From *Ars Moriendi* to *Ars Transitus*: Christian Perspectives on Advance Care Planning in the United States

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Abstract

This exploratory study aimed to analyze Christian perspectives on advance care planning and to present a conceptual model of collaborative care in the United States, one which better integrates healthcare with spiritual care for the purposes of educating, equipping and assisting individuals to transition from life spiritually, emotionally, physically free of distress, thereby creating a new *Ars Transitus* (The Way of Transition). Technological advances of the past century have tended to change the focus of medicine from a caring, service-oriented model to a technological, cure-oriented model. Today, death and dying are a healthcare "problem" managed by healthcare institutions, insurance companies and government policy. Utilizing Osmer's (2008, 4) practical theological approach as a primary tool for the study, the research reveals how medical advances have influenced how our society and the church approach the end of life. This research attempts to present fundamental truths from the Scriptures and marries them with current structures and best practices found within the United

States healthcare systems. In doing so, the study hopes to provide a cohesive approach to end-of-life care that will enable caregivers to assist individuals to better do the "work of dying" and, in their preparation, finish well.

Keywords

spirituality, death and dying, advance care planning, end of life

1. Introduction

This practical theological research sought to study and engage the current practices of healthcare and the church in the United States in order to understand the present context in which spiritual care is provided. Osmer's (2008, 4) empirical methodology is employed because his four questions, "What is going on? Why is this going on? What ought to be going on? How might we respond?" harmonize well with the style used in medical research. He categorizes these as the descriptive-empirical task, the interpretive task, the normative task, and the pragmatic task.

For centuries, the church has guided individuals in all matters of life and death. Death was familiar and the church provided leadership and practical guidance for the dying and those attending them through a body of literature known as the *Ars Moriendi* (The Art of Dying). These manuals, written in the fifteenth century, informed those dying about what to expect and prescribed prayers, actions, and attitudes that would lead to a "good death" (which was viewed as "peace with God and man"). Relief from pain or symptom management was limited because medicine, as we know it today, was non-existent.

Sadly, the church no longer holds such a vital place of leadership in our society in the context of death and dying. The journey to one's death has long since moved from a spiritual, communal experience to a highly medicalized process (Ariés 1974). In the twenty-first century, advances in medical science and technology have rendered the traditional definition of death obsolete (Zander 2000, 617). The new ways of prolonging life have led people to become fearful of dying alone or suffering "dehumanized deaths." It appears that ethics and theology have been left behind during fast-paced advances in the field of medicine, which has created a quandary for people of faith who lack both medical and theological literacy. Families throughout America find little advice and guidance regarding the difficult moral decisions that emerge at the end of life (Kayne n.d.). The growing availability of sophisticated life-support technology only increases the likelihood of anguished decision-making if not planned for in advance (Rogne and McCune 2014).

2. Research Objectives

A combination of empirical research, literary review and both quantitative and qualitative research was used to answer the question: How can we best prepare and support Christians in the United States to finish life physically, emotionally, and spiritually distress-free? In addition, the research sought to answer the following subsidiary questions:

- Has the medicalization of dying impacted the role of the church in preparing Christians to transition well from this life?
- What can the church do to re-establish its influence in end-of-life care?
- Would Advance Care Planning from a spiritual perspective better prepare religious patients and their advocates for future medical decisions?
- How can spiritual caregivers provide continuous, integrated spiritual

> care that supports individuals throughout their temporal life until their transition to immortal life?

The objective of this research was twofold. Firstly, to stimulate change and action within the church to restore it to its mission of educating, preparing, and supporting those who are seriously ill. Secondly, to offer new models of care and collaboration between institutional chaplains and local clergy in providing continuous spiritual care to people of faith in their last phase of life. The research focused on the medical and spiritual praxis found within the medical and church communities in the United States. There are likely to be many parallels to others from similar Western cultural perspectives. Therefore, any conclusions and recommendations for any new praxis could possibly be applicable or adaptable in whole or in part.

3. Research Results

This corresponds to Osmer's (2008, 31–78) descriptive-empirical task. The research examined the impact of pastors' attitudes towards individuals within the church and in the healthcare system to determine the spiritual needs and the readiness of those who are, or might become, seriously ill. It became apparent that those who are charged to give both healthcare and spiritual care are very well intentioned in their desires to meet the needs of those for whom they care. It is equally evident that there is a lack of congruency between processes/theory and practice. In both settings, the practice of caregivers did not match up with the views they expressed.

These results are elaborated upon below as concerns the current state of healthcare, physicians' attitudes to faith, patients' attitudes to faith, the pastoral preparation of chaplains, and religiosity and Advance Care Planning.

3.1 The state of healthcare for the dying

Although there is much to be celebrated with regards to the advancement in curative treatment, the quality of end-of-life care has not seen significant improvement since the end of the twentieth century. Statistics have uncovered that the overall quality of communication between clinicians and patients with advanced illness was identified as weak, particularly concerning discussing prognosis, dealing with emotional and spiritual concerns, and finding the right balance between hoping for the best and preparing for the worst (Institute of Medicine 2015, 12).

The transference from home-centered death to hospital-centered death creates a very complex relationship between individuals with chronic or progressive illness, health professionals, and the bureaucratic institutions they represent. There is mounting evidence to show that spirituality and religion play a critical role in this complex relationship and affect how patients cope with illness. In a meta-analysis of over 1,200 published studies on religion, spirituality, and health, substantial evidence was found to support the notion that spiritual and religious beliefs are used to cope with illness and result in positive outcomes (Koenig 2007, 10, 45).

An extensive study conducted by the Joint Commission, with help from the Press Ganey Associates' national databases, determined that care for patients' emotional and spiritual needs constitutes a significant opportunity for quality improvement for the majority of hospitals (Clark et al. 2003). Research shows that an alarming 72 percent of the patients reported that the medical system met their spiritual needs to a small extent or not at all (Balboni et al. 2007, 555).

3.2 Physicians are reluctant to address spiritual distress

There is significant data to indicate that a vast majority of physicians support or at least believe that a patient's spiritual well-being is an appreciated factor in health (Balboni et al. 2014; Curlin et al. 2006). When asked, 99 percent of the physicians associated with the American Academy of Family Physicians believed that religious beliefs can help in healing, and 75 percent believed that other's prayers can promote healing (Larimore 2001, 36). Given that such a high percentage of physicians acknowledge the benefit of supporting their patients' spirituality, it would be safe to assume that they would be eager to do so. Yet it seems that although healthcare providers may address patients' spiritual concerns themselves, they are mostly ambivalent about doing so (Kristeller 1999). Generally speaking, physicians have been reluctant to address patients' spiritual concerns in practice. The importance of addressing patients' spiritual distress is thought to be a low priority when compared to other clinical concerns (Silvestri 2003, 1379).

3.3 Patients' spiritual needs are mostly not being addressed

Puchalski (2009, 804) finds that spirituality has become an increasingly prevalent topic in current models of healthcare. A study of family practice patients was conducted to determine when patients feel that a physician's inquiry about spirituality or religious beliefs is appropriate. Of 1,413 adults who were asked to respond, 921 completed questionnaires, and 492 refused (response rate = 65 percent). Of the respondents, 83 percent wanted physicians to ask about spiritual beliefs in at least some circumstances. The most acceptable scenarios for spiritual discussion were life-threatening illnesses (77 percent), serious medical conditions (74 percent), and loss of loved ones (70 percent). Among those who wanted to discuss spirituality, the most critical reason for discussion was a desire for physician-patient understanding (87 percent). Patients believed that information concerning their spiritual beliefs would affect the physician's ability to encourage realistic hope (67 percent), give medical advice (66 percent), and change medical treatment (62 percent) (McCord 2004, 356). For many patients, it is a matter of trust. When a physician solicited information about their faith, they felt more confident to trust that the physician understood them and would make recommendations for treatment based on their beliefs and values.

Unfortunately, a large number of people report that when hospitalized their spiritual needs are not being met by either the medical system (including chaplains) or their spiritual community. Patients report that their spiritual needs are supported by religious communities, to a large extent or entirely, only 38 percent of the time, with 40 percent reporting that their needs are met to a small extent or not at all. Among religious individuals, their faith communities wholly supported African Americans more frequently than Whites (52 percent vs 19 percent) and Hispanics (52 percent vs 26 percent) (Balboni et al. 2007, 555). It would seem there is opportunity for local clergy to strengthen their support to hospitalized patients.

This research confirms that for those people who self-identify as being Christian or part of a Christian denomination, God and the teachings of their faith are a regular, natural part of everyday life. It is clear that the individual and who she or he is as a spiritual being cannot be separated. Patients representing the African American community and those coming from evangelical, Pentecostal, and Charismatic paradigms attached even greater importance to religion and desired healthcare providers to understand their faith backgrounds.

3.4 Spiritual leaders are not preparing their people to face death

One hundred and fifty healthy individuals (n=150) were asked a series of questions to describe their perceptions and preparation to face death. This survey aimed to gain insight into individual attitudes towards death and dying, spiritual preparation to face death, and practical needs to "get one's house in order." On issues of faith, 83 percent indicated that their faith would be most important to them when facing the end of life. Just over half (58 percent) felt that they had a great deal of biblical understanding about death; however, 61 percent thought that their spiritual community should teach them more about death and dying. When asked how well they felt their spiritual leaders prepared them to face the practical (not theological) issues surrounding death, almost 70 percent felt that they were not at all or hardly prepared.

This may well be because studies indicate that clergy have low comfort levels with the medical aspects of the dying process. This may be the reason for their reluctance to engage with those with a terminal illness. Only 44 percent mentioned that they were comfortable with their understanding of medical terminology and had only a slightly higher comfort level (56 percent) with the physical symptoms of illness (Norris 2004, 34, 58).

3.5 Many religious people are unprepared for the healthcare issues surrounding dying

Respondents to surveys (93 percent) overwhelmingly indicated a significant experience of the divine, with 94 percent indicating that their religious beliefs were behind their whole approach to life. It is therefore to be expected that this would also include their approach to death. While this might be true, practically speaking, people of faith show no more preparation by way of discussion about future healthcare needs with either their families or physicians than those who claim no faith at all. Indeed, those who self-identify as Lutheran, Methodist, and Presbyterian are likely to have spoken to their family and doctors and to have completed an advance directive. Yet, surprisingly, people who may appear to claim a greater sense of religiosity (such as those coming from evangelical, Pentecostal, or Charismatic traditions) demonstrated the lowest preparation regarding discussion or completion of an advance directive for healthcare.

Finally, even more surprisingly, highly religious copers from all Christian traditions (those at peace with God and well supported by their church) were more inclined to pursue aggressive treatment, regardless of the benefit or efficacy. As a result, they were more likely to experience spiritual distress as a result of health-related suffering and were more likely to perceive less quality of life and satisfaction in care at life's end (Balboni 2007, 555).

4. Suggested Reasons for Healthcare Deficiencies Concerning the Dying

This corresponds to Osmer's (2008, 79–1284) interpretive task. It is suggested that the above deficiencies in the healthcare system are due to some of the reasons outlined below.

4.1 The medicalization of dying

The destiny of all living creatures is the inevitable conclusion of life. Although experienced by every one of us, it is responded to in different ways. Shaped through the ages by religious, intellectual, and philosophical beliefs, attitudes towards death and dying are continually changing. Never as much as in the twenty-first century did advances in medical science and technology continue to influence our thoughts on death and dying (Alters 2006, 1).

We experience death on a personal level; however, we do not experience our illness in a vacuum. Instead, many times we journey with our illness in community. These communities influence our understanding and approach to illness via their teaching, traditions, rituals, and practices (DeSpelder and Strickland 1983, 85). One such community is the community of faith. For centuries the role of faith in God and the influence of the church reflected these aspects of dying. However, through time, individuals became more humanistic and secular in their thinking. As a result, death morphed from a communal, spiritual experience to a private, primarily biological, phenomenon.

"The Golden Age of Medicine" (1860–1960) played a major role in this shift by introducing significant technological advancement that increased medicine's capacity to save and sustain biological life (Brandt and Gardner 2000, 21–37). The technological advancement of hospitals and the resulting increased life expectancy of patients shifted the focus of healthcare from care to cure (Fontana and Keene 2009, 35). As a result, the medical field began to distance itself from death and dying. Now hidden and mysterious, death became something to be feared and avoided.

4.2 The redefinition of death

Over the past thirty-five years, technological advances have rendered the traditional definition of death obsolete. Such advances have included methods to resuscitate victims from cardiac arrest, mechanical respirators, and artificial heart pacemakers (Zander 2000). Faced with the challenge of finding a more fitting definition of death, philosophers and physicians sought an alternative. Machines can replace practically all the functions of the body's organs except those of the brain. Therefore, after many heated debates on the issue of brain function, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1981) confirmed the following redefinition of death: The irreversible cessation of all functions of the entire brain, including the brain stem.

This new definition of death based on whole-brain death is not person-oriented (Basta 1996). As such, this definition relies on the death of an organ rather than the death of an individual, a person. Instead of technology helping to clarify when death occurs, it has served to primarily frame the death event as a medical process while disregarding the entire personhood of the individual who is dying. This paradigm of death creates a considerable theological and practical challenge, because it has shifted the focus away from what constitutes personhood to what constitutes a state of physiology. Thus, the full nature of man and what God considers life is not properly addressed when death is organ-centered and not person-centered.

4.3 The church's loss of influence concerning palliative healthcare

The medical and technological advances and the consequent redefinition of death have caused confusion between 'the prolonging of life' and 'the dying process.' In the broadest sense of the term, 'dying' can refer to that state in which one is medically incurable and one's condition will eventually lead to death, or a state in which one's physical condition cannot be restored back to health, and the consequences of such condition will result in death. As a result, death and dying today primarily fall under the auspices of science and medicine, with the church's role being minimized. In its place, the responsibility for spiritual support in large part has been yielded to institutional chaplains when many of the dying would also like their own spiritual leaders to be involved with them at this time.

4.4 An emergence of a religiously pluralistic hospital chaplaincy

Since the early twentieth century, the practice of healthcare chaplaincy has evolved from ordained, faith-based chaplains to specially trained, interfaith spiritual care providers employed by healthcare organizations. Early healthcare ministry was deeply rooted in a sound practical theological approach to call attention back to the central task of the church, that of saving souls, and to the central problem of theology, that of sin and salvation (Health Care Ministry Association 2013). Today, however, clinical pastoral education is a professional education for ministry that brings students and ministers of all faiths (pastors, priests, rabbis, imams, and others) into supervised encounters with persons in crisis. Yet this new paradigm in ministry does not guarantee that someone who represents their faith tradition will minister to those who are in spiritual crisis.

5. A Biblical Theology of Healthcare

This section corresponds to Osmer's (2008, 129–174) normative task. The pragmatic intervention I suggest in chapter six is based upon what I consider should be the normative theology informing palliative healthcare.

A theology of healthcare is of paramount importance because as Kraft says, "It is my experience as a hospital chaplain for over twenty-five years that it is nearly impossible for many, when facing death, to avoid grappling with spiritual issues such as the nature of life and death, the meaning of suffering, the place of hope, and the actions of God in miracles and medicine." This means that caregivers must honor and pay attention to a patient's non-physical side (spirit, beliefs, and values) for they are the foundation that will most likely drive much of the decision-making processes. As Evans (2011, Introduction) comments, this contending with issues of death and dying immediately confronts us with our worldview and, hence, our theology.

The theology set out below is based upon a biblical hermeneutic that is in conformity with the generally accepted catholic traditional creeds and doctrines of the Christian church. It is thus applicable to many of the patients and healthcare workers in the United States today, even if they do not consciously adhere to this worldview. I suggest that the palliative care decisions of healthcare workers best reflect this tradition when they are informed by the biblical teachings concerning the image of God in human beings, the meaning of life, personhood, and God's purpose for man. Yet it must always be applied with sensitivity and never forced upon vulnerable people. Although my worldview is that of an evangelical Christian, I realize that in counselling one must always seek to sensitively discover the worldview of those being given palliative care in order to counsel them appropriately and in a manner that they will find helpful.

Christian anthropologies affirm that a biblical concept of personhood may be developed from the special resemblance of the human creature to its Creator, contained in the *imago Dei* mentioned in Genesis 1:27 (Vanhoozer 1997, 163). Whatever else this resemblance signifies it may be inferred that being made in God's image means that human beings are transcendental creatures with dignity and worth, a unique sense of selfhood, the freedom to reason and make decisions, teleological purpose, and a need for relationality. These are factors that must all be considered as the end of life approaches.

5.1 Human beings have a unique dignity and worth

The *imago Dei* indicates that human beings have a special relationship with God that somehow reflects his being and nature and are psychophysical creatures with an ensouled body or an embodied soul with a unique capacity to relate to God. They are also 'vice-regents' who care for creation on God's behalf. A human being then, is not just a physical, material being but also a transcendent, spiritual being who shares God's dignity (Vanhoozer 1997, 163–170). This means that they should always be treated with dignity and as holistic beings and must never be treated as just physical machines in need of fixing by healthcare workers.

5.2 Each human being is a unique person

From a commonsense perspective it may seem obvious that each human being is a unique person, although in the light of the postmodern deconstructionist critique, such as Foucault's (1974) The Order of Things, it must be openly stated as a Christian premise. The premise of uniqueness is fully in accord with a theological anthropology, which starts from the presupposition that the selfness of all human beings is determined by the concept of man created in the *imago Dei*.

In the context of a dialogue with postmodernity, Genesis 1:27 may be interpreted as indicating that every human self is genetically determined according to God's purpose to be a structured, distinct, determinate, unique entity with an identity of selfness, influenced as it develops by existing place, culture, and gender, continuously contingent upon God, and molded by the God-givenness of life. Each unique person's choices cannot be predicted and must be respected, provided they do not implicate other humans in an illegal activity such as euthanasia. From the palliative healthcare perspective this suggests that they cannot all be treated in the same way or as determined by what medical professionals consider to be their physical needs. Everyone should and must be given the freedom to decide and express how they would prefer to be treated, whether by, say, a hospice care approach or by aggressive medical intervention, and this decision must be respected.

5.3 Human existence has a teleological purpose

"The image of God concerns not only human origins but human destiny" (Vanhoozer 1997, 165). Human beings were created in God's image so that they would be able enjoy him and glorify him forever. Despite the sin and death that resulted from their rebellion, the potential for this was enabled once more by their redemption through the one who is "the image of the invisible God" (Col 1:15) and "bears the very stamp of his [God's] nature" (Heb 1:3). This is the one whose image they are destined to bear, upon their death when the recreation of his image in them would be completed (Bonhoeffer 1959, 269, 270). Thus, death has a completely different meaning for the follower of Jesus than for one whose worldview does not permit him or her to believe. For the follower it is something to be looked forward to as the consummation of their teleological purpose.

5.4 Dying and suffering

Yet even for the Christian, dying can be an extremely painful, fearful and lonely experience of impending loss and grieving as the physical body decays, previous aptitudes and abilities disappear, and physical functions fail. Suffering is an inescapable part of our human existence. Jesus, who was the image of the invisible God incarnate, lived in the temporal, decaying, and transitory time/space reality in which we human beings live and die (Moltmann 1993, 88). As a result, he suffered. As Ware comments on Hebrews 4:15:

> [Jesus] lived out his life on earth under the conditions of the fall … in his solidarity with fallen man he accepts to the full the consequences of Adam's sin. He accepts in full not only the physical consequences, such as weariness, bodily pain, and eventually the separation of the body and soul in death. He accepts also the moral consequences, the loneliness, the alienation, the inward conflict. (1995, 75)

This description depicts the ugly features of illness: physical, emotional, and spiritual (Luzarraga 2019, 85), which all may accompany the dying process.

On the other hand, he who was the image of the invisible God did not seek to suffer when it was not necessary. When he was hungry, he naturally sought to satiate that need by eating (Mark 11:12). When he was tired, he naturally rested (John 4:6). When facing the pain of an agonizing death, he asked the Father that if it was possible it might be might avoided (Matt 26:39). The Bible also records that Jesus sought at times to relieve pain and suffering (see for instance Matt 4:24; 8:26; 11: 28–30; Mark 5:1–15). The suffering that must be borne without alleviation is that which comes from being persecuted (John 15:20, 21). This is the suffering that Paul mentions in Philippians 3:10 as "sharing in his [Christ's] sufferings" and none other.

5.5 Relational creatures in need of accompaniment

Because humans are made in the image of a triune God, relationality is an essential prerequisite of their being. This is reflected in the theological model of care called “accompaniment.” This is a widely accepted model within the evangelical Lutheran Church in America and, because of the writings of Pope Francis (2013, 169 ff.), also among Latin American and United States-based Hispanic theologians. Accompaniment is the process of walking alongside someone and joining with him or her in solidarity. It is essentially the idea that those who suffer are unable to endure the burden of suffering their illness and suffering by themselves (White 2011, n.p.; Luzarraga 2019, 78).

It is theologically based upon the trinitarian concept that in Jesus Christ, who was anointed by the Spirit to accomplish this mission (Luke 4:18), God engaged with our brokenness and sin and accompanied groaning humanity in order that it might regain the image of God through the salvation of the cross (Younan 2005, 23). Likewise, Jesus, through the indwelling Spirit, promises to continue to accompany believers through suffering and death to a new and resurrected life. Then if we are to follow Christ and respond to his call to “come and die” as Bonhoeffer (1959, 37, 79) explains, this would mean that we as individuals and as his body are to accompany others through illness, suffering, and death so that we may transform a situation of despair into hope. Accompanying one in suffering makes it, “more bearable for the person who is ill because more are carrying that burden … (and) reasserts life in the face of illness” (Luzarraga 2019, 86). This includes those who are suffering chronic illness and those who face death.

6. The Pragmatic Task

This corresponds to Osmer’s (2008, 175–218) pragmatic task. The research suggests there is an urgent need for the church to re-establish its influence in the United States medical healthcare system. This has been reinforced by the impact of the coronavirus pandemic on this system. The research suggests that this requires the following.

6.1 A new paradigm for ministry to the dying

The changes and interventions that this research suggests need to be made are based upon acceptance of a new paradigm for ministry to the dying. This paradigm is that, coupled with support from family, a well-coordinated cadre of spiritual care providers will provide the most effective support for those who are sick or seriously ill. The cadre would consist of pastors, faith community nurses, institutional chaplains, community or outreach chaplains, and support teams that would create a continuum of care linking both the local church and healthcare systems.

6.2 The training and mobilizing of pastors in the local church context

Spiritual care begins and ends in the local context. Individuals are discipled and cared for by the body of Christ within their local church. Pastors/churches need to be encouraged to re-establish their role of assisting the seriously ill in their many transitions toward eternal life by offering biblical teaching regarding suffering, hope, and healing in the context of illness. This may be by seeking a holistic approach to discipleship by developing healthcare ministries within their congregations to ensure holistic health—body, mind, and spirit. In addition to contextualizing the Scriptures to issues that emerge during illness, one area of discipleship would be to assist parishioners in shifting from a temporal to eternal paradigm.

Support groups and support teams may then be established to help congregants explore the various approaches to end-of-life issues so they might harmonize their faith and values with their goals of care. This will require the researcher cooperating with other healthcare ministers to establish seminars within denominations and national church networks.

6.3 Advance Care Planning and spiritual assessment by faith community nurses

As part of the health ministry, faith community nurses would perform a spiritual assessment with the parishioner and counsel them in Advance Care Planning. By assisting individuals to consider future medical treatments according to their faith and values, a written advance directive for medical care can then be created. Should the congregant enter into the hospital system, this document would be relayed with the parishioner to the medical staff, and the hospital chaplain then notified that a congregant is in the hospital and in need of spiritual support.

Once hospitalized, the hospital chaplain (and visiting pastor) would now provide support to the congregant and seek to address any spiritual distress created by the hospital admission. In addition, they can identify any issues that might need to be addressed by the pastor and/or faith community nurse post-discharge. This suggestion will need to be presented and justified to hospital administrations before it can be actioned.

6.4 The actioning of a spiritual care discharge plan

While in hospital, a patient would also be assessed by the outpatient/community chaplain for potential needs (if the patient desires and qualifies for a support team post-discharge). Upon discharge, the patient can be given a spiritual care discharge plan which summarizes concerns discussed during hospitalization and identifies any additional spiritual care needs.

The outpatient chaplain notifies the pastor and/or faith community nurse of the patient's discharge and the spiritual care discharge plan.

If the patient does not attend a local congregation and desires ongoing spiritual support, the community chaplain seeks to coordinate care from a local church that matches with the patient's preferences. With permission, the community chaplain arranges to meet with the patient in the community to make sure they are adjusting to the outpatient setting until support from the local church or support team is established.

6.5 Transformational leadership

Not all professional healthcare personnel may welcome this because they may perceive it as unnecessarily complicating their jobs and as Osmer (2008, 178) comments, also as a loss of, "power and control." Local congregational leaders may also resist this since they are content with the existing arrangements, feel overawed by the medicalization of dying and feelings of inadequacy and would see it as being an unnecessary complexification of their congregational responsibilities. It is therefore anticipated that its implementation will require a transformational leadership approach involving deep change and thus may well be a lengthy process arousing significant opposition (Osmer 2008, 177–178).

7. Addendum

7.1 Research update concerning the COVID-19 pandemic

As may be expected the author, being a hospital chaplain, was and is very much involved in the pastoral care of medical staff and the dying as a result of the ongoing COVID-19 pandemic. Despite the heroic sacrificial care of medical health personnel at this time, it would be remiss not to comment on how the healthcare system functioned in this crisis and if it confirmed the results of this research.

The researcher audited 3,419 charts of patients who had been discharged with a positive COVID-19 diagnosis over a 120-day period. Results were consistent with this research and found that the percentage of patients who had a medical advance directive in their electronic medical record at the time of discharge was 21 percent (considerably under the national average). Of those who were discharged due to death (17 percent), 22 percent had an advance directive in their medical record. Again, consistent with research findings, Black patients had the lowest level of advance directives compared to White patients (15 percent vs 26 percent). Data according to faith tradition (or denomination) also proved reliable with 14 percent of evangelical, Pentecostal and Charismatic traditions having an advance directive compared to the greater Protestant group (20 percent) and Catholics (27 percent).

Thus, results from the COVID-19 audits did not show a significant divergence from non-pandemic patient characteristics. However, the ramifications of not having a formal indication of patient preferences for treatment, as seen in an advance directive, now had detrimental effects on patients/families and indescribable moral distress for those charged with providing medical care. Pre-pandemic, medical providers could rely on spouses or family members to provide insight and guidance as to a patient's possible desire for treatment given a life-threatening event. However, the pandemic altered all hospital policies regarding patient visitors. Due to the great risk of infection, family members who would otherwise act as surrogate decision makers were now not present. Given the volatile nature of the disease, there were many times medical providers could not interact with surrogate decision makers in real time and were therefore left to make decisions for care that may or may not have been consistent with the patient's values and goals of care. The COVID-19 pandemic has only emphasized the importance of Advance Care Planning and the need to greatly increase education and engagement with all adults.

Works Cited

Alters, Sandra M. 2006. *Death Through the Ages: A Brief Overview*. Detroit: Gale Cengage.

Ariés, Phillipe. 1974. *Western Attitudes Toward Death: From the Middle Ages to the Present*. Baltimore: John Hopkins University Press.

Balboni, Michael J., et al. "Nurse and Physician Barriers to Spiritual Care Provision at the End of Life." *Journal of Pain and Symptom Management* 2014:400–410.

Balboni, T. A., L. C. Vanderwerker, and S. D. Block. "Religiousness and Spiritual Support Among Advanced Cancer Patients and Associations with End-of-life Treatment Preferences and Quality of Life." *Journal of Clinical Oncology* 2007:555-560.

Basta, Lofty L. 1996. *A Graceful Exit*. New York: Plenum Press.

Behavioral, President's Commission for the Study of Ethical Problems in Medicine and Biomedical. 1981. *Defining Death: Medical Legal, and Ethical Issues in the Determination of Death*. Washington, DC: U.S. Government Printing Office.

Bonhoeffer, Dietrich. 1959. *The Cost of Discipleship*. London: SCM Press.

Brandt, A. and Gardner, M. 2000. "The Golden Age of Medicine?" In *Medicine in the Twentieth-Century*, edited by Cooter and Pickston. Netherlands: Hardwood Academic Publishing.

Clark, P. A., M. Drain, and M. Malone. "Addressing Patient's Emotional and Spiritual Needs." *Joint Commission Journal on Quality and Safety* 2003:659–670.

Curlin, Farr A., Marshall H. Chin, Sarah H. Sellergren, Chad J. Roach, and John D. Lantos. "The Association of Physicians' Religious Characteristics With." *Med Care* 2006:446–453.

DeSpelder, Lynne and Albert L. Strickland. 1983. *The Last Dance: Encountering Death and Dying*. New York: McGraw Hill.

Evans, Abigail. 2011. *Is God Still at the Bedside*. Grand Rapids: Eerdmans Publishing Company.

Fontana, Andrea and Jennifer R. Keene, eds. 2009. *Death and Dying in America*. p. 14. Cambridge: Polity Press.

Pope Francis. 2013. "Homily of the Holy Father Pope Francis." Online article. Accessed November 9, 2018. http://w2.vatican.va/content/francesco/en/homilies/2013/documents/pap a- francesco_20130314_omelia-cardinali.html

Health Care Ministry Association. 2013. "History of Healthcare Chaplaincy and HCMA." Online article. Accessed December 31, 2017. http://www.hcmachaplains.org/history- of-healthcare-chaplaincy-and-hcma/

Institute of Medicine. 2015. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Consensus, Washington, D.C.: National Academy of Sciences.

Kayne, D. C. n.d. "Dying Well and Assisted Suicide, and the Law." Online article. Accessed on February 27, 2018. http://old.usccb.org/prolife/programs/rlp/99rlkave.shtml

Koenig, Harold. 2007. "Religion, Spirituality and Medicine in Australia: Research and Clinical Practice." *Medical Journal Australia* 186:10, S45–S46.

Kristeller, J. L., C. S. Zumbrum, and R. F. Schilling. 1999. "I Would if I Could: How Oncologist and Oncology Nurses Address Spiritual Distress in Cancer Patients." *Psychoonocolgy* 451–458.

Larimore, Walter. 2001. "Providing Basic Spiritual Care for Patients: Should it Be the Exclusive Domain of Pastoral Professionals." *American Family Physician* 36–41.

Luzarraga, R. "Accompaniment with the Sick: An Authentic Christian Vocation that Rejects the Fallacy of Prosperity Theology." *Journal of Moral Theology* 8(1):76–88.

McCord, Gary. 2004. "Discussing Spirituality with Patients: A Rational and Ethical Approach." *Annals of Family Medicine* 356–361.

Norris, Kaye, Gretchen Strohmaier, Charle Asp, and Ira Byock. 2004. "Some Clergy Lack Training in End-of-life Care." *Health Progress* 34–39, 58.

Moltmann, J. 1993. *The Crucified God*. Minneapolis: Augsburg Fortress Publishers.

Osmer, Richard. 2008. *Practical Theology*. Grand Rapids: Eerdmans Publishing.

Puchalski, C. et al. 2009. "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference." *Journal of Palliative Medicine* Vol. 12, No. 10.

Rogne, L, and S. L. McCune. 2014. *Advance Care Planning, Communicating About Matters of Life and Death*. New York: Springer Publishing.

Silverstri, G. A., S. Knttig, J. S. Zoller, and P. J. Nietert. 2003. "Importance of Faith on Medical Decisions Regarding Cancer Care." *Journal of Clinical Oncology* 1379–1382.

Vanhoozer, K. 1997. "Human Being, Individual and Social." In *The Cambridge Companion to Christian Doctrine*, edited by C. Gunton, 158–188. Cambridge: Cambridge University Press

Ware, K. 1995. *The Orthodox Way*. rev. ed. Crestwood: St. Vladimir's Seminary Press.

White, R. 2011. *Walking Together in Solidarity: A Theology of Accompaniment*. Chicago: Global Mission Unit of ELCA.

Younan, M. 2005. "Theological Reflection and Testimony." In *Theological Reflection on Accompaniment*. Geneva: World Council of Churches.

Crandell, Zander. 2000. *Human Development*. The McGraw-Hill.