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# The Holy Week of Our Lives: How to Help Faith Leaders Have Conversations Around Death and Dying in Our Faith Communities.

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

by

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Lancaster, Pennsylvania May 2020 The Holy Week of Our Lives © 2020, Kimberly Mae Ruth Stryjak

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

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#### **Abstract**

This project seeks to demonstrate the critical need for general conversations on death and dying in our faith communities. Using theologies on death and dying, Christian practices, as well as current books, journals, and first hand experiences, the project presents ways in which conversations on end-of-life are happening in society and in our faith communities. It also presents the deep need for these conversations to continue to take place and how we can support our faith leaders in having these conversations in our faith communities. The project proposes a workshop as a resource to help faith leaders and faith communities have general conversations on death and dying. The workshop is designed based on specific responses to surveys given to faith leaders in the Pennsylvania Southeast and Pennsylvania Northeast conferences of the United Church of Christ; interviews with 10 of these faith leaders and surveys to 5 congregations in this region. In those surveys, faith leaders identified what conversations on death and dying they have within their faith communities and also their desired resources and elements for a workshop for education in end-of-life issues and death and dying. The faith community members identified what conversations they have had in faith communities on death and dying and what information would be beneficial in future conversations on this topic. The end result of this project is the demonstrated need for additional resources to support faith leaders in having conversations on end-of-life planning in their faith communities. An additional resource proposed in this project is an annotated bibliography of resources on death that faith leaders can use to increase comfort in having end-of-life conversations in their faith communities.

This project is dedicated to all those who have supported me in this journey.

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# **Contents**

Abstract	i
Acknowledgements	vii
Introduction	1
Why Do Conversations on End-of-life Matter?	1
1	10
Conversation on End of Life	10
Significance of Conversations	11
Faith and Death	12
Central Terms	15
Type of Project and Research	18
Why this Topic?	20
2	22
How Did We Get Here?	22
What History Can Teach Us	24
What Faith Communities Have to Say	26
How Faith Impacts Death	29
Preparing for Conversations on Death	31
3	33
What Conversations on Death and Dying are Happening in Faith Communities?	33
Courses/Training of Faith Leaders	35
What is Going-on?	41
Thinking about Death	45
Funerals	48
How Prepared are We?	49
Faith Community Participation	52
Conversations around Death	53
Why Not?	55
What's Needed	56

Conclusion	58
4	60
Workshop on End of Life	60
Introduction	61
Professional Panel	63
Theologies	64
The Dying Process	70
Faith Leader Panel	81
Case Studies/Shared stories	82
Review of Annotated Bibliography	83
What Do We Say?	84
Visiting and Meeting	85
Sermon Series/Book Studies	86
Caring for Our Loved Ones	87
5	90
Where Do We Go From Here?	90
Annendix	95

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### Introduction

# Why Do Conversations on End-of-life Matter?

Death is a dirty word. Well, at least it seems to be seen that way in our society today. In the United States, death is a feared word, one that is kept on the hush, hush. We don't like to talk about our own mortality, let alone that of a loved one. Death is a part of the life cycle and part of the created order. Death is a universal; every person in their own time and way will face death. However, we very rarely talk about it; we don't mention it. We seem to fear the word and the topic. We go about our days acting like we are immortal, "We know it [death] will happen to us, to those we love, and yet we live in denial." We avoid the topic and instead "talk in metaphors about 'brave battles' and shy away from anything that might remind us of our own mortality." <sup>2</sup> In our hospitals and doctors' offices, we have become so medicalized that we don't want to accept that death is a reality anymore. "Today's medical technologies provide the means to extend a human life span longer than ever before. Ironically, technology also often extends the dying process." We think of death as failure. It is "regarded as the great enemy to be defeated by the greater powers of science and medicine."4 If it is not defeated by medicine, we have failed in some way. Instead of being a natural part of our lives, failure is how death is seen in our medicalized world. It is no longer a part of our created order or part of everyday conversations.

<sup>&</sup>lt;sup>1</sup> Brandy Schillace, *Death's Summer Coat: What the History of Death and Dying Can Tell Us about Life and Living* (New York, NY: Pegasus Books LLC, 2017), 4.

<sup>&</sup>lt;sup>2</sup> Schillace., 8.

<sup>&</sup>lt;sup>3</sup> C. Ben Mitchell and D. Joy Riley, *Christian Bioethics : A Guide for Pastors, Health Care Professionals, and Families*, B & H Studies in Christian Ethics (Nashville, Tennessee: B&H Academic, 2014), 71.

<sup>&</sup>lt;sup>4</sup> Allen Verhey, *The Christian Art of Dying: Learning from Jesus* (Grand Rapids, Mich: William B. Eerdmans Pub, 2011), 3.

In today's society we fear that if we utter the word, death will be upon us. Instead, we need to turn back to the "...importance of seeing death as part of life and not as simply medical failure."<sup>5</sup>

In 2018, a Stanford School of Medicine study found that "80% of Americans would prefer to die at home, if possible." However, only 20% died at home; 60% died in acute care hospitals and 20% in nursing homes.<sup>6</sup> The ideal death the majority of Americans would prefer is not happening. Advancements in medicine have made it possible for people to continue to return to the hospital for treatment, ultimately to die in the sterile setting around them. Rather than talk with their families and doctors about their wishes, about wanting to go home to die, they continue the silence and medical treatments until it's too late to die in the comfort of their own beds. Medical treatments have given us many blessings and have shown God's healings in many ways. However, we have also taken God out of the equation when we continue to put medical treatments above quality of life, when medical treatments surpass their need, and when we hang on only to suffer more. In our society, we have taken away our ability to be the owners of our own death, the masters of death have "...pass[ed] from the dying man himself to his family... [and] today the initiative has pass[ed]...to the doctor and the hospital team." We have allowed the advancement of medicine to become the voice of our dying. We instead need to "join the chorus of voices that have complained that medicalization of death makes dying well difficult."8

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<sup>&</sup>lt;sup>5</sup> Kelli I. Stajduhar and Harold G. Coward, *Religious Understandings of a Good Death in Hospice Palliative Care*, SUNY Series in Religious Studies (Albany: State University of New York Press, 2012) 126, https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=nlebk&AN=463958&site=eds-live&custid=s9005776.

<sup>&</sup>lt;sup>6</sup> "Where Do Americans Die?," *Palliative Care: Education & Training*, April 21, 2013,

<sup>&</sup>lt;sup>7</sup> Philippe Ariès, Western Attitudes toward Death: From the Middle Ages to the Present, Johns Hopkins Symposia in Comparative History 4th (Baltimore: Johns Hopkins University Press, 1974), 89.

<sup>&</sup>lt;sup>8</sup> Verhey, *The Christian Art of Dying*, 3.

We need to talk about death and dying in our churches and communities today. Death needs to be something that is honored and celebrated. Death needs to return to being a natural part of our everyday lives, something we honor and then mourn openly, in that way becoming an accepted part of our culture and part of who we are. Death doesn't need to be the scary elephant in the room, but rather the natural part of life that it is, for us and for our loved ones. Death does not need to be seen as a failure, but rather as the transition from this life to the next. It is a spiritual process that we as United Church of Christ faith leaders should honor and discuss with our people, just as Jesus discussed death with his disciples. As protestant Christians we celebrate the week leading to Jesus death. Holy Week is one of the most important weeks in our liturgical calendar. The Last Supper is celebrated as Jesus makes his way to Jerusalem, to his place of death. At that Last Supper, Jesus himself is having his final goodbye/conversation with his disciples, telling them what he wants them to do and getting his affairs in order. Yet in our everyday lives we don't apply the model given by Jesus at the end of his life to end-of-life care. Sure, we speak about Jesus' death in Holy Week, but we do not often talk about death in our own lives. We do not live out or relate this time in Jesus' life to our own. He was open with his disciples about his own death, but we do not do the same with our loved ones. We need to change that and we need to break the norms of society as Jesus did. We need to focus on the holy week of our own lives, just as we faithfully walk with Jesus during Holy Week. I believe churches are obligated and called to do this work in our communities.

As Christians we believe in the resurrection, in life after death. In order to truly honor the resurrection, we need to make death the reality it is. We need to be open about it and talk with one another. Often as a hospice chaplain, I walk into a visit and the first thing the family says is, 'Don't mention the word hospice' or 'Don't tell him (her) s/he is dying.' How are our

loved ones supposed to say goodbye? How are they supposed to find peace in end-of-life if they are not aware it is the end for them? How are we doing justice to our families and communities by not giving them the ability to choose, if possible, how they want their end-of-life to go? Dying with grace and honor is how we can keep dignity in the dying process. Having conversations and encouraging our congregations to have conversations about end-of-life care and their wishes will help those we minister to find meaning and purpose in their dying. This reminds me of a song by a country band named Old Dominion. The song is titled, "No Such Thing as a Broken Heart." The band members said that this song is about facing the world headon and not letting life get you down. The chorus states "Love like there is no such thing as a broken heart." I think this type of love can be seen in open conversations about death and dying. As loved ones sometimes we don't want to think about those around us dying and not being with us anymore. We want to protect ourselves from the pain that losing the special person in our life will bring. However, we are called to love them enough to be open to having the conversations about end-of-life care, open to make sure their wishes are met, open to love like there is no such thing as a broken heart. When we do this, we give ourselves and our loved ones the dignity or the honor and respect that we all deserve.

I was sitting in my dad's hospital room hanging out with him. It was his birthday and the day he found out he had cancer. Earlier that day the doctor had informed my dad that he had multiple myeloma – a cancer of the blood that is not leukemia. The doctor had given him some information about the type of cancer he had and told my dad to follow up with an oncologist. So there we were hanging out on this day of mixed emotions. I really don't remember much about

<sup>&</sup>lt;sup>9</sup> Songfacts, "Lyrics for No Such Thing as a Broken Heart by Old Dominion - Songfacts," accessed February 10, 2020, https://www.songfacts.com/lyrics/old-dominion/no-such-thing-as-a-broken-heart.

the time after I learned my dad had cancer. I know I hung out with my dad that day, but don't remember much about what was said or what we did. The one thing I do remember, and will always remember, is as we sat there that day, just the two of us, my dad turned to me and said, "I hate this for your mom. She doesn't deserve this. I have no regrets, I have had a great life and have great kids, so if it is my time, I am ready...but your mom doesn't deserve this." Five months later, after an exhausting and wearing battle, my dad died. He declined so quickly that he ended up dying in the hospital. Although he was surrounded by family, his cancer was so aggressive and moved so quickly taking over his body that we didn't get to talk about his wishes. I am not sure if he and my mom had these conversations, but as a family we did not get to discuss it directly with my dad. However, that short conversation, I had with him the day he was diagnosed, allowed me to know that even though he wanted to fight and survive, he was prepared to die. It has been twelve years since my dad has passed and I do not doubt that God has used that experience to lead me into my calling in ministry and ultimately to this project. That is why I have a passion for this project. That is why I believe it is important for our faith leaders to be having conversations on end-of-life care and death and dying in our faith communities. This is why I believe these conversations need to become more common-day discussions. So those who are dying can express themselves and families can feel peace in the difficult times of grief. In our faith communities we need to honor our mortality; we need to recognize the finality of life and the gift that God has given to us that this life is not the end. In order to do this, we need to start having conversations with one another about our final wishes, about our end-of-life and dying experience, and about Jesus' model of Holy Week for our own lives. We need to ask the question: "How do we as faith leaders and faith communities have a meaningful presence in conversation about end-of-life preparations?"

This paper will seek to answer this question and propose ways in which we can be a part of these conversations around death, dying and end-of-life. The first chapter in this paper will discuss the research topic surrounding conversations on death and dying in the United Church of Christ faith communities in eastern Pennsylvania. This chapter will include my background as the author and my qualifications to write a project on the topic of death and dying. There will be discussion on why this topic of research was chosen and what the significance of the research is for ministry. I include in Chapter 1 my own theology as it impacts my paper, for I believe it is important for the reader to know what my foundation is. I also believe that if I am going to be asking people to think about their own theology about the end-of-life, then I too needed to reflect on this as part of writing this project. Chapter 1 will also include some central terms so that the reader understands what the words mean for the context of this project. Finally, this chapter also includes my hypothesis and research question and the methodology in which I will use to test the hypotheses and answer the research question.

As Chapter 2 begins I move into the background of the research topic itself. This chapter looks at the topic of death in our society and how it has changed over the years. The chapter highlights some of the known authors who have written on the subject of death and dying. It looks at death from the middle ages with author Philippe Ariès and moves into today's medicalized death in hospital. This chapter discusses some of the major blockades when it comes to talking openly about death and dying, such as the fear of death or seeing death as a failure. It talks about the death movement of Elisabeth Kubler-Ross with other authors encouraging us to talk about our end-of-life before we miss the opportunity. Chapter 2 then goes on to discuss the Christian faith as related to death and theologies on death and dying and how these things can impact not only our decisions at the end of life, but also how we die. The

chapter will conclude with how conversations around death and dying can be part of our faith communities.

Chapter 3 includes the explanation of the research I did for this project and the analysis of that research. In this chapter I identified themes that presented themselves through the research and a thematic discussion of the responses provided by survey and interview questions that pertain to that theme. The chapter first looks at the themes related to the research with the faith leaders and then addresses the themes found in the research with faith communities.

The first theme discussed from the research with the faith leaders is what courses/training faith leaders have had in end-of-life. This theme not only looked at what education faith leaders have had on the topic of death and dying but also where this training took place.

The next theme in this chapter is what conversations on death and dying are happening in our faith communities. I thought it was important to get an idea of what, if anything is already happening in our faith communities as it directly correlates to my hypothesis and research question. This theme also looked at how these conversations where happening in the faith communities that are having the conversations.

The next theme in Chapter 3 is on death and the dying process. My research around this topic intended to get people to think about the dying process and what is important to them when they face their end-of-life. It also brought the topic of death and dying to a personal level that individuals could connect with.

Related to the topic of death was the theme that emerged on Funerals. It was a point of discussion brought up many times throughout the interview process with UCC faith leaders in southeast and northeast Pennsylvania and I thought it important to discuss the significance this had for the faith leaders and also in the research on death and dying conversations.

The last theme in the research with the faith leaders is whether the leaders themselves felt comfortable or equipped to have conversations on death, dying and end of life with their faith communities. This directly relates to my hypothesis and is an important discussion point in my research. This section ends with the outcome of my hypothesis and where that leads in my project.

Chapter 3 then moves into discussion of the research done within the faith communities in Pennsylvania Southeast and Penn Northeast conferences of the United Church of Christ. The first theme discussed here is what conversations on death and dying do those in faith communities remember having as part of that faith community. This topic is important to analyze to see the comparison on what the faith leaders say they are doing within the context of their faith community and what the people are experiencing.

From there I looked at why conversations might not be happening and what are the barriers present that stop people from having conversations around death and dying with their loved ones or what is stopping them from joining conversations that might be happening in their faith community. If I am going to suggest ways in which we can join the conversation around death and dying in our faith communities then I need to know what is stopping people from having these conversations in order to help address these issues.

Chapter 3 then closes with the theme what's needed in conversations around end-of-life in our faith communities? It was important to me to see what the people in our faith communities desired or felt they needed in having conversations about death, dying and end-of-life care so that any resources or trainings that I suggest could address these needs.

Chapter 4 discusses what was created out of my research and what this project has to offer. It provides an explanation of the new resources that I created out of this project for faith

leaders. The chapter first goes through the new workshop I created for faith leaders, addressing each part of the workshop, the analysis of why it was included, and the details of how that section would run during the workshop. The last part of Chapter 4 includes an explanation of the different resources on death, dying and end-of-life included in the annotated bibliography that I created for faith leaders. The discussion includes what can be found in the resources along with what ways the faith leaders could use the resources.

Chapter 5 is the last chapter in this project. It includes the significance of my conclusions along with pastoral implications and further research areas. After the conclusion of Chapter 5 there are appendices that include the research questions, outline of the workshop, presentations within the workshop, and the annotated bibliography.

### Conversation on End of Life

How can the church help break the silence around death and dying in our society today? From conversations with fellow clergy colleagues and lay people at different church events, there is an immediate interest and desire for these conversations on death and dying. People seem eager to enter into a conversation with me about how churches can talk about death and dying. Many people make comments such as "This is much needed work" or "This is an important topic." The desire for this topic is prevalent in society as evident by events such as "death cafes" popping up around the country as places to go and have conversations about the end-of-life and our mortality. There is a website where you can find death cafés in your area, get together with others to drink tea, eat and discuss death. As a hospice chaplain and one who cares about the institution of the church, I believe my voice and perspective can add value to this dialogue. I believe talking about death and dying is important. By having conversations around our mortality, we can help our faith communities break the silence around death and dying so individuals are able to live life to the fullest and do justice to the experiences of those who are in the dying process.

The fear of death has seemed to take over in our society; so much so that the word death has become a "bad" word or taboo. Intentional conversations in our United Church of Christ faith communities on death and dying can help bridge the gap between those conversations that are happening out in the secular society and how we in the Christian faith can enter into the conversations and provide a meaningful presence in those conversations. An important aspect in breaking the norms in society is to think about what role the church plays in guiding these

conversations around mortality and how faith leaders can help initiate these conversations in our faith communities.

# **Significance of Conversations**

The Christian faith is a faith of birth, death and resurrection. This is what we teach and believe, yet we often don't live out this theology or apply it to our individual lives. We don't talk about how death and resurrection are part of our everyday lives. We do not discuss our own mortality or our beliefs about end-of-life and dying. The church could be a place of encouragement and meaning to help prepare individuals for the end of life. Having conversations around death and dying would help honor people for who they are and how they want to live, even during the dying process. If we can start having general conversations around death and dying in our faith communities then people could start to gain a comfort level with these conversations. Becoming comfortable will allow people to start talking more freely and openly about their own mortality; bringing the conversations around death and dying into their personal lives with friends and family. In creating this safe place and level of comfort with conversations on mortality, we are giving our congregations an opportunity to voice their desires about their ideal death. We are giving individuals the ability to face mortality and possibly the fear of death head on, surrounded by love and support. Having open conversations around death and dying is empowering and allows our congregants to focus on dignity of life and peace at the end of their lives.

As we gain comfort in having these conversations within our faith communities, my hope is that we can become more open and comfortable having conversations around dying churches.

Churches are dying and many times it is not until the "last days," when the faith communities

feel defeated and are at a place of closing their doors, that the faith communities finally acknowledges they are at the end of their life as a church. But, if we begin to have more conversations around death and dying in our faith communities and become more comfortable in our personal lives with these conversations, then I think that these conversations could extend to other areas beyond individual death. As we begin to gain comfort with the topic of death and as we begin to be at ease in these conversations, then the members of a faith community will be more open to having conversations about the end-of-life wishes for their faith community if it is dying. Together they could talk about how they want to live their last days as a faith community, what legacy they want to leave behind to the next generations of faith, and what their resurrection might look like. This resurrection might include a new group of faith meeting in their worship space and will those that were part of the dying faith community be a part of this new one? Will this dying faith community sell there building and move on? In our faith communities, if we were able to get to a place of comfort when talking about our own death and dying process, an unintended outcome could be that we open up the conversation to include the death of our churches. While not the focus of this research paper, the possible unintended outcome of being able to talk about our faith communities that are dying would be significant for the place in which the church finds itself today.

# **Faith and Death**

As Christians we are a people of birth, death and resurrection. We are born into this world as children of God, created and loved by God. We are baptized to recognize that the love of God unites us to Christ, providing our hope in resurrection. Yet in life, and also in death, there can be suffering. Bad things happen because it is part of our created order, part of our fallen-

ness. We are a created and creating people; a world that has free will which at times can lead to suffering. That is why we need God and why God has given us each other. God is with us in that suffering and can give us strength and can provide us with others to help us get through our suffering. Sometimes in our suffering there are no words to say; there is only being present and showing love to one another.

God provides grace out of the suffering and death through resurrection. We experience resurrection in our lives in many different ways. Each loss and change comes with grace and new life. When we come to the end of our physical lives and die, (in death) resurrection unites us for eternity with Jesus Christ. This is the promise of our God and the hope we have in our faith. The souls of all the people who lived on this earth will be with God, in peace, after they die. This is known as universal salvation or the belief that God will save all people through the redeeming work of Jesus Christ. In Christian belief "...each individual, whether Christian or not, believer or not...is in the image of God" and "No individuals life may be judged as worthless." Therefore, if we are all created in the image of God, we are all reconciled back to God at the end of life. God's will is ultimately done and God's power ultimately wins out. In the end we are all God's children and get to be in a place of peace beyond all understanding.

In the UCC funeral liturgy this is seen in the commendation when we offer up the person who has died into God's merciful embrace and shelter of care. This is the time in the service that no matter who the person was, and no matter where they were on their faith journey, God's embrace brings the person into eternity with God. As Luke 3:6 (New Revised Standard

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<sup>&</sup>lt;sup>1</sup> Kelli I. Stajduhar and Harold G. Coward, *Religious Understandings of a Good Death in Hospice Palliative Care*, SUNY Series in Religious Studies (Albany: State University of New York Press, 2012) 141-142, https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=nlebk&AN=463958&site=eds-live&custid=s9005776.

Version) states when recalling the words of Isaiah, "and all flesh shall see the salvation of God" each person gets to experience this salvation and grace of God. Again we are told this in Romans 5:18 (New Revised Standard Version) "Therefore just as one man's trespass led to condemnation for all, so one man's act of righteousness leads to justification and life for all."

United Church of Christ churches in eastern Pennsylvania have a unique opportunity to help break the societal norms and be leaders in bringing conversations about end-of-life care into the forefront of everyday life. "...communities of faith bear a responsibility to teach the rest of us how to die well." I believe that as church, we are called by God to love others by using Jesus as a model for our lives. Jesus spoke about his death and prepared his disciples for his death as a part of his ministry. During Holy Week Jesus got his affairs in order. In Luke 19:46 (New Revised Standard Version) He cleared the temple reminding those around him what the house of God is for "My house shall be a house of prayer." He talked to his disciples about faith and prepared them for his death during this week. He also shared in a last meal with his disciples, instructing them on the first communion, his legacy for us Christians to share in his grace and promise of eternal life. Holy Week is Jesus' preparing for his death, and as those called to follow Jesus and be teachers and livers of faith, it is our obligation to love each other by talking about and helping one another plan for end-of-life, just as Jesus did.

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<sup>&</sup>lt;sup>2</sup> Allen Verhey, *The Christian Art of Dying: Learning from Jesus* (Grand Rapids, Mich: William B. Eerdmans Pub, 2011), 26.

### **Central Terms**

The National Institute on Aging describes *end-of-life care or EOL care* as "...support and medical care given during the time surrounding death." This project focuses on thinking about this time in our own individual lives and helping us think through things that will be important to us during this time. End-of-life will happen for each of us, and having conversations on our hopes and wishes, if we are able to have a choice in our care at this time, could help provide us with peace and comfort.

An important commentator, Henri Nouwen describes spirituality as a "…basic quest for meaning." Another biblical and spirituality writer, J.P. Hartin takes it one step further and discusses *Christian spirituality* as "The search to integrate life through the transforming experience of encountering God in Christ. This experience animates and gives life meaning and direction. For the purposes of this project, looking at one's spirituality and what brings meaning into their life can also help them understand what will be important to them in the dying process.

**Death** in this project refers to "total death" or death of the whole organism.<sup>6</sup> This is when all of the organs and systems within our body cease to function and will not be revived. Death is part of life as it is the end of our human life here on earth. What happens at the end of life for each of us affects our death and dying process.

<sup>&</sup>lt;sup>3</sup> "End of Life," National Institute on Aging, accessed May 5, 2019, https://www.nia.nih.gov/health/end-of-life.

<sup>&</sup>lt;sup>4</sup> Henri J. M. Nouwen, Michael J. Christensen, and Rebecca Laird, *Spiritual Direction: Wisdom for the Long Walk of Faith*, 1st ed (San Francisco: Harper San Francisco, 2006), 9.

<sup>&</sup>lt;sup>5</sup> P. J. Hartin, *Exploring the Spirituality of the Gospels* (Collegeville, Minn: Liturgical Press, 2011), 6.

<sup>&</sup>lt;sup>6</sup> Hans Küng, Walter Jens, and Philip Lamantia, *Dying with Dignity: A Plea for Personal Responsibility* (New York: Continuum, 1998).

In its simplest form, *afterlife* is the belief of an existence after death.<sup>7</sup> In Christian theology it is often a belief in heaven (and sometimes hell). Intertwined with the belief of an existence after death, is how we get to that existence...is it based on our works (actions and choices here on earth) or by faith alone? Individuals will often wonder about afterlife asking questions such as: who will be there, what does it look like, how will it feel? The questions that surround the afterlife are important because they "...help us to begin the process of speaking more openly about death and preparing for it.<sup>8</sup> The afterlife for many is a belief that brings comfort when facing terminal illnesses. The belief that we move from this world to another once we die can bring hope that this is not the end. This belief in an afterlife also brings comfort to those who are left to grieve. In many ways the belief in an afterlife is complex but very important in one's dying journey.

Faith communities in this project are referring to United Church of Christ churches within eastern Pennsylvania that gather together and worship our triune God. These faith communities are the congregations which I am challenging to respond to Jesus' love of one another, which I believe is part of our call from God, through conversations around end-of-life care so that people can experience peace in their dying process.

Faith Leaders, within the context of this project, are clergy and pastors that lead congregations of United Church of Christ churches in eastern Pennsylvania on a regular basis. They are supported by an association or conference within the United Church of Christ. Faith leaders have answered a call from God to do God's work in the world and show God's love to

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<sup>&</sup>lt;sup>7</sup> "Afterlife | Definition of Afterlife by Merriam-Webster," accessed May 22, 2019, https://www.merriam-webster.com/dictionary/afterlife.

<sup>&</sup>lt;sup>8</sup> Virginia Morris, *Talking about Death Won't Kill You* (New York: Workman, 2001), 108.

all. Part of this love is to speak about our own mortality, because "To deny that we are mortal is, in a way, to deny God's creation."<sup>9</sup>

**Legacy** is what we leave behind when we die to those who are still living. This is often thought of in the form of a tangible gift, but can also be memories of experiences and relationships that loved ones can treasure.

The fear of death has been termed *death fear or death anxiety* within our society. Being mortal makes us vulnerable and also gives us a deep sense of finality to our lives. <sup>10</sup> When we feel threatened in the face of our own mortality we begin to experience anxiety over the situation.

Medicalization of death is the way advancements in medicine have affected the dying process. With prolongation of life, death more commonly occurs in sterile places such as hospitals and intensive care units rather than in the home. End of life was once something that happened in homes surrounded by loved ones and was a normal occurrence in communities. However, medical advancements have taken death out of our homes and into the hospitals. This move to the hospital "...spelled the end of the 'dying role' with its rituals and communities." As medicine takes over to provide the hope and miracle cure people are searching for, death and "...the very notion of 'the natural' is vanishing from our vocabulary."

<sup>&</sup>lt;sup>9</sup> Martha R. Jacobs, A Clergy Guide to End-of-Life Issues (Cleveland: Pilgrim Press, 2010), 5.

<sup>&</sup>lt;sup>10</sup> Scott David Landes and Monika Ardelt, "The Relationship between Spirituality and Death Fear in Aging Adults," *Counseling et Spiritualité* 30, no. 2 (2011): 89.

<sup>&</sup>lt;sup>11</sup> Verhey, *The Christian Art of Dying, 14*.

<sup>&</sup>lt;sup>12</sup> Daniel Callahan, "Death, Mourning, and Medical Progress," *Perspectives in Biology and Medicine* 52, no. 1 (2008): https://doi.org/10.1353/pbm.0.0067.

### **Type of Project and Research**

Faith leaders are in important positions to have conversations around end-of-life as it is part of our Christian theology. However, in my experience and conversation with others, conversations around death and dying are limited in our faith communities. It is my assumption that faith leaders don't know the resources that are available to them for end-of-life conversations with those they serve. Faith leaders also don't feel comfortable using the resources they might have to start conversations around death and dying in their faith communities, especially with those who may not initiate these conversations or those who display discomfort with the topic. The hypothesis that feelings of inadequacy in faith leaders is what is causing conversations around end-of-life, outside of impending death, not to occur will be tested. A constructive method of research and qualitative research was done to develop a workshop that can be offered at an association or a conference level within the United Church of Christ (UCC) to educate faith leaders around preparing for end-of-life conversations. This workshop will help introduce general concepts around death and dying, start the conversation with the faith leaders and help faith leaders gain understanding and use the resources that are available to them for end-of-life conversations. The workshop will also be a resource for the faith leaders as a model in how to continue the conversation around this important topic within their own faith community. This resource is vital to our faith communities and an important step for our faith leaders to be able to have conversations on death and dying in places of ministry.

In order to create this workshop, I will need to learn through research the way in which dying has changed in America. I know that medical advancements have made a huge difference on life expectancy and the ability for doctors to keep patients "alive." But learning more detail around these changes will help me have a better understanding of how people experience death

my own experience with people who are nearing death, I will learn what the needs of people who are dying are to gain a better understanding of what kind of resources pastors may need in order to have end-of-life conversations with their faith communities. Learning the connection of our Christian faith to death and dying will also be beneficial to this resource. While I have my own understanding, I have not studied how our faith intersects with different aspects of death and dying. This learning will be of great value as I enter into conversations with faith leaders in our faith communities.

The qualitative approach to research will allow me to gain data for a better understanding about whether faith leaders in my area are having general conversations around end-of-life care. Surveys to UCC faith leaders in eastern Pennsylvania will be distributed to find out ways, if any, they currently approach these conversations in their places of ministry. Interviews will also be done with UCC faith leaders to learn:

- if they are having conversations about morality and end-of-life
- what kind of conversations/programing on end-of-life and the dying process is already happening within our faith communities
- what resources faith leaders use at this time in having conversations on death and dying in their congregations
- what resources they use to support their conversations when dealing with a congregation member who is dying and their family.
- what faith leaders need or know or would like to learn in a workshop in order to have conversations around death and dying in their faith communities.

Surveys will also be distributed to 5 UCC congregations in eastern Pennsylvania to gain the perspective that the congregations members have on what programs or conversations on death and dying are happening within our faith communities. This survey will assess:

- the need for these conversations
- what, if anything, is keeping people from having these conversations with loved ones
- what ways individuals have experienced or participated in conversations around end-oflife care
- what individuals would find beneficial in conversations around death and dying
- if what the faith leaders say or feel that they are doing with programs, sermons, bible studies and conversations is perceived in the same way from the congregation members.

This survey allows me to give UCC congregations in eastern Pennsylvania a voice in this project to address if this is a topic that interests those in our faith communities and whether they feel that programs or conversations around mortality and end-of-life care would be beneficial for our faith communities to initiate.

## Why this Topic?

Through five units of Clinical Pastoral Education, which comprised of a summer intensive course and one year residency program and experience as a hospice chaplain in ministry, I have had training in caring for individuals during different life events. This included caring for people as they approached the end of life and also for individuals in an acute care hospital where individuals and families had to make decisions to stop care or remove life support. These experiences have given me the knowledge, confidence and desire to conduct this research project. As a hospice chaplain I bring expertise to the conversations around death and

dying. Being required to have these conversations on an almost daily basis, I have started to think about what would be helpful in facilitating these conversations within our faith communities. I also bring a passion to provide people with the ability to live the end of their lives to the fullest and to find peace and comfort as they approach death and move through the dying process and transition into the next life.

My personal experience of my dad's death has led to a passion surrounding the conversations on death and dying and preparing for the end of life. As I stated in the introduction, my dad didn't get to have conversations with us around his end of life care/plans, as his disease moved much faster than anyone imagined. He was open with us when he got diagnosed about his peace in dying if he was not able to beat the cancer. I found even this small conversation with him brought me peace during his disease process and so I have a passion and feel God's call to help others open up in conversations around death, dying and end-of-life care. The impact the end-of-life has on an individual and their families is great. The ability to talk about the dying process helps individuals come to terms with their own mortality. The dying process gives individuals time to better understand the meaning in life. It is a spiritual experience that brings us face to face with our faith. Having conversations about our end-of-life wishes, allows loved ones to honor their family member/friend, gives meaning to the end-of-life experience and brings peace in caring for the individual as they transition from this world to the next.

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### **How Did We Get Here?**

Phillipe Aries is a well cited author on the history of death. His description starts with what he terms a "tame death," that is a death that was "...both familiar and near, evoking no great fear or awe." In the Middle Ages death was forewarned and accepted, there were rituals surrounding the dying process; death was a public event. "The "deathbed" was a real place, and the dying person usually knew where s/he was and when it was time to assemble the family and call for the priest." The old way of death had a normalcy to it, death was expected. Aries describes death changing in the late nineteenth century into "forbidden death," death that was spared from the one dying. Death became silenced and as it moved from the home to the hospitals there was "...no longer the occasion of a ritual ceremony...death is [now] a technical phenomenon" or as author and historian, who writes about the intersection of medicine, history, and literature, Brandy Schillace puts it "Modern dying is managed dying..."

In our society today we have "...discovered that ...dying can be prevented." Dying has become sanitized and medicalized. Death no longer occurs in homes with the person dying having control over their dying process, directing the rituals and being surrounded by loved ones. Instead, today we focused on "...stalling death entirely and living in a medically extended

<sup>&</sup>lt;sup>1</sup> Ariès, Western Attitudes toward Death, 13.

<sup>&</sup>lt;sup>2</sup> Thomas Lewis, *The Social Meaning of Death*, ed. Renée C. Fox, vol. 447, The Annals of the American Academy of Political and Social Science; v. 447 (Philadelphia: American Academy of Political and Social Science, 1980), 3.

<sup>&</sup>lt;sup>3</sup> Ariès, Western Attitudes toward Death, 86.

<sup>&</sup>lt;sup>4</sup> Ibid., 88.

<sup>&</sup>lt;sup>5</sup> Brandy Schillace, *Death's Summer Coat: What the History of Death and Dying Can Tell Us about Life and Living* (New York, NY: Pegasus Books LLC, 2017), 160.

<sup>&</sup>lt;sup>6</sup> Lewis, *The Social Meaning of Death*, 447:3.

eternity."<sup>7</sup> We have transitioned the masters of death "...from the dying man himself [sic] to his [sic] family...to the doctor."<sup>8</sup> In this medicalization of death, the ability of technology to keep us alive gives us "...choices our parents didn't have about treatment and care, including choices about how much of our care to consign to professionals and how to protect the intimacy and privacy of dying in the midst of loving people who gather to see us home."<sup>9</sup>

In our society we have lost the respect for dying; "...we have become ashamed of death, and we try to hide it, or hide ourselves away from it. It is, to our way of thinking, failure." We think it is failure because we couldn't beat the disease, failure of the medical staff to save us, failure because "Death is the ultimate exclusion from the party, isn't it?" Today, as we experience the death of loved ones, we "...find ourselves conflicted and less willing to see death as 'natural.' If anything, death breaks into our lives as an unexpected surprise." This feeling of failure is not only for those who are dying but it is also reflected in our medical systems. "Some doctors, even today, feel that a death is a failure of their practice of medicine." This fear of failure pushes doctors and the medical system to try everything or to push treatments on individuals that have gotten to the point where treatments no longer assure any additional quality of life. We have lost the value of quality in our lives. We have forgotten that each person is the child of God and instead we see individuals as the illness we need to conquer. In this view we fail to see the whole person and neglect to provide holistic care.

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<sup>&</sup>lt;sup>7</sup> Schillace, *Death's Summer Coat*, 39.

<sup>&</sup>lt;sup>8</sup> Ariès, Western Attitudes toward Death, 89.

<sup>&</sup>lt;sup>9</sup> Marilyn Chandler McEntyre, *A Faithful Farewell: Living Your Last Chapter with Love* (Grand Rapids, Michigan: William B. Eerdmans Publishing Company, 2015), x.

<sup>&</sup>lt;sup>10</sup> Lewis, *The Social Meaning of Death*, 447:3.

<sup>&</sup>lt;sup>11</sup> Virginia Morris, *Talking about Death Won't Kill You* (New York: Workman, 2001), 2.

<sup>&</sup>lt;sup>12</sup> Schillace, *Death's Summer Coat, 8-9*.

<sup>&</sup>lt;sup>13</sup> Neville A. Kirkwood, *Pastoral Care in Hospitals*, 2nd ed (Harrisburg, Pa: Morehouse Pub, 2005), 156.

# **What History Can Teach Us**

Death as a taboo topic or as failure is the reason that Schillance felt compelled to write on what the history of death has to teach us and why I feel inspired to bring back the old death.

"Death used to be a 'natural' part of life. When clergy address, teach, and model these realities of our living and our dying, death can once again become a natural and much less frightening part of life."

We need to rediscover death as a common reality that connects each of us, the dying person being the master of their own death, and death as part of community. It is when these things can come together we can once again help one another experience a graceful death.

Elisabeth Kubler-Ross most notably is known for starting the death movement with her book *On Death & Dying* written in the mid twentieth century. This movement gave rise to individuals who wanted to bring death and dying back into conversations. Kubler-Ross proposed that we talk about death by focusing on what the dying have to offer us and challenges the medical field to "...refocus on the patient as a human being." While Kubler-Ross' books are still widely used today, Virginia Morris entered into the conversation more recently by challenging our society's way of thinking that, we don't have to talk about death because it doesn't pertain to us yet. We cannot wait to have these conversations "...because by the time we determine that we are "there," at that magical border, we have, quite often, missed our chance." I agree with Morris and her argument that we need to bring these conversations into our lives and I think we need to go one step further and bring these conversations into our faith communities. I will enter into this conversation with Morris and Kubler-Ross and add the new perspective that

<sup>&</sup>lt;sup>14</sup> Martha R. Jacobs, A Clergy Guide to End-of-Life Issues (Cleveland: Pilgrim Press, 2010), 4.

<sup>&</sup>lt;sup>15</sup> Elisabeth Kübler-Ross and Ira Byock, *On Death & Dying: What the Dying Have to Teach Doctors, Nurses, Clergy & Their Own Families*, 2014, xxiii.

<sup>&</sup>lt;sup>16</sup> Morris, Talking about Death Won't Kill You, 215.

our faith leaders can guide their faith communities to have these conversations now, before it is too late. These general conversations in our faith communities, around death and dying, will call us to examine our lives, participate in our death, and give end-of-life care the importance it deserves. By "...bringing death out into the open, by witnessing it, talking about it, learning about it, and trying, in whatever way we can, to accept it as an inevitable part of our lives, we can be better prepared...we can change the way we die – for ourselves and our loved ones."<sup>17</sup>

Not only are authors, journalists, professors, and doctors stressing the importance of end of life conversations, the dying themselves "...want to talk about what is happening to them." People don't want to feel isolated or forgotten when it comes to the end-of-life but an expert on healing and loss, David Kessler argues they want continued friendship, honesty, respect and compassion. Theology and ethic professor Kenneth L. Vaux and author of ethics, religion and film, Sara Anson Vaux discuss they have found that the needs of the dying include someone to listen, help with practical needs, and bring the sacred to them. From my experience as a hospice chaplain, I, too, find these as needs of those who are at the end-of-life. However, I also believe these are essential to us throughout our lives. When we are struggling in life whether due to injury, loss of employment, family struggles or the many other things life brings our way, don't we too want someone to listen, to help with practical needs, to understand our fear and to feel the sacred? If we think of death as another part of life, then those practices of caring for each other can carry over into end-of-life care. In helping to meet people's needs, we can contribute to a good death or dying well.

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<sup>&</sup>lt;sup>17</sup> Morris, Talking about Death Won't Kill You, 3.

<sup>&</sup>lt;sup>18</sup> David Kessler, *The Needs of the Dying: A Guide for Bringing Hope, Comfort, and Love to Life's Final Chapter,* 1Tenth anniversary ed.; 1st Harper pbk (New York: Harper, 2007), 166.

<sup>&</sup>lt;sup>19</sup> Ibid., 154

<sup>&</sup>lt;sup>20</sup> Kenneth L. Vaux and Sara Anson Vaux, *Dying Well*, Challenges in Ethics (Nashville, Tenn: Abingdon Press, 1996).

A good death according to Daniel B. Hinshaw, in his discussions on studies done within the United States includes "...preparation for death...[and]affirmation of the whole person."<sup>21</sup>

This theme of caring for the whole person repeats itself in the literature on what the dying person needs. A "...good death, therefore has a lot to do with community and communication."<sup>22</sup>

Communication is something that we can start now. Affirmation for the whole person to me is respect for one another, seeing others as beloved children of God and in our faith communities we can honor and value people as human beings with uniqueness and importance, and honor our relationship with one another. Having conversations around death and dying within our faith communities will help individuals and their families to prepare for their own death through respecting who they are as an individual. These conversations on end-of-life care can lead to deeper meaningful relationships between loved ones and the affirmation and dignity in dying can lead to deeper contentment and peace at the end-of-life.

# What Faith Communities Have to Say

While the resources listed above helped me in gathering research about death and dying and what individuals need in conversations around end-of-life (EOL) care, additional resources helped me bridge the gap between what conversations are happening around death and dying in our communities and how, if at all, these conversations are happening in our churches. Allen Verhey's book not only discusses death and the medicalization of death, but also faith and

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<sup>&</sup>lt;sup>21</sup> Daniel B. Hinshaw, "Spiritual Issues in Surgical Palliative Care.," *The Surgical Clinics of North America* 85, no. 2 (2005): 259.

<sup>&</sup>lt;sup>22</sup> Vaux and Vaux, *Dying Well*, 54.

faithfulness in the face of death. <sup>23</sup> He focuses' on how we can use Jesus as a teacher to bring back the "art of dying" or faithful dying. I agree with his resource on using Jesus as an example to us as Christians to talk about our own death and dying. We are a church with a theology of birth, death, and resurrection. Holy Week is set aside in our Christian faith as a time spent in reflection and we as Christians walk each year with Jesus as he prepares for his death. We listen to the scriptures as Jesus prepares his disciples for his death and yet we do not talk about our own. We have rituals and services to commemorate Jesus' death, and in our liturgical calendar we repeatedly come back to Jesus' death on the cross. Yet we do not talk about our own mortality. How can we use Jesus' examples and last words to help us talk about our own death? One way to live out Jesus' example is to either start having or enhance the general conversations on death and dying in our faith communities. Having these conversations will help recognize our mortality and prepare of our loved ones for our death, just as Jesus did.

When we look to Jesus' death as a role model for our own deaths, we are also led to how we view our own death in light of Jesus' death. We are led to the promise of eternal life from God through the death and resurrection of Jesus Christ. One of the scripture readings that support this concept is from 1 Corinthians 15, that "...this life is not all there is." This view sees death as a friend, this isn't the end and there is more than this life we live now; death is a "...friend coming to take us to a better place." An alternative view is death as enemy which is reflected in Romans 5. In this view death is seen as a destruction of the created life, as the enemy of God. Death is "...an intruder, a rude usurper who consumes all our powers of endurance, grace and

<sup>&</sup>lt;sup>23</sup> Allen Verhey, *The Christian Art of Dying: Learning from Jesus* (Grand Rapids, Mich: William B. Eerdmans Pub, 2011), 174.

<sup>&</sup>lt;sup>24</sup> Vaux and Vaux, *Dying Well, 32*.

<sup>&</sup>lt;sup>25</sup> N. T. Wright, *Surprised by Hope: Rethinking Heaven, the Resurrection, and the Mission of the Church,* 1st ed (New York: HarperOne, 2008), 16.

dignity."<sup>26</sup> Death "…is our enemy, and it is God's enemy"<sup>27</sup> that Jesus defeated in a moment of time, and what God will ultimately defeat in the next coming of Christ. Yet death "can sometimes be seen as a friend, ending pain and halting the merciless fall of sufferers"<sup>28</sup> transitioning us from this life to the afterlife; the event that takes us to be seated with God in Kingdom of Heaven.

Our Christian liturgies, especially in our funeral practices, are reflective of our "...thought [being] oscillated between seeing death as a vile enemy and a welcome friend."<sup>29</sup> In the UCC Book of Worship the options for the prayers of thanksgiving can be seen to include both of these views. Choice "b" is reflective of death as friend as these words are spoken: "...death itself is past and that *she/he* has entered the home where all your people gather in peace."<sup>30</sup> Following that choice "c" reflects death as enemy as the leaders states "...for by death Christ has conquered death, and by rising Christ has opened to all of us the gates of everlasting life."<sup>31</sup> Both of these views are also reflected in the committal sentences, choice "a" speaks about God bringing all who have fallen asleep with Jesus to eternal life, reflecting the view of death as friend. And choice "b" is a reflection of death as enemy, speaking of victory over death through Jesus Christ.<sup>32</sup>

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<sup>&</sup>lt;sup>26</sup> Vaux and Vaux, *Dying Well.*, 39.

<sup>&</sup>lt;sup>27</sup> Thomas G. Long, *Accompany Them with Singing: The Christian Funeral*, 1st ed (Louisville, Ky: Westminster John Knox Press, 2009), 38.

<sup>&</sup>lt;sup>28</sup> Ibid., 39.

<sup>&</sup>lt;sup>29</sup> Wright, Surprised by Hope., 17.

<sup>&</sup>lt;sup>30</sup> United Church of Christ, ed., *Book of Worship* (New York: United Church of Christ, Office for Church Life and Leadership, 1986)., 377.

<sup>&</sup>lt;sup>31</sup> Ibid., 377.

<sup>&</sup>lt;sup>32</sup> Ibid., 386.

# **How Faith Impacts Death**

Our Christian practices not only reflect our beliefs and theologies around death, but also play an important role in our death as John Swinton and Richard Payne pointed out in their book Living Well and Dying Faithfully. They argued that "We need to rediscover the fact that the process of dying is a deeply meaningful and spiritual human experience."33 Our Christian practices of spirituality make us into the people we are, "...the outworking in the real life of a person's religious faith - what a person does with what they believe. Christianity is not just about ideas...it concerns the way in which the Christian life is conceived and lived out, with its ultimate goal being the full apprehension of the reality of God." <sup>34</sup> Living out our faith each day in our Christian practices ultimately leads to dying well or faithfully. This can be seen in our funeral practices as Christians walking our sisters/brothers in their final mile. Funerals are "about giving thanks to God for a life we have known only in embodied ways, in what the dead did and said, in what they crafted with their hands, in where their feet took them, in the intimacy they experienced by giving themselves bodily to others, in the commitments they signified by their choosing to place their bodies here rather than there...it is to look into their face and to see a saint" and then carry them into the arms of God. 35 This practice of our faith provides us the ability to walk our fellow Christian home to God and reminds us that one day we too will need to be walked into the arms of God.

Christian practices and scripture are a way to bridge the conversation from our faith to our own death and dying. Marilyn McEntyre showed us this in her book, *A Faithful Farewell*, by

<sup>&</sup>lt;sup>33</sup> John Swinton and Richard Payne, eds., *Living Well and Dying Faithfully: Christian Practices for End-of-Life Care* (Grand Rapids, Mich: William B. Eerdmans Pub. Co, 2009)., xviii.

<sup>&</sup>lt;sup>34</sup> Alister E. McGrath, *A Brief History of Heaven*, Blackwell Brief Histories of Religion (Malden, MA: Blackwell Pub, 2003), 162

<sup>&</sup>lt;sup>35</sup> Long, Accompany Them with Singing, 34-35.

discussing many of the issues/fears individuals face in the dying process and used prayer and scripture to reframe these issues within the lens of faith. I loved the personal feel of her writing and believe this will help clergy in having conversations with those who are dying and also can be a resource for our congregations to understand what the dying process can be like. Our dying process is not just about being mortal, or leaving this world; in our dying we "have numerous things – physical, emotional, and spiritual – to deal with...discouragement, embarrassment, boredom, curiosity, loss of privacy...small losses along the way...sadness, gratitude." When we are aware of the things that individuals face while dying, and pray for these things with them, we acknowledge them and lift them up to God. In doing so we can let the dying person know that they are seen and heard, that they still matter and are sacred and beloved by God.

I agreed with John Swinton and Richard Payne that how we live our lives will lead to how we live through the dying process. I, also, believe that we not only need our spiritual practices to die a faithful death, we need to address death in our lives in order to die well. Having these conversations now in the present will help us prepare for when our end-of-life comes. These resources all contributed to the importance of our Christian faith in the conversation on death and dying and will be valuable for the workshop for faith leaders on EOL care.

Our spirituality and faith has already begun to affect the way we die in this new medicalized world. "The lack of integration of spiritual and material care of the human person in contemporary life has led to increasingly evident tensions, most notably in the mechanization and isolation of the experiences of illness and dying." Studies have shown that individuals with higher religious community support and coping mechanisms are more likely to use aggressive

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<sup>&</sup>lt;sup>36</sup> McEntyre, A Faithful Farewell, xi.

<sup>&</sup>lt;sup>37</sup> Michael J Balboni and Tracy A Balboni, "Reintegrating Care for the Dying, Body and Soul," *Harvard Theological Review* 103, no. 3 (July 2010): 351.

measures and die in the ICU.<sup>38</sup> This was a surprising study, as my assumption was that someone more connected to their faith would be better at "letting go." However, the study concludes that theological beliefs (and possibly misunderstandings) play a role in EOL decisions. Some of the beliefs or understandings shared that individuals hold were that the individual needed to stay alive so God could provide a miracle or that because God gave life; we need to do all we can to keep living. The study also found that the lack of clergy conversation with their congregants on EOL, along with the lack of clergy knowledge of EOL "…leaves little to guide the religious person facing illness." Having conversations on death and dying in our faith communities can help individuals integrate religious principles and gain religious understanding of illness and EOL care. These conversations will "…regularly invite congregation members to reflect on their frailty and mortality, and in so doing to further their preparations for and spiritual appreciation of the experience of sickness and death."

# **Preparing for Conversations on Death**

Encouragement for these conversations was seen in *A Clergy Guide to End-of-Life Issues* by Martha R. Jacobs. This is a resource from my faith tradition, the United Church of Christ, and is a guide for faith leaders about end-of-life issues that I have come across. She touched on all aspects of end-of-life care: the fear of dying, medical, legal, and ethical issues, preparing for end-of-life and working with faith communities. While this resource did a wonderful job creating a tool to help people reflect on their own mortality and gain understanding on EOL

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<sup>&</sup>lt;sup>38</sup> "The National Clergy Project on End-of-Life Care," accessed May 21, 2019, https://projects.iq.harvard.edu/rshm/national-clergy-survey-health-care-end-life.

<sup>&</sup>lt;sup>39</sup> Balboni and Balboni, "Reintegrating Care for the Dying, Body and Soul," 355.

<sup>&</sup>lt;sup>40</sup> Ibid., 361.

issues, what I am proposing in this project takes this resource one step further. This project seeks to create a workshop to help educate and prepare faith leaders so that they feel better equipped to use the resources available to them, such as this book, and have conversations about death, dying and end-of-life care with their faith communities.

Another thing I believe is needed in the workshop for faith leaders, is addressing the integration of our faith and Christian beliefs with EOL care. While the resources I have read have addressed the theological and Christian beliefs around death and dying, the integration into EOL care has not been direct. I believe in order to help our faith leaders provide a "...ministry that allows for a graceful death, that is, one where God's presence is felt" we need to provide training in EOL care that not only includes some of the issues/facts surrounding death but also the theological and religious understandings that can help individuals in preparing for EOL.<sup>41</sup> Because spirituality is so important in the lives of the faithful and at death "The theme of the hope of heaven, and especially the consummation of all things in the heavenly Jerusalem, is of major importance in Christian spirituality."42 We as faith leaders need to have an understanding of the beliefs that surround this hope. In order to help our people transition from this world, we need to have an understanding about our own death, our own theologies and what others may hold in their theologies so that we can have open conversations that encourage people to discuss their end of life care. This workshop will challenge faith leaders to address their own discomfort in order to be able to foster conversations with their faith communities so individuals can experience being cared for at the end of life and death can once again be seen as sacred.

<sup>&</sup>lt;sup>41</sup> Jacobs, *A Clergy Guide to End-of-Life Issues*, 1. <sup>42</sup> McGrath, *A Brief History of Heaven, 172*.

# What Conversations on Death and Dying are Happening in Faith Communities?

Surveys were distributed to faith leaders in the Pennsylvania Southeast (PSEC) and Penn Northeast (PNEC) conferences of the United Church of Christ (UCC) to find out what general conversations around death and dying are happening in faith communities. Surveys were distributed electronically with responses being anonymous (complete list of questions can be found in Appendix 1). The survey was sent out to all active faith leaders in these two conferences. Thirty-seven people responded to the survey in which thirty-six participated for qualitative/ thematic identification, which involved taking each of the seven content questions and reading for common themes and ideas that may stand alone, yet still require attention.

Along with the surveys, ten interviews were done with faith leaders currently serving faith communities within the two identified conferences to find out what conversations on end-of-life are happening, how these conversations are happening, what resources they use to have general conversations around death and dying, and what resources they use when they are visiting the sick and dying in their community. I used the conference ministers in each conference to help identify individuals willing to participate; there was diversity in gender, years in ministry, and ethnicity as stated in my Human Subject application. These interviews were done by phone or in person; however, there will be no identifying information within this paper so that no link between participant and responses can be made. The interviews consisted of seventeen questions, which can be found in Appendix 2. I will identify questions in this project as I analyze them for common themes or important issues that were addressed. This will aid in

gaining deeper insight into what faith leaders need in a resource to support them in having conversations on end-of-life (EOL).

Surveys were also distributed to members of five faith communities in the PNEC and PSEC of the UCC to ask what conversations around death and dying have ever happened in their faith community and what information they think would be beneficial in these conversations. I again used the conference ministers and staff to help identify congregations that would be willing to participate in the surveys. The surveys were sent out by mail or personally distributed to the faith communities. The consent forms and surveys were kept separate and a label system was used to identify the church on the surveys so that there is no possibility of identifying the person who filled out a survey. Out of the five congregations surveyed, I received a total of 137 surveys. However, eight surveys returned did not include an informed consent and therefore I had to discard these surveys. That left 129 surveys reviewed to identify themes in conversations on end-of-life care in our faith communities. The surveys also helped identify whether faith communities find these conversations to be beneficial, and helped to address the gap in conversations on death and dying that is present in our faith communities.

This chapter will reflect the qualitative and thematic analysis of the interviews and surveys to address both the faith leaders' needs and individual's needs in conversations around death and dying. This analysis will lead to the design of a workshop intended to support our faith leaders in having end-of-life conversations with their faith communities. This analysis serves as the building block for the structure and content of the workshop constructed to serve as a tool for faith leaders. This tool will help faith leaders to gain experience, learn about end-of-life care and feel equipped to engage in conversations with their faith communities in preparation for death and dying. The format for the remainder of this chapter will consist of themes identified in bold

print at the top of each section and a thematic discussion of the responses provided to survey and interview questions that pertain to that theme.

# **Courses/Training of Faith Leaders**

The following Tables in this chapter are based on the survey and interview responses. The questions were open ended so some individuals gave multiple answers to the question which led to more answers than the total number of responses, but the information for each column is accurate and therefore reflects the results accurately.

Table 1. Faith Leaders Survey Results for Training on Death and Dying	
Seminary	21
Class(es)	
One Class or	15
Less in Seminary	
CPE	16
Post-Seminary	11
Training	
Hospice	4
Chaplain	

Table 2. Faith Leader Interview Results for Training on Death and Dying	
Part of Seminary	3
Class	
One or More	3
Classes in Seminary	
Training/Worship	2
with Funeral Home	
Workshop	1
Clergy Clinic	1
None	4

I addressed the issues of classes or trainings that faith leaders may have received in both the surveys and interviews that I conducted with faith leaders in the PSEC and PNEC of the United Church of Christ. In the survey, the question I asked was 'What classes or trainings on death and dying have you had?' (see Appendix 1) Thirty-five people responded to this question, with 60% (or 21 participants) indicating that they had training in seminary that discussed the topic of death and dying. Out of those twenty-one individuals who indicated they had training in seminary on death and dying, 71% (or fifteen of the twenty-one individuals) stated that they had one class or less, meaning only part of a class addressed end-of-life issues or conversations on

death. That left just six faith leaders or 17% that indicated having had more than one class that fully focused on death and dying in their ministry training (Table 1).

Similar results can be seen in the interviews with faith leaders. The question addressing the issue on training in death and dying was 'What if anything in seminary prepared you for these conversations (on death and dying)?'(see Appendix 2) There were two follow-up questions on what was most helpful and also what they wish they had been taught or had learned. The first question I will address is 'What if anything in seminary prepared you for these conversations?' Out of the ten interviews I did, only three people, or 30% of interviewees, had courses in seminary that were focused on grief, death or dying. When adding in the people that had part of a course, such as courses on pastoral care that addressed death and dying within the coursework, it adds an additional three people. The conclusion, as seen in Table 2, is that six faith leaders or 60% of my interviewees had some training in seminary on death and dying.

Given that death and dying is a significant life event and will happen to 100% of us, it was surprising that seminaries are not doing more to prepare their faith leaders in having these conversations in their places of ministry they serve. As a seminary graduate myself, I know that there were sometimes elective courses addressing death and dying, but they were not offered every year. The topic was also addressed in my class on pastoral care, but again this was only one topic of many that was taught throughout the semester. It saddens me that the institutions that are training our leaders in faith are not more aware and concerned about this major part of the pastoral care faith leaders take on. As we leave our places of education to go out into the world and do God's work, and at the start of our ministry, we are often faced with situations of congregation members being diagnosed with terminal illnesses, loved ones going into hospice care, or funeral planning for a member that has passed. These situations are times when we as

faith leaders need to have conversations with our people on what their final wishes are, discuss their mortality and help an individual have a graceful and grace-filled death. It seems it would be essential to make sure our faith leaders are prepared for this aspect of their ministry through courses, trainings and conversations around mortality. However, according to my research and personal experience, it seems seminaries are not focused on preparing their faith leaders for this part of ministry. Martha Jacobs found this to be true as well stating that "Unfortunately, death and dying concerns were not a major part of my seminary education, nor are they part of most seminary course requirements."

This lack of training is continued as faith leaders leave our educational institutions and go out into our faith communities to do ministry. If we look again at the question from the survey with faith leaders, 'What classes or trainings on death and dying have you had?'? (see Appendix 1) We know that thirty-five people responded to this question. The results as reflected in Table 1 show that sixteen individuals, or just under half of the respondents indicated that they took clinical pastoral education (CPE) which is training to work as a chaplain in the medical field. This training focuses on many aspects of pastoral care and many different emotions and situations that people face while in a hospital or healthcare setting. While part of the training does focus on death, dying and grief, this is only a portion of the CPE training. Also, in more recent years, seminaries are often adding CPE as a requirement of seminary studies. Only eleven people or 31.4% responded to this question that they had some type of post-seminary training (other than clinical pastoral education) on death and dying. An additional four individuals had been hospice chaplains at some point in their careers which provided them with training and

<sup>&</sup>lt;sup>1</sup> Martha R. Jacobs, *A Clergy Guide to End-of-Life Issues* (Cleveland: Pilgrim Press, 2010), 3.

experience to have these conversations. These results show that faith leaders have had minimal training on death, dying and end-of-life care.

I addressed this post-training issue within the interviews with faith leaders by asking the question, 'What trainings or workshops on death and dying have you taken?' (see Appendix 2) One person answered that they had a course in their undergraduate work, but this does not pertain to training after seminary. The rest of the results are reflected in Table 2, showing two individuals stated that they have done trainings or workshops with funeral homes on this topic; one of those faith leaders also has done training with a clergy clinic. One additional faith leader did a workshop on the topic of death and dying and another took a seminary course after graduating. Clinical pastoral education was often mentioned in this question on trainings; however, only part of this training addresses death and dying and, as stated above, most of the time CPE is now a requirement in seminary, which means it would not be considered a postseminary training. Four of the faith leaders I interviewed specifically indicated that they have had no training nor had they attended any workshops on the topic of death and dying. This means that only four or 40% of the faith leaders had done some type of training, on the topic of death and dying, since graduating from seminary. This leads me to believe that one of three issues are happening; the first being that the UCC of the two eastern Pennsylvania conferences in the project (larger regional offices that oversee the congregations and faith leaders in their geographical area) do not have trainings or workshops on death, dying and end-of-life care for the faith leaders to attend in order to gain additional support and education on the topic. The second issue may be, if these trainings are available either within the conference or wider community, our faith leaders are not getting informed of their availability in order to take

advantage of the trainings. The third issue may be that faith leaders may just be choosing not to take trainings on this topic when available.

The continuation of the need for more support in discussing end-of-life (EOL) issues for our faith leaders and communities can be seen in the follow-up questions asking what individuals wish they had learned in a training or class and what resources they wish they had for conversations on end-of-life. In the survey given to faith leaders in eastern Pennsylvania, the question reflected in Appendix 1 asks, 'As you prepare to have general conversations about death and dying with all (those not terminally ill) in your congregation, what resources do you wish you had?' There were twenty-nine responses to this question. Eighteen faith leaders identified some type of resource they wish they had in order to have conversations on death and dying with those in their faith communities. This indicates that 62% of the faith leaders felt like they needed something more in order to have or enhance conversations on end-of-life in their faith communities. This is a significant number of faith leaders who feel like there is something more they wish they had when trying to have conversations on death and dying in their faith communities. Only seven individuals or 24% felt they had what they needed or didn't feel like they needed any additional resources. This left four faith leaders who answered they were unsure what they would want. Phrased as an open-ended question, here is list of some of the topics that faith leaders identified: conversation starters, planning guides, prayers, denominational resources, study questions, scripture references, theology of the cross and resurrection, medical options, and living wills.

In the interviews, there was a question that addressed feeling equipped to have conversations on death and dying. The follow up question pertains to this discussion. The follow up question as seen in Appendix 2 was, 'If yes, what has helped you feel prepared for these

conversations?' Only three faith leaders or 30% of the individuals I interviewed answered that they have had a class/training that has helped them feel prepared for conversations on death and dying. However, everyone gave answers that were experience related. This is a significant finding that most faith leaders have only had their own on-the-job experience to prepare them for having conversations on death and dying with those they serve. This again highlights that our faith leaders are being left to their own devices and skills when trying to have conversations on death and dying within their faith communities. At the end of the interviews I asked, 'What do you need so that you can empower your congregation members to have conversations around mortality and end-of-life?' (see Appendix 2) Not all the faith leaders answered this question and some said they weren't sure what they needed. However, six individuals or 60% of the faith leaders indicated a need to be able to empower their people to have conversations on death and dying. These needs included: programing, having professionals help in the conversation, a resource to help their congregation to plan their end of life, spiritual aspects of death, and example of groups that they could run within their own faith community. Even though all these pastors felt equipped to have conversations because of the experience they had in ministry, there were still significant needs they identified in order to be able to empower their faith communities to have conversations around death and dying. I think this speaks loudly to the need of the two conferences within the UCC in eastern Pennsylvania to support our faith leaders in this important topic that they will address throughout their ministry. As one of the interviewees said about a class on death and dying she took "...it was a realization this will be my life now." For faith leaders talking about death and dying, comforting families at the end of a loved one's life, being a spiritual support and presence, helping to plan funerals and burying members of their faith

community is a part of life in ministry. It is my belief that we need to support our leaders more in this part of their ministry with skill and confidence so they can do justice to those they serve.

What is Going-on?

Table 3. Faith Leaders Having General Conversation on Death (surveys)	
Yes	28
No	6

Part of the research was to find out what conversations on death and dying or end-of-life care are happening in the UCC faith communities of

Table 4. How are Faith Leaders having Conversations on Death and	
Dying? (surveys)	
Sermons	18
One-on-one	11
Conversations	
Bible Studies	6
Professional	5
Workshop	1
Confirmation	2
Class	
Study Groups	5
Grief Groups	1

eastern Pennsylvania. In my survey to faith leaders I asked two questions on this topic. The first was, 'Do you have general conversations with your congregation on death and dying outside of the impending death of a member or loved one?' (see Appendix 1) There were thirty-four responses with twenty-eight faith leaders or 82.4% stating yes they do have general conversations on death and dying with their congregations and only six or 17.6% answered no. This can be seen in Table 3. Those twenty-eight who said yes then responded to the follow up question, 'If yes: How do you present them? (sermons, bible studies, seminar, etc.) What size group? (individuals, families, small groups, whole congregation, etc. "(see Appendix 1) The responses varied greatly, as can be seen in Table 4, but the most common response in the survey indicated faith leaders are having conversations with their faith communities on death and dying through sermons. It was eight-teen individuals or 64.3% of faith leaders stated that they present conversations on death and dying through sermons. Out of the twenty-eight responding to this

question, eleven or 39.3% stated they have one-on-one conversations or conversations with individual congregation members and their families. Therefore, the majority of faith leaders in the UCC in eastern Pennsylvania are either preaching on death and dying or having individual conversations. While there were study groups, workshops/seminars, bible studies and prayers addressing the topic of end-of-life care, these were less likely and more varied among the faith leaders.

Table 5. How are Faith Leaders having Conversations on Death and Dying? (interviews)	
With individuals or families	4
Sermons	1
Other	4

In the interviews, faith leaders were directly asked 'Do you have conversations on preparing for end of life with your congregation?' (see Appendix 2)

However, people also gave insight into what they

were doing in their own faith communities while answering other questions as well. Again, faith leaders reported having conversations on death and dying within their faith community.

However, seen in Table 5, four or 40% stated they had individual or small group conversations and one individual or 10% stated they do sermons on the topic. Some of the other programing happening is inspiring and encouraging. Programs with youth who get to visit a funeral home, touch a casket and ask questions to the funeral home director, bible studies or studies during Lent, and seminars where professionals come together to talk about this topic and answer questions are happening in UCC faith communities. While these results are encouraging, these studies and programs where reported in only 40% of the interviews. Therefore, the majority are either, not having conversations on end-of-life, preaching on the topic or having individual/small group discussions.

Table 6. What Sermon on Death and Dying those in Faith Communities Have Heard	
Left Blank	18
None/Don't	54
remember	
Varied topics	57

In relation to the previous question listed above to the faith leaders, on the congregational surveys, Appendix 3, I asked the faith communities this question, 'What sermons have you heard

preached on human mortality and death?' Table 6 shows that out of the 129 responses fifty-four (54) stated they have not heard any or they couldn't remember. An additional 18 respondents just left the question blank all together. This is the majority (56%) of individuals in five different faith communities stated either never having heard a sermon on death and dying or they couldn't remember. One of the pastors stated to me, when I sent the surveys to him for his faith community to participate, "After 20+ years in the pulpit, I'm pretty certain the vast majority of congregants will not remember whether a sermon preached five years ago, or even one or two years ago, included death and dying themes." The problem here is even though we know, as faith leaders, that our congregants don't recall sermons in detail, this is the primary way our faith leaders are addressing death and dying conversations within their faith communities. Although some of those that took the survey were able to recall conversations on death and dying, 56% could not remember hearing a sermon and 55% could not remember any bible study on the subject. This research shows while faith leaders think they are having conversations on end-oflife and impacting their faith communities, it seems there needs to be other ways for these conversations to happen so the faith communities feel the benefit of those conversations.

Another important theme that arose in my interviews and surveys is the entangled understanding of death and grief. While there were no direct questions related to this theme, this data result arose out of conversations with the faith leaders and in some of the open-ended responses in the survey to faith leaders and faith communities. Yes, death and grief are closely

related to one another – for the death of a person leads to the grief of another. However, my intent in this project was to ask questions about the conversations happening before a loved one dies, to find out how faith leaders are helping our faith communities prepare for death. While I used language such as end-of-life care, preparation for death, conversations on death and dying outside an impending death, often the responses would seem to pass over the conversations that happen before death and go directly to grief. In response to what conversations are happening on death and dying, often individuals would jump to grief support, books on grief, or issues of grief within their faith communities. In the interviews faith leaders often spoke about funeral preparation with families and responses around conversations on death and dying often focused on funerals or funeral preparation. In each of these cases the answers did not address the preparation for death, but rather the issues that come up once a person dies.

These responses made me realize for some faith leaders and individuals in our faith communities, the preparation for death and the grief of death are intertwined into one. For some, these are not two separate things, but are connected in such ways that there is anticipatory grief in the preparation for death. This may explain why some people are so reluctant to talk about death. It may also contribute to the disconnect between what the faith leaders say they are doing pertaining to conversations around death and dying, and what the faith communities are experiencing. If faith leaders are doing grief support groups or bible studies on grief, as a way to address death and dying in their faith communities, they are not addressing the needs of the individuals to talk about the preparation for death or what happens before we die. While helping our faith communities through their grief or allowing people to share in their grief and educating them in and about grief is very important, I believe it is just as important to also address the dying process and preparation for death with individuals and the grief that is felt when

approaching death, which is very different then the grief loved ones feel once a person had died. When we talk openly about death in our faith communities, faith leaders can help people prepare for death in a way that invites them to think about their wishes, medical options, finances, funeral arrangements and the dying process. These are things, from my research, our faith communities are looking for. These topics are what was reported in the question 'What information do you think would be beneficial in these conversations?' (on death and dying) that was on the survey given to the five UCC faith communities in Penn Northeast and Pennsylvania Southeast conferences (see Appendix 3). The desire for these more complete conversations is there and as faith leaders we need to address these topics in our ministry. In our faith communities, faith leaders need to hold conversations so there is a safe place for people to come and learn, discuss, and even plan for the end-of-life.

### **Thinking about Death**

Another area I addressed in my surveys and interviews was about death. This question intended to get people to think about the dying process and what is important to them when they face the end-of-life. It also brought the topic of death and dying to a personal level so individuals could personalize their responses. In my survey to faith leaders I asked two questions surrounding the topic of death. These questions are reflected in Appendix 1 and stated, 'What would your ideal death be and what would an ideal preparation for death be?' These questions had thirty-five answers each in the survey. The majority of people, eleven out of the thirty-five responses stated they would want to be with family or loved ones when they die. An additional eight people stated they would want to die in their sleep or when they lay down to sleep.

Additional answers included pain controlled or free of pain, the dying process being short and

that the person would be at peace. This is what our faith leaders found important for themselves when death comes. However, if we never talk about it, if we push the topic to another time or to another place how can we make our wishes become reality? If we are not giving our faith communities the opportunities to think about their own deaths and their wishes at the end of life, then aren't we doing a disservice to those we serve in ministry?

The second question in the survey to faith leaders related to preparing for death. All thirty-five responders listed one, if not many things, that would require someone to know that death is near. The following is a compiled list from faith leaders indicating characteristics of an ideal death:

- Finances in order
- Family cared for
- Funeral plan done/known by loved ones
- Knowing our faith/that we belong to God
- Time to say goodbye
- Prayer
- Finalized plans
- With love ones
- Medical/Legal issues in order
- Ready/Realistic in expectations
- Time to let go
- Music

*Time to say goodbye* had the most responses with fifteen people indicating this would be important to them. This is 42.9% of the faith leaders whose ideal preparation for death included

saying goodbye to loved ones. However, if we look over the list above, it is significant to note that all the answers indicated needing to know one was dying. Many times we don't talk about death and dying or those in our faith communities never open up the conversations themselves with their loved ones. However, in order to plan for an ideal death or preparation for death, and for families and loved ones to help meet the last wishes of a loved one, they need to know what they are. The person themselves needs to know they are dying and the family/loved ones need to have had a conversation about their wishes so that they do whatever is within their power to make an ideal death happen. Many times in hospice work, people don't want to let their loved one know they are at the end of life. Many times these are the families who have not had discussions on final wishes and the dying process. However, if we don't talk about it, we are possibly robbing the individual from being able to say goodbye or being surrounded by family when the end comes. Having the goodbye and end-of-life we desire cannot happen if we don't start opening up the conversations on death and dying. Our faith communities are one place within which we can invite individuals to have these conversations with one another.

In the interviews with faith leaders the question that addressed the topic of death was 'What is your greatest fear about your own death?' (see Appendix 2) Although this is different from the questions in the surveys, this question still got the faith leaders thinking about their own death and mortality, bringing this topic back to a personal one. While most of the faith leaders stated they do not have a fear of death because their faith has brought them comfort and peace, some stated fears for the dying process. These fears were being a burden to one's family, assuring husband and kids are taken care of, and of being in pain during the dying process.

Again these are all issues people can share about in planning their end-of-life care. Being able to opt to have pain medication, having discussions about or creating legal documents for the care of

children, being able to set up care for oneself or share end-of-life wishes with loved ones so they don't feel burdened all require advanced planning and conversation. We need to talk to one another about dying, about end-of-life. We can demonstrate our love for one another by having these conversations before our end-of-life comes. We can live through Jesus' example of being open about his dying and preparing those around him for his death as he walked the road to Jerusalem.

### **Funerals**

I did not have any specific questions about funerals, because although they can be part of the preparation for death, they occur after death has happened. Although there was not a specific question on funerals, it was a topic brought up many times throughout the interview process with UCC faith leaders in southeast Pennsylvania. I thought it was significant to note that in my interviews with faith leaders, many mentioned the shift in funerals they have noticed. One faith leader stated "There is more fear in the room during funerals." This information was echoed by another faith leader who noticed funerals are being less attended, that people may come for the visiting hour but do not stay for the services, "...such cultural resistance even for Christians." This faith leader goes on to state "People are reluctant to talk about death or consider their own death." Other faith leaders spoke of the difficulty people have with conversations around death. Faith leaders also indicated difficulty in identifying resources to help with these conversations. From my study faith leaders want resources for programing to help the conversations get started, or practical resources that help people think and plan for their death. One faith leader when asked what was most helpful in the trainings he had, spoke about being able to open up the conversations, "...they don't want to talk about death and dying, don't want to talk about funeral

arrangements." Also, many faith leaders spoke about funeral preparation with families as ways in which they have conversations on death and dying within their faith communities. However, this is often after the person has died and is not always a part of the preparation for death. This reluctance to have conversations around funeral planning before a loved one dies and the shift in funerals themselves was felt by many of the faith leaders interviewed. I think this shift in funerals and the decrease of attendance at funerals points to a wider issue in our society; the medicalization of death that was talked about earlier in chapter 2. People have come to accept or strive to push off death for as long as possible; there are new drugs or new treatments that are being developed each day; there are machines and artificial life support that can hold off death. The question becomes, at what cost? It is not that these treatments, new drugs or machines cannot be blessings and helpful, but when we keep pushing death away, we begin to fear the topic itself. The farther it seems from us, the farther away it is in our conscious, and therefore, we don't want to talk about it. When we are faced with the funeral of a loved one or friend, we are brought back to the reality of mortality, and we are faced once again with the knowledge that we, too, will die. This fear and reluctance is why I believe we need to empower our faith leaders to feel more comfortable with having conversations around death and dying in their faith communities. We can encourage our faith communities to bring these conversations back to everyday life, to normalize the topic of death so people are less afraid and more prepared to discuss their end of life wishes.

### **How Prepared are We?**

My hypothesis for this project was that pastors feel ill equipped to have conversations on end-of-life care and preparing for death with their faith communities and therefore conversations on this topic are not happening. To assess this hypothesis in my surveys to the faith leaders in the United Church of Christ serving in eastern Pennsylvania, shown in Appendix 1, I asked the question 'On a scale of 1-5, how comfortable are you talking about death and dying to your congregations?' The scale was "1" being the least comfortable and "5" being the most comfortable or very comfortable. There were thirty-five faith leaders that responded to this question, and I was surprised that 74.3% or twenty-six of the individuals indicated a "5" which equaled very comfortable. It seemed from this survey faith leaders were comfortable with the topic and having conversations on death and dying in their faith communities. This comfort or feeling equipped for these discussions could be seen in my interviews as well. In my interviews with ten faith leaders from the United Church of Christ in eastern Pennsylvania I asked the question in Appendix 2, 'Do you feel equipped to have general conversations with your congregations around preparing for end-of-life?' All ten individuals interviewed answered the question with a "Yes" they feel equipped to have conversations around death and dying with their faith communities at this time in their ministry.

Again, I was surprised by this response and thankfully there was a follow-up question within the interview that let me gain more insight on this topic. The follow up question was 'If yes, what has helped you feel prepared for these conversations?' (see Appendix 2) Each and every person that interviewed indicated it was experience that has helped them to be comfortable in these conversations. This 'on the go job training' was the thing that helped them come to a place of feeling equipped to have conversations on end-of-life care. During one of the interviews when I asked this question the faith leader responded with, "Yes, now I do. When you are as old as I am and have been doing this as long as I have, I feel pretty confident in opening up the difficult conversations with family." Another person stated "I kind of feel I grew into that the

more I had the courage to have the conversation." This theme, the more experience faith leaders had in ministry the more comfortable they were with the topic of death and dying, was present in some way through every interview I did. This is a significant finding in my research as these faith leaders felt it was on-the-job training which ultimately made them feel comfortable and equipped to have conversations with their faith communities on death and dying, not trainings, conference support through workshops or seminars, but rather by being in ministry. One person I interviewed was new to parish ministry, less than a year, but she had come from hospice chaplaincy. Again, it was her experience with hospice that made her feel equipped to have conversations around end-of-life. While it is true in many areas of life and ministry, as we gain experience we become more comfortable with a topic, it would be my hope that as we prepare faith leaders for ministry we can help them feel more equipped with this topic at the start of their ministry. No matter where faith leaders are serving they will be in situations where they need to have these conversations as soon as they start leading a faith community.

Therefore, the hypothesis was correct just wrong in its timing...my research indicates it is not those who have been in ministry who feel ill-equipped to have conversations around death and dying, but those starting out in ministry. I, therefore, propose we start to do better training for our faith leaders as they begin their ministry. One way I believe we can better prepare our faith leaders is through a workshop available for those who are considered members in discernment and those new to ministry. In the United Church of Christ, a member in discernment is someone who has been called by God and is preparing for authorized ministry. By having more training available to those who are preparing for authorized ministry or those starting out in ministry we can help simulate 'on the go' training so they feel more prepared

when doing programs or having conversations on death and dying within their faith communities.

## **Faith Community Participation**

Surveys were sent out to five faith communities in eastern Pennsylvania to United Church of Christ churches. These congregations averaged anywhere from 60-100 people in service on any given Sunday. I had contacted the faith leaders of these communities to ask if they would distribute the survey for me. The instructions were to hand them out during service (i.e. with the bulletins for that day) or after service but requested the individuals fill them out and hand them back in before they left the building. It was done this way in hopes to receive the highest return rate. (Often when individuals leave with something to fill out it is less likely that they will do so and remember to bring it back. Limiting the individual's responsibility in filling out the surveys helps to get the most return.) I sent the surveys out to the faith leaders either electronically or in physical form in the mail. After I sent the survey electronically, one pastor responded with critiques to my questions on the survey and made assumptions about how those in the faith community might answer or perceive the survey questions. It was only email communication but my reflection on this faith leader's reaction was s/he seemed defensive after reading my questions, stating that the individuals are not going to remember if sermons or bible studies have been done on this topic over the years. The email seemed to indicate this faith leader might be upset and perceive that I was questioning the work s/he was doing as a faith leader. However, one of my intents for this survey was to see if there is disconnect in the survey results with what faith leaders reported during their survey and interviews. One faith community that was willing to participate asked me to attend the worship service in person and hand out the

survey after the service so if anyone had questions I would be available to answer them. This was the only service in which I attended personally to hand out the surveys. It was also the faith community from which I received the most participation. From this faith community I received fifty-three surveys back, significantly more than any other faith community participating, with the next highest response amount being thirty-two. This was an interesting finding as I did my research. Although the sample was a small group of faith communities, it seemed being present encouraged the individuals to participate in the survey which in turn provided more information to analyze.

#### **Conversations around Death**

Table 7. Have You Spoken About Death? (Faith Community Survey)	
Yes	102
No	19
Some	8

Family/Friends
Faith Leader
Church/Sunday
School
Other (varied

responses)

None

Table 8. What Conversations On Death and Dying Have Happened?

32

31

4

13

43

(Faith Community Surveys)

In the surveys to the faith

communities, two questions addressed what

conversations individuals are already having around end-of-life and preparation for death. These two questions where: 'Have you ever talked with your family members or anyone else about your end-of-life wishes?' and 'What conversations on death and dying (through speakers, meetings, seminars, workshops, etc.) have you had?'(see Appendix 3) Table 7 shows in the first question the majority of individuals, 102 out of the 129 responses, responded with yes. That is 79% of individuals who stated they have indeed had conversations with their loved ones about their end-of-life wishes. Along with this, another eight individuals said they have talked a little with family or loved ones. This brings the total to 110 or 85% of people in our UCC faith

communities who have had some conversation with their loved ones about death and dying. This response was surprising to me as many of my literature resources and personal experiences as a hospice chaplain have shown there is an understanding or finding that many people are uncomfortable with the topic of death and avoid talking about it. However, it seems most of the people I surveyed have been in conversation with their loved ones about end-of-life care. This finding could indicate two different things. First, it is possible there is a shift happening within our society on death and dying as things like death cafés, which are pop-up gatherings where people come to drink tea, eat cake and talk about death, are becoming more popular. As a society, our comfort may be increasing or at least there is an increase in the level we find this conversation important in our lives. Second, the finding may be higher due to this specific study being done in faith communities. Since we talk about Jesus' death and resurrection, what Jesus' death means for us as Christians – the promise of eternal life, and often attend funerals within the walls of our worship space, these experiences may inspire those who hear these sermons or experiences these words and services to leave the worship space and talk about their own mortality.

In the second question, surrounding conversations of death and dying, there were 123 responses. This question asked what type of conversations people had participated in (see Table 8), and thirty-two people or 26% stated they have had no conversations through speakers, meetings, seminars, workshops, etc. Thirty-one or 25% of the responses stated these conversations happened with family/friends. Therefore, it seems although 85% of responses answered yes to the first question, the number of conversations dropped as they moved beyond personal family conversation. There were twenty-four different ways in which the remaining sixty people indicated they had conversations outside of personal ones with family and friends.

That means 48.8% of the respondents indicated a variety of ways that they participated in conversations around death and dying. While this is a great number, it is still less than the amount of people who stated they have spoken to family about their end-of-life wishes in the previous question above. To go even further than this, only seventeen people or 14% gave an answer directly related to their faith community. Only four people answered they have had conversation with their faith leader, and thirteen people stated they have had conversations in church or Sunday school about death and dying. This is a very low number at 14%, of people who stated they have had conversations that directly took place within their faith community. This leads me to believe we need to and can do a better job in our faith communities supporting people in conversations around death, dying and end-of-life care.

# Why Not?

Table 9. Why Have You Not Talked About End-of-life with Loved Ones? (Faith Community Surveys)	
Not Time/Not	5
Ready	
Haven't Thought	5
About It	
Too Busy	1
Too Hard	2
No Children	1
Not Sure	2

Table 10. Ages of Those Who Responded "No"	
18/19	1
40s	1
50s	2
60s	10
70s	4
Did not indicate	1
age	

In contrast to the answers above, there were also people that answered "no" to having talked with anyone

about their end-of-life wishes (see Table 9). This was only nineteen of the 129 responses to this survey. While this is only 14.7% it is more the follow up question of 'Why not?' that I found significant. Out of the nineteen people that responded, one of the individuals fell into the 18/19

years old age group so I could see this individual as not having given the end of their life much thought, as the topic is not usually on the minds of teenagers as they go through their day. However, all the other respondents were forty or older, with the majority, ten out of the nineteen people, being in their 60s and four out of the nineteen being in their 70s (see Table 10). The majority of answers as to why they have not had these conversations were: five stated they were not ready or it was not time yet and another five stated they just haven't thought about it. This was surprising to me as I recently had a friend who lost a close family friend unexpectedly at the age of thirty and her mom who was in her early 60s. There is so much that can happen each day, so to see people in their 60s and 70s, who are approaching the average life span, respond that it is not time to talk about their end of life wishes yet leaves me baffled. I think it is a testament to how important it is in our faith communities to encourage and start these conversations so that if the unexpected happens, families are not left wondering what their loved one would want at the end-of-life. The best way we can show the love of God to our family members and friends, at the end-of-life, is by doing our best to follow their wishes and give them a death with dignity. However, the only way we can do that is if we have had the conversations so we can know what those wishes are.

What's Needed

Table 11. Should We Be Having Conversation On Death and Dying in our Faith Communities?	
Yes	109
No	6
Maybe	9

The final part of the faith community surveys addressed what should be done around death and dying education within our faith communities and if individuals think it is needed. The questions that addressed this topic are as follows: 'Do you think it would be beneficial to have conversations around death and dying in your church and if yes, why?' and 'What information do you think would be beneficial in these conversations?' (see Appendix 3) Out of the 129 survey returned 124 individuals answered the first question. Out of the 124 responses, 109 or 88% answered yes, they think it would be beneficial to have conversation around death and dying in our faith communities (see Table 11), a significant number of people who desire these conversations. Even though the majority of individuals in this survey stated they have had conversations with loved ones about their own end of life wishes, there is still a significant desire to have conversations about death, dying and preparation for end-of-life in our faith communities. The most commonly identified reason for having these conversations was that death/dying is a part of life or that death/dying happens to everyone. The realization that we are mortal individuals drives our desires to have discussion around end-of-life issues.

The desire for conversations on death and dying in our faith communities leads to the last question identifying what information the people in our faith communities believe would be beneficial in these conversations on death, dying and end-of-life care. Phrased as an open-ended question with individuals being able to answer with whatever they thought would be helpful in these conversations. Only ninety-six (96) of the 129 surveys returned had answers to this question meaning only 74% of the people who participated in this survey provided ideas that they believed would be beneficial in these conversations. While there were a varied number of responses in a wide-range of topics, the most commonly written response surrounded what happens at death. People want to know what to expect in the dying process. With the

medicalization in our society, death is not as common in our homes and in our lives – death is often relegated to the hospitals. Therefore, there is not the same awareness of what one goes through at the end of life as there was hundreds of years ago, when loved ones died in their homes with everyone in the community knowing they were dying. There were an additional seven topics, which had nine or more people indicate as significant in conversations around death and dying. These topics included:

- What the Bible has to say
- After-life
- Final wishes
- Medical Options (hospice/palliative care)
- Funeral Planning
- Living Wills
- Loss/grief/coping

These areas addressed both the practical aspects of preparing for end-of-life but also the spiritual aspects of understanding the theologies of death.

### **Conclusion**

Through these surveys and interviews with faith communities and faith leaders of the United Church of Christ in Penn Northeast and Pennsylvania Southeast Conferences, the research supports a finding that a workshop for individual training would be beneficial and would help facilitate conversations around death, dying and end-of-life care within faith communities. Specifically, a workshop would benefit those faith leaders in ministerial preparation or for faith leaders new to ministry. The responses to these surveys and interviews

will provide the groundwork for choosing topics to discuss and address in the workshop. These results also indicate the desire for a resource of an annotated bibliography available to these faith leaders as a resource to use in their places of ministry for conversations on death, dying and end-of-life care.

## Workshop on End of Life

Based on the research and my findings analyzed in Chapter 3, it is apparent that we, in the Pennsylvania Southeast and Penn Northeast Conferences of the United Church of Christ, need to provide more support to our faith leaders in having conversations around end-of-life planning with people in their faith communities. I am proposing two ways in which these conferences can provide additional support to the faith leaders in having these conversations. One way will be through an annotated bibliography which I will create to provide faith leaders with a resource list of books, booklets, guides, games and websites that can be used within their faith communities to support and enhance conversations on death, dying and end-of-life care.

The second way is through a resource I am proposing to provide support to the faith leaders; a workshop created based on the research in this project. I am proposing this workshop be specifically targeted for those faith leaders new to ministry in a church setting or members in discernment (MIDs). The idea that this workshop will be for MIDs and those faith leaders starting in ministry came from my research and interview with faith leaders. In my interviews, each faith leader I interviewed indicated it was experience that has helped them to be comfortable in conversations on death, dying and end-of-life care. This 'on the go job training' was mentioned in the interviews as what faith leaders found helped them most often come to a place of feeling equipped to have conversations in their faith communities. Therefore, this project proposes a workshop for those new to ministry or in discernment so they can get support though the synthesis of resources and experience that will simulate on the job training. The workshop will provide a model for conversations on end-of-life that faith leaders can use within

their own faith communities to engage the topic of death and dying. The workshop will also be a resource that provides faith leaders with the information they need to feel comfortable initiating and engaging conversations around death and dying.

Through the surveys and interviews with faith leaders, and the surveys with the faith communities, I gained insight into what resources are needed in order to engage in conversations on end-of-life in our faith communities. Once I compiled my findings and analysis from Chapter 3, I was able to use the information in order to focus on the issues both faith leaders and people in our faith communities indicated would be beneficial for general conversations on death and dying. This information was used to decide the topics included in the workshop for faith leaders. The outline of the workshop can be found in Appendix 4 as a reference. The following chapter will discuss each part of the workshop, what in my research supports the inclusion of the topic, and what will be done in each part of the workshop. The parts of the workshop are as followed:

- Introduction
- Professional Panel
- Theologies
- Clergy Panel
- Case Studies
- Review of Annotated Bibliography

# Introduction

The start of the workshop will be an interactive experience that the participants will engage in to introduce the topic of end-of-life care. Each participant will get playing cards called

"Go Wish." This game is a deck of cards that gives the participant the words to discuss your wishes should your life be shortened by a serious illness. It is an easy way to start this conversation on what is most important to you. "...describe things that people often say are important when they are very sick or dying. The cards describe how people want to be treated, who they want near them, and what matters to them. One card is a "wild card." You can use this card to stand for something you want that isn't on any of the other cards." The participants will have about 10-15 minutes to play the game "Go Wish." The game is played by taking the deck of cards and making three piles: very important to me, somewhat important to me and not important to me. They will then take their pile with the value of very important and pick the top ten cards. If they do not have ten cards in this pile, they will choose from their somewhat important pile to get ten cards. Once they have their top ten cards they will rank them in order from most to least important. After they are done they will have about 15-20 minutes of small group discussion on what was easy/hard about choosing their top 10 last wishes.

This game not only provides an introduction into the topic of death and dying, but also provides a hands-on experience where the faith leaders can learn about themselves. Often as faith leaders we have not thought about our own wishes even though this is something we help others with regularly within our ministry settings. Even if the faith leaders are young, we never know when a tragedy or serious illness might happen to us so it is important to start thinking through these issues. This experience can also be something the faith leaders can do within their own faith communities. By having played the game themselves, they can empathize with the emotions people in their faith community may be feeling as they play the card game. Through

<sup>&</sup>lt;sup>1</sup> "Go Wish - How To Play," The Go Wish Game, December 11, 2019, http://www.gowish.org/article.php/how\_to\_play.

this experience, faith leaders will be able to speak to their faith communities about why it is important to think about end-of-life wishes and provide their communities a way (through this game) to do so with their loved ones. By playing this game with family and friends their faith communities can learn the best ways to comfort loved ones and what their loved ones need most at end-of-life.

### **Professional Panel**

A panel of different professionals to discuss important topics of death and dying will gather at this time during the workshop. This panel will be made up of a funeral director, a palliative care doctor, and an attorney. I chose the professions to include in this panel based on my research involving the interviews with faith leaders, the surveys with the faith communities, and the resources in my literature review. Analysis of these materials provided me with insight on what is important at the end-of-life and with a deeper understanding of the information that would be helpful to have in conversations on end-of-life care in our faith communities. This part of the workshop is meant to provide faith leaders with an understanding and knowledge of the topics discussed from the panel so in turn they feel more comfortable in sharing this information with their own faith communities. This panel discussion could also be used as a model for a way in which faith leaders can have conversations within their own faith communities. By bringing in professionals to provide information on important issues someone facing a critical illness confronts, the workshop gives the people in their faith communities another way to experience and encourage conversations on end-of-life care with their loved ones.

Each of the panel members will have 20 minutes to discuss their topic with the faith leaders present. Before the workshop takes place I would contact each professional and ask them to talk about the following topics, plus anything else they feel is pertinent.

- funeral director will discuss funeral preparation, options, and cost
- palliative care doctor will discuss medical options
- attorney will discuss advance directives, estate planning, living wills and memorial funds.

During my research with the faith leaders, one of the faith leaders stated it would have been helpful to have learned the "nuts and bolts of having a service" and also learning the "logistics of a memorial trust." In the surveys with faith communities three of the top eight answers to what would be beneficial in conversation on death and dying (see Appendix 3) were funeral arrangements, living wills, and medical options. Having a panel to discuss these topics with faith leaders new to ministry or members in discernment (MIDs) will give them the background knowledge and increase their comfort in having conversations on death and dying in their places of ministry. After each of the professionals shares their information, there will be 20 minutes where those in attendance can ask questions or get clarification on anything shared by the panel. In addition to the question and answer time there will be a break after the panel discussion to allow for individuals to talk further with any of the participants.

## **Theologies**

It was important to include the theologies of death and dying because "The theme of the hope of heaven, and especially the consummation of all things in the heavenly Jerusalem, is of

major importance in Christian spirituality."<sup>2</sup> This part of the workshop will be spent discussing some of the theologies surrounding death and dying common within the United Church of Christ. These theologies will include death, afterlife, sanctification and salvation. This part of our Christian belief system affects so many of our choices, our emotional comfort and our decision at the end of life. "We need to rediscover the fact that the process of dying is a deeply meaningful and spiritual human experience within which the search for God, meaning, hope, purpose, and forgiveness and even salvation should be seen as central to the task of end-of-life care."<sup>3</sup> As faith leaders, we need to have an understanding of the beliefs that surround this hope. In order to help our people transition from this world, we need to have an understanding about our own death, our own theologies, and what others may hold in their theologies so we can have open conversations encouraging people to discuss their end of life care.

One of the resources I found discusses the use of religion in the dying process. This resource states that our religion and beliefs around end of life affect our dying process. First, our belief serves as a "...means to bring meaning to experience." For example, the belief about an afterlife helps a person to come to acceptance of death because for them death is not the end. However, some may view acceptance of death as "...abandoning faith or hope in God" which is then "...giving up on God before God has given up on them." Our experiences of faith help rebalance fear of death with God's love for us which provides us with support when dealing with

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<sup>&</sup>lt;sup>2</sup> Alister E. McGrath, *A Brief History of Heaven*, Blackwell Brief Histories of Religion (Malden, MA: Blackwell Pub, 2003), 172.

<sup>&</sup>lt;sup>3</sup> John Swinton and Richard Payne, eds., *Living Well and Dying Faithfully: Christian Practices for End-of-Life Care* (Grand Rapids, Mich: William B. Eerdmans Pub. Co, 2009), xiii.

<sup>&</sup>lt;sup>4</sup> Kenneth L. Vaux and Sara Anson Vaux, *Dying Well*, Challenges in Ethics (Nashville, Tenn: Abingdon Press, 1996), 78.

<sup>&</sup>lt;sup>5</sup> Michael J Balboni and Tracy A Balboni, "Reintegrating Care for the Dying, Body and Soul," *Harvard Theological Review* 103, no. 3 (July 2010): 354.

the fear of death. The practices of our faith: prayer, scripture readings, and worship services help us to internalize our relationship with God which brings comfort in the dying process. However, alternately our religious belief can be "...associated with a strong belief in miracles. Hence, patients may choose aggressive care on a hope that God will perform a miracle through yet untested therapies or high-risk procedures." Finally the relationships we form and that grow through our life of faith, with those in our faith communities, provide us with human connections and support as we face end-of-life. "Christian hope is often expressed in terms of seeing the face of God" and as we help others prepare for that face-to-face meeting or think about our own, it is important to understand our faith, theology and how these beliefs impact the decisions we make.

During my research two prominent views on death emerged. One view is from 1 Corinthians 15 (New Revised Standard Version), where death is viewed as a friend because "...this life is not all there is." When we leave this world it isn't the end; there is more than this life we live now; death is a "...friend coming to take us to a better place." The alternative view is death as enemy which is reflected in Romans 5 (New Revised Standard Version). In this view death is seen as a destruction of the created life, as the enemy of God. Death is "...an intruder, a rude usurper who consumes all our powers of endurance, grace and dignity." "Death is our enemy, and it is God's enemy" that Jesus defeated in a moment of time, and what God will ultimately defeat in the next coming of Christ, yet death "...can sometimes be seen as a friend,"

<sup>&</sup>lt;sup>6</sup> Ibid., 354.

<sup>&</sup>lt;sup>7</sup> McGrath, A Brief History of Heaven, 181.

<sup>&</sup>lt;sup>8</sup> Vaux and Vaux, *Dying Well, 36*.

<sup>&</sup>lt;sup>9</sup> N. T. Wright, *Surprised by Hope: Rethinking Heaven, the Resurrection, and the Mission of the Church,* 1st ed (New York: HarperOne, 2008), 16.

<sup>&</sup>lt;sup>10</sup> Vaux and Vaux, *Dying Well*, 39.

<sup>&</sup>lt;sup>11</sup> Long, Accompany Them with Singing., 38.

ending pain and healing the merciless fall of sufferers"<sup>12</sup> transitioning us from this life to the afterlife; the event that takes us to be seated with God in the Kingdom of Heaven.

Along with these views of death come different theologies on atonement, how we are reconciled to paradise. These different theologies try to describe the different thoughts about how Jesus' death impacts "...the restoration of humanity to paradise through redemption." 13 Because "...an integral aspect of the Christian understanding of sin is that humanity has become alienated as much from God as from Eden, prompting the question of how restoration is to be achieved."<sup>14</sup> Some of the common theologies on how Jesus atoned for our sins and reconciliation happens are: Christ the victor, Christ the hero, Christ the Harrower of Hell, Christ the Redeemer, Christ the Lover and Privatization of Atonement.

Christ the Victor is founded in scripture of 1 Corinthians 15:57 (New Revised Standard Version). This belief is that the gates of heaven have been thrown open and "...gloried in the triumph of Christ upon the cross, and the victory he won over sin, death and Satan." The victorious Christ has paid for our sins and we are reconciled to the Kingdom of God through his death and resurrection. Christ the Hero stays with this theme of being triumphant over death. In this view Christ is "...thought of as the greatest hero, doing glorious battle with the forces of darkness, death and despair and emerging triumphant." <sup>16</sup> In this view of reconciliation Jesus has a very active role in the victory over death.

Christ the Harrower of Hell is seen in the scriptural reference of 1 Peter 3:18-22 (New Revised Standard Version) and believes Jesus as reconciling all of God's children in his death

<sup>&</sup>lt;sup>12</sup> Ibid., 39.

<sup>&</sup>lt;sup>13</sup> McGrath, A Brief History of Heaven, 79.

<sup>&</sup>lt;sup>14</sup> McGrath. A Brief History of Heaven, 77.

<sup>&</sup>lt;sup>15</sup> Ibid., 79.

<sup>&</sup>lt;sup>16</sup> Ibid., 83.

and resurrection. In this view "...after dying on the cross, Christ descended to hell, and broke down its gates in order that the imprisoned souls might go free." Jesus not only broke the gates of heaven opened, but also broke down the gates of hell in order to save the souls of all of God's creation.

Christ the Redeemer is a well-known view of the atonement within the Christian faith. In this view Jesus' death is offered as fulfillment to God for human sin. "...God became incarnate in order that, as the God-man, Christ would possess both the human *obligation* to pay the satisfaction, and the divine *ability* to pay a satisfaction of the magnitude necessary for redemption." In other words "...the admission-price of the believer to heaven is the death of the Son of God." In a contrasting view of Christ, being the substitute to pay for our sins, is the view of atonement as Christ the Lover. This view is focused on the determination of God to save humanity no matter the cost. In this belief God initiates "...the act of divine humility in leaving the glory of heaven to enter the poverty and suffering of the created order, and finally to suffer death upon the cross." God's love for humanity is so great that God was willing to enter our world that "...has unjustly come under the power and authority of Satan, obliging God to act justly in order to deliver us from this Satanic thrall." In this view, God's love is the gift that reconciles us back to God in death.

The final view of atonement we will consider is the Privatization of Atonement. This view is the personal conversation, a choice we make to admit Christ into our lives and it is this

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<sup>&</sup>lt;sup>17</sup> Ibid., 88.

<sup>&</sup>lt;sup>18</sup> McGrath, A Brief History of Heaven, 94.

<sup>&</sup>lt;sup>19</sup> Ibid., 96.

<sup>&</sup>lt;sup>20</sup> Ibid., 97.

<sup>&</sup>lt;sup>21</sup> Ibid., 97.

"...free decision to repent and admit Christ into the soul that secures the hope of heaven." 22 So it becomes "The experience of Christ in the believer's soul [that] serves both as a reassurance of faith, and an anticipation of finally being with Christ in heaven."<sup>23</sup> As we consider these views of atonement, I think it is important to reflect on our own beliefs and the way we think about how Jesus' death reconciles us to God and makes us worthy to enter the Kingdom of God. If we are comfortable with our own beliefs then we are able to walk with others helping them find peace within their own theological beliefs. After all, "Pastoral care becomes most helpful when meaning is drawn out from the patient or family, rather than you imposing meaning upon them."24 Having an understanding of our own beliefs and beliefs that differ from ours or that we may struggle with can help us make sure we are providing the pastoral care and guidance when needed, but not transferring our own beliefs or discomfort onto others. As faith leaders we need to be strong in our own conviction and teach others the promise of God, but we also need to be open to welcome other thoughts and beliefs as we walk the difficult end-of-life journey with those in our faith communities. The workshop will provide a place for faith leaders to reflect on their own beliefs and learn and review some of the theologies those they are providing care to may believe. Taking the time in the workshop for the faith leaders to reflect on their understanding about their own death and theologies, and what others theologies they may find difficult will better prepare them to help others transition from this world.

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<sup>&</sup>lt;sup>22</sup> Ibid., 108.

<sup>&</sup>lt;sup>23</sup> Ibid., 109.

<sup>&</sup>lt;sup>24</sup> Kirkwood. *Pastoral Care in Hospitals.*,156.

## **The Dying Process**

What happens to us as we transition from this earthly world to an afterlife? What changes does the body go through, physically, mentally, emotionally and spiritually? During the surveys with faith communities of the United Church of Christ in eastern Pennsylvania, when asked what information would be beneficial in conversations around end-of-life, the number one response was what happens at death. With the medicalization of death in our country, people are not as aware what a person goes through as they transition from this world to the next. There is a lack of knowledge when it comes to the dying process and people want that knowledge back. I think it is important for our faith leaders to have an understanding of what happens at the end of life, so they can take this information back to their faith communities. In this section of the workshop we will review what happens as a person goes through the dying process. Those in attendance will get to share personal stories or experiences they have had with those that are dying. Sharing stories seemed to interest both faith leaders and people in faith communities during my research. This time will allow for that personal sharing as participants gain knowledge about end-of-life. Participants will not be required to experience or stories. They may just discuss further the information that was provided about the dying process.

It is very difficult to write about the usual death, as every death, just like every life, is unique. It does not follow exact steps or stages, and often is influenced by the personality of the one who is dying. While we do know about things that often happen as someone is approaching death, these things may or may not happen. Also, there is no specific order in which these things happen. There are time frames in which a loved one will likely see some of the changes, for instance weeks before death or days/hours before death, however nothing is exact. Death is not always the peaceful event we like to think about; often people suffer and go through a time of

transition where their symptoms can be difficult to get under control. The struggles seem as "...if the body and soul that have been intertwined for so many years do not want to let go of each other." Yet there comes a moment when the struggle ends and a peace is felt as the body prepares for the final part of the journey home. Before we get to that final journey home, there are physical, spiritual and emotional experiences that one who is dying experiences. The following information will be in this section of the workshop which is focused on the dying process.

We will start with some of the social changes that happen as a person approaches death. Oftentimes someone who is dying will slowly start withdrawing from activities around them. This may start as early as weeks (or months) before death. The person may spend more time in bed or asleep, talk less, and be less likely to go out or participate in activities. This is a time when the faith community can be a support to the person, because "The dying are often out of the loop...no one says their name, no one cherishes their presence...what they experience is earthly death by isolation." However, "Death need not be a solo affair. It can be communal, and is perhaps best approached in just that way." The faith community can be there for those who are dying by providing continued friendship and help with practical needs even when someone begins to withdraw.

Not only might the person withdraw, in the weeks before death comes, sleep continues to increase until the person is in a coma like state of unresponsiveness. This is nature taking its course and our role as loved ones is to help make the person as comfortable as possible. The

<sup>&</sup>lt;sup>25</sup> David Kessler, *The Needs of the Dying: A Guide for Bringing Hope, Comfort, and Love to Life's Final Chapter,* Tenth anniversary ed.; 1st Harper pbk (New York: Harper, 2007), 134.

<sup>&</sup>lt;sup>26</sup> Brandy Schillace, *Death's Summer Coat: What the History of Death and Dying Can Tell Us about Life and Living* (New York, NY: Pegasus Books LLC, 2017), 160.

increase in sleep is often the body "...conserving energy, shunting what energy it has left only to the most vital organs." In the weeks before death approaches, a person may start to get more confused about place, time or people. This can be hard on loved ones who are visiting when the person who is dying doesn't recognize them or is confused about who they are. As a hospice chaplain I always encourage visitors to talk with the dying person and be present with them because although their body and brain may be getting confused, the soul is able to recognize and connect with their loved ones even if the person is unable to express it.

The dying person may begin to use symbolic language, such as "I am going on a trip" or "I want to go home." These things can often reflect the fact that they are dying and coming to the end-of-life. Continuing to touch and talk to the person as though they are fully present with you is important. Hearing is often the last sense to fail, so I always encourage family and loved ones to say what they want to say, to play music, to hold their loved one's hand or just spend time with them. The relationship and time spent together has moved to a deeper than physical level and the emotional and spiritual interactions are just as important to the person who is dying.

A person who is approaching death also has changes in their food and fluid intake. Often intake decreases as a person nears death. Many people no longer want food or drink; nothing tastes good, and cravings come and go. As the body slows down, the person approaching death will "...no longer use food in the same way." This is one of the hardest things for families to accept. So much of our love and care is around food. We spend time with family and friends by sharing a meal together, when someone is hurt or coming home from the hospital, we take them meals to provide care and support. We ourselves get hungry when we don't eat. All these things

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<sup>&</sup>lt;sup>27</sup> Kessler, The Needs of the Dying, 139.

Hospice of Santa Cruz County, When the Time Comes: A Caregiver's Guide, Main Line Heath HomeCare & Hospice (Quality of Life Publishin Co., 2008), 5.

lead us to struggle with watching the person who is dying as they stop eating. However, this is also a natural part of the process. If you try to force food or drink on the person you may cause more harm than good. At this time, we need to let the person who is dying be our guide, if they want something and it is safe for them to eat it, then give it to them. However, if they are not asking for food or if they are clamping their teeth closed, turning their head when offered food or spitting the food out, then don't force the food. Just let them be.

The loss of control over bladder and bowel is another physical change that happens to someone in the dying process. This occurs as the body and muscles weaken. This change can be embarrassing for the person who is declining. As pastoral caregivers we can make sure to continue to treat the person with respect and make sure they have someone to help them stay clean, dry and comfortable. In the days before death occurs, the urine amount will decrease and often become darker in color, this is a sign that the kidneys are slowing down and is a normal response to less fluid intake.<sup>29</sup>

Breathing changes happen at the end of life and this is one of the most notable changes as death approaches. Again, this does not happen to everyone. Some may continue to breathe relatively normally until the end. However some may struggle or have breathing changes that last hour or days. If someone has a lung disease these breathing changes can be for weeks or months. There may be many breathing changes that happen at the end of life. Some common ones are: dyspnea, apnea, Cheyne-Stokes and rattling. "*Dyspnea* is a complaint defined as labored breathing and short breaths." This can also be described as shallow breathing. For some, taking a breath seems to take great effort and energy and this can be scary if the person is

<sup>&</sup>lt;sup>29</sup> Hospice of Santa Cruz County, 6.

<sup>30</sup> Kessler, The Needs of the Dying, 141.

still conscious. Pain medication and medication for anxiety can help make someone more comfortable during this time.

Apnea is when a person stops breathing for a period of time. This pause in breathing can last for a few seconds or up to a minute. This is caused by "...a decrease in circulation and a buildup of the body's waste products."<sup>31</sup> This starts out brief at first, but the pauses in breathing can get longer as the body continues to weaken and slow down. This is often a sign death is near and one can think their loved one has passed only to have them take a breath again. Cheyne-Stokes is an irregular pattern of breathing where "...breathing begins with slow, shallow breaths. Breathing then becomes faster and deeper building in intensity...Then there is a period of no breathing (apnea) for one to sixty seconds, and the cycle repeats itself."<sup>32</sup> This, too, can be an indication that death is near. Being present and making sure any medical staff know about the changes in breathing are things we can do at this time.

The last breathing change is rattling or also known as "the death rattle." Family and friends that are gathered around their dying loved one are often disturbed when they hear this noise. The noise is caused by secretions gathering at the back of the throat as the person cannot swallow any longer. The family often wants to do something about it as they feel like their loved one is drowning. However, sometimes things like suctioning will only cause more discomfort.<sup>33</sup> While there is medication to help dry up the secretion, I often remind families that it sounds worse than it is and air is still getting to the lungs. Knowing this is a normal part of the process can prepare faith leaders to be able to provide support to family without being anxious themselves over these changes in breathing.

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<sup>&</sup>lt;sup>31</sup> Kessler, *The Needs of the Dying*, 141.

<sup>&</sup>lt;sup>32</sup> Ibid., 141

<sup>&</sup>lt;sup>33</sup> Hospice of Santa Cruz County, When the Time Comes: A Caregiver's Guide ,7.

As death approaches "The brain will start to lose control of body temperature as the body weakens. This can cause a fever or cause the body to become cool."<sup>34</sup> Cool compresses to the forehead or armpits are a good way to comfort those who have a fever and extra layers of blanket or turning the heat turned is appropriate ways to comfort those that are cold. As the blood flow slows down, hands and feet may become cool to the touch. This slowing in circulation can also cause skin color changes near the end of life. The person may look pale, their hands and feet may look purple or blue in color, their fingernails and lips may be blue or they may get maroon colored blotches on their legs, feet or their underside. These are all due to the circulation in a person slowing down as the heart is no longer able to pump the blood around a person's body like it once did.

Restless and anxiety can also plague a person at the end of life. They may pick at their sheets or clothing or do the same motion over and over. These symptoms can be due to less oxygen getting to the brain because of circulation slowing down. However, these symptoms can also be caused by pain, anxiety or emotional/spiritual distress. As pastoral caregivers we can provide a listening ear and check in with the person who is approaching death to see if they feel like they have any unfinished business. This can help alleviate emotional or spiritual concerns relating to restlessness.

The last physical change that can happen near death is a wave of energy. If this happens at the end of the life, the person may:

- be more alert and clear
- talking to loved ones
- want to eat when haven't in days

<sup>34</sup>Hospice of Santa Cruz County, When the Time Comes: A Caregiver's Guide, 8.

75

- want to get up to visit when they haven't been out of bed
- may be awake more often

This wave of energy can give false hope to families that the person is getting better, but sadly that is unlikely. However, as faith leaders we can encourage the family to enjoy this special time for what it is, and encourage the family to use the time to share memories and say goodbye and enjoy being with their loved one.<sup>35</sup>

Along with the social and physical changes a person goes through there are spiritual aspects at the end of life that are often experienced by many going through the dying process. Often, people will speak about being visited by loved ones who have already died, or even religious figures or groups of people. Frequently, "They will say these apparitions have come to "collect" them or help them let go.... Even when semi-conscious and unable to communicate with those sitting with them, it may appear that they are reaching out to take hold of something and then feeling it between their fingers as if puzzled."36 I will never forget one of my first experiences of this as a hospice chaplain. I was visiting with a gentlemen and his wife in their home, but because of this patient's disease process, he was unable to speak when I met him. However he would always give me a big smile when I came in to visit. As his death neared he stopped smiling and in the days before he died, he was unresponsive. As her husband was dying, his wife was struggling with her own faith and beliefs. She had always been a Christian, but this experience with her husband was bringing up questions and struggles for her. One of her questions was how would she know that her husband was in heaven, would he really be with those that had already died? When I would visit with them I would do spiritual exploration with

<sup>&</sup>lt;sup>35</sup> Hospice of Santa Cruz County, When the Time Comes: A Caregiver's Guide, 13.

<sup>&</sup>lt;sup>36</sup> "The Spiritual Aspects of Death," Dying Matters, July 10, 2013, https://www.dyingmatters.org/page/spiritual-aspects-death.

her and provide pastoral counseling. While I wasn't there as this patient died, when I called his wife a few days later to offer condolences, she asked me to come by because she wanted to talk with me. I was surprised she wanted me to come by, but I wanted to provide her with support. When I got to her house she invited me in with a big smile on her face. Unsure of what she was going to share, I sat down with her in her living room. She began to tell me about the patient's death. She stated as he laid there unresponsive, his whole family was all around the bedside. All of a sudden he got a huge smile on his face, reached his hands up and looked like he embraced someone in a hug, then he laid back down in the bed and died. It gave me chills to hear her share this story. It was a way in which God answered her questions and struggles with her faith. After that moment she knew he had gone with someone he knew and he was in heaven waiting for her. It was a profound story and one that will always inspire the work I do.

Not only might people see others who have passed, but they may talk about embarking on a journey or "...describe other worldly realms... They may also appear to be thinking deeply, as if they are being 'shown' information that they may not have considered before" This happened while I was still orienting for my work as a hospice chaplain. I was out visiting with one of the social workers and we went to visit a gentleman and his wife. As we visited with them his wife said the patient had been telling her, they needed to go or would say to her "let's go." When she asked her husband where they were going he stated to the garden and then began to describe the most beautiful garden. She stated that he always loved to garden and to be outside and she believed he was describing heaven. No matter the spiritual experience, many of

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<sup>&</sup>lt;sup>37</sup> "The Spiritual Aspects of Death."

"...those who witness these end of life experiences, usually describe them with loving, reassuring words such as calming, soothing, greeting, comforting, beautiful, readying." 38

As I stated above our theology and belief systems affect not only our life and faith practices, but also our dying process and end of life decisions. Elizabeth Kuber-Ross discusses the five stages we go through when we face death; these are the same stages that we face in grief (denial, anger, bargaining, depression and acceptance). It is important to recognize that the person who is dying may indeed go through these stages of grief as the move to the acceptance of their death. As faith leaders it is important to recognize and help individuals and their loved ones process this grief. As faith leaders an important role we play in ministry is helping those we serve in their spiritual journeys. One of the resources I encountered in my research stated that there is a process in spirituality that one moves through when facing death. There are five stages of spiritual reconciliation we go through when we are faced with the end-of-life. <sup>39</sup> As faith leaders I think it is important to know and understand these stages of reconciliation so we can help those in our faith community moved through these stages as they face terminal illnesses or end-of-life.

The first stage is expression. This is the understanding that "...until we admit our feelings, we cannot heal." We need to release our feelings, those that we have kept hidden or haven't voiced for fear of how they will be perceived by others. Whether it is anger or jealousy of a family member or friend or being upset with God because of one's circumstance, admitting your feelings can help you find peace. As faith leaders we can help people release these feelings. Those facing end-of-life don't have to confront the person they are angry or jealous with; they

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<sup>38</sup> Ibid.

<sup>&</sup>lt;sup>39</sup> Kessler, The Needs of the Dying, 102.

<sup>&</sup>lt;sup>40</sup> Ibid., *103*.

just need to set those feeling free. This can be done through confiding in a friend or faith leader, writing a letter, whispering it into the air or yelling into their pillow. It is not about the other person at this time; it is about admitting the feelings the dying person has so s/he can move into peace. Being a listening ear for the dying person can help them set their feelings free.

The second stage of spiritual reconciliation is responsibility. Facing death helps to take responsibility for our actions and lives. Through an example the author, David Kessler, explains this is the understanding that although we may not be to blame for the misdeeds of others, we do bear responsibility for all that has happened in our lives. After we have admitted our feelings and taken responsibility for things that have happened in our lives, the next stage is forgiveness. When we die, our part in relationships will be over and "The dying understand this intuitively, which is why they often have a meeting with forgiveness." Forgiveness does not mean that we accept bad behavior, but instead forgiveness releases us from the binds of hate and hurts. Forgiving ourselves is just as important as forgiving others. We seem to be hard on ourselves as we partake in life review and focus on all the things we did wrong. However, forgiveness can help us release any regret and provide peace at the end of life. If we can't forgive ourselves, then we can ask God for help in this forgiveness.

The third stage is acceptance; acceptance that death is coming and we are mortal. This is when, as faith leaders, we can help people understand their faith in relation to their death, that God created and gave us life, created us as mortal, not to last forever. Faith leaders can help those they serve to "...be willing to fight when fighting is appropriate, but we will all face that

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<sup>&</sup>lt;sup>41</sup> Ibib, 104.

<sup>&</sup>lt;sup>42</sup> Kessler, *The Needs of the Dying, 104*.

moment in life when it is time to stop fighting, to stop treating death as the enemy."<sup>43</sup> It is important to let those we serve know that it is not giving up on God to let go and accept that we are dying. When we do this we are accepting that dying is part of the life God created when God made humanity.

The fourth final stage is gratitude. When a person becomes grateful for his or her life, both the good and the bad they have reached gratitude. As one participates in life review, they begin to realize that all the things that happened in life made them into the person they are and brought them to their current time and place. Reviewing life gives us the ability to appreciate the good times and possibly see the lessons the bad times taught us. It also brings meaning and purpose to the dying person at the end-of-life. As faith leaders it is an honor to hear life stories and allow someone to express gratitude for the life they lived. Although not all people will go through this spiritual journey and some may not be able to participate in parts of it, it is our responsibility as faith leaders to help those who have a genuine desire to explore their spiritual selves go through this reconciliation.

Through learning about what happens in the dying process and ways in which we can provide care for those that are dying "It is highly probable that the dying patient makes you think of a special person in your own life...This is a negative unless you have developed your own understanding of death and its ramifications. In other words, you must be comfortable with the idea of your own mortality."<sup>44</sup> This is why it is important to have these trainings on end-of-life care with faith leaders new to ministry and MIDs. Through these trainings they will not only learn about death and dying and how to have conversations around end-of-life, but they will also

<sup>&</sup>lt;sup>43</sup> Kessler, *The Needs of the Dying, 106*.

<sup>44</sup> Kirkwood. *Pastoral Care in Hospitals, 156*.

get to consider their own personal experiences with death. By recalling these experiences in a safe place of training, rather than with a person who is dying or with their family, faith leaders are able to process their emotions and process through them. This will provide the faith leaders the time to develop their own understanding of death and mortality.

### **Faith Leader Panel**

Three faith leaders will be invited to the workshop to share their experience dealing with death and dying within their faith communities. They may possibly share a difficult death and how they dealt with different situations they found themselves in. Each faith leader will have 20 minutes to share their experiences and then there will be 20 minutes left for questions from those in attendance at the workshop. This part of the workshop stemmed from my findings that faith leaders stated experience was what helped them feel the most prepared for having conversations around end-of-life within their faith communities. While we cannot get on-the-job training outside of our jobs, the workshop can provide stories about what others have experienced and how they dealt with situations to help faith leaders new to ministry and faith leaders in training gain knowledge and understanding about death and dying.

It is the goal that through the experienced faith leaders on the panel, those in attendance will learn conversation methods, talking points, or ways to react in the different situations they may find themselves in as they are in their faith communities working with those around them. Through the stories of this panel of faith leaders, they will gain an understanding that they are not alone in ministry. When they find themselves in a challenging situation in ministry, it is my hope that they will be able to remember others have been through similar situation and survived.

The panel of faith leaders share their experience and learnings so those new to ministry feel more prepared to deal with death and dying in their congregations.

### Case Studies/Shared stories

This will be an interactive experience in the workshop. After those in attendance break into small groups the participants will be invited to use their own experience as case studies to discuss in their groups. If no one is comfortable sharing their own experience or no one has had an experience with conversations around death and dying, there will be case studies provided for the group to discuss. The reason I am giving them an opportunity to share their own experience is because, by making the situations more personal, those in attendance will be able to gain more from this experience. Being able to reflect on their personal situation and hear the thoughts and suggestions of others from their small group will help "gain experience" to take with them into their places of ministry.

During this time together, they will share/read the situation and then discuss what they would do. For example, they may discuss how they would talk with the person/family, what programs or events they could have at the faith community if the situation warrants this and what resources they might use and how they would use them. Through this time in small groups/discussing real life situations or case studies, it is the goal that this experience will simulate on the job training so many of the faith leaders stated was one of the things that prepared them to have conversations around end-of-life.

### **Review of Annotated Bibliography**

As the workshop draws to a close, there will be a review of the annotated bibliography that was created as a resource for faith leaders to support them in having conversations around death, dying, and end-of-life care in their faith communities. This will be time for an explanation of what is included in the annotated bibliography with attention given to anything that we did or discussed during the workshop that is included in the bibliography. The bibliography will be available in both hard copy and electronic forms. My hope is to be able to create a website or social media group that can be shared with faith leaders along with this resource list for having conversations around death and dying with faith communities. In this way, the list can be edited and updated as needed as more information becomes available or other faith leaders suggest resources that have been helpful to them.

The books and websites for the annotated bibliography were chosen based on my literature review and the interviews that were done with faith leaders in the UCC in eastern Pennsylvania. During these interviews, one of the questions was, 'Do you have any resources for talking about death and dying with your congregation?' The interview followed-up by asking what they liked about the resource. Through discussion around these questions faith leaders shared what resources they have used within the context of their faith community. I also asked 'What kind of resource they wished they had' if they didn't identify any resources in the question above (see Appendix 2). This discussion with the faith leaders and my own research revealed resources that might be helpful to faith leaders as they have discussions on death and dying in their faith communities or visit with those in their faith communities that are facing a terminal illness and death. I felt like an annotated bibliography offered faith leaders a list of resources in one place, but also provided them with some information on the resource and how it could be

beneficial for them. The resources fall into the following four categories: conversation guides or starters, resources to use for visitation or family meetings, resources for a sermon series and book studies and resources for caregivers. The rest of this chapter will discuss each category and the resources available for each topic; the annotated bibliography can be found in Appendix 7.

### What Do We Say?

A few of the resources found in the annotated bibliography include resources that faith leaders could use to help start or facilitate conversations with their faith communities around death and dying. The resources of "Go Wish" and "Five Wishes" are both ways in which faith leaders can encourage those in their faith communities to begin to think about their end of life wishes. These resources provide a guide and the words to use to start the conversation of end-of-life wishes with loved ones. The "Five Wishes" is a unique document because it not only speaks to the medical, personal, emotional and spiritual needs of individuals, but it also becomes a legal document once completed. These are a great resource for faith leaders to use to introduce the topic of end-of-life (EOL) with their congregation in an easy non-threatening way. These resources encourage others to take an honest look at their EOL wishes and planning, but do it in a way that doesn't leave people feeling burdened or disheartened.

There are two resources included that are specific to the faith denomination this project was focused in, The United Church of Christ. One is a book called *A Clergy Guide to End-of-Life Issues* written by an ordained minister in the denomination and the other, *Making End of Life Decisions* is a booklet that was written by the United Church of Christ Chaplains in Health Care and The Council for Health and Human Services Ministries of the United Church of Christ, two national organizations for the denomination. They both cover basics of end-of-life issues

with the book including things such as legal, medical, theological and pastoral issues at the endof-life. The booklet includes advanced directives and living wills, barriers to decision making
such as fear of dying, guilt, procrastination, and perspectives of the United Church of Christ.

Both of these resources can be used by faith leaders as they focus on the practical issues facing
someone who is dying. It also provides faith leaders with a way to guide those who are dying in a
graceful, peaceful and dignified death.

### Visiting and Meeting

The resources in this section will be beneficial to faith leaders when visiting those facing a terminal illness and their families/loved ones. What to Say When You Don't Know What to Say by H. Norman Wright is a practical and specific guide that can help faith leaders gain the insight needed in order to be supportive and point to God as the ultimate healer. I discovered this resource while doing my Clinical Pastoral Education, or my chaplaincy training. This resource not only provides ways in which faith leaders can respond in difficult conversations, it also reviews some of the clichés used when we talk to others who are going through a hard time and give insight on why these clichés are not as helpful as we might think. This book along with Pastoral Care in Hospitals by Neville A. Kirkwood are great resources to provide faith leaders with guides in visiting parishioners with knowledge on how people may be feeling, things to consider during visiting such as reading nonverbal cues and knowing the time and place for prayer. Pastoral Care in Hospitals also provides ways to give encouragement and provides biblical wisdom for helping others cope in times of despair.

Pastoral Care in Hospitals along with A Faithful Farewell: Living Your Last Chapter with Love by Marilyn McEntyre provides practical resources as they both include prayers that can be

said when visiting with those who are sick and/or dying. While the book on pastoral care addresses certain circumstances and issues you may face when visiting someone in the hospital, *A Faithful Farewell* goes even further by re-framing issues those who are sick and dying face with connections to the Bible and Christian beliefs. These resources will help faith leaders understand the physical, spiritual and emotional issues someone deals with as they are facing illness and death.

The last resource that falls in this category is *Accompany Them with Singing: The Christian Funeral* by Thomas G. Long. This resource is beneficial for clergy to use when preparing to talk with families about funeral planning. The book looks at the Christian funeral and how it is changing, offering a look into the cultural trends that are happening at funerals today. It provides faith leaders with some questions to think about as they help loved ones plan a funeral as well as encourages faith leaders to think about decisions that are becoming more popular in the current culture with regard to funeral services. This resource also provides a practical detail section including the different patterns and options of funeral services along with guidance for preaching at funerals.

### Sermon Series/Book Studies

One of the types of resources that faith leaders said would be beneficial in having to support them with conversations around death and dying were resources that could be used for sermons or for bible/book studies. There are three resources in the annotated bibliography that seem to work well for this intent. These books not only discuss death, but also the grief and fear that surrounds death. *Dessert First: Preparing for Death While Savoring Life* by J. Dana Trent, *Unafraid: Living with Courage and Hope in Uncertain Times* by Adam Hamilton, and *Living* 

Life Backward: How Ecclesiastes Teaches Us to Live in Light of the End by David Gibson all provide a different look into death and how it can inspire/impact our lives now. These resources provide thoughtful, literate, faith-filled guides to re-claiming our lives and our death. The resources don't shy away from the reality of death and instead use that reality to cultivate faith and help us view life as the wondrous gift from God that it is.

These books show us how to love more deeply through grief and embrace death as essential for life. They remind us that we are all going to experience death sooner or later, and therefore encourage us to start the conversations now. The books provide faith leaders with stories and examples for sermons, but also the important points needed when preaching about death and dying from the pulpit. These resources go beyond mere analysis of their discussions on death and dying to offer spiritual practices and biblical wisdom which can bring real peace to struggling people. They include biblical insights, scriptural references, questions and resources within the book that makes them a good choice for small group or bible studies.

## Caring for Our Loved Ones

During my research with faith leaders and faith communities, when asked what information or resources would be beneficial in conversations around end-of-life care, at least one person in each medium of research stated 'resource for caregivers.' There is a desire from the faith communities to know how we as caregivers can help care for someone who is facing death. The faith leaders wanted to know how they could support those in their congregations who are caring for someone who is on the journey to death.

The two resources that are beneficial to those caring for loved ones who are dying are

Gone from My Sight: The Dying Experience by Barbara Karnes, RN and A Sacred Walk:

Dispelling the Fear of Death and Caring for the Dying by Donna M. Authers. The first resource

is about the process of dying and it reviews the signs and symptoms of death. The booklet includes both an outline of things that can happen along with pages that describe each of those things in further detail. Not only can this booklet be used by faith leaders to help them understand the dying process, it can also be used by family and loved ones to help them prepare for what is to come as their loved one goes through the dying process. Having knowledge about the dying process and knowing what natural things might occur as someone approaches the end-of-life can reduce fear and uncertainty around death.

The second resource above can be used by anyone, faith leaders and family alike, who are caring for someone and show how facing death with love and acceptance can bring peace and closure. This book helps to dispel the fear of death that is so common in today's society and uses the experiences of the dying to show how best to meet the practical, emotional, and spiritual needs of a loved one who is facing death. The stories and lessons shared in this book will comfort and help others learn how best to care for their loved ones facing death. The book covers practical, emotional, spiritual and psychological preparation for death which can be a great resource for families and loved ones of someone who is dying. This book brings a beautiful spiritual clarity and an organized approach to the complicated and sacred work of dying which will be a comfort for those caring for someone in the dying process.

The resources in this bibliography (see Appendix 7) are intended to be one of many supports faith leaders can use when opening up conversations around death and dying in their faith community. The goal is for faith leaders to feel more confident and prepared to have general conversations on death, dying and end-of-life as they are able to access resources to help aid these conversations. By having access to these resources it is my goal that more faith leaders will have intentional conversations on death and dying in their faith communities so that

we can begin to help people take back some control over their dying experience and die with grace and peace.

### Where Do We Go From Here?

Faith leaders play a role in bridging the gap between faith and spiritual practices and the dying process. They can also bridge the communication gap that exists at times between their parishioners and their family and loved ones when it comes to conversation on end-of-life care. As a hospice chaplain I have often met families who don't want to let their loved one know they are dying. They state that they don't want to upset them or that the dying individual would worry about their family left behind when they die. This communication gap between loved ones around conversations on end-of-life is very much present in our society today. Therefore, faith leaders need to bridge this gap by encouraging conversations on end-of-life within their faith communities. As my research earlier states, many people want to be able to get their affairs in order or say goodbye to those they love, however if families don't communicate with one another, or don't let their loved one know their illness is terminal, then that person misses out on preparing for their death.

Through my hospice work, I have encountered times when people have shared stories with me or remembered things from their life that they had never shared with anyone before. While some of these things were kept private intentionally, much of the time it was the fact that the person had never been invited to share stories from their life in a way that is provided through pastoral care. Life review is a big part of the dying process, whether it is for spiritual reconciliation and forgiveness or just to get a story out there for others to hear.

This process of reviewing one's life gives meaning to the individual in the dying process.

If we continue to stay silent around the conversations of death and dying these individuals will

never get a chance to reflect on their lives and their stories. They will not get to share their legacy with the next generation or tell their loved one about what is important to them from their life. By not talking with one another, individuals do not get to share what will bring them comfort in the dying process.

This project found that while many faith leaders are having conversations around death and dying in some form, many of the individuals within the faith communities either don't remember these conversations or feel like more intentional conversations are needed. The implication for faith leaders is that we need to do better at having intentional conversations around death and dying in our faith communities. There needs to be more open conversations that normalize the topic of death so that people can ask their questions or get the information they desire.

My research also indicated that the more experience pastors had in conversations around death and dying, the more comfortable and equipped they were to have these conversations in their faith communities. The implication then, for our conferences in the United Church of Christ, is to do a better job at providing faith leaders in the discernment process or starting in ministry with either the training and/or resources they need to be able to have these conversations within their faith communities. Based on my research there is a desire from both the individuals within faith communities and from the faith leaders for these conversations to be happening more often. Places of faith, our faith communities, should be one place where these conversations occur. Faith leaders need to be able to provide a safe space where people can discuss their wishes, fears, theology and questions openly with one another. Our faith communities can be a place where people explore their faith in relationship to their death; where people experience faith being lived out in conversations on death and dying.

As the literary research took place for this project I came across a study called the National Clergy Project on End-of-life Care from Harvard University. This study found that "…clergy are both-ill prepared and reluctant to engage in end of life conversations." However, in my research I found that all the faith leaders I interviewed and a majority of those surveyed felt equipped and prepared to have these conversations on end-of-life care. Therefore, I think a broader based, multi-denominational/faith research like the one being done by Harvard is needed to increase awareness of the needs of faith leaders in conversations around death, dying and end-of-life care.

A critical look at the understandings or assumptions that many people are 'uncomfortable' with death or 'fear the word' and therefore don't talk about it, is needed. Many of the resources on death and dying that I found while doing my literary research stated these understandings and assumptions within our society, yet while I was doing my field research, 85% of the people I interviewed in faith communities did talk about death and dying with their family or a loved one. This leads to a suggestion that further research is needed to find out if the comfort with the topic of death is changing in our society. In this project, the places of study being faith communities may have impacted the results, as people of faith may feel more comfortable talking about death since it is part of our everyday faith. However, I do believe that further research could still be done to look at the ways conversations on death and dying are happening in our society. With new interest of bringing back the normalcy of death as part of life and the movement of death cafes in our society, are we doing better at talking about death even through the assumptions that we avoid it still exist? Or are people just more comfortable to

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<sup>&</sup>lt;sup>1</sup> David Briggs, "Studies Show Help, Hurt That Can Come from How Clergy Talk about End-of-Life Care," *The Christian Century* 134, no. 15 (July 19, 2017): 16.

talk about plans for end-of-life or death because it seems as if it is still a faraway event, but when death becomes a present reality, we are less comfortable talking about it? Further research is needed to study the way conversations of death are changing in our society.

Faith leaders need to continue encouraging conversations on death and dying within their faith communities along with providing space and examples of ways to have conversations around end-of-life care. How best do we do this within our faith communities? This is a question for further research. In this project, I provided an annotated bibliography to help faith leaders have conversations on death, dying and end-of-life care and also created a workshop that can be used with faith leaders that are still in training or new to ministry. However, I think further research can focus on best practices or ways to have conversations within our faith communities. During my research, when I was distributing the surveys with United Church of Christ faith communities in eastern Pennsylvania, I had one of the five faith communities ask me to be present to hand out the surveys at the end of service. This is also the church where I received the most surveys back. The difference in returned surveys was a significant amount with this church having nineteen more surveys than any other church who participated. It led me to wonder if the same would be true for programming on conversations about death, dying and end-of-life care within faith communities. Would there be a better response if the information was given or presented by someone outside the faith community rather than the faith leader? The area for further research would be to see in what ways the wider church and community can best support their faith communities in having conversations surrounding preparation for death and dying.

As conversations around death, dying and end-of-life care continue and faith leaders feel encouraged and supported in these conversations, the hope is that we begin to refocus on the natural process of life and death; that death becomes part of our living and people become more

comfortable talking about the subject in everyday conversations. As individuals begin to be more open about our human mortality and have conversations around end-of-life wishes within our faith communities, can this comfort transition into conversations around the death of our faith communities? As we move into this new time, where death conversations seem to be on the rise, a future study on what ways these conversations on death and dying have impacted the way mainline Protestant churches die would be an area of further research.

Churches have been dying since Christianity began, leaving legacies and examples of how to be Christ-like in the world. Even though this has been the case since the beginning we struggle to recognize and admit that the faith community around us is dying. People often do everything they can to "keep it alive" struggling to stay afloat until there is no choice but to close the doors and walk away. What would it be like if the comfort of conversations around death and dying spread to conversations around dying churches in our United Church of Christ denomination? How could we better assist our churches to die with dignity and grace, to express their final wishes, and create legacy work so that they can be a model for those that come after them? It is the hope of this project that bringing back the natural process of death and helping to dispel the fears surrounding death, will not only benefit individuals within our faith communities but, will also allow faith communities that are dying to die with dignity and grace.

## **Survey Questions to Faith Leaders**

1. How old are you?
a. 20-29
b. 30-39
c. 40-49
d. 50-59
e. 60-69
f. 70+

2. What gender are you?a. Maleb. Female

3. How long have you been in ministry?	
a. 1-5 years	
b. 6-10 years	
c. 11-20 years	
d. 20+ years	
4. What classes or training on death and dying have you had?	
5. On a scale of 1-5, how comfortable are you talking about death and dying to your	
congregations? (1= not at all, 3=somewhat comfortable, 5= very comfortable)	
a. 1	
b. 2	
c. 3	
d. 4	
e. 5	
6. What resources do you use when visiting the sick and dying members of your	
congregation and their families?	
7. Do you have general conversations with your congregation on death and dying out	side of
the impending death of a member or loved one?	
a. If yes:	
i. How do you present them? (sermons, bible studies, seminar, etc.)	
95	

- ii. What size group? (individuals, families, small groups, whole congregation, ect.)
- iii. What resources do you use?
- b. If no:
  - i. What is preventing you from having these conversations?
- 8. As you prepare to have general conversations about death and dying with all (those not terminally ill) in your congregation, what resources do you wish you had?
- 9. What would your ideal death be?
- 10. What would an ideal preparation for death be?
- 11. Would you be willing to participate in an interview on this topic?
  - a. If so, please leave your contact information:

### **Interviews with Faith Leaders**

- 1. What is your age?
- 2. How long have you been in ministry?
- 3. What trainings or workshops on death and dying have you taken?
  - a. What was the most helpful thing you learned?
  - b. What do you wish you had been taught?
- 4. What if anything in seminary prepared you for these conversations?
  - a. What do you wish you learned?
- 5. Do you feel equipped to have general conversations with your congregations around end-of-life?
  - a. If yes, what has helped you feel prepared for these conversations?
  - b. If no, what do you feel you need in order to have these conversations?
- 6. Do you have any resources for talking about death and dying with your congregation?
  - a. If so, what do you like about the resources you have?
  - b. If not, what kind of resource do you wish you had?
- 7. Do you know what resources are available to start general conversations around end-of-life, outside of impending death, with your congregation members?
- 8. What is your greatest fear about your own death?
- 9. What is your greatest fear about a congregation member's death?
- 10. What is your greatest fear about a community member's death?
- 11. Where do you see God (or maybe don't see God) in dying?
- 12. Where do you see God at work in medicine?
- 13. Where do you see God at work in medical treatments for the terminally ill?
  - a. How do you think, if at all, this affects our decision making around end-of-life care?
  - b. Is it faithful to "give up"?
- 14. How do you think about your own death in light of Jesus' death?
- 15. What do you need so that you can empower your congregation members to have conversations around mortality and end-of-life?
- 16. follow-up questions as needed

## **Survey to Faith Communities**

- 1. How long have you been attending church?
- 2. How old are you?
  - a. 18/19
- e. 50s
- b. 20s
- f. 60s
- c. 30s
- g. 70s
- d. 40s
- h. 80+
- 3. Have you ever talked with your family members or anyone else about your end-of-life wishes?
  - a. If no, why not?
- 4. What conversations on death and dying (through speakers, meetings, seminars, workshops, et.) have you had?
- 5. Has your pastor or congregation ever had a bible study related to death and dying and end-of-life?
- 6. What sermons have you heard preached on human mortality and death?
- 7. Do you think it would be beneficial to have conversations around death and dying in your church?
  - a. If so, what do you wish your pastor would talk about?
- 8. What information do you think would be beneficial in these conversations?

## Workshop on Death, Dying and End-of-life Care – 6 Hours

- Introduction 30 minutes total
  - Play the game "Go Wish" individually and then have small group discussions on what was easy/hard about choices your last wishes.
- Professional Panel 1 hour
  - A panel made up of a funeral director to discuss funeral preparation, palliative care doctor to discuss medical options, and an attorney to discuss estate planning and fund giving. Each will have 20 minutes to discuss their topic then 20 mins of questions from those gathered. There will be a break after this also to allow for individuals to talk further with any of the participants.

[BREAK - 20 min]

- Theologies 30 minutes
  - We will review the more common theologies on death, afterlife, sanctification and salvation. Then we will have time to think about our own theologies.
- The Dying Process- 45 min
  - There will be a presentation of what commonly happens as someone that goes through the dying process including the spiritual aspects of death. Then there will be small group time where people can share their own experiences or discuss some of what was learned.

[LUNCH – 1 hour]

### • Faith Leader Panel – 1 hour

O Panel made up of three faith leaders to share their experience on dealing with death and dying in their faith communities and how they dealt with different situations they have found themselves in. Each faith leader will have twenty minutes to talk and then there will be twenty minutes left for questions from those at the workshop.

[BREAK – 10 mintues]

## • Case Studies/Shared stories – 30 min

- The participants will be in small groups using their own experience as case studies or using the case studies I supply to simulate on the job training.
- Review of Annotated Bibliography 15 min
  - I will review the annotated bibliography that I created as a resource for them, letting
    them know what is included on the list and anything that we did during the workshop
    that is on the bibliography.

## Appendix 5

## Slide Show On Theologies on Death

Slide 1

Theologies on Death/Dying

Slide 2

### Death as Friend

1 Corinthians 15

- that this isn't the end
- there is more than this life we live now;
- death is a "friend coming to take us to a better place." N. T. Wright, Surprised by Hope: Rethinking Heaven, the Resurrection, and the Mission of the Church, 1st ed (New York: HarperOne, 2008), 36.

#### Death as Enemy

Romans 5

- · destruction of the created life
- as they enemy of God.
- Death is "an intruder, a rude usurper who consumes all our powers of endurance, grace and dignity." Kenneth L. Vaux and Sara Anson Vaux, Dying Well, Challenges in Ethics (Nashville, Tenn: Abingdon Press, 1996), 39.

Slide 4

# **Atonement Theologies**

- · Christ the victor
  - founded in scripture of 1 Corinthians 15:57. This belief is that
    the gates of heaven have been thrown open and "...gloried in the
    triumph of Christ upon the cross, and the victory that he won
    over sin, death and Satan." The victorious Christ has paid for our
    sins and we are reconciled to the Kingdom of God through his
    death and resurrection. Alister E. McGrath, A Brief History of Heaven, Blackwell Brief
    Histories of Religion (Malden, MA: Blackwell Pub, 2003),79.
- · Christ the hero
  - In this view of reconciliation Jesus have a very active role in the victory over death. Christ is "thought of as the greatest hero, doing glorious battle with the forces of darkness, death and despair and emerging triumphant." Alister E. McGrath, A Brief History of Heaven, Blackwell Brief Histories of Religion (Malden, MA: Blackwell Pub, 2003), 83.

### **Atonement Theories**

- · Christ the Harrower of Hell
  - scriptural reference of (1 Peter 3:18-22) and sees Jesus reconciling all of God's children in his death and resurrection. Jesus not only broke the gates of heaven opened, but also broke down the gates of hell in order to save the souls of all of God's creation.
- Christ the Redeemer
  - Jesus' death is offered as fulfillment offered to God for human sin. "God became incarnate in order that, as the God-man, Christ would possess both the human obligation to pay the satisfaction, and the divine ability to pay a satisfaction of the magnitude necessary for redemption." Alister E. McGrath, A Brief History of Heaven, Blackwell Brief Histories of Religion (Malden, MA: Blackwell Pub, 2003), 914.

Slide 6

## **Atonement Theologies**

- · Christ the Lover
  - In contrast to Christ the Redeemer, this view is the determination of God to save humanity no matter the cost. God's love is so great that God was willing to enter our broken world to deliver us from evil. In this view God's love is the gift that reconciles us back to God in death.
- Privatization of Atonement.
  - This view is the personal conversation, a choice we make to admit Christ into our lives. So it becomes "the experience of Christ in the believer's soul [that] serves both as a reassurance of faith, and an anticipation of finally being with Christ in heaven." Alister E. McGrath, A Brief History of Heaven, Blackwell Bird Histories of Religion (Malden, MA: Blackwell Pub, 2003), 94.

## Appendix 6

### Slide Show on Death and Dying

Slide 1

# **Dying Process**

What Happens as we transition from this world to the next?

Slide 2

# Social/Emotional Changes

Hospice of Santa Cruz County, When the Time Comes: A Caregiver's Guide, Main Line Heath HomeCare & Hospice (Quality of Life Publishin Co., 2008).

- 1 to 3 Months
  - Withdraws from people and activities
  - Talks less
  - Sleeps more
- 1 to 2 weeks
  - Confused about place, time, or people
  - Uses symbolic Language (I want to go "home")

# **Physical Changes**

Hospice of Santa Cruz County, When the Time Comes: A Caregiver's Guide, Main Line Heath HomeCare & Hospice (Quality of Life Publishin Co., 2008).

- 1 to 3 Months
  - Eats and Drinks less
  - Sleeps more
- 1 to 2 weeks
  - Pulse speeds up or slows down
  - Blood pressure drops
  - Skin color changes
  - Breathing weakens or is uneven
  - Body temperature turns hot or col
  - Does not eat and only drinks little or no fluid

Slide 4

# **Physical Changes**

- · Days to hours
  - Sleeps most of the time
  - Wave of Energy
  - Restless
  - Hard time swallowing
  - Weak Pulse
  - Drop in blood pressure
  - More changes in skin color
  - Changes in breathing pauses between breaths
  - Rattling sound while breathing
  - Eye lids do not close all the way

# **Physical**

- Minutes until Death
  - Short breaths with long pauses
  - Mouth open
  - Does not respond

Slide 6

## Spiritual

"The Spiritual Aspects of Death," Dying Matters, July 10, 2013,

- It is also not uncommon in the weeks or days before death for a dying person to speak of being 'visited' by dead relatives, friends, groups of children, religious figures or even favorite pets. They will say these apparitions have come to "collect" them or help them let go.
- The person may also talk about moving in and out of 'reality', and describe other-worldly realms. They may speak of embarking on a journey, or may suddenly stare at a point in the room or turn towards the window and experience a sense of amazement, joy or wonder.

## Spiritual

- Even when semi-conscious and unable to communicate with those sitting with them, it may appear that they are reaching out to take hold of something and then feeling it between their fingers as if puzzled.
- They may also appear to be thinking deeply, as if they are being 'shown' information that they may not have considered before. Dying people, and those who witness these end of life experiences, usually describe them with loving, reassuring words such as calming, soothing, greeting, comforting, beautiful, readying.

Slide 8

### **Spiritual Reconciliation**

David Kessler, The Needs of the Dying: A Guide for Bringing Hope, Comfort, and Love to Life's Final Chapter, Tenth anniversary ed.; 1st Harper pbk (New York: Harper, 2007).

- 5 stages of spiritual reconciliation
  - Expression "until we admit to our feelings, we cannot heal"
  - Responsibility "they have played a role in all that has happened to them in life.
  - Forgiveness "our part of the quarrel will be over....release ourselves from the binds of hate and hurt [to ourselves and others]"
  - Acceptance "patients be willing to fight when fighting in appropriate, but we will all face that moment in life when it is time to stop fighting, to stop treating death as the enemy."
  - Gratitude grateful for the life we have had.

#### Appendix 7

#### **Annotated Bibliography**

Authers, Donna M. A Sacred Walk: Dispelling the Fear of Death and Caring for the Dying. Charlottesville, Virginia: A&A Publishing, 2008.

This book helps to dispel the fear of death that is so common in today's society and uses the experiences of the dying to show how best to meet the practical, emotional, and spiritual needs of a loved one who is facing death. The stories and lessons shared in this book will help others learn how best to care for their loved ones and also help them die with dignity when their own time comes. The author covers practical, emotional, spiritual and psychological preparation for death which can be a great resource for family and loved ones of someone who is dying.

"Faith-Based Organizations." Five Wishes for Faith Based Organizations. Accessed December 17, 2019. <a href="https://fivewishes.org/five-wishes/communities/five-wishes-in-your-community/faith-and-community-organizations">https://fivewishes.org/five-wishes/communities/five-wishes-in-your-community/faith-and-community-organizations</a>.

Five wishes is an easy to use advanced directive documentation that is in everyday language that helps people consider how they want their end of life to go. The five wishes is a unique document because not only does it speak to "all of a person's needs: medical, personal, emotional and spiritual," but also becomes a legal document once completed. This document provides a guide to structure discussions with family and doctors making having these conversations easier. This link provides faith communities with a way to access the 'Five Wishes' document.

Gibson, David. *Living Life Backward: How Ecclesiastes Teaches Us to Live in Light of the End.* Wheaton, Illinois: Crossway, 2017.

Living life backward is a book that takes the one thing that we are all certain of in this life

– death, and letting that inform our lives. To live well means to die well, and this book is a

reminder of that. The book looks at the scriptures found in Ecclesiastes as influence and for wisdom. It takes the reality of death and uses that to help us view life as the wondrous gift of God that it is. This book is a great resource for a sermon or sermon series on using the reality of death to encourage us to like the life God wants from us now. There are also questions found at the end of the book that makes it a good choice for small group or bible studies.

Hamilton, Adam. *Unafraid: Living with Courage and Hope in Uncertain Times*. First edition. New York: Convergent, 2018.

Fear is something that robs us of our peace and can take our lives from us one moment at a time. This book addresses all different types of fears. This book is a wonderful faithfilled guide to reclaiming our lives. The book addresses many different types of fear, the fear of death being one of them. Through biblical insight along with real-life examples and research the other provides us with a way to cultivate faith through facing facts, examining assumptions and overcoming anxieties. This book helps its readers understand and counter fears in life, including the fear of death. This book could be used as a resource for sermons or used as a small-group book study.

Jacobs, Martha R. A Clergy Guide to End-of-Life Issues. Cleveland: Pilgrim Press, 2010.

This book provides practical details to end-of-life issues for protestant faith leaders. It can be a resource for clergy to know the practical issues that face someone who is dying and also provide them with a way to provide a graceful death to congregants who are dying.

She speaks about a peaceful and dignified death and how faith leaders can guide people on this journey. The author includes legal, medical, theological and pastoral issues at the end-of-life. The book includes talking points and a process for faith leaders to have

conversations on death and dying with their faith communities as well as resources for endof-life resources.

Kames RN, Barbara. *Gone from My Sight: The Dying Experience*. Vancouver, WA: Barbara Karnes Publishing, 1986.

Dying is a process and this booklet goes through the stages of dying. It reviews the signs and symptoms of death. The booklet includes both an outline of things that can happen along with pages that describe each of those things in further detail. This booklet can be used to help people to understand dying, either their own or loved ones and also reduce the fear and uncertainty around death.

Kirkwood, Neville A. *Pastoral Care in Hospitals*. 2nd ed. Harrisburg, Pa: Morehouse Pub, 2005. This book provides a practical guide to visiting those that are sick and dying. While written for both clergy and lay leaders, there is a section specifically for faith leaders to help guide them in visiting parishioners in the hospital and things to consider during visiting such as reading nonverbal cues, knowing the time and place for prayer, knowing when to leave, and handling feelings of depression and despair. There are also prayers for different circumstances included in the book.

Long, Thomas G. *Accompany Them with Singing: The Christian Funeral*. 1st ed. Louisville, Ky: Westminster John Knox Press, 2009.

This book looks at the Christian funeral and how it is changing. It reflects on the historical and theological basis of Christian funerals and offers a look into the cultural trends that are happing at funeral today. This book provides faith leaders with some questions to think about as they help loved ones plan a funeral, encouraging faith leaders to think about decisions that are becoming more popular in the current culture with regard to funeral services. This book provides a basic pattern for a funeral service, details options in funeral

planning, identifies characteristics of a "good funeral," and provides thoughtful guidance for preaching at a funeral.

McEntyre, Marilyn Chandler. *A Faithful Farewell: Living Your Last Chapter with Love*. Grand Rapids, Michigan: William B. Eerdmans Publishing Company, 2015.

This book is a book of prayers and reflections on issues we face at the end-of-life. Through these prayers and reflections the author re-frames these issues in new light with connections to the Bible and Christian beliefs. This resource will be a valuable resource to faith leaders as they prepare to have conversations with those facing the end of life. The issues included will help faith leaders understand the physical, spiritual and emotional issues we deal with as we are facing death and the prayers could be used when faith leaders visit with those that are facing these issues.

The Go Wish Game. "Go Wish - How To Play," December 11, 2019. http://www.gowish.org/article.php/how\_to\_play.

This game is a deck of cards that gives individuals the words to discuss thier wishes should their life be shortened by a serious illness. It is an easy way to start this conversation on what is most important. "...describe things that people often say are important when they are very sick or dying. The cards describe how people want to be treated, who they want near them, and what matters to them. One card is a "wild card." Individuals can use this card to stand for something they want that isn't on any of the other cards."

Trent, J. Dana. Dessert First: Preparing for Death While Savoring Life, 2019.

This book is a compilation of stories from the author's experience being a hospital chaplain on a death ward to shed light on the complexity of death and grief. She uses her experiences and lessons to encourage a way in which we might better prepare for a "good death." It is a more personal look at ways in which we cope and create meaning for end-of-

life. It is a book that reminds us that we are all going to experience death sooner or later, so why not start the conversation now? The stories would make it a good book to use as a resource for sermons. Also the book also includes an appendix with practical, legal, religious, and spiritual resources that would make it a good book to use in bible studies or a book study.

"UCCMakingEndofLifeDecisions.Pdf." Accessed December 17, 2019. http://uccfiles.com/pdf/UCCMakingEndofLifeDecisions.pdf.

This booklet is a study guide that can be used by faith communities and faith leaders to address "specific moral issues at the end of life." It covers a variety of topics including advanced directives and living wills, barriers to decision making such as fear of dying, guilt, and procrastination, and also includes the United Church of Christ perspectives on the stewardship of life, euthanasia, and includes synod statements/resolutions on end-of-life.

Wright, H. Norman. *What to Say When You Don't Know What to Say*. Eugene, Oregon: Harvest House Publishers, 2014.

This book is a handbook on how to respond to others during tragedies or crises. The author is part of the national team that provides grief counseling following tragedies. This book provides ways in which faith leaders can respond in difficult conversations as well as provides understanding to how people may be feeling, giving encouragement, and provides biblical wisdom for helping others cope. This would be a great resource for faith leaders to use when dealing with a difficult situation themselves, or to give to those in the faith communities who are caregivers.

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