

Lancaster Theological Seminary

**Dignity Therapy as a Pastoral Care Approach:
Exploring Family Jewels**

A Major Project Submitted to the Faculty
in Candidacy for the Degree of
Doctor of Ministry

by

Holly S. Wildhack

Lancaster, Pennsylvania
May 2019

Dignity Therapy as a Pastoral Care Approach: Exploring Family Jewels
© 2019, Holly S. Wildhack

**Submitted by the author in partial fulfillment
of the requirements for a DMin degree
and approved by:**

Trina Armstrong, Project Supervisor

Anne T. Thayer, Chair, Doctor of Ministry Committee

April 26, 2019

Abstract

“Dignity therapy (DT) is a brief, individualized intervention to increase the sense of purpose, meaning and worth and reduce spiritual and psychological suffering.”¹ It comprises a recorded interview which is transcribed, edited and returned to the individual who can give it to people of their choosing. Dignity therapy has been well studied,^{2,3} much of the research has been done by the developer and prolific researcher, Chochinov, and his teams.⁴ DT is beginning to come to the attention to the pastoral care/chaplaincy communities.⁵ This study examines how four community-dwelling older adults who have expressed feelings of hopelessness, loss of meaning, and despair, experience dignity therapy as a pastoral care approach.

¹ Sue Hall et al., “Assessing the Feasibility, Acceptability and Potential Effectiveness of Dignity Therapy for People with Advanced Cancer Referred to a Hospital-Based Palliative Care Team: Study Protocol,” *BMC Palliative Care* 8, no. 1 (December 2009), <https://doi.org/10.1186/1472-684X-8-5>.

² George Fitchett et al., “Care of the Human Spirit and the Role of Dignity Therapy: A Systematic Review of Dignity Therapy Research,” *BMC Palliative Care* 14, no. 8 (2015), <https://doi.org/10.1186/s12904-015-0007-1>.

³ Marina Martínez et al., “‘Dignity Therapy’, a Promising Intervention in Palliative Care: A Comprehensive Systematic Literature Review,” *Palliative Medicine* 31, no. 6 (June 2017): 492–509, <https://doi.org/10.1177/0269216316665562>.

⁴ Harvey Max Chochinov, *Dignity Therapy: Final Words for Final Days* (New York: Oxford University Press, 2012).

⁵ George Fitchett et al., “Monthly Article April 2015,” ACPE Research, April 2015, <http://www.acperesearch.net/apr15.html>.

Contents

Chapter 1: Introduction

Topic.....	1
Significance.....	4
Research Methodology.....	11

Chapter 2: State of the Field

Literature Review.....	17
Definition of Central Terms.....	37

Chapter 3: The Research42

Alice.....	44
Betty.....	50
David.....	55
Cathy.....	60

Chapter 4: Analysis and Conclusions

Thematic Analysis.....	68
Conclusions.....	75

Chapter 5: Next Steps.....79

Bibliography.....	82
Appendix 1: Dignity Therapy Protocol.....	90
Appendix 2: Institutional Review Board Approval.....	97

Chapter 1: Introduction

*Do not cast me off in the time of old age;
do not forsake me when my strength is spent. . . .
So even to old age and gray hairs,
O God, do not forsake me,
until I proclaim your might to all the generations to come. (Psalm 71:9,18)*

Topic

As a chaplain in a continuing care retirement community for the last eleven years, I frequently encounter residents who feel hopeless and have lost any sense of meaning in their lives. They no longer have the careers from which they derived much of their identity, their spouses may have passed away or are very ill, or they may be physically impaired themselves. Some struggle with finding any purpose or worth in their lives, believing they are too old to be of value to anyone. As the residents get closer to the end of their lives, issues of meaning and purposes become pronounced, profound and urgent. My ministry includes caring for those in the midst of this struggle and search for meaning.

For many older adults, they find themselves fighting to maintain a quality of life they once enjoyed as their health begins to decline. They often must move to smaller accommodations with higher levels of care, frequently losing their independence and their privacy, and finding themselves dissatisfied with unwanted roommates. They can be misunderstood by family members and staff who do not understand or who do not fully

appreciate their challenges. Their physical hardships often leave them asking hard questions about what they are doing with their lives and even wondering whether life is worth living.

When I found dignity therapy, I realized it could be an effective pastoral care approach to help address this overwhelming need that I saw in my residents. Canadian psychiatrist, Harvey Max Chochinov is widely credited with putting forth the theory behind and the practice of dignity therapy. He compares “dignity” with words such as self-esteem, self-worth, and self-respect. It is a broader concept than that though, especially in those nearing the end of their lives.

Early studies suggested that among patients with terminal conditions, there is an association between the undermining of dignity and psychiatric symptoms relating to anxiety and depression including worry and guilt and a sense of hopelessness and worthlessness. Moreover, loss of a sense of meaning, feelings of burdening others, spiritual distress and loss of dignity were all found to correlate with patients’ requests of hastening deaths.⁶

“Dignity therapy (DT) is a brief, individualized intervention to increase the sense of purpose, meaning and worth and to reduce spiritual and psychological suffering.”⁷ While DT has been well studied,⁸ much of the research has been done by the developer and prolific researcher, Chochinov, and his teams.⁹ Long-term care communities have recently become aware of dignity therapy for pastoral care providers.¹⁰ These studies focus almost exclusively on palliative care and hospice communities. While Chochinov and others encourage chaplains to serve as

⁶ Shapir Rosenberg, “Dignity Therapy,” *The American Journal of Psychiatry Residents’ Journal*, August 2018, 6, <https://doi.org/10.1176/appi.ajp-rj.2018.130803>.

⁷ Sue Hall et al., “Assessing the Feasibility, Acceptability and Potential Effectiveness of Dignity Therapy for People with Advanced Cancer Referred to a Hospital-Based Palliative Care Team: Study Protocol,” *BMC Palliative Care* 8, no. 1 (December 2009): 2, <https://doi.org/10.1186/1472-684X-8-5>.

⁸ Fitchett et al., “Care of the Human Spirit and the Role of Dignity Therapy: A Systematic Review of Dignity Therapy Research.”

⁹ Chochinov, *Dignity Therapy: Final Words for Final Days*.

¹⁰ Fitchett et al., “Monthly Article April 2015.”

clinicians,¹¹ little research has been done from that perspective. Numerous authors, in research reviews, have pointed to that need for future studies that focus more on the spiritual and existential dynamics.¹² Fitchett et al. state: “We propose that DT should be studied as a spiritual as well as a psycho-social intervention that assists with the existential tasks faced by the majority of elderly patients, especially as they encounter a life-threatening illness like cancer.”¹³

Dignity therapy has also been shown to lower depression and anxiety scores. While the effect has not always been long-lasting, it has proved to be beneficial for individuals and families.

Martinez et al. conclude their review:

The available evidence suggests that DT is beneficial. Patients and families evaluate it positively, suggesting that it has a variety of effects and can go beyond traditionally considered variables (e.g., anxiety or depression). The results suggest that patients with the highest distress levels can benefit the most from therapy, but more studies are needed to confirm DT’s outcomes. DT can be adapted to different populations.¹⁴

Fitchett adds: “... we perceive that [DT’s] mechanisms may be related to role completion and spiritual aspects of a person’s life. .and they hold out the possibility that [DT’s] main impact is in a spiritual dimension.”¹⁵ Given this background, I explored the experiences of community-

¹¹ Fitchett et al., “Care of the Human Spirit and the Role of Dignity Therapy: A Systematic Review of Dignity Therapy Research,” 2.

¹² Olav Lindqvist et al., “Reflections on Using Biographical Approaches in End-of-Life Care: Dignity Therapy as Example,” *Qualitative Health Research* 25, no. 1 (January 2015): 10, <https://doi.org/10.1177/1049732314549476>.

¹³ Fitchett et al., “Care of the Human Spirit and the Role of Dignity Therapy: A Systematic Review of Dignity Therapy Research,” 9.

¹⁴ Martínez et al., “‘Dignity Therapy’, a Promising Intervention in Palliative Care,” 508.

¹⁵ Fitchett et al., “Care of the Human Spirit and the Role of Dignity Therapy: A Systematic Review of Dignity Therapy Research,” 10.

dwelling older adults facing end-of-life challenges who received dignity therapy as a pastoral care approach.

Significance

I believe every person is created by God, is here for a purpose and should be treated with dignity regardless of age, abilities, condition, or faith group. The mission statement for the non-profit continuing care retirement community (CCRC) in which I work states well the values I hold when it says:

We are a church-related, not-for-profit community service organization dedicated and committed to providing services for older adults.

We create and preserve excellent residential and health care communities promoting wellbeing and encouraging active and healthy lifestyle choices.

We believe in and are committed to respecting and honoring each person's dignity, rights, and independence.

We are committed to a program of stewardship that recognizes the responsibility to use our resources well.”¹⁶

Spiritual well-being and treating everyone in a manner which raises each one's dignity, rights and independence are central to who we are.

I see many older adults approaching the end of their lives struggling with who they are, and what life is all about. In most instances, their professional careers have ended, their spouses

¹⁶ “Mission Statement” Westminster Communities of Florida. <http://www.westminstercommunitiesfl.org/our-mission>. Last modified, May 30, 2018.

have passed and their children live far away, or may even have passed away as well. What remains is a profound search for meaning; or what MacKinlay describes as one of the spiritual tasks of aging, the search for the ultimate meaning in life.¹⁷ While Victor Frankl reminds us that no one can ever give meaning to someone else; that meaning must be discovered by the individual.¹⁸ The therapist, or in my case, the chaplain, can only walk with and possibly help the person to interpret and discover their own meaning. Kenyon helps us understand that our lives are like stories that, are composed of both facts and possibilities, and are open to change and review.¹⁹

In my experience, too frequently seniors, especially those nearing the end of life in long-term care facilities, give up on life believing they have nothing left to give and that they are just sitting around waiting to die. They have no sense of meaning or purpose. It is not uncommon for these seniors, to have a need to resolve or re-establish their relationship with God or their faith. At times they may be struggling with how they believe God is treating them,

To address this hopelessness, caregivers, chaplains, pastors, and family members can provide the support that helps them find meaning and purpose in their lives. The “diological” nature of qualitative therapy, as VandeCreek describes it²⁰, encourages this necessary interaction

¹⁷ Elizabeth MacKinlay, *The Spiritual Dimensions of Ageing* (Philadelphia: Jessica Kingsley Publishers, 2017), 140.

¹⁸ Viktor E. Frankl, *The Will to Meaning: Foundations and Applications of Logotherapy* (New York, NY: Plume, 1988).

¹⁹ Gary M. Kenyon, “Telling and Listening to Stories: Creating a Wisdom Environment for Older People,” *Generations* 27, no. 3 (2003): 31.

²⁰ Larry VandeCreek, Hilary Bender, and Merle R. Jordan, *Research in Pastoral Care and Counseling: Quantitative and Qualitative Approaches* (Eugene, Oregon: Wipf and Stock Publishers, 1994), 77.

and relationship between the chaplain and the resident who can facilitate this significant exploration of meaning and purpose.

These older adults also frequently need to resolve or re-establish their relationship with God or their faith and come to grips with how that impacts their future. They wrestle with meaning and often wonder why God is treating them as they believe God is. What they seem to be missing is an experience of grace. What presents to physicians, who spend very little time with these men and women, as despair or depression may just as easily be spiritual, relational, meaning-making or existential concerns.

Scripture teaches us to honor our father and mother (Ex. 20:12). Many cultures place a high value on respecting the elderly, and yet those values are not always upheld in modern American society. Karen Scheib notes that a review of prime-time network programming in the 1990s showed merely 3 percent of the leading roles being given to seniors. In the same study, men were considered “elderly” significant later than women. Scheib summarizes: “Overall, the findings of this study indicate that the primary message on television is one that celebrates youth and marginalizes the elderly.”²¹ That message seems to have become internalized by many in our modern society.

In my own experience, older adults often do not feel valued. They have often been forced to retire before they desired so someone younger could be hired. They feel the younger society looks upon them as outdated and unneeded. As their bodies begin to fail, they start to believe

²¹ Karen D. Scheib, *Challenging Invisibility: Practices of Care with Older Women* (Danvers, MA: Chalice Pr, 2004) p. 32.

many of the negative images themselves and they enter a time of truly questioning their value, meaning, and purpose. This disconnect between theological and societal values has a profound impact.

Frankl, wrote, “Man is not destroyed by suffering; he is destroyed by suffering without meaning.”²² Puchalski points out that medical ethicists have reminded us “that religion and spirituality form the basis of meaning and purpose for many people.”²³ Dr. Puchalski continues: Cure is not possible for many illnesses, but I firmly believe that there is always room for healing. Healing can be experienced as acceptance of illness and peace with one’s life. This healing, I believe is at its core spiritual.²⁴ I believe chaplains and pastors who have relationships with the older adults, are in a unique position to aid in this kind of healing.

One of the goals for pastoral caregivers who work with older adults is to help them find peace at the end of life. While there are many medical professionals who are exceptional in helping patients and families cope with end-of-life issues, pastoral caregivers are uniquely positioned to sensitively approach issues and concerns of spirituality and late-life meaning to the aging, dying and their families.

The palliative care community has focused on the importance of spiritual care for some time. In February 2009, in Long Beach, California, the Archstone Foundation sponsored a Consensus Conference “based on the belief that spiritual care is a fundamental component of

²² Viktor E. Frankl, William J Winslade, and Harold S. Kushner, *Man’s Search for Meaning* (Boston: Beacon Press, 2006).

²³ Christina M. Puchalski, “The Role of Spirituality in Health Care,” *Baylor University Medical Center Proceedings* 14, no. 4 (October 2001): 352, <https://doi.org/10.1080/08998280.2001.11927788>.

²⁴ Puchalski, 352.

quality palliative care.”²⁵ The event brought together 61 of the nation’s spiritual and palliative care leaders, who work as physicians, nurses, mental health specialists, social workers, professors, chaplains, and clergy. The conference identified points of agreement about spirituality and health care and made recommendations to advance the delivery of quality spiritual care in the palliative care setting.²⁶ Recommendations are reported under the categories of Spiritual Treatment/Care Plans, Interprofessional Team, Training/Certification, Personal and Professional Development and Quality Improvement (QI).

Overall, they hoped this gathering would result in a significant increase in well integrated, theoretically based, outcome-oriented spiritual care that included assessments and screening done by the medical staff, referrals to chaplains, well-written treatment plans and documentation, and full staff education. In the area of quality improvement, they included the addition of spiritual care in (QI) plans, the evaluation of assessment tools, the increase of QI guidelines and the testing of QI efforts. Of significant relevance was the recommendation that research is supported and contribute to improving spiritual care outcomes to palliative care patients. Recognizing the complex definition of spirituality and its difficulty in measuring these outcomes, they also argued that research should use multiple quantitative and qualitative methods for evaluation.²⁷

²⁵ Christina Puchalski et al., “Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference,” *Journal of Palliative Medicine* 12, no. 10 (October 2009): 885, <https://doi.org/10.1089/jpm.2009.0142>.

²⁶ Puchalski et al., 885.

²⁷ Puchalski et al., 902.

The final recommendation called for funding additional spiritual care arguing that: “spiritual care is an essential domain of quality palliative care as determined by the National Consensus Project (NCP) and National Quality Forum (NQF). Studies have indicated the strong desire of patients with serious illness and end-of-life concerns to have spirituality included in their care.”²⁸

These recommendations are the foundations of the care I provide to residents. Though I realize that more is needed for those who are suffering from hopelessness and loss of meaning, this project aimed to improve the quality of life these residents, the majority of whom are in palliative or hospice care. Given the magnitude of suffering I witness from these residents; I was drawn to dignity therapy (DT). I was particularly drawn to the way DT incorporates the use of narrative, its focus on existential issues, and the creation of a legacy or generativity document with memories residents share for families to keep. All have the potential to aid the residents in using their spiritual resources to find greater meaning and purpose in their lives, increasing their quality of life. Throughout this study, I sought to make this process meaningful and life-giving for my residents and their families. I have hoped to add to the prior research. I continued to gain a better understanding of how the seniors in my community approached and/or struggled with questions of faith and meaning in later life and to provide them a means with which they could express these feelings and experiences and even share them with their families.

The Templeton Foundation's Handbook on chaplaincy research, states that “A research question is significant “enough” when the answer invites reflection on clinical practice and

²⁸ Puchalski et al., 902.

whether or not it is relevant for continuing or changing what you do.”²⁹ Exploring the experience of dignity therapy can potentially and significantly improve the care I provide to residents, improve how staff in my community care for families, and more broadly serve as a pastoral care resource for chaplains in long-term facilities across the country. In just the short amount of time, I have been conducting the study, I have found a significant benefit to using dignity therapy as a pastoral care approach. Dignity therapy provided me with a pastoral care approach that not only enabled me to guide my residents in a deeper reflection on their past and on what experiences they might wish to pass on to their families but to reflect on their futures and their faith as well. I have learned from this experience, as will be explained further, and hope to continue to develop this knowledge and share it with others. I will likely be less formal in how I utilize the information I have gained, but I have certainly gained a greater appreciation for the use of story and spiritual reminiscence in pastoral care and will continue to develop my skills in this area.

²⁹ Gary E. Myers and Rabbi Stephen Roberts, eds., “Handbook: An Invitation to Chaplaincy Research: Entering the Process” (John Templeton Foundation, 2014), 44, www.healthcarechaplaincy.org/docs/publications/templeton_research/hcc_research_handbook_final.pdf.

Research Methodology

For the project, I designed a phenomenological research study with community-dwelling older adults who had expressed feelings of hopelessness, loss of meaning or despair and had experienced dignity therapy (DT) administered as a pastoral care intervention. This research focused on how the DT was personally experienced by four residents in a continuing care retirement community.

While much of the research regarding the effectiveness of DT has been done with quantitative studies, for this purpose and with this population a phenomenological study seemed appropriate, as I sought to determine what meaning each would make of DT as a pastoral care approach. I also realized my previous experiences with my research participants would prove to be a valuable resource as Groenewald elaborates: “Phenomenologist, believe that the researcher cannot be detached from his/her presuppositions and that the researcher should not pretend otherwise.”³⁰ He continues to add that at the root of phenomenology is the intent to “understand the phenomena in their own terms – to provide a description of the human experience of the person and allow the essence of the experience to emerge.”³¹

As VandeCreek elaborates, the goal was to design a study that would: “describe the lived experiences of the individual about a phenomenon as described by participants which culminates

³⁰ Thomas Groenewald, “A Phenomenological Research Design Illustrated,” *International Journal of Qualitative Methods* 3, no. 1 (March 2004): 45, <https://doi.org/10.1177/160940690400300104>.

³¹ Groenewald, 47.

in the essence of the experiences for several individuals who have all experienced the phenomenon.”³²

Harold Koenig explains that originally phenomenology: “focused on describing researchers’ own thoughts, feelings, and perceptions, such as the emotions experienced during anger or the cognitive processes involved in decision-making.”³³ . . . He adds that “this approach involves the researcher asking participants to write down or provide verbal descriptions of their experiences (such as the experience of visual hallucinations by a participant who is psychotic), with the goal of understanding participants’ experiences as they experience them.”³⁴

As I sought to explore the residents’ experiences of dignity therapy, phenomenology seemed to be the appropriate methodology for this type of study. By in large, the approach itself followed the method outlined in Harvey Max Chochinov in *Dignity Therapy: Final Words for Final Days*.³⁵ The details of the protocol are provided in the attached appendix. As other researchers have done with the Patient Dignity Inventory (PDI),³⁶ I changed the wording to focus more on spirituality than the original protocol provided.

³² VandeCreek, Bender, and Jordan, *Research in Pastoral Care and Counseling: Quantitative and Qualitative Approaches*, 13.

³³ Harold G. Koenig, *Spirituality and Health Research : Methods, Measurements, Statistics, and Resources* (West Conshohocken, Pa: Templeton Press, 2011), 118, <https://eds.a.ebscohost.com/eds/ebookviewer/ebook?sid=b54e4f3c-7881-4ecc-a25a-ba52ad8648b2%40sdc-v-sessmgro2&vid=0&format=EB>.

³⁴ Harold G. Koenig, *Spirituality and Health Research : Methods, Measurements, Statistics, and Resources* (West Conshohocken, Pa: Templeton Press, 2011), 118, <https://eds.a.ebscohost.com/eds/ebookviewer/ebook?sid=b54e4f3c-7881-4ecc-a25a-ba52ad8648b2%40sdc-v-sessmgr02&vid=0&format=EB>.

³⁵ Chochinov, *Dignity Therapy: Final Words for Final Days*.

³⁶ Rosaria Di Lorenzo et al., “Psychometric Properties of the Patient Dignity Inventory in an Acute Psychiatric Ward: An Extension Study of the Preliminary Validation,” *Neuropsychiatric Disease and Treatment* 14 (2018): 904.

The data for the study was acquired through multiple formal and informal interviews, participant observation as well as examining personal documents. Interviews were done before and after the DT process while medical and biographical information was acquired through available documents. Participants were observed and interviewed in their own “natural settings.” Field notes were taken at all interviews and throughout the process as they were observed throughout the community. Koenig concludes his discussion of the data methods saying: “The greatest strength of these research methods is that they provide data that are rich, detailed, deep with meaning, salient, and relevant.”³⁷

The selection of the residents was based on four criteria: 1) their known expressions of hopelessness, loss of meaning or despair 2) their cognitive ability to engage in the reflection and discussion involved in the protocol 3) their having some family or important relationship with whom they would care to pass down a legacy document, and 4) their willingness and interest in participating in this process.

Because nearly all of the available research regarding the use of dignity therapy seemed to be within the palliative care and/end-of-life community, I intentionally sought broader criteria for the selection of research participants. As extremely small as this study was, it seemed that there may be a number of very good reasons that few researchers have chosen to take the research beyond the palliative care and/end-of-life community. Perhaps too many are not ready to address ultimate meaning, for “exploring family jewels” until it truly becomes an end-of-life situation.

³⁷ Koenig, *Spirituality and Health Research : Methods, Measurements, Statistics, and Resources*, 124.

I sought suggestions from the staff of who might most be most familiar with the residents and I acquired background information from the medical or admission records. I appreciate the guidance of VandeCreek to look for "'strategic informants,' individuals who have been particularly immersed in the experience yet are capable of reflecting and able to articulate that experience—mature, reflective, verbal individuals, when possible."³⁸ Regarding the question of how many interviews to conducted VanderCreek explained:

There is no numerical answer to this [question of how many] since qualitative research is not concerned with numbers but with depth. The issue is one of *saturation*—when do I arrive at a gestalt a full understanding of the experience beyond which more material gives me repetition and confirmation of my understanding, but no new facets of the experience or its meaning.³⁹

I interviewed the residents both before and after the sessions and 4-6 weeks after as well to see if there had been lasting benefits to my pastoral care. In addition, interviews with the families were also included when possible.

I administered the DT protocol with four older adults. My conversations were recorded and transcribed. I also took extensive written notes especially on what would not be evident on a recording. Body language, interruptions, and other visual images were carefully noted for later review. The protocol allowed for a significant degree of collaboration and flexibility between the chaplain and the research participants.⁴⁰ The DT protocol ordinarily involved creating a generativity or legacy document containing an edited transcription for each resident who chose to share or not to share with their families.

³⁸ VandeCreek, Bender, and Jordan, *Research in Pastoral Care and Counseling: Quantitative and Qualitative Approaches*, 103.

³⁹ VandeCreek, Bender, and Jordan, 103.

⁴⁰ Chochinov, *Dignity Therapy: Final Words for Final Days*, 79.

Given my full-time proximity to these residents, I was a participant-observer. I was intentionally aware and noted my observations not only during the interviews but as I encountered these residents in the community. This primarily involved noting their activity level and social engagement. I stayed abreast of their medical status and any changes in condition. This proved important with two of the residents.

When I presented the residents with the dignity therapy documents, I conducted post-therapy interviews. I asked each resident, “How did you experience the dignity therapy process?” and “What was your experience reading the dignity therapy document?”

The notes from each resident’s interview were looked at in relation to the others, paying particular attention to themes. I then added in any additional information gathered from the interviews as well as the information I gathered from the observations. Their stories helped me see themes that were consistent amongst my research participants. These themes were synthesized in the final report.

While many had limited sight and ability to focus, most were eager to share their stories. I was confident that guiding them through their narratives would prove meaningful for those who engaged in the process. I also believed their families would appreciate a legacy document since it is the hallmark of DT. Each of these assumptions proved true. I believe that the families who had the opportunity to hear how their loved ones felt about creating the document found that experience to be quite meaningful as well.

My hope for the project was to explore how residents who were feeling a sense of hopelessness, despair, and loss of meaning, could experience a better quality of life. I believed

that given the opportunity to review their lives and share their stories, hopes, and wisdom through a pastoral care approach of dignity therapy, they could positively impact their sense of meaning or purpose, by reflecting on their spiritual lives and relationship with God.

Chapter 2: State of The Field

*So God created humankind in his image,
in the image of God he created them;
male and female he created them. (Gen. 1:27)*

Literature Review

There is a growing volume of literature in fields related to aging and gerontology as our national population continues to age. That issue is no stranger to those sitting in most churches.

James Davies lays out seven biblical concepts about life and aging that serve as foundations for an understanding of aging that grounds this project.⁴¹ Each is well explained and referenced by biblical texts. The seven, are as follows:

All human life is precious and sacred.

Physical life is temporal.

The aging process is natural, inescapable and dynamic.

Chronological age does not deteriorate the value of a soul and need of a Savior.

Aging provides an opportunity for increased growth toward spiritual maturity and wisdom.

⁴¹ James James Davies, "A Practical Theology of Aging: A Biblical Perspective for Individuals and the Church," *Christian Education Journal*, 3, 5, no. 2 (2008): 274–92. *Christian Education Journal*. Series 3, 5 (3). 2008.

The journey of the faith life enables the believer to face difficulties and death with confidence and hope.

Physical death opens the doorway to a new quality of existence for the Christian.⁴²

I particularly resonate with the last three of Davies' points because I believe aging is part of a life-long journey that always encompasses opportunities for spiritual development. This is important for my own life and how I understand the lives of my residents. Over the course of our lives, I believe life is about growing in wisdom and a sense of God's purpose.

Davies goes on to identify three scriptural themes about aging:

Old age is seen as Divine Tribute – people living to old age are to be honored and respected.

Old age is a time of Definite Testing – aging presents a significant opportunity for faith development. God allows older adults to be renewed and refreshed daily.

Old age is also one of Distinctive Triumph -- a time of growth and new life. The bible has much to say about aging from which we can all gain.⁴³

Davies' stresses the sacredness of life and the importance of growth and development across the lifecycle. For him, honor, respect, opportunity, faith development, renewed and refreshed, growth and new life are key to his theology of aging.

⁴² Davies, 275–76.

⁴³ Davies, 277–87.

Ronald Crossley recognizes that aging can challenge theology.⁴⁴ Real life presents cruel dilemmas and very hard answers. His examples include the senior looking forward to retirement, only to learn they will need to be taking care of an ailing parent, or the unending grief of a family living watching a loved on ravaged by Alzheimer's disease. Crossley finds that the way Christians can make sense of aging is to recognize that: "we worship a God who, in becoming human, revealed what it eternally means to be God and what it temporally means to be human."⁴⁵

Subsequently, if God in Christ shares our human aging, suffering, and death, according to Crossley whatever aging means, its meaning can be sought in relationship with God.⁴⁶

Ironically, my very devote 83-year resident who suffered a massive stroke, response to that was, "Jesus only lived to 33. I was 33 a long time ago."

William Simpson offers a concise theology of ageing.⁴⁷ He argues that aging provides a universal concept and gives an opportunity to offer hope, fulfillment, and meaning.

Ageing is really a paradox. It has the potential for serving as the medium through which we move to discover the reality of God on the one hand and the awesome possibility for destroying our meaning on the other hand. Ageing is the constant reminder of our own mortality and the finitude of life itself upon the earth. To deal effectively with the phenomenon of ageing we hold these two potentials in juxtaposition.⁴⁸

⁴⁴ Ronald C Crossley, "What Purpose, If Any, Does Our Aging Play in God's Plan for Our Lives?," *Church & Society*, February 1999, 9–16.

⁴⁵ Crossley, 19.

⁴⁶ Crossley, 13.

⁴⁷ William C. Simpson, Jr, "Can We Speak of a Theology of Ageing?," *The Living Pulpit*, no. January-March (2001): 23.

⁴⁸ Simpson, Jr, 23.

With older adults, I believe we are particularly aware of the balancing of these two paradoxes. Death is a very present reality at all times in a community where neighbors and friends die routinely, and memorial services are scheduled in advance because death is certain.

In a special issue of “Religion, Spirituality, and Meaning in Later Life,”⁴⁹ Susan McFadden, and Rabbi Cary Kozberg’s article “Religious and Spiritual Supports for Late-Life Meaning” recognizes that two decades of research have shown that “religion matters to older people.” Further, they consider religion to be the most important support for coping and dealing with anxiety.⁵⁰ This understanding is foundational to this study. They rely on the rest of the issue to ask: “What do we mean when we talk about religion?” and “How does religion differ from spirituality?” Further asking, “Why is late-life meaning important to professionals in gerontology, sociology, psychology, epidemiology, social work, nursing as well as to chaplains, counselors, and pastors?” This article was important research for distinguishing religion from spirituality in all caregiving settings.

Another article in that issue of *Generations* was “Spirituality, Meaning and the Experience of Aging,” where Robert Atchley defines spirituality as “an inner, subjective region of life that revolves around individual experiences of being, transcending the personal self, and connection with the sacred.”⁵¹ His definition lacks specificity and ranges from experiences of nature to deep spiritual encounters in Judaism, Christianity, and Islam.

⁴⁹ Susan McFadden and Rabbi Cary Kozberg, “Religious and Spiritual Supports for Late-Life Meaning,” *Generations* 32, no. 2 (Summer 2008): 6–11, <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=rh&AN=34921310&site=eds-live&custid=s9005776>.

⁵⁰ McFadden and Kozberg, 8.

⁵¹ Robert C. Atchley, “Spirituality, Meaning, and the Experience of Aging,” *Generations* XXXII, no. 2 (2008): 51, <http://web.b.ebscohost.com/ehost/command/detail?vid=55&sid=8354c71a-b79a-4354-b0e5->

One piece that Atchley adds to the discussion on religion and spirituality is his understanding of spiritual journeys. For him, spiritual journeys are “histories of the experiences, actions, and insights connected with a quest for spiritual meaning.” According to Atchley, these become an opportunity for insight into where we have been and often where our journeys are leading.⁵² This piece was particularly useful when working with my residents. Many of them already appreciate telling their stories, and guiding them and reframing them was very helpful. Thus, confirming that the use of narrative is particularly advantageous to elderly adults in long-term care facilities.

Atchley also includes a discussion of Lars Tornstam's gerotranscendence theory which asserts that spiritual development gradually and steadily increases with aging. According to the theory, gerotranscendence is present to some extent in most aging adults but becomes prevalent in adults over 70. Gerotranscendence theory presumes that spiritual development is “intrinsic” with age although the source of the development is not clear. This development can be encouraged through education and the environment.⁵³

Tornstam's gerotranscendence theory has not been widely accepted amongst the gerontology community. He has some proponents, but many find his theory poorly researched and unsupported, for example, Solveig Hauge questions many of Tornstam's assumptions and many of his research methods.⁵⁴ For the purpose of this project, I believe Tornstam's theory is

22a824619148%40sessionmgr4006&bdata=JkF1dGhUeXBIPXNzbyZzaXRIPWVob3N0LWxpdmU%3d#AN=34921307&db=rlh.

⁵² Atchley, “Spirituality, Meaning, and the Experience of Aging,” 13.

⁵³ Atchley, “Spirituality, Meaning, and the Experience of Aging,” 14.

⁵⁴ Solveig Hauge. “An Analysis and Critique of the Theory of Gerotranscendence,” Text.Monograph, Notat / Høgskolen i Vestfold ; 1998:3, August 19, 1998, <http://www-bib.hive.no/tekster/hveskrift/notat/1998->

applicable to many seniors at the end of their lives and is useful for understanding the internal challenges they face.

Atchley's article also mentions the history of sages. He asserts that "How people answer the question 'What is life about?' impacts how they experience aging and how aging affects their end-of-life experiences."⁵⁵ He adds, "My greatest hope is that researchers, practitioners, and policymakers in the field of aging will begin to treat spirituality as a central theme in the lives of people as they age. I hope that spirituality will no longer be viewed as a tangential topic to deal with only if we have surplus time and money, but as an important topic in its own right, one that has the powerful explanatory potential for helping us understand the experience of aging."⁵⁶

One of the most significant pieces of research on late-life meaning was a large study done by Albert Jewell, Pastoral Director and Senior Chaplain with Methodist Homes for the aged in the British Methodist Church. His quantitative and qualitative study measured the purpose of life for more than 400 older British Methodists. He related it to a collaborative religious coping style, an approach-centered death attitude, intrinsic religiosity, and spiritual transcendence. He then ends with the pastoral implication of all these findings,⁵⁷ arguing that many of his research participants expressed gratitude that the subject of death was raised and they were more than willing to express their views. He encouraged churches to become a "safe place" where "death is

3/#5.0%20CRITIQUE%20OF%20THE%20THEORY.

⁵⁵ Atchley, "Spirituality, Meaning, and the Experience of Aging," 16.

⁵⁶ Atchley, 16.

⁵⁷ Albert Jewell, "The Importance of Purpose in Life in an Older British Methodist Sample: Pastoral Implications," *Journal of Religion, Spirituality & Aging* 22, no. 3 (July 2, 2010): 138–61, <https://doi.org/10.1080/15528030903321170>.

not treated as a taboo subject and fears, and fatalistic attitudes can be faced.”⁵⁸ He invited churches to do more to encourage older adults to reflect on their lives in meaningful ways and that this may well be found “to enhance their purpose in living.”⁵⁹ This gives further support for a pastoral care intervention focused on meaning-making. Jewell’s description affirmed that my residents are willing to engage in conversations on existential issues, religious experiences, and purpose at this stage of their lives.

Ellor offers another important article on religion, spirituality, and aging is “Finding Meaning in Perceived Meaninglessness.”⁶⁰ In this article, he tells the story of Maria, an 82-year-old woman who experienced the death of her husband and two children. She has two other daughters who live in other parts of the country and she lives with one of her daughters’s family. While she appreciates this hospitality, she is grieving the deaths of her family while simultaneously wondering what it all means for her own life.⁶¹

Ellor explains that mental health counselors often diagnose and treat grief in older adults like Maria’s as depression which for some leads to psychotropic medications. Ellor goes on to address the pervasiveness of perceived meaninglessness not only in the older adult population but our society in general.

⁵⁸ Jewell, 158.

⁵⁹ Jewell, 159.

⁶⁰ James Ellor, “Finding Meaning in Perceived Meaninglessness,” in *The Essential Spirit: Providing Wholistic Services to and with Older Adults*, ed. Donald Koepke (Eugene, Oregon: Pickwick Publications, 2016), 26–41.

⁶¹ Viktor E. Frankl, *The Unheard Cry for Meaning: Psychotherapy and Humanism* (New York, NY: Simon & Schuster, Inc, 1978), 23.

Using the work of Victor Frankl, Ellor suggests that logotherapy may be an effective means of helping those struggling with finding meaning even in suffering. Frankl understands the experience of meaninglessness as the absence of meaning. Frankl suggests that patients see therapists due to “feelings of futility.” He goes on to say that the problem that brings them crowding into our clinics and offices is a term he coined as “existential vacuum”⁶²

While it is simple to say that meaninglessness is more than a lack of motivation, recognizing that meaninglessness is an existential issue worthy of attention, especially with the older adult population, is not something I frequently see. Frankl insists that meaning can always be found if the client is pointed to reflect upon their will to meaning.⁶³

Another valuable source was the extensive work of Elizabeth MacKinlay, a Registered Nurse, a priest in the Anglican Church of Australia, and a frequent contributor in the field of spirituality and older adults. In her work focusing on social isolation, MacKinlay defines spirituality as “the sphere of ultimate meaning in people’s lives,” and “the meaning which arises from the core of one’s being.”⁶⁴ She found that when individuals had a meaningful relationship with God, which included prayer, worship, and study, along with a developed sense of spirituality, there did not seem to be severe issues of social isolation.

What I found particularly profound in that study was the question MacKinlay poses regarding failure to thrive syndrome, a diagnosis that comes in and out of favor. Initially, a

⁶² Frankl, 24.

⁶³ Viktor E. Frankl, *The Will to Meaning: Foundations and Applications of Logotherapy* (New York, NY: Plume, 1988).

⁶⁴ Elizabeth MacKinlay, “Ageing and Isolation: Is the Issue Social Isolation or Is It Lack of Meaning in Life?,” in *Aging, Spirituality and Pastoral Care: A Multi-National Perspective*, ed. Elizabeth MacKinlay, James W. Ellor, and Stephen Pickard (Binghamton, New York: The Haworth Press, Inc., 2001), 91.

pediatric diagnosis, failure to thrive syndrome moved into the gerontological literature to describe loss of appetite, physical and cognitive disabilities and social and environmental impairment.⁶⁵ Recognizing that there comes a time where physiological changes at the end of life make it impossible to stop the decline, for many, intervening earlier may make a significant difference in their quality of life. MacKinlay suggests that failure to thrive is a loss of meaning in life.⁶⁶ This idea puts a very different perspective on a commonly used, although not always permitted, diagnosis.

In a second study, MacKinlay presents the spiritual tasks of aging. Through in-depth interviews with 24 independent-living older adults on the meaning of life, growing older and the presence of God in their lives, she developed six themes: ultimate meaning, response to meaning, self-sufficiency versus vulnerability, wisdom and the search for final meanings, relationship versus isolation and hope versus despair.⁶⁷ Using a developmental approach to spirituality in aging, MacKinlay identified tasks for each of the themes identified in the study of the spiritual dimensions as seen in the table below.⁶⁸

Model of Spiritual Themes

Theme	Task
Ultimate meaning	To identify with what brings ultimate meaning
Response to meaning in life	To find appropriate ways to respond

⁶⁵ MacKinlay, 98.

⁶⁶ MacKinlay, 96.

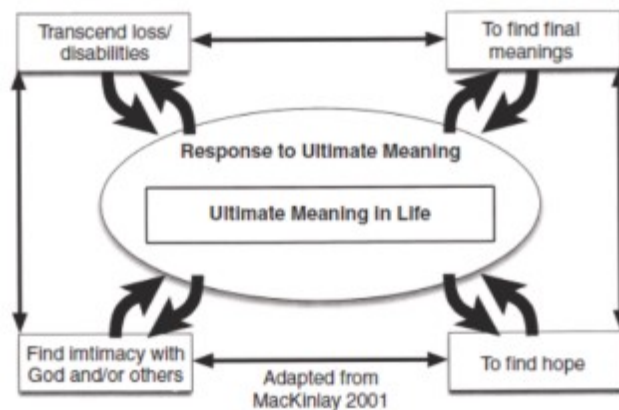
⁶⁷ Elizabeth MacKinlay, *"The Spiritual Dimension of Caring: Applying a Model for Spiritual Tasks of Aging "in Aging, Spirituality and Pastoral Care: A Multinational Perspective.* (The Haworth Press, Inc., 2001), 153.

⁶⁸ MacKinlay, 154.

Self-sufficiency/vulnerability	To transcend disabilities, loss
Wisdom/provisional to final meanings	To search for final meanings
Relationship/isolation	To find intimacy with God and/or others
Hope/despair	To find hope

MacKinlay sees these tasks as the means by which human beings move toward wholeness, something which becomes more urgent as one gets closer to the end of life. She asserts that the content of these tasks will differ depending on a person's understanding of and response to ultimate meaning. Both the themes and the tasks are in dynamic relationships with the ultimate meaning in life.⁶⁹

FIGURE 2. Spiritual Tasks and Process of Ageing Spirituality in Later Life: Tasks—A Continuing Process



⁶⁹ Elizabeth MacKinlay, "Spiritual Care: Recognizing Spiritual Needs of Older Adults," *Journal of Religion, Spirituality & Aging* 18, no. 2–3 (July 20, 2006): 67, https://doi.org/10.1300/J496v18n02_05.

Among the findings of McKinlay's study, is the diversity of ways of aging, and the many and varied spiritual needs that accompany the aging process. It is clear that these needs are heightened during times of crisis. McKinlay believes that ongoing examination of the spiritual needs of older adults leads to more effective ways of providing for a better quality of life in aging. This awareness of the role of spiritual care becomes more prevalent. As the model becomes available in health care settings, pastoral care providers could see more improvement in holistic care.⁷⁰

MacKinlay's third paper addresses the specific issue of the assessment of spiritual needs of older adults.⁷¹ This article builds on her previous research to summarize how clinical assessments can aid in effective spiritual care. She concludes that spiritual care is now recognized as an essential part of a holistic treatment plan.

MacKinlay's book "The Spiritual Dimension of Ageing"⁷² repeats much of what had been presented in her various journal articles. This research gives a more extensive explanation of her model while clarifying the themes and tasks of aging. It also adds a model of spiritual tasks of aging for Christians,⁷³ and issues of cognitive decline and spirituality⁷⁴ Among the many areas of the research that are beneficial for this project is the new discipline of narrative gerontology where there is a growing awareness of the importance of human story. She notes that the story

⁷⁰ MacKinlay, *"The Spiritual Dimension of Caring: Applying a Model for Spiritual Tasks of Aging" in Aging, Spirituality and Pastoral Care: A Multinational Perspective.*, 165.

⁷¹ MacKinlay, "Spiritual Care," 59–71.

⁷² MacKinlay, *The Spiritual Dimensions of Ageing*.

⁷³ MacKinlay, 121.

⁷⁴ MacKinlay, 331.

has become such an important part in aging people's lives that it has led to the fields of narrative gerontology, narrative sociology, narrative psychology, narrative theology.⁷⁵⁻⁷⁶ This project uses elements of each of these.

Gary Kenyon is one of the foundational names in the field of narrative gerontology. Kenyon explains that storytelling and story listening are the means by which we create and discover our identity as human beings. He explains that it is not sufficient to say we have a life story:

“Rather, there is an ontological dimension to the relationship between a person and his or her life story. That is, the processes of story-telling and story listening take on a spiritual quality in the sense that our stories express what is meaningful (or meaningless) to us in life.”⁷⁷

Kenyon considers our stories as our most intimate possession. He encourages the sharing of such stories and the wisdom that can be gained from them but warns of the potential harm that can be done if the process is coercive in any way. He asserts that all sharing must be given freely and by the choice of the owner. “For wisdom to emerge, narrative interventions can only be offered and freely accepted.”⁷⁸ He also explains the importance of realizing that people need not feel locked in by the fact-related aspects of their stories, arguing that in principle, there is no story that cannot be rewritten, recomposed, or regenerated. It is always possible to recast a life story because we *are* fundamentally our stories.⁷⁹

⁷⁵ MacKinlay, 143.

⁷⁶ MacKinlay, 144.

⁷⁷ Kenyon, “Telling and Listening to Stories: Creating a Wisdom Environment for Older People,” 30.

⁷⁸ Kenyon, 32.

⁷⁹ Kenyon, 31.

In a similar vein, Haber, explains that life reviews can help people cope with loss, guilt, conflict or defeat; or help someone find meaning in one's accomplishments.⁸⁰ He elaborates on the therapeutic benefits of a life review as opposed to a simple reminiscence. Mills writing on centenarians adds to the discussion with an article on the stories of centenarians.⁸¹ According to Mills, "Narratives contain key themes that display an individual's experiences and the person's values. Through stories, we explain our actions and beliefs, and we lend meaning to our lives."⁸² Zeilig adds the dimension of narratives as a tool for teaching gerontology and focuses on critical gerontology.⁸³

A different and less well-known approach is dignity therapy (DT) a treatment protocol developed by a Canadian psychiatrist, professor, and researcher, Harvey Max Chochinov. Chochinov specializes in palliative care and designed dignity therapy to address many of the psychological, existential, and spiritual challenges that patients and their families experience as their bodies decline and death becomes an imminent reality. Dignity therapy is designed to preserve meaning and hope for patients approaching death and for those who will grieve their passing.⁸⁴

It combines many of the benefits of life reviews and reminiscence, with elements of logotherapy and existential psychotherapy. Chochinov explains that DT "is a recounting of

⁸⁰ David Haber, "Life Review: Implementation, Theory, Research, and Therapy," *The International Journal of Aging and Human Development* 63, no. 2 (September 2006): 155, <https://doi.org/10.2190/DA9G-RHK5-N9JP-T6CC>.

⁸¹ Terry L. Mills, "Listening from the Sidelines: The Telling and Retelling of Stories by Centenarians," *Generations* 27, no. 3 (2003): 16–20.

⁸² Mills, 16.

⁸³ Hannah Zeilig, "The Critical Use of Narrative and Literature in Gerontology," *International Journal of Ageing and Later Life* 6, no. 2 (2011): 11.

⁸⁴ Chochinov, *Dignity Therapy: Final Words for Final Days*.

thoughts, ideas, and events that are particularly relevant and meaningful for patients to recount and pass along to others.”⁸⁵ The protocol includes the creation of a legacy document to share with families. Chochinov continues,

“An important difference of Dignity Therapy is its grounding in sound research into dying patient’s self-reported notions of dignity. It addresses the dying patient’s need to feel that life has had meaning, and to do something for loved ones that will endure beyond the patient’s own life. It also helps the patient get in touch with the accomplishments and experiences that have made them unique and valued human beings.”⁸⁶

Other therapists and researches have taken note of DT. In an editorial review of dignity therapy, Ferrell writes:

“The dignity-therapy intervention is commendable in its simplicity, in recognizing that individuals have a need for life closure and enhanced communication with those whom they love. . . . This research could be a model for other palliative care researchers in constructing theoretically based detailed interventions that recognize the burden to these vulnerable subjects.”⁸⁷

Ferrell notes that Chochinov does not deal with “troublesome” patients in his research and does not explain how the therapist dealt with patients with intense regrets about their lives or who have conflicts surface from life-long struggles that need resolution. She also adds that Chochinov’s team focused on the impact of this intervention without providing evidence of the

⁸⁵ Harvey Chochinov, “Advantages of Dignity Therapy,” Dignity in Care, 2016, <http://www.dignityincare.ca/en/toolkit.html>.

⁸⁶ Chochinov. “Advantages of Dignity Therapy,” Dignity in Care, 2016, <http://www.dignityincare.ca/en/toolkit.html>.

⁸⁷ Betty Ferrell, “Dignity Therapy: Advancing the Science of Spiritual Care in Terminal Illness,” *Journal of Clinical Oncology*, September 21, 2016, 5428, <https://doi.org/10.1200/JCO.2005.04.912>.

ultimate outcomes of dignity therapy through interviews of family members after the patient has died. She extends the invitation to future researchers to address this absence.⁸⁸

Some of Ferrell's objections seem unfounded based on Chochinov, Hack, Hassard, Kristjanson, McClement, and Harlos' study published in the same issue of the *Journal of Clinical Oncology*.⁸⁹ This study sought to examine how dignity therapy addressed the psychosocial and existential distress among terminally ill patients. While following the protocol, this study added qualitative measures and follow-up with participants and the family members of the participants after they had passed away.

Chochinov's team also presents the dignity model of palliative care which serves as the framework for this treatment modality. As Table 1 shows⁹⁰, Chochinov's protocol seeks to address a significant number of issues or tasks observed in individuals facing the end-of-life, referred to as dignity themes..

Table 1. Dignity Themes, Definitions, and Dignity-Therapy Implications⁹⁰

Dignity Theme	Definition	Dignity-Therapy Implication
Generativity	The notion that, for some patients, dignity is intertwined with a sense that one's life has stood for something or has some influence transcendent of death	Sessions are tape-recorded and transcribed, with an edited transcript or "generativity document" being returned to the patient to bequeath to a friend or family member
Continuity of self	Being able to maintain a feeling that one's essence is intact despite advancing illness	Patients are invited to speak to issues that are foundational to their sense of personhood or self

⁸⁸ Ferrell, 5428.

⁸⁹ Harvey Max Chochinov et al., "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life," *Journal of Clinical Oncology* 23, no. 24 (August 20, 2005): 5520–25, <https://doi.org/10.1200/JCO.2005.08.391>.

⁹⁰ Harvey Max Chochinov et al., "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life," *Journal of Clinical Oncology* 23, no. 24 (August 20, 2005): 5521, <https://doi.org/10.1200/JCO.2005.08.391>.

Dignity Theme	Definition	Dignity-Therapy Implication
Role preservation	Being able to maintain a sense of identification with one or more previously held roles	Patients are questioned about previous or currently held roles that may contribute to their core identity
Maintenance of pride	An ability to sustain a sense of positive self-regard	Providing opportunities to speak about accomplishments or achievements that engender a sense of pride
Hopefulness	Hopefulness relates to the ability to find or maintain a sense of meaning or purpose	Patients are invited to engage in a therapeutic process intended to instill a sense of meaning and purpose
Aftermath concerns	Worries or fears concerning the burden or challenges that their death will impose on others	Inviting the patient to speak to issues that might prepare their loved ones for a future without them
Care tenor	Refers to the attitude and manner with which others interact with the patient that may or may not promote dignity	The tenor of dignity therapy is empathic, nonjudgmental, encouraging, and respectful

In further research, Chochinov and his team also present a model for measuring dignity-related distress along with the validity research. The Patient Dignity Inventory (PDI) is a 25-item psychometric “designed to measure various sources of dignity-related distress among patients nearing the end of life.”⁹¹ The simplicity of the PDI enables it to be used effectively by a wide range of clinicians.

An Italian team published a study on the PDI seeking to extend its validation among hospitalized patients in an acute psychiatric facility. They found that the PDI could be a reliable tool in accessing dignity in the psychiatric setting. What I particularly appreciated was that they amended two items on the PDI. They changed “physically distressing symptoms” to “experiencing physically distressing symptom (such as pain, shortness of breath, nausea) for example, adverse drug effects.” They also changed “concerns regarding spiritual life” to “concerns that my spiritual

⁹¹ Harvey Max Chochinov et al., “The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care,” *Journal of Pain and Symptom Management* 36, no. 6 (December 1, 2008): 559, <https://doi.org/10.1016/j.jpainsymman.2007.12.018>.

life is not meaningful.”⁹² I appreciate this clarification in language and have made a similar move in my dignity therapy questions.

Chochinov and a different team published a study that looked at the degree to which dignity therapy addressed psychosocial and existential distress among the terminally ill. Three pieces were of particular note from this study: that there were beneficial effects obtained irrespective of whether patients indicated initial psychosocial/existential distress, that the patients were moving imminently closer toward death during the study, making the task of showing improvement on measures of distress more challenging, and the recognition that in spite of any decline in health, depressed mood and suffering seem particularly responsive to dignity therapy.⁹³ This result informed my criteria for selecting those who were expressing despair and feeling of meaninglessness.

Other researchers beyond Chochinov and his various teams have studied the effectiveness of dignity therapy. One literature review of the research by Fitchett and team concluded that there was “robust evidence for DT’s overwhelming acceptability,” something which he found “rare for any medical intervention, especially in psycho-social-spiritual care.”⁹⁴ While I noted the significant challenges some researchers found with recruitment and retention, I failed to pay significant attention to this issue. This would become a problem I did not fully appreciate nor anticipate. They also noted that there was not a significant amount of evidence of efficacy in the larger studies. He

⁹² Di Lorenzo et al., “Psychometric Properties of the Patient Dignity Inventory in an Acute Psychiatric Ward: An Extension Study of the Preliminary Validation,” 904.

⁹³ Chochinov et al., “Dignity Therapy,” 5524–25.

⁹⁴ Fitchett et al., “Care of the Human Spirit and the Role of Dignity Therapy: A Systematic Review of Dignity Therapy Research,” 10.

does note that “smaller studies did find effects for increased hopefulness, and lower depression and anxiety.”⁹⁵ This result again informed my selection criteria.

Of particular note to me in this review was their comment that chaplains may be more interested in DT than many of the medical staff “due to the significant and growing demand for evidence-informed interventions for chaplains.”⁹⁶

Fitchell’s review references Puchalski’s article on the role of spirituality in health care. In her article, she outlines recommendations for a curriculum on spirituality for medical colleges. Puchalski notes that the Association of American Medical College’s definition of spirituality is broad.

Spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual’s search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, humanism, and the arts. All of these factors can influence how patients and healthcare professionals perceive health and illness and how they interact with one another.⁹⁷

One cannot miss the intricate and often profound relationship between spirituality, healthcare and the experience of illness.

Chochinov is not without critics. Linqvist and team conducted a feasibility study of the dignity therapy protocol in Sweden, primarily of palliative patients receiving home care.⁹⁸ They discovered significant challenges in recruitment, even after taking into account the level of illness of those being asked. They also found that even among the willing participants, their desire to

⁹⁵ Fitchett et al., 10.

⁹⁶ Fitchett et al., 10.

⁹⁷ Puchalski, “The Role of Spirituality in Health Care,” 356.

⁹⁸ Lindqvist et al., “Reflections on Using Biographical Approaches in End-of-Life Care.”

please or lack of perceived ability to say “no” may have skewed the results. They also raised issues regarding the role of the therapist in creating the legacy document. They discovered that frequently what ended up being received by the families seemed to represent poorly the individual who had supplied the data. They conclude their study with a central unanswered question: “Who benefits the most from biographical approaches in EoL care and how might they be recruited?” and a determination to discontinue any implementation of DT in their Swedish context and to call for further research to ensure that such treatments “are used with the same sophistication as other theories” and that the “complexity of biographical approaches, when applied in EoL care, matches the complexity of ordinary life.”⁹⁹

While it is not without challenges, a significant majority of studies and reviews conclude that DT is well received by those who participate. There is limited data regarding effectiveness. Many see promise in future research particularly in relation to spirituality.

It is this the combination of Frankl’s “will to meaning,” Ellor’s “finding meaning in perceived meaninglessness,” MacKinlay’s “tasks to ultimate meaning”, Kenyon’s narrative gerontology with the disciplines of reminiscence and life review, and then the addition of Chochoniv’s dignity therapy that formed and reformed the direction of this project. It began with the frustration of residents who just did not see why they were still living. They saw no purpose left in their lives. While many had diagnoses of mild or intermittent depression or anxiety, none were suicidal. Often their families were either gone or far away. Most of their friends had died. They were tired of having worn out bodies and not feeling well. In their minds, life was

⁹⁹ Lindqvist et al., 10.

meaningless; it was time to go. Hence, my attraction to Frankl, Ellor, McKinlay, Kenyon, et al. and Chochoniv.

I believed when I began, and still believe, that the issues of meaninglessness are deeply rooted in spiritual and existential issues and that the struggles of my residents are not unique. If I could understand and assist in their mediating these struggles at difficult times in their lives and aid in their search for meaning as they approach the end of their days, I certainly wanted to do so. The use of dignity therapy seemed to combine many of the benefits of narrative therapy, reminiscences and life reviews and add on an opportunity to leave a legacy with one's family. Its simplicity made it accessible without excessive training. I believed the research showed that dignity therapy could be a very beneficial tool for pastoral care, and I sought to show how this protocol would be experienced the older adults in my research. My study could add to the available studies and provide guidance as to the addition of dignity therapy as a pastoral care approach.

Definition of Central Terms

Language of Aging

Seniors and **Older Adults** are the generally preferred terms for those over 65. Much of the literature still uses the terms “elderly,” “old,” and “aging/ageing.”

Old Old and **Very Old** usually refer to those over 75 and 85 respectively. I have not found these terms to be used consistently since “old” tends to be much less a matter of years than it is a matter of health. A healthy 90-year-old can seem much younger than an unhealthy 70-year-old. The following chart has been helpful as a recognition of the differences, but I admit I have not heard anyone actually referred to as a YO, MO, OO, VO, or FO.¹⁰⁰

<i>Mature Adult Subgroups</i>		
YO's	Young, New Old	55–65 years
MO's	Middle Old	65–75 years
OO's	Old Old	75–85
VO's	Very Old	85+ years
FO's	Frail Old	House or Institution Bound

¹⁰⁰ Davies, “A Practical Theology of Aging: A Biblical Perspective for Individuals and the Church,” 281.

Third and Fourth Ages is an additional method of delineating seniors. Third agers are defined as those who are older and living independently, while fourth agers are those who are older and frail, being unable to live independently without assistance.¹⁰¹

Frailty is associated with physiological changes that are evidenced by weakness, lowered energy levels, poor appetite, dehydration, and weight loss. The condition often leads to falls, injuries, increasing disability dependency, and being admitted to healthcare facilities or death.

Failure to thrive in elderly persons is defined by The Institute of Medicine as weight loss of more than 5%, decreased appetite, poor nutrition, and physical inactivity, often associated with dehydration, depression, immune dysfunction, and low cholesterol. Failure to thrive is not a single disease or medical condition; instead, it is a nonspecific manifestation of an underlying physical, mental, or psychosocial condition.¹⁰²

Additional Terms

Dignity -- typically synonymous with terms such as self-esteem, self-worth, and self-respect. It is arguably a complex and multifactorial concept involving aspects such as physical independence, cognitive acuity, self-pride, and autonomy.¹⁰³

¹⁰¹ MacKinlay, *The Spiritual Dimensions of Ageing*, 20.

¹⁰²“Failure to Thrive” *Medscape*, “*Failure to Thrive*” Last modified December 5, 2015. <https://emedicine.medscape.com/article/2096163-overview>.

¹⁰³ Rosenberg, “Dignity Therapy,” 6.

Reminiscence -- The recall of memories – usually characterized as simple daydreaming, storytelling or nostalgia by oneself or with others.¹⁰⁴

Life Review -- A structured and systematic process of recalling memories; typically structured around one or more life themes, most often family themes ranging from childhood or being a parent; and work themes from jobs to retirement. Other themes include major events, health, experiences with aging, dying and death; and meaning, values, and purpose. Participants examine how their memories contribute to the meaning of their life, and they may work at coming to terms with more difficult memories.¹⁰⁵

Critical Gerontology -- Onlinelibrary.wiley.com defines critical gerontology as an approach to aging research, policy, and practice which questions the assumptions underpinning the biomedical mode of aging and the notion that people are a burden on society.

Spiritual Reminiscence -- reminiscence that focuses on life meaning in remembering and in particular, this strategy seeks to consider the person's story in relation to his or her spiritual journey and with God.¹⁰⁶

Stage Theory/ Developmental Theory -- These theories assume that development is a discontinuous process involving distinct *stages* which are characterized by qualitative differences in behavior. A theorist who espouses these theories also assumes that the structure of the stages is not variable from person to person, however, the time of each

¹⁰⁴ Haber, "Life Review," 154.

¹⁰⁵ Haber, 154.

¹⁰⁶ Elizabeth MacKinlay and Colin Dundon, "An Exploration of Health and Religion in Elderly People Through the Lens of Scriptural Reminiscence," *Journal of Religion, Spirituality & Aging* 24, no. 1–2 (2012): 44, <https://doi.org/10.1080/15528030.2012.632714>.

stage may vary individually. Stage theories can be contrasted with continuous theories, which posit that development is an incremental process.

Gerotranscendence – an added stage in development theory for those over 80 years of age. It is a time when the individual is thought to be motivated to resolve and overcome one's past difficulties and prepare for death. Individuals often have a change in self-perception and relationships and a sense of peace with the world.¹⁰⁷

Spiritual well-being (SWB) "Spiritual well-being is the affirmation of life in a relationship with God, self, community, and environment that nurtures and celebrates wholeness (NICA, 1975)."¹⁰⁸ Another definition comes through the nursing profession (North American Nursing Diagnosis Association, 2005) where "'enhanced spiritual well-being' is defined as an 'ability to experience and integrate meaning and purpose in life through a person's connectedness with self, others, art, music, literature, nature, or a power greater than oneself'"¹⁰⁹

Spirituality – While there are many definitions of spirituality. Two that stand out for me are the one from the Consensus Conference:

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.¹¹⁰

¹⁰⁷ Lars Tornstam, *Gerotranscendence: A Developmental Theory of Positive Aging*, 1 edition (Springer Publishing Company, 2005).

¹⁰⁸ David O. Moberg, "The Reality and Centrality of Spirituality," in *Aging and Spirituality: Spiritual Dimensions of Aging Theory, Research, Practice, and Policy*, ed. David O. Moberg (Binghamton, New York: The Haworth Press, Inc., 2001), 15.

¹⁰⁹ Holly Nelson-Becker, *Spirituality, Religion, and Aging: Illuminations for Therapeutic Practice* (Los Angeles: Sage, 2018), 43.

¹¹⁰ Puchalski et al., "Improving the Quality of Spiritual Care as a Dimension of Palliative Care," 887.

And also, the definition is that used by H. M. Chochinov: "That which contains a quality of inspiration, mystery, or transcendence that imbues life with an overarching sense of meaning and purpose."¹¹¹

Meaning -- According to Viktor Frankl and other existential psychologists, meaning reflects a rich combination of philosophy and psychology that can offer comfort at times of suffering and hope for persons struggling with self-understanding.¹¹²

Logotherapy is a school of therapy designed by Victor Frankl focusing on the meaning of human existence as well as on the search for meaning.

Religion – Frankl wrote, "One may be justified in defining religion as man's search for ultimate meaning."¹¹³

¹¹¹ Chochinov, *Dignity Therapy: Final Words for Final Days*, 26.

¹¹² James W. Ellor, *Aging, Spirituality, and Pastoral Care: A Multi-National Perspective*, 1 edition (New York: Routledge, 2002), 27.

¹¹³ Ellor, 37.

Chapter 3: The Research

The selection of participants for the dignity therapy research was based on four criteria: 1) their known expressions of hopelessness, loss of meaning or despair 2) their cognitive ability to engage in the reflection and discussion involved in the protocol, and 3) their having some family or important relationship with whom they would care to pass down a legacy document, and 4) their willingness and interest in participating in the process. Residents were chosen after consulting with medical staff and administrators. All of the residents were individuals whom I had known for at least a year. Each had the program explained, asked if they were interested in participating, given the questions in advance and each signed a release.

I acquired the background information on each resident and family. This included the age of the resident, members, and locations of the nuclear family, some basic medical history, and any religious history available. In some cases, this was very limited, but it did guide what questions I would ask above and beyond the initial DT protocol questions.

I met with each resident, explained the program and acquired written consent and agreed to meet for the interview. In most cases, I returned the following day at the agreed upon time and began recording. I generally started with "Tell me a little about your life. . ." or in one case, "If I were flipping through the pages of your photo album, what would I see?" and from there they took off. Again, they had already had the dignity therapy questions to look at and think about, so some of them were really "ready to go." In one case the interview began immediately after he was handed the questions. He didn't give me an opportunity to arrange for another time. He just started talking.

In a couple of the interviews, I was able to use a number of questions, but generally, they each told their own stories in their own way. As is consistent with the dignity therapy model, I simply encouraged them and asked clarifying questions. Although the sessions were being recorded, I took extensive written notes, specifically noting body language, gestures, interruptions, distractions, or issues that were not going to be clearly apparent on the recordings. Some of the interruptions and distractions were significant.

Following the sessions, I transcribed and edited the recordings and returned them to the residents. Each read through the edited transcripts/documents and corrected anything she/he felt was in error. Each had the opportunity to add anything that she/he wanted to be sure her/his family would have that may not have been mentioned earlier, or to removed anything she/he wished to remove. The goal was not a word for word transcription but a legacy document meaningful to the resident and the family.

I then re-edited the documents, came up with a brief conclusion/summary and printed them as high-quality documents in covers and presented them to the residents with enough copies for themselves and for each of their children. They can choose to give them to their family members if and when they so desire. When I presented the residents' with the dignity therapy documents, I conducted post-therapy interviews. I asked the questions:

“How did you experience the dignity therapy process?” and

What was your experience reading the dignity therapy document?

In the following weeks, I observed the residents' interactions with me and with the greater community. I was also able to talk with one family member concerning his reaction to reading the document. The notes from those interviews were compared paying attention to themes. I then

added in any information gathered from the interviews as well as notes made through observations. This was synthesized into the final report.

Alice

Alice moved into the community two years ago following a long stay in the Health Center. After a few months of floating back and forth between her house in town and an apartment in our community, she finally committed to selling her home and staying in the community permanently. Alice is 86 years old with 3 sisters, 2 of whom are local, 1 in New York and a brother who is local; none of whom seem to have much of a relationship with her. She has a son in the area who she complains about on a regular basis and a daughter in the Atlanta area who seems even more estranged than her son.

Since she has been in the community, Alice has developed warm and supportive friendships with a significant number of residents. She still struggles with depression and “seeing things that she knows are not really there.” She is convinced there are bugs in her carpet and we can’t seem to get past that one. In the past, she has seen interesting happenings going on at the pool outside her window. Interesting happenings include large bands playing in the middle of the night and dance parties. These hallucinations have not seemed to overly concern her physician and do not yet seriously impact her daily living. While she was not raised within a faith community, Alice has become a regular participant of the chapel community, never missing a service. I have had a meaningful relationship with Alice since her original admission.

Alice was selected for the study because she has repeatedly gone through periods of significant despair, hopeless and loss of meaning. When Alice was asked about dignity therapy, she was quite interested but very self-deprecating. She did not think her she could say anything of value; certainly not of value to my study. Much of that stems from her low-self-worth. Knowing that she would have a hard time saying “no” to me about anything, I tried exceptionally hard to make sure I explained what this study was about and that she controlled what she wanted to share, that she was free to stop any time and that was perfectly fine with me. I added that sometimes talking through some of what you're going through can make you feel better. I knew she would need a little more TLC than some of the others. She was given the questions in advance, with the meeting scheduled the following day.

I believe our personal relationship certainly was a factor in our meeting. Alice and I have been close since she arrived at the Health Center. We simply get along very well. She tends to open up to me easily, and quickly and can get embarrassed because she starts crying. Soon I hear, “There I go again. Here come the waterworks.” I’m frequently telling her that there is nothing wrong with her tears, they can be helpful and cleansing. She did cry a couple of time during the interview but just briefly.

I don’t always know what will trigger her. I knew that her childhood was abusive. I knew that her children knew little of that. I did not know if she would choose this as an opportunity to share any of that information. She says:

My mother was an alcoholic. I did a lot of singing then. My Godmother taught me how to sing Italian. I was only three years old then. But my childhood was not good. This was my aunt. Then I went back again with my mother. We bounced from town to town. My mother had a different man every time. She had good spells and bad spells. I got married at 18. I wanted to get out of the house.

When I asked her about her father, Alice shared that:

He knocked my mother up and took off for Scotland. I wrote to him three times and one letter didn't come back, but the other two came back so I never did converse with him.

I was very struck by the tragedy inherent in that line: "one letter didn't come back, but the other two came back." It was the little bit of hope that makes the pain all the worse.

He never supported my Mom. My Godmother said he was a dentist and he was a wonderful man. Most of the time if she didn't get money from her friends, we lived on Welfare. I was a good whipping poll. I was a lot of "choice names." I learned those names quickly.

I found myself wondering how much of her story her children knew.

They don't know a lot about our life. The one that hurts the most is that their father could do nothing wrong.

I don't know when they found out, I think Sandy was just baby, and I don't think she actually ever found out, about how Nanny, my adopted mother had carried on an affair with my husband. We still lived up in New York. I never told her.

We came down here. She was always Daddy's favorite and I was the witch.

I was not a good mother.

He was always a good daddy. He could do no wrong.

So, you protected her.

I didn't want them to find out. But after, when he died, and he didn't want a funeral, this is a part of the story that hurts, Richie had a funeral at their house, like a party, and then when he was shipped up north to the National Cemetery, Sandy held another one at the National Cemetery. During the services, Sandy would be looking at me at the corner of her eye in hate. Such hate, like it was my fault.

We are getting further apart. On the phone, I don't want to talk to her because she's always got something nasty to say.

I never see Richie. And he is the other side of town. When the money came through from the sale of the house, I gave it to him. He needed some money for something, I gave it to him. Then Sandy decided she needed money and I decided not to give to her. She's living with her daughter. So, I've heard about that. And I've heard of the matter more than once. I'm seeing myself as if I did the wrong thing. I'm here. I'm not going out spending. . . but I could use some clothes.

What hurts the most is the two of them thinking that he is some saint.

Alice left home at 18 and married soon thereafter. She became pregnant at 24 but lost the baby girl. Within a year, she was pregnant with twins, she lost one of the twins. Within eighteen months she was pregnant again and delivered her daughter. She continued to repeat. "I wasn't ready to have children. He was interested in kids. "I wasn't a great mommy." I heard that refrain numerous times throughout the conversation. As the relationship with her children has continued to go poorly in their adult years, she goes back to that refrain. And yet, when asked, do they know your/their story, the answer is no.

I've had to take care of someone as soon as I got married. My mom couldn't have anymore and I didn't know anything about how to take of kids. But listen to kids crying, I yelled, "shut up." I'm being truthful. I had my life. It was all my own. I mean, I didn't have anybody to take care of me, right? So now all the sudden, I've got to open life and now I'm tied down with a child and then bingo, two children.

Daddy's baby. Daddy's little baby. And as it stands right now on the phone, she's still daddy's little baby. I don't do anything right and I probably do things wrong because I'm so used to it. It just comes out automatically, but I know they'd rather that I had died first and then they would have Daddy for themselves.

Alice is 86 years old. Her children must be in their sixties but the issues of early childhood continue to cloud their relationship.

Part of her mixed feelings over their love for their father is that he had an affair with her step-mother. She never wanted to share that information with her children, protecting them and their love for their dad, and yet being jealous of their love for their dad at the same time. Family secrets can be dangerous for decades and generations.

It is also mixed with the pain of her own childhood. "I didn't have anybody to take care of me." She had never learned to mother.

They bought my car. They bought my house. They treat Mommy like a piece of dirt. That's the first time I've said that. I guess that's how I feel. The people here treat me so much better than my own family does. There go the tears again. That's why I want to see my friend for Thanksgiving, not go see my daughter.

She struggled with her feelings. She believed she was supposed to want to see her daughter for the holiday, but she simply did not, which made her feel guilty. She continually did what she felt was the "right thing" for her children (sold them the house and car) but they did not reciprocate with appreciation or affection.

Alice desperately wants a positive relationship with her children that neither she nor they know how to have. None of them have learned how to be that kind of family. None are in a position or have a willingness to work on it either. Alice is finding friendship and acceptance in our community that she has never experienced before, at least not one that does not include lots of alcohol. She had expressed a history of excessive drinking. Going through the dignity therapy process gave her a sense of perspective on her story, as painful as it was, and that it did not have

to control her. Her children have made demands for money, and her perceived guilt for being “not a great mommy” has allowed their efforts to be successful and worsen her sense of guilt.

This process was a step in helping her to gain a better understanding of herself. By the end, Alice was beginning to question her belief that maybe she really was more than “not a great mommy.” But clearly, it was only a small step in a long process. The DT further strengthened my relationship with Alice and enabled me to continue my pastoral care in a deeper and more supportive manner. I will also continue to advocate for mental health services. Follow-through is a challenge for Alice and she will need continued assistance and professional psychiatric care.

My discussion with Alice after the session, went as I expected. She was self-deprecating, somewhat embarrassed about her tears, and hoping to please. I assured her she had done fine and I thanked her for being honest with me. She experienced the dignity therapy as “interesting,” not quite knowing what to make of the experience. Alice is very appreciative, and remarkably surprised, at the friendship she has found in our community and the fact that there are people who do care about her and are interested in her.

Betty

Betty is only 79 years old. She is wheelchair bound with advancing Parkinson's disease. While she is by no means a large woman, she sits in a larger and heavier than average wheelchair with extended leg supports. With minimal upper body strength, she is able to move independently only to a very limited degree.

Betty was selected on the recommendation of the Health Center Administrator who was more aware of her despair than I. Betty had been an Independent Living resident in our sister community for a couple of years before she moved into our Assisted Living unit at the beginning of 2016. At the time she was still able to ambulate with the use of a cane. Her condition declined rapidly and she required skilled care necessitating a move by April of 2017. She continues to reside in the Health Center as her condition continues to worsen.

Even though I have had a long relationship with her and see her on a very regular basis, I was genuinely surprised to learn of her extensive list of serious psychiatric diagnoses. I do not routinely dig deeply into residents' medical records unless I see a need to do so, hence I was unaware of her diagnoses of bipolar disorder, persistent mood [affective] disorder, anxiety disorder, and schizophrenia along with the continually advancing Parkinson's disease.

Betty has a supportive family; a son and a daughter-in-law who live locally in Florida, and a daughter and son-in-law who live in Virginia. While the daughter is unable to visit frequently, she happened to be visiting the week I was doing the interviews. Unexpectedly, she became a significant part of the process and the study. Betty was very receptive when asked

about dignity therapy. She was given the questions the day before and was pleased to get started that day.

Betty began by telling me about her days teaching and how proud she was of her students. Teaching drama to high school students was very rewarding to her. She saw a number of her students continue with what she had taught them. I could see the pride that she still feels for the students she taught so many years ago.

Not long after we had begun, Betty's daughter walked into the room and joined into the conversation. She added that her mom loved teaching *Romeo and Juliet*. It was one of the students' favorite plays and she taught it every year. She also mentioned that Betty was an exceptional musician. I learned then that her mother had sung opera for a time, and had also performed in a few musicals. As long as I had known Betty, this was completely *surprising* to me. I am pretty sure I would not have learned any of that if her daughter had not arrived. I was grateful to her daughter for taking us down this road. Betty is a bit too humble to have shared her time on the stage.

Betty spoke of her travels. Her husband served in the Navy and she "followed the ship," meeting the ship at ports in various destinations: like Hong Kong and Barcelona. This is a common practice during deployments for Navy spouses who are able to do so.

Later, I realized that I had not heard much of anything about Betty's family during the interview so I asked if I could meet her a second time. I wanted to ask her some questions when her daughter was not present. I thought that might give her some freedom to answer questions she might have felt uncomfortable answering with her daughter in the room.

The next day I just said, "I know your family has been a very important part of your life, what are some of your hopes and dreams for them."

She gave expected answers like:

As for [Son and Daughter-in-law], I would really hope for them that they have a good marriage and keep on with the Christian faith that they have developed. I think they had that before they got together, so I think that's good. And they're also into sports a lot and I hope they keep that up. I think that's a good thing for young people to be into...

I've had such a good family. My aunts and uncles and grandmother and grandfather, have been so wonderful, my dad always wanted me to keep on studying my religion, he was the one who really got me into catechism and confirmation. He studied Kierkegaard in the original Danish. You know it's funny, my father really didn't have that much formal education. It's just what he could read on his own.

He was a gardener for the city of Chicago and yet he read Kierkegaard in the original Danish!

That set quite a precedent for her.

When Betty talked about her family in Chicago she was slowly and deliberately exploring and sharing her cherished family.

My dad is a gardener. He works with plants and he's very good with plants. He works for the park district in Grant Park ... I don't know if you know anything about Chicago Parks, but they are very well developed. They have a long history of people being very interested in developing them and so my father is doing a good job for what he's interested in. Oh no, I talked about him as if he's got 50 more years to live, and he doesn't, he's at the end of his life. (nursing intervention)

Faith was important to her family. They were deeply rooted in the Lutheran Church in Chicago, and while her father may not have had much formal education, he made sure his family was committed to the church and was trained in it. He kept studying himself so much so that he read Kierkegaard in Danish. Betty has continued her devotion to the church her entire life. Her family has continued in the church as well.

Betty's husband was a career Navy pilot who died in an accident due to a tragic malfunction on a small plane. Her children were only six and ten when their dad died.

We moved to Orange Park where we had lived before, so we knew people there but it wasn't like having your dad there and moving near your family . . . well, I moved to be near my friends.

My family wanted me to move near them. My brother and sister-in-law wanted us to move near them, but I didn't want to leave my friends. I had good friends in Orange Park. They were very good friends.

She made her choice, and that choice was important. Very important.

I asked about her kids now. [Her son] is a financial planner, he's taken a real interest in youth work. He is very active in the youth group program at our church. His wife is involved in the youth group as well. They have what they call "boot camp." His wife is great with kids. [Her daughter] enjoys theater, but her real love is producing original translations -- Spanish to English.

Betty recounted a number of other stories about her kids and granddaughter. I then asked her if there was another other memory, she wanted to be sure to pass on to her family.

We had our favorite uncle who went by the name of Unc. He was my mother's brother and he was such a funny wonderful extroverted man. He just could walk into a room and just know exactly how to go about getting people to talk to him and really open up to him. He was my favorite uncle; my favorite person and he lived a good long life so we had him a for a long time which was really wonderful. I know you can't control that, but you can definitely appreciate it.

She had lost her husband in a tragic accident very at a very young age. She had two young children. She lost her home (military housing) and had to move and create a new life. Her family did not agree with the decisions she made, but it was her decision and she stood by that

decision. She struggled with mental illness which left her in and out of mental hospitals at least a couple of times but her parents stepped up to help with her kids and her uncle was always the hero figure. What I kept hearing from Betty, and her theme seemed to be when it comes down to it: appreciate what you have while you have it. You don't know how long it will last.

There were a number of interruptions during Betty's interviews. Her roommate came in and out numerous times during the first interview, as did the nurse. There were also times where Betty seemed to pause for unusual lengths of time. I would ask if she needed a break or needed more time. She would be surprised at my question, oblivious to the issue.

At one point she told me that her daughter had just taken her to the mountains to show her where she went school, and that she had been very excited to see it, and that the daughter's husband had gone along and that was unusual because he doesn't usually go because he doesn't like to be in the pictures.

We live in Florida. There are no mountains, and Betty is wheelchair bound and not going anywhere. I got confused quite quickly and realized all was not as it seemed. This was when the psychiatric diagnoses began to make a bit more sense. Sometimes reality may be more fluid for some than others.

In spite of the confusing part, I was able to write up Betty's interview, editing out the interruptions, and much of the daughter's conversations, and present it back to Betty.

Betty seemed quite pleased with the final document. She enjoyed the dignity therapy process and remembering the good parts of her past. She was genuinely appreciative of having someone interested in listening to her story and to have the opportunity to revisit those positive memories; to unveil the family jewels that had been buried for so long. In spite of some of the

deeply painful periods in her past, she had been able to put them in perspective and was able to learn to appreciate the good times. She recognized the importance of her faith and the fact that she was deeply root in the church. She valued the deep Lutheran heritage she inherited and how it had helped get her through the challenges she had faced. Telling her story reminded her of the strength of those roots.

The DT process was rewarding and enjoyable for Betty. The fact that her daughter ended up participating in it was completely unexpected but, I believe it worked out to everyone's advantage.

David

David is 80 years old and has two daughters and a son. One of the daughters is local and is supportive. I knew when I mentioned the dignity therapy that David would enjoy the process. David appreciates the opportunity to tell his story. He has done significant genealogical research, so asking him about his history opened up more than I could have ever imagined. When I gave him the DT questions to look at, he started talking before I even had a chance to arrange a time to meet. Fortunately, I had my tape recorder with me and I had the time to sit and listen because he was off and running.

David moved into the community nearly four years ago with his wife June. At the time, June was living with him in their one-bedroom independent living apartment. June was diagnosed with Alzheimer's disease but was still able to be cared for by David, and could live at

home comfortably and safely. David was a regular participant in my Alzheimer support group and both he and June came to chapel services when they did not go out to their local Presbyterian Church of which they were members. As June's condition deteriorated making the trip too difficult to for David to handle alone, they attended their church less and less frequently. Eventually, my service became their Sunday home.

Within a year or so, June needed increasing physical care both day and night and David worked himself into the ground. After significant effort from many, David was convinced to move June to the Health Center (skilled nursing) for her health as well as his own. He probably had a more difficult adjustment than she. While she would wonder where he was, she could be easily redirected. He struggled with guilt and a sense of failure for not taking care of his wife and thinking too much of himself. Yet, he continues to visit her and takes her to worship and music events he knows she would enjoy, he has started spending time on his hobbies, specifically photography, for which is he is exceptionally gifted. He takes trips to locations where he can get especially good photographs and is often the photographer for events on campus. He exhibited some of his work in the art show on campus as well. In spite of these outlets, David goes through periods of despondency and has had repeated hospitalizations and illnesses, expressing his fear that he might die before his wife. She is doing very well in the Health Center, actually seeming to improve in some ways especially in her behaviors. He just hopes to be around long enough to be there for her as she needs him.

David's story is one of overcoming significant adversity. Being a depression child, his father moved away for a factory job, his mother moved away when he was 5 years old to earn a nursing degree leaving him to be raised by a grandmother.

I didn't see much of my mom because she went to Washington DC to get a nurse's cap. When she got her nurse's cap, she got a job at Fordham University Hospital in the Bronx. I was brought up by my grandparents, my maternal grandparents. I basically had the run of the land. I had a job. I had my grandmother. My dad was pretty much out of the picture. He just lived across the river. I don't know whether he helped support us or not. I have no idea. He was working. He was in maintenance. But it was the depression.

I didn't get a sibling until my father remarried about 1948.

I never had a chance to live with my mom again. She died while she was a nurse at Fordham University Hospital where she basically had access to everything. Her death certificate says she took an overdose. It doesn't say she had cancer, but we know she did. We figure she was in a lot of pain and that is why she had taken so much medication, but we don't know that. We don't even know what kind of cancer she had. I'm not even sure what cancer my grandma had because they don't even have that on her death certificate.

I graduated in 45. I lived my dad for 1 year and after that, I was on my own. I was trying to go to college and I couldn't.

It didn't happen overnight. I moved from my father's house to the YMCA sometime in 1945 or 46. I'm not sure when exactly— for fun. I had buddies. We all learned how to drive in the same 1936 Chevy. We learned there. Herbie and Donny's older brother taught us all how to drive the twin's family car. There were Herbie and Donny's older brother, Herbie, and Donnie, Jonnie Tisbaugh, Chris Henson and Me, that's six of us.

Do you want to know the rest of the story? None of us had a license. Except maybe Donnie older brother. The reason was none of us were old enough. I was just barely sixteen and the rest of them were a year younger than I was.

David's memories are something he treasures, truly his jewels. In the midst of difficult and challenging times, living in the depression, having lost his mother to an overdose, and being sent away to live at the YMCA, he remembers living with his friends and piling into a car and learning to drive without have a license. He is the “make lemonade out of lemons” type of person. The humor is an important part of getting through all the pain and the challenges.

David enjoyed trying to answers questions before I would ask them. I asked almost no questions in his interview.

If you're wondering how I did as well as I did with what I had to start off with: someone up that likes me. Was I brought up in church? Yes. Originally, the Evangelical Brethren Church. . . .

David continued on with an extensive genealogical history including a number of ministers in his family line. He has traced his family history and his wife's back to colonial days enabling his daughter and granddaughter to have DAR membership. He has enjoyed spending the time digging through historical documents and traveling around locate information.

David had a long career first as an active duty member of the Army and then as a civilian working for the Air Force. He had specialized training in linguistics being able to understand Russian and in cryptography. While he has been retired both from active duty and from civil service for some time, that is still an important part of his identity and his story.

Faith is a very important element of David's life. He has been a church member his entire life. He raised all of his three children in the church. Only one of them is currently involved in a congregation now. He is concerned that his grandchildren have no faith whatsoever. That hurts him deeply. His comment, "I don't know where I failed [them.]" He has felt God's leading his whole life. "I have let Him lead me. I can safely say He is my guiding light."

When asked about what gives him the greatest meaning or purpose right now, he answered very quickly. "Taking care of June." His purpose is the care of his wife, and he is very faithful to it.

Near the end of the interview, David said:

I'd like all my family to know where they come from but they don't seem to be interested.

This clearly caused a great deal of pain.

I'm not going to try and give my children advice; probably a good thing. If they want to talk to me, I'll talk to them. If they want advice, they can ask for it and I'll tell them what I think. So far, I haven't got that.

David was trying to unveil some of his family jewels. In this case, it was his deep interest in genealogy and what he has learned about their ancestry. That interest is not shared by his children. One of his daughters has much of his research, but apparently not his passion.

It seems that David would also like a different kind of relationship with his children, but is not willing to push for it, being unwilling to risk losing the relationship he already has. He sees the fragility of the relationship he has and is trying to be sure he does not lose that.

The pain of not being able to share the depth of his faith with his family, and now not with his wife, due to her disease process, has left him lonely and lost. He has spent his life overcoming adversity, making the best out of the difficult situation. His current challenges are threatening to be more than he knows how to overcome.

Cathy

Cathy is an 83-year-old woman who suffered a massive stroke following a minor cardiac procedure. She turned out to be the ideal dignity therapy candidate. While her body is in poor shape her mind is not. She is a deeply religious, extraordinarily delightful woman, with a loving family and is uniquely reflective. When I asked her about the dignity therapy, she thought it was a wonderful idea, and thought her sons would appreciate the legacy document. She was eager to get started the next day when I returned.

Prior to the cardiac procedure, she was an extremely active, fast-moving, 1000+ hour hospital volunteer. She has had not only a stroke but open-heart surgery leaving her with a very weak and failing heart, as well as no use of her left side what-so-ever. She is completely reliant on others to move from bed to chair. She cannot dress or clean herself. Her ability for self-care is virtually non-existent. She says, "I feel like I'm in storage. I just get moved from one place to another."

Fortunately, she is right-handed, and can still speak well, eat well, breathe well, and her mind is fully intact. She is a very devout Roman Catholic, married with two married sons and four grandchildren.

I began by asking her what we would see if we were flipping through her photo album.

A little girl who is very much loved, who came from a very loving close-knit family. I grew up in Williamsport, Pennsylvania. I had one sister and three brothers. All of my brothers are gone now. The Lord needed them upstairs. They can help take care of those "pearly gates."

We had a very religious family. Every Sunday morning, we went to the earliest Mass and then we would go to the cemetery and visit the graves of all our family members. Then we would go down and visit my grandmother. I would always be sitting near her feet. I think I made her nervous. She lived to be in her nineties. My three brothers lived to be about 89. My sister though is still alive, she is four years older than I.

She continued by telling me about her Catholic education. She was sent out of state to a Catholic boarding school beginning in eighth grade and then to a Catholic university.

I'm the only one of my siblings to go to college – except Carl, my brother, who became a Jesuit missionary.

Carl served in India working with Mother Teresa for over 50 years. He helped her write the constitution for the community. He went to India in 1950 or 1951. He died in 1989 and he is buried over there. That's okay because he always considered them his family. He spent so much of his life in different villages. He spoke Hindi and many of the other languages. He taught them how to raise fish in the rice paddy so they could be self-sufficient.

My brother Louie was a sailor in the war, serving on a transport ship.

I commented on the family's commitment to service.

Yes. Dick and his wife Jane did a lot of work with the church, volunteering for their festivals and stuff like that. He and his wife cooked for different events and worked in the church. She still cleans the church.

My dad used to help a lot too. I remember when they opened the hospital; he and I went out and helped unload furniture and stuff. We spent days out there. I was just ten or twelve.

We tried to pass that on our own kids. I think we have. We were involved. We wanted to be examples of love, generosity and helping others wherever we could. We were not perfect by a long shot. God knows I wasn't.

I was really struck by how she had laid out this history and culture of service within her family and then she comes up with her own summary, “we wanted to be examples of love, generosity and helping others wherever we could.”

But then she gave me a powerful childhood memory:

One of my earliest memories is when I was about three or four, maybe a little younger. I don't know. I remember one day my mom was doing something down in the kitchen and she was standing up on a chair, I was on a chair too, and for some reason or another I yelled out to her “Your nuts!” I have no idea why. She lifted me off that chair so fast and took me upstairs. That was it for the afternoon. I came to the top of the steps and I said: “I'm sorry Mom, I didn't mean it.” That was a very clear memory in my mind. I knew I offended her. I don't know why I would ever call my mother that because we didn't use that kind of language. I probably didn't even know what it meant. But I remember it 80 years later.

Faith and trust and lots and lots of love were very important in my family. Not ostentatious loving — you know I didn't receive that. I don't know that I ever saw my dad kiss my mother. Our kids have seen us kiss all the time.

So that was something you ended up doing differently than your parents.

Absolutely! And that's mainly because of the man I married.

Sometimes you do things differently.

Sometimes it's a lot better. Most of the time it is.

Cathy is at that point of making meaning. She doesn't always realize it, because she still has some anger, but far less so than her husband. She is finding meaning in her circumstances and her life. She continues to be seeking answers – seeking from a position of very deep faith.

There was an awareness that her marriage was different from her family of origin, but that had been a very good thing. She is humbly proud of her family and the life she had the led, giving credit to God and to her husband.

I asked her about her hopes and dreams for her family.

My hope is that Ted (husband) and I have succeeded in setting values that will carry our children through life; showing and modeling for them a good Christian life of helping other people and loving each other dearly.

Cathy's interview was filled with "quotable quotes," but this one of the most memorable concerned how she helped her adopted sons understand their origins:

When the boys started to ask me questions, I would tell them, "You may not be the baby of my body but you are the baby of my heart and I couldn't love you more. You really can't get much better than that."

I continue to be in awe of the depth and the strength of Cathy's faith. I asked her how she saw God working in her life.

I feel His hands guiding me a lot even in this disastrous time. I was just telling Ted this morning if there's anything to be thankful for in a stroke, and I can't think of many things, the one thing that I am very grateful for is that it happened on my left side and I'm right-handed. It could have been really disastrous for me because I don't do anything with my left hand. I'm not ambidextrous. He was merciful to me.

Cathy had the ability to see the spirituality and existential amidst the mundane. Others may see her as depressed or despondent but she is uniquely realistic and grateful. She truly sees the grace amidst the horror. It is extraordinarily difficult when her husband cannot share either of those realities. He continues to "encourage" her and try to hire more therapist to "make her better." The chance of physical recovery is unrealistic and the therapy is unwarranted at this time. She understands that completely. His denial is understandable but hard on the relationship.

When I wake up in the morning, I think it was going to be over. There is a reason. I don't know what it is. But now I'm trying to work it through with Him. There is something He wants me to do for Him, I don't know what it is. It must be important. I thought by now I would be gone.

She is able to recognize that she still has a purpose in life. Even sentenced to life in a bed or wheelchair, she still recognizes that God has a purpose for her.

The only thing Jesus didn't do is live to old age. I was 33 a long time ago but I don't begrudge him that.

She is even able to laugh about God's grand plan and Jesus' getting out of growing old.

I tried to come up with a way to get Cathy to summarize what she had learned and what lessons she wanted to pass on to her children.

Life is very difficult. You meet all kinds of people that you don't even realize that you're touching and they become friends.

I had no idea I had so many friends but I do. I have a lot of friends and I'm thrilled. I have worked with a lot of very good people, all these years. Fifty-one years in the classroom. I started teaching at eighteen – right after high school. Back then we didn't have to have an actual certification apparently. I had to be responsible for kids that were in 8th grade. I taught the sciences. That was in New Jersey, Jersey City and then I went to Florham Park, New Jersey. It was a very tiny school. It was a new school. And I taught eighth grade. Actually, I taught everything.

Life has been good for me or to me. Successes and failures. I don't always get along with everybody but in general, I tend to get along with people. I have worked with a lot of very good people, all these years.

My dad died two months shy of 95. He died in 1996. I had brothers who lived to 89. All my brothers lived to 89. I guess that is the magic number.

But I'd just as soon not live that long. At least not like this, though I'm getting closer to it at 84.

And my husband is across the street. We miss each other immensely. We have a very close relationship. I love him dearly.

Cathy is trying to end with role completion. How can she finish out who she was meant to be? She doesn't want to live a long time the way she is now. But she is also thinking about the husband she dearly loves.

Throughout the session, Cathy opens herself up and unveils her jewels in all their splendor. "This is who I am." "This is who we are." "This is who we were meant to be." I could not have asked for more openness, more honesty or more love.

When Cathy read the legacy document, she felt a sense of completion. She was tying up some loose ends. She had told her story, passed on what she needed to say to her sons. There was a sense of relief for her. She appreciated the process.

Shortly after the interview, Ted was hospitalized. During this that time, Cathy and Ted's youngest son came down to stay with them. I asked him about reading the legacy document made by his mother. He was very moved by the experience. He felt it did reflect his experience of his family very closely and portrayed his mother extremely well. He was very appreciative of it and felt it is something he will treasure.

As the weeks went on, Cathy's health declined and Ted's rage increased. One Sunday morning, Ted come angrily out complaining about getting his wife ready for Mass. I explained to him that Mass had been on Friday. He had attended Mass and his wife had been taken the Eucharist after the service because she had been unable to attend the Mass. He yelled, "That's not good enough, she needs confession!" I was surprised by the intensity of his outburst.

Talking to Cathy later that day, without Ted in the room, she says, "There is something I didn't tell you before. Before I was married, I was a nun. I was in the Order for several years." Not much later Ted returned. Cathy told him that she had told me about her. He then informed

that he had been a priest. They had been living in our community for over a year and successfully kept that information from everyone; particularly commendable given that they lived surrounded by retired clergy.

When I began the study with her, I had no idea I was walking into major family secrets. I had no intention of trying to “uncover their secrets,” which was not only their previous vocations but also his medical diagnoses that, as it turned out, had not been disclosed hindering his medical care. I offered to open a door, make a connection and Cathy decided it was time to move through it. The pastoral care approach used for this study became the beginning of a meaningful and significant relationship.

The depth of both Cathy’s and Ted’s faith cannot be understated. For Cathy, her ability to see grace and mercy in the midst of horror and pain was truly inspiring. For Ted, even as, what I later learned were his worsening dementia and delirium, the rituals of his deep faith continued to hold powerful meaning for him. Learning that Ted had been a priest explained a great deal about his outburst concerning the need for confession that made so little sense in its original context.

Ted’s own psychiatric difficulties and behaviors reached a point that necessitated that he be transferred to a memory care facility away from Cathy. In the meantime, their son arranged for a medical flight for the two of them to a facility in Missouri where they would be on different floors, but at least in the same building and the family can visit them both on a regular basis.

Unfortunately, Cathy was dying. Her heart failing. When she began the dignity therapy, she realized it was an opportunity to share with her sons some of what really mattered to her. She knew there would not be many chances left to do that. It was truly exploring family jewels and tenderly and lovingly giving them to her sons. The fact that she knew her time was short made a

difference. Her perspective was not the same as those who were not looking at their past with the end at arm's length. The process enabled her to take advantage of the time she had for her benefit and that of her family. It also helped me to do my best to serve as their chaplain for as long as they were in my care. Cathy passed away four weeks after moving to Missouri.

Chapter 4: Analysis and Conclusions

Thematic Analysis

The dignity therapy was administered as a pastoral care approach to four residents. The choice of the content was completely up to the residents and what they wished to share with me and eventually with their families. The questions asked were intentionally vague. While the content of each interview differed, there were themes that were remarkably consistent across all or most of the encounters. While not focusing so much on the content itself, the themes illustrate and speak to the similarities of the resident's experience of the intervention.

Needing to Be Heard

Understandably, the most commonly seen element from all of the sessions was the resident's desire to simply be heard. Most people appreciate telling their stories to someone who genuinely will listen. Alice at one point said, "I have never told anyone that before." She was telling me pretty horrible things about her abusive parents, her unfaithful husband, her own alcoholism, and miscarriages and yet, she appreciated that I listened. I had not asked her to bare her soul or tell me anything painful, and yet that was exactly what she did.

When I asked her if her kids knew her story, the answer was, "They don't know a lot about our life." As angry as she had been at her husband's unfaithfulness, she was willing to

concede that he was a good father to the children and she wasn't willing to demean him in their eyes. Her children didn't know of his infidelity and don't understand her feelings. She needed to tell her story and be heard.

Betty's experience, which was distinctly different from Alice's, was also tragic. Her tragedies involved the accidental death of her husband while serving on active duty in the Navy, which necessitated moving with small children. She also had possibly related mental illnesses and early-onset Parkinson's disease.

What the intervention did for Betty though, was allow her, not to focus on the tragedy, but rather to remember that she survived and thrived through those times. She remembered her family and her friends who were there to help her through. She remembered how much she enjoyed teaching, watching her students perform and being on stage herself. She appreciated the jewels that were her family, always the rocks she could hold on to during the rough storms in her life. Those were the stories she enjoyed telling so much. Sharing those gems were what made the experience worthwhile.

David will always be eager to tell his story and share his gems. One of the challenges of having a spouse with Alzheimer's disease is often that one no longer has someone with whom to carry on a conversation. It can become very lonely. David cares deeply for June, but the June he spent his life with is gone. The dignity therapy helped him remember when she was the woman he married. His jewels though, go back many generations. He never wants anyone to forget that.

Cathy needs to be reminded that we know, and God knows, she is still in there. As I listened to her and truly heard her, she could become more than the stroke victim in bed A. She suffers from the curse so often faced by victims of physically disabling conditions where others assume, they are mentally disabled as well. Being heard meant a great deal to Cathy. We didn't have to talk about her physical needs, we could talk about her history, her family, her theology, her philosophy or whatever else she wanted. And I would listen. She could unveil her jewels and they would shine and be celebrated. Cathy shared her life, her faith, and her world that did not have to be related to anything physical. Few others would listen to her in that manner. And of course, she needed to tell her sons what she wanted to be sure they would remember or know about their family and how much they were loved.

Have Their Children Understand and Appreciate Where They Came From

There was an interesting thematic commonality in the need for having their children understand or appreciate where they came from. Cathy had the line to her adopted sons that I'll never forget: "You may not be the baby of my body but you are the baby of my heart and I couldn't love you more." At some point in our lives, we all care about where we come from.

Cathy talked about all of her strong Roman Catholic family members. Her roots were so strong they went to the cemetery after Mass on Sundays. The strength of family had come down through the generations, as had the commitment to serve. There is no question that her children have picked up the message.

David was so hoping that his children would be as interested in genealogy as he. He had obtained the documentation for DAR memberships for his daughters but knew that the interest was more his than it was really theirs. He had spent much time learning of his roots and those of his wife and he found it all fascinating. It was hard for him that none of his children shared his passion.

Betty talked about her strong Danish Lutheran roots. Her father was still in touch with his Danish side and deeply committed to his faith. He “schooled” her well and made she learned her catechism. She hoped her children would stay as involved with their faith communities as she had been in hers.

Alice though had given up even trying to hope her children would care about their past. She wanted her children to understand where they came from but had long since decided that it was easier if they didn’t know. They thought their dad was a saint and she was a witch. So be it. That was a burden she chose to bare alone.

Believe They Made A Difference

As each of us reflects back on our lives, we hope that we have made a difference somewhere, somehow. No one wants to believe that we could disappear unremembered.

Betty celebrates the years she spent teaching drama to high school students; many of whom continued in the theater. Who knows, we may be watching her students on television or in

movies. She celebrates her children's successes. In spite of having some serious hurdles to overcome, her family has done well and she is grateful.

David had a long career in government service. He is proud of his work. He advanced well and was able to turn down advancement that would have taken him to areas he did not want to go. He was able to travel to a number of different assignments with the same commanding officer because his service was being requested. This led to being recognized and appreciated.

Cathy also celebrates the students she taught over the many years of teaching in the public school system. She also prays that she passes on the values of faith and service that she grew up with to her children.

To Be Recognized and Appreciated

David was recognized by the military and he still needs to tell that story, especially for those who do not understand that system. It seems odd to non-military that someone could be retired at age 59. He is much older now, but it has caused much confusion for him.

Alice has spent her life not feeling appreciated or recognized at all for that matter. Just being noticed is a big deal for her. Having someone be grateful instead of demanding makes a big difference in her life. Her children have never been taught how to do that.

Betty is appreciative of every day. Telling her story made her acutely aware of the value of each day. That was her conclusion: "when it comes down to it: appreciate what you have while you have it. You don't know how long it will last." For someone who lost her husband

when she was in her 20's or early 30's and lives with a very significant disability, she has more than earned the right to say that. From what I have seen, Betty's family does a pretty good job of appreciating her.

Want to See God in Our Lives/

Pulling It All Together – Making Way for The End

Each of the residents used the dignity therapy intervention to tell her/his story in a unique way. Each found her/his own meaning. Each had a sense of God working in their lives, most of them, very profoundly. Alice, couldn't articulate that like others, but her present actions speak to a deep spiritual searching and hunger. Alice is still in the midst of conflict with her family but dignity therapy intervention allowed her to take a step in seeing herself in a new way, and possibly as more than the negative image that she carried with her. She began to recognize the positive relationships in her life now and was moving toward a seeing that God was working in her life.

Betty had a long commitment to the traditional church. Her children have carried that on. She talks less of faith than doctrine or church involvement. Her father was clearly committed and fascinated with theology and passed along some interest. She stayed actively involved in congregations throughout her life as did her children. As her health continues to decline, she may enter a new phase of reflection.

David was very clear about his experience of God. "I have let Him lead me. I can safely say He is my guiding light." His sadness in feeling he cannot share his faith with his children in a manner that they will hear was painful.

Cathy had the most developed thoughts. She was also the one with the most serious medical condition. I'm still amazed at Cathy's ability to be thankful in the midst of her nightmare:

I feel His hands guiding me a lot even in this disastrous time. . . if there's anything to be thankful for in a stroke, and I can't think of many things, the one thing that I am very grateful for is that it happened on my left side and I'm right-handed. It could have been really disastrous for me because I don't do anything with my left hand. I'm not ambidextrous. He was merciful to me.

Cathy was truly able to see the grace and mercy and live it every day. She was a blessing to everyone. That is not to say she was not suffering greatly, she was, but she was feeling God's strength. She would spend much of a day in tears, trying to figure out what it all means. Why the stroke? What was her purpose now? What did God want from her? What was left for her to do in the condition she was in? How could she get by without her husband by her side? The questions were difficult. She was deeply faithful and devout. She just had a really messed up body. The pain was getting worse and the medication was not extremely effective. She was very tired of living as she did.

Cathy was beginning to accept that she was dying and she is going to have to help her family understand that. She knew God had been with her in the past, she had to trust God was with her in the midst of the nightmare in which she is now living. Cathy and her husband moved to be near their son immediately after this study. She passed away four weeks later.

Conclusions

Dignity therapy was a new approach to my community. For the residents, it was an opportunity to search and explore family jewels, the stories that had been buried in the recesses of their minds for decades but had shaped their experiences over the last 60 or 70 years. Used as a pastoral care approach, it was like pulling out that old dusty bag of jewels, not necessarily even remembering what was in the bag, but pulling them out slowly and exploring them, one at a time. With each new story told, one of the old gems is cleaned, polished and made new. Some of the jewels are sad stories, some happy, some rather tragic. Some are very beautiful and bright, others kind of dull. Some have a rather scandalous history that might better be left untold or at least selectively told. But each jewel, as it is explored, is washed, put in a fresh bag and given a new future. The opportunity to explore the family jewels, and preserve them for both the older adults and their families is cathartic for some, deeply meaningful and spiritual for others and maybe kind of strange for another. In this small study, each of the participants found great value in the process.

None followed the interview protocol exactly as designed by Chochinov. That was one of the benefits of a flexible protocol. I saw some significant changes from a couple of study participants. Cathy made some dramatic changes during the early period of the study. At the beginning of the study, she was never seen out of her room unless it was for medical care. Almost immediately after the interview, she began asking to go to activities, worship, hymn sings and other events as she was able. That was a dramatic change. She tired easily, and could

not stay out for long, but it was a surprising and very significant change. She also appeared more animated and engaged. When asked how she experienced the DT process, she talked about how important this was. She gave the legacy document to her son as soon as possible. He greatly appreciated the document and felt it reflected her well and will treasure it. Little did we know when we began the process how little time we would have with Cathy. It makes one realize how powerful this process can be.

Alice was more active and engaged as well after her meeting. She also agreed to see a psychiatrist. We had been trying to make that happen for many months and this was the first time she had actually agreed. That has yet to be followed through, but I am still hoping we can make it happen. She is seeing a new physician and seems to be taking her medication. This is also a welcome change. She has since had multiple hospitalizations for other medical issues, so there is still work to be done. When asked about her experience, she had a difficult time putting it into words. Primarily for her, being heard means a great deal. Hopefully, this was an important first step.

Betty continues to do well and takes advantage of every opportunity she can. She attends every activity and event and participates as much as any resident on the unit. She is living life as fully as she is able. She understands too well how quickly you can lose everything you that matter to you.

David struggles with his wife's declining condition and his own increasingly poor health. His interest in history is in many ways his escape, so he is always eager to tell his stories and, in that way, appreciated participating in the study. He found the process painful in that it was a reminder of where he feels he has failed his children. He was hopeful, but not optimistic that his

children would find a legacy document meaningful. With that thought in mind, he took my draft of the legacy document, formalized it and expanded it significantly turning it into a wonderful, and extraordinarily well-written family history. He ended up feeling quite proud of his final project. I copied it onto quality paper and returned it in folders for he and his children.

All of my residents felt some benefits from the dignity therapy as a pastoral care intervention. All expressed enjoying the process. The family members who I had any response from, had all appreciated receiving the legacy document.

Most of Chochinov's research was done with a palliative care community, I intentionally did not want to use that population, looking for a different client base. This change may have been beneficial to the study. If anything, this may have been helpful in showing the wider applicability of the protocol. Chochinov's protocol was a thorough guideline. Admittedly, I was never able to use more than three or four of his questions, occasionally less. All of my residents had no difficulty taking control of the conversation.

It seems there could be a place for combining some of the tools of dignity therapy with a spiritual inventory or spiritual assessment. In my practice, it is not always easy to have deep conversations about a person's spiritual life and I appreciate what tools I can find that encourage those conversations. Dignity therapy can help open doors to meaningful discussions.

What I found and greatly appreciated was that, as the chaplain, the dignity therapy protocol resulted in the rapid development of trust between these older adults and myself. I had known all of these individuals for many months, if not years, and yet there was much that they shared that I had not heard before. They each also spoke of issues and topics, especially of

spiritually that I know they could or would not have discussed, had they not first spent the time telling their stories and feeling heard. That was the benefit of the DT.

My hope going into the project was to find a way to better the quality of life for those who were feeling a sense of hopelessness, despair, and loss of meaning. I believed sharing their stories, hopes, and wisdom during the DT, the residents could positively affect their sense of meaning or purpose, and how they were able to reflect on their spiritual lives and relationships with God. I am confident, for those who were involved, that goal was met, at least to some degree. I hope to improve the process in the future. While these results are mere observational correlations, I can hope that dignity therapy as a pastoral care approach contributed to their well-being.

Chapter 5: Next Steps

Dignity therapy is still a relatively new modality, especially in the United States. Developed in Canada, it may be more recognized in long-term-care communities up north. While there are a significant amount of available studies, it is an unrecognized term for the average physician or administrator.

I have found the name “dignity therapy” unfortunate. All of our corporate literature states that we treat our residents “with dignity and respect.” Why should we have to provide an intervention for something as basic as human dignity? I found throughout my study; I did not use the term dignity therapy. It was in the literature I gave the residents, but I did not actually use the term because of my discomfort with it. I talked about preserving your thoughts and memories for your family.

Pastors and Chaplains can play a role in helping to bridge the communication gaps between patients/parishioners and families. Those bridges can be formal or informal. The legacy document was designed as a formal keepsake. It took a significant amount of time to produce. More frequently, the bridges are much less formal. It may be taking the son out into the hallway for a couple of minutes to check if he understood his mom’s comments the same way that you understood them or asking if he had talked to her about her wishes to go on Hospice Care.

In each of the interviews, there were times where the resident/older adult realized that what he/she was sharing was something he/she had never told his/her child. Generally, it was not something that had been intentionally withheld, except in one case where the child was being protected from painful information. Usually, they were surprised at their own realization that

they had not broached the subject before. If clergy fail to offer parishioners opportunities to explore family jewels, it is possible no one else will. There is a fair chance that they may stay buried forever and soon be forgotten.

The question with which I began was how would this community within which I have worked for eleven years, experience the unfamiliar pastoral care approach called “dignity therapy” when presented by the chaplain. More specifically, how would residents who were experiencing hopelessness, loss of meaning and despair experience dignity therapy?

One of the questions I have not really addressed is the “pastoral care approach” aspect. I was not simply there as someone asking about their life story. I was there as the chaplain with whom they had a long history. I had known all of these residents for at least a year, and most of them had worshiped with me for the time they had resided on campus.

Medicine has long recognized the importance of spirituality in healthcare. Spirituality helps people find hope in the midst of pain and despair and helps them survive nearly impossible situations. My interview with Cathy was an amazing example of the power of faith in the midst of tragedy.

When I presented the dignity therapy, I was presenting it as a spiritual care provider. I was the chaplain to them. One was Roman Catholic, one Lutheran, one Presbyterian, and one unchurched, but to all of them, I was the chaplain who they knew well. All of them could talk about God with me. They could talk about pain and loss, fear and doubt, anger and rage, love and hope, joy and peace. And all of it was ok. They could cry. And that was ok too. Three out of four of them did cry.

Dignity therapy interventions are not something to be administered by a volunteer. The protocol reads as if it could be. Hand out the questionnaire and turn on the tape recorder. It sounds easy. That does not do justice to either the approach nor more importantly, to the participant. DT was designed initially for medical personnel or volunteers and recommended as useful for chaplains. I would suggest, it is might be most useful for chaplains. DT, done well can open the door to further conversations about spirituality because it does help foster a deep level of trust between the DT provider and the participant. People's stories are precious, like jewels and should be treated as such. They should be treasured and more importantly, they should be *handled with care*.

Dignity therapy should not be an end in and of itself, but rather a beginning. DT helps to open doors, to bring out the jewels that can then be examined, admired, polished, shared, treasured, sold, and possibly discarded. DT can be a wonderful pastoral care approach, well used, to help a pastor or a chaplain guide someone in exploring the treasures of their past, and in appreciating, celebrating and redeeming the wonderful gifts for which God has blessed them.

BIBLIOGRAPHY

- Administration for Community Living*. "Publications and Fact Sheets: Challenges of Global Aging" Last modified 5/30/18 <https://www.acl.gov/news-and-events/fact-sheets/publications-and-fact-sheets#AoAfs>.
- Atchley, Robert C. "Becoming a Spiritual Elder," in *Aging, Spirituality, and Religion: A Handbook*. Vol 2. eds. Melvin A. Kimble and Susan H. McFadden. (Minneapolis: Augsburg Fortress, 2003), 33-46.
- Atchley, Robert C. "Continuity, Spiritual Growth, and Coping in Later Adulthood: Discovery Service for Lancaster Theological Seminary." *Journal of Religion, Spirituality & Aging* 18, no. 2/3 (2006): 19-29. Accessed April 30, 2018. <https://www.tandfonline.com/doi/pdf/10.1300/496v18n0202?needAccess=true>.
- Atchley, Robert C. "Spirituality, Meaning, and the Experience of Aging." *Generations* XXXII, no. 2 (2008): 12-16. Accessed May 23, 2018. <http://web.b.ebscohost.com/host/command/detail?vid=55&sid=8354c71a-b79a-4354-b0e5a824619148%40sessionmgr4006&bdata=JkF1dGhUeXBIPXNzbyZzaXRIPWVob3N0LWxpdmU%3d#AN=34921307&db=rlh>.
- Bredle, Jason M., John M. Salsman, Scott M. Debb, Benjamin J. Arnold, and David Cella. "Spiritual Well-Being as a Component of Health-Related Quality of Life: The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp)." *Religions* 2011, no. 2 (2011): 77-94. Accessed August 10, 2018. <https://doi.org/10.2290/rel1010077>.
- Brown, Linda. "Making the Case for Case Study Research." *Chaplaincy Today* 26, no. 2 (July 2010): 2-15. Accessed August 17, 2018. <https://doi.org/10.1080/10999183.2010.10767407>.
- Chenfeld, Mimi Brodsky. "Finding Meaning in Engagement: 'I May Be Old, But I'm Fun!'" *Generations* 32, no. 2 (2008): 70-71 Accessed April 21, 2018. <http://web.b.ebscohost.com/ehost/detail/detail?vid=10&sid=8354c71a-b79a-4354-b0e5824619148%40sessionmgr4006&bdata=kF1dGhUeXBIPXNzbyZzaXRIPWVob3N0LWxpdmU%3d#AN=34921306&db=rlh>.
- Bruyneel, Sabrina, Alfons Marcoen, and Bart Soenens. "Gerotranscendence: Components and Spiritual Roots in the Second Half of Life" *Katholieke Universiteit*. Leuven, Belgium Accessed May 7, 2018. <https://lirias.kuleuven.be/bitstream/123456789/122696/1/0564.pdf>.

- Chenfeld, Mimi Brodsky. "Finding Meaning in Engagement: 'I May Be Old, But I'm Fun!'" *Generations* 32, no. 2 (2008): 70-71 Accessed April 21, 2018. [http://web.b.ebscohost.com/ehost/detail/detail? vid=10&sid=8354c71a-b79a-4354-b0e5824619148%40sessionmgr4006&bdata=kF1dGhUeXBIPXNzbyZzaXRIPWVob3N0LWxpdmU%3d#AN=34921306&db=rlh](http://web.b.ebscohost.com/ehost/detail/detail?vid=10&sid=8354c71a-b79a-4354-b0e5824619148%40sessionmgr4006&bdata=kF1dGhUeXBIPXNzbyZzaXRIPWVob3N0LWxpdmU%3d#AN=34921306&db=rlh).
- Chochinov, Harvey Max. *Dignity Therapy: Final Words for Final Days*. New York: Oxford University Press, 2012.
- Chochinov, Harvey Max, and Beverley J. Cann. "Interventions to Enhance the Spiritual Aspects of Dying." *Journal of Palliative Medicine* 8, no. supplement 1 (December 2005): s-103-s-115. <https://doi.org/10.1089/jpm.2005.8.s-103>.
- Chochinov, Harvey Max, Thomas Hassard, Susan McClement, Thomas Hack, Linda J. Kristjanson, Mike Harlos, Shane Sinclair, and Alison Murray. "The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care." *Journal of Pain and Symptom Management* 36, no. 6 (December 1, 2008): 559-71. Accessed August 10, 2018. <https://doi.org/10.1016/j.jpainsymman.2007.12.018>.
- Chochinov, Harvey Max, Thomas Hack, Thomas Hassard, Linda J. Kristjanson, Susan McClement, and Mike Harlos. "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life." *Journal of Clinical Oncology* 23, no. 24 (August 20, 2005): 5520-5525. Accessed August 10, 2018. <https://doi.org/10.1200/JCO.2005.08.391>.
- Chochinov, Harvey Max, Linda J Kristjanson, William Breitbart, Susan McClement, Thomas F Hack, Tom Hassard, and Mike Harlos. "The Effect of Dignity Therapy on Distress and End of Life Experience in Terminally Ill Patients: A Randomised Controlled Trial." *The Lancet Oncology* 12, no. 8 (August 2011): 753-62. Accessed August 31, 2018. [https://doi.org/10.1016/S1470-2045\(11\)70153-X](https://doi.org/10.1016/S1470-2045(11)70153-X).
- Coleman, Peter G. *Belief and Aging*. Bristol, UK: The Policy Press, 2011.
- Creswell, John W, and Creswell, J. David. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Fifth Edition. Los Angeles: Sage, 2018.
- Crossley, Ronald. "Aging with God: Old Age and New Theology." *Church and Society*. Jan/Feb (1999) 9-16. Accessed May 23, 2018. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=a6h&AN=ATLA0000984434&site=eds-live&custid=s9005776>.

- Damen, Annelieke, Allison Delaney & George Fitchett (2018) Research Priorities for Healthcare Chaplaincy: Views of U.S. Chaplains, *Journal of Health Care Chaplaincy*, 24:2, 57-66, Accessed August 21, 2018. DOI: 10.1080/08854726.2017.1399597.
- Davis, James. "A Practical Theology of Aging: Biblical Perspectives for Individuals and the Church." *Christian Education Journal*. 5 no. 2 (Fall 2008) 274-293. Accessed May 23, 2018. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=rh&AN=ATLA0001684885&site=eds-live&custid=s9005776>.
- Di Lorenzo, Rosaria, Paola Ferri, Carlotta Biffarella, Giulio Cabri, Eleonora Carretti, Gabriella Pollutri, Cinzia Del Giovane, and Harvey Chochinov. "Psychometric Properties of the Patient Dignity Inventory in an Acute Psychiatric Ward: An Extension Study of the Preliminary Validation." *Neuropsychiatric Disease and Treatment* 14 (2018): 903-13. Accessed August 10, 2018. doi: 10.2147/NDT.S153902.
- Ellor, James. "Finding Meaning in Perceived Meaninglessness" in *The Essential Spirit: Providing Wholistic Services to and with Older Adults*, ed. Donald R. Koepke (Eugene Oregon: Pickwick Publishers, 2016), 26-41.
- Erikson, E. H. *Childhood and Society*. 2nd ed. New York: Norton.1963.
- Erikson, E. H. and Joan M Erikson. *The Life Cycle Completed: Extended Version with New Chapter on the Ninth Stage of Development*. New York: Norton. 1997.
- Fitchett, George. "Making Our Case(S)." *Journal of Health Care Chaplaincy* 17, no. 1-2 (April 25, 2011): 3-18. Accessed August 21, 2018. <https://doi.org/10.1080/08854726.2011.559829>.
- Fitchett, George, Linda Emanuel, George Handzo, Lara Boyken, and Diana J. Wilkie. "Care of the Human Spirit and the Role of Dignity Therapy: A Systematic Review of Dignity Therapy Research." *BMC Palliative Care* 14, no. 8 (2015). <https://doi.org/10.1186/s12904-015-0007-1>.
- "Monthly Article April 2015." ACPE Research, April 2015. Accessed August 31, 2018. <http://www.acperesearch.net/apr15.html>.
- Fowler, James W. *Becoming Adult, Becoming Christian: Adult Development and Christian Faith*. New York: Harper and Row. 1984.

- *Stages of Faith: The Psychology of Human Development and the Quest for Meaning*. Revised ed. edition. San Francisco: HarperOne. 1995.
- Frankl, Viktor E. *The Unheard Cry for Meaning: Psychotherapy and Humanism*. New York: Simon & Schuster, Inc., 1978.
- *The Will to Meaning: Foundations and Applications of Logotherapy*. Expanded Edition. New York: Plume.1988.
- *Man's Search for Meaning*. Boston: Beacon Press. 2006.
- *The Feeling of Meaninglessness. A Challenge to Psychotherapy and Philosophy*. Milwaukee: Marquette University Press. 2010.
- Grewe, Fred. "The Soul's Legacy: A Program Designed to Help Prepare Senior Adults Cope With End-of-Life Existential Distress." *Journal of Health Care Chaplaincy* 23, no. 1 (January 2, 2017): 1–14. Accessed April 20, 2018. <https://doi.org/10.1080/08854726.2016.1194063>.
- Groenewald, Thomas. "A Phenomenological Research Design Illustrated." *International Journal of Qualitative Methods* 3, no. 1 (March 2004): 42–55. Accessed March 2, 2019. <https://doi.org/10.1177/160940690400300104>.
- Haber, David. "Life Review: Implementation, Theory, Research, and Therapy." *The International Journal of Aging and Human Development* 63, no. 2 (September 2006): 153–71. Accessed May 28, 2018. <https://doi.org/10.2190/DA9G-RHK5-N9JP-T6CC>.
- Hall, Sue, Polly Edmonds, Richard Harding, Harvey Chochinov, and Irene J Higginson. "Assessing the Feasibility, Acceptability and Potential Effectiveness of Dignity Therapy for People with Advanced Cancer Referred to a Hospital-Based Palliative Care Team: Study Protocol." *BMC Palliative Care* 8, no. 1 (December 2009). Accessed August 10 2018. <https://doi.org/10.1186/1472-684X-8-5>.
- Hauge, Solveig. "An Analysis and Critique of the Theory of Gerotranscendence." Text. Monograph. Notat / Høgskolen i Vestfold ; 1998:3. August 19, 1998. Accessed April 22, 2018. <http://www-bib.hive.no/tekster/hveskrift/notat/1998-/#5.0%20CRITIQUE%20OF%20THE%20THEORY>.
- "Health, United States Trend Tables." CDC, 2016. Accessed August 20, 2018. http://www.cdc.gov/nchs/hsr/content2016.htm#001_

- Julião, Miguel, António Barbosa, Fátima Oliveira, Baltazar Nunes, and António Vaz Carneiro. "Efficacy of Dignity Therapy for Depression and Anxiety in Terminally Ill Patients: Early Results of a Randomized Controlled Trial." *Palliative and Supportive Care* 11, no. 06 (December 2013): 481–89. <https://doi.org/10.1017/S1478951512000892>.
- Kenyon, Gary M. "Telling and Listening to Stories: Creating a Wisdom Environment for Older People." *Generations* 27, no. 3 (2003): 30–33. Accessed June 17, 2018. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=rlh&AN=11702744&site=eds-live&custid=s9005776>.
- King, David B., and Teresa L. DeCicco. "A Viable Model and Self-Report Measure of Spiritual Intelligence." *International Journal of Transpersonal Studies* 28 (2009): 68–85. Accessed May 12, 2018. www.transpersonalstudies.org.
- Koenig, Harold G. *Spirituality and Health Research: Methods, Measurements, Statistics, and Resources*. West Conshohocken: Templeton Press. 2011. Accessed March 3, 2019. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=nlebk&AN=430190&site=eds-live&custid=9005776>.
- Krause, Neal. "Stressors Arising in Highly Valued Roles, Meaning in Life, and the Physical Health Status of Older Adults." *Journal of Gerontology* 59b no. 5 (2004) s287–s297. Accessed April 19, 2018. <http://academic.oup.com/psychsocgerontology/article-abstract/59/5/s589/669163>.
- Lindqvist, Olav, Guinevere Threlkeld, Annette F. Street, and Carol Tishelman. "Reflections on Using Biographical Approaches in End-of-Life Care: Dignity Therapy as Example." *Qualitative Health Research* 25, no. 1 (January 2015): 40–50. Accessed Sept. 1, 2018. <https://doi.org/10.1177/1049732314549476>.
- Man-Ging, Carlos Ignacio, Jülyet Öven Uslucan, Martin Fegg, Eckhard Frick, and Arndt Büssing. "Reporting Spiritual Needs of Older Adults Living in Bavarian Residential and Nursing Homes." *Mental Health, Religion & Culture* 18 no. 10 (2015): 809–821. <http://doi.org/10.1080/13674676.2015.1100159>.
- Martínez, Marina, María Arantzamendi, Alazne Belar, José Miguel Carrasco, Ana Carvajal, María Rullán, and Carlos Centeno. "'Dignity Therapy', a Promising Intervention in Palliative Care: A Comprehensive Systematic Literature Review." *Palliative Medicine* 31, no. 6 (June 2017): 492–509. Accessed August 31, 2018. <https://doi.org/10.1177/0269216316665562>.
- Myers, Gary E., and Rabbi Stephen Roberts, eds. "Handbook: An Invitation to Chaplaincy Research: Entering the Process." John Templeton Foundation, 2014.

www.healthcarechaplaincy.org/docs/publications/templeton_research/hcc_research_handbook_final.pdf.

McFadden, Susan and Rabbi Cary Kozberg, eds. "Religious and Spiritual Supports for Late-Life Meaning." *Generations* 32 no. 2 (2008) 6-11. Accessed April 21, 2018.
<https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=rlh&AN=34921310&site=eds-live&custid=s9005776>.

MacKinlay, Elizabeth. "The Spiritual Dimension of Caring: Applying a model for Spiritual Tasks of Aging." In *Aging, Spirituality and Pastoral Care: A Multi-National Perspective*, eds Elizabeth MacKinlay, James W. Ellor, and Stephen Pickard. 151-166. Binghamton, NY: Hayward Press. 2001.

----- "Mental Health and Spirituality in Later Life: Pastoral Approaches." In *Mental Health and Spirituality in Later Life*. ed. Elizabeth MacKinlay. 129-147. Binghamton, New York: Hayward Press. 2002.

----- "Spiritual Care: Recognizing Spiritual Needs of Older Adults." *Journal of Religion, Spirituality & Aging* 18 no. 2/3 (2006) 59-71. Accessed May 10, 2018.
http://doi:10.1300/j496v18n02_05.

----- *The Spiritual Dimension of Ageing, Second Edition*. Philadelphia: Jessica Kingsley, 2017. MacKinley, Elizabeth and Colin Dundon. "An Exploration of Health and Religion in Elderly People Through the Lens of Scriptural Reminiscence." *Journal of Religion, Spirituality & Aging* 24, no. 1-2 (2012): 42-54. Accessed June 28, 2018.
<https://doi.org/10.1080/15528030.2012.632714>.

Mills, Terry L. "Listening from the Sidelines: The Telling and Retelling of Stories by Centenarians." *Generations* 27, no. 3 (2003): 16-20. Accessed June 28, 2018.
<https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=ssf&AN=510300790&site=eds-live&custid=s9005776>.

Moberg, David O. "The Reality and Centrality of Spirituality." In *Aging and Spirituality: Spiritual Dimensions of Aging Theory, Research, Practice, and Policy*, edited by David O. Moberg, 3-20. Binghamton, New York: The Haworth Press, Inc., 2001.

Naylor, Thomas H., William H. Willimon and Magdalena R Naylor. *The Search for Meaning*. Nashville: Abingdon Press.1994.

Nelson-Becker, Holly. *Spirituality, Religion, and Aging: Illuminations for Therapeutic Practice*. Los Angeles: Sage, 2018.

- Pargament, K. I., Van Haitsma, K. S., & Ensing, D. S. "Religion and coping." In *Aging, Spirituality, and Religion: A Handbook*, edited by M. A. Kimble, S. H. McFadden, J. W. Ellor, & J. J. Seeber, 47–67. Minneapolis: Fortress. 1995.
- Puchalski, Christina. "Spirituality and End-of-Life Care: A Time for Listening and Caring." *Journal of Palliative Medicine* 5, no. 2 (2002): 289–94.
- "The Role of Spirituality in Health Care." *Baylor University Medical Center Proceedings* 14, no. 4 (October 2001): 352–57. <https://doi.org/10.1080/08998280.2001.11927788>.
- Puchalski, Christina, Betty Ferrell, Rose Virani, Shirley Otis-Green, Pamela Baird, Janet Bull, Harvey Chochinov, et al. "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference." *Journal of Palliative Medicine* 12, no. 10 (October 2009): 885–904. Accessed August 8, 2018. <https://doi.org/10.1089/jpm.2009.0142>.
- Park, Crystal L. "The Meaning Making Model: A Framework for Understanding Meaning, Spirituality, and Stress-Related Growth in Health Psychology." *European Health Psychologist* 15, no. 2 (2013): 40–47. Accessed Jul 14, 2018. www.ehps.net/ehp/index.php/contents/article/viewfile/ehp.v15.i2.p40/1041.
- Rahner, Karl. *Faith in a Wintry Season: Conversations and Interviews with Karl Rahner in the Last Years of his Life*. Edited by Paul Imhof and Hubert Biallowons. Trans & ed. Harvey D. Egan. New York: Crossroads. 1990.
- Rosenberg, Shapir. "Dignity Therapy." *The American Journal of Psychiatry Residents' Journal*, August 2018, 6–7. <https://doi.org/10.1176/appi.ajp-rj.2018.130803>.
- Scheib, Karen D. *Challenging Invisibility: Practices of Care with Older Women*. St. Louis: Chalice 2004.
- Seebeck, John "Gerontology expert to older adult conference, get ready for the coming tsunami of aging" Accessed June 14, 2018. <https://www.presbyterianmission.org/story/gerontology-expert-to-older-adult-conference-get-ready-for-the-coming-tsunami-of-aging>.
- Simpson, William C. Jr. "Can We Speak of a Theology of Ageing?" *The Living Pulpit*. "Jan-Mar (2001) 22-23. Accessed May 23, 2018. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=a6h&AN=ATLA0001386100&site=eds-live&custid=s9005776>.

Tobin, Sheldon S. *Personhood in Advanced Old Age.: Implications for Practice*. New York: Springer Publishing Company. 1991.

Thorsen, Kirsten. "The paradoxes of gerotranscendence: The theory of gerotranscendence in a cultural gerontological and post-modernist perspective." *Norwegian Journal of Epidemiology*. 8 no. 2 (1998) 165-176. Accessed May 12, 2018. https://scholar.google.com/scholar?start=20&q=lars+tornstam+gerotranscendence&hl=en&as_sdt=0,10.

Tornstam, Lars. *Gerotranscendence: A Developmental Theory of Positive Aging*. 1 edition. Springer Publishing Company. 2005.

----- "Maturing into Gerotranscendence." *The Journal of Transpersonal Psychology* 43 no. 2 (2011). 166-180. Accessed April 22, 2018. [https://thewisdomfactory.net/wp-content/Readings-for-show/Transcendence %20ageing.pdf](https://thewisdomfactory.net/wp-content/Readings-for-show/Transcendence%20ageing.pdf).

----- "Transcendence in Later Life." *Generations*, 23 no. 4 (1999) 10-14. Accessed April 22, 2018. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=ssf&AN=511144165&site=eds-live&custid=s9005776>

VandeCreek, Larry, Hilary Bender, and Merle R. Jordan. *Research in Pastoral Care and Counseling: Quantitative and Qualitative Approaches*. Eugene, Oregon: Wipf and Stock Publishers, 1994.

Vieira, Emanuel Meireles, Jacqueline de Oliveira Moreira, and Rosana Figueiredo Vieira. "Old Age, Finitude and Meaning: Reflections on the Care of Older Adults Based on Logotherapy." *Pastoral Psychology* 66, no. 1 (February 2017): 117-28. Accessed May 27, 2018. <https://doi.org/10.1007/s11089-016-0700-x>.

Wolf, Mary Alive. "ERIC - Tapping the World of the Older Adult., 1984-Nov-8." Louisville, KY, 1984. Accessed June 28, 2018. <https://eric.ed.gov/?id=ED249366>.

Yount, William R. "Transcendence and Aging: The Secular Insights of Erikson and Maslow." *Journal of Religion, Spirituality & Aging* 21 no. 1/2 (2008). Accessed April 22, 2018. <http://www.tandfonline.com/doi/abs/10.1080/15528030802265361>.

Zeilig, Hannah. "The Critical Use of Narrative and Literature in Gerontology." *International Journal of Ageing and Later Life* 6, no. 2 (March 8, 2012): 7-37. Accessed June 28, 2018. <https://doi.org/10.3384/ijal.1652-8670.11627>.

APPENDIX I

The Dignity Therapy Protocol¹¹⁴

Step 1: Determine which residents might benefit from Dignity Therapy and who meet the criteria.

I have the benefit of working in a continuing care retirement community affording me access and relationships with a significant number of older adults. The selection will not be random. I will choose those who have already a medically recorded diagnosis of depression and/or anxiety. If possible, I would like to see those who have exhibited issues of loss of meaning, hopelessness, despair or any form of existential distress. I will focus on the oldest or frailest residents for whom death is a very real companion. They will not be actively dying, but aware that it is not too far off.

Chochinov notes though, that while physical distress tends to be quite obvious to the observer, suffering and existential torment can be far less noticeable.¹¹⁵ Someone whose physical symptoms are well controlled may be suffering and in deep despair for other reasons. One cannot know until one asks. Dignity Therapy can provide comfort and enhance meaning and purpose for those who express severe distress as well as for those who have not.

The resident must be able to share their memories, thoughts, and reflection, be interested in trying this therapy and be expected to live for more than a couple of weeks. "It is safe to

¹¹⁴ Chochinov, Harvey Max. *Dignity Therapy: Final Words for Final Days*. New York: Oxford University Press, 2012.

¹¹⁵ Chochinov, *Dignity Therapy: Final Words for Final Days*, 55.

assume that *every* [resident] has a story to tell, insights to share, memories or wishes they might want to pass along by means of Dignity Therapy – the best way to affirm this is simply by asking.”¹¹⁶

The residents must also be willing and cognitively intact such that they can engage on this level. Given my long tenure with the institution (ten years), most of the residents, although possibly not all, will be familiar with me before the interview. In previous interviews done for class projects, this has been an advantage, providing the residents with a sense of comfort and familiarity.

I will interview 3-5 residents who are willing and cognitively able to engage in the process. Most of my interviews will be with Christians. There are a small number of residents from other faith groups, but at best, I might get a couple of these interviews. The community has a covenant relationship with the PC(USA), so we tend to attract residents who have or have had church affiliations.

Step 2: Once eligibility has been determined, Dignity therapy can be formally introduced to the resident and family (if appropriate).

Dignity Therapy is a “well-researched intervention that can enhance end-of-life experience for people dealing with life-limiting medical conditions.”¹¹⁷ The concept will be new to those I approach, and it will have to be thoroughly explained. I will inform them that for many

¹¹⁶ Chochinov, 56.

¹¹⁷ Chochinov, 61.

people, the process has improved their ability to cope, how they feel about themselves and their circumstances, and also improved their overall quality of life. It only takes one or two meetings during which I will give them the opportunity to talk about things that are most important to them, things they want to share with those they are closest to and that they feel they need and want to say. I will guide them and encourage them through the process. I will explain that the conversations will be recorded, transcribed and edited. The final product is a written document which I will return to them. They will make sure it is correct, and choose whether or not to share it with others.

I will also explain that I am working on my major project and would like their permission to share what I learn without identifying them by name and if they agree, ask for their written permission.

*Step 3: Once Dignity Therapy has been introduced,
answer any question that they have.*

I will then ask if they have any questions and seek to answer them to the best of my ability. I will emphasize that they will be in control of what they include and can stop if they feel uncomfortable, that there is no right or wrong way to do this and that they need not worry about preparing, I will give them any help they may need.

*Step 4: After all the resident's question have been answered, offer him or her a
copy of the basic Dignity Therapy question protocol*

DIGNITY PSYCHOTHERAPY QUESTION PROTOCOL¹¹⁸

- ☐ Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
- ☐ Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- ☐ What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)? Why were they so important to you, and what do you think you accomplished in those roles?
- ☐ What are your most important accomplishments, and what do you feel most proud of?
- ☐ Who or what gives the greatest meaning or a sense of purpose in your life? (What matters most right now?)
- ☐ Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
- ☐ What are your hopes and dreams for your loved ones?
- ☐ What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, other[s])?
- ☐ How has your faith or your experience of God influenced your life?
- ☐ Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- ☐ In creating this permanent record, are there other things that you would like included?¹¹⁹

¹¹⁸ Chochinov, 54-73.

¹¹⁹ Chochinov, 71.

Step 5: Once the resident has agreed to take part, collect basic demographic, social and medical information.

This will help guide the content of the upcoming Dignity Therapy interview.

Acquiring the demographic information, including the names and ages of children and grandchildren, where they lived, and their past vocations prior to the interview is helpful for preparation. For my own preparation, I will also obtain any medical information I have available regarding the current condition that they have not shared.

Step 6: Arrange an appointment with the resident (with or without a friend, family member or loved one) to conduct the Dignity Therapy interview.

I will arrange a meeting time that will not interfere with scheduled meals, preferably when the resident is not likely to be sleeping. The goal is to do this as soon as possible after the introductory meeting. The meeting will take place in the resident's room/apartment unless for some reason that is not possible.

Step 7: Meet for the Dignity Therapy session.

The interviews themselves will follow the protocol given above, but also allow for flexibility. The residents can talk about whatever they feel is important. I will also respond and ask for further clarification if I believe it to be beneficial. Chochinov calls it “guided conversation.” Active listening is clearly the objective here. He writes: “the therapist needs to follow their leads, while at the same time providing a structure that enables them to easily follow sequences, provide elaboration or make logical connections. There should be a high degree of collaboration between the therapist and the patient to ensure that the patient feels engaged, encouraged and nurtured.”¹²⁰

Step 8: Transcribe the interviews and edit to ensure clarity.

Following the session, I will transcribe the interview; I will edit it to ensure clarity, correct time sequences and finding a suitable ending. Often the last words are not when the interview ended. Editing needs to take that into account.

Step 9: Return the document to the resident for review and corrections.

¹²⁰ Chochinov, 79.

I will then return the transcription to the resident to ensure that it appropriately conveys the speaker's intent. If corrections need to be made, they will be, so as provide the resident with the most meaningful document.

Step 10: Follow-up with the resident to receive any additional feedback.

In the weeks following the process, I will meet again with each resident to discuss their experience. This will be the focus of the research.

Appendix II

RE: Your Research Protocol entitled: "Questions of Meaning at the End of Life." (Human Subject Study Application [LTS UN-NUMBERED]) Approval Date: 10/30/18

First Renewal Date (please renew by): 10/30/19

Project HSS Application Expiry Date: 10/30/21

Dear Holly,

I am writing on behalf of the Franklin & Marshall College's Institutional Review Board to tell you your above-referenced research has been approved exempt under 45 CFR 46.101(b) (2) from requirements of 45 CFR 46 using the advisor letter from Dr. David Mellott delivered to me on Oct. 29. Because your application was mailed to the IRB office, a PDF of all documentation is attached for the record.

All protocols involving ongoing data collection or interaction with human participants must be renewed *annually* and are subject to a de novo review after **3 years**. Please contact the administrator (Kathy Hertzler) if you wish to renew after one year or amend your protocol. Please also ensure that you allow at least two weeks prior to the *expiry date* of your study to submit a new Human Subject Study Application if you wish to continue work on your research protocol after that date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation (use link above). Any adverse or unanticipated events should be reported to Marcus Thomsen, Associate Dean of the Faculty, as soon as possible.

Best wishes for the successful completion of your project.

Marcus Thomsen, Associate Dean of the Faculty and IRB Chair, and Kathy Hertzler,
Administrative Assistant for College Grants