we knew our date and time of death, we would have meaningful conversations with people who need to hear from us. "You'd be making peace with your loved ones and seeking closure."<sup>4</sup> I concur with Dr. Pettit, who adds, "If we don't give dying people the time and the support to do this [die a good death], we're robbing them of a priceless opportunity."<sup>5</sup>

This paper will begin by introducing the reader to the construct of End-of-Life Legacy Projects – essentially, art-based projects designed to create the priceless opportunity of which Dr. Pettit writes.

The next two sections of the paper will provide research that supports multiple benefits of legacy work to the patient, the recipient, those who facilitate such work, and even those too young or intellectually unable to derive desired outcomes from participating in funeral rituals. It is from these two sections of the paper that this author postulates the full value of legacy projects and provides sufficient reasons for making them part of one's end-of-life planning.

The paper will then provide examples of legacy art projects, most of which can be accomplished on one's own and can be completed in a relatively short period of time.

In conclusion, this paper will recapitulate the benefits that legacy projects provide to those involved in their creation as well as the recipients of the art. It will reconfirm how legacy work can serve as a communication tool and an outlet for those facing end-of-life when words do not come easily or the patient is simply coming to terms with their impending death.

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<sup>3</sup> They Call Me Doctor Death (p. 67)

<sup>4</sup> Ibid.

<sup>5</sup> Ibid.

II.  
CONTEXTUALIZATION OF LEGACY ART PROJECTS  
IN HOLISTIC PALLIATIVE END-OF-LIFE CARE

Merriam-Webster Dictionary defines the noun *legacy* first, as a gift by will especially of money or other personal property and, second, as something transmitted by or received from an ancestor or predecessor or from the past. End-of-life legacy art projects represent both definitions.

We all have a story that deserves to be told. Our unique story is a summary of all that has meaning to us. For most of us, it requires organization and prioritization before it can be thoughtfully shared. But there are those who, with little preparatory thought, know exactly what is and has been important in their lives – what they want us to remember them by. It might be their profession, or their deep faith in Gd. Perhaps it is as simple, yet profound, as the loving relationships they have with family and friends. But for many, the thought of one's own legacy is elusive. Few of us take the time to identify, let alone put into words, exactly what we want passed on to our loved ones and others who will come after us.

One's legacy is meant to communicate one or many messages and, as one begins their legacy work, their message(s) will begin to surface. This is when they'll come to recognize the best medium for their project. It could be a photo collage of holiday gatherings, an audio or video recording, or a handwritten journal.

Before the dying patient can explore why their legacy should be represented through an art project, they must first value their legacy. For many, entering the final journey of their time in this world means that waking hours are predominantly spent dealing with doctors and other

health professionals, lawyers, employers or employees, clergy, or funeral directors. These endeavors are very serious, somber, and physically and mentally taxing obligations, leaving little or no desire to have potentially difficult face-to-face conversations with loved ones regarding end-of-life situations and decisions. They want their loved ones to know how much they are loved but it's easier to avoid saying or doing anything that may cause them additional emotional discomfort and sadness. They may still be struggling with the inevitable acceptance of their own mortality and experiencing grief within their own sense of self. "With acceptance comes detachment, a drawing away from others no matter how close they have been. This can be painful for those being left behind."<sup>6</sup>

If the terminally ill patient is experiencing any of what famed Swiss American psychiatrist, and pioneer in near-death studies, Elisabeth Kübler-Ross, M.D. identified as the first four of five emotional stages of dying (denial and isolation, anger, bargaining, or depression),<sup>7</sup> creating a legacy art project may prove therapeutically beneficial to the patient's end-of-life journey. It's common for patients to experience interludes of acceptance and then, in one day, in one conversation, in one sentence, slip into another emotional stage.<sup>8</sup>

In 1974, the modern hospice movement in the United States was established in Connecticut and the medical community began to recognize suffering as an inevitable part of our humanity by highlighting the moral responsibility we have to alleviate our fellow humans' distress as far as

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<sup>6</sup> Final Gifts (p. 55)

<sup>7</sup> On Death and Dying (pp. 38-85)

<sup>8</sup> Final Gifts (p. 55)

we are able. To receive palliative care is to feel welcomed by others, to feel understood for who you are, and be supported to find what you need to continue living well up to the end.<sup>9</sup>

I am convinced that a holistic palliative care approach to treating the terminally ill patient – which includes addressing the medical and non-medical needs of the dying – allows the patient to have the best possible quality of life up to the end. Pettit calls this, “dying a good death.”<sup>10</sup>

### III.

#### OVERARCHING BENEFITS OF LEGACY ART PROJETS

Evidence-based research supporting the efficacy and benefits of art therapy on dying patients remains sparse, according to Dr. Val Huet, CEO of the British Association of Art Therapists.<sup>11</sup> My exhaustive search for evidence-based data that specifically supports the benefits of legacy art projects in the lives of terminally ill patients also proved less than fruitful. Dr. Andrew Collins, palliative care physician at the University of British Columbia, Vancouver, Canada, reports, “...individuals who feel they are leaving behind a legacy are more secure in their sense of well-being.”<sup>12</sup>

However, much of Collins’ research has focused on the benefits experienced by those who facilitate legacy project sessions as part of the delivery of palliative care to terminal patients. In a study published in 2019, Collins reported the facilitators (henceforth participants), all from the same organization, had previously received special training to ensure their competency to handle any emotional difficulties that may arise while working with this specific population.

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<sup>9</sup> The International Handbook of Art Therapy in Palliative and Bereavement Care (p. xviii-xix)

<sup>10</sup> They Call Me Dr. Death (p. 3)

<sup>11</sup> Case Study of an Art Therapy-based Group (p.22)

<sup>12</sup> American Journal of Hospice & Palliative Medicine (p. 66)

The composition of the participants was 80% female ( $n = 4$ ) and 20% male ( $n = 1$ ). At the time of their interviews, the participants had collectively facilitated 29 legacy projects at hospice facilities, acute care facilities, or in the residences of their patients.

Two specific research questions were asked of the five participants: 1) *Does legacy facilitation result in a positive or negative experience?* 2) *Do facilitators require a formal self-care program?* Five themes emerged from the data: “providing a benefit,” “internal validation,” “it’s all been positive,” “self-awareness,” and “if you need support.”

All participants stated that legacy work provides benefits, specifically noting the connection that reaches back to the patient/creator of the art. Various comments from patients, or members of their families, or positive changes in patients’ attitude toward their impending death, provided the participants with internal validation that they had made a positive impact on the patients and their families. Because no one [in their program] is forced into participating in legacy work, the participants only reported positive outcomes. Self-awareness, in the form of humility and priority shifts within their own lives and personal situations, was reported by all participants. Finally, through their organization’s training program, each participant knew to watch for their own warning signs of needing self-care. All reported seeking help when necessary.

I agree with Dr. Collins’ assessment that the research is limited by a sample size derived from a single program. Further research would be needed to fully determine if the same experiences are shared by other facilitators before generalizing to the larger population.

There also exists some evidence-based research on the positive effects experienced by caregivers who participate in legacy-through-art. Dr. Girigi Kaimal, Associate Professor in the PhD Program in Creative Arts Therapies at Drexel University College of Nursing and Health



Professions, completed a small-sample study in 2016 ( $n = 7$ ) that examined how art-based approaches might help with physical and psychological well-being of caregivers of patients in home-hospice, end-of-life care. She writes, “As an art therapist and researcher, I felt deeply moved by my interactions. I felt honored and privileged to enter the lives of the caregivers. Many had been married for over 60 years and were caring for their spouses in their 80s and 90s. ... To me, the time and opportunity to listen to the stories was very impactful. Often on the days when I collected data, I could do little else. I would reflect on what I had heard, make notes, make art, and try to respect and honor the stories of lives around me that I had briefly encountered. ... The human connection that transcends all demographic barriers was illuminated for me through this study.<sup>13</sup> Dr. Kaimal believes that there are more opportunities for future studies of this sort and they should be conducted. I agree with her and would add that her results could be interpreted as anecdotal and not statistically significant. I would also be interested in knowing if any of the caregiving spouses experienced negative psychological consequences from the legacy work, perhaps in the form of exacerbated anticipatory grief.

This modest pool of evidence-based research led me to consider what theorists had published on the benefits of art therapy on the dying patient. “Art theorists (Ehrenzweig, 1973; Fiorini, 1995) suggest that during the different phases of the creative process, the psyche of the artists goes through several states, which can be seen as related to the beneficial effect observed in art therapy (Paín & Jarreau, 1995). The first stage is the exploration phase: it begins in the world of what is already known (materials) and already established (ideas) and necessary to penetrate into an unknown world of creative chaos. The transformation phase follows ... then the culmination

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<sup>13</sup> American Journal of Hospice & Palliative Medicine. (pp. 181, 183)

phase (when the search is ending) and finally the separation phase (which is necessary to continue to another creative destiny). Once the art has been produced, it is self-supporting and the person who made it can move away. In this way, the creative process also involves the process of grief (López Fernández Cao & Martínez Díez, 2006), a facet that becomes particularly important at end-of-life in which the experience of saying farewell, to oneself and others, is one of the main tasks of the person who understands and accepts the imminence of death (Byock, 2002).”<sup>14</sup>

Finally, I offer my own thoughts on the potential benefits that can be experienced by representing one’s legacy through art. Because death is difficult for most people to talk about, legacy art projects can provide the dying patient a medium through which they can communicate their innermost wishes and feelings to their loved ones. When words fail them, a legacy project empowers the dying to share the gifts of wisdom, faith, and love through a creative process.

#### IV.

##### LEGACY ART FOR THOSE UNABLE TO PARTICIPATE IN FUNERAL RITUALS

Sometimes, it is pre-determined that certain family members are simply unable to derive the desired benefits that come from participating in funeral rituals. They may have physical or intellectual challenges or are just too young.

Gifting a legacy project can make processing grief easier for children and other family members who may not have attended the funeral of their deceased loved one. Some parents struggle with whether children will suffer further emotional pain or distress by attending

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<sup>14</sup> The International Handbook of Art Therapy in Palliative and Bereavement Care (p. 5)

funerals. Questions often arise as to the appropriateness of children's attendance and participation in funerals. "Some parents may simply be uncomfortable with death rituals themselves; others are confused by conflicting advice from friends and family who suggest that funerals are no place for children."<sup>15</sup>

It is not my intent to sway the reader one way or the other. However, I would be remiss if I didn't share research that supports children's attendance at, and appropriate participation in, funeral services and related rituals.

Weller et al. (1988) interviewed 38 children (ages 5-12) shortly after their parents' death, unexpectedly finding that children's attendance at funerals was not detrimental to their health. In the Harvard Child Bereavement Study, Silverman & Worden (1992) interviewed 120 children, and findings strongly affirmed the value of funerals two years later, not only in honoring their parents but also in enabling them to connect with social support.<sup>16</sup>

Fristad et al. (2000-2001) studied 318 grieving children (ages 5-17) at 1, 6, 13, and 25 months after their parents' deaths. Children attending funeral visitations (89%) reported significantly improved long-term outcomes, whereas those who did not attend displayed greater depression, anxiety, and behavioral symptoms. The choice of cremation itself did not directly affect grief, but families choosing cremation also tended to avoid social support services expected to improve grief outcomes. The researchers posited the choice of cremation may be an indicator of social distance.<sup>17</sup>

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<sup>15</sup> Handbook of Thanatology (p. 223).

<sup>16</sup> Ibid.

<sup>17</sup> Ibid.

In a small qualitative study, Sjøfting et al. (2016) interviewed 11 Norwegian children aged 7-12 from one to three years following the death of a parent or sibling. Their findings indicated children found it very important to “see for themselves” and to be recognized in their own right as full members of the family’s grief. Participants all appreciated the opportunities to better comprehend and accept the loss and to be involved in saying farewell to loved ones.<sup>18</sup>

In the end, it is the responsibility of the adults within the family to decide what would be most beneficial to each child. Ideally, the children will have age-appropriate voice in this important decision. Should the decision be made to include children in the funeral rituals, I recommend talking to the child prior to the event, asking them what they expect to happen, and avoiding any misinformation or miscommunications. On the other hand, should it be determined that some family members will not attend or participate in funeral rituals, it is still important to acknowledge and support their grief even if it doesn’t fit within the family’s attitude surrounding death and loss to avoid their grief becoming disenfranchised.<sup>19</sup>

## V.

### MEANINGFUL LEGACY ART PROJECT IDEAS

Living with a life-threatening illness, or receiving a terminal diagnosis, means that, eventually, one may begin thinking about how they will be remembered by loved ones and those who will come after them. One might wish to help shape those memories in some way. A legacy art project can provide that opportunity. I have added helpful

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<sup>18</sup> Handbook of Thanatology. (p. 223-4).

<sup>19</sup> Ibid. (pp. 224-5).

notes to some of the more meaningful projects that I encountered during my research for this paper:

Letter Writing: The goal here is to say, “I want you to know how much I love you.” Creating something on your computer first will help you be concise and ensure your message is well represented. You’ll want to remember to include what you want them to know about you that they don’t already know. Offer words of wisdom or sage advice as the patriarch or matriarch of the family. Tell them what you cherish most about them. If appropriate, this is an excellent opportunity to resolve misunderstandings or offer (or ask) forgiveness for past transgressions. Remember to use your favorite personalized stationery – order some if necessary. This is not something to write on a scratch pad. These words will be the lasting memories that your loved one(s) will cherish and eventually pass along to other family members.

Keepsake Box: These can often be found on Etsy or may be your own personal jewelry box that you choose to gift to a loved one. It can contain photos, cuff links, ticket stubs – any small treasures that hold a connection between you and the recipient. Often the outside can be embellished with a meaningful message like, “*When someone you love becomes a memory, the memory becomes a treasure.*”

Legacy Scrolls: Licensed Clinical Social Worker, Henry Fersko-Weiss, is credited for the creation of the legacy scroll. The scroll might express important aspects of a person’s life in pictures, collages, or in words.<sup>20</sup> Legacy scrolls are often blank parchment paper, measuring approximately five inches wide and available in various lengths. They

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<sup>20</sup> Caring for the Dying (p. 102)

can be found online. The finished scroll can be hung on a wall or displayed in other creative ways by the recipient.

Journaling: This is a wide-open field as legacy projects go. If time and health permit, consider writing your biography. Tell important stories. Teach life lessons. Everything doesn't have to be 100% truth; embellishment may provide humor to the reader. You have more creative license with a journal than many other projects. Draw your family tree. Draw pictures of each of your loved ones perhaps depicting a favorite memory with them. Share your favorite Scripture verses. Remember to tell the recipient how much you love them.

Quilt or Pillow: Consider sending a favorite shirt (perhaps recognizable from family photos) to a company that will custom make a pillow from the fabric, including a personalized, embroidered message from you. There are Etsy Stores that can easily accommodate the crafting of a simple pillow to an entire quilt if you provide enough fabric.

Audio or Video Recordings: This is fairly easy with today's cell phone technology. Write out your message in advance and practice reading it a few times. Keeping the message to five minutes or less allows the listener to enjoy it more often as they will only need to set aside a small amount of time to reminisce. You can also use a professional video service. Often these can be found through wedding planners and funeral directors. This is also the perfect time to tell all your "Dad Jokes," or offer words of encouragement and sage wisdom.

3D Keepsake Hands Casting Kits: This is a more challenging yet incredibly touching legacy project. It will require you and the recipient work together to create a three-dimensional cast of you and your loved one holding hands. You simply mix a pre-measured rubber-molding powder and place your clutched hands into the mixture to create the mold. After a few minutes, you remove your hands and pour in the plaster formula. Once dry, simply peel away the rubber mold to reveal your preserved-forever, detailed clutch hands.

Last Will and Testament: Not intended to replace a living trust or other legal instruments, your will and testament can convey wishes for your loved ones, and the ones who will come after you, regarding personal preferences and situations that may be too difficult to discuss face-to-face such as religious obligations. Examples include covenantal acts, such as your desire that all your grandchildren be baptized - or that the tradition of Bar or Bat Mitzvah be carried on in your family. Some will use the last will and testament to designate who is to receive specific pieces of jewelry or how real estate, money, or other assets not otherwise represented in legally binding instruments are to be divided among the heirs.

## VI.

### DISCUSSION AND CONCLUSION

Because the terminally ill patient is often preoccupied with the overwhelming number of doctor appointments, legal matters, and in some cases their own struggle to come to terms with their demise, there is little if any thought given to the value of legacy work.

Research that has identified many benefits derived from facilitating and receiving legacy art, but more research is needed to fully supports this paper’s thesis statement which posits that, rather than giving up, the terminal patient can be encouraged to continue living until they die, experiencing a time of personal growth for themselves and their loved ones through the creation of simple, yet meaningful legacy projects.

These projects are useful tools for thanatologists and end-of-life doulas who are helping the dying identify and assign value to their lives and enable them to tell their personal life stories. Creativity is key to a successful legacy project. In addition, the mere act of crafting a project may be beneficial if the patient is traversing the various emotional stages of dying as outlined earlier in this paper, identified by Kübler-Ross.

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