

RECORDING LIFE STORIES: A PRACTICAL WAY TO CREATE A LEGACY

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SUMMARY

- We developed a practical and easy method to help patients nearing the end of life build a legacy project by sharing their life stories with their families using audio recordings.
- Qualitative analysis of the recordings demonstrated that patients nearing the end of life talk most consistently about the past, share positive emotions and acceptance, and discuss important people, such as children, parents, and spouses.

Poster Category: Innovative Clinical Interventions

INTRODUCTION

Many terminally-ill patients find themselves grateful for time spent with loved ones when nearing the end of life¹. Dignity therapy can be helpful during this time to improve the patient's quality of life, increase well-being, and decrease suffering². Life review is one method to perform dignity therapy, in which a patient evaluates his/her life through reflection, with similar benefits as the formal process³. Legacy projects allowing the patients to tell these life stories and reflections decrease patients' symptoms, increase meaning, and even decrease caregiver stress⁴. While analyses of the benefits of legacy work and dignity therapy have been studied, no literature discusses the important themes brought up by patients nearing the end of life. We developed "Life Stories," a legacy building project using a life review method that shares the stories of patients nearing the end of life with their families. We used qualitative analysis to investigate the topics that patients discussed in these stories.

METHODS

A palliative care specialist conducted interviews between 2015 and 2017 with twenty adult patients admitted to Vanderbilt University Hospital. Written consent was obtained for media use. All interviews were performed at the patient's bedside by the same palliative care specialist and recorded using a hand-held recorder. Interviews were open-ended with no formal template. The audio recordings were then sequenced using iTunes™, saved to a CD disk, and mailed to the patient's family, most of whom did not know about the recording project.

Qualitative analysis of the recordings was performed by two field experts. A thematic coding system was developed to define the timing and content of the recordings (Figure 1). The audio-recordings were transcribed using Rev™ and separated into quotes. Each quote of the twenty transcripts was assigned one timing code and up to five thematic codes. We established coder reliability using two coders. The quotes were then compiled together, organized by code, and then analyzed for frequency of a code.

¹ Fisher B, Fisher J. Life is a Gift: Inspiration from the Soon Departed. New York, NY: Faith Works; 2008.

² Chochinov HM, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. Lancet Oncology. 2011;12(8):753-62.

³ Ando M, et al, Japanese Task Force for Spiritual Care. Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. Journal of pain and symptom management. 2010;39(6):993-1002.

⁴ Allen RS, et al. Legacy activities as interventions approaching the end of life. Journal of palliative medicine. 2008;11(7):1029-38.

CODING SYSTEM

Code	Code Category	Code Definition and Rules
1	Time orientation	Each quote must be coded with a time orientation. Refers to the time frame that is currently being discussed.
1.1	Past	Events, people, places, or things that were in the past
1.2	Present	Events, people, places, or things that are in the present
1.3	Future	Events, people, places, or things that are in the future
1.4	Mixed	The time reference in the quote mixes past, present, or future
1.5	Uncertain	The time frame is unclear and/or impossible to code
2	Self	Discussion about himself/herself. Sub-categories reflect ways of thinking about one's thoughts, feelings, and experiences.
2.1	Reflections on self	Reflections about aspects of his/her person
2.2	Values	An important value, including faith and philosophy
2.3	Personal history/ upbringing	Personal history, upbringing, or childhood
2.4	Goals and aspirations	Personal goals and aspirations
3	Emotions	Discussion of emotional experiences. Likely paired with other codes to identify context.
3.1	Positive emotions	Happiness, joy, contentment, and other positive emotions
3.2	Negative emotions	Fear, anxiety, anger, hate, sadness, and other negative emotions
3.3	Other emotions	Emotions that cannot be coded as positive or negative
3.4	Coping/ acceptance	Coping and acceptance of life situations or medical illness
4	People	Discussion about or reference to people
4.1	Grandparent	Grandparents or great grandparents
4.2	Parents	Mother, father, or step-parents
4.3	Siblings	Brothers, sisters, step-brothers or sisters, half-brothers or sisters
4.4	Extended family	Aunts, uncles, cousins, and other extended family
4.5	Spouse/partner	Spouse, ex-spouse, significant romantic partner
4.6	Children	Children or step-children
4.7	Grand children	Grandchildren or great grandchildren
4.8	Friends	Friends
4.9	Community	Community (for example, church, neighbor)
5	Personal experience	Discussion centers on personal experiences
5.1	Job or career	Job or career, including retirement
5.2	Hobbies/pastimes	Hobbies or pastimes
5.3	Education	School and college
5.4	Travel	Travel, trips, or adventures
5.5	Military	Military experience
5.6	Special events	Special events, such as weddings
5.7	Trauma/hardships	Trauma or hardships experienced by the patient
6	Medical condition	Discussion about medical condition
6.1	Mortality	Reflections on death, dying, or the end of life
6.1.1	Prognosis	Personal expectations of own life span
6.2	Morbidity	Symptoms and/or complications of an illness
6.2.1	Cognitive	Discusses cognitive changes or loss of executive functioning
6.2.2	Physical function	Difficulty with functioning, doing tasks of daily living, and mobility
6.2.3	Pain	Pain
6.2.4	Other symptoms	Any symptoms that are not captured by the other categories such as shortness of breath, nausea, numbness, tingling, etc.
6.3	Diagnosis	Experience of receiving and processing the diagnosis

Figure 1: Thematic coding system

RESULTS

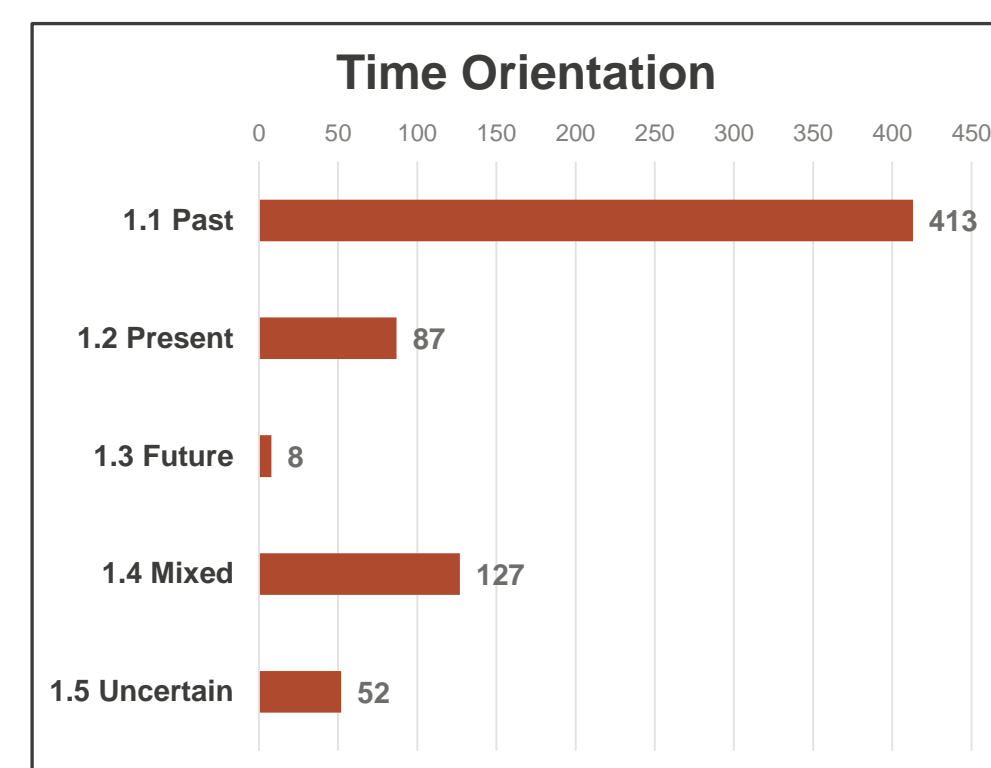


Figure 2: Number of quotes with each time orientation

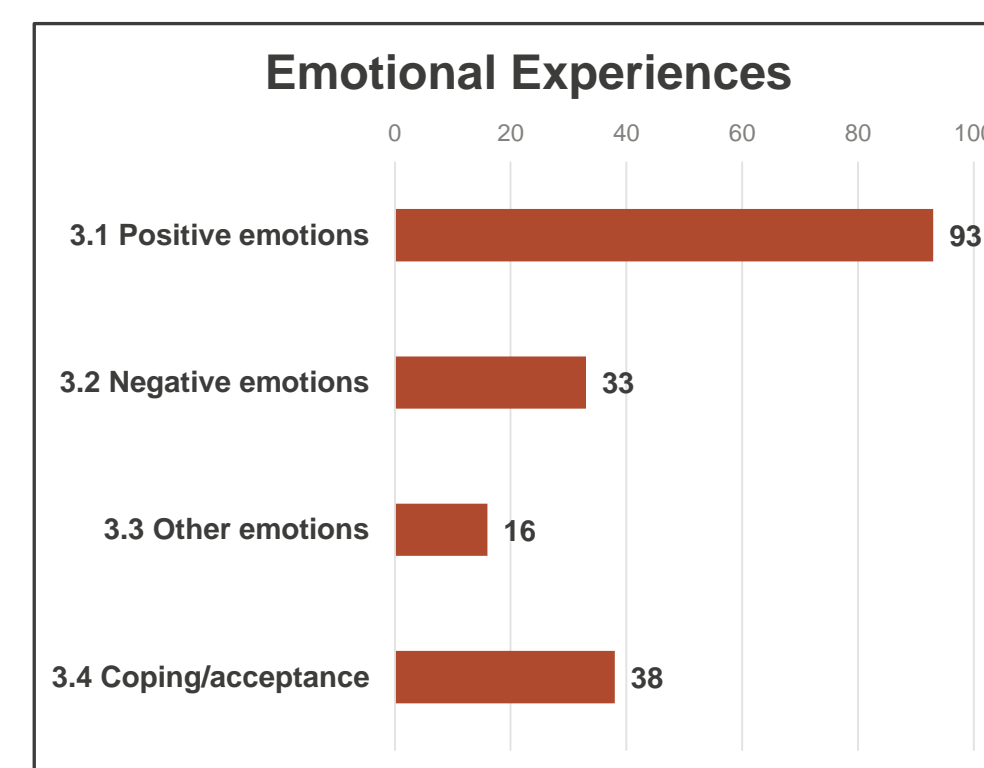


Figure 3: Number of quotes discussing each emotion

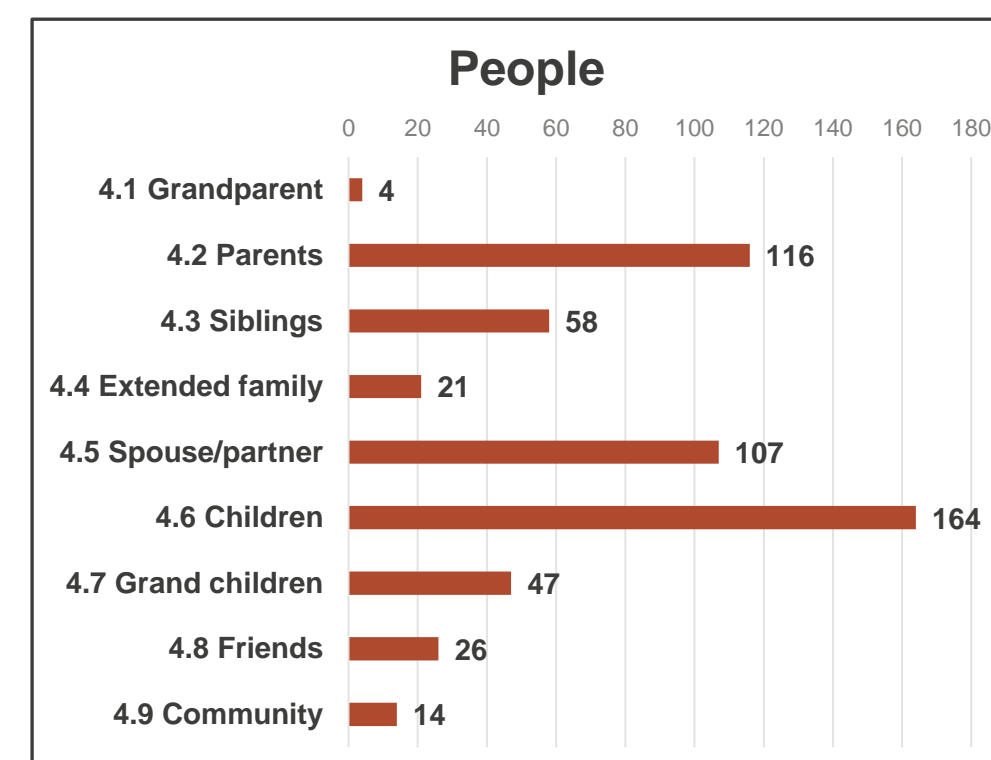


Figure 4: Number of quotes discussing each type of person

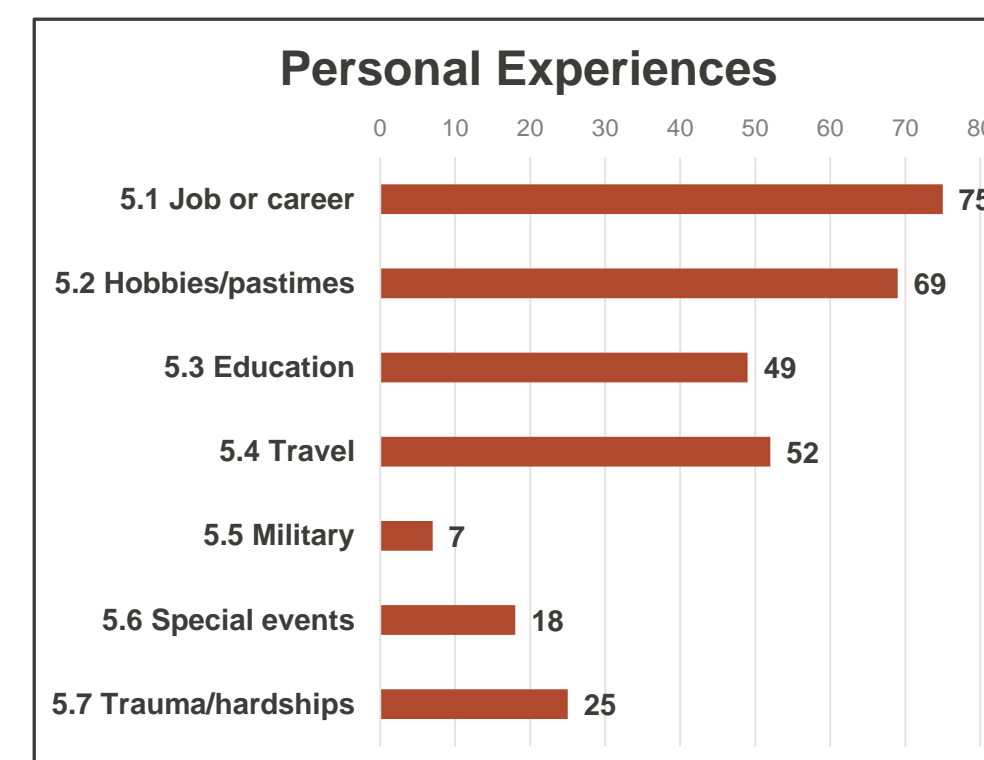


Figure 5: Number of quotes discussing each type of personal experience

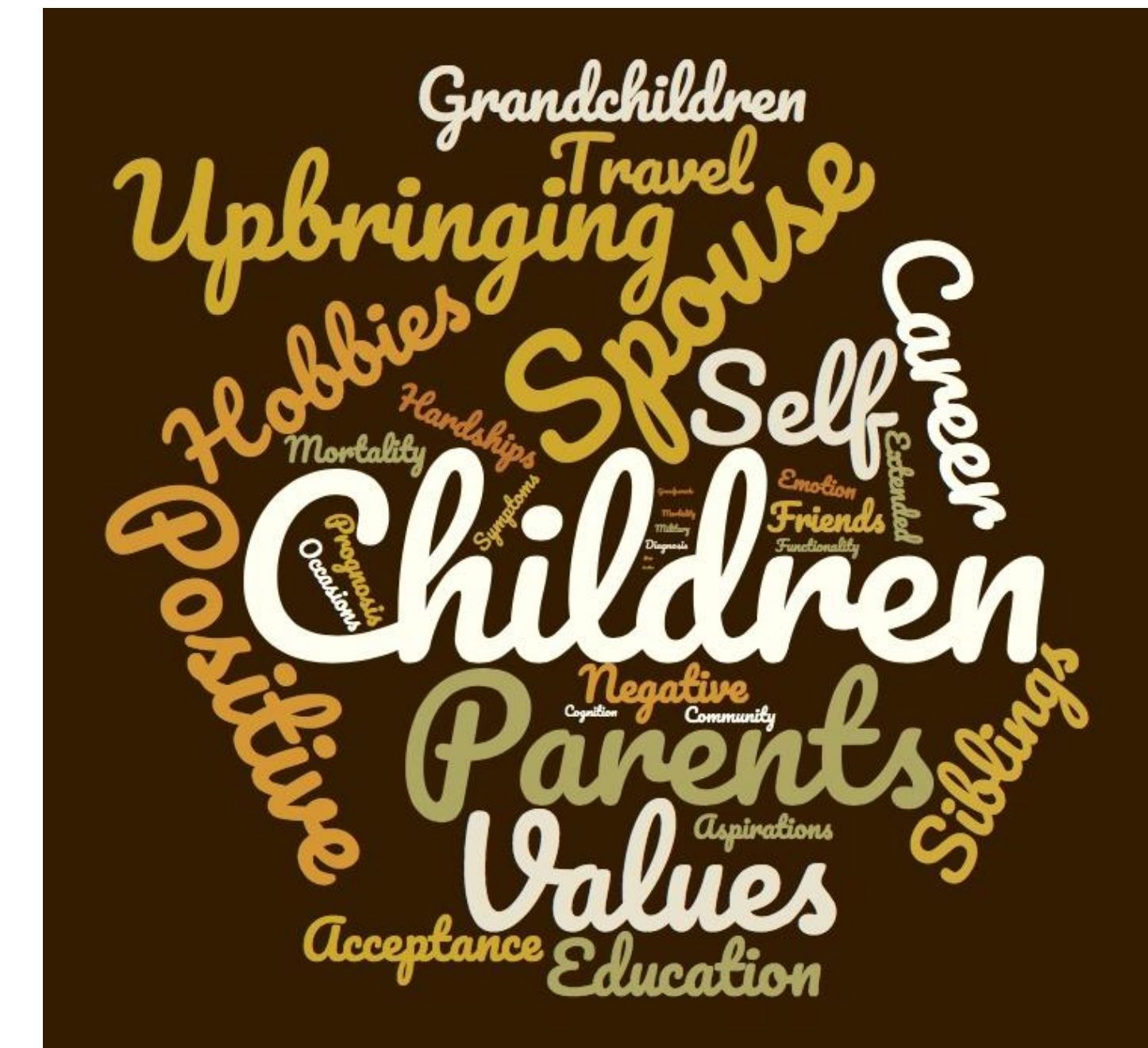


Figure 6: Themes discussed by patients nearing the end of life, created using www.wordclouds.com

QUOTES

"I'm not looking back wishing I had done this or wishing I had done something different. I feel like I did what I was accomplished to do, bound to do, and right for me to do." - Reflections on Self

"I guess there's good in everyone if you find it. Sometimes it's just little things that make the big difference." - Values

"Well, there's still a lot that I want to do." - Goals/Aspirations

"My father was an alcoholic. And he beat the heck out of all of us, especially my mother." - Parents, Trauma/Hardships, and Personal History/Upbringing

"I tell you what. I laugh a lot. When my kids are around. Just to talk about my kids is the greatest thing ever." - Children and Reflections on Self

"This is the memory I'm always going to take with me. These 21 days, of her sleeping on one of these chairs 24/7. Not ever going home staying with me. Strongest woman I know. By far." - Spouse

"I would want to tell her [daughter] that I'm so proud of her and that I hate that I couldn't be there. That I love her so much. To please stay focused...Do what I didn't get to do." - Children

"Life these days. I think we've lost a lot of it, but we've also gained a lot. I mean, I don't know how to tell you, about the loss and a lot have gained." - Coping/Acceptance

CONCLUSIONS

Audio-recordings of patients telling their life stories are a practical and easy method to help patients build a legacy for their loved ones. Through qualitative analysis of interviews with twenty hospitalized patients nearing the end of life, we found that patients talked about the past 60% of the time as compared to the future, which was only 1% of their quotes. The five most common topics during these interviews in order, were children, parents, spouse, personal values, and positive emotions. Patients rarely discussed their medical condition or related symptoms. In conclusion, patients focus on reflections about their past as well as their family during their end of life.

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