

## STORIES OF THE LIVING, STORIES OF THE DYING

Legacy, at its core, is about story and story is personal. The narrative of our lives is something we are all interested in, but reflecting on life becomes even more essential when facing death. Reflection about the course of one's life can provide healing and closure, and telling the story in your own words can contribute to a sense of purpose and dignity. There is precedent for recording the stories of the dying, allowing them to tell those stories in their own words and that precedent has found success. Documenting the stories—the legacies—of the dying can be beneficial not only to the person facing death, but to their families and even the community. In my artistic past, I shared my own stories, and the stories of others—but of others who were facing life after death. For my final project, I began to tell the stories of the dying, with the hope that we, the living, could be impacted by what they shared.

### Defining and Documenting Legacy

Like hospice, the term legacy seems to be both a philosophy and an actuality—a way to preserve memories and the preserved memories themselves. After polling several dictionaries, the most descriptive definition of legacy still seems oddly esoteric: “something transmitted by or received from an ancestor or a predecessor or from the past” (“Legacy”). By that measure, legacy can be something tangible—assets—or intangible—traits, memories, the accumulation of stories. For the purposes of this project, I proposed that a legacy is essentially the story of a life, and that every life story deserves the opportunity to be heard.

As humans, we each face death slowly and rather unknowingly; hospice patients, on the other hand, face a more immediate understanding of death. To even qualify for hospice services in the United States, you must be terminally ill. At that point, when the quantity of life is diminishing, the focus transfers to quality of life. Improving the quality of life for dying patients and their families lies at the foundation of hospice care (McClement et al. 1076). Methods for increasing quality of life—interventions—are generally comprehensive and address physical, mental, psychosocial and emotional distress. Increasingly, evidence points to psychosocial and existential issues as the greatest areas of concern for dying patients—even greater than physical symptoms and pain (Chochinov et al. 5520). Symptoms of a poorer quality of life include “an undermining of dignity and depression, anxiety, desire for death, hopelessness, feeling of being a burden on others” (Chochinov et al. 5520). Symptoms of a greater quality of life for dying patients include having a feeling of spiritual peace, strong relationships with family members and loved ones, and not feeling like a burden on others. Studies have shown some correlation between a loss of dignity and meaning in the life of dying patients with increased requests for death to come sooner (Chochinov et al. 5520-21).

### Framework and Precedent

From that research on the impacts of quality of life for dying patients came a new type of therapeutic intervention: dignity therapy, pioneered by Max Chochinov, in which mental, emotional and psychosocial distresses are alleviated and a patient's sense of meaning and dignity are increased (Chochinov et al. 5521). In this intervention, patients are invited to “discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member” (Chochinov et al. 5520). The necessary parts of this type of

intervention are allowing the patient to share his or her story and transcribing that story into written word. The act of putting the words on paper formalizes the story and has an incredible value (McNees 17).

The dignity therapy approach is individualized and comes at a time in the patient's life when reminiscing about the past is nearly unavoidable. Allowing a dying patient to document what is important to them and what they want to be remembered for allows them to have control of the legacy they leave (McClement et al. 1076). On studies of the implications for success of Chochinov's dignity therapy, researchers found that 91% of participants were satisfied with the approach; "76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family" (Chochinov et al. 5520).

Dignity therapy has major possibilities in the local hospice community, for those facing the end of their lives as well as for their families. Providing a written document—the recorded legacy—for the families of the dying family member offers a way for that relationships to endure, before and even after the dying have deceased (McClement et al. 1080). A large part of bereavement is figuring out how to shift the relationship you had with the dead to a relationship with the memories of the dead. Allowing dying patients to leave those memories in a tangible form facilitates this process (McClement et al. 1080). And the messages the dying leave are often unexpected, poignant and insightful (McNees 17).

### *Translating Legacy*

If the legacy is simply the story, then translating the story is the continual work that I have done, at increasingly larger scales—both conceptually and physically. Up until this final project, I was telling the stories of the aftermath of death through the stories of those still living, not through the stories of those facing death. Going into the final project, I knew how my translations had worked in the past, what the concepts, the materials and the processes were made of and from, but this most recent attempt at translation was the largest shift in my work and the outcome, for quite some time, remained relatively unknown. My artistic point of view and sensibility remained the only project certainties, and in an effort to understand what the project could look like, it seemed reasonable to look at the concepts, materials and processes surrounding my past translations.

### *Stories of the Living*

The heaviness of certain emotions and experiences are difficult to give words to, and they seem to elude verbal expression. The process of creating something visual and tangible allows me to sort through the experiences and find meaning in them. I told my own story in fragments—the partial stories of the weight of anticipatory grief and then the raw pain of realized grief. Telling those stories, for me, was always a quest for clarity, an attempt to understand the grief more and to ultimately learn something about how to heal.

Part of understanding my grief was eventually understanding the grief of others—how it manifested and hid, morphed and overflowed. I wanted affirmation that my grief was in the range of normal. Initially, most important to my understanding was gaining access to the workings of grief in the lives of my family members. I wanted to know if they felt their lives had been mangled by the grief as mine had. They acquiesced to my request and answered my questions. There was, understandably, a strange mix of feelings wrapped up in the answers to those questions. Their responses were honest, and reflective of themselves and how they were dealing with their individual losses. Their responses were my evidence for making my first piece of art that

dealt with emotions besides those of my own reality and projected reality. The dichotomy present in their responses—their attempts to hold on while letting go—was my concept.

For me, everything starts with and stems from my concepts. Concept informs what research is necessary, the processes that must be utilized, even the way I work. More than anything else, the concept informs what materials I use. My materials and how I treat them must speak the same language as my concept, which is why I typically resort to using alternative materials. These materials are already speaking a certain language, even if the language exists in remnants. The associations we have with found materials and the stories they already come with can easily be manipulated or exploited. Each material and each medium already has an intrinsic character that I can work with to add layers of concept-related content to the work and its meaning, allowing it to evocatively speak to the viewer.

For the piece I created based on my interviews with my family members, I chose facial tissues, Kleenex, to construct the piece with. The material already comes with meaning—crying, sickness, drying tears. After deciding on the base material, which served as installation substrate, I experimented with joining, manipulating and marking techniques, determining with methods most consistently correlated with the concept. Each family member's component of the piece was comprised of four stiffened and joined facial tissues which were molded enough to indicate ambiguous facial features. Through sketches, I made notations for where actual tears, discoloration, stitches and markings in the tissue fabric should be placed, based on the answers they gave. I then converted the markings in the sketch to actual markings on the stiffened tissue components (see figure 16).

I have come to know my grief fairly well; it is something I carry with me constantly. As a means of understanding and visually articulating grief in more collective terms, I felt the need to transition the perspective of my concepts. From accepting my own grief as it related to my mother's death, to comprehending my family's grief as it related her death, to eventually perceiving the grief of other daughters as it related to their own mothers' deaths, this was my fieldwork. I have and continue to slowly search for and collect data, stories of grief and loss from others who have suffered, steadily expanding my focus, even if only slightly at times, to bring an understanding of death to a larger audience.



Figure 16. Megan Bostic, *Family Portrait* detail, 24" x 26" x 12"

## Stories of the Dying

For my final project, instead of telling the stories of the living, I began to tell the stories of the dying. Typically, when approaching a new shift in my work, I analyze it and attempt to get an understanding through making. This results in a sort of visual documentation, as I approach things from an almost scientific perspective, with the finished piece labeled, ordered and incorporated onto the wall. As I become more comfortable with the nature of the concept, the pieces become larger, less rigidly structured, and move away from the wall. As I become more comfortable with the concept, I am able to gain understanding. That approach made sense for this transition to the stories of the dying, as my first three goals for the project were more knowledge-based and research-oriented. Those first three goals were the quantitative, the measuring and marking: develop a working hypothesis for an outreach program for hospice patients, create a model based on the hypothesis, and then implement the hypothesis according to the model.

The final goal of my research project was to create an art installation of my response to the experience. This was the intuitive part, my emotional response—the more qualitative undertaking. It was within this goal, the making portion of the project, that I set extremely high expectations for myself. When working with the stories of others, the need for integrity is always a compelling, driving force; when working with the stories of the terminally ill—the need for integrity is imperative. Emotional integrity, conceptual integrity and intellectual integrity each play fundamental roles. If I want to evoke empathy, to create an understanding of loss within my viewer, then I have to tell the story as honestly as possible. If someone gives me access to their story by allowing me to be a witness to it, then I hold part of the responsibility for that story.

For myself as an artist, part of the difficulty of that responsibility lies in finding the balance between conceptual integrity—staying true to the stories—and providing visually interesting solutions. After a phone interview with a local community outreach artist, Marguerite Gignoux, I determined which questions to ask myself to elicit necessary responses and to prompt internal monologue. Staying true to the story involves, of course, actually telling the story. So what can reveal personal narrative? How much truth do I reveal, obscure or abstract? What materials resonate with the story, the storyteller and the viewer? (Gignoux).

Before I actually embarked on this final project journey, I wrote down vague truths about what form the making component of the project might take: the piece would be an installation that cultivated viewer interaction physically through its placement within the space and emotionally through the use of materials. As a catalyst to begin, I knew I had to define the active verbs that would guide the creation of the installation; in the *Family Portrait* piece, the active verbs came from immersion in my family's responses, their stories: *suspend*, *stiffen*, *mark*. And in order to cultivate viewer interaction, I needed to understand my intended viewer. If I wanted to increase the discussion and the conversation surrounding death, who was my intended audience? What kind of interaction was I pursuing? How would I guide the interaction? How involved would the interaction be? Was catharsis the goal? Was there a goal? Making can become ritualistic and in so can become healing and cathartic. How would viewer interaction provide those same things to my audience? Would the piece be confined to a gallery, or would it reside in a different setting that would be complicit in my goals?

## The Compulsion

After months of partnering with HOWC, those questions lingered. I was left with few answers and the definitive knowns remained vague. In this program, I was told repeatedly and often to trust what I knew, and was confident that I was on a correct path; I just was not sure why that path was meandering so slowly. I spent August through December of 2012 meeting with the Volunteer Coordinator and the VP of Clinical Operations at HOWC, sharing the results of my research and determining our next steps for the legacy-gathering program. I had an understanding of the desire for terminally-ill patients to share a legacy, and precedent for the program based on my contact with hospice providers around the country. I had immersed myself in this research.

For the purposes of the making portion of this project, the crux of my partnership with hospice was the implementation of the legacy-gathering program—the point in the collaboration where we implemented the research, the theories and the framework, and began actually spending time with patients and hearing their stories. In our meetings at the end of last year, we drafted a timetable for each level of involvement: when we would recruit volunteers and patients, and when we would begin the interviews. The timetable was scheduled to begin in January of this year, which is precisely when things instead came to a standstill and got put on hold indefinitely.

At that point, I had been volunteering with hospice for over a year and I had an understanding of the sadness, grief, awareness and compulsion inherent in the experiences of being with terminally-ill patients. But, once the project halted, I faltered. Without permission to begin gathering the stories, I thought I could not continue.

## Reconciliation

I thought incorrectly. I had already gathered stories of the dying. At that point, I had worked with four hospice patients, not in the official legacy-recording capacity, but in the capacity of a family support volunteer, visiting with patients weekly. So I began thinking about the patients I spent time with. The youngest was eighty-one and I was able to visit with her twice before she died. The oldest was ninety-five, Ms. Dorothy, and I was fortunate enough to visit her once a week for almost a year. Each of these women had a similar aspect of their diagnoses: dementia. It was their secondary diagnosis, secondary to cancer or to debility. The overwhelming similarity of the experiences I had with these women was the gradual loss of themselves they experienced—loss of independence, autonomy, memory, body function, awareness, cognition. And those losses were related to the debility, but the dementia made the losses more profound. Considering my time with the patients and being able to witness their existence towards the end of life raised more questions: Is the piece supposed to be about dementia? About debility? About dying a natural death? About all of those things?

I went back and looked at what I had written and discussed so far. Consulting my project goal again, what did I actually hope to achieve? *The project will bring awareness to the local community about hospice, as well as contribute to the culture of death awareness and acceptance.* I wanted the piece to be accessible, not too cerebral, and to be poignant, emotional and provoking. I wanted viewers to get a sense of the vulnerability and desperation that occurs with a diagnosis of dementia. A voiceover in the opening scenes of the PBS documentary *The Forgetting: A Portrait of Alzheimer's* shares:

I don't think there's any greater fear for a person than to think I've lived my whole life accumulating all these memories, all of these value systems, all of this place and my family and a society. And here's a disease

that's just going to come in and every single day just rip out the connections, just tear out the seams that actually define who I am as a person. (PBS)

According to the National Alzheimer's Association, dementia is the second leading contributor to death among older Americans. Alzheimer's, the most common form of dementia, affects 5.4 million Americans and is currently the sixth leading cause of death in the United States, the only cause of death (among the top ten) in America without any type of prevention, cure or treatment to slow its progress. Since 2000, deaths have from dementia have risen 66%.

The specter of dementia in old age has fascinated and terrified human beings for all of recorded history. As far back as 2800 B.C., an ancient Egyptian myth tells the story of the sun god, Ra, all-knowing, all-powerful, and immortal, but in a cruel twist, losing his memory and living forever in a senile haze. It's one of the most basic human fears, the loss of memory, the loss of self. It's the ultimate attack on the healthy person to lose the very essence of who you are. I will no longer know who I am. My family, friends, and loved ones will no longer know me as myself. (PBS)

When I first met Ms. Dorothy, we were able to play cards for two hours at a time; she was a fierce competitor who strategically distracted me with her stories of being my age during WWII. As the months passed, she could play cards for only a half hour and her stories became less and less coherent. Her recognizing smile and "hey, sugar" when I walked into her room started receding until eventually I had to remind her repeatedly during each visit who I was and why I was there. After one of my last visits before her death, I wrote this poem:

### ***For Dorothy***

Beginning our sequence again,  
her gray eyes flicker open, now  
my hazel eyes are forced to feign

another *good morning*, announce  
myself and *it's good to see you*.  
She whispers *why don't you lie down*

*for just a while?* looking to  
me, patting the expanse of bed  
with her swollen hand, bruised and blue.

I wanted viewers of my installation to feel uncomfortable, trapped and question why they were feeling that way—all responses I had witnessed from my four patients, especially Ms. Dorothy, over the course of their experience with dementia.

*Proceeding*

After analyzing the other pieces I completed during my time here, I realized I was missing three things: a piece that manipulated the space it was in, a piece that used the whole material and text that was integral to and integrated into the piece. I wanted this piece to be the first in a series of my responses to stories of the dying—to tell the story of dying with dementia.

Considering technique and utilizing, not disguising, the material brought me to the work of Brooks Harris-Stevens. In 2009, she completed *Patterned Memory* (see figures 17-18), a piece about her father who died of lung cancer. Using her unthreaded sewing machine, she stitched through over one hundred cotton tobacco rolling papers, allowing the needle to puncture the material and leave its mark.



Figure 17. Brooks Harris-Stevens; *Patterned Memory*; installation variable; cotton cigarette wrappers

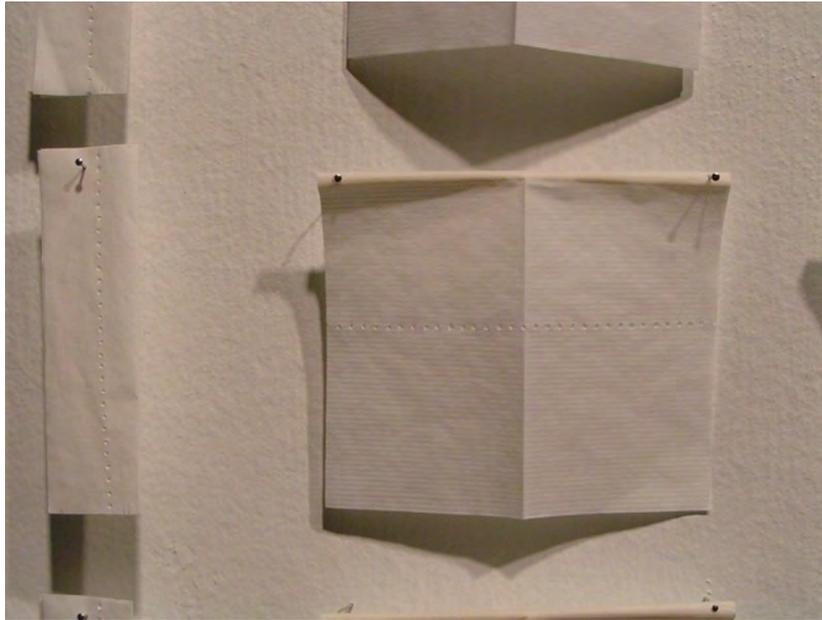


Figure 18. Brooks Harris-Stevens; *Patterned Memory* detail; installation variable; cotton cigarette wrappers

I knew my materials needed to vary between translucent, transparent and opaque, to abstractly replicate the cloudiness, bleakness and progression of dementia. Initially, I resisted the idea of using a hospital-sourced material. It was still vital that this piece have some tangible connection to hospice, and my association with dying under the hospice care was a death at home, not in a hospital or facility.

However, upon looking up information from the National Hospice Organization, I rethought my initial reluctance. In 2011, 35.7% of hospice patients were on services for less than seven days, which means they were removed from services (by death, by doctor order, or by personal insistence) within that time frame. 58.4% died in a medical facility—hospital, hospice home, nursing home or critical care facility. And dementia accounted for 12.5% of primary hospice diagnoses. (National Hospice and Palliative Care Organization). I began considering that a hospital-sourced material could have other project-appropriate associations—with the nursing homes and hospice homes, where dementia holds a constant presence. After unsuccessful tests with a variety of transparent materials (photo insert pages, page protectors, saran wrap), translucent materials (wax paper, tissue paper) and opaque materials (old photographs) using the thread-less stitching technique, I finally tested my hospital identification bracelet samples. I decided to order 2000.

Considering the integration of text brought me to Jenny Holzer, the concept of visual poetics and allowing the text to have as much utility to people as possible (PBS). If dementia was about loss of memory and loss of self, what would I use an identifier on the bracelets? My first impulse: to use names. Our names are our most basic identifiers. Upon deliberation, I was concerned that a specific name, or many specific names might not resonate with viewers. I came instead to the phrase *I am* (a statement) and its inverse *am I* (a question), and what a transition from one phrase to the other would imply.

Considering the experiential qualities of the piece and what type of experience I wanted the viewer to have in the space, I considered three viewer scenarios. The first involved the viewer walking in the installation space and having to look up

to comprehend; the second involved the viewer walking through the installation space, surrounded on either side; the third involved the viewer being able to walk around the installation, with the capacity for movement within the space. The second option was the most consistent with my concept, so I considered material placement and angles, and how to get people in the space: a greater width at the entrance that increasingly narrowed, with no exit except having to turn around and leave through the entrance.

I calculated the number of hospital bracelets that I needed to stitch with each phrase (*I am* and *am I*), how many to paint with solid coats of gesso and how many to paint with a more translucent, watered-down layer of gesso in order to achieve somewhat of a gradation from transparent to opaque. I painted. I stitched. And then I brought all 2000 of my stitched and painted hospital identification bracelets into the smallest room in the Fish Market Gallery, marked the lines on the floor and began installing (see figures 18-26).



Figures 19-26. Megan Bostic; *I AM / AM I* installation process; installation variable; hospital identification bracelets.

### *Resulting*

This piece, *I AM / AM I* (see figures 28-31) occupied the entire room it was installed in with its arrangement, its shadows and its emotional weight. Consisting of nearly 300 strands of hospital identification bracelets, with each strand containing seven connected bracelets, the piece asked viewers to consider the loss of their own identity, if only for a moment.



Figures 27-28. Megan Bostic; / AM / AM / detail; installation variable; hospital identification bracelets.



Figures 29-30. Megan Bostic; *I AM / AM I*; installation variable; hospital identification bracelets.