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#### I. Abstract

**Purpose**: Spirituality and religion are primary aspects when faced with death. The purpose of this study is to explore the possible correlation between Lutheran Christian ministers and lay-leaders experience with caring for the dying and those who have facilitated end-of-life preparation in their own families and ministries.

**Methods**: 79 participants completed anonymous, online surveys regarding personal and professional experience with end-of-life issues. Participants were limited to Evangelical Lutheran Church of America Masters degree holding ministers and lay-leaders.

**Results**: The percentage of those surveyed who have completed an Advance Directive or have designated a Durable Power of Attorney outnumbered the national average more than two-to-one (62.5% vs. 29%). While 100% of participants have ministered to a dying congregant, 88% have been present with a family that was unsure of their dying loved one's end-of-life wishes, and only 37% have helped a congregant fill out an Advance Directive for themselves. The majority indicated they filled out an Advance Directive themselves because they did not want to burden their families. Exposure through their ministry, namely Clinical Pastoral Education, came in close second. Nearly all participants stated that their seminary did not properly equip them to help others complete Advance Directives.

**Conclusion**: The tendency to avoid talking about death is not necessarily because of a disinterest but rather lack of exposure or education. However, the elephant in the room remains nameless in many families, homes, congregations, and hospital rooms. Seminaries can take the initiative to fully prepare their students by proactively including end-of-life preparation in their curriculum; addressing the psychology of why we avoid the topic of death; how to best incorporate the topic into congregational ministry, and how to help both ourselves and others complete Advance Directives. Likewise, clergy and lay-leaders can take the initiative first by starting in their homes and discussing end-of-life planning with their families, then their congregants.

# II. Background: a history of Advance Directives

It was winter in Missouri, 1983. She did not see the black ice in the road ahead. Her car spun out of control. Her body was launched through the windshield. She landed face-first in a ditch. Paramedics found her unresponsive. Though resuscitated, her parents were told that she was in a "persistent vegetative state."<sup>1</sup> She was at the mercy of feeding tubes and medical machinery. "Is this what she would have wanted?" her parents asked. The darkness settled in when they realized her fate: they had never asked her of her end-of-life preferences. The responsibility, and the future, was left in their hands.

Though it was predicted that 25-year-old Nancy Cruzan might live for another 30years, her parents argued that she would not have wanted to exist in such a state and pleaded with the hospital to remove her from life sustaining machinery. When the hospital refused, Cruzan's parents appealed the case to the Missouri Supreme Court and to the United States Supreme Court. Supreme Court again denied her parent's appeal because there was no "clear and convincing evidence" that Cruzan's wishes applied to her circumstances. A new hint of evidence finally tilted the case, allowing Nancy to die seven years after she was first put on life-sustaining devices.<sup>2</sup>

The Supreme Court concluded the following when this groundbreaking case was closed on June 25, 1990:

- "A competent patient has a constitutional right to refuse medical treatment, including artificial nutrition and hydration;
- "A state may require that before support measures of an incompetent patient (for example, someone who is unconscious) may be removed, 'clear and convincing evidence' must be shown that this is what the patient would want if he/she were competent; and
- "One way individuals may protect their right to terminate treatment, if they are later unable to speak for themselves, is to sign a Living Will of Durable Power of Attorney" (i.e. Advance Directives).<sup>3</sup>

# Patient Self-Determination Act (PSDA)

Later that year, the Patient Self-Determination Act (PSDA) was passed by the United States Congress and put into effect on December 1, 1991. This new law put into practice the ruling of the Supreme Court from Cruzan v. Director, Misouri Department of Health case, stating that all health-care facilities that received federal funding (including institutions such as Saint Luke's Hospitals) must take the following steps with both staff and new admits:

- "Provide written information to each adult patient about an organization's policies concerning the exercise of decisional rights;
- "Document in the patient's medical record whether or not the patient has executed an advance directive;
- "Insure that the provision of services to a patient is not based on the existence or absence of an advance directive;
- Provide educational programming to staff and to the community regarding advance directives."<sup>4</sup> (Definitions of Advance Directives and other related terms follow in the next section).

At the time the PSDA was proposed and implemented, it was estimated that anywhere from 4-28% of Americans had completed an Advance Directive.<sup>5</sup> However, a decade after the PSDA was implemented, the percentage of Americans who had completed an Advance Directive had not increased.<sup>6</sup> In a 2011 study, it was estimated that the percentage of those who have completed Advance Directives had risen to 29%. This is still a low percentage considering that 56% of those surveyed stated that they knew people who had created a living will for themselves. The percentage of those who have filled out an Advance Directive is nearly double for those over the age of 65.<sup>7</sup>

Looking at the numbers, it is easy to conclude that the PSDA has not changed the popularity of Advance Directives. A study specifically addressing the ineffectiveness of the PSDA concluded that, though "PSDA requirements increased patient awareness of living wills, they failed to increase the number of patients who act on this awareness... simply informing patients about their right of self-determination is insufficient to meet the intended

goals of the legislation."<sup>8</sup> The assumption that hospital patients who are exposed to Advance Directives should be more inclined to fill them out is only true in theory, statistically speaking. A recent study attributes the lack of statistical participation to the complex legal and medical language of advance directive forms, in addition to state's legal limitations, such as requiring notary signature, etc.<sup>9</sup> Furthermore, it may be argued that medical technology has grown more rapidly than ethics of end-of-life care, especially since the PSDA's implementation in 1991.

The lack of popularity and execution of Advance Directive completion has resulted in a recent push of educating the public about their right to their own medical directives. The National Healthcare Decisions Day (NHDD) Initiative, for example, "is a collaborative effort of national, state and community organizations committed to ensuring that all adults with decision-making capacity in the United States have the information and opportunity to communicate and document their healthcare decisions."<sup>10</sup> In the initiatives' first year of existence, 5,300 advance directives were completed via the organization's website alone.

The NHDD is one of many initiatives aimed at clearing up misconceptions about Advance Directives while providing the general public easy access to related resources. One of the main goals of NHDD and its counterparts is to clarify the definitions of the resources available, namely the differences between Advance Directives, Living Wills, Do No Resuscitate/Intubate (DNR/DNI), Advance Directive Proxy, and Durable Power of Attorney (DPOA), just to name a few. In the interest of space and authenticity, I will use the definitions provided from a recently published medical journal:

**Advance Directive:** "An advance directive... refers to a written statement or document by a competent adult that is designed to provide medical personnel, family members, and others information as to the person's wishes regarding the nature and extent of medical care to be provided in the future should he or she lose decision-making capacity."<sup>11</sup> The most common types of Advance Directives include living wills, DNR/DNI orders, and DPOA assignments.

Instructional Advance Directive: "Tells caregivers, family members, and others what sort of specific medical treatments and interventions the patient does or does not want in particular circumstances."<sup>12</sup> This includes living wills and DNR/I orders.

**Proxy Advance Directive:** an advance directive "in which the patient authorizes a named person or persons to make medical treatment decisions in the event that the patient in unable to do so."<sup>13</sup>

**Living Will:** "An instructional written directive that indicates the author's wishes for medical treatment should he or she become incapacitated and unable to participate in medical decision-making."<sup>14</sup> A living will includes, in written form, as much or as little information a patient cares to provide regarding their medical care and end-of-life preferences. Some states require living wills to be notarized; others require at least two witnesses.

**Do Not Resuscitate/ Do Not Intubate (DNR/DNI) orders:** "Unlike other written advance directives that are prepared and executed by the patient, the DNR/[DNI]

order is typically entered by the physician on the patient's chart in the hospital after discussion with the patient (if competent) or the patient's legal representative (if the patient is incapable of making a decision)."<sup>15</sup> Some states honor out-of-hospital DNR/DNI orders.

**Durable Power of Attorney for Health Care (DPOA**): a type of Proxy Advance Directive which "identifies and designates a named person or persons to make decisions about the patient's care if and when the patient is incapable of doing so." The agent should "exercise 'substituted judgment,' that is, the agent will make decisions that are consistent with what the patient would have decided for himself or herself under the circumstances."

**Competence**: "a legal term... determined by a judge [who] determines whether or not one has basic cognitive and functional capacity to participate in decision-making."<sup>16</sup>

**Capacity**: "a medical term. Doctors determine the extent of which one is able to understand the information concerning a treatment decision and appreciate the reasonably foreseeable consequences of a decision or lack of a decision."<sup>17</sup>

Assigning a Durable Power of Attorney for Heath Care is even more important than completing a Living Will, as a DPOA can become a patient's "living word" when incapacitated since it is assumed that the patient and their respective DPOA have discussed the patient's end-of-life preferences. In his article on the legal implications of Advance Directives, Eugene Bastana notes, "For the durable power of attorney to function [properly], it is critical that the agent know and understand the patient's moral and religious values, attitudes regarding life, death, and medical care generally, as well as any specific preferences the patient has concerning particular treatment scenarios."<sup>18</sup> Though it is assumed that the patient articulates their preferences to their agent, a recent study found that as many as 19% of Americans have "discussed their wishes for end-of-life medical treatment with 'no one.'"<sup>19</sup>

Therefore, a patient's duty to their DPOA is not just in assigning an agent, but also informing their agent of their preferences. Recent initiatives have been made nation-wide to promote end-of-life conversations, decision-making, and advance planning. For example, The Center for Practical Bioethics, located in Kansas City, has published a workbook that addresses some of the most important topics in advance planning. The workbook includes questions about one's relationships, spiritual/religious values, end-of-life preferences (essentially a Healthcare Treatment Directive), and career, legal, and financial decisions. This "Caring Conversation" workbook (very similar to the popular "5 Wishes") is intended to be completed with a trusted friend, loved one, or DPOA in the hopes that it will clear up future unanswered questions, while also putting in writing the patient's wishes should there be confusion in the future when the patient can no longer speak for him or herself. The workbook also includes blank Advance Directive and DPOA assignment forms and answers to frequently asked questions.

#### Spirituality/Religiosity and the Role of the Church

Bastana noted that informing a DPOA of one's values is critical for the assignment to properly function, including the patient's moral and spiritual/religious values. Based on the definition of spirituality as the "human need for meaning, purpose, hope, forgiveness,"<sup>20</sup> and religion as an organized system of spiritual beliefs, topics of spirituality and religion will inevitably be included, either directly or indirectly, into any thorough caring conversation. Furthermore, a patient's spiritual or religious beliefs may dictate the course of action in times of illness or impending death. Though studies have shown that there have been no direct correlation between those who consider themselves spiritual/religious with those who have completed any kind of Advance Directive,<sup>21</sup> studies have shown that those who consider themselves spiritual measures to extend life<sup>22</sup> and less likely to support physician-assisted suicide.<sup>23</sup>

For those who consider themselves religious, it is presumed that the patient's church or other religious organization will be involved with their spirituality along their medical journey. But in a recent study of advanced cancer patients, 47% of participants stated that their religious community did not support or only minimally supported the patient's spiritual needs.<sup>24</sup> In the same study, 56% of the participants reported regularly attending church before their cancer diagnosis, though only 44% reported attending after their diagnosis. Inversely, 47% reported engaging in private religious or spiritual activities at home before their diagnosis; 61% reported doing so after their diagnosis.<sup>25</sup>

If a patient's religion is important in determining their end-of-life preferences, and if "churches are spiritually orientated and propose structures within which to understand and transit major life events, such as birth, marriage, illness, and death,"<sup>26</sup> shouldn't the statistics of those who incorporate their church into their end-of-life stages be higher? Furthermore, if churches are presumed to unite our physical lives with our spiritual lives, why did nearly half of the cancer patients surveyed report that their religious community hardly supported their spiritual needs?

This is not to say that churches do not address death from the pulpit. A 2006 survey that sampled 1,500 adults over the age of 18 discovered that clergy do in fact discuss death from the pulpit. However, the majority reported that these end-of-life issues focused mostly on abortion and the war in the Middle East. Only 33% of those surveyed reported that their clergy addressed end-of-life decisions from the pulpit (the majority being Catholics).<sup>27</sup>

In a 2001 study of the role of the church in improving end-of-life care, 121 clergy and congregants in Honolulu, Hawaii overwhelmingly stated that spiritual preparation must be made in order to prepare for a good death. The participants then articulated specific ways churches can assist in this task, including, but not limited to:

- help congregants both spiritually and practically prepare for death
- facilitate resolution of conflict and forgiveness
- clarify if or how church theology should guide attitudes and practices related to death and dying
- administer the appropriate rituals
- provide outreach to sick, dying, and bereaved members.<sup>28</sup>

Members even went so far to say that churches hoping to expand in membership should adapt these practices, an ironic statement considering that the practices relate to a literal decline of church membership due to death. The study concluded that "these findings suggest that faith communities can have a major impact on improving end-of-life care and that pastoral education [should] include attention to these issues."<sup>29</sup> In the previously mentioned study with advance cancer patients, the principle investigators concluded that "improving connections between the medical system and outside religious communities may facilitate incorporation of spiritual supporters into patient care. Some first steps toward this integration include inquiring about patients' spiritual supports and inviting their involvement in care. Direct communication between the medical team and spiritual supporters when desired by patients may also be beneficial at times."<sup>30</sup>

These studies raise the question: what is preventing clergy from incorporating end-oflife discussions into their ministry? If 40% of Medicare's annual budget is spent on caring for people in their last month of life,<sup>31</sup> for example, why do the last days of our lives not warrant equal attention within our churches? If churches have historically visited the sick and dying while they are in hospitals, what is preventing them from talking about what happens once we end up sick or in the hospital? Should we charge seminaries for not adequately training their clergy? Should we charge clergy for not taking the initiative themselves? Does exposure to the dying during hospital visits prompt clergy to complete their own advance directive? Previous studies have found that clergy have reported being either uncomfortable, too busy, or ill-prepared to discuss or even teach death and dying within their congregations.<sup>32</sup> What other factors are preventing our churches from taking this issue seriously?

# III. The Study

#### Purpose

Based on the questions just raised, I conducted an Institutional Review Boardapproved survey during a chaplaincy residency at Saint Luke's Hospital, Kansas City to try to shed light on trends in clergy attitudes toward Advance Directives. The primary purpose of the study was three-fold:

- to examine the percentage of ministers within the subgroup of the Evangelical Lutheran Church of America who have completed an advance directive, appointed their own durable power of attorney, and who have communicated their end-of-life wishes with their family and friends;
- to examine the possible correlation between those who have taken the above preventative measures and those who have ministered to those facing end-of-life decisions of their own;
- to examine whether or not seminaries have adequately prepared their future leaders to confidently help themselves and others within the scope of their respective ministries complete Advance Directives.

#### Objective

Through these findings, I hope to prove that seminaries in the ELCA tradition have not adequately equipped their ministers to properly advise others on the completion of Advance Directives and appointments of Durable Power of Attorneys.

#### Methods

In order to create a sound and thorough study, a minimum of fifty Masters Degree holding ministers within the Evangelical Lutheran Church of America were needed to participate in an online survey. The participants were recruited by means of synodical email distribution list invitations, namely within the Indiana-Kentucky Synod (22 participants) and the Central States (Kansas and Missouri) Synod (36 participants), in addition to Facebook invitations. Participants received no compensation or reward for their participation; those who chose to participate will receive a pdf copy of this final project via said synodical e-mail distribution. Survey data was anonymously collected via an online survey platform. Any Masters-Degree holding ELCA minister (Ordained, Diaconal Minister, Associate in Minister, etc) was welcomed to participate. Participants may be actively serving a congregation or organization, retired, out of commission, etc. Participants include both those who are actively seeking rostered ministry and those who are rostered by the ELCA.

#### Limitations

Certain factors should be regarded considering the breadth and scope of this study. Since e-mail was the means of communication to the participants, those without e-mail access could not participate. Further study on the topic of end-of-life decisions would do well to address the following which were not included in this study: life span differences between those who filled out Advance Directives compared to those who have not; ELCA clergy initiatives toward including end-of-life preparation in their ministry; trends between economic background and political affiliation of participants and their attitudes toward endof-life issues. Raising questions on the helpfulness of possibly incorporating end-of-life preparation into seminary curriculum would have been warranted based on the survey results.

#### Results

In May 2011, 79 surveys were completed electronically. All questions were optional. Participants were mostly between the ages of 39-65, with a nearly equal women-to-men ratio. All those who chose to identify their ethnicity elected "Caucasian" to best describe themselves, not surprising considering this historically European-derived denomination is 97% Caucasian itself.<sup>33</sup> 88% of those surveyed hold a Masters degree or PhD.

Since those who were surveyed have been, will be, or currently are pastors or layleaders, it is not surprising that the majority of participants indicated that they have taken part in some form of end-of-life ministry as part of their ministry. In fact, 100% of those surveyed reported to have cared for someone at the end of their life. 97% stated that they had visited a hospitalized parishioner, and 72% indicated that they have been physically present with a parishioner at the time of their death. Furthermore, 79% reported to have been present with a parishioner when they were making end-of-life decisions; inversely, 77% reported to have ministered to family members who were unsure of their loved one's end-of-life care preferences.

When asked to explain their responses, most participants attributed their answers to experience in chaplaincy, notably during Clinical Pastoral Education as part of their Masters' degree, in addition to hospital, nursing home, military, and Hospice chaplaincy.

Several participants reported that the role of being involved in end-of-life circumstances is humbling and an important part of their ministry: "As ministers, it is indeed an honor to be invited to be a part of helping families to make end-of life decisions, to be present with them (as God's representative) during and after the death. If is part of our call." Another participant noted: "Ministry to the dying and their families has been a key part of my work. I bring a calming presence so that decisions can be made for the best of everyone's interest."

Hospice seemed to play a role in exposure to the circumstances listed, both personally and professionally. One participant reported: "I have a current parishioner on Hospice care and was present for the family discussion of end of life care with the doctor at the hospital;" while another stated: "As a pastor and intimately involved with parish members, questions such as these were routine in conversation(s) and in planning for the future. I was involved when Hospice was explained. Hospice also helped our own family member."

Length of years in the ministry and age of congregation can also play a role in leaders involvement in end-of-life circumstances. One participant admitted that during CPE "I did all of those [listed] things, but being here at my call has not afforded me all of these opportunities as of yet. Thankfully, I am part of a healthy, vibrant, and younger congregation." Another noted that he had been a hospital chaplain for 2 years and a pastor for 39 years: "In this pastor experience I had opportunities to minister to families in all these situations. I would have to say that these were some of the most meaningful experiences I had in the ministry." Circumstances are also eye-opening: "I have been with a family deciding to remove life support. I am ministering with a family now awaiting a double lung transplant and who will die in the hospital if she does not receive it soon. Hospital and end-of-life ministry is an integral part of being a parish pastor."

Though 79% of participants indicated that they had been present with a parishioner while making end-of-life decisions, only 37% said "yes" when asked, "Has a parishioner ever given you a copy of their Advance Directive?" Even more interesting is when the participants indicated having been first exposed to the topic of Advance Directives; the majority (35%) indicated having first been exposed to Advance Directives during Clinical Pastoral Education: 31% attributed their exposure to family experience, and 20% to vocational experience. Other places of initial learning included high school/college, conferences, hospitals, and internships. Only 13% were first exposed during seminary.

A primary objective of this study was fulfilled and the principle investigator's hypothesis proven when participants responded to the question: "Did your seminary adequately prepare you to help yourself or another prepare his or her own Advance Directive?" 64% answered, "No." 15% answered, "Somewhat" and the rest who chose to respond to the question answered with a simple, "Yes." One participant put it bluntly: "I learned during seminary because it was a personal interest of mine. Not because it was a part of the curriculum."

Additionally, a correlation between those who have engaged in end-of-life preparation and those who have ministered to those facing end-of-life decisions of their own proved true among the participants. 63% answered that they had filled out a Living Will or another form of an Advance Directive. Thus, this focus group outnumbers the national average of those who have completed an Advance Directive (29%) by double.

However, the reasons participants engaged in end-of-life preparation of their own were not limited to exposure through their ministry. When asked to indicate all the reasons why they chose to complete their own living will, 74% of participants stated that they took action because they did "not want to burden" their families with making decisions on their behalf. In close second for completing a living will for oneself was exposure to end-of-life decision-making through ministry (67%), followed by death in the family (48%), and wanting autonomy and control in one's own life (39%). 6 people stated that they completed a Living Will because their lawyer suggested it, 3 because their doctor suggested it, and only 2 because a pastor suggested it. The majority of those who had completed a living will gave a copy to a family member (88%), in addition to their doctor (46%) and lawyer (38%). Only 3 participants stated that they had given a copy to their pastor.

In addition to the 63% who indicated that they had completed a Living Will, 62% of those responding stated that they had assigned themselves a Durable Power of Attorney for Health Care in the event that they would not be able to make medical decisions on their own. However, 77% stated that they had spoken with their family about their end-of-life preferences (with an additional 15% stating that they had only non-intentionally spoken with their family on the subject in passing).

On the other hand, those who had not completed a Living Will (37%) stated many reasons for not doing so, including "I am in good health" (14%), "I do not see a need for one," (11%), and "I fear that it will take my rights away from me," (4%). However, 54% of responses stated, "I've been thinking I might want to sign an Advance Directive but have yet to do it." Several people added, that they hadn't taken the time, they keep forgetting, or that they are "not ready" to complete an Advance Directive. Another noted; "Our family structure/size is such that my wife and son know my preferences." Fear and chance seemed to play a factor, as other comments include: "Fear of a lot of things," and "What if I change my mind?" Finally, misunderstandings of what a Living Will/Advance Directive can and can not do may have influenced not completing the forms: "It did NOT help family members -caused more stress at time of family member's death;" and "I know I should, and want to but haven't gotten around to it and don't own anything of value yet or have a family so why bother yet?"

Finally, when asked, "If you have not completed an Advance Directive or assigned yourself a Durable Power of Attorney, has this survey made you think of doing so?" 79% said, "Yes."

# IV. Discussion

The results of this survey were surprising, yet also expected. Though the ELCA minister's average more than doubled the national average of those who have filled out Advance Directives or have designated a DPOA, most attributed personal and professional exposure, not seminary, to their knowledge on the subject. The percentage of ministers who had completed an Advance Directive and designated themselves a DPOA (63% and 62%, respectively), not only outnumbered the national average, but also nearly tripled the results of a similar study of ministers conducted in 1998 (26% and 23%, respectively).<sup>34</sup>

Though many ministers have been with their congregants during their end-of-life decisions, only a handful of them have been given a copy of a congregant's Advance Directive or have given their own Advance Directive to another pastor. The majority of those who have completed an Advance Directive did so because they did not want to burden their family, not because their pastor suggested it. Finally, of those who had not yet completed an Advance Directive or assigned themselves a DPOA, an overwhelming 79% stated that taking a simple survey on the topic has made them think of doing so.

While the overwhelming majority of respondents indicated that they have been present with their congregants during the end of their lives, only 37% reported to have a copy of a congregant's Advance Directive. This discrepancy makes one wonder if pastor's are taking a pro-active effort to have end-of-life conversations with their parishioners and, furthermore, to help congregants with their own Advance Directives. In a similar study of over one hundred clergy and lay-leaders, discussing end-of-life wishes with a clergy in preparation for a "good death" was mentioned 49 times; discussing the same subject with one's physician in preparation for a "good death" was only mentioned once.<sup>35</sup>

What is preventing ministers from preaching about, talking about, and preparing for their own and their congregant's deaths? In his award-winning book, "The Denial of Death," author Ernest Becker concluded that one of our most basic drives in human behavior, as mirrored in how we act individually and culturally, is our psychological denial of death.<sup>36</sup> Even at a basic psychological level, we are not comfortable with death. No wonder it is not a hot-topic on the pulpit or in Sunday School.

A dissertation could be written on the correlation between the Christian's emphasis on salvation in the after-life but the lack of emphasis on what leads to the pivotal moments which lead us there. Even Martin Luther emphasized the importance of discussing and facing death first hand, stating: "taste death with the lips of your living body so that you can know emotionally that you are a creature who will die."<sup>37</sup> But Luther is also quoted for putting the responsibility into the individual's hand "Every man must do two things alone; he must do his own believing and his own dying."<sup>38</sup> If, to each his and her own in terms of preparing for death, and if a Christian's role is to care for the sick and the dying, as commissioned by Jesus, why are we allowing our psychosocial discomfort and our individualism to prevent us from this very important task of the ministry?

Perhaps one of the reasons why ministers are not prepared to tackle this large issue is the lack of training. In her book, "A Clergy Guide to End-of-Life Issues," Rev. Dr. Martha Jacobs makes the case for a more focused seminary curriculum: "In seminary, we learn how to do rituals that are required of us as clergy that cover the life-span of our congregants. We learn to deal with death by ensuring that people are 'saved' before they die. We learn to do funerals, and we may learn how to do a memorial service. What we don't learn is how to deal with our mortality and with our actual dying. We do not have the opportunity to learn ministry for what I call a graceful death."<sup>39</sup> In my survey, only 9% stated that their seminary adequately prepare them to help themselves or another prepare an Advance Directive; an additional 15% answered that their seminary only "somewhat" helped prepared them. In my own recent seminary experience, my pastoral care of the dying curriculum was focused more on the psychology, theology, and phases of grief, not what we could physically encounter when ministering to others when faced with death. In some personal conversations I have had with representatives of ELCA seminaries, it is assumed that CPE will hopefully address these matters. However, as anyone who has been a chaplain knows, CPE exposure often is at the mercy of when you have the pager. A re-evaluation of our seminary curriculum is crucial to provide a more well-rounded and proactive population of ministers and lay-leaders.

# **Education Practiced**

What is preventing seminaries from including this important topic in their curriculum? Does this issue not apply to Divinity School graduates? Is the low numbers of clergy who are involved in their congregant's end-of-life decisions and who are avoiding the topic from the pulpit indicative of a lack of interest? In short, my answer is no. After collecting an overwhelming large amount of survey results in May of 2011, I took the results to an ELCA synod assembly in Indiana the following month to continue the conversation and share resources related clergy involvement in end-of-life planning. I'll admit, I was a bit worried that my study would be rather boring compared to the other break-out presentations and "celebration of ministries" tables, which included creative Vacation Bible School curriculum and how to incorporate yoga into personal self-care. My booth consisting of several dozen copies of advance directives, FAQ's on the topic, wallet inserts, Donate Life organ donation bumper stickers and nail files looked weak next to the tote-bag giveaways of the investment agency booth on one side and a colorful assortment of stuffed animals promoting a weekend retreat on the others. My plan was simple: stand faithfully at my booth and beg people to attend my breakout session, plead with them to take the information I transported from Kansas City to Fort Wayne for the occasion, then present my study and resources to the only two people I knew for a fact would show up, my parents.

I sent a text-message to a colleague of mine less than 3-hours after I began standing at my booth: "Here I thought the nail files and bumper stickers would go first. I am nearly out of handouts! I have to save some for the presentation because people have already stated that they are coming AND bringing a friend!" I was completely overwhelmed by the turnout. Every person who walked by the booth eventually stopped to see what the headline "Have You Had the Talk?" was all about. Not a single person walked away empty handed. Young and old not only took handouts, but also engaged with me in conversations about experiences they have had with end-of-life planning and how they wish they knew more. The breakout session that afternoon was equally impressive. My parents could hardly find a place to sit. Over three-dozen people showed up and took more information on the subject, in addition to supplying me with their e-mail to receive an link of a website I made with more resources once I ran out of handouts. In one person's words, "I sure am glad you flew from Kansas City to Fort Wayne to share this information with us. This kind of booth is the reason why I come to synod assemblies."

#### Application

There was a clear interest in those present at the assembly, and as evident in the large amount of feedback to my survey, for direction as to how to help ourselves and others in end-of-life planning. So - where are we to begin? The ways a minister, lay-person, chaplain, or even a church visitor can begin to help others prepare for their end-of-life starts in the home: we must face the reality that we all have an expiration date and the responsibility to prepare ourselves and our loved ones for it. In her book, "A Clergy Guide to End-Of-Life Issues," Rev. Dr. Martha Jacobson notes, "If we don't face our own demons with regard to death and dying, we cannot empower our congregants to face those most difficult-to-face decisions."<sup>40</sup> She suggests that we begin with what she calls the "Prayerful Discernment Process" in which she lists a series of questions to ask oneself in a contemplative, oral or written fashion, either privately or in a small group of fellow leaders. Relevant scripture readings and prayer, in addition to follow-up points for discussion, surround the questions. Questions include issues of legacy, the "ideal" death, belief systems, and God's role in our individual death. Jacobs concludes by noting: "If you have concerns, imagine how your congregants feel; they believe that you have a closer relationship with God then they have. How can you help your congregants to have these conversations with themselves and their loved ones? How can you empower them to search their souls for answers they can live and die with?"<sup>41</sup> Jacobs mentions that since these are tough and exhausting topics, tackling these questions will require an extra dose of self-care to be both effective to the congregant and, moreover, to ourselves.

Once we have asked ourselves the important questions, we can begin by presenting them to those we love and our congregants. In my presentation at the Synod Assembly, I noted that taking the first step of attending a session such as mine, picking up Jacobs' book, or even reading this research paper (!) is a perfect start. Next, begin by familiarizing yourself with what has come to be called a "Caring Conversation." The Center for Practical Bioethics has coined this concept into a workbook form that includes questions for contemplation and conversation, in addition to a blank Advance Directive and DPOA Proxy form. Rev. Dr. Tarris Rossell of the Center for Practical Bioethics and his wife, Ruth have also qualified such "Caring Conversations" with a Biblical basis, as seen in the 3<sup>rd</sup> and 4<sup>th</sup> chapters of 2<sup>nd</sup> Timothy.<sup>42</sup> Paul spends these two chapters coming to terms with the end of his own life and helping a trusted "son" do the same. In it, Paul does the following: remember, forgive, reiterate core values and beliefs, give advice, hand over responsibilities to others, express hope in the future, and give final requests.<sup>43</sup>

Having a "Caring Conversation" can take many shapes and forms. During my presentation, I suggested the following venues: sermons, Bible studies, small groups, individual conversations, retreats, hospital visits, confirmation or new members classes,

council meetings, pre-martial or other forms of pastoral-counseling sessions. These can be done through private conversations, group "discernment" processes, case studies, or presenting and discussing what your particular denomination says about dying. Jacobs lists resources for how to facilitate all of the above in her book, stressing the importance of record keeping: "If you met with a congregant who tells you what his or her wishes are, you should write down what the person said, as much word for word as possible, and make a note in your calendar as to the date that the conversation took place."<sup>44</sup>

Jacobs also mentions Dr. Joseph Fins' proposal that there are theological implications of designating a DPOA. Fins believes that "when one appoints a health care agent, one is establishing a covenant between two people."<sup>45</sup> Jacobs concludes that when a person joins a church, there is a covenant made between the individual and the church, the first being the responsibility of the church to inform the new member of ways the church can help its members, including what will happen to them when they are sick. Jacobs asserts, "Under this covenant, it is your obligation to let your congregants know about these issues and help them navigate them. The best time to do this is when people are healthy, not when they are being rolled into the emergency room."<sup>46</sup> Thus, by empowering our congregants to prepare for their futures, the church can play a crucial and important part in the future when it becomes the present. As a participant in a similar survey stated, "If we don't take the lead in this important and appropriate task, people will look for it elsewhere."<sup>47</sup>

#### V. Conclusion

Our tendency to avoid talking about death is not because of a disinterest. On the contrary, my survey and presentation at the synod assembly proved otherwise. Exposure to end-of-life situations through the ministry is just one of the reasons why ELCA ministers more than doubled the national population in Advance Directive completions. However, the elephant in the room has yet to be named. Seminaries, hospitals, community centers, and educators can take the initiative to fully prepare their students by proactively including endof-life preparation in their curriculum, addressing the psychology of why we avoid the topic of death, how to best incorporate the topic into congregational ministry, and how to help both ourselves and others complete Advance Directives. Likewise, clergy and lay-leaders can take the initiative by starting in their homes and discussing end-of-life planning with their families. Doing so will gain them the experience and confidence to share this crucial information with their congregation. Because our congregants look to their leaders for spiritual guidance, they will more than likely be open to a leaders confidence in naming this very real subject with humility, knowledge, and transparency. Being involved with end-oflife discussions while congregants are healthy will make for a more peaceful, more integrated pastoral encounter when ministering to others at the end of their lives.

# VI. Appendix

a. Survey Results in Graph Form

# 1. Please select your age: 76 responses

Under 30	7 (9.21%)
30-49	30 (39.47%)
50-65	30 (39.47%)
65+	9 (11.84%)

#### 2. Please select your gender: 76 responses

Male	37 (48.68%)
Female	39 (51.32%)

# 3. Please select your highest level of education: 75 responses

Undergraduate	2 (2.67%)
MDiv/MA	61 (81.33%)
Other Graduate	3 (4.00%)
Doctorate	5 (6.67%)
Professional Degree	3 (4.00%)

# 4. If you attended a Lutheran seminary, please select all that apply: 71 responses

Luther Seminary (Saint Paul, Minnesota)	7 (9.86%)
Lutheran Theological Seminary at Philadelphia (Pennsylvania)	6 (8.45%)
Lutheran School of Theology at Chicago (Illinois)	14 (19.72%)
Lutheran Theological Seminary at Gettysburg (Pennsylvania)	6 (8.45%)
Lutheran Theological Southern Seminary (Columbia, South Carolina)	2 (2.82%)
Trinity Lutheran Seminary (Columbus, Ohio)	7 (9.86%)
Pacific Lutheran Theological Seminary (Berkeley, California)	22 (30.99%)
Wartburg Theological Seminary (Dubuque, Iowa)	10 (14.08%)

# 5. Please choose all that apply to you. Have you professionally: 75 responses

visited a hospitalized parishioner?	73 (97.33%)
visited someone who was in the process of dying?	75 (100.00%)
been present with a parishioner or their family when making	59 (78.67%)
end-of-life decisions?	55 (10:0170)
been present with a parishioner at the time of their death?	54 (72.00%)
ministered to family members who were unsure of the	58 (77.33%)
parishioner's end-of-life care preferences?	50 (77.55/0)

6. Has a parishoner ever given you a copy of their Advance Directive? 75 responses

Yes	28 (37.33%)
No	47 (62.67%)

7. When were you first introduced to the topic and stipulations of Advance Directives (also known as a Living Will)? 74 responses

High School/College	8 (10.81%)
Vocational Experience	15 (20.27%)
Seminary Class	10 (13.51%)
Clinical Pastoral Education (CPE)	26 (35.14%)
Family Experience	23 (31.08%)
A Conference	3 (4.05%)

8. Did your seminary adequately prepare you to help yourself or another prepare his or her own Advance Directive? 74 responses

Yes.	7 (9.46%)
No.	47 (63.51%)
Somewhat	11 (14.86%)

9. If you have completed any of the above forms of an Advance Directive, to whom have you given a copy (choose all that apply)? 52 responses

Doctor	24 (46.15%)
Lawyer	20 (38.46%)
Financial Planner	6 (11.54%)
Colleague	1 (1.92%)
Hospital	16 (30.77%)
Family Member	46 (88.46%)
Friend	5 (9.62%)
Pastor/Mentor	3 (5.77%)

10. Have you intentionally spoken to your family about your end-of-life needs/ preferences? 73 responses

Yes.	56 (76.71%)
No.	6 (8.22%)
Only in passing, not intentionally	11 (15.07%)

11. Have you assigned yourself a Durable Power of Attorney for Health Care in the event that you will not be able to make medical decisions on your own? 71 responses

Yes.	44 (61.97%)
No.	27 (38.03%)

12. Have you completed a Living Will or another form of an Advance Directive? 73 responses

Yes	46	(63.01%)
No	27	(36.99%)

13. If you HAVE completed a living will, what were your reasons (please select all that apply)? *46 responses* 

My own health	13 (28.26%)
Exposure to end-of-life decision making through my ministry	31 (67.39%)
Death in my own family	22 (47.83%)
I do not want to burden my family with making decisions on my behalf	34 (73.91%)
I want autonomy and control of my own life	18 (39.13%)
My lawyer suggested it	6 (13.04%)
My doctor suggested it	3 (6.52%)
My pastor/mentor suggested it	2 (4.35%)

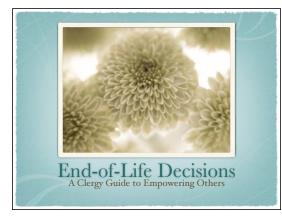
14. If you have NOT completed a living will, what are your reasons (please select all that apply)? 28 responses

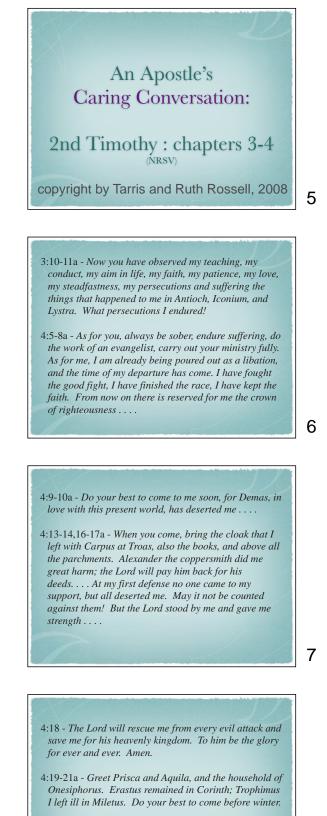
Do not see a need for one	3 (10.71%)
I am in good health	4 (14.29%)
I fear that it will take my rights away from me	1 (3.57%)
I've been thinking I might want to sign an advance directive but have	15 (52 57%)
yet to do it	13 (33.37%)

15. If you have not yet completed an advance directive or assigned yourself a durable power of attorney, has this survey made you think of doing so? 53 responses

Yes.	23 (43.40%)
No.	6 (11.32%)
Not applicable.	24 (45.28%)

# b. PowerPoint Presentation to clergy





Poll: Who has completed an Advance Directive for themselves? National Average: 15-25% ELCA Average: 63%

2

1

Poll: Who has ministered to others who where unsure of their loved-one's end-of-life preferences?

ELCA Average: 77%

3

What is End-of-Life planning?

"Caring Conversations" : A Biblical Example :

4

8

# What's going on here?

Paul is coming to terms with the end of life, with his own death and dying.*"The time of my departure has come..."* (4:6)

Recognizing this, Paul engages in a conversation with a trusted "son"... it is a "caring conversation."

9

# A Caring Conversation involves:

#### **Remembering:**

- Reflection on important past life events...
- "Now you have observed my teaching, my conduct, my aim in life, my faith, my patience, my love, my steadfastness, my persecutions and suffering the things that happened to me in Antioch, Iconium, and Lystra. What persecutions I endured! (3:10-11a) ...
- "I have fought the good fight, I have finished the race, I have kept the faith (4:7) ...
- "Alexander the coppersmith did me great harm (4:14a) ... "At my first defense no one came to my support, but all deserted me (4:16a)."

10

# A Caring Conversation involves: Forgiving:

Mending broken relationships...

- "Alexander the coppersmith did me great harm; the Lord will pay him back for his deeds (4:14a)...
- "At my first defense no one came to my support, but all deserted me. May it not be counted against them!" (4:16a)

11



# A Caring Conversation involves:

Advice to survivors & handing over the work responsibilities: Passing on the mantle of ministry...

"As for you, always be sober, endure suffering, do the work of an evangelist, carry out your ministry fully." (4:5)

13

#### A Caring Conversation involves:

Expressions of **hope** for the **future** with **faith** in God who holds the future, the present, and the past.

"From now on there is reserved for me the crown of righteousness... (4:8a)
"The Lord will rescue me from every evil attack and save me for his heavenly kingdom. To him be the glory for ever and ever. Amen." (4:18)

# 14

# A Caring Conversation involves: Final requests: especially that of presence and non-abandonment...

- "Do your best to come to me soon, for Demas, in love with this present world, has deserted me ... (4:9). "When you come... (4:13)
- "Do your best to come before winter."
- (4:21*a*)

15





# : Key Terms and Phrases : See Caring Conversations Book, page 10

# Advance Directives include:

- Healthcare Treatment Directive: "In the event the medical care is futile, I would like the
  - following done/not done for me ....
- Defines individuals ideal of "acceptable quality of life." • This can include wises to be resuscitated/intubated.
- · May also include organ donation preferences.
- · Must be completed by the patient so long as they are mentally capable to make decisions on their own.
- Different from a living will, which only deals with terminal illness.

25

# **Advance Directives:**

- When? Now is the time. Don't wait until you have a medical emergency.
- How? Involve others in your conversation to create mutual accountability. Sit down together, start the conversation knowing that it should continue as life evolves.

26

# **Advance Directives:**

- Who should be involved?
  - Your DPOA
  - Family or friends that you trust
  - People whom you would like to play a role in your medical care in the future.
- To Whom should I give a copy of my AD? • Lawyer

• Colleague

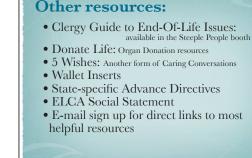
• Pastor...?

- Your DPOA
- Spouse • Doctor
- Children
- Friends

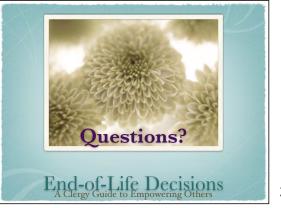
27

#### **Advance Directives:**

NOTE: Though writing your end-of-life healthcare treatment preferences is monumental toward ensuring that you get the care you prefer, Advance Directives need to be state-specific in order to be most legally binding. Indiana and Kentucky AD's are available at the *"Have You Have The Talk?"* Celebration of Ministry booth and also online.



29



30



# VII. Endnotes

<sup>1</sup> House, Deborah. "Advance Medical Directives and the Role of the Church." *Christian Century*, 4 December 1991: page 1138.

<sup>2</sup> House, 1138.

<sup>3</sup> House, 1138.

<sup>4</sup> Basanta, W. Eugene. "Advance directives and life-sustaining treatment: a legal primer." *Hematology/Oncology Clinics of North America*, 16 (2002): page 1390. <sup>5</sup> Pastana, 1391

<sup>5</sup> Bastana, 1391.

<sup>6</sup> Browning, Annette M. "Incorporating Spiritual Beliefs Into End-Of-Life Care." *Journal of Christian Nursing* Volume 26, Number 1 (January-March 2009): page 13.

<sup>7</sup> The Harris Poll #9, January 25, 2011. Question: "Have you created [an advance] directive for yourself?" Method: National Internet survey of 2,340 American adults. harrisinteractive.com/vault/HI-Harris-Poll-BBC-Doctor-Suicide-2011-01-25.pdf <sup>8</sup> Robinson, Mary, Mark J. DeHaven, Kathryn A. Koch. "Effects of the Patient Self-Determination Act on patient knowledge and behavior." *Journal of Family Practice,* Volume 37, Number 4 (October 1998): page 363.

<sup>9</sup> Castello, Lesley, et al. "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care." *Annals of Internal Medicine,* Volume 154, Number 2 (18 January 2011): pages 121-128.

<sup>10</sup> "National Healthcare Decisions Day: Home" nhdd.org web.

<sup>11</sup> Basanta, 1382.

<sup>12</sup> Basanta, 1383.

<sup>13</sup> Bastana, 1383.

<sup>14</sup> Bastana, 1384.

<sup>15</sup> Bastana, 1386.

<sup>16</sup> Jacobs, Martha R. *A Clergy Guide to End-of-Life Issues*. Cleveland: Pilgrim Press, 2010: page 30.

<sup>17</sup> Jacobs, 30.

<sup>18</sup> Bastana, 1388.

<sup>19</sup> Pew Research Center Poll. January 5, 2006. Question: "Have discussed **your** treatment with no one?" Method: National telephone interviews of 1,500 American adults.

people-press.org/files/legacy-pdf/266.pdf

<sup>20</sup> Ferrell, B.R., and Coyle, N. *Textbook of palliative nursing*; 2<sup>nd</sup> Edition. Oxford, England: Oxford University Press, 2006: page 595.

<sup>21</sup> Balboni, Tracy, et al. "Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life." *Journal of Clinical Oncology* Volume 25, Number 5 (10 February 2007): page 558.
 <sup>22</sup> Balboni, 555.

<sup>23</sup> Daaleman, Timothy P. and Larry VandeCreek. "Placing Religion and Spirituality in End-of-Life Care." *Journal of the American Medical Association,* Volume 284, Number 19 (15 November, 2000): page 2514.

<sup>24</sup> Balboni, 555.

<sup>25</sup> Balboni, 555.

<sup>26</sup> Durkeim, Émile. The elementary forms of the religious life. Glencoe, H.: Free Press, 1954: page 704.

<sup>27</sup> Pew Research Center Poll, ibid. Question: "Do clergy at your place of worship ever speak out on end-of-life decisions?"

<sup>28</sup> Braun, Kathryn L. and Ana Zir. "Roles of the Church in Improving End-of-Life Care: Perceptions of Christian Clergy and Laity." Death Studies, Volume 25, Issue 8 (8 April 2001): page 685.

<sup>29</sup> Braun, Kathryn L. and Ana Zir, 685.

<sup>30</sup> Balboni, 559.

<sup>31</sup> "Before I Die: Medical Care And Personal Choices." *Public Broadcast System*. Originally aired on 29 April, 1997. Online write-up and summary at: thirteen.org/bid/sbhowmuch.html

<sup>32</sup> Braun, Kathryn L. "Death education in churches and temples: Engaging religious leaders in the development of educational strategies." B. DeVries (Ed.), End-of-life issues: Interdisciplinary and multidimensional perspectives New York: Springer, 1999: pages 319-335.

<sup>33</sup> The Pew Forum on Religion and the Public Life. Question: What is your race? Are you white, black, Asian, or some other? Method: interviews with more than 35,000 Americans ages 18. religions.pewforum.org/pdf/table-ethnicity-by-denomination.pdf <sup>34</sup> Braun, Kathryn L. and Ana Zir, page 690.

<sup>35</sup> Braun, Kathryn L. and Ana Zir, 690.

<sup>36</sup> Becker, Ernest. *The Denial of Death*. New York: Simon and Schuster, 1973.

<sup>37</sup> Becker, 88.

<sup>38</sup> Source unknown.

<sup>39</sup> Jacobs, 1.

<sup>40</sup> Jacobs, 62.

<sup>41</sup> Jacobs. 67.

<sup>42</sup> Rossell, Revs. Tarris and Ruth. "An Apostles Caring Conversation. End-of-Life Dialogue in 2 Timothy 3-4." 2001/2008, Powerpoint Presentation.

<sup>43</sup> Rossell, ibid.

44 Jacobs, 31.

<sup>45</sup> Fins, Joseph J, "Commentary: From Contract to Covenant in Advance Care Planning," Journal of Law, Medicine, and Ethics Volume 27, Issue 1 (1999): 46-51. <sup>46</sup> Jacobs, 98.

<sup>47</sup> Braun, Kathryn L. and Ana Zir, 700.

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